
The Current State of Health Care for People with Disabilities



National Council on Disability
September 30, 2009

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

The Current State of Health Care for People with Disabilities

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

September 30, 2009

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit this report, entitled “The Current State of Health Care for People with Disabilities.” NCD undertook this study in 2007 to focus the nation’s attention on the health care disparities experienced by people with disabilities, and to provide information and recommendations that can help to eliminate health care inequities for people with disabilities.

Some key findings include the following:

- People with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities.
- People with disabilities frequently lack either health insurance or coverage for necessary services, such as specialty care, long-term services, prescription medications, durable medical equipment, and assistive technologies.
- Most federally funded health disparities research does not recognize and include people with disabilities as a disparity population.
- The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care.
- The Americans with Disabilities Act (ADA) has had limited impact on how health care is delivered for people with disabilities. Significant architectural and programmatic accessibility barriers still remain, and health care providers continue to lack awareness about steps they are required to take to ensure that patients with disabilities have access to appropriate, culturally competent care.

The report offers a broad range of recommendations for reforms that will address some of the most significant obstacles to health, health care, disease prevention, and health promotion for people with disabilities. We believe that this report provides a road map for eliminating the pervasive barriers to health care for people with disabilities, which will improve the quality of life, productivity, and well-being of greater numbers of Americans as the population ages. We also believe that this report is in keeping with the Administration's goals for inclusive health care reform.

Our Council stands prepared to work with your Administration in the planning and implementation of cooperative actions on these matters.

Sincerely,

A handwritten signature in black ink, appearing to read "John R. Vaughn". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

John R. Vaughn
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Executive Summary

Primary barriers to health and health care for the general population are beginning to be well documented, and heightened national awareness of these obstacles has spurred numerous proposals for health care reform. Among the groups that face such barriers are Americans with disabilities. Information remains limited, but recent studies indicate that people with disabilities experience both health disparities and specific problems in gaining access to appropriate health care, including health promotion and disease prevention programs and services. They also frequently lack either health insurance or coverage for necessary services such as specialty care, long-term care, care coordination, prescription medications, durable medical equipment, and assistive technologies.

Although there have been attempts to address some of these barriers, significant problems remain. For example, Federal health care funding agencies such as the Centers for Medicare & Medicaid Services (CMS) neither conduct oversight of Americans with Disabilities Act (ADA) architectural and programmatic accessibility compliance by states, health plans, and medical providers, nor assess health providers' disability cultural competence. Few professional health care training programs address disability issues in their curriculums, and most federally funded health disparities research does not recognize or include people with disabilities as a disparity population. These and related challenges will affect the quality of life, productivity, and well-being of greater numbers of Americans as the population ages, which is projected to lead to an increase in the number of people with disabilities. Given these changes, it is especially important to understand the complex and interrelated factors that contribute to health and health care inequities for people with disabilities, and to identify practical solutions.

According to the U.S. Census Bureau, of the 291.1 million people in the population in 2005, 54.4 million (18.7 percent) had some level of disability, and 35.0 million (12.0 percent) had a severe disability. Rates of disability also increase with age. By 2030, estimates suggest that the number of people aged 65 years and older will rise to 69.4 million from 34.7 million in 2000. People with disabilities comprise the largest and

most important health care consumer group in the United States, yet the Institute of Medicine and others have warned that Federal agencies, policymakers, and health care systems have not yet responded to the broad-ranging implications, for individuals and for society, of the demographic increase in disability as the population ages.

People with disabilities tend to be in poorer health and to use health care at a significantly higher rate than people who do not have disabilities. They also experience a higher prevalence of secondary conditions and use preventive services at a lower rate than others. Moreover, people with disabilities are affected disproportionately by barriers to care. These barriers include health care provider stereotypes about disability, lack of appropriate training, and a lack of accessible medical facilities and examination equipment, sign language interpreters, and individualized accommodations.

People with certain disabilities experience specific health disparities and additional unique problems in accessing health care and services. If these problems can be resolved, crosscutting solutions hold the potential to improve health care for the broader disability community. For example:

- Women with significant disabilities are likely to have fewer Pap tests and mammograms than women who do not have disabilities, and they appear to have less knowledge and awareness of risk factors for cardiovascular disease and participate in less preventive screening for this disease compared with women without disabilities.
- Adults who are deaf or who experience significant problems hearing were three times as likely to report fair or poor health compared with those who did not have hearing impairments. American Sign Language (ASL) is the primary language for many people who are deaf, yet interpreters frequently are not provided during medical visits. Consequently, people who are deaf have significant difficulty communicating effectively with their health care providers and receiving health care information and instructions.

- Adults with developmental disabilities are at risk for hearing and vision difficulties, cardiovascular disease, obesity, seizures, mental health and behavioral problems, poor oral health, and poor general fitness. Young adults with developmental disabilities often encounter significant problems when they attempt to make the transition from coordinated childhood medical care to adult services. Problems include primary care physicians who are not trained to provide needed care and insurance schemes that do not adequately compensate health care providers for the time required to provide care and care coordination.
- People who experience significant vision loss are more likely to have heart disease and hypertension, experience a greater prevalence of obesity, and smoke more than the general population. Health care providers rarely supply printed health care instructions, educational materials, and information such as directions for taking prescription medications in accessible formats, and people who are blind or have vision impairments also appear to be excluded systematically from receiving high-quality diabetes education. Access to vision rehabilitation services also can be limited.

Complex historical and structural factors have contributed to the health and health care inequities people with disabilities experience. Research conducted by NCD revealed overarching problems related to the Federal effort to promote health for people with disabilities, identified deficiencies in the roles of certain key non-Federal stakeholders, captured important ideas for reorienting the discussion about future reforms, and identified effective health programs for people with disabilities.

NCD's key findings include the following:

Health Coverage and Benefits

- The health care system in the United States is complex, highly fragmented, and sometimes overly restrictive in terms of program eligibility. This leaves some people with disabilities with no health care coverage and others with cost-

sharing obligations and limits on benefits that prevent them from obtaining health-preserving prescription medications, medical equipment, specialty care, dental and vision care, long-term care, and care coordination.

Health and Health Disparities Research

- Dissonance is evident in the research goals and objectives of key agencies of the Department of Health and Human Services (HHS) and the National Institutes of Health (NIH) between the longstanding public health goal of eliminating disability and disease and the emerging view fostered by the U.S. Surgeon General's report "Call to Action To Improve the Health and Wellness of Persons with Disabilities" and Focus Area 6 in "Healthy People 2010," which for the first time in public health parlance, defines disability as a demographic characteristic.
- Much of the Federal research effort remains focused on disability and disease prevention rather than on improving access to, and quality of, health care for people with disabilities, reducing their incidence of secondary health problems, and promoting healthy living.
- People with disabilities experience significant health disparities compared with people who do not have disabilities, yet they are not included in major Federal health disparities research, as mandated by the Minority Health and Health Disparities Research and Education Act of 2000 and undertaken by the National Center on Minority Health and Health Disparities (NCMHD) and other centers and institutes of NIH.
- It is very difficult to determine accurately the extent of the overall current Federal research effort aimed at addressing health disparities and promoting health and wellness for people with disabilities. This problem stems in part from the fact that no single Federal agency collects and catalogues health, health disparities, and health promotion research for people with disabilities conducted across all the agencies that have a role in health.

- Federally conducted or supported disability and health research appears to be poorly integrated into overall health disparities and health promotion research.
- Specific structural problems evident in Federal agency disability research functionally impede the development of a unified, coherent plan for disability and health research and program development. Specifically, (1) the level of funding and research is wholly inadequate to spur a coherent investigative strategy that will inform policy and planning for the growing number of people who will acquire disabilities with age and for the overall future impact of disability on society; and (2) within the Federal research community, commitment to disability health disparities and health promotion research is weak, and coordination mechanisms are lacking.

Professional Training and Education

- The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care.
- Disability competency is not a core curriculum requirement for (1) accreditation or receipt of Federal funding for most medical and dental schools and other professional health care training institutions; or (2) for hospitals to participate in federally funded medical student internship and residency programs. In addition, applicants who seek either a medical or other professional health care license are generally not required to demonstrate disability competency.
- Federal agencies such as the Health Resources and Services Administration (HRSA) have not identified people with disabilities or subgroups of people with disabilities as “underserved health care populations.” As a result, recent medical school graduates are not eligible for Federal loan forgiveness programs sponsored by these agencies if they work with programs that serve people with disabilities, and they are not provided with incentives to work in these settings.

- Federal funding is limited for the development of core curriculums on disability competency for medical, dental, and other professional health education institutions.

Americans with Disabilities Act (ADA) and Section 504 Monitoring and Enforcement

- The ADA has had limited impact on how health care is delivered for people with disabilities. Significant architectural and programmatic accessibility barriers remain, and health care providers continue to lack awareness about steps they are required to take to ensure that patients with disabilities have access to appropriate, culturally competent care, and about incentives for implementing such steps.
- Federal agencies such as HHS, CMS, and HRSA do not require that procedures be established to collect information that would reveal the extent of compliance with the ADA and Section 504 of the 1973 Rehabilitation Act by the chain of recipients that administer health care funds and deliver health care. In the absence of such requirements as a condition of receiving funds, states simply pass through their nondiscrimination obligations in contracts with HMOs, health plans, and health provider organizations, which in turn pass on the same obligations to the health providers with whom they contract for services. Thus, Federal agencies, states, HMOs, and health plans take refuge behind the providers, who are subject to the lowest level of ADA and Section 504 obligations. In the end, no one is held responsible for physical and programmatic accessibility in health care facilities and programs.
- The U.S. Department of Justice and the Office for Civil Rights of the U.S. Department of Health and Human Services are charged with responsibility for enforcing the ADA and Section 504 in health care settings, yet they have taken on only a relatively small number of cases involving disability discrimination in health care, particularly when offices of health providers are involved. Without robust enforcement, the disability rights laws are ineffective tools for challenging

discriminatory conduct or care that people with disabilities often report experiencing.

Availability and Accuracy of Federal Health Data Concerning People with Disabilities

- There appears to be progress in the development and use of a consistent indicator of disability in Federal health surveys. For example, (1) in a number of recent reports on health, disability is used as a population variable; (2) there has been increased attention to and acknowledgement of the importance of collecting data about the health care experiences of people with disabilities; (3) promising research is underway to develop survey questions that will gather information not previously measured about the health care experiences of people with disabilities; and (4) some surveys are developing and implementing data collection methods that will result in the inclusion of people with disabilities who were previously excluded from surveys.
- No regular sources of data exist to measure participation in wellness programs such as exercise classes, smoking cessation programs, or self-help or AA-type groups for substance abuse, nor do surveys ask people with disabilities about their access experiences with such programs.
- The calculation of long-term benefits for people with disabilities from participation in wellness and prevention programs depends on the presence of studies that have measured outcomes. Currently, few studies measure the outcomes of interventions for smoking cessation, increased mammography screening, exercise, or other programs for people with disabilities. Nor do studies show whether the participation of people with disabilities in programs for broader populations were affected by access issues. A clear understanding of impact will require further research on the outcomes of health and wellness programs that include people with disabilities.

Universal Design

- Key stakeholders from diverse communities highly recommended that principles of universal design be applied in all aspects and venues of health care, ranging from facilities design and construction to the development of quality measures, research design, and delivery of care that embrace everyone, including people with disabilities.

Health Care Accreditation

- Leading health care facility accreditation organizations, such as the Joint Commission, do not assess facilities for basic compliance with the ADA's architectural accessibility guidelines as a requirement for accreditation.

Federal Legislation

- Legislation will be required to address some of the key gaps and barriers to health care that affect people with disabilities, including access to wellness and prevention services, health and health disparities research, development of care models built on principles of patient-centered care, and professional training.

Disability Community Advocacy

- Long-term health care reform must include the voices of people with disabilities, not only to advocate for improved health care insurance coverage, eligibility, and core benefits, but also to resolve issues of access to critical accommodations that ensure that health care is effective, such as payment coverage for sign language interpreters and requirements that providers demonstrate disability cultural competency.

Effective Programs

The following effective health and health care programs for people with disabilities were identified.

- The Deaf Access Program (DAP) of Mt. Sinai Hospital, Chicago, which offers a comprehensive program that provides both medical and mental health services for 1,300 deaf children and adults
- A clinic operating in conjunction with the Sanford School of Medicine at the University of South Dakota, Sioux Falls, which identifies children on the Rosebud Reservation who are at risk for developmental disabilities and provides immediate care through early intervention
- The Center for Women with Disabilities, Magee-Women's Hospital, University of Pittsburgh Medical Center, which offers comprehensive, patient-centered care that integrates accessibility and accommodation for women with physical disabilities
- The LightHouse for the Blind and Visually Impaired, San Francisco Vision Loss Resource Center (VLRC) offers an adaptive technology and health seminar that provides an audio transcript and information handouts of presentations on adaptive equipment, including accessible tools for glucose monitoring, weight management, healthy food preparation, and exercise equipment that aid in maintaining health.

Recommendations

NCD has identified a broad range of recommendations for reforms that are required to address some of the most significant obstacles to health, health care, and disease prevention and health promotion for people with disabilities. Recommendations are directed to key stakeholders, including Congress and the Administration, accreditation and professional medical organizations, states, and non-Federal organizations concerned with disability, health, and health care policy and research.

Recommendations are organized and presented in four categories: (1) research; (2) professional education, training, and technical assistance; (3) monitoring, oversight, and accountability; and (4) improving systemic access to health care services and programs.

Research

Some research is available concerning health and people with disabilities, yet significant problems, gaps, and challenges remain related to research needs. NCD has identified key areas in which additional research is required and recommends that specific actions be taken to ensure that issues of health and disability are included in ongoing research, and that new research is undertaken where it is needed. Research recommendations can be found in [chapter 8, section H; they are numbered 1.1 through 1.18.](#)

Professional Education, Training, and Technical Assistance

Information related to disability cultural competency is lacking in most professional medical education programs, and only limited information is available for health care institutions and providers about methods to ensure physical and programmatic access for people with disabilities. Moreover, disability competency is generally not a requirement for medical practitioner licensing, educational institution accreditation, or medical education loan forgiveness. NCD has identified recommendations intended to address these and related issues. Recommendations concerning professional education, training, and technical assistance can be found in [chapter 8, section H; they are numbered 2.1 through 2.8.](#)

Monitoring, Oversight, and Accountability

Limited implementation of key disability rights laws by health care systems, managed care organizations, and health care providers directly affects the quality of care available to people with disabilities. Poor Federal agency oversight of health care program and facility compliance with the ADA and Section 504 further exacerbates the problem. Likewise, leading accreditation organizations do not evaluate health care facilities for compliance with ADA architectural accessibility requirements. NCD has identified recommendations intended to increase oversight and spur enhanced

compliance, thereby improving access to health care services and programs for people with disabilities. Recommendations concerning monitoring, oversight, and accountability can be found in [chapter 8, section H; they are numbered 3.1 through 3.9.](#)

Improving Systemic Access to Health Care Services and Programs

People with disabilities have identified specific gaps and barriers to health care that can only be resolved through changes in current public policy. Recognizing that some of these problems appear to be intractable and significantly affect health outcomes for people with disabilities, NCD has identified specific recommendations aimed at addressing the most immediate gaps and barriers to care. Recommendations for improving systemic access to health care services and programs can be found in [chapter 8, section H; they are numbered 4.1 through 4.10.](#)

Introduction

A. Need for the Study

Primary barriers to health and health care for the general population are becoming well documented, and heightened national awareness of these obstacles has spurred numerous proposals for health care reform. Among the groups that face such barriers are Americans with disabilities. Even as information remains limited, recent studies indicate that people with disabilities experience both health disparities and specific problems in gaining access to appropriate health care, including health promotion and disease prevention programs and services. They also frequently lack either health insurance or coverage for necessary services such as specialty care, long-term care, prescription medications, durable medical equipment, and assistive technologies.

Although attempts have been made to address some of these barriers, significant problems remain. For example, Federal health care funding agencies such as the Centers for Medicare & Medicaid Services (CMS) do not conduct oversight of Americans with Disabilities Act (ADA) architectural and programmatic accessibility compliance by states, health plans, and medical providers or assess health providers' disability cultural competence. Few health care training programs address disability issues in their curriculums, and most federally funded health disparities research does not recognize and include people with disabilities as a disparity population. These and related challenges will affect the quality of life, productivity, and well-being of greater numbers of Americans as the population ages and the number of people with disabilities increases. Given these changes, it is especially important to understand the complex and interrelated factors that contribute to health and health care inequities for people with disabilities, and to identify practical solutions.

NCD undertook "The Current State of Health Care for People with Disabilities" study to focus the nation's attention on these concerns and provide information and recommendations that will help guide the development of long-term solutions for Congress, the Administration, and other stakeholders, including health care

organizations, insurers, health care providers, the health and disability research community, and people with disabilities.

This chapter sets the stage for the report by introducing key problems and barriers to health and health care, and summarizing health trends for the nation's 54.4 million people with disabilities. It also sets forth the project's research questions and presents a brief overview of the research methodology NCD used to collect and evaluate information. The chapter provides a short discussion of the differences among disability, impairment, and health condition, and why these distinctions are important, especially for health and health care policy and research. The chapter concludes with a short road map, or overview, of the report.

B. Overview: Disability Prevalence and Key Problems and Barriers to Health and Health Care for People with Disabilities

According to the U.S. Census Bureau, in 2005, of the 291.1 million people in the noninstitutionalized population, 54.4 million (18.7 percent) had some level of disability, and 35.0 million (12.0 percent) had a severe disability.¹ Physical disabilities tend to be more common than sensory or mental health disabilities. African Americans and Hispanics typically experience disability at a higher rate than do whites.² Rates of disability also increase with age; 41.9 percent of individuals over the age of 65 report disability, compared with 18.6 percent of people who are younger. Further, the numbers of older persons are expected to grow substantially during the next several decades.³ By 2030, the number of persons aged 65 years and older will rise to 69.4 million, from 34.7 million in 2000. By 2050, the number of individuals aged 85 and older will also increase significantly, to 18.2 million, from 4.3 million in 2000.⁴ Death rates from conditions such as heart disease are decreasing, which accounts for both the increase in life expectancies and an increase in the number of people who experience chronic disabilities, including arthritis, which is the leading cause of disability among adults.⁵

Although it has been well documented that this rapidly growing demographic is among the largest and most important health care consumer groups in the United States, the

Institute of Medicine (IOM) and others have warned that Federal agencies, policymakers, and health care systems have not yet mobilized their resources to respond to the broad-ranging implications of this increase in disability for individuals and for society.⁶

Responding to the implications of an expanding population of people with disabilities necessitates addressing the disparities they experience. People with disabilities tend to be in poorer health and to use health care at a significantly higher rate than people who do not have disabilities. They also experience a higher prevalence of secondary conditions and use preventive services at lower rates.⁷ People with disabilities experience more problems accessing health care than other groups, and these difficulties increase for those with the most significant disabilities and who are in the poorest health. Moreover, lack of access to health care has been associated with increased risk for secondary conditions for people with significant disabilities.⁸

Problems with accessing health care stem from barriers to care. People with disabilities are affected disproportionately by such barriers, including health care provider misinformation, stereotypes about disability, and lack of appropriate provider training; limited medical facility accessibility and lack of examination equipment that can be used by people with diverse disabilities; lack of sign language interpreters; lack of materials in formats that are accessible to people who are blind or have vision impairments; and lack of individualized accommodations. Many people with disabilities report gaps in health care insurance coverage that limit or prevent access to needed prescription drugs, durable medical equipment, specialist care, postacute and physical and vision rehabilitative services, and care coordination that are critical for health, independence, and self-determination. Further, inadequate transportation, limited personal assistance services, and patchwork financial assistance for people with low incomes compound the health problems and affect the overall health status of people with disabilities.⁹

C. Research Questions

NCD set out to answer the following research questions for this report:

1. What are the key Federal efforts that promote health care as it relates to Americans with disabilities, including wellness and prevention services, and how effective are these efforts?
2. Are accurate health data available concerning Americans with disabilities?
3. What are the access barriers to health care, including barriers to wellness and prevention services, for people with disabilities?
4. What are the unique access barriers to health care for women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities?
5. What programs initiated by the public and private sectors have improved access to coverage and care for Americans with disabilities?
6. What are key disparities and gaps in third-party coverage of the types of programs and services most needed by Americans with disabilities, particularly women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities?
7. How can the extensive recommendations identified in studies conducted by the Institute of Medicine and others be advanced?
8. Are accurate health data available concerning access to wellness and prevention services and their relative long-term costs and benefits for Americans with disabilities?
9. How effective are Federal efforts at health promotion and disease prevention (public health) as they affect Americans with disabilities, particularly women with disabilities, and people who are deaf or hard of hearing, people who are

blind or have vision impairments, and people with intellectual and developmental disabilities?

10. What are the long-term costs and benefits of third-party coverage of programs and services most needed by Americans with disabilities?

D. Research Methodology

NCD undertook the following activities to collect and evaluate information for the report:

1. *Conducted a Literature Review*

An extensive literature review was undertaken to identify journal articles, studies, commentaries, conference proceedings, and other materials related to health, health care, health disparities, and health outcomes for people with disabilities. NCD consulted primary sources, including electronic databases, Federal agency resources, and specific academic journals, and spoke with key informants who identified specific reports and related documents. NCD also reviewed specific journals concerned with health and health care issues for the broad population of people with disabilities and for women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities.

2. *Conducted Key Informant and Informational Interviews*

Semistructured key informant telephone or in-person interviews were conducted with 23 subject matter experts concerned with health, access to health care, health disparities, and health outcomes for people with disabilities. Informants included health care practitioners, researchers, Federal agency officials, and individuals with disabilities. Individuals were specifically identified and interviewed who had expertise not only on health matters of concern to the broad community of people with disabilities but also to women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. Data experts were also interviewed.

In addition to the key informant interviews, informational telephone interviews were conducted with an additional 20 Federal agency staff, health care professionals, program managers, researchers, and others to clarify the scope and duration of certain research and programmatic activities or to confirm specific information regarding programs that might be considered effective for increasing access to health care or improving health. (See appendix A for a list of key informants and others with whom interviews were conducted.)

3. *Assessed the Role and Impact of Disability Rights Laws in Health and Health Care for People with Disabilities*

NCD summarized the applicability, effectiveness, and impact of the Americans with Disabilities Act (ADA) and Section 504 of the 1973 Rehabilitation Act to health care services and facilities for people with disabilities and conducted a review of key cases and their impact under each law.

4. *Reviewed the Legal and Administrative Framework for Key Health, Health Care, and Health Disparities Programs and Research*

NCD reviewed the Federal legislation that established major health research and health care programs and other health initiatives to determine the extent to which people with disabilities are included, to identify problems and gaps as they relate to the health care needs of people with disabilities, and to identify opportunities for increasing their participation.

5. *Reviewed Key Federal Health, Health Care, and Health Disparities Initiatives*

NCD identified key Federal agencies, departments, centers, and offices¹⁰ whose missions include health and health care research, health promotion and disease prevention, program development, and health care service delivery. NCD then determined the extent to which health care issues, including health disparities for people with disabilities, had been identified as a topic for research and whether health promotion, public and professional education, program intervention, health care

services delivery, and other related activities included people with disabilities and their issues.¹¹

6. *Convened a Summit on Health Care for People with Disabilities*

NCD convened a Summit on Health Care for People with Disabilities to translate current knowledge about the problems people with disabilities experience in health, health care, and health outcomes into a plan for action. Twenty-five key stakeholder/expert participants attended the two-day meeting. Attendees were opinion leaders in their fields, including people with disabilities, policymakers, health care providers, leaders of professional associations and accreditation organizations, and health policy experts.

The specific objectives of the summit were (1) to build on and refine the recommendations for systemic reform that have been identified by such organizations as the IOM, the U.S. Surgeon General, and others; (2) to identify step-by-step strategies for the implementation of key recommendations; and (3) to encourage participants to consider taking action within their spheres of influence. (See appendix B for a list of summit participants.)

7. *Assessed Data Availability*

NCD carried out a data assessment to determine the availability and accuracy of health data regarding Americans with disabilities. This review focused specifically on the current state of health care delivery for people with disabilities; health and health care disparities and access to wellness services by people with disabilities; and services specifically for women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities.

The data assessment was focused on the large national datasets that regularly collect information about the health status, health care utilization, and health care delivery experience of Americans.¹² (See appendix C for a list of content, framing, collection, and other methods related to data collection assessment.)

8. *Identified Effective Programs That Improve Access to Health Care for People with Disabilities*

NCD identified examples of effective models in health care service delivery, professional education and training, disability competency assessment, and policy implementation. NCD also identified specific programs that serve women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. Programs are included that meet three general criteria:

- They respond to specific needs that have been defined either by people with disabilities or others who are very familiar with the health and health care needs of people with disabilities.
- They are well established in terms of factors including longevity, funding, and institutional commitment.
- They have conducted customer satisfaction or other evaluations that were available for review to determine their effectiveness and to make improvements.¹³

E. Definitions

1. *Disability, Impairment, and the Relationship Between Disability and Health*

Concepts of disability, impairment, and the relationship between disability and health have been evolving over many decades. Historically, disability was measured solely by the presence of an impairment or health condition. Since the 1970s, spurred by the disability rights movement, there has been a move away from this medical view to an alternative that acknowledges the interplay between levels of impairment and the facilitating or limiting effects of the physical, social, technological, and economic environment. In 2001, the World Health Organization (WHO) adopted the International Classification of Functioning, Disability and Health (ICF), which attempts to provide a coherent, global interpretation of these different perspectives. The ICF is a classification of domains from perspectives of the body, the individual, and society. Since function

and disability occur in a context, the ICF also includes a list of environmental factors. The ICF refers to disability as “an umbrella term for impairments, activity limitations, and participation restrictions.”¹⁴ Most disability and health researchers and advocates agree that this unified definition reflects a meaningful balance of factors and provides a useful approach to understanding disability in the health research context. Important recent population research reflects the influence of the ICF, yet no survey fully applies the ICF’s theoretical conceptualizations of disability.¹⁵ Various other, more traditional definitions of disability and impairment are still in use and appear throughout this report. They reflect the diverse perspectives, influence, and roles of the medical and research communities and of Federal agencies such as the Social Security Administration, as well as the impact of disability rights laws and policies.

2. Health Disparity, Health Inequality, and Health Inequity

The phrase “health disparity” is widely used in the articulation of health care research, funding, and service delivery priorities by both public and private organizations. The exact definition of health disparity varies. In some cases, it includes many population subgroups and indicators; in other cases, it is narrowly restricted to specific populations and health conditions. In broad terms, “health disparity” can be defined as “differences in health outcomes and health care access that occur between specific populations and the general population.” Many discussions of the definition of health disparity note that it incorporates two concepts: health inequality and health inequity.¹⁶ Health inequality indicates differences in health outcomes, some of which may be unavoidable and not judged unfair (such as outcomes related to biological variation). Health inequity describes differences in health outcomes or health care services received that are considered avoidable, unfair, and unjust. In most instances in the United States, when the phrase “health disparity” is used, it is understood to describe circumstances in which differences are interpreted to indicate bias or unacceptable disproportion in health outcomes, aspects of health care system access, or differences in health treatment for one group compared with the general population. (See appendix D for several Federal agency definitions of disparity.)

F. Organization of the Report

Chapter 1 sets the context for the report by presenting a profile of the population of people with disabilities based on self-assessed health status, health risk factors, and participation in physical activity, and the extent to which they have access to health insurance and basic and preventive care compared with people who do not have disabilities. Next, specific gaps and barriers to care for people with disabilities are presented in more detail. To illustrate some of the specific problems people with disabilities experience, the chapter continues with a discussion of health and health care for four groups within the disability population: women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. The chapter ends with recommendations for reform.

Chapter 1 describes how the 1990 Americans with Disabilities Act (ADA) and Section 504 of the 1973 Rehabilitation Act relate to health care services and facilities. It also examines some of the civil actions and settlements brought under these laws that illustrate both the usefulness and the shortcomings of individual and class action lawsuits in the area of health care. The chapter ends with recommendations for reform.

Chapter 3 summarizes key Federal laws that establish major health programs in the United States—such as Medicaid, Medicare, and the State Children’s Health Insurance Program (SCHIP)—that serve significant numbers of people with disabilities. Laws are also introduced that relate to the Federal Government’s response to the existence of health and health care disparities among specific population groups but that generally exclude people with disabilities. This chapter suggests reasons for fully including people with disabilities in the nation’s ongoing effort to combat health and health care disparities. The chapter ends with recommendations for reform.

Chapter 4 examines the extent to which people with disabilities are or are not included in the recent activities of key Federal agencies, departments, and centers as they relate to health, health care, health promotion, disparities research, data collection,

professional education, and other activities. The chapter also summarizes the Federal Government's level of effort related to health disparities research and program development for people with disabilities, and ends with recommendations for reform.

Chapter 5 reports on progress toward collecting data that help shape health research goals and health care policy and programs so that the specific needs of people with disabilities are identified and included. The chapter ends with recommendations for reform.

Chapter 6 reports on outcomes of the Summit on Health Care for People with Disabilities. The meeting brought together health care experts, opinion leaders, Federal agency and disability community representatives, researchers, funders, and practitioners to discuss barriers to health and health care for people with disabilities and to create a strategic action plan to begin to address the problems. The chapter ends with recommendations for reform.

Chapter 7 presents examples of effective programs that emphasize health and mental health care, as well as health education and promotion for people with disabilities, including women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. Chapter 7 also includes several projects that involve structural innovations holding some promise for improving health care and health outcomes for people with disabilities. The chapter ends with recommendations for reform.

Chapter 8 presents a summary of answers to the research questions and an overall analysis of findings, and lists the recommendations presented earlier.

Appendixes A through F provide additional information that supplement issues presented in the report.

CHAPTER 1. **Health and Disability**

The health of people with disabilities is gaining national attention, and new research is beginning to sharpen the focus on the health status of people with disabilities, the barriers to care they encounter, and factors that contribute to their health risks, including participation in health promotion and disease prevention programs. Such studies are also revealing in greater detail the extent to which people with disabilities have access to health care insurance, regular sources of care, and appropriate services—including specialty care and assistive technologies—under both publicly funded and private coverage.

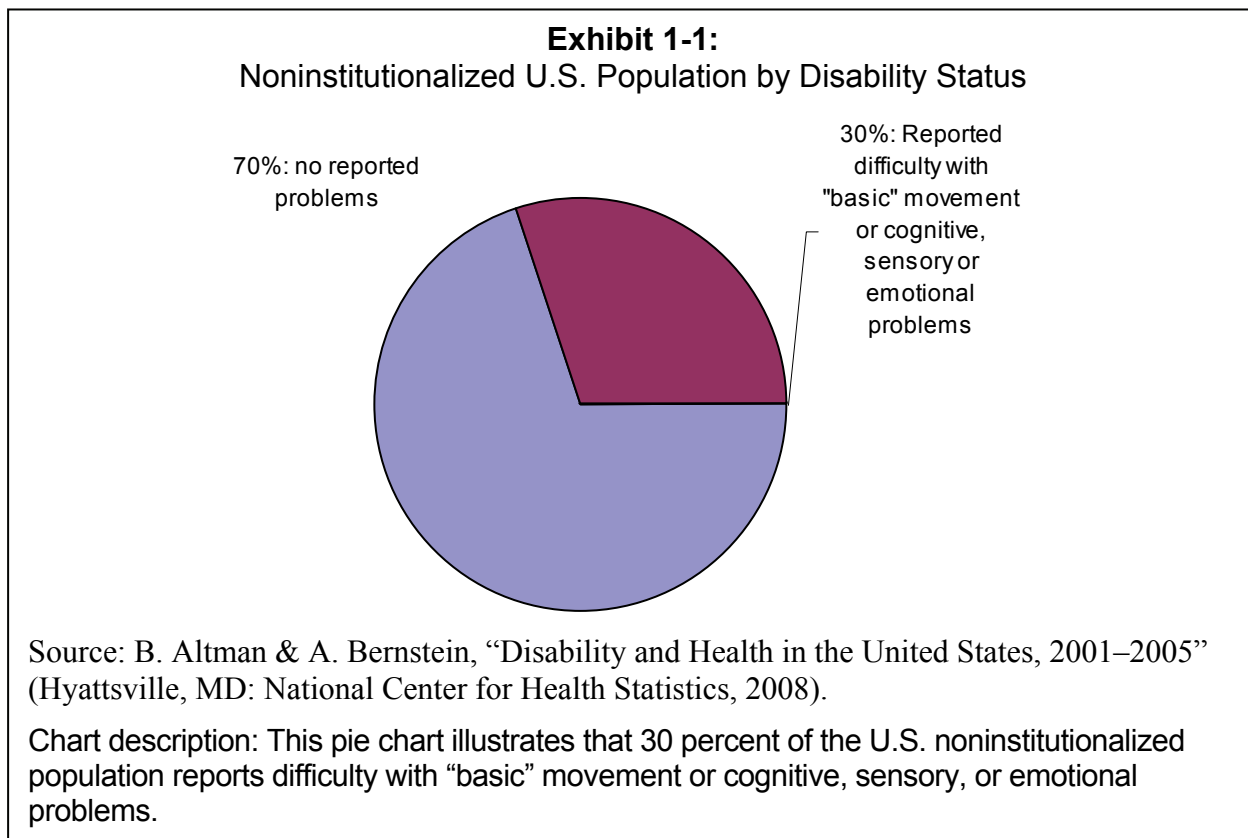
The chapter begins with a profile of the population of people with disabilities based on self-assessed health status, health risk factors, and participation in physical activity, and the extent to which they have access to health insurance and basic care and preventive care, compared with people who do not have disabilities. Next, specific gaps and barriers to care for people with disabilities are presented in more detail. To illustrate some of the specific problems people with disabilities experience, the chapter continues with a discussion of health and health care for four groups within the disability population: women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. The chapter ends with recommendations for reform.

A. Self-Assessed Health Status and Access to Care

1. *Defining Disability*

A 2008 special report by the CDC's National Center for Health Statistics (NCHS)¹⁷ tackles the challenging problem of defining disability by relating two levels of activity difficulty and by limitation to health status and other health indicators. The report also acknowledges the interaction of disability with environmental and social factors.¹⁸ Using 5 years of data from the National Health Interview Survey (NHIS), the report provides a comparative analysis across dimensions that include health status, health risk factors, and access to care and clinical services for people with various levels of activity limitations and for people who do not have disabilities.

According to the study, about 62 million (30 percent) of noninstitutionalized people living in the United States experienced either some difficulty with “basic” movement, or cognitive, sensory, or emotional problems. (See exhibit 1-1.)¹⁹ The most common problem reported by more than one-fifth of those surveyed relates to basic physical actions such as walking, bending, and reaching. A little over 13 percent reported problems with vision or hearing, and about 3 percent reported emotional or cognitive difficulties.



About 14 percent of noninstitutionalized people experience “complex activity limitations” in their ability to participate fully in social roles, including maintaining a household, working, pursuing hobbies, visiting friends, and going to the movies or sporting events. In some cases, these activity measures can overlap and describe the same person.²⁰

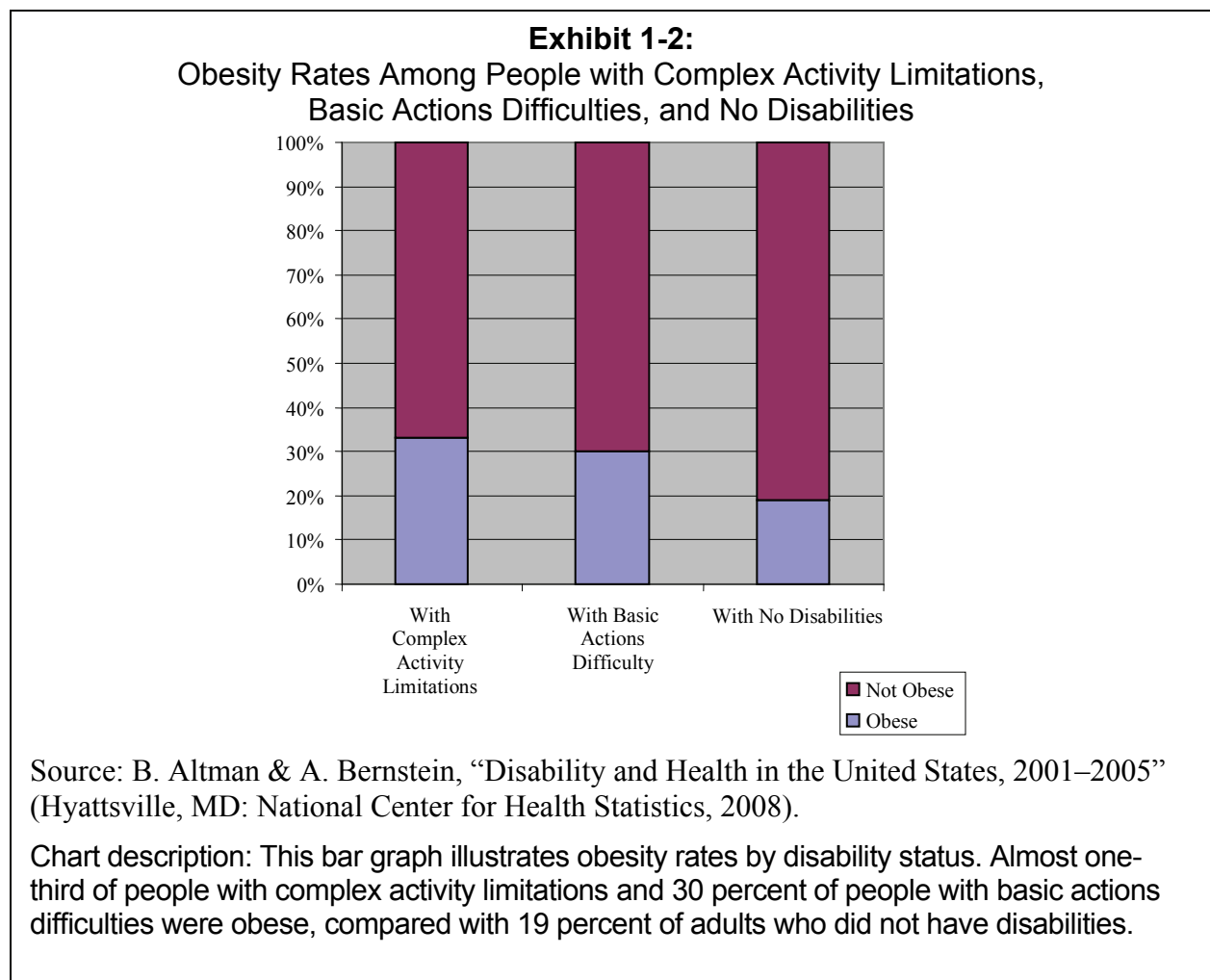
2. *Health and Disability*

About half of people with complex limitations and one-third of people with basic actions difficulties assessed their health status as fair or poor, compared with the three-fourths

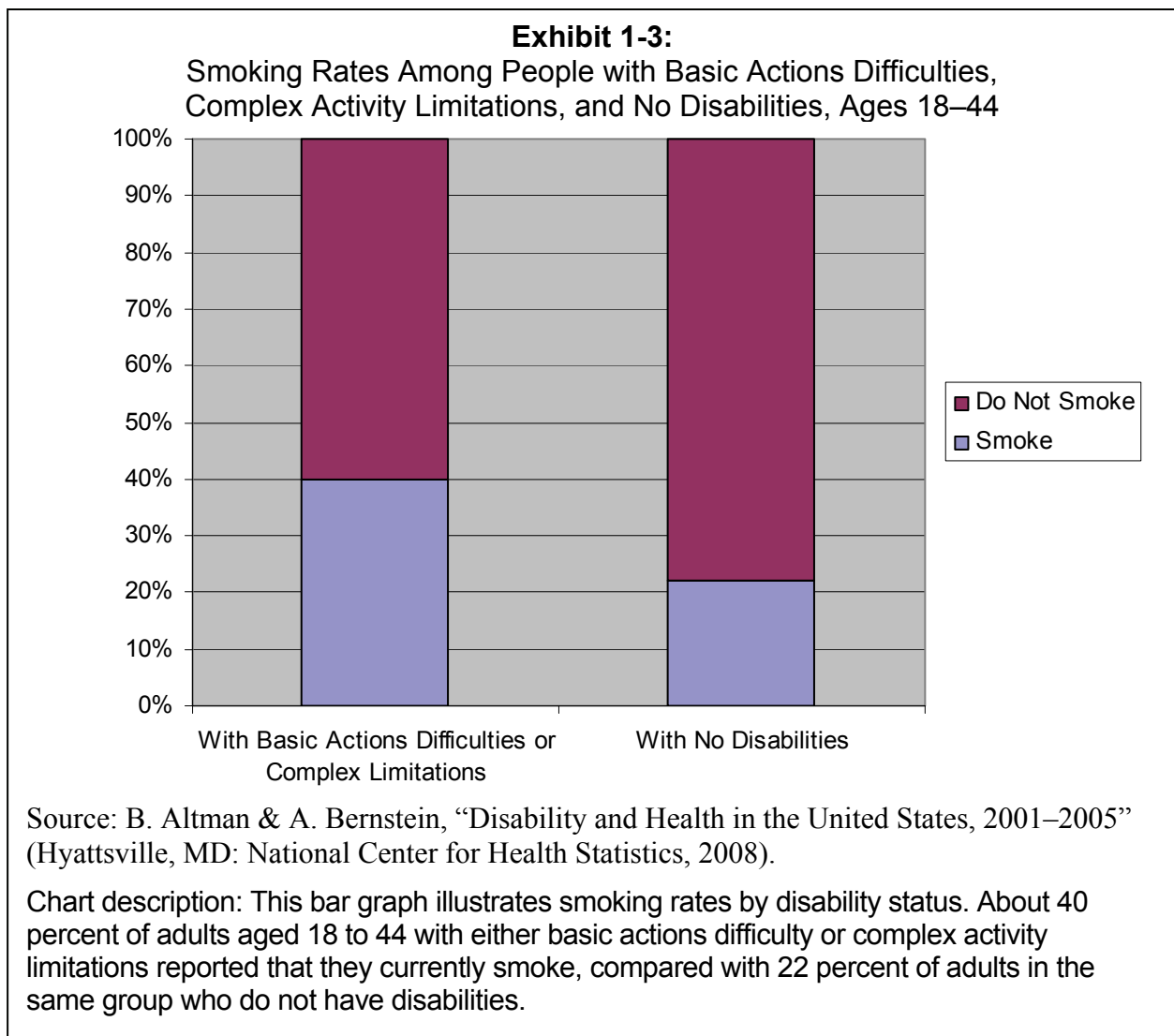
of adults who did not have a disability who assessed their health as excellent or very good. Health status declines with age for people with and without disabilities. Across people in all age categories (18–64 years), however, the percentage reporting fair or poor health was greater among those with complex activity limitations than among those with basic actions difficulties. Fair or poor health status was more likely to be reported by people with cognitive problems or self-care limitations.²¹

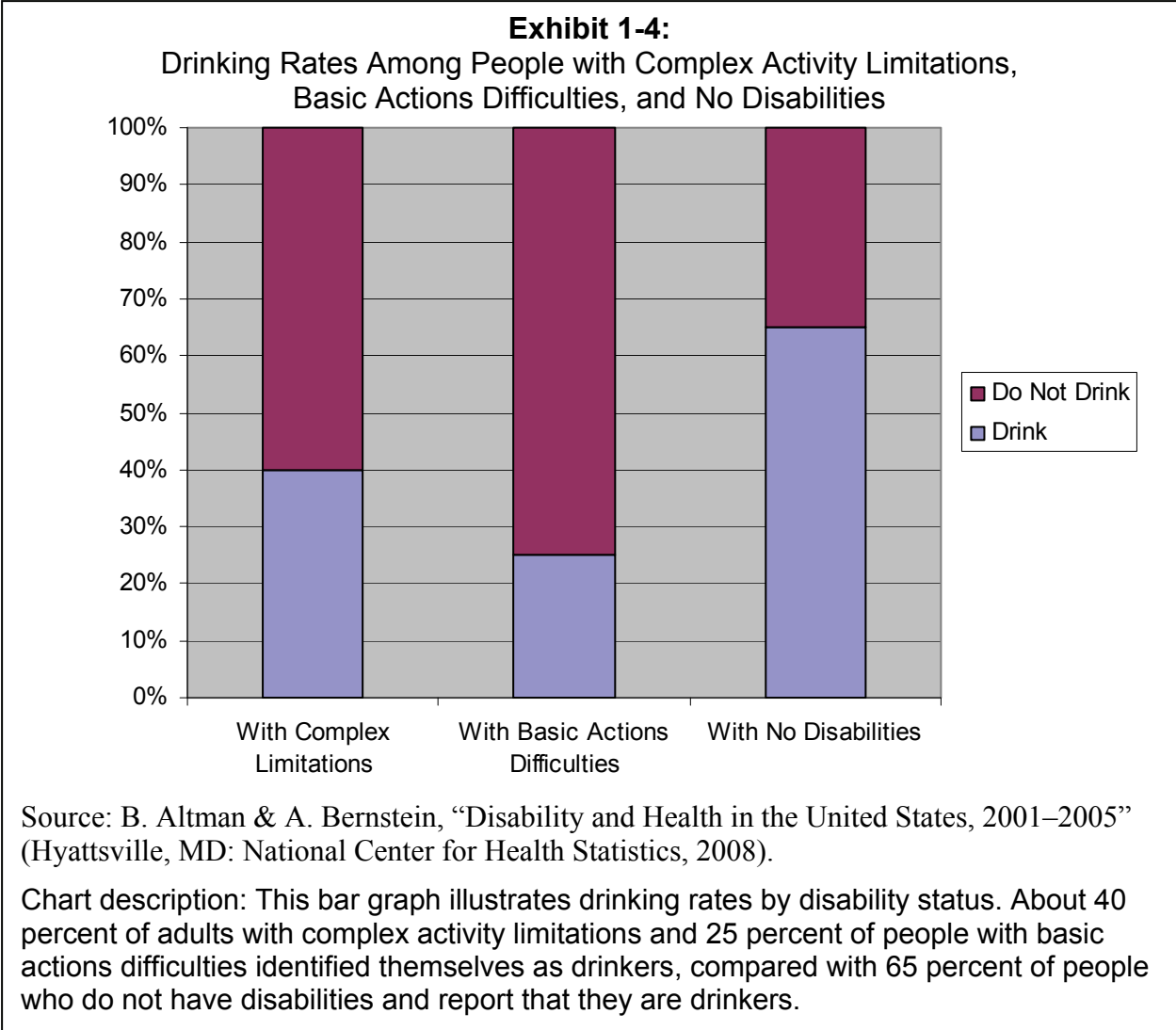
3. Health Behaviors and Risk Factors

Adults with disabilities are more likely to be overweight or obese than adults without disabilities. According to the NCHS report, almost one-third of people with complex activity limitations and 30 percent of people with basic actions difficulties were obese, compared with 19 percent of adults who did not have disabilities. (See exhibit 1-2.)²²



About 40 percent of adults aged 18 to 44 with either basic actions difficulty or complex activity limitations reported that they currently smoke, compared with 22 percent of adults in the same group who do not have disabilities. (See exhibit 1-3.) Although smoking declines with age, among adults aged 65 or older in basic and complex activity groups, about 9 percent still smoked.²³ The NCHS study also found that about 40 percent of adults with complex activity limitations and 25 percent of people with basic actions difficulties identified themselves as drinkers. While these percentages suggest significant alcohol use among people with disabilities, they compare with 65 percent of people who do not have disabilities and report that they are drinkers. (See exhibit 1-4.) Further, patterns of heavy drinking (five or more drinks per day on 21 or more days in

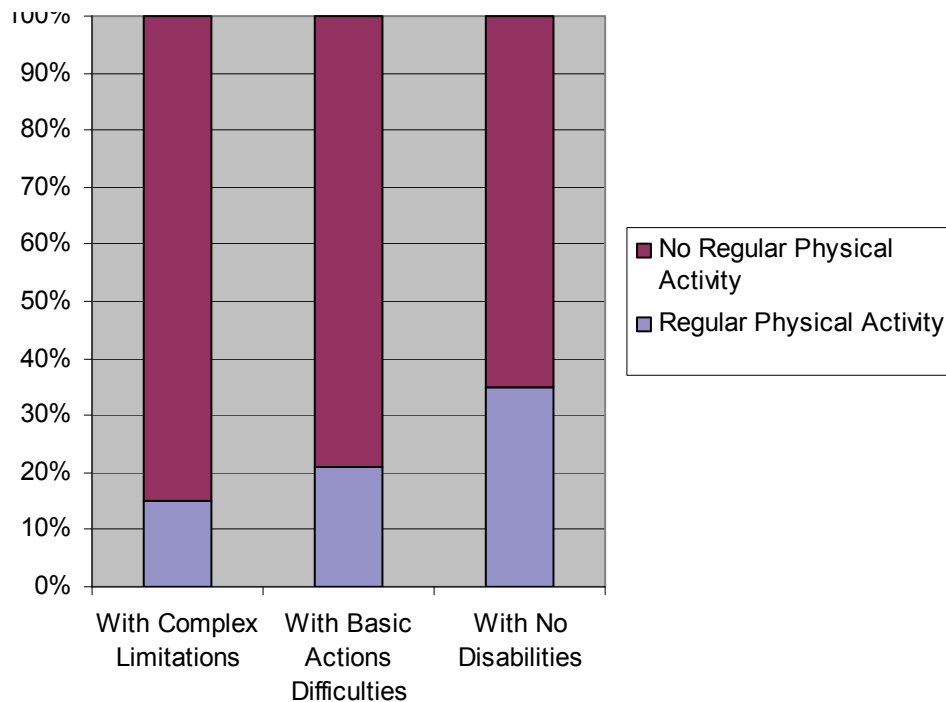




the past year) were similar for people with basic actions difficulty and complex activity limitations and those who did not have disabilities. Men were more than twice as likely as women to be heavy drinkers in all three groups.²⁴

The benefits of physical activity in reducing risks for various conditions—including cardiovascular disease, osteoporosis, and diabetes—are well documented. However, adults with all types of activity limitations were less likely to participate in leisure time physical activity than adults without disabilities. Only about 15 percent of people with complex activity limitations reported that they engaged in regular physical activity, while 21 percent of adults with basic actions difficulties engaged in such activity, compared with 35 percent of adults who do not have disabilities. (See exhibit 1-5.) Various barriers

Exhibit 1-5:
Physical Activity Among People with Complex Activity Limitations, Basic Actions Difficulties, and No Disabilities



Source: B. Altman & A. Bernstein, “Disability and Health in the United States, 2001–2005” (Hyattsville, MD: National Center for Health Statistics, 2008).

Chart description: This bar graph illustrates physical activity by disability status. Only about 15 percent of people with complex activity limitations reported that they engaged in regular physical activity, while 21 percent of adults with basic actions difficulties engage in such activity, compared with 35 percent of adults who do not have disabilities.

may prevent people with disabilities from engaging in physical activity, barriers including lack of access to fitness facilities, inaccessible exercise equipment, lack of access to adapted sports programs, or physical inability to exercise.²⁵

4. Access to Health Care

Insurance coverage tends to determine whether people with disabilities visit a doctor regularly or have access to a usual source of medical care. Adults with disabilities were less likely than those without disabilities to have private health insurance coverage. According to the NCHS study, less than half of people with complex activity limitations and about 61 percent of people with basic actions difficulties had private coverage,

compared with about 75 percent of people who did not report having a disability when the study was conducted. (See exhibit 1-6.) Although public insurance programs—including Medicaid and Medicare—cover many people with disabilities, they do not provide coverage for everyone who does not have private insurance. (See exhibit 1-7.) During the period 2001–2005, about 19 percent of adults with a basic actions difficulty and 17 percent of those with a complex activity limitation reported being uninsured. These figures compare with about 19 percent of adults who do not have a disability who were without insurance. Twenty-eight percent of people with emotional disabilities reported being uninsured, the highest rate among people with disabilities, followed by 20 percent of people who are blind or have vision impairments or who are deaf or hard of hearing. Eleven percent of those with self-care limitations reported that they did not have insurance, the lowest uninsured rate of any group.²⁶

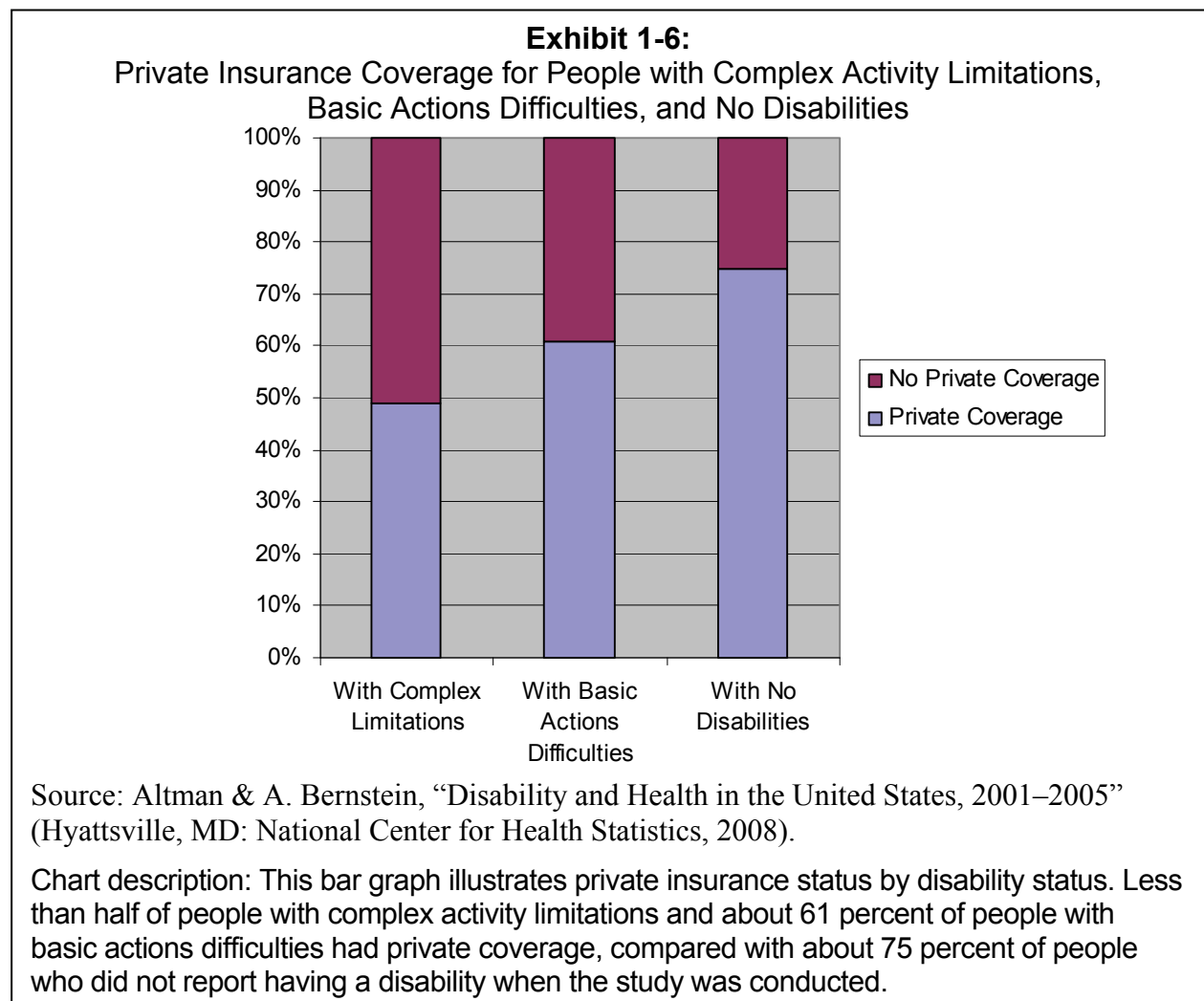
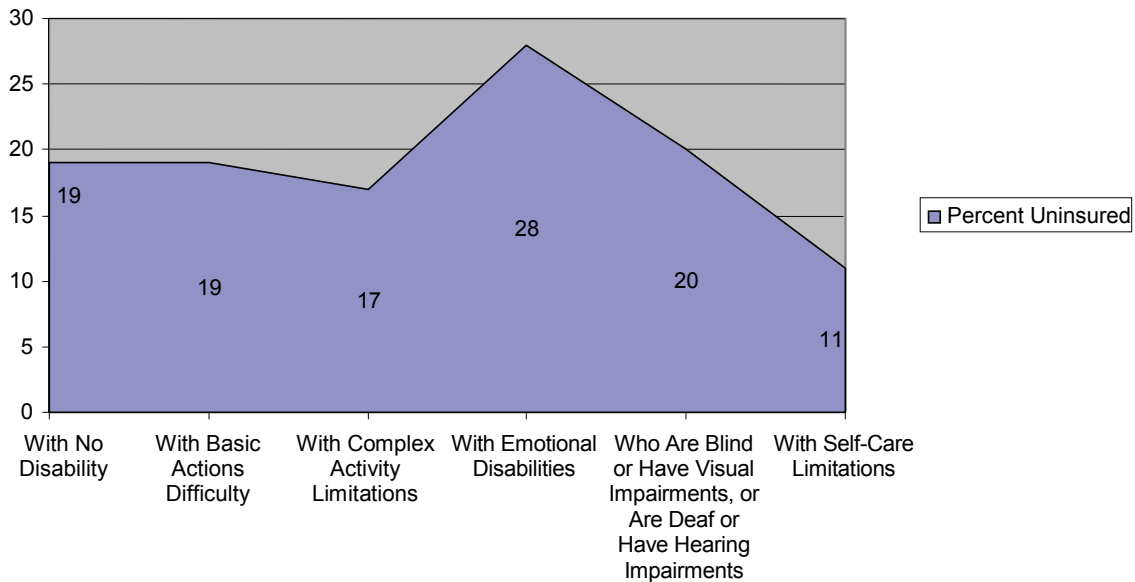


Exhibit 1-7:
Percentage of Uninsured Adults, by Disability Status

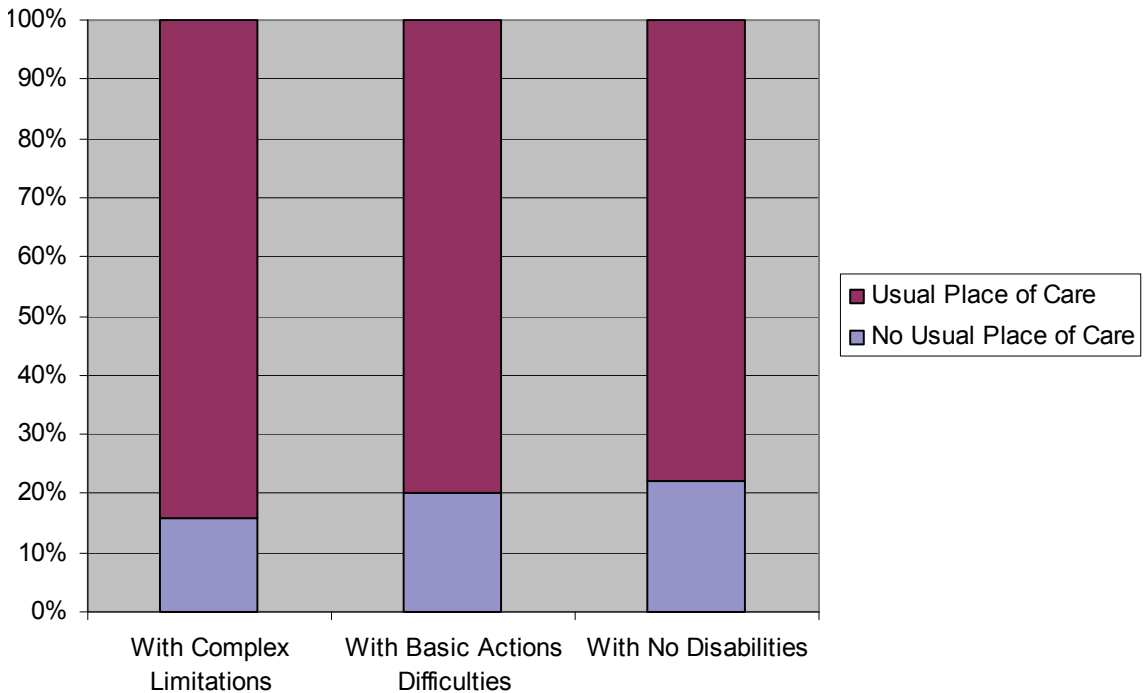


Source: B. Altman & A. Bernstein, “Disability and Health in the United States, 2001–2005” (Hyattsville, MD: National Center for Health Statistics, 2008).

Chart description: This area chart illustrates uninsured rates by disability status. Nineteen percent of adults with a basic actions difficulties, 17 percent of those with a complex activity limitations, 19 percent of adults who do not have a disability, 28 percent of people with emotional disabilities, 20 percent of people who are blind or have vision impairments or who are deaf or hard of hearing, and 11 percent of those with self-care limitations reported that they did not have insurance.

Having access to a regular source of health care fosters control of chronic conditions and facilitates the acquisition of preventive services. The NCHS study reports that adults aged 18–44 were more likely to lack a regular source of medical care than older adults, regardless of disability status. However, fewer people with basic actions difficulty and complex activity limitations reported lacking access to usual care compared with people with no disabilities. For people aged 18–44, 16 percent of those with a complex activity limitation, 20 percent of those with a basic actions difficulty, and 22 percent of those with no reported disability did not have a usual place of medical care. (See exhibit 1-8.)²⁷

Exhibit 1-8:
Lack of Access to Usual Care for Adults with Complex Activity Limitations,
Basic Actions Difficulties, and No Disabilities, Ages 18–44



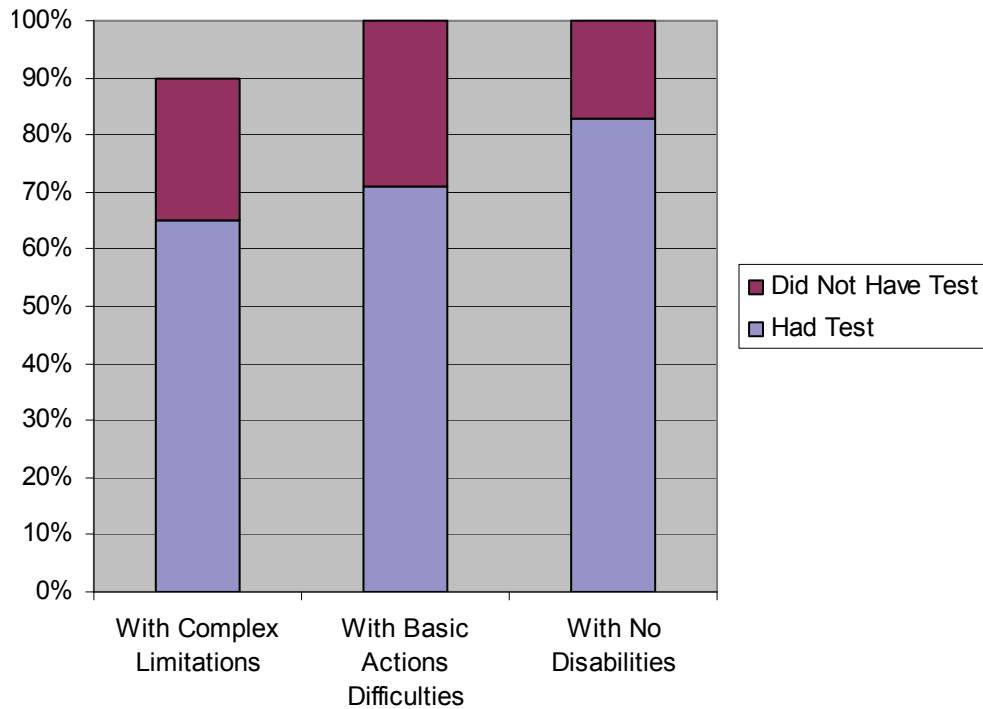
Source: B. Altman & A. Bernstein, “Disability and Health in the United States, 2001–2005” (Hyattsville, MD: National Center for Health Statistics, 2008).

Chart description: This bar graph illustrates rates of lack of access to usual care by disability status, among people ages 18–44. Sixteen percent of those with complex activity limitations, 20 percent of those with basic actions difficulties, and 22 percent of those with no reported disability did not have a usual place of medical care.

5. Use of Certain Preventive Services

Regular Pap tests and mammography studies are used to identify certain breast and cervical cancers and other conditions in women. The NCHS study found that women aged 18 and older with disabilities were less likely to have had a Pap test within the past 3 years than women without disabilities. (See exhibit 1.9.) Seventy-one percent of women in this age group with basic actions difficulties and 65 percent of women with complex activity limitations had had the test, compared with about 83 percent of women without disabilities.

Exhibit 1-9:
Women Who Had the Pap Test Within the Past 3 Years, Ages 18 and Older



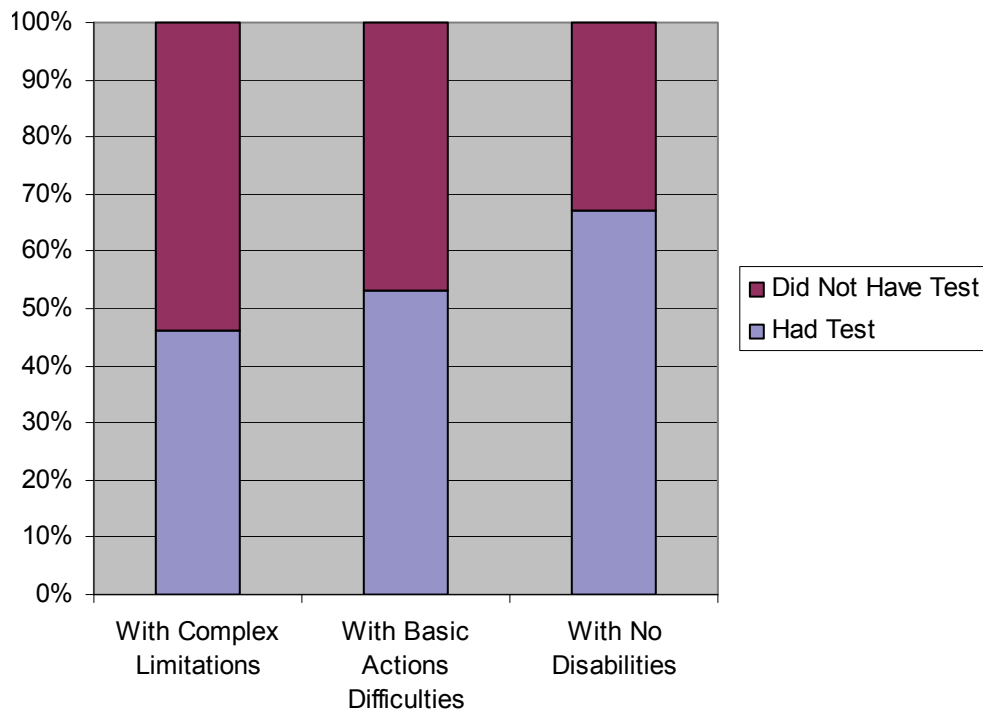
Source: Altman & A. Bernstein, “Disability and Health in the United States, 2001–2005” (Hyattsville, MD: National Center for Health Statistics, 2008).

Chart description: This bar chart illustrates rates of women 18 and older who had the Pap test within the past 3 years by disability status. Seventy-one percent of women in this age group with basic actions difficulties and 65 percent of women with complex activity limitations had had the test, compared with about 83 percent of women without disabilities.

For women aged 65 and older, 53 percent with basic actions difficulties and 46 percent with complex activity limitations had a Pap test in the past 3 years, compared with 67 percent of women who did not have disabilities. (See exhibit 1-10.)²⁸

Evidence of the effectiveness of mammography screening is greatest for women between the ages of 50 and 69, and annual exams are recommended for women 40 years and older. The NCHS study reports that mammography rates were higher for women who did not have disabilities than for women with both basic actions difficulties and complex activity limitations. (See exhibit 1-11.) Seventy-four percent of women who did not have disabilities had mammography exams, compared with 67 percent of women with basic actions difficulties and 61 percent of women with complex activity limitations. Women with

Exhibit 1-10:
Women Who Had the Pap Test Within the Past 3 Years, Ages 65 and Older



Source: Altman & A. Bernstein, “Disability and Health in the United States, 2001–2005” (Hyattsville, MD: National Center for Health Statistics, 2008).

Chart description: This bar chart illustrates rates of women 65 and older who had the Pap test within the past 3 years by disability status. Fifty-three percent with basic actions difficulties and 46 percent with complex activity limitations had a Pap test in the past 3 years, compared with 67 percent of women who did not have disabilities.

limitations in their ability to perform certain instrumental and other activities of daily living had mammography exams at the lowest rate (51 percent), followed closely by only 52 percent of women with cognitive disabilities who received the test.²⁹

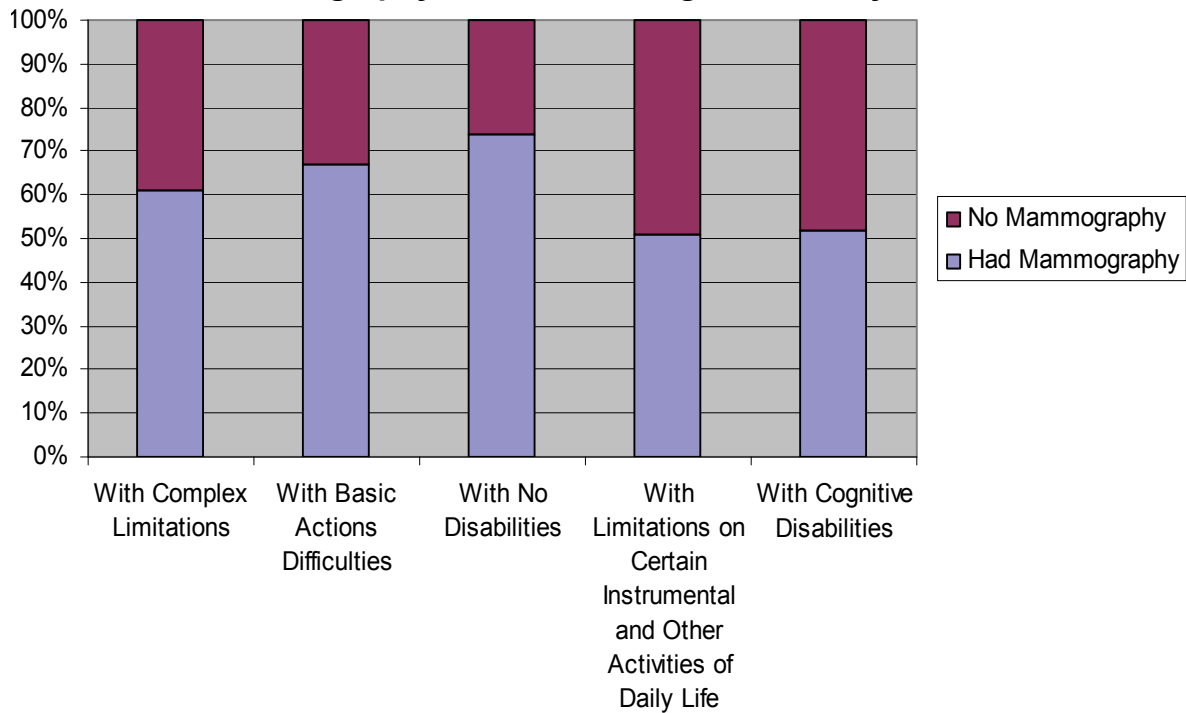
B. Gaps in and Barriers to Health Care for People with Disabilities

1. Health Care Insurance

Health care insurance availability, affordability, and coverage for important benefits—including medications, long-term care, durable medical equipment, mental health, rehabilitative and specialty care, and care coordination—are key issues for people with disabilities. Yet national surveys have reported that people with disabilities commonly

Exhibit 1-11:

Mammography Rates According to Disability Status



Source: Altman & A. Bernstein, “Disability and Health in the United States, 2001–2005” (Hyattsville, MD: National Center for Health Statistics, 2008).

Chart description: This bar chart illustrates mammography rates by disability status. Seventy-four percent of women who did not have disabilities, 67 percent of women with basic actions difficulties, 61 percent of women with complex activity limitations, 52 percent of women with cognitive disabilities, and 51 percent of women with limitations in their ability to perform certain instrumental and other activities of daily living had mammography exams.

experience difficulty navigating the insurance system, finding and obtaining approval to visit specialists, and obtaining durable medical equipment. Estimates suggest that these factors obstruct or delay care for as many as 30–50 percent of adults with disabilities.³⁰ One national survey found that health insurance is inadequate for more than one in three people with disabilities who reported delaying care, skipping medication, or going without needed equipment because of cost. People who do not have health insurance face the greatest challenges.³¹

Publicly financed health insurance provides an important safety net for many people with disabilities. Medicaid provides health and long-term care coverage for 8 million low-

income individuals with disabilities and chronic illnesses,³² and Medicare covers about 7 million people with disabilities who are under age 65.³³ Both Medicare & Medicaid beneficiaries, however, have reported difficulties obtaining the care and services they require. With higher copayments, Medicare beneficiaries with disabilities report significant cost-related problems, including forgoing needed equipment, postponing care, and paying for long-term care. Further, Medicare imposes a 2-year waiting period for coverage for individuals who are under age 65 who become eligible for the program when they receive Social Security Disability Insurance (SSDI). While cost-sharing is lower under Medicaid, people with disabilities who are covered by the program report, among various problems, difficulties finding physicians who will accept Medicaid payments, which compromises access to care for those with low incomes. Seventy-eight percent of Medicaid beneficiaries with disabilities qualify for Medicaid because they meet the income and asset limitations required for receipt of Supplemental Security Income (SSI).³⁴ For many of these low-income beneficiaries, however, essential health care services—including dental and vision care, medical supplies, and durable medical equipment—may be out of reach financially, even with low cost-sharing under Medicaid.

Further, although many people with disabilities have some type of health insurance, a significant number of individuals with chronic health conditions remain uninsured. According to the NHIS, nearly half of all uninsured, nonelderly adults report having a chronic condition, and almost half of those forgo medical care or prescription drugs because of the cost. Nonelderly adults who lack health insurance include people with hypertension (14 percent uninsured), high cholesterol (11 percent uninsured), heart disease (13 percent uninsured), asthma (18 percent uninsured), diabetes (15 percent uninsured), and arthritis-related conditions (12 percent uninsured).³⁵

Private group plan health insurance is usually offered through employers and some trade unions. However, many working-age individuals with disabilities do not qualify for such coverage, because they are not employed; work part time (only 31 percent of workers with part-time jobs qualify for employer group plans, compared with 82 percent of full-time workers);³⁶ or their employers do not offer health insurance. Employer-

sponsored health insurance is also becoming less available as health premiums increase at rates consistently greater than inflation. The average annual group premium for a family of four in 2007 was \$12,106, nearly double what it was in 2000.³⁷

For those who have employer-sponsored group health insurance, plans often do not provide adequate benefits for people with disabilities, because they are crafted to cover basic care required by average working populations with fewer health care needs.³⁸ For example, private insurance plans increasingly limit annual payments for durable medical equipment such as wheelchairs, crutches, braces, and ventilators, regardless of medical necessity and at a level that makes the individual's out-of-pocket costs for higher priced items such as motorized wheelchairs prohibitively expensive.³⁹ Many private insurance plans also limit mental health services and prescription drugs, which are generally restricted to medications on approved lists, or formularies.⁴⁰ Private insurance plans also do not reimburse providers for sign language interpreters or cover the cost of vision rehabilitation for people who are blind or who have vision impairments. For families who have a child with intellectual and developmental disabilities and complex medical problems, private insurance does not provide for adequate reimbursement to health care providers for key services such as specialty care and care coordination.⁴¹

Purchasing individual private insurance is rarely an option for people with disabilities, because it is unaffordable or because they are denied coverage outright on the basis of disability. While group plans may not exclude an individual with a disability from coverage, no such prohibition exists for individual private insurance. For example, a General Accounting Office (GAO) study found that individuals with HIV, heart disease, or leukemia are "virtually always" denied individual private health insurance. People with other disabilities have also been denied full coverage, including those with orthopedic impairments, mental health disabilities, diabetes, asthma, arthritis, nervous system disorders, cancer, mobility disabilities, and vision impairments.⁴²

In addition to paying more for an individual plan than a group plan, purchasers are often charged premiums that are higher than those charged to individuals without disabilities.⁴³ One study examined the availability of individual health insurance

coverage for hypothetical individuals with minor and major health problems. The study found that these hypothetical individuals were unable to obtain coverage at the standard rate 90 percent of the time, and benefit restrictions and premium surcharges were imposed on the applications that were accepted.⁴⁴

2. Third-party Coverage of Health Programs and Services Most Needed by Americans with Disabilities

The structure for payment of health care services in the United States is based on third-party payers, either through private insurance or through the public insurance programs including Medicare, Medicaid, SCHIP, and Title V. Health care services are sufficiently costly that it is not feasible to assume that those without a third-party payer can afford to pay out of pocket. For the 45.7 million Americans without health insurance, this means mostly going without care until health problems are urgent.⁴⁵ In these circumstances, providers may never be adequately compensated for the care they provide, and individuals may find themselves struggling with large health-care-related debt.⁴⁶ For people with disabilities, as for most Americans, assessments about the impact of the third-party payment structure on long-term costs and benefits are wrapped up in the larger national policy debate about how best to finance health care so that it meets the two objectives of enabling everyone to access appropriate quality care and controlling the rapid rise of health care expenditures.

As the discussion in the preceding section on health insurance gaps indicates, people with disabilities rely greatly on health insurance. Those who do not have insurance or are inadequately insured often delay care or go without care. Both circumstances can produce high costs in the long run, to the health care system and to individual patients. While not intrinsic to the concept of third-party payment, the current structure permits the denial of coverage based on health status or prior health events. It also has led to the development of a reimbursement system geared to the expenses of acute medical care. This leaves people with chronic conditions and the costs of chronic care with less coverage. The costs of durable medical equipment and other assistive devices, which

often are not considered “medical,” sometimes fall outside the insurance coverage umbrella.

For people with disabilities to derive benefits from health insurance coverage that are similar to those for people without disabilities, third-party coverage needs to include some specific services and supports, such as care coordination, access to specialty providers, rehabilitative services, prescription drugs, durable medical equipment and assistive technologies. Third-party reimbursement also should account for the need for longer appointments, assistance with communication (e.g., sign language interpreters), and other modifications in the processes used to deliver care to ensure equitable quality in the health care received by people with disabilities.

Currently, there is no body of research demonstrating with any certainty the long-term costs and benefits of third-party health care coverage that incorporates the services that may be most needed by people with disabilities. The best that can be offered is a hypothesis for future research: Better third-party coverage of people with disabilities and the services they need will result in longer, healthier lives; improved overall health status; greater productivity and community participation; and less high-cost care for conditions for which earlier intervention is effective.

3. Lack of Health Care Provider Training and Awareness

Among barriers that affect the quality of care that people with disabilities receive, lack of disability competency and awareness among health care providers ranks high with focus group participants and in other participatory research.⁴⁷ Physicians and other care providers themselves report inadequate training and awareness. In a survey of Connecticut physicians, 91 percent of primary care physicians revealed that they had received no training in intellectual and developmental disabilities, and 71 percent thought they would benefit from such training. Most respondents thought that providing care for people with intellectual and developmental disabilities was likely to be more difficult than caring for other patients.⁴⁸

Lack of disability and knowledge is a leading barrier to care, according to women with disabilities and those with diverse disabilities, including people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. Without appropriate training and awareness, health care providers hold incorrect assumptions and stereotypes about people with disabilities, which can affect every aspect of care and can result in inadequate and inappropriate care. Research has revealed, for example, that some providers incorrectly assume that people with disabilities do not have a good quality of life; that people with developmental disabilities do not feel pain and, therefore, do not require anesthesia; that people who are deaf have cognitive deficits because they may not be fluent in standard English; and that women with disabilities do not require reproductive counseling and care because they may be incorrectly perceived as sexually inactive. Beyond undermining quality of care, such humiliating and frustrating encounters with health care providers can damage patient-provider trust and deter people with disabilities from seeking care.

4. *Structural and Communication Barriers*

People with disabilities encounter other structural barriers to health care, including inadequate transportation, lack of architectural accessibility in the facilities and offices of health care providers, and lack of accessible exam and diagnostic equipment. Communication barriers are also frequently cited as problems that prevent access to care or reduce the quality of care that people with disabilities receive.

For many people with mobility disabilities, access to examination and diagnostic equipment such as mammogram machines can be difficult or impossible if the equipment is not height-adjustable. Medical office staff members often are not trained to provide lifting assistance and are unwilling to lift patients onto inaccessible examination tables. Some patients do not wish to be lifted, out of fear that they will be dropped or injured. Health care providers, therefore, frequently conduct examinations or diagnostic tests while patients are seated in their wheelchairs, which can generate inaccurate test results or conceal physical evidence required for appropriate diagnosis and treatment. This fact was made evident by one of the plaintiffs who participated in a landmark

lawsuit, brought in 2000 against the largest nonprofit health maintenance organization in the country. This plaintiff was usually “examined” in his wheelchair during his check-ups rather than given needed lift or transfer assistance. He developed a pressure sore that remained undetected, became infected, and eventually required surgery.⁴⁹ Recent research reports that about 5,596,000 Americans live with paralysis from causes such as strokes, spinal cord injury, and multiple sclerosis; this is about 40 percent more than previously estimated, thereby adding to the urgency of the need to address structural barriers to care.⁵⁰

For many people with disabilities, poor communication with providers and limited time for office visits reduces the quality of care they receive and may impede diagnosis of new health conditions and prolong or leave untreated chronic health problems. Communications difficulties have long been reported by people who are deaf or hard of hearing. Standard English is not the primary language for many people who become deaf prelingually. People who become deaf prelingually constitute a distinct cultural and linguistic minority, and they do not always communicate effectively in English. Their primary language is likely to be American Sign Language (ASL); yet interpreters frequently are not provided during medical visits. As a consequence, people who are deaf often have significant difficulty communicating effectively with their health care providers and receiving health care information and instructions. Lack of interpreters impedes effective communication, which serves as a disincentive to seeking care. People who are hard of hearing often have difficulty communicating effectively with health care professionals, who may be unaware of appropriate techniques for communication and who rarely provide accommodations, such as conducting an examination in a room with limited ambient noise, offering assistive listening devices, or scheduling additional time to ensure that the patient has understood the information being provided. Other people with disabilities, including people who are blind, report that medical providers sometimes do not speak to them directly and do not make prescription information, return appointment, and other health care instructions available in formats that are accessible. Diabetes care training can be difficult to obtain for people who are blind or have vision disabilities, because some diabetes care professionals are

not aware of blood glucose testing equipment that provides an audio output of readings. People with developmental disabilities also report difficulty communicating with some health care providers, because too little time is available during standard office visits for discussion of complex health issues or the appropriate, understandable presentation of information so that people with developmental disabilities can participate in their health care decisions and become informed about wellness and prevention activities.

C. Health Status and Unique Barriers to Care for Women with Disabilities, People Who Are Deaf or Hard of Hearing, People Who Are Blind or Have Vision Impairments, and People with Intellectual and Developmental Disabilities

Research has shown that certain groups within the disability population sometimes experience specific health disparities and, in some cases, unique and ongoing problems accessing health care. Among many such groups, the following discussion examines specific health and health care problems and issues for four groups: women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities. Elucidating health disparities and barriers to health care for these groups brings into focus the scope and magnitude of difficulties and problems faced by the broader disability community into focus. Moreover, solutions that benefit members of these groups will also have a crosscutting impact on those with multiple impairments and those who belong to specific demographic populations, thereby improving access to care for everyone.

1. *Women with Disabilities*

Women experience different challenges to health and wellness than men do. Among women living in the United States, as many as one in five experiences some level of disability, a number that is growing as the population ages. However, there is limited research about the health status, barriers to health care, and level of participation in health and wellness programs of this large and important group.⁵¹

Many of the known health disparities women with disabilities experience are rooted in longstanding structural, financial, and personal barriers to health care access. These include limited access to culturally competent care from primary and specialty providers; negative provider attitudes; lack of insurance, including medical, dental, prescription, and vision insurance; and restrictive coverage under available health plans. Additional barriers include poor access to services and programs dedicated to wellness and prevention; inaccessibility of health facilities, services, and diagnostic and examination equipment; ineffective communication between provider and patient; and inadequate transportation.

Public health research on health disparities experienced by women with disabilities receives only a fraction of overall disparity research funding, which focuses primarily on racial and ethnic minority populations. While these populations also include women with disabilities, and women who are members of racial and ethnic minorities face additional health disparities and risks,⁵² research and program development funds that would aid in understanding and responding to the unique needs of women with disabilities are limited. Federal health, wellness and prevention, and literacy programs have not yet fully recognized, acknowledged, or responded to the unique health and health care issues of women with disabilities.

a. Disability Prevalence Among Women

In 2005, according to the U.S. Census Bureau, 20.1 percent of girls and women in the noninstitutionalized civilian population reported disability, compared with 17.3 percent of males. Further, severe disability was more prevalent among girls and women (13.4 percent) than among males (10.6 percent).⁵³ The number of women living in nursing homes is 1 million—5.3 percent of the population of women over age 65. This statistic does not include girls under age five, women in the military, or women in any type of congregate living situation besides nursing homes, such as dormitories or group homes. It is not clear whether this statistic also excludes women living in nursing homes who are under age 65.⁵⁴

Disability affects women more significantly as they age. Among women aged 16 to 64, a little over 17 percent have one or more disabilities, compared with 43 percent of women who are 65 or older.⁵⁵ The incidence of severe disability is higher among African American women (15.4 percent) than among Hispanic women (10.0 percent) and white non-Hispanic women (13.8 percent).⁵⁶

b. Health Status and Health Experiences

Recent research reveals that women with disabilities experience poorer health than women who do not have disabilities, despite the fact that both groups report the same types of health problems. Nearly a third of women with extensive functional limitations rate their overall health as poor compared with less than 1 percent of women with no limitations.⁵⁷

One study of Medicaid beneficiaries concluded that women with disabilities were about 50 percent less likely than women who did not have disabilities to be satisfied with their medical care. These women were 24 percent less likely to have received a Pap test during the previous year than women without disabilities and were nearly three times more likely than women without disabilities to have postponed needed medical care. Outcomes for this group were substantially worse in terms of receiving necessary medical care and being able to obtain prescription drugs. Women with disabilities who received Medicaid were more than twice as likely to have postponed taking medication they needed during the previous 12 months.⁵⁸

As they age, women with disabilities tend to have poorer health than women who do not have disabilities. They are more likely to be overweight, smoke, have high blood pressure, and experience mental health problems. Women with more significant disabilities are more likely to live alone, be unemployed, have less education, be divorced, and live in poverty.⁵⁹

According to the 2008 NCHS study, about 30 percent of women with basic actions difficulties were overweight, and 31 percent were obese. Among those with complex

activity limitations, almost 30 percent reported being overweight, and over 34 percent were obese. Slightly over 23 percent of women with complex activity limitations smoke, compared with 22.5 percent of women with basic actions difficulties.⁶⁰

c. Barriers to Health Care

Physical, attitudinal, and policy barriers; lack of information about how disability affects health; limited finances; and inadequate personal assistance limit access to health care services for women with disabilities. Many women with disabilities also face multiple barriers to health care because of racial or ethnic minority membership, sexual orientation, type of disability, or geographic location.⁶¹

Women report that financial and cost concerns and inadequate health insurance are the primary reasons they cannot obtain needed services.⁶² Women with disabilities who had three or more functional limitations were more likely to report being unable to get general medical and dental care, prescriptions, or eyeglasses, regardless of age group, compared with women who do not have disabilities. Women with disabilities also report problems with access to prevention services.⁶³

- **Health Care Coverage**

For most noninstitutionalized people in the United States, health insurance coverage determines the extent to which they have access to every aspect of health care. This includes access to inpatient care, prescription drugs, diagnostic procedures, durable medical equipment, and prevention and health promotion services and programs. Most women over age 65 are covered by Medicare. Among women under age 65, women with disabilities are much less likely to have private health insurance than women who do not have disabilities.

Most private insurance is available through employers. Women with disabilities have higher rates of unemployment, underemployment, and poverty, and therefore are less likely to have access to private health insurance. They are also less likely to be married than women who do not have disabilities, and therefore are less likely to be covered by

a spouse's policy. Among women who do not have disabilities, slightly over 75 percent have private insurance, compared with almost 62 percent of women with basic actions difficulties and only about 49 percent of women with complex activity limitations.⁶⁴

Women with disabilities are more likely than women without disabilities to be covered by publicly financed health care programs, primarily Medicare and also Medicaid, which provides health coverage for low-income people with disabilities under age 65. Medicaid generally provides a higher level of certain services, assistive technologies, long-term care, and prescription drugs than either most private health plans or Medicare.⁶⁵ Nearly 28 percent of women with complex activity limitations are covered by the Medicaid program, while 16 percent of women with less significant disabilities are Medicaid beneficiaries. Depending on the level of disability, 15 and 18 percent of women with disabilities who are age 18 to 64 have no health care coverage at all.⁶⁶

Even when a woman with disabilities has health insurance, her plan may not adequately cover required prescriptions, physical or occupational therapy, durable and expendable medical equipment and supplies, assistive devices, or personal assistance services.⁶⁷ Limited coverage or lack of coverage means that both women and men with disabilities must often pay higher out-of-pocket expenses than people who do not have disabilities. These out-of-pocket expenses include deductibles and copayments for needed services, prescriptions, and equipment. The more significant a person's disability, the higher the probability that out-of-pocket expenses will be greater.⁶⁸

- **Reproductive Care**

Women with disabilities require health services related to sexuality, reproductive care, and childbearing, just as women without disabilities do. However, social misperceptions and stereotypes about disability can make it difficult for women with disabilities to obtain information, medical care, and services to ensure that their reproductive needs are met. Such needs include routine gynecological and breast examinations; screening for sexually transmitted diseases (STDs); contraception; consultations about sexuality and sexual function; fertility consultation and support; obstetrical care during pregnancy,

labor, and delivery; and information about healthy parenting and about issues related to menopause, including osteoporosis, loss of libido, and insomnia.

Structural barriers to receiving adequate and informed reproductive care include limited professional training and competency of primary care and reproductive care specialists; inadequate or no health insurance coverage for visits to specialists; poor physical access to usable and adapted or specialized examination and diagnostic equipment; and negative or discriminatory provider attitudes.⁶⁹

According to one qualitative study, health care providers sometimes expressed surprise that women with disabilities would be sexually active. As a result, they frequently did not discuss the use of contraceptives or evaluate the women for STDs. Some women with disabilities reported that they avoid regular visits to the gynecologist because services are so difficult to obtain.⁷⁰ In a telling example, one study reported that a gynecologist caring for a woman who uses a wheelchair assumed she was not sexually active and, therefore, saw no need to test for STDs.⁷¹ In another example that arose during focus group research, a deaf woman spoke about her doctor's negative attitude toward people who are deaf.

The doctor had a mask on so I could not read his lips, but we had this interpreter with us, and [she interpreted when] the doctor said, "Well, the Deaf woman should tie her tubes so she doesn't get pregnant again."⁷²

Among women who received Medicaid, women with disabilities were also more likely to have had emergency room visits, hospital admissions during pregnancy, cesarean deliveries, and readmissions within three months of delivery.⁷³

d. Disease Prevention and Health Promotion

Few studies have been conducted that document the use of primary health care and disease prevention services by women with disabilities. The existence of a primary disability can increase the possibility that a woman with a disability will acquire secondary conditions. One national study comparing health care and preventive care

among women with and without disabilities concluded that women with disabilities experience worse health care and worse preventive care than women without disabilities.⁷⁴ Wellness promotion and health screening tests are essential to avert secondary conditions that can reduce functional capacity, diminish quality of life, and potentially lead to early death. Yet women with disabilities face numerous hurdles to participation in health screening programs. Measures that support wellness, including exercise, can be difficult or impossible for women with certain disabilities, because most exercise equipment is inaccessible and exercise facilities rarely accommodate people with disabilities.⁷⁵ For women with disabilities, factors such as having both health insurance and a regular source of health care predicted whether or not they received all types of clinical preventive services.⁷⁶

- **Breast and Cervical Cancer Screening and Treatment**

Women with disabilities frequently face barriers to health care access that may delay detection and increase poor outcomes from breast cancer. One study that focused on breast cancer screening also noted that financial, architectural, environmental, and attitudinal barriers particularly affected the health care services received by women with physical disabilities. In this study, women with disabilities reported that their health care providers held them in lower regard and were more likely to disregard or overlook symptoms when treating women without disabilities.⁷⁷ Outcomes from focus groups conducted in Massachusetts include the following anecdote:

In one particularly troubling instance, a provider's value judgment about a patient with mental retardation led to a year-long delay in treatment for a life-threatening medical condition. The patient suffered from advanced breast cancer that required surgery, but her physician implied that due to her already low quality of life (owing to her disability), she did not merit the intervention, and her guardian did not want to make the decision to go forward without the physician's support. This woman reportedly died within a year, and there was concern that her death may have been precipitated by the delay in surgery.⁷⁸

In a large breast cancer study of more than 100,000 women, those who received Social Security Disability Insurance (SSDI) and who had Medicare coverage had lower rates of breast-conserving surgery than other women (43.2 percent versus 49.2 percent).

Women with SSDI and Medicare who had breast-conserving surgery were also less likely than other women to receive radiotherapy and axillary lymph node dissection. These women had lower survival rates from all causes and specifically from breast cancer.⁷⁹ Explanations for such disparities could include lack of early diagnosis, lack of breast health awareness or education on the part of the woman herself, inaccessible or unreliable transportation, and cultural capacity of the treating facility. Inaccessible equipment and other physical barriers could also add to the problem.⁸⁰

Another recent study compared breast cancer treatment for women with disabilities who had Medicare insurance through health maintenance organizations, fee-for-service health care programs, or a combination of both. This study concluded that women with continuous HMO insurance had earlier stage breast cancer diagnosis and were more likely to receive radiation therapy following breast-conserving surgery. Women with continuous HMO insurance had a higher rate of breast cancer survival, primarily resulting from earlier stage diagnosis.⁸¹

The following example from a national summit on health care for women with disabilities illustrates disparities in breast health care and early breast cancer diagnosis.

A 42-year-old woman with paraplegia notices a lump in her right breast. Her medical provider tells her it is a bulging pectoral muscle from pushing her wheelchair. Later diagnosed with Stage III breast cancer, she dies within three years.⁸²

In focus groups with deaf women, some participants in the study expressed limited awareness of the importance of mammography and breast self-examination. During the focus groups, facilitators became aware of several women who clearly required breast care. The following comments from participants underscore their need for access to information about health screening as well as education about the importance of regular examinations:

Participant 1: I've never had a mammogram, not in 15 years, and I don't need one. I feel fine. I don't feel sick at all.

Participant 2: I don't want to have a mammogram—I'm scared of the radiation! Radiation will destroy my breast.

Participant 3 (over 65 years of age): I went every year for a checkup with my family doctor; he never advised me to get a mammogram.⁸³

Several studies report that women with disabilities who had significant functional limitations were much less likely to receive Pap tests and mammograms, even when they had health insurance, than women with disabilities who had fewer limitations.⁸⁴ Similarly, in a study intended to compare prevention procedure rates of Medicare beneficiaries with disabilities, women with the most significant disabilities reported fewer Pap tests and mammograms compared with those without disabilities. Women with significant disabilities were 57 percent less likely to report receiving Pap tests and 56 percent less likely to report receiving mammograms compared with women who did not have disabilities, regardless of age.⁸⁵ The 2008 NCHS study reports that 64.6 percent of women with complex activity limitations and 70.8 percent of women with basic actions difficulty had received a Pap test within the past 3 years, compared with 82.5 percent of women who did not have disabilities.⁸⁶

The following illustrates the indifference of one physician when faced with patients who may be difficult to examine or treat.

A nurse for a woman with mental retardation who had difficulty undergoing gynecological exams reported that the woman's doctor downplayed the importance of such exams for the woman, ostensibly because she was not sexually active.⁸⁷

- **Cardiovascular Disease Prevention**

Although it is a major cause of death in the United States, cardiovascular disease (CVD) has received little attention in women with disabilities. Recent research suggests that women with disabilities had less awareness of CVD risk factors and have participated in less preventive screening for CVD than women without disabilities. Even when women seek care for potential cardiovascular problems, inadequate diagnostic techniques can result in dire outcomes. This problem was illustrated in a 2007 article published by the

Journal of the American Medical Association (JAMA) that highlighted an example of how women with disabilities do not always receive a standard of care afforded women who do not have disabilities.

Susan, who uses a wheelchair, had trouble breathing. She needed an echocardiogram, which was performed while she sat in her wheelchair [rather than lying in the supine position]. The echocardiogram was of poor technical quality and yielded little information.⁸⁸

Research suggests that measurement of weight, electrocardiograms, and inquiries about smoking habits occurred less frequently for women with disabilities than for women of similar age without disabilities. Women with disabilities who are physically inactive and postmenopausal were likely to be at higher risk for CVD. The risk of CVD, therefore, appears to be under-recognized and under-assessed, particularly in women with physical disabilities.⁸⁹

e. Conclusion

The structural and environmental problems and barriers to health and health care services and programs experienced by women with disabilities call for additional research funding and a heightened public health emphasis on women with disabilities in all programs concerned with women's health. Future public health research, policy, and health program initiatives should fully foster and integrate issues and concerns of women with disabilities. Such initiatives include those in professional medical training institutions, in continuing education of medical professionals, and in Federal intramural and extramural research focused on health and wellness.⁹⁰ Future health disparities research must specifically investigate secondary health disparities, such as obesity, and the outcome of programs aimed at reducing these disparities, including disease prevention and health promotion activities for women with disabilities.

2. *People Who Are Deaf or Hard of Hearing*

People who are deaf or hard of hearing experience extensive, largely unrecognized communication problems when they seek health care services. One researcher eloquently summarized these difficulties.

Deaf or hard of hearing individuals in the U.S. must often cope with extraordinary communication barriers when working with their health care providers; receive health care services that are inadequate, inappropriate for their needs, and unethical due to the interplay of numerous complex individual, interpersonal, and systematic factors; and have a poorer self-reported health status than the general population. Within the subset of the U.S. population that uses English as a second language, Deaf individuals may be at greatest risk for poor physician-patient communication.⁹¹

a. *Prevalence of Deafness and Hearing Loss*

Definitions of hearing impairment vary widely, as do estimates of the number of people in the United States who are deaf or hard of hearing. According to a 2008 report published by the National Center for Health Statistics (NCHS), 37,000,000 adults experience some degree of hearing loss, ranging from a little trouble hearing to deafness. About 3.3 percent of adults in the United States who are over age 18 experience deafness or have a lot of trouble hearing.⁹² Hearing impairment is the sixth most common chronic condition in the civilian population.⁹³ Some estimates suggest that more than 4,800,000 people in the United States have hearing impairments severe enough that they cannot hear or understand speech, while other estimates indicate that roughly 1,800,000 people in the United States are deaf.⁹⁴

As with many other disabilities, the prevalence of hearing loss increases dramatically as the population ages. The number of people who experience deafness or who have a lot of trouble hearing increases from 0.9 percent among adults under the age of 45 to 3.1 percent among those aged 45 to 64. Among adults over 65, 11.1 percent report deafness or a lot of trouble hearing. Similarly, the number of people who experience lesser hearing loss also increases with age: 27 percent of people aged 65 and over report a lot of trouble hearing.⁹⁵

b. Health Status and Health Experiences

According to health experts, research about the health status, health behaviors, risk factors, and diseases experienced by people who are deaf or hard of hearing is limited, because research is generally focused on hearing loss itself.⁹⁶ Moreover, early studies may be misleading, because they excluded certain important segments of the deaf population. Conflicting research and a relative lack of data, therefore, make it particularly challenging to identify the health care needs of this heterogeneous group.⁹⁷ Further, few studies have examined deaf adults' experiences with the health care delivery system.⁹⁸ Research has revealed, however, some important preliminary information about the health status of people who are deaf or hard of hearing, as well as some of the pressing problems this community encounters in the health care delivery system.

- **A Distinct Cultural and Linguistic Group**

Most researchers and most deaf individuals consider the Deaf community a distinct cultural and linguistic group. As a distinct group, the Deaf community is entitled to the same acknowledgment that society affords other groups with their own culture and language. The syntax and grammar of American Sign Language (ASL) is independent of English, and those who use it are a distinct linguistic group. People who use ASL as their primary language share experiences that parallel those of other cultural and linguistic minority groups. For example, the Deaf community shares a cultural heritage that includes similar family and educational experiences, and common social and community interests. Similarities to other minority groups include limited use of English in day-to-day communication; limited access to information from radio, television, and other forms of mass media; lack of access to information that is present in the ambient environment; and dependence on family members, friends, and others as interpreters.

People who use ASL frequently identify their linguistic identity by spelling "Deaf" with an uppercase "D," while "deaf" with a small "d" indicates hearing impairment as a physiological characteristic.⁹⁹ However, not all people who are deaf identify with the cultural minority that uses ASL. The U.S. Census and other large population and health

surveys do not inquire about ASL use, so the size of this community is not known; estimates range from 100,000 to 1,000,000 people. Among adults who are deaf, about 8 percent acquired their disability prelingually (i.e. before the age of three), and an estimated additional 11 percent became deaf between the ages of 3 and 19.

- **Health Disparities**

The 2008 NCHS study reports that as hearing loss increases, people experience a higher prevalence of fair or poor health status; problems walking, bending, and reaching; and psychological distress. Adults in the study who were deaf or who experienced significant problems hearing were three times as likely to report fair or poor health compared with those who did not have hearing impairments. Hypertension and diabetes were more prevalent among adults who were deaf or had a lot of trouble hearing than among those who did not; they were highest among adults under age 65. People who were deaf or had a lot of trouble hearing were more likely to smoke (40 percent of those between ages 18 and 44, compared with 24 percent of people who were not deaf or hard of hearing). People who were deaf or had a lot of trouble hearing were also more likely to be overweight and less likely to participate in leisure time physical activity.¹⁰⁰ The NCHS study and other research have also shown that people who are deaf or have a lot of trouble hearing are more likely to drink alcohol at higher rates than adults with no hearing difficulties, and have more difficulty finding appropriate accessible treatment services and programs.¹⁰¹ More than 40 percent of adults who are deaf, or have a lot of trouble hearing, smoke cigarettes, compared with 24 percent of people who do not have hearing problems.¹⁰² Deaf women of color appear to experience the greatest health disparities and difficulty accessing appropriate health care. They tend to have lower incomes and poorer health, and to be less educated compared with white women. Among women of color, African American deaf women experience the greatest health disadvantages.¹⁰³

- **Health Care Experiences**

People who are deaf or hard of hearing have a range of experiences with health care professionals, and these experiences may differ according to when they acquired

hearing loss or became deaf. However, people who are deaf or hard of hearing have different health care experiences compared with people who do not have hearing loss. One study suggests that people who become deaf prelingually use health care at about the same rate as other minority language groups, while people who become deaf postlingually use health care services at about the same rate as individuals who have chronic illnesses.¹⁰⁴ Medicare beneficiaries over age 65 who experience some hearing loss report lower satisfaction with health care access and quality of care than do other groups.¹⁰⁵

c. Barriers to Health Care

- **Lack of Effective Communication**

Communicating effectively in health care settings presents complex challenges for people who are deaf or hard of hearing. Research has revealed that people who are deaf or hard of hearing identify similar communication problems that compromise health care, including the following:

. . . medication errors and misdiagnoses, problems during surgery and anesthesia, missed and delayed appointments, and less complete and accurate information than other patients receive.¹⁰⁶

Hearing loss varies from person to person, and communication styles and needs can be unique to the individual. As a result, diverse, individualized strategies are necessary to achieve effective communication. For example, while many people who are deaf communicate using ASL, others who are deaf or hard of hearing use speech-reading, speaking, writing, or a combination of these methods.¹⁰⁷ Some people who are hard of hearing also use hearing aids or other devices, including assistive listening devices that are necessary to communicate effectively during medical visits. For others who are hard of hearing, effective communication may require that their health care provider modify the way he or she speaks. Because most hearing loss occurs in the higher frequencies, the provider's speech may be more accessible if he or she speaks in a lower voice. The patients may also need for the provider to be face to face and avoid turning away or covering his or her face. Some people may benefit if noise distractions are reduced.¹⁰⁸

Some people with hearing loss, including older people, may not acknowledge their hearing loss and may act as though they understand what is being communicated, while not in fact understanding. These individuals may require additional time and attention during health care provider visits to ensure that information has been communicated clearly and effectively. Also, communications can be especially demanding physically and emotionally for patients who are deaf or hard of hearing, making fatigue a potential factor in determining effective communication.¹⁰⁹ One study concluded that older adults with mild-to-moderate hearing loss may expend so much cognitive energy trying to hear accurately that their ability to remember spoken language suffers as a result.¹¹⁰ Thus, they may have difficulty retaining information presented during a health care visit.

Most health care practitioners have little understanding of how people with hearing loss communicate or how to communicate effectively with them. This lack of awareness directly affects the quality of health care these practitioners can provide.

Focus group research has revealed widespread problems that affect health outcomes for many people; these problems often begin with provider assumptions about hearing loss. Most providers mistakenly assume that people who are deaf are fluent in both ASL and English. However, ASL is completely independent of English and does not have a written form. Attempts to write ASL using standard English words produces what appears to be broken English. This “broken” English leads some providers to assume that their deaf patients lack intelligence, an assumption they may not make about other people who are not fluent in English. If an immigrant from China with a Ph.D. in physics wrote in broken English, the health care provider would probably assume that the immigrant’s communication difficulties stemmed from the language barrier. However, lack of awareness about ASL and assumptions about people who are deaf lead health care providers to incorrectly assume that a patient with limited English skills is cognitively impaired. As evidence of this, deaf patients often report that their physicians do not appear to respect their intelligence and think that they do not want to take responsibility for their health.

People who are deaf or hard of hearing report that health care providers rarely use appropriate and effective methods of communication. Problems begin when an individual attempts to schedule an appointment with a health care provider and continue during office visits, diagnostic procedures, emergency room visits, hospitalizations, and even in hospice care. Health care providers sometimes do not understand that providing appropriate methods of communication is medically necessary to ensure that health care is effective. Rather than asking the person what method of communication would be most effective, physicians and other health care practitioners frequently employ modes of communication that do not take into account specific individual needs. For example, they may rely on family members to interpret for patients who are deaf. Patients who are deaf can find it difficult to request an interpreter, because they are concerned that physicians might question the need or might expect the deaf individual to pay for the interpreter. In addition, some people who are deaf have reported that health care providers have denied requests for interpreters. Others have noted that interpreter services are not reimbursed by insurers, which presents a serious barrier to hiring them.¹¹¹

Many people who are deaf or significantly hard of hearing communicate using Internet technologies, including videophone/video relay interpreting services (VP/VRS), facsimile (FAX), text messaging, and instant messaging. Others use older technologies such as text telephones (TTYs), devices that allow the user to place a telephone call and then type a message to a person who also has such a device. Many people with hearing, speech, and language difficulties use the nationwide relay service established by the 1990 Americans with Disabilities Act (ADA). The relay service allows a caller using an Internet connection or TTY to contact a relay operator, who in turn places a call to the desired person and then “relays” the conversation between the two parties. Most health care practitioners, however, either are unaware that many people who are deaf and significantly hard of hearing people communicate using these technologies or are uncomfortable using them to communicate with patients. Moreover, some health care providers have raised the concern that these modes of communication do not preserve confidentiality and might violate the Health Insurance Portability and Accountability Act

(HIPAA), even though they are the modes by which people who are deaf communicate most effectively.¹¹²

Most practitioners have complex menu-driven voice message systems that make it difficult for relay operators to type the options to the caller before the connection times out.¹¹³ Thus, people who are deaf or hard of hearing are sometimes unable to make appointments with their health care providers or communicate directly with them. Regarding these basic communication barriers, one focus group participant said:

We just go right to the hospital. I wouldn't call my doctor at all. I just go right to the emergency room.¹¹⁴

Typically, health care providers expect deaf patients to be able to read their handwriting or to lip-read as they speak. Deaf participants from several focus groups said they had significant problems with writing as a mode of communication, not only because it is slow and inefficient, but also because the vocabulary is unfamiliar and the handwriting often illegible. Because ASL is not English, medical terms are often interpreted using a vision description rather than a single corresponding word. This means that many deaf individuals never have the opportunity to learn medical terms. For example, there is no sign for the word "cholesterol," so a certified interpreter would describe cholesterol as a type of fat build-up in the blood vessels. Another interpreter might simply finger spell the word "cholesterol," but the patient might not know what the word means. Syntax differences between English and ASL can compound the communication problem when unfamiliar medical terms are used. Similarly, speech-reading is ineffective because only about 30 to 40 percent of spoken English can be understood using this technique.¹¹⁵ One focus group participant illustrated the problems with speech-reading.

I was so shocked when they had five people, doctors and aides. . . . All these people came towards me. . . . I wondered what was going on. So I started writing notes to them. . . . I could see they were talking. . . . I had no idea why there were five people there looking at me. . . .¹¹⁶

Many deaf participants in focus groups said that they frequently relied on family members or friends to interpret for them during medical visits. This practice not only raises serious confidentiality issues for the person who is receiving care but also does not necessarily ensure effective communication between the patient and clinician. Health care providers typically overestimate the sign language skills of friends or family members who are neither trained in medical interpretation nor certified as sign language interpreters. Sometimes young children interpret for parents or family members. However, it can be quite difficult for children to accurately convey medical information. They may not fully understand the information or may find the information distressing. People who are deaf may have difficulty understanding their health care provider's instructions about therapeutic programs, prescription dosages, or side effects, which can lead to new health problems and reinforce stereotypes about the intellectual capacity of the person who is deaf. In one study, a deaf participant talked about having surgery without an interpreter available.

I needed a tonsillectomy. I went to the hospital and I was scared. I was sedated and anesthetized, and I woke up afterwards, scared and crying. I didn't know what to expect or what was going on with the swelling. There was no interpreter there.¹¹⁷

Another deaf individual noted that the problems are a deterrent to seeking care.

There are a lot of deaf people who won't go to the doctor. [They think] I'll just bear with it until it goes away.¹¹⁸

In several studies, deaf focus group participants indicated that communication is most effective when they have the opportunity to work with medically experienced, certified ASL interpreters. However, often an interpreter is not available.¹¹⁹ One study revealed that even though physicians acknowledged that communication with deaf patients was most effective when ASL interpreters were available, they did not employ them frequently.¹²⁰ This study also revealed that physicians overestimated the accuracy of speech-reading.

When people who are deaf or hard of hearing have access to deaf-friendly medical organizations (i.e., organizations in which methods for effective communication such as ASL interpreters and assistive listening devices are readily available and providers understand cultural aspects of deafness), screening rates for colorectal, cervical, and breast cancer are similar to rates for the general population.¹²¹

- **Mental Health System Concerns**

For some people who are deaf or hard of hearing, longstanding concern over the lack of qualified interpreters is greater when seeking mental health services, where inadequate communication has sometimes resulted in inappropriate institutionalization and loss of liberty. Research has shown that some people who are deaf or hard of hearing distrust mental health providers in part because of concerns that communications will be ineffective in mental health settings. Some focus group participants expressed fear that confidentiality might be violated and that the ASL skill levels of interpreters would not be adequate. Others said that in mental health settings people who were deaf were at the mercy of hearing authorities, who were likely to be prejudiced about deafness. Participants in several studies expressed the concern that people who were deaf could mistakenly be committed to mental health facilities solely because of barriers to communication.¹²² People who are deaf or hard of hearing have expressed strong concern that mental health professionals have misdiagnosed patients who are deaf and prescribed incorrect medication for them because of stigma, stereotypes, and ineffective communication.

Some health care providers who are deaf or hard of hearing have observed that standard psychological testing can be inappropriate for people who are deaf because testers are rarely fluent in ASL and rarely understand Deaf culture.¹²³ Deaf patients who were willing to visit a therapist preferred to work with a deaf therapist. If that was not possible, they preferred to work with mental health counselors and therapists who were fluent in sign language.

Perceptions of mental health services can also depend on age. A study of senior, middle-aged, and young adults who were deaf asked the subjects what they would do if they needed mental health services. Those in the senior group said they would seek help from a friend or family member, while younger people said they would probably seek a mental health professional.¹²⁴

- **Lack of Insurance Coverage**

According to unpublished data from the 2007 National Health Interview Survey, among people in the U.S. civilian population between the ages of 18 and 64 who identify as deaf or hard of hearing,¹²⁵ 21.3 percent do not have any health insurance, while 34.2 percent are covered by private insurance, and 55.3 percent are covered by public insurance (30.1 percent by Medicare and 27.9 percent by Medicaid).¹²⁶

d. Disease Prevention and Health Promotion

Studies suggest that people who are deaf or hard of hearing experience specific barriers to participating in prevention programs, may have limited access to appropriate and accessible information about health promotion activities, and may not understand why such programs and activities are important. In particular, adults who are deaf tend to have less health literacy compared with the hearing population.

Lack of access to information in the media limits awareness of health-related information on the part of people who are deaf. Topics such as the latest health studies, and information about prevention and health services, nutrition, alcohol and substance abuse, sex education, and domestic violence prevention, are often discussed in popular media outlets, which are typically presented only in an audible format. It is not surprising, then, that adults who are deaf tend to have less health literacy compared with the hearing population. Some people who are deaf or hard of hearing are unaware of mental health services available in the community and unfamiliar with terminology used by mental health practitioners, suggesting a lack of information about these services as well.¹²⁷

For example, a comprehensive survey of 203 deaf patients in two health care systems that offer programs and services aimed at the Deaf community illustrated the respondents' lack of basic knowledge about health conditions. Forty percent of survey participants could not identify any of the seven most common warning signs of a heart attack, while 62 percent could not identify any of the seven most common warning signs of a stroke. In fact, 32 percent of study participants could not identify any risk factors for a heart attack or stroke, and one in three could not define the word "cancer."¹²⁸ In another study, more than 70 percent of deaf participants said that people who were deaf could not get HIV, and more than 50 percent did not know the meaning of "HIV-positive."¹²⁹ According to one survey, high school students who are deaf or hard of hearing had some understanding about HIV and AIDS, but there were significant gaps in their awareness of how the infection is prevented and transmitted.¹³⁰

Focus group research has shown that women who are deaf have unique linguistic and cultural issues that affect their health and their health care experiences. Participants were unaware of the need to assess health risks through prevention and diagnostic screening procedures, including those for cardiovascular disease. Some participants also lacked knowledge and information about screening and diagnostic procedures for breast and cervical cancer, and about the purpose and importance of treatments such as surgery.¹³¹

In general, women reported that they avoided visiting a health care provider because of the lack of effective communication, although they also reported positive experiences with some practitioners who use qualified interpreters.¹³² Studies comparing the prenatal health care of women who are deaf and women without hearing impairments reveal significant differences between the two groups. Women who were deaf were less satisfied with their prenatal care than hearing women, and they expressed less satisfaction with the quality of communication with their health care provider.¹³³ When deaf patients had access to ASL interpreters and to providers who understand cultural aspects of deafness, screening rates for colorectal, cervical, and breast cancer were similar to rates for the general population.¹³⁴

A recent literature survey produced no information specifically aimed at men who are deaf regarding the benefits of early screening, detection, and treatment of prostate cancer. In response to this gap, a prostate cancer education program was adapted and tested on a small sample of men whose baseline knowledge about the disease increased, as shown in followup surveys. While this program evolved into an Internet ASL-accessible video on prostate health, research on the effectiveness of this strategy must still be conducted, and ensuring that all men who are deaf have access to such information remains a challenge.¹³⁵

Similarly, little research has been carried out on tobacco use by youth who are deaf or hard of hearing. However, a recent study reveals that middle and high school students generally smoke less than their hearing peers, and that students who attend integrated educational programs were more likely to have tried smoking than their peers in schools for deaf students. This study also shows that although health care providers are important sources of prevention information, few students reported that they had received anti tobacco messages from their health care providers or in clinical settings—another missed opportunity to convey prevention guidance.¹³⁶

e. Conclusion

There is a tremendous need for increased attention to issues people who are deaf or hard of hearing have identified as deterrents to their health promotion and health care. The longstanding problems that arise from inequities in communication and poor access to culturally and linguistically appropriate health care and health information have failed to draw the level of institutional response from policymakers that is required to bring about systemic change.

At a minimum, additional public resources must be allocated to encourage and support ASL interpreter training and payment for interpreter services in medical settings. Congress should explicitly direct Medicare & Medicaid to pay for interpreter services, and states should require private health insurers to include payment for interpreters as a

reimbursable expense to health care professionals or as an accepted cost to be negotiated in managed care provider payment schemes.

There is also an important role for medical educators, who must train young professionals, including people who are deaf or hard of hearing, about issues of concern to the Deaf community and challenge negative stereotypes that currently influence practitioners' attitudes and methods for providing care. Accreditation organizations must include methods in their survey and monitoring mechanisms to evaluate the extent to which health care facilities have the capacity to provide interpreters for deaf or hard-of-hearing patients in a timely and effective manner. Patient education materials should also be assessed and modified to ensure that they are accessible.

3. *People Who Are Blind or Have Vision Impairments*

In the United States, vision impairment and blindness rank among the top 10 most common disabilities, and aging is associated with the leading causes of vision loss.¹³⁷ While the population of people who are blind or have vision impairments is heterogeneous and generally similar to the general population, the group as a whole tends to be older and poorer, and to include more women.¹³⁸ The number of people who are blind in the United States is projected to increase by 70 percent to 1.6 million by 2020, with a similar rise projected for vision impairment.¹³⁹ Research has shown that these conditions can be associated with a reduced quality of life and shorter life expectancy.¹⁴⁰

a. Prevalence of Blindness and Vision Impairment

Approximately 10 percent of the population aged 18 and older experiences vision problems, defined as difficulty seeing even when using glasses or contact lenses. Among these, 0.7 million people (0.3 percent) are blind. Women are more likely to have vision impairments than men, and vision problems increase with age.¹⁴¹ More than two-thirds of adults who have vision impairments are over age 65, and the leading causes of

vision impairment in the United States are age-related. These include cataracts, macular degeneration, glaucoma, and diabetic retinopathy.¹⁴²

Diabetes is the leading cause of blindness among adults aged 20 to 74; between 12,000 and 24,000 new cases of blindness attributed to diabetes are reported annually.¹⁴³

Income, education, and membership in certain racial and ethnic minority groups are significantly associated with vision impairment.¹⁴⁴ For example, 16 percent of adults in poor families had vision difficulties, compared with 9 percent of adults in families that were not poor.¹⁴⁵ People who are Hispanic have higher rates of vision impairment than people who are African American, and both groups have higher rates than those for people who are white.¹⁴⁶ In addition, approximately 27 percent of the 4 million people living in nursing homes have vision impairments. These individuals have not been counted or included in national health surveys until recently.¹⁴⁷

b. Health Status and Health Experiences

- **Health Disparities**

Approximately 30 percent of people over age 18 who have vision impairments rate their overall health status as either “fair” or “poor,” compared with 8 percent of the population that does not have vision impairments. They also experience a greater prevalence of obesity. Studies suggest that slightly over 26 percent of adults with severe vision impairments are obese, compared with only 15 percent of adults who do not have such vision loss.¹⁴⁸ Numerous medical conditions have been linked to obesity and being overweight, including Type II diabetes, cardiovascular and pulmonary disease, certain cancers, sleep apnea, and liver and gallbladder disease. Adults with vision impairments are also more likely to have heart disease and hypertension than the general population. People with significant vision impairments also smoke more than the general population.¹⁴⁹

People who experience significant vision loss report higher rates of depression and anxiety than people without vision impairments. One study reports that among the estimated 5.7 million older people who have vision impairments, 3.3 million are at increased risk for mild or moderate depression, and 350,000 may experience severe depression.¹⁵⁰ Recent evidence suggests that young and middle-aged people who develop vision loss, rather than experiencing it from birth, may have depression at even higher rates than older adults.¹⁵¹ Further, some evidence suggests that adults who have vision impairments and have depression are less likely to seek vision rehabilitation services. When they do participate in these services, they have poorer outcomes than people who have vision impairments and do not have depression.¹⁵²

Among Medicare beneficiaries, 8.1 percent of people with severe vision impairments indicate dissatisfaction with the overall quality of their health care, compared with about 4 percent of the general population. About 11 percent of Medicare users who have vision impairments report that they do not receive adequate information from their providers about their health conditions, compared with 6 percent of people who do not have vision disabilities.¹⁵³ Within the population of older people, vision impairment is associated with reduced mobility, falls, increases in hip fractures, depression, and even mortality.¹⁵⁴

Adults under age 65 who are covered by Medicaid are more likely to have problems with their vision than those who have private insurance or no insurance. Among adults age 65 and over, those covered by Medicaid and Medicare are more likely to have vision problems than those with only Medicare health care coverage or private insurance.¹⁵⁵

- **Health Experiences**

National surveys provide new information about the health of people who are blind or have vision impairments, as well as about their general satisfaction with health care. However, few studies inquire in detail about the health care experiences of people who are blind or have vision impairments, or explore their ideas for improving their care.¹⁵⁶

One cross-disability focus group study revealed that people with diverse disabilities, including people who are blind or who have vision impairments, have encountered disrespect, insensitivity, and lack of disability awareness in health care settings. Distressing encounters with the health care system can lead to distrust and even fear, which in turn leads people to avoid getting health care.¹⁵⁷

One participant in a focus group of people who are blind or have vision impairments described how he would like to be treated by health care providers.

We are not accepted as a . . . human being, over and over again. We have got to be seen as persons of worth and people who actually can contribute to our own care. . . . We should be treated as individuals with intelligence.¹⁵⁸

Similarly, older persons with vision disabilities may find it difficult to negotiate an unfamiliar health care setting and, as a result, appear confused or hesitant. This demeanor can lead to misunderstandings and even spark impatience on the part of health care professionals, leading to a negative experience for the person who has the vision disability.¹⁵⁹

c. Barriers to Health Care

• **Lack of Health Care Provider Awareness**

Participants in one focus group frequently reported that health care providers and their staffs were unaware of how to relate appropriately to people who are blind or have vision impairments. They indicated that some health care providers are uncomfortable communicating with patients who are blind or have vision impairments. For example, providers frequently speak to a companion who is sighted, rather than speaking directly to the person who is seeking medical care. Almost 10 percent of people who have vision impairments indicate that clinicians tend to focus on discrete symptoms rather than on the whole person, compared with 5.1 percent of people who do not have vision impairments.¹⁶⁰ One woman who is blind described her experiences with her health care providers.

They don't really know how to deal with a blind person. They don't know how to treat you. As opposed to coming up and saying, "I'm so-and-so. I'm going to take you in the room now," they grab you. They snatch you. They push you. They'll grab you around the shoulders and push you along.¹⁶¹

People who are blind or have vision impairments may also need assistance filling out forms. They report that, while office staff are willing to assist them, the staff frequently do so in the waiting area. Doing this means that patient confidentiality cannot be maintained.¹⁶²

- **Lack of Transportation and Facility Accessibility**

Focus group participants also identified other barriers to care. Barriers related to public transit included lack of public transportation in suburban and rural areas, difficulty scheduling rides, and difficulty relying on paratransit to get to appointments on time. Barriers in the facilities of health care providers included lack of appropriate, accessible signage using Braille and raised letters. Without such signs, it is difficult to identify destinations within suites of medical offices.

- **Poor Diabetes Care and Lack of Information in Accessible Formats**

Health care providers rarely supply information in formats that are accessible to people who are blind or have vision impairments. Health care instructions, educational materials, and information about medications are typically provided only in print.¹⁶³ Outcomes from one focus group indicate that people who are blind or have vision impairments do not receive diabetes education and care equivalent to people without vision impairments.¹⁶⁴

Many people who are blind or have vision impairments and who also have diabetes report that diabetes care professionals are poorly equipped to serve them appropriately. Professionals rarely understand their need for information in an accessible format. One informal survey revealed that three of nine diabetes educators recommended that their patients who have vision impairments get help from a sighted person rather than learn self-care for their diabetes. Further, this survey revealed that health care providers are

generally unaware of speech-output devices that enable people who have vision impairments to measure their blood sugar and blood pressure independently. Managing diabetes properly requires training and regular monitoring, so individuals who have vision impairments must be able to do so independently. However, these barriers act as a deterrent for many.¹⁶⁵ Recognizing the urgency of this problem, the leading national organizations in the United States that work on behalf of people who are blind and have vision impairments published a consensus statement calling for accessible diabetes education.¹⁶⁶

In addition to blood glucose and blood pressure information, people who are blind or have vision impairments also require access to prescription information. Conventional medication vials provide information only in printed form, but new technology has been developed that provides independent access to print information required to identify and use prescription medications. Called ScripTalk, the system involves an encoding unit housed at the pharmacy that is attached to the computer that pharmacists use to create print prescription labels. This unit creates a prescription label containing a tiny chip in which information is embedded. The label is read by a battery-powered radio frequency identification reader in the possession of the person who is blind or who has a vision impairment. Thus far, only the Department of Veterans Affairs (VA) is making ScripTalk available to veterans with vision loss.¹⁶⁷ ScripTalk, or other similar technologies as they develop should be made available in pharmacies and to people with vision impairments to meet the critical need for such customers to have full and independent access to prescription medication information. Further, public and private health care insurance plans should include this technology in coverage agreements to ensure that it is readily available to those who need it.

- **Lack of Insurance Coverage for Mental Health Services**

Although the demand for mental health services is great, funding is inadequate and available services cannot meet the need. Medicare and Medicaid provide some mental health care. However, significant disparities exist between the coverage they provide for physical health services and the coverage they provide for services related to mental

health. Insurance reimbursement frequently requires people who need mental health services to pay higher deductibles and copayments for mental health care than for physical care. Insurers often cap benefits and restrict the number of treatment visits as well. Further compounding the problem, primary care and mental health providers sometimes incorrectly assume that an individual's mental health problem relates directly to her or his vision impairment. They may refer the individual to vision rehabilitation services, which do not treat the underlying depression.¹⁶⁸

- **Limited Vision Rehabilitation**

Vision rehabilitation provides opportunities for many people who are blind or have vision impairments to regain personal and functional independence. Vision rehabilitation typically includes such services as “low vision evaluations; training in techniques for using one’s remaining vision; provision of low vision devices and training in their use; mobility training to enable a person to travel safely indoors and outdoors; and training in adaptive techniques for communication and for home and personal management.”¹⁶⁹ However, access to vision rehabilitation services is limited, in part because of eligibility definitions. Even people who are eligible for services may not know that they are available or may find their cost prohibitive. Further, too few vision care specialists, including ophthalmologists and optometrists, refer eligible people who have vision impairments to vision rehabilitation services. This is largely because these services have typically been provided by social service or community organizations rather than through traditional health care service delivery systems.

For working-age people who have vision impairments, public funding for vision rehabilitation services is limited unless they have explicitly employment-related objectives. Medicare and other health insurers also do not cover certain services that help older people who are blind or have vision impairments to live and function independently. Older people make up a large majority of the population experiencing severe vision loss, and more than two-thirds of adults who have vision impairments are over age 65.¹⁷⁰ Among beneficiaries of Medicare, approximately 9 percent (or 3.2 million) are people who are blind or have vision impairments; of these, almost

90 percent (2.9 million) are aged 55 and older. Vision rehabilitation services are particularly critical for older people to help mitigate the negative effects of additional medical problems such as diabetes and cognitive, hearing, or balance problems.¹⁷¹ Since the late 1990s, some vision rehabilitation services have been available to Medicare beneficiaries in some geographic areas when they are provided by certified occupational, physical, and speech therapists. Such services are available in medical facilities under the supervision of a physician but are not available in the home or community.¹⁷²

In 2003, Congress initiated a Low Vision Rehabilitation Demonstration Project to assess the impact of adding certified low vision therapists, certified vision rehabilitation therapists, and orientation and mobility specialists to the list of those who can receive Medicare payments for services. Such services include those provided in the home and community when they are provided under the supervision of an optometrist or ophthalmologist. If the program succeeds, Congress could permanently recognize the benefit of including these vision rehabilitation professionals as approved Medicare service providers. Although advocates and service providers have worked diligently to overcome financial barriers that deter people of all ages who need these services from obtaining them, these and other barriers remain a significant challenge.¹⁷³

d. Disease Prevention and Health Promotion

Although people who are blind or have vision impairments experience overweight and obesity at a higher rate than the general population, health maintenance programs emphasizing weight management and fitness have not been directed toward or tailored to them. Likewise, diabetes education and care management have not reached people who have vision impairments and diabetes. The public health community may treat people who are blind or have vision impairments as though their vision problems are their only—or their most serious—health issues. Traditionally, public health programs have emphasized preventing vision loss, but they have devoted little attention to preventing secondary diseases and promoting healthy lifestyles for people who are blind or have vision impairments. However, experts in vision rehabilitation and public

health officials have begun a dialogue that suggests that the fundamental differences in orientation between the two disciplines may be changing.

- **Overweight and Obesity**

Research has shown that people with disabilities are significantly more likely to be obese than those without disabilities. For people who are blind or have vision impairments, the odds of being obese are 1.5 times greater than for the general population.¹⁷⁴ People who have vision impairments are less physically active, and are generally in poorer physical condition, than people who do not have vision impairments. Further, studies show that older children who have vision impairments are less physically active than are younger children who have vision impairments.¹⁷⁵ Various factors contribute to inactivity and overweight among people who have vision impairments, including difficulties obtaining and preparing fresh foods, lack of transportation, inaccessible exercise equipment, and the inaccessibility of the pedestrian environment.¹⁷⁶ However, little effort has been made to promote health and weight management for people who are blind or have vision impairments. The lack of tailored programs and accessible exercise equipment prevents people who have vision impairments from participating in exercise programs that could lead to weight loss.¹⁷⁷

- **Access to Fitness Equipment**

Most health experts agree that exercise is essential to achieve and maintain good health. However, people who are blind or have vision impairments encounter numerous problems using standard exercise equipment. For example, fitness experts frequently recommend using treadmills or stationary bikes to achieve a cardiovascular workout. However, most of these devices do not feature either tactile markings or speech output on the control panel. Display screens and control labels cannot be easily read by people who have vision impairments. Because information about the speed, heart rate, and duration of the workout is displayed in numbers or graphs, few people who are blind or have vision impairments can benefit fully from technology that is readily available to others. Similarly, elliptical trainers typically have tactile buttons for adjusting the angle of

the motion or resistance but also feature display screens that present information only visually rather than both visually and audibly.¹⁷⁸

Some new computerized systems attach to existing fitness equipment and provide feedback to users, which helps them achieve better form and exercise more safely. However, these systems typically have a touchscreen interface, which is not accessible to someone who is blind or has vision impairment. Again, this creates a barrier to using equipment that is readily available to others.¹⁷⁹

Recreation facilities are often not accessible. Features that could make the outdoor recreation environment more usable by people who have vision impairments include benches along trails, tactile maps, and raised character or audible signage. Accessible signage would also help people who are blind or have vision impairments to navigate efficiently and safely around an exercise or fitness facility.¹⁸⁰

e. Public Health and Vision Rehabilitation

In recent years, researchers concerned with promoting health for people who are blind or have vision impairments have begun building alliances among public health, vision rehabilitation, and aging programs. Such alliances have the potential to leverage public resources to improve the health of the broad population of people who have vision impairments.

Traditionally, the primary goal of public health has been disease and disability prevention. The primary goal of the independent living movement has been economic and social independence for people with disabilities. Progress toward social equality and full community participation for people with disabilities, spurred in part by the 1990 Americans with Disabilities Act (ADA) and advances in medicine and technology, make it possible for these communities to begin reconciling their differences and exploring and adopting complementary goals. A progressive health perspective for people who have vision impairments recognizes the dynamic and interrelated aspects of

contemporary community life and places the experience of blindness and vision loss at its center rather than on the periphery.¹⁸¹

Some leaders in the public health field, as well as some working in vision-related rehabilitation and access, have begun to acknowledge that their aims are essentially the same. . . . They may emphasize different intermediate outcomes—improved health on the one hand, improved functioning in daily living on the other—but their common long-range goal is the full participation in society of people with disabilities. That goal, it is worth noting, corresponds to the mission of the Americans with Disabilities Act (ADA, 1990), which states that “the Nation’s proper goals regarding individuals with disabilities are to ensure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.” Because the ADA expresses the nation’s current disability policy rationale, it further justifies and supports the aim of bridging public health and vision rehabilitation.¹⁸²

In light of the high prevalence of obesity, lack of fitness, diabetes, and depression among the large and growing number of people who have vision impairments, it is imperative that the diverse communities of public health and vision rehabilitation professionals join forces to identify solutions that address these and other systemic gaps in health promotion. As the philosophical divisions between these groups blur, they will identify and successfully implement long-term solutions to improve overall health for the community of people who are blind or have vision impairments.

f. Conclusion

Diabetes is the leading cause of blindness among adults, yet information about diabetes management and care is rarely available in accessible formats. People with vision impairments also do not have ready access to blood glucose and blood pressure testing equipment with audio functions or devices that provide prescription information in an audible format, so they have difficulty managing their diabetes and other care independently. In general, people with vision impairments are not included in preventive care and health promotion, and they experience significant barriers to health care. These barriers include inaccurate provider attitudes about blindness and vision impairment; physical barriers such as inadequate or lack of transportation and physically inaccessible health care facilities and fitness equipment and programs;

limited educational and instructional materials in accessible formats; inadequate access to vision rehabilitation services, programs, and related accessible technologies; and inadequate access to prescription drugs and specialty care.

Action must be taken where existing research reveals the clear need for such strategies as enhanced health care provider education, enhanced payment systems, and the removal of structural and other physical barriers to providing and receiving quality health care services.

4. People with Intellectual and Developmental Disabilities

Historically, society has isolated people with intellectual and developmental disabilities in large institutions. These institutions were often characterized by inhumane living conditions and inadequate care. The deinstitutionalization movement of the 1960s and 1970s established the right of people with intellectual and developmental disabilities to live and participate in their communities and created programs that provide support and assistance to ensure that these goals are met. The movement both enabled and encouraged parents and families to provide care at home for their relatives. It also created opportunities for independent living for adults. Community-based services and supports, advancements in medical care, and assistive technology have led to improvements in quality of life for people with intellectual and developmental disabilities.

While people with developmental disabilities have better health and are living longer as a direct result of these fundamental reforms, they continue to experience significant health disparities compared with the general population.¹⁸³

a. Prevalence of Intellectual and Developmental Disabilities

For the purpose of establishing eligibility for community services, the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines developmental disability as chronic physical or mental impairments or a combination of impairments that appear before age 22 and that create substantial functional limitations in at least three or more of the following areas of major life activity: self-care, language,

learning, mobility, self-direction, capacity for independent living, and potential for economic self-sufficiency during adulthood.¹⁸⁴ The term “developmental disability” may include people who have intellectual disabilities (formerly referred to as mental retardation); sensory impairments involving hearing, vision, and speech; orthopedic impairments; and other disabilities such as cerebral palsy, autism, and pervasive developmental disorder. People with developmental disabilities sometimes require individualized services and supports (for example, housing, employment, education, civil and human rights protections, and health care) to live in the community.

Approximately 4.5 million people with developmental disabilities live in the United States.¹⁸⁵ About half of the estimated 2.3 million people with intellectual disabilities are also considered people with developmental disabilities, because they experience the required functional limitations.¹⁸⁶ While people with disabilities such as cerebral palsy and autism do not necessarily have intellectual disabilities, both groups share the experience of disability stigma and discrimination. Both encounter barriers to participating fully in their community, including barriers to obtaining adequate health care.¹⁸⁷ For the purpose of this report, the term “developmental disability” includes cognitive, intellectual, and developmental disabilities.

b. Health Status and Health Experiences

Many of the health needs of people with intellectual and developmental disabilities are similar to those of the general population. These health needs include access to primary health care, wellness and prevention services, dental services, mental health care, care coordination, accessible facilities and services, culturally competent care, personal assistance and caregiving, and nutrition.¹⁸⁸ However, compared with people without disabilities, people with intellectual and developmental disabilities are more likely to have poor health, be susceptible to illness, have limited access to care, and be excluded from health promotion opportunities.¹⁸⁹

- **Health Disparities**

Health programs based on research evidence about the general population have excluded or ignored the needs of people with disabilities, including those with intellectual and developmental disabilities.¹⁹⁰ People with intellectual and developmental disabilities experience a constellation of health and health care disparities, including inadequate health and wellness promotion and inconsistent access to high-quality health care services. As a result, they are in poorer health and have shorter life spans than people who do not have these disabilities.¹⁹¹ A recent study summed up the “cascade of disparities that result in poor health status of people with intellectual and developmental disabilities.”¹⁹²

The effects of differences in prevalence rates of adverse health conditions and behavior disorders are compounded by disparities in attention to care needs, which are further impacted by disparities in preventive care and health promotion practices, and all are finally impacted by disparities in equitable access to health care.¹⁹³

Studies report that adults with developmental disabilities are at risk for multiple health and behavioral problems, including hearing and vision difficulties, cardiovascular disease, obesity, seizures, mental health and behavior problems, poor oral health, and poor general fitness.¹⁹⁴

Some studies suggest that people with intellectual and developmental disabilities are at higher risk for behavioral and emotional difficulties than the general population, and that more people experience psychiatric disabilities than are actually diagnosed. There are several possible explanations for this gap. One is that this group lacks mental health services. Another is that disorders go unrecognized because clinicians wrongly attribute mental health symptoms to the individual’s disability rather than to a separate condition.¹⁹⁵ Another study reviewed records of people with intellectual and developmental disabilities, and discovered that one-third to one-half of them had been prescribed medications for mental health conditions despite not having any psychiatric diagnosis.¹⁹⁶

Two common secondary conditions found among people with intellectual and developmental disabilities are lack of physical fitness and obesity. While rates of obesity are high in the general population, the overall prevalence of obesity for adults with intellectual and developmental disabilities is significantly higher (35 percent) compared with adults who do not have these disabilities (21 percent).¹⁹⁷

- **Poor Dental Health**

While most people who live in community-based residential settings or with friends or family had access to dentists, they had poor dental health because of lack of preventive care and inadequate dental hygiene. Access to care can also pose significant problems. Case managers have indicated that dental services are more difficult to find than any other type of service for individuals with intellectual and developmental disabilities who live in the community. Families and support personnel also indicate that quality of care is lower than it should be, because dentists lack the skills required to work or communicate with people with intellectual and developmental disabilities.¹⁹⁸

c. Barriers to Health Care

Studies have shown that people with intellectual and developmental disabilities—as well as the families, caregivers, and advocates who help them to get care—face extraordinary barriers to preserving health and getting health care when they need it:

They feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs. They struggle with unwieldy payment structures that were designed decades ago when people with [intellectual and developmental disabilities] often died in childhood or lived out their lives in residential institutions.¹⁹⁹

- **Lack of Needed Health Care Services**

Approximately 480,000 people with intellectual and developmental disabilities receive Medicare, while Medicaid covers 1.5 million adults living in the community and 246,000 people with intellectual and developmental disabilities living in institutions. About 70 percent of Medicare beneficiaries with intellectual and developmental disabilities are

also enrolled in Medicaid, the largest source of funding for health care for people with disabilities, providing both acute and some long-term care benefits.²⁰⁰ About 7 percent have insurance through their employers. Although some children with intellectual and developmental disabilities are insured through their parents' health plan, private insurance often has gaps in coverage, high premiums and copayments, and no mandate to provide needed benefits.²⁰¹

Because Medicaid includes both mandatory and optional services, certain critical services may not be available to people with intellectual and developmental disabilities. These services include dental care and certain prescription drug coverage.²⁰² To reduce health costs, many states have developed managed care programs and either require or encourage the enrollment of people with disabilities who participate in the program. These programs have potential benefits, but they can also present certain drawbacks for people with intellectual and developmental disabilities. In some cases, Medicaid managed care programs are poorly equipped to meet the needs of people with disabilities, including people with intellectual and developmental disabilities.²⁰³ Problem areas include inadequate care coordination, limited access to specialists, limited consumer choice, and inadequate risk adjustment for capitation rates.²⁰⁴ One study revealed that in a managed care system, one-third of children with autism had difficulty gaining access to specialists, and one-fifth of children with intellectual disabilities experienced difficulty getting referrals to specialty services.²⁰⁵

Even with its limitations, Medicaid can be a better option than commercial plans. One study compared the experiences of parents with Medicaid and parents with private insurance. Parents with Medicaid had difficulties accessing specialty care three-fifths as often as parents with private health insurance. Similarly, when Medicaid provided secondary coverage, fewer problems were reported with access to care at the plan and provider level.²⁰⁶ However, annual budget cuts to publicly financed health care and regular reduction of services under these plans continue to threaten access to comprehensive, coordinated care for people with intellectual and developmental disabilities.

- **Lack of Adequate Health Care Provider Awareness and Communication**

Medical providers lack training and experience in treating individuals with intellectual and developmental disabilities. Some providers are uncomfortable providing care or are unwilling to serve patients with these disabilities. For their part, people with intellectual and developmental disabilities have indicated that some health care providers may not understand the extent to which people with these disabilities can contribute to their communities as well as to their own health. One self-advocate expressed her frustration with the negative attitudes of some health care providers this way:

I am who I am, and I can be the best of who I am. All I'm trying to do is make a living, and the only way I can do that is to have good health care. Whenever I go into the doctor's office . . . they talk to the people that bring me. But it's my life and it's my illness. . . . Can you respect me enough to talk to me?²⁰⁷

Communication between health care providers and patients with developmental disabilities can prove difficult, as can communication between providers and caregivers. This communication difficulty can hinder continuity of care and make providing care more difficult. Lack of financial incentives and burdensome administrative paperwork add to the problem. Often, providers are concerned about how long it might take to treat a person with an intellectual or developmental disability. Focus group research revealed the difficulty that one mother experienced obtaining dental care for her son.

[We] can't really get full care. It's hard to find people with the patience to work with him, because he has to be given general anesthesia. When he was a child, he had to get caps put on his teeth, and this was a two-hour process. . . . Dentists don't want to deal with the hassle.²⁰⁸

People with intellectual and developmental disabilities can find it difficult to communicate their health care needs to medical providers, and can also have difficulty following recommended treatments. Patient education materials are often written in ways that people with intellectual disabilities cannot understand, making follow-through less likely. Incorrect assumptions and stereotypes about people with intellectual and developmental disabilities, coupled with limited scientific knowledge about appropriate

standards of care, further contribute to health disparities. Negative experiences with health care providers also deter people with intellectual and developmental disabilities, and their families and caregivers from seeking care. Focus group research showed that providers' misconceptions sometimes created dangerous situations for patients.

One nurse reported that some emergency room doctors believe that patients with mental retardation do not feel pain and therefore do not need anesthesia.²⁰⁹

Participants sometimes got the message from providers that individuals with disabilities were not worthy of receiving a high standard of care, particularly as the patients grew older. A woman with a sister in her 50s with developmental disabilities noted that her sister's doctor suggested reducing the frequency of visits from every few months to once a year. When challenged, the doctor replied, "She's lived a good life—once a year is fine."²¹⁰

Further, language and cultural barriers can complicate communications between health care providers and people with intellectual and developmental disabilities and their families.²¹¹ Intellectual and developmental disabilities occur disproportionately in low-income communities, where disparities in health and health care stem from economic, social, and environmental causes.²¹²

- **Inadequate Health Care Transition from Childhood to Adult Care**

Serious problems arise most often as individuals make the transition from child health programs to services for adults. Nearly half a million young people with special health care needs make the transition into adulthood and adult health care services annually.²¹³ Many children with intellectual and developmental disabilities receive medical care that is managed through an interdependent and complicated system that can include medical, educational, vocational, and social services. The transition from this multilayered system to adult health care can be fraught with difficulties. At a minimum, people with intellectual and developmental disabilities require a primary care physician who can focus on providing adult care. Health systems may fail to support the

transition process, and young adults and their families can find themselves without appropriate care. Problems include primary care physicians who are not trained to provide needed care and insurance schemes that do not adequately compensate health care providers for the time required to provide care and care coordination. Further, insurance plans can limit access to the few specialty providers who are familiar with the care needs of young adults with intellectual and developmental disabilities. Because these problems are widespread, the boards of the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and American Society of Internal Medicine have adopted a policy statement that represents

. . . a consensus on the critical first steps that the medical profession needs to take to realize the vision of a family-centered, continuous, comprehensive, coordinated, compassionate, culturally competent health care system that is as developmentally appropriate as it is technically sophisticated.²¹⁴

Finally, environmental factors such as poverty, inadequate and inaccessible housing, unemployment, and poor transportation contribute to the poor health status of people with intellectual and developmental disabilities and limit access to necessary medical care and mental health services for them and their families.²¹⁵

- **Barriers to Dental Care**

A number of studies have identified major barriers associated with poorer dental care for people with intellectual and developmental disabilities. Many lack insurance coverage for dental care and lack alternative funding for dental services. Case managers in smaller urban and rural areas report more difficulty finding dental services than those in large urban areas or rural communities. Architectural barriers in dental offices, including small examination rooms, also present obstacles to care. Some research reveals that characteristics such as severity of disability, challenging behaviors, and even wheelchair use may deter dentists from providing effective dental care. Families and caregivers also report that some dentists were “ineffective in dealing with extraordinary needs such as sedation, were not flexible in making unexpected accommodations, and had poor knowledge about people with ID.”²¹⁶

d. Disease Prevention and Health Promotion

Adults with intellectual and developmental disabilities are more likely to lead sedentary lives, and more often report being in fair or poor health than adults without disabilities, according to a study conducted in North Carolina.²¹⁷ However, research on issues related to health promotion for people with intellectual and developmental disabilities relies primarily on case studies. Little research has been conducted about secondary conditions they may experience.²¹⁸ In one national study, family practice and internal medicine physicians indicated that they conducted fewer health promotion activities for patients with physical disabilities than for patients who did not have disabilities.²¹⁹ Thus, it is particularly difficult for people with intellectual and developmental disabilities who also have physical disabilities to gain access to health promotion services. Women with intellectual and developmental disabilities receive fewer breast and cervical cancer screening examinations than women in the general population and are, therefore, at higher risk for these diseases. Similarly, men living on their own or with family members rarely have prostate exams.²²⁰

Disease prevention and health promotion for people with intellectual disabilities appear not only to vary depending on their living situation but also to be inconsistent within the same type of living arrangement. For example, one study showed that people either living alone or with family or friends lacked preventive health care screening and services such as flu shots, TB tests, and Pap tests.²²¹ Also, people living with friends or family appear to be at increased risk for obesity compared with people who live in residential settings. Another study revealed that, while most people with intellectual and developmental disabilities living in community-based settings had primary care physicians, only half had received tetanus inoculations, less than half had received protection against hepatitis B, and fewer than three-quarters had received the flu vaccinations during the previous year.²²²

Family satisfaction with the quality of care provided by primary care physicians reflects broad, system-level problems. For example, in a study of 121 families in Massachusetts, parents who had children with intellectual and developmental

disabilities gave low ratings to their children’s primary care physicians on their ability to put the parents in touch with other parents, their understanding of the impact of the child’s condition on the family, their ability to answer questions about the child’s condition, and their ability to provide information and guidance on prevention.²²³

e. Conclusion

Current data on the lives of people with intellectual and developmental disabilities confirm that an initial diagnosis of an intellectual or developmental disability results in greater susceptibility to physical and mental health issues, poorer health status, limited inclusion in preventive care and health promotion, and unequal access to health care. These unequal health outcomes are not all attributable to the functional limitations or impairments that arise from disability. Children and adults with intellectual and developmental disabilities encounter various economic, social, and environmental health disparities. They also are affected by limitations on commercial and public insurance and a highly fragmented health care system that lacks any systematic way to coordinate care across medical disciplines, type of health coverage, and age progression. As with any other identifiable minority group whose basic health care needs are not being met, people with intellectual and developmental disabilities are also affected by physical, financial, cultural, socioeconomic, and other environmental barriers. Immediate action must be taken where existing research reveals the clear need for such strategies as enhanced health care provider education, increased clinical and health disparities research, enhanced payment systems, and the removal of structural and other physical barriers that impede access to quality health care services.

D. Conclusion and Recommendations

The available research that describes the health status and health care experience of people with disabilities—especially women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities—presents a stark picture of health and health care disparities, preventable secondary disease, and diminished quality of life for many. While additional research is required to inform effective long-term public policy

responses, immediate action should be taken in response to what is already known. Specifically, the structural and environmental problems and barriers to health and health care services and programs that people with disabilities experience every day demand targeted actions and reforms that will have an immediate impact, as well as long-term, comprehensive reform.²²⁴

RECOMMENDATION:

Congress should direct the Centers for Medicare & Medicaid Services (CMS) to establish a mechanism to pay for American Sign Language (ASL) interpreters when they are required for deaf or hard-of-hearing beneficiaries of Medicare, Medicaid, the State Children’s Health Insurance Program (SCHIP), and other federally funded health care to ensure that people who are deaf or hard of hearing who use sign language receive effective services from health care providers, including mental health providers, clinics, hospitals, diagnostic centers, and laboratories, and in other health care settings.

RECOMMENDATION:

Congress should direct the Centers for Medicare & Medicaid Services (CMS) to identify and implement mechanisms to pay for vision rehabilitation services and assistive devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and Medicare programs or other federally subsidized health care.

RECOMMENDATION:

The Centers for Medicare & Medicaid Services (CMS) should identify and implement mechanisms to pay for vision rehabilitation services and assistive devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and Medicare programs.

RECOMMENDATION:

The Centers for Medicare & Medicaid Services (CMS) should identify and implement mechanisms to pay for vision rehabilitation services and assistive

devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and Medicare programs.

RECOMMENDATION:

The Centers for Medicare & Medicaid Services (CMS) should update their current definitions of durable medical equipment and medical necessity, which are outdated and give little consideration to increasing an individual's functional status. The current patchwork of both Federal and state health care and private insurance coverage contains barriers and gaps that leave many people with disabilities unable to obtain needed assistive technology. As a starting point, more consistent and coherent Federal eligibility and reimbursement policies are needed. New definitions of medical necessity are needed to ensure that effective assistive technology will be deemed eligible for coverage and reimbursement.

RECOMMENDATION:

Agencies of the Federal Government, including the institutes and centers of the National Institutes of Health (NIH) that are involved in providing Federal grants and Federal loans, including loan forgiveness programs for medical education, should require that medical training institutions whose students receive support include in their training curriculums material that ensures that graduates will possess disability knowledge, cultural competency, and a basic capacity to work effectively with people with disabilities.

RECOMMENDATION:

The U.S. Department of Health and Human Services (HHS) should direct key Federal agencies charged with health promotion and disease prevention to collaborate and implement methods that ensure that people with disabilities are fully included in health promotion and disease prevention research, program development, public education, and development of best practices.

RECOMMENDATION:

States should enact legislation that requires health insurers either to pay for sign language interpreters through employer-based group health insurance plans or to pay directly into a state fund or another mechanism established specifically to cover ASL interpreter expenses for people who are deaf who receive health care services through a private insurance plan.

RECOMMENDATION:

Congress should ensure that reform of the health care system in the United States responds to the basic needs of people with disabilities by making certain that health care coverage is available and affordable to all people with disabilities without preexisting condition limitations. Benefits made available through either private or public coverage, or a combination, must include access to appropriate prescription medications, specialty care, care coordination, durable medical equipment and assistive devices, and long-term care services. Any coinsurance payments must be affordable, and annual or lifetime limits on these key benefits must not be permitted. Health care reform efforts must take into account the fact that achieving health care equity for people with disabilities includes the additional dimensions of physical and programmatic accessibility and health provider disability cultural competency. Some key elements of these additional dimensions include the need for more time for medical visits for some people with disabilities; methods that ensure effective communication, including provision of sign language interpreters and educational and instructional materials in accessible formats; and accessible diagnostic and other common medical office equipment, such as height-adjustable exam tables and wheelchair-accessible weight scales. To the extent possible, methods must be established to ensure that these essential elements are readily available when health care is delivered. These methods might include reimbursement for sign language interpreters by public and private insurers, new tax credits or other tax benefits that help offset costs, equipment sharing, and other schemes that create incentives for health care providers to acquire necessary equipment and services that are needed by patients with disabilities.

CHAPTER 2. **Health Care and Federal Access Requirements**

Federal disability rights laws have explicitly mandated the removal of physical and programmatic access barriers in health care for many years; yet as this report clearly documents, myriad access problems remain. This chapter describes how these laws relate to health care services and facilities, and examines some of the civil actions and settlements brought under them that illustrate both the usefulness and the shortcomings of individual and class action lawsuits in the area of health care.

Two key Federal civil rights laws address discrimination against people with disabilities in the provision of health care services.²²⁵ Section 504 of the Rehabilitation Act of 1973 (Section 504)²²⁶ prohibits programs that receive Federal financial assistance, as well as federally conducted programs and activities, from discriminating against individuals with disabilities. Titles II and III of the Americans with Disabilities Act of 1990 (ADA)²²⁷ also prohibit disability discrimination and require health care providers to be physically and programmatically accessible to people with disabilities.

A. The Americans with Disabilities Act and Section 504

Title II of the ADA applies to state and local government entities, while Title III applies to “public accommodations.”²²⁸ Title III states that “private entities are considered public accommodations for purposes of this title, if the operations of such entities affect commerce” in 12 listed categories, one of which is a “professional office of a health care provider, hospital, or other service establishment.”²²⁹

Title II and Title III place somewhat different accessibility obligations on the entities that fall within their respective provisions, particularly in the area of removing architectural barriers in existing facilities.²³⁰ While no single entity can, by definition, fall within both Title II and III, as it will either be a Government entity or privately owned, private entities can be contractually bound to follow nondiscrimination laws that are applicable to state and local government entities. Similarly, a private entity can be obligated to follow

Section 504's nondiscrimination obligations as a recipient of Federal funds. For example, a private nonprofit hospital that serves Medicaid patients is both in a contractual relationship with the state Medicaid agency as a Medicaid provider and a recipient of Federal Medicaid funds. That hospital's contract with the state doubtless includes language that requires it to comply with any state nondiscrimination laws and the state's own ADA Title II and Section 504 nondiscrimination obligations.²³¹ Such a hospital is also a recipient of Federal funds and is therefore independently subject to Section 504. Another example is a private clinic that receives Federal monies under a Maternal and Child Health Services Block Grant to provide services such as newborn screening and immunizations. As a recipient of Federal funds,²³² the clinic would be subject to Section 504 in addition to its own Title III obligations as a private health care service establishment.

Title III prohibits "any person who owns, leases (or leases to), or operates a place of public accommodation" from discriminating against individuals "on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation."²³³ The law and its regulations are directly applicable to all the natural or corporate "persons" that own, lease to or lease, or operate the offices of individual health care providers. Larger nonprofit or for-profit private hospitals and health maintenance organizations (HMOs) are also subject to Title III.²³⁴ It is "discriminatory to subject an individual or class of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of an entity."²³⁵ It is equally discriminatory to provide an opportunity to participate in or benefit "that is not equal to that afforded to other individuals" or one "that is different or separate from that provided to other individuals" unless such action is necessary for equal effectiveness."²³⁶

Under Title III, discrimination includes the failure to make reasonable modifications, provide auxiliary aids and services, or remove architectural barriers, because such

failures effectively prevent people with disabilities from enjoying the goods and services offered by a public accommodation. In the health care context, this means that a health care entity must modify its policies, practices, and procedures when necessary to enable people with disabilities to gain full and equal access to its services, unless a requested modification constitutes a fundamental alteration of the health care service itself. For example, an office would have to modify a policy of providing no assistance to patients who needed help with undressing or transfers if someone with a mobility impairment required such assistance to receive a proper examination. Health care entities must also provide auxiliary aids and services such as sign language interpreters, assistive listening devices, and written medical information in such alternative formats as Braille and large-font print unless the provider can establish that doing so would fundamentally alter the nature of the health care service or constitute an undue burden.²³⁷ Finally, health care entities are required to remove architectural barriers such as steps, narrow doorways, and inaccessible toilets in existing facilities if doing so is “readily achievable.” Health care facilities that operate in new construction or that undertake alterations to existing facilities must ensure that the new construction or alteration meets the higher standard of being readily accessible.

Section 504 prohibits discrimination against otherwise qualified people with disabilities under any program or activity that receives Federal financial assistance; it directly applies to state Medicaid agencies²³⁸ and the many corporate health care entities and providers that receive Federal monies through Medicaid, Medicare, or Federal block grants.²³⁹ State Medicaid agencies also fall under Title II of the ADA, which states that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”²⁴⁰ Section 504 regulations prohibit Federal financial recipients from providing directly—or through contractual, licensing, or other arrangements—“any aid, benefit, or service that denies people with disabilities the opportunity to participate in or benefit from Medicaid, affords people with disabilities an opportunity to participate in or benefit from health care services that are not equal to that afforded others, or provides people with disabilities an

aid, benefit or service that is not as effective as that provided to others.”²⁴¹ Regulations enacted under Title II require state agencies to “make reasonable modification in policies, practices, or procedures, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the program service or activity.”²⁴² State agencies and other Federal financial recipients such as city or county governments or HMOs are bound to these fundamental Section 504 and Title II obligations, regardless of whether they enter subcontracts with additional third-party organizations or individual providers.²⁴³

If these legal requirements were effectively implemented at the various levels of our health care system—from individual providers to HMOs to state Medicaid agencies—it would significantly decrease the health and health care disparities experienced by people with various disabilities, even if financial, coverage, and other barriers remained. Federal laws have explicitly mandated the removal of physical and programmatic access barriers in health care for many years; yet as this report clearly documents, myriad access problems remain. A closer look at some of the civil actions and settlements brought under these laws can illustrate both the usefulness and the shortcomings of individual and class action lawsuits in the area of health care. Title III applies to privately owned health care entities regardless of size, and lawsuits under the ADA have been brought against solo practitioners as well as large hospital complexes and multistate corporate HMOs that employ hundreds of providers and operate hospitals, clinics, and laboratories.

Legal actions brought by individual plaintiffs against providers under Title III have achieved mixed results. ADA plaintiffs generally seek change in a defendant’s behavior, and are asking a court to either prevent the provider from engaging in discrimination or provide reasonable structural or programmatic modifications in the future. One initial hurdle for Title III plaintiffs has been the procedural requirement that a plaintiff must have standing to initiate a lawsuit and request injunctive relief.²⁴⁴ Among other factors, a plaintiff must have suffered “an injury in fact” (one that is actual or imminent and not merely a matter of conjecture) and must establish a very significant possibility of future

harm to achieve injunctive relief. When a couple, one of whom was a wheelchair user, initiated a lawsuit against a local hospital to have its birthing center made wheelchair-accessible in anticipation of future pregnancies, the court ruled that the couple was only asserting a speculative future harm that they could not prove.²⁴⁵ If a medical injury has already occurred, an individual plaintiff's lawsuit can be successful and could garner the level of publicity needed to generate greater awareness of ADA requirements among medical professionals.²⁴⁶ Focusing on lawsuits brought by individual plaintiffs also highlights the simple reality that it is very difficult for most patients to initiate a legal action against their treating physician, a difficulty that is exacerbated when the patient is likely to encounter access barriers that makes finding an alternative provider difficult. As the deaf plaintiff in a recent New Jersey case testified, she continued to see a provider despite his refusal to supply an interpreter, because she had been specifically referred by her primary care physician, was unsure of the nature of her illness, was fearful about worsening symptoms, and was unable to simply pick up the phone and easily find another doctor.²⁴⁷

The U.S. Department of Justice (DOJ) is not subject to the same restrictive standing requirements as private individuals and has achieved more consistently positive results through administrative and legal actions brought under Title III against health care providers and hospitals. However, DOJ has limited human and financial resources and a mandate that requires a determination of "a pattern or practice" of discrimination or "an issue of general public importance" before commencing a civil action.²⁴⁸ The department has tended to focus on large, high-profile health care providers and issues when commencing action under Title III and has emphasized settlements and consent decrees over litigation.

Nonetheless, some very significant results have been obtained through a few important lawsuits initiated against larger hospital complexes and HMOs, many with DOJ involvement. In 2000, three wheelchair users represented by Disability Rights Advocates (DRA) sued Kaiser Permanente, the largest nonprofit HMO in the country. The suit was brought in California Superior Court under state access laws, alleging that

Kaiser failed to provide equal and adequate care for patients with physical disabilities because of inaccessible examination equipment and pervasive barriers. A landmark settlement was reached in March 2001 in which Kaiser agreed to review and maintain its physical accessibility under state and Federal access laws; identify, procure, and install accessible medical equipment; and develop access policies and procedures over the settlement's 7-year term.²⁴⁹ Given Kaiser's size, one of the most far-reaching consequences of the lawsuit was that it prompted medical equipment manufacturers to develop such equipment as height-adjustable exam tables that have subsequently become more widely known, available, and affordable to other providers. The Kaiser settlement helped pave the way for a Federal action brought in November 2003 against the Washington Hospital Center, the largest private hospital in the District of Columbia, by DOJ and the Disability Rights Project of the Washington Lawyers' Committee on behalf of four former patients of the hospital and one organizational plaintiff. This action also focused on architectural and equipment barriers for patients with mobility and other disabilities. In the settlement achieved 2 years later, Washington Hospital agreed that all exam tables and chairs purchased after the date of the agreement would be accessible and committed to providing staff training to ensure implementation and use of its new equipment and programmatic access policies.²⁵⁰

Some new accessibility issues raised by technological developments are also being addressed with respect to larger Title III entities. For example, the adequacy of video interpreting services (VIS—the provision of a remote interpreter through video conference technology over high-speed Internet lines), which are becoming more commonly used in medical settings, was part of the 2006 Consent Decree negotiated by DOJ, the Disability Rights Project of the Washington Lawyers' Committee, and the private firm of Sutherland Asbill & Brennan LLP on behalf of seven deaf individuals.²⁵¹ Laurel Regional Hospital had refused the individuals' specific and repeated requests for in-person qualified sign language interpreters but had made available in some instances VIS. However, VIS alone is inadequate without performance standards or when used with patients with medical conditions or injuries that compromise their ability to see the video screen or be seen by the video camera. The decree is the first ADA case

resolution to include appropriate criteria for VIS use and monitoring, as well as requiring a communication assessment of each patient, appropriate auxiliary aids and services, DOJ-approved VIS equipment, notice to patients of their rights under the decree, and staff training.²⁵²

Actions against and settlements with hospitals and HMOs can play an important role in reducing access barriers for the population of people with disabilities who live in the geographic area serviced by a specific Title III entity. Even with these larger entities, however, it is hard to gauge the wider influence of these individual lawsuits in the context of all the hospitals operating in the country. Similarly, HMOs—especially those that are harder to characterize as direct providers of health care services and those outside of California—do not appear particularly motivated to grapple with their physical and programmatic responsibilities under Title III, or even to be aware of those responsibilities. People with disabilities and disability rights attorneys and advocates cannot be expected to change the health care system hospital by hospital, and the problem is exacerbated a thousand-fold when considering the degree to which provider practices and clinics outnumber hospitals.

Ensuring that individual providers and clinics become and remain accessible is especially important because of the role outpatient health care services and nonhospital settings play in our health system. A 2006 summary of the National Ambulatory Medical Care Survey found that “[a]mbulatory medical care in physician offices is the largest and most widely used segment of the American health care system.”²⁵³ An estimated 902 million visits were made to office-based physicians in 2006; over 50 percent of these visits were made by patients with one or more chronic condition such as hypertension, arthritis, or depression.²⁵⁴ “Physician offices comprised about four-fifths of all ambulatory medical care delivered in 2006, and physician consultation services included everything from primary care to highly specialized surgical and medical care.”²⁵⁵ These figures reflect visits to private practices, urgent care centers, public health clinics, family clinics, mental health centers, community health centers, and family practice plans but not hospital emergency or outpatient departments, VA medical

offices, or industrial, occupational, or institutional clinics. Overall, 83.4 percent of the visits surveyed were to practices “that were either owned by a physician or a group of physicians.”²⁵⁶ Over half of the office visits “were made to physicians who were part of a group practice, defined as having three or more physicians,” while “[s]olo practitioners accounted for 31.8 percent of the remaining identified office visits.”²⁵⁷ It is critical that offices involved in delivering ambulatory care be physically and programmatically accessible, given the wide-ranging types and amounts of services delivered in those offices and clinics. If they remain physically or programmatically inaccessible, or are allowed to set arbitrary policies that require patients to be “ambulatory” in the narrow sense of being able to walk, people with disabilities will inevitably experience inferior health care choice and quality.

While Title III lawsuits and settlements are important and must continue to be brought, they cannot take the place of a commitment to systemic implementation of access principles that exist under Federal law. Public entities should develop health-care-specific standards of physical, programmatic, and clinical accessibility for providers, hospitals, and HMOs. These standards must be robustly monitored and enforced from top funding entities on down, through such intermediate organizations as HMOs and accreditation organizations, so that individual providers with the fewest resources—and consequently the greatest defenses to a Title III action—are not left to achieve accessibility on their own. Where the public entity is a state Medicaid agency, it is subject to Section 504 and Title II of the ADA and should take on a greater burden of ensuring health care accessibility at the provider level than simply passing on a contractual obligation. HMOs are also subject to Section 504 when they receive Medicaid and Medicare funding. While no case has actually argued that such an approach is mandated under 504 or the ADA, there are cases that provide some foundation to this legal theory of “kicking up” access responsibility from providers to HMOs to state Medicaid agencies.

A Federal court in Pennsylvania has acknowledged that a state Medicaid agency can bear responsibility for ensuring that HMO managed care providers meet the

accessibility requirements of Federal law. In *Anderson v. Department of Public Welfare*,²⁵⁸ the Pennsylvania Medicaid agency mandated Medicaid recipients in five counties to receive health care services through HealthChoice, an HMO network. The plaintiff class had initiated the action because they encountered physically inaccessible HealthChoice provider offices. The state agency had not considered or looked for accessibility when it initiated the HMO bidding process or when it conducted “readiness reviews” of the HMOs that were awarded the contracts. The court found the HealthChoice program inaccessible because it “does not comply with the minimum program accessibility regulations promulgated under Title II and Section 504” for new and existing construction.²⁵⁹ As a result, the court partially granted the plaintiffs’ Motion for Summary Judgment and issued an order that required the state to ensure that every participating HealthChoice provider met the accessibility requirements of Title II of the ADA.

In *Zamora-Quezada v. HealthTexas*,²⁶⁰ a group of HMOs and one of the provider medical groups in the HMO provider network were sued by two physicians employed by the medical group and a number of HMO enrollees with disabilities. The HMOs and its provider groups had entered contractual arrangements that divided the risk of service provision so that the network providers assumed greater risk for patients who had a higher cost per month. The plaintiffs charged that this financial and contractual arrangement gave network providers an incentive to delay or deny professional treatment services to higher cost enrollees with disabilities and resulted in discrimination under Section 504²⁶¹ and Title III. The two physicians also alleged that they had been retaliated against and dismissed by the defendant provider medical group when they advocated for their patients with disabilities. The court denied defendants’ motion to dismiss and found that plaintiffs had stated a viable claim under Section 504 and the ADA. In doing so, the court at least implicitly acknowledge that an HMO’s contractual relationships with its provider network can both influence how those providers deliver health care and result in discrimination when people with disabilities are forced to seek the health care they need elsewhere.²⁶²

These cases help set the stage for the argument that state Medicaid agencies and HMOs that receive Medicaid and Medicare payments have their own independent obligation under Section 504 to ensure that Medicaid and Medicare enrollees with disabilities are not excluded from participation in, denied the benefits of, or discriminated against in the receipt of health care services solely by reason of their disability. When HMOs enter a contract with state Medicaid agencies, they receive Federal funds to recruit and enter contracts with health care providers, design health care products for enrollee members, and act as an ongoing intermediary between providers and members. This is generally the case even if the HMO does not also directly operate hospitals and clinics and employ providers. HMOs purport to offer certain levels of health care services and provider choice to their members. If any enrollee cannot actually receive those services or choices because an HMO's provider network is riddled with architectural or programmatic barriers, then the HMO is in violation of Section 504. As recipients of Federal funding, state Medicaid agencies and HMOs have a responsibility under Section 504 to notify enrollees with disabilities of their Federal accessibility rights, as well as the right to auxiliary aids where necessary for effective notice or to provide equal benefit from the service in question.²⁶³ Neither state Medicaid agencies nor HMOs that receive Federal financial assistance should be allowed to disregard their own, generally greater, financial and administrative capacity to set policies and procedures that will inform, provide incentives, monitor, and enforce accessibility requirements among the providers that deliver health care services.²⁶⁴

B. Conclusion and Recommendations

Lawsuits are limited in their impact and can cost plaintiffs time, effort, and peace of mind to a degree that can affect their own health. In addition, they need attorneys conversant with disability nondiscrimination law, but far more negligence legal expertise is commonly available than disability nondiscrimination expertise. Also, most medical providers are far more aware of their obligations and the potential for liability under negligence and tort law than under Section 504 or the ADA.

Ultimately ADA and Section 504 lawsuits and settlements are an important component of the systemic health care reform to achieve accessibility, and disability rights advocates and attorneys must continue to bring high-impact litigation that will bring about change in the greatest numbers of providers at the ground level. These efforts must be supported through additional legislative, policy, and institutional reform. This is particularly true in such forward-looking areas of policy as investigations into health disparities, evidence-based health care quality standard setting, and the linkages between health and various environmental factors, such as socioeconomic status and the built environment. Discoveries made through innovative cross-disciplinary research and public health and policy discussion are leading the way, rather than lawsuits. This is why disability as a demographic factor, and people with disabilities as an affected population, must be included in the discussion.

RECOMMENDATION:

Congress should direct the Department of Health and Human Services (HHS) to identify performance standards that must be included as a condition of receiving Federal financial assistance to ensure that states, health plans, managed care organizations, and health care providers who receive Federal health care funds under Medicaid, the State Children’s Health Insurance Program (SCHIP), and other Federal programs that pay for health care for people with disabilities meet the minimum requirements of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that they possess sufficient cultural competency to provide effective health care to people with disabilities.

RECOMMENDATION:

The Department of Health and Human Services (HHS), the U.S. Department of Justice (DOJ), the Centers for Medicare & Medicaid Services (CMS), and the U.S. Access Board should enter into an interagency agreement to identify and adopt performance standards to ensure that states, health plans, managed care organizations, and health care providers who receive Federal health care funds under Medicaid, the State Children’s Health Insurance Program (SCHIP), and

other federally funded health care programs meet the minimum requirements of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that they possess sufficient cultural competency to provide effective health care for people with disabilities. Such methods could include a Federal contractual requirement that states, health plans, and providers collect and submit data concerning architectural and programmatic accessibility, capacity to accommodate patients with disabilities, and a showing of cultural competency and disability awareness. Such a contractual obligation should also include regular monitoring mechanisms.

RECOMMENDATION:

States should develop mechanisms whereby health insurers, managed care organizations, and other health plans provide assurances that the health care providers (for example, hospitals, clinics, diagnostic centers, provider offices, and laboratories) with whom they contract for Medicaid and other federally funded health care services provide physical and programmatic access for people with disabilities. Such mechanisms could include annual physical and programmatic access surveys of providers and adherence to other performance standards that would be required in order to renew health service delivery contracts. Failure to provide the required information to appropriate state agencies should result in contract termination.

RECOMMENDATION:

The Department of Justice (DOJ) must step up monitoring and enforcement of the Americans with Disabilities Act (ADA) and Section 504 of the 1973 Rehabilitation Act for health care facilities and programs. DOJ must focus additional resources on compliance monitoring and investigation of Title III complaints concerning programmatic access violations of the ADA and Section 504 by health care providers.

CHAPTER 3. **Legal and Administrative Framework for Health Care and Health Disparities Programs and Research**

This chapter summarizes key Federal laws that govern, or are relevant to, the health care provided to people with disabilities in the United States. Some of the legislation outlined below is included because it enacts programs such as Medicaid and Medicare that serve significant numbers of people with disabilities or people with such specific disabilities as developmental disabilities. Other laws are included because they relate to the Federal Government's relatively recent and ongoing research on, and response to, the existence of health and health care disparities among specified population groups. Health disparities legislation currently includes people with disabilities as a health disparity population to only a limited extent. This chapter suggests reasons for fully including people with disabilities in the nation's ongoing effort to combat health and health care disparities. The chapter concludes with recommendations for reform.

A. Social Security Act

1. Medicaid

Medicaid is a Federal initiative that was created through the Social Security Amendments Act of 1965²⁶⁵ to provide acute and long-term health coverage to low-income Americans of any age. Medicaid's authorizing and controlling legislation comprises Title XIX of the Social Security Act and is overseen federally by the Centers for Medicare & Medicaid Services (CMS), an agency in the U.S. Department of Health and Human Services (HHS). The program began as a collaborative venture between the Federal and state governments (including the District of Columbia and U.S. territories) to jointly fund health care for individuals and families with low incomes and resources. In 1972, Congress linked Medicaid to the creation of the Federal Supplemental Security Income (SSI) program. Thereafter, SSI coverage (at approximately 74 percent of the Federal poverty level, or FPL) became the minimum national income floor for Medicaid eligibility. Before this, many states had set lower income levels for Medicaid eligibility.

The Medicaid program offers states the flexibility to expand their Medicaid coverage beyond the Federal minimum eligibility levels, and all states have extended Medicaid coverage through “medically needy” or “special low income” options to the elderly and people with disabilities beyond minimum program levels. Medicaid has now grown to encompass over 58 million Americans, including 8 million persons with disabilities who generally lack any other source of health insurance or care, and 6 million low-income frail, elderly, and disabled Medicare beneficiaries who depend on Medicaid to fill in the gaps left by Medicare coverage.²⁶⁶ The program has become the “largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities.”²⁶⁷

To receive matching Federal funds, states must provide certain mandatory services under Medicaid, such as physician and hospital services, laboratory and diagnostic testing, and nursing facility services.²⁶⁸ Other services, such as prescription drugs, personal care, and home and community-based long-term care, are optional, and individual states vary considerably in the degree to which they will cover such services and how eligibility is established.²⁶⁹ The category of “medical supplies, equipment and appliances suitable for use in the home” is a mandatory home health service benefit, but a state can establish reasonable standards under the Medicaid statute and set limits on coverage based on such factors as “medical necessity” or “utilization control.”²⁷⁰ The distinction between mandatory and optional services can be particularly important for people with disabilities, because many optional services can be critical to maintaining health and the ability to function in the community. Significant variance in what states cover, their scope of coverage, and their eligibility standards for coverage create gaps and complications in service for people with disabilities across the country.

Medicaid’s importance to a critical core population of low-income individuals with the most complicated chronic health needs cannot be overstated. Seniors and people with disabilities comprise 24 percent of all Medicaid enrollees, but account for 70 percent of program spending.²⁷¹ Eleven percent of all enrollees with disabilities incur annual costs over \$25,000 and account for 61 percent of all expenditures on people with

disabilities.²⁷² The 1.2 million Medicaid enrollees who use long-term services and supports account for 58 percent of all Medicaid spending on people with disabilities. One-quarter of this group used institutional care and averaged total per person spending of \$76,331, while three-quarters of the group averaged total per person spending of \$35,930 for community-based services.²⁷³ These figures can be compared with total per person spending of \$6,277 on enrollees who received little or no long-term care services. For the 7 million low-income Medicare recipients with chronic health needs who are “dual eligible” for Medicaid coverage, the latter program “is the only source of financial assistance with long-term care within the community and in institutional settings.”²⁷⁴

The majority of Medicaid enrollees with disabilities live in the community and require access to Medicaid providers, clinics, and hospitals through either fee-for-service arrangements or managed care. For these enrollees, structural inaccessibility and programmatic barriers²⁷⁵ have as detrimental an impact on health care quality as coverage gaps and financial barriers. Regulations enacted under Title XIX place ultimate responsibility for access to health care with the states. Each state is required to have a state Medicaid plan that “must ensure that all services covered under the State plan are available and accessible to enrollees of MCOs [managed care organizations], PIHPs [prepaid inpatient health plans], and PAHPs [prepaid ambulatory health plans].”²⁷⁶ While the regulations do not go into detail about what access requires,²⁷⁷ it is arguable that state Medicaid agencies receive matching Federal monies under an obligation to ensure that all Medicaid enrollees, including enrollees with disabilities, receive equal access to all aspects of the health care delivery system. A state’s tolerance of structural and programmatic barriers in the multiple levels of its health care system is an ongoing violation of the Medicaid program and greatly contributes to the health care disparities endured by people with disabilities. These levels range from Medicaid enrollment to the making of appointments to the actual examination, including the failure to monitor or gather information about the extent of these problems.

2. Medicare

The Social Security Amendments Act of 1965²⁷⁸ also established Medicare, a Federal health insurance program intended to provide for the medical needs of Americans aged 65 and older, regardless of their income/asset levels and medical history. In 1972, Medicare was expanded to include coverage of people with permanent disabilities under the age of 65 who received Social Security Disability Insurance (SSDI).²⁷⁹ CMS is the Federal agency that now administers Medicare. The Medicare program is legislated as Title XVIII of the Social Security Act; in 2007, the program included 7 million people with disabilities under age 65—about 15 percent of the total of almost 44 million Medicaid enrollees.²⁸⁰ This subgroup of 7 million younger people with disabilities tends to have relatively high rates of health problems and lower incomes than other enrollees: almost two-thirds live on incomes below twice the FPL, and 40 percent are dual eligible for both Medicare and Medicaid.²⁸¹ Among all Medicaid beneficiaries, 36 percent live with three or more chronic health conditions such as hypertension or arthritis, 29 percent have a cognitive or mental impairment that limits their ability to function independently, and 16 percent have functional limitations in activities of daily living such as eating or bathing.²⁸²

The Medicare program is structured in four parts. Part A is known as the Hospital Insurance program and covers inpatient hospital services and care at skilled nursing facilities, home health care, and hospice care. Part B, known as “Supplementary Medical Insurance,” is voluntary, requires payment of beneficiary premiums, and covers physician, outpatient, home health, and preventive services, including diagnostic screenings and imaging such as mammography and durable medical equipment such as wheelchairs and ventilators.

Part C, the “Medicare Advantage Program,” was created in the 1970s; it enables Medicare enrollees to sign up with and receive Medicare-covered benefits through private health plans. These plans can take a variety of forms,²⁸³ are paid by the Federal Government, and are obligated to use any gains between the amount received and their costs to reduce premiums or improve the benefits they offer. If these private plans offer

such supplemental benefits as vision or dental care beyond Medicare benefits, they are allowed to charge enrollees a supplemental premium. In recent years, the number of both enrollees and private plans in Part C has rapidly increased, with enrollees growing from 5.3 million in 2003 to 8.3 million in January 2007. However, this growth has been uneven across the states. In 2006, the four states of Alaska, Maine, New Hampshire, and Vermont had less than 1 percent of their Medicare beneficiaries enrolled in Part C, while half of all Medicare Advantage enrollees nationally live in the five states of Arizona, California, Florida, New York, and Pennsylvania.²⁸⁴ Medicare enrollees are eligible for coverage under Part C if they are entitled to benefits under Part A and are also enrolled in Part B.

Part D, known as the Outpatient Prescription Drug Benefit of Medicare, was initiated in 2006 under the Medicare Modernization Act of 2003.²⁸⁵ In return for premium payments, Part D provides enrollees with a “standard benefit” through either a Part C Medicare Advantage drug plan or a stand-alone prescription drug plan. Medicare enrollees are eligible for coverage under Part D if they are either entitled to benefits under Part A or are enrolled in Part B.

Many people with disabilities, both older and younger than 65 years of age, rely on Medicare. However, the program contains significant gaps in coverage benefits for items or services that can be both expensive and particularly important for maintaining function and independence. For instance, Medicare does not pay for long-term care services at home or in an institution, routine dental care or dentures, routine vision care or eyeglasses, or hearing exams hearing aids. These notable gaps in coverage may result in significant out-of-pocket expenses to meet medical, equipment, and long-term care needs for some people with disabilities.²⁸⁶ Another serious gap involves people who become disabled before age 65. They must wait 2 years after they establish eligibility for SSDI before they can receive Medicare coverage, a period during which many do not have any insurance coverage.

Part D enrollees also face gaps in terms of both coverage and payments. The private plans that participate in Part D vary widely in terms of their formularies (list of covered

drugs), placement of drugs on certain tiers within the formulary, monthly premium charges, cost-sharing requirements, and cost-management tools (for example, the imposition of prior authorization requirements). In addition, Part D's "standard benefit" provides an initial coverage limit of \$2,400 in total drug costs, followed by a coverage gap until total drug costs reach \$5,451. This means that enrollees with over \$2,400 in total prescription drug costs must spend \$3,850 out of pocket (not counting premiums) until they reach the point at which Medicare again kicks in, at which time the enrollee pays either 5 percent of the drug cost or a copayment.²⁸⁷ In 2006, an estimated 4 million Medicare beneficiaries were forced to pay for their prescription drugs when they reached this coverage gap.

Just as for Medicaid enrollees with disabilities, Medicare enrollees with disabilities face structural and programmatic barriers in addition to the administrative and financial barriers that confront all Medicare enrollees. Because CMS and the Federal Government bear direct responsibility for the Medicare program, and CMS is part of HHS, Medicare is undeniably a federally conducted program or activity that is subject to Section 504 of the Rehabilitation Act of 1973.²⁸⁸ Both Section 504's prohibition against disability discrimination and the detailed HHS regulations enacted under Section 504²⁸⁹ require that no qualified person with a disability be excluded from participation in or denied the benefits of Medicare services, programs, or activities. CMS and HHS retain control over Medicare, and these agencies should ultimately be responsible for ensuring that all components of Medicare—from enrollment to architectural access to practices, policies, and procedures in hospitals, provider offices, and pharmacies—are accessible for enrollees with disabilities.

3. *State Children's Health Insurance Program (SCHIP)*

SCHIP was enacted through the Balanced Budget Act of 1997²⁹⁰ as Title XXI of the Social Security Act; it was the largest single expansion of public health insurance coverage since the creation of Medicaid and Medicare in 1965. Like Medicaid, SCHIP is a collaborative partnership between the Federal Government and all 50 states, five territories, and the District of Columbia. CMS has Federal oversight authority over all

SCHIP programs, activities, and expenditures. When first enacted, SCHIP was aimed specifically at providing health insurance coverage for more than 10 million uninsured low-income children under age 19 who were not eligible for Medicaid, primarily because their family incomes were above Medicaid eligibility limits. Most of these children lived in families with incomes that were below twice the FPL, in which at least one parent worked full or part time but for whom employee health insurance was either unavailable or unaffordable.²⁹¹ While much smaller in scale than either Medicaid or Medicare, SCHIP's enactment was accompanied by substantial state outreach efforts that resulted in significant enrollment of eligible children in Medicaid.²⁹² SCHIP served 6.6 million children in 2006.

Title XXI was meant to give individual states flexibility to design a program that would effectively reach and provide health insurance for uninsured children. It therefore gave states three options for using their SCHIP funds. States could expand their existing Medicaid programs by covering SCHIP children, create a separate child health insurance program with a benefit package that differed from Medicaid, or combine those two options. States that choose to expand Medicaid must offer the full Medicaid benefit package and are required to follow Medicaid's cost-sharing rules.²⁹³ States that choose to offer a separate SCHIP program are generally required to cover primary and preventive health benefits such as immunizations, well-baby and well-child care, and emergency services.²⁹⁴ Separate SCHIP programs generally can impose limited cost-sharing and no more than \$5 copayments for provider visits for families that are below 150 percent of FPL. For families with incomes above 150 percent FPL, these separate programs may not exceed 5 percent of the family's annual income for any cost-sharing charge.

Each state laid out its plans for SCHIP funds, including information on the benefit package, cost-sharing, and eligibility standards, in the initial applications and must receive CMS approval before amending its plan. Unlike Medicaid, SCHIP is a finite block grant. The Federal funds set aside for SCHIP were capped at 40 billion from 1997 through 2007. Thus, the states can cap enrollment when they run out of funds, even if

they are not covering children who otherwise meet all program eligibility requirements. In 2007, the matching Federal fund rate for SCHIP program costs ranged from 65 percent to 83 percent.²⁹⁵

It is difficult to say how many children with disabilities are covered under SCHIP, because there is no requirement on state programs to collect or maintain this information. In comparing the relative importance of Medicaid and SCHIP to children with disabilities, the National Association of Children's Hospitals stated:

SCHIP children generally have higher incomes and less serious health care needs than children on Medicaid. Medicaid is the primary source of health coverage for low-income children with disabilities; 7 of 10 children with severe disabilities below the Federal poverty level receive Medicaid benefits.²⁹⁶

Nonetheless, SCHIP clearly provides critical assistance to eligible families that include children with disabilities, even if the benefit package is less than that provided under Medicaid or enrolled children have less complex health needs. These are families that essentially have no other source of health insurance, and this assistance is arguably more precarious than a Medicaid entitlement because of SCHIP's block grant status.

SCHIP's reauthorization was required in 2007, but Congress and the Administration failed to reach agreement on a reauthorization. President Bush vetoed a compromise bipartisan bill that would have expanded SCHIP coverage to 3.8 uninsured children. In December 2007, Congress passed S. 2499, which extended SCHIP authorization through March 2009 and appropriated sufficient funds to maintain the program at current levels. The bill did not address CMS's August 2007 directive against states' expansion of SCHIP coverage for families above 250 percent of FPL (\$43,000 for a family of three in 2007) without proof that 95 percent of children in families with income below 200 percent of FPL were already enrolled.²⁹⁷ This is particularly significant in light of findings such as those of the 2008 University of North Carolina study, in which researchers found "chilling" rates of hardship among poor, middle-class, and even upper-income families with disabled children as they struggled "to keep food on the table, a roof over their heads, and to pay for needed health and dental care."²⁹⁸ The

study found that 40 percent of the families surveyed who earned between \$36,200 and \$54,300 for a family of four and had a child with a disability experienced at least one food hardship, including concerns that food would run out or missed meals because of a lack of money.²⁹⁹

4. *Maternal and Child Health Block Grant*

Title V of the Social Security Act, which provides the basis for federally funded public health programs, was first enacted as a Federal-state partnership in 1935, when the Social Security Act was initially passed. In 1981, Congress converted the Title V program to a block grant³⁰⁰ and consolidated seven categorical programs into the Maternal and Child Health Services Block Grant (MCH Block Grant), as Title V is now known. Further amendments enacted in 1989 imposed stricter state planning and reporting requirements and funding criteria.³⁰¹ The MCH Block Grant is federally administered by the Maternal and Child Health Bureau (MCHB) under the Health Resources and Services Administration (HRSA) within HHS.

Title V continues to be a Federal and state matching program—every \$4 provided by the Federal Government for the program must be matched by \$3 of state funds.³⁰² Most of the Federal appropriations for the MCH Block Grant (approximately 85 percent) are awarded to state health agencies, mainly on the basis of the number of children in poverty in the state relative to the total number of children in poverty nationally. The remaining 15 percent supports discretionary grants awarded by MCHB for Special Projects of Regional and National Significance (SPRANS). SPRANS grants generally support the continuation of certain categorical programs in such areas as genetic disease testing, counseling and information dissemination, and MCH research and training.³⁰³

Title V is intended to provide comprehensive services for mothers and children. MCHB describes Title V as the only Federal program that consistently provides all four possible levels of services: (1) direct health care; (2) enabling services such as transportation, translation, and health education; (3) preventive services such as newborn screening,

immunization, and oral health; and (4) infrastructure-building services such as needs assessment, policy development, and information systems support.³⁰⁴ One national grassroots organization of families of children with disabilities reports that Title V state programs operated a clinic-based system of care that has recently been turning more toward care coordination services, though some state programs still provide direct clinical services, usually in collaboration with Medicaid and private insurance.³⁰⁵

Title V allows billing of patients for services on a sliding scale on the basis of income. Many services are provided free of charge, unless the patient has Medicaid or private insurance. States may set the types of services that they provide and set eligibility, resulting in a wide variety of benefits and eligibility criteria across states in MCH Block Grant programs. States that receive Title V funds are subject to detailed annual reporting requirements. States must document how many children in the state have special health needs and how services will be received, along with infant mortality and child and maternal health statistics according to such categories as county, race, and ethnic group.³⁰⁶ The Secretary of HHS is to compile this information nationally and by state, for annual transmission to Senate and House of Representatives committees.

Like enrollees in Medicaid and the other federally funded programs described above, children with disabilities who receive services under Title V encounter a variety of structural and programmatic barriers to health care access and are entitled to coverage under Section 504 of the Rehabilitation Act. Title V also contains a specific reference to nondiscrimination that expressly incorporates Section 504 and states that “programs and activities funded in whole or in part with funds made available under this title are considered to be programs and activities receiving Federal financial assistance.”³⁰⁷ The Secretary of HHS is authorized to request compliance with Title V’s nondiscrimination provision from any state’s chief executive officer and to refer the matter to the U.S. Attorney General for a civil action. The logical next step is to link a state’s responsibility for ensuring nondiscrimination in its Title V programs with the state’s existing reporting requirements. For example, currently required information on the number of maternal and child-health-related providers licensed in the state in a year could incorporate

information on the degree to which those providers have received training in the accessibility needs of children with disabilities. Currently required information on the proportion of women who did not receive prenatal care during the first trimester of pregnancy could include information on whether the mother had a disability, as well as on her racial and ethnic origin. Indicators specific to the structural and programmatic accessibility of maternal and child care providers in Title V programs could be systematically incorporated in annual audits.

B. Developmental Disabilities Assistance and Bill of Rights Act of 2000

The Developmental Disabilities Assistance and Bill of Rights Act³⁰⁸ (DD Act) has its genesis in the much older Mental Retardation Facilities and Community Health Centers Construction Act of 1963, the first legislation to address the recognized needs of a group of people with disabilities designated as developmentally disabled. Currently, the act is administered by the Administration on Developmental Disabilities (ADD), which is part of the HHS Administration for Children and Families. The law today remains the main route by which grant monies are used to improve the lives of people with developmental disabilities, but a series of amendments over the past four decades reflects a modified focus from service delivery and demonstration to public policy advocacy, mirroring the social and political changes that prompted the development and enactment of more recent Federal disability rights laws such as the Americans with Disabilities Act (ADA). In 1999, Congress made a number of findings under the DD Act that are significant for health care delivery.³⁰⁹

- People with developmental disabilities often encounter discrimination in the provision of critical services and are at greater risk than the general population for abuse, neglect, financial and sexual exploitation, and legal and human rights violations.
- Many service delivery systems and communities are unprepared to meet the needs of the 479,862 adults with developmental disabilities living at home, for whom the primary caregiver is a parent (or parents) who are 60 years or older.

- Eighty-eight percent of persons with developmental disabilities live with their families or in their own households, and there is a critical need for a well-trained workforce that can provide appropriate services, supports, and other forms of direct assistance to enable people with developmental disabilities to continue living, learning, working, and participating in their communities.
- Many people with developmental disabilities and their families do not have access to appropriate support and services such as access to assistive technology, and so are either underserved or not served at all.
- Services, supports, and other assistance should be provided in a culturally competent manner that fully includes individuals from racial and ethnic minority backgrounds in the activities provided under the law.

The DD Act's four distinct grant programs are intended to ensure that "individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs."³¹⁰ Grantees are required to work with state governments, local communities, and the private sector, and grants are used to fund activities in one of eight areas of emphasis: quality assurance, education and early intervention, child care, health, employment, housing, transportation, and recreation activities.³¹¹ The four grant programs currently consist of the State Councils on Developmental Disabilities (SCDDs), the state Protection and Advocacy (P&A) systems,³¹² the University Centers for Excellence in Developmental Disabilities (UCEDDs), and Projects of National Significance (PNSs).

These four programs overlap to some extent and are intended to support one another, but the P&A systems and the UCEDDs are most likely to provide direct services to people with developmental disabilities and their families. The P&A systems provide administrative and legal information, referral, investigation, and representation to people with developmental disabilities on their civil and human rights. The UCEDDs provide community services such as training or technical assistance to people with disabilities,

their families, professional and paraprofessional service providers, students, and other community members, and may provide services, supports, and assistance through demonstration and model activities. The UCEDDs also have a broad research mandate to conduct basic or applied research, evaluation, and public policy analyses in “areas that affect or could affect . . . individuals with developmental disabilities and their families,”³¹³ and to disseminate information about their activities and any areas of substantive expertise. The UCEDDs also provide coordinated and multidisciplinary direct health care.

The UCEDDs were formerly known as University Affiliated Programs (UAPs) but were renamed in the 2000 DD Act. A few specific subsections in the existing regulations are worth noting, as they relate to health care accessibility for people with developmental disabilities and disabilities in general.³¹⁴ The ADA is mentioned twice in the regulation on governance and administration of the UAPs. First, “UAP faculty and staff must represent the broad range of disciplines and backgrounds necessary to implement the full inclusion of individuals with developmental disabilities in all aspects of society, consonant with the Americans with Disabilities Act.”³¹⁵ Second, and more significantly, “[t]he UAP physical facility and all program initiatives conducted by the UAP must be accessible to individuals with disabilities as provided for by section 504 of the Rehabilitation Act and Titles II and III of the Americans with Disabilities Act.”³¹⁶ Because the UAPs/UCEDDs are federally funded, as well as associated with universities that are either Title II or Title III entities under the ADA, they are already subject to Section 504’s mandate of nondiscrimination and either Title II or III. Nevertheless, the regulations’ mandate to comply with Section 504 and ADA accessibility requirements strengthens any kind of self-advocacy action or complaint brought directly against a UAP with inaccessible facilities or program initiatives. Additional measures of accountability for UAP accessibility result from the UAP’s obligation to maintain collaborative relations with the state P&A agency and SCDD³¹⁷ and to solicit the active participation of consumers of UAP services and programs to evaluate its programs.³¹⁸

UAPs are explicitly directed to make a difference in their university homes, to consider the needs of the developmental disabilities community, and to work with the community, agencies, and advocacy organizations. UAPs are to “influence University curriculums to prepare personnel who, in their future career in a broad range of social and community roles, will contribute to the accommodation and inclusion of individuals with developmental disabilities, as mandated in the Americans with Disabilities Act.”³¹⁹ The UAP system interventions must be collaboratively planned with people with developmental disabilities and their families³²⁰ and, where direct services are offered, “must integrate direct services and projects into community settings,” “include adult and elderly individuals with developmental disabilities” as appropriate, “maintain cooperative relationships with other community service providers,” and “interact with and involve community members, agencies, and organizations.”³²¹ Finally, UAPs are to “produce a variety of products to promote public awareness and visibility of the UAP, and facilitate replication of best practices,”³²² use the input of people with developmental disabilities and their families,³²³ and make materials “available in formats accessible to individuals with a wide range of disabilities.”³²⁴

The UAPs/UCEDDs serve as models because they have been consistently funded for more than four decades and were thoughtfully embedded within a network of grant programs that address technical assistance, community and provider training, diversity in higher education, administrative and legal enforcement, and builds in collaboration among all the programs. Accessible health care is recognized as one of the key elements through which people with developmental disabilities will achieve “increased independence, productivity, inclusion, and community integration.” It could be argued that UCEDDs and the DD Act are directed toward a specific population of people with developmental disabilities and therefore need to be physically and programmatically accessible to this population. The UCEDDs should place special emphasis on accessibility because they serve a population with specialized needs.

On the other hand, accessible health care is necessary not only to the numerous people with a variety of disabilities—and seniors, who often develop disabilities as they age—

but to every person, because one's health is always in flux. The directives, institutional programs, and accountability measures in the DD Act illustrate much of what needs to be in place to achieve universally designed and accessible health care.

C. Title IX of the Public Health Service Act, As Added by Public Law 106-129

Title IX of the Public Health Service Act establishes the Agency for Healthcare Research and Quality (AHRQ) and its mission and duties. Essentially, AHRQ is “the lead Federal agency charged with improving the quality, safety, efficiency, and effectiveness of health care for all Americans,”³²⁵ primarily through supporting health services research. Approximately 80 percent of the AHRQ annual budget is invested in grants and contracts with research institutions and organizations focused on improving some aspect of health care delivery or evidence-based decision making.³²⁶ Title XI authorizes the AHRQ Director to gather information on the quality and cost of health care, primarily in the form of a nationally representative survey on the cost, utilization, and quality of health care, including the following:

their access to health care services, frequency of use, how much is paid for the services used, the source of those payments, the types and costs of private health insurance, access, satisfaction, and quality of care for the general population, including rural residents and also for populations identified [as “priority populations”].³²⁷

Other than this admittedly important task of statistical information gathering, Title XI does not address in any way the monitoring of individual access to health care or the enforcement of nondiscrimination rights; even systemic standard setting is outside the AHRQ mandate. The agency's legislative authorization explicitly states that AHRQ “shall not mandate national standards of clinical practice or quality health care standards. Recommendations resulting from projects funded and published by the Agency shall include a corresponding disclaimer.” Moreover, nothing in AHRQ's responsibilities “shall be construed to imply that the Agency's role is to mandate a national standard or specific approach to quality measurement and reporting.”³²⁸ In

common parlance, Title XI does not take a carrot-and-stick approach to systemic improvement; it simply encourages research that is intended to lead to systemic improvement.

AHRQ's very limited ability to implement or enforce necessary change or establish binding standards for improving health care quality is somewhat dismaying given that, among the 12 HHS agencies, AHRQ has the broadest and most systemic mandate with regard to people with disabilities. The AHRQ Director is specifically charged to conduct and support research and develop evaluations, including demonstration projects, with respect to "health care for priority populations, which shall include (1) low-income groups; (2) minority groups; (3) women; (4) children; (5) the elderly; and (6) individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care."³²⁹ People with disabilities fall squarely within the AHRQ mandate because they are explicitly recognized as a priority population.

AHRQ is further charged with establishing an Office of Priority Populations to help conduct and support research to gather scientific evidence regarding "all aspects of health care," including the enhancement of patient participation, cost-effectiveness, innovative technologies, access, quality measurement, best practice dissemination, and how health care organization and financing affects the quality of patient care.³³⁰ Many of these aspects of health care quality are vitally important to people with disabilities. For example, people with a variety of disabilities find themselves unable to gain access to innovative diagnostic and imaging technologies because they are not universally designed. Many people with disabilities rely on items of durable medical equipment or communication technologies that are increasingly out of reach because of narrow public insurance interpretations of what is "medically necessary" and private insurance coverage limitations.

The AHRQ mandate includes the promotion of innovation in evidence-based health care practices and technologies by "conducting and supporting research on the development, diffusion, and use of health care technology" and "developing, evaluating,

and disseminating methodologies for assessments of health care practices and technologies.” The agency is also authorized to conduct and support specific assessments of existing and new health care practices and technologies.³³¹ Such a broad mandate should be able to encompass research and assessment of the kinds of on-the-ground concerns with access to durable medical equipment and new and developing technologies that have a tremendous practical impact on access to health care for people with disabilities. Once again, however, there is the significant limitation that AHRQ’s discoveries are to be disseminated and potentially influential, but cannot mandate change.

Overall, AHRQ is given an important role in assessing health care quality for people with disabilities, but it is a role that forms only a small part of an extremely broad mandate to research health care quality for all Americans. The agency is further charged with coordinating “all research, evaluations, and demonstrations related to health services research quality measurement and quality improvement activities undertaken and support by the Federal Government.”³³² As a result, the agency must deal with an extremely fragmented Federal network of specialized services, research, and funding related to adults and children with disabilities. Finally, AHRQ has no authority to set binding standards or establish monitoring systems in relation to its research findings, no matter how clearly those findings signal a need for such standards or monitoring. Since AHRQ-conducted and -supported research findings and quality assessments do not place any kind of mandate on Federal or private entities, it would be difficult for any individual or group to use such findings to show that a standard of care has been established, much less violated. Nevertheless, if AHRQ promoted research that clearly identified the various barriers encountered by people with disabilities as a priority population when seeking health care, it could help advocates document a statistically accurate record of, for example, the extent to which health care technologies, facilities, and equipment remain inaccessible to people with disabilities³³³ and bolster efforts to effect change.

AHRQ was originally required to submit an annual report to Congress, beginning in 2003, regarding “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations.”³³⁴ Even when Title IX was first enacted, the language and reference of health and health care disparities linked to racial and socioeconomic factors did not acknowledge the presence of disability itself as a demographic characteristic that could be linked to health and health care disparities. In any event, this requirement was struck a year later with the enactment of the Minority Health and Health Disparities Research and Education Act of 2000 (MHDREA). MHDREA added health care disparities generally to the AHRQ research and dissemination mandate, and simultaneously centralized a more specific and greater authority to research and address biomedical and behavioral factors relating to health disparities in a different Federal entity, the National Center on Minority Health and Health Disparities (NCMHD). The following section assesses the impact of this division.

D. Minority Health and Health Disparities Research and Education Act of 2000

The Minority Health and Health Disparities Research and Education Act of 2000 (MHDREA)³³⁵ amends the Public Health Service Act (PHSA) to establish the National Center on Minority Health and Health Disparities (NCMHD) and expand the AHRQ research mandate to include the issue of health disparities. The new national center has its roots in the Office of Research on Minority Health (ORMH), created in 1990 by the NIH Director and formally established in the Office of the Director by the Health Revitalization Act of 1993.³³⁶ ORMH is the predecessor of NCHMD, and the 2000 law was prompted by the same underlying concern with “continuing disparities in the burden of illness and death experienced by African Americans, Hispanics, Native Americans, Alaska Natives, and Asian Pacific Islanders, compared with the United States population as a whole.”³³⁷ Under the act, NCMHD has two main purposes. First, it is to develop and support a national research agenda at NIH with respect to minority health conditions and other populations experiencing health disparities. Second, it is to promote and fund increased research capacity on health disparities in minority and

medically underserved communities, and to train students from minority and other health disparity groups in biomedical and bio-behavioral research careers.

Under the act, a population is a “health disparity population” if “there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.”³³⁸ The NCHMD Director is to determine, after consultation with the AHRQ Director, whether a population fits these criteria; the Director is specifically required to give “priority consideration” to whether minority groups qualify as health disparity populations.³³⁹ This definition of a health disparity population poses something of a barrier to the inclusion of persons with disabilities, as it seems easiest for researchers to assume a common “healthy” or “zero disease” starting point for comparing a particular population group and the general population, even though people with disabilities could experience the described disparities in a way that is not directly attributable to the mere presence of disability. That is, a population group consisting of people who have disabilities or a particular disability could well have a higher overall incidence rate of secondary disease (for example, coronary heart disease or cancer), higher morbidity rates, or lower survival rates on diagnosis. These differences could be due to such factors as inappropriate clinical treatment, lack of preventive knowledge, adoption of risk behaviors, or systemic physical, programmatic, or cultural barriers that impede access to health care. These are among the factors that NCHMD could target when coordinating, planning, and budgeting NIH’s health disparities research on “the causes of such disparities and methods to prevent, diagnose, and treat such disparities.”³⁴⁰

Research is needed for people with disabilities, just as it is for other demographically identifiable groups such as minorities. Unfortunately, however, a disability is often incorrectly assumed to determine a person’s general health status. NCMHD has rarely undertaken even basic research on the existence of health disparities in disease prevalence, morbidity, mortality, and survival rates for people with disabilities. The lack of such research may stem from the center’s need to establish the most straightforward

connection between a demographic characteristic, such as race, and evidence of significant health disparities.

The definition of a health disparity population used by NCMHD contrasts distinctly with the expanded definition available to the AHRQ Director; the latter definition may include “populations for which there is a significant disparity in *the quality, outcomes, cost, or use of health care services or access to, and satisfaction with, such services*, as compared to the general population.”³⁴¹ The AHRQ Director need not compare two groups that have the same overall starting health condition to establish a significant difference in the fact of disease, morbidity, or survival. Instead, the additional focus on health care quality, outcomes, and utilization, including access, provides an objective means for establishing a significant disparity that is not so tied to the amorphous concept of community or individual health status. However, even if the AHRQ Director included people with disabilities or specific disabilities in the definition of a health disparity population, the expansion would only hold true for AHRQ’s own mandate on health disparities research. The heart of the AHRQ mission is to conduct and support research and evaluate and disseminate research findings. AHRQ cannot require other agencies to investigate, prioritize, or budget for disparities research. The agency is required to support the development of quality health care measures for health disparity populations that will “assess the experience of such populations with health care systems” and “assess the access of such populations to health care,” but the agency cannot mandate the creation of such measures or their adoption once developed.³⁴²

These limitations on AHRQ’s mandate and authority mean that, even if people with disabilities are explicitly acknowledged as a health disparity population by the agency, this particular population group can continue to be excluded from NCMHD and NIH’s attention and research agenda. This agenda includes such tangible incentives for changing the status quo as awarding grants or contracts of up to 5 years to Centers of Excellence in biomedical and behavioral research training for members of health disparity populations³⁴³ and loan forgiveness programs of up to \$35,000 a year for health professionals who agree to engage in health disparities research.³⁴⁴ If people

with disabilities as a group are seen as falling outside the ambit of NCMHD's jurisdiction, they would also forgo the benefit of potential future congressional actions that could expand or build on the act's capacity to require systemic health care monitoring and civil rights enforcement.

One author who applauded the MHDREA as a first step toward reducing the institutionalized use of unscientific race-based research in clinical decision making for African Americans suggests that, in addition, "[i]f we are serious about invigorating Title VI enforcement, the cornerstone is the systemic collection of data from each health care provider that receives Federal funds on racial disparities in the use of services and the choices of diagnostic and therapeutic alternatives."³⁴⁵ A 2007 proposed amendment to the MHDREA elaborates on this suggestion and requires the HHS Secretary to collaborate with the HHS Office of Civil Rights to (1) review cases filed with the Office of Civil Rights against health care providers that have been closed without a finding of discrimination to ensure that there is in fact no pattern or practice of activities that could lead to discrimination; (2) provide technical assistance or education to providers in particular geographic areas where such patterns or practices are identified; and (3) biannually publish the name and location of any entity that has had a finding of discrimination made against it by the Office of Civil Rights, including the office's findings and any agreement entered into with the entity.³⁴⁶ This collaboration between the Secretary and the Office of Civil Rights is, however, tightly focused on discrimination and technical assistance related to racial and ethnic minority groups. No congressional proposal yet appears to suggest enforcement and monitoring for disability discrimination as well as racial or ethnic discrimination under MHDREA. While such information gathering about the structural and programmatic accessibility of provider offices and the enforcement of Section 504 of the Rehabilitation Act would not in itself turn the tide of pervasive health care inaccessibility, it could provide critical additional support for such a systemic sea change.

Another notable feature of the MHDREA is that health disparities research is defined as "basic, clinical, and behavioral research on health disparity populations (including

individual members and communities of such populations) that relates to health disparities... including the causes of such disparities and methods to prevent, diagnose, and treat such disparities.”³⁴⁷ This concept of health disparities research is quite broadly worded, which is in accord with the congressional finding listed at the beginning of the act: “[b]ehavioral and social sciences research has increased awareness and understanding of factors associated with health care utilization and access, patient attitudes toward services, and risk and protective behaviors that affect health and illness. These factors have the potential to then be modified to help close the health disparities gap among ethnic minority populations.”³⁴⁸ Despite the potential breadth of NCHMD’s research under the act, the center’s online vision and mission statement clearly gives the impression that disparities caused by access issues fall outside NCHMD’s authority.

Although some of the causes of disparate health outcomes such as differences in access to care, are beyond the scope of biomedical and bio-behavioral research, the National Institutes of Health (NIH) can play a vital role in addressing and easing health disparities involving cancer, diabetes, infant mortality, AIDS, cardiovascular illnesses, and many other diseases. Accordingly, the NIH has made health disparities a priority.³⁴⁹

The clear sense is that NCMHD is concerned only with health disparities linked to the initial acquisition of a disease, and much less with if and how health and function can be maintained *when a disease or health condition has been acquired*. Presumably AHRQ, with its far more limited authority, is left to investigate social and environmental factors relevant to health care disparities and health access, including those involving minority health disparity populations.

Ultimately, these distinctions among health and health care disparities and the factors that contribute to disparities serve neither minority health disparity populations nor other populations. Scholars have noted and raised objections to the decontextualized “race-only lens” of the MHDREA as one that offers only narrow explanations for racial disparities in health such as biological race, socioeconomic status, and personal responsibility, in effect foreclosing the analysis and addressing of issues of racism in

health care policy development.³⁵⁰ For people with disabilities, the traditional medical emphasis on genetic and biological determinism has always overshadowed investigation into issues of socioeconomic status and behavioral factors. While specific environmental issues related to physical and communication access barriers experienced by people with disabilities have increasingly risen to the surface in scholarly research, the MHDREA essentially confines the issue to AHRQ's domain of health care quality assessment.

There does not appear to be any Federal coordination or means of investigating how numerous factors such as socioeconomic status; environmental, financial, structural, and programmatic barriers; institutionalized prejudice; cultural and other communication issues; and biological and clinical factors interact together to create and maintain health disparities. The initiation of such an approach, across Federal agencies and sustained over time in terms of funding, would undoubtedly help establish the fact that people with disabilities experience health and health care disparities, and would better enable all demographic groups that experience such disparities, including minority populations, to unearth the causes of disparity and develop better health outcomes.

E. Title II of the Rehabilitation Act of 1973 and the National Institute on Disability and Rehabilitation Research

Unlike many agencies and organizations that have a disability-related research mandate, the National Institute on Disability and Rehabilitation Research (NIDRR) is authorized under the Rehabilitation Act of 1973, Title II,³⁵¹ rather than the Public Health Service Act. NIDRR is not part of HHS but is located in the Office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education (ED).

NIDRR's mission is to conduct and coordinate research and related activities that will enable people with disabilities of all ages to maximize full inclusion, social integration, employment, and independent living, and to maximize society's capacity to provide accommodations and equal opportunities for its citizens with disabilities. To that end, NIDRR's research and development mandate includes health and function and also more broadly encompasses other key areas such as employment, participation and

community living, and assistive technology. NIDRR's statutory authority requires dissemination of its research findings to people with disabilities and their families, private researchers, rehabilitation service providers, and all levels of Government and public entities; the promotion of technology transfer; increased opportunities for minority institutions and research with disabilities or from minority groups; and the provision of advanced training in disability and rehabilitation research. NIDRR has formed numerous partnerships with other Federal agencies, research institutions, and consumer organizations through its funding of various research projects,³⁵² and the agency holds designated responsibility for chairing the Interagency Committee on Disability Research (ICDR). The ICDR is required to meet at least four times a year and has the goal of coordinating Federal rehabilitation and disability research, including research relating to assistive technology and the principles of universal design.³⁵³

F. Entities Created and Authorized Under the Public Health Service Act

1. Health Centers

The Health Resources and Services Administration (HRSA) is part of the Public Health Service and is authorized under the Public Health Service Act (PHSA). HRSA "is responsible for general health services, and it acts as a resource center with respect to issues of access, equity, quality, and cost of care."³⁵⁴ In particular, HRSA supports states and communities in organizing and delivering preventive and primary health care services to underserved residents and specific groups, such as migrant workers and the homeless, by approving grants or contracts that fund health centers.³⁵⁵ Four different health center programs (two of which were initiated in the 1960s) were legislatively combined through the Health Centers Consolidation Act of 1996,³⁵⁶ although each health center continued to maintain its own distinct resource stream. The four programs originally served migrant farm workers, medically underserved populations living in urban and rural communities, homeless persons, and residents of public housing. These target populations have been maintained in the current definition of "health center" as "an entity that serves a population that is medically-underserved, or a special medically underserved population comprised of migratory and seasonal agricultural

workers, the homeless, and residents of public housing.”³⁵⁷ Health centers must provide, either directly or through contracts or cooperative arrangements, primary health services as defined in the PHSA and additional health services as appropriate for particular centers and necessary for the adequate support of the primary health services.³⁵⁸ In addition, community health centers must provide these services to all residents of the area served by the center.³⁵⁹

Health centers are addressed here because substantial numbers of people with various disabilities are included in the four population groups served by these entities. This raises the issues of architectural and programmatic accessibility, and the question of whether people with disabilities could in fact be designated as a medically underserved population that receives health care services through new or existing health centers.

On the first issue, the PHSA contains a specific provision that states that “programs and activities funded in whole or in part with funds made available under [preventive health and health services block grants] are considered to be programs and activities receiving Federal financial assistance” under nondiscrimination laws.³⁶⁰ Assuming that the health center funding grants constitute a preventive health or health service block grant, this means that Section 504 applies to the health centers, which are required to undertake reasonable architectural and programmatic modifications to ensure access for people with disabilities. Moreover, the PHSA’s own requirement that community health centers that serve medically underserved populations must provide health care services to “all residents of the area” also argues for barrier removal as a priority in these clinics. This is especially the case in rural areas that have few health care service options for residents with various disabilities.

With regard to the second issue, PHSA has a relatively broad definition of “medically underserved population” as “the population of an urban or rural area designated by the Secretary as an area with a shortage of personal health services or a population group designated by the Secretary as having a shortage of such services.”³⁶¹ In addition, the Secretary is to prescribe criteria for determining what it means to have specific shortages of personal health services and “include factors indicative of the health status

of a population group or residents of an area, the ability of the residents of an area or of a population group to pay for health services and their accessibility to them, and the availability of health professionals to residents of an area or to a population group.”³⁶² While, as a group, people with disabilities experience lower health status, difficulty paying for health services, and shortages of available health professionals because of inaccessibility, these experiences are not necessarily linked to geography in the way that PHSA seems to contemplate. Nonetheless, pursuing the inclusion of people with disabilities as a medically underserved population is an idea worth further exploration.

2. Substance Abuse and Mental Health Services Administration

Section 290aa of the Public Health Service Act (PHSA) established SAMHSA as an agency of the Public Health Service.³⁶³ SAMHSA is made up of three centers that deal respectively with substance abuse treatment, substance abuse prevention, and mental health services.³⁶⁴ A presidentially appointed SAMHSA administrator supervises and appropriately supports the implementation of each center’s programs, which are primarily carried out through grants, cooperative agreements, and contracts with appropriated funds. Through the centers, SAMHSA is required to establish and implement “a comprehensive program to improve the provision of treatment and related services to individuals with respect to substance abuse and mental illness, and to improve prevention services, promote mental health, and protect the legal rights of individuals with mental illnesses and individuals who are substance abusers.”³⁶⁵ SAMHSA’s specific tasks include conducting and coordinating demonstration projects, evaluations, and other activities to improve the availability and quality of treatment, prevention, and related services; disseminating knowledge and public information related to substance abuse and mental health; and coordinating with other Federal agencies, including NIH, CDC, and AHRQ concerning HIV and tuberculosis prevention and the community impact of treatment and prevention services.³⁶⁶ The administrator of SAMHSA is required to report biennially report to House and Senate committees concerning the agency’s activities.³⁶⁷

Beyond the fact that SAMHSA's programs are meant to serve specific groups that can be characterized as having disabilities, the agency's enabling legislation says nothing about the need for or provision of substance abuse or mental health services among people with disabilities in general. For instance, there is a specific provision that calls on the administrator to ensure "that services provided with amounts appropriated under this subchapter are provided bilingually, if appropriate"³⁶⁸ but no similar direction regarding sign language, alternative communication formats, or physical accessibility. Such access requirements could nevertheless be implied if SAMHSA grants are considered Federal financial aid under Section 504. There is also a specific directive to work with the National Institutes on Aging, Drug Abuse, Alcohol Abuse and Alcoholism, and Mental Health to "promote and evaluate substance abuse services for older Americans in need of such services, and mental health services for older Americans who are seriously mentally ill."³⁶⁹ Such a directive concerning people with disabilities would help to highlight the substance abuse treatment and mental health needs of people with various disabilities.

The SAMHSA legislation's silence on disability status or access can be contrasted with subsections devoted to the establishment of an associate administrator and an Advisory Committee for Women's Services.³⁷⁰ One duty of the associate administrator and the committee is to ensure "that the unique needs of minority women, including Native American, Hispanic, African American and Asian women, are recognized and addressed" in SAMHSA's activities.³⁷¹ For the purposes of these subsections, "women's substance abuse and mental health conditions, with respect to women of all age, ethnic, and racial groups," means all aspects of substance abuse and mental illness that are (a) unique to or more prevalent among women or (b) characterized by insufficient services or data involving women.³⁷² This report has noted elsewhere the prevalence of substance abuse and mental illness, and the difficulty of obtaining treatment, experienced by women with disabilities and people with communication difficulties. Women with disabilities could benefit from explicit inclusion in the work of the associate administrator and the Advisory Committee for Women's Services, which essentially reports on disparities of data collection, diagnosis, treatment, and employment

experienced by women in the areas of substance abuse and mental illness.³⁷³ People with disabilities could also benefit from the establishment of a parallel to the associate administrator and the Advisory Committee for Women's Services that would focus on the state of substance abuse and mental health services among people with disabilities.

3. National Center on Birth Defects and Developmental Disabilities Within the Centers for Disease Control and Prevention

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) was established and authorized as a center within the Centers for Disease Control and Prevention (CDC) by section 247b-4 of the Public Health Service Act.³⁷⁴ Many of NCBDDD's duties involve operating programs to collect and analyze data, conduct research, and promote and provide public education and information dissemination on the prevention of birth defects and developmental disabilities.³⁷⁵ These duties are generally carried out through grants and contracts with public and nonprofit private entities.³⁷⁶ NCBDDD is also responsible for reporting on the incidence and prevalence of birth defects, developmental disabilities, and the health status of individuals with disabilities. In its biennial report to House and Senate committees, NCBDDD is to include information on the impact of these conditions on quality of life and among various racial and ethnic groups, the effectiveness of various approaches to preventing secondary health conditions among people with disabilities, and health disparities experienced by people with disabilities.³⁷⁷ This reporting mandate includes development of "recommendations for improving the health and wellness and quality of life" of people with disabilities.³⁷⁸ This mandate enables NCBDDD to be a source of potentially important research funding and data concerning the health status of people with disabilities. (See chapter 4 for a discussion of NCBDDD's disability-related programs and for recommendations aimed at CDC and NCBDDD.)

4. National Institutes of Health

The National Institutes of Health (NIH) is an agency of the Public Health Service; its overall organization is established in section 281 of the Public Health Service Act,³⁷⁹ although references to specific authorization, duties, and funding for NIH and its

component national research institutes and centers are made throughout the act. Each institute “conducts and supports research, training, health information and other programs with respect to a particular disease or group of diseases or any other aspect of human health”; this is also the criterion by which the Secretary of HHS would establish the need for any additional national research institute.³⁸⁰ Most of the current institutes focus on specific disabilities or on human conditions such as aging. The National Center on Minority Health and Health Disparities profiled earlier in this chapter. In addition, the Office of the Director of NIH contains a Division of Program Coordination, Planning, and Strategic Initiatives, which consists, in turn, of specific offices such as the Office of AIDS Research and the Office of Research on Women’s Health.³⁸¹ There may be a total of no more than 27 national research institutes and national centers.³⁸² Section 281 also establishes an advisory council within NIH known as the Scientific Management Review Board, which has such significant responsibilities as periodically reviewing and evaluating the research portfolios of the institutes, recommending organizational changes to the institutes, and submitting reports on organizational issues to significant House and Senate committees.³⁸³ However, the NIH Director retains the authority to override organizational changes recommended by the board, which otherwise are to be implemented, and to unilaterally initiate functional reorganization, establishment, and termination of institutes and offices within the Office of the Director.³⁸⁴ NIH’s annual appropriations are authorized under section 282a.³⁸⁵ (See chapter 4 for a discussion of NIH programs that have engaged in research on disability health disparities or other disability and health issues.)

G. Conclusion and Recommendations

Numerous opportunities exist within the current legal framework of key Federal laws that establish health, health care, health research, and other programs to incorporate a focus on people with disabilities and include disability surveillance in key areas where data are already being collected for other demographic groups. The following recommendations identify these and other opportunities.

RECOMMENDATION:

Congress should amend the Public Health Service Act that established the Substance Abuse and Mental Health Services Administration (SAMHSA) to include an emphasis on people with disabilities through the following changes:

- Add a directive that identifies people with disabilities. Such a directive could be modeled after the existing directive to work with the National Institutes on Aging, Drug Abuse, Alcohol Abuse and Alcoholism, and Mental Health to “promote and evaluate substance abuse services for older Americans in need of such services, and mental health services for older Americans who are seriously mentally ill.”³⁸⁶
- Amend the specific provision that ensures “that services provided with amounts appropriated under this subchapter are provided bilingually, if appropriate”³⁸⁷ to include provision of effective methods of communication for people who are deaf or hard of hearing, including sign language interpreters.
- Include mental health and substance abuse issues of concern to women with disabilities among the identified duties of the associate administrator and the Advisory Committee for Women’s Services, which ensure that “the unique needs of minority women, including Native American, Hispanic, African American and Asian women, are recognized and addressed” in SAMHSA’s activities.³⁸⁸ This should include aspects of substance abuse and mental illness that are (a) unique to or more prevalent among women or (b) characterized by insufficient services or data involving women.³⁸⁹

RECOMMENDATION:

The Director of the National Institutes of Health (NIH) should require that institutes and centers within NIH that conduct health disparities research include people with disabilities as a demographic population for the purpose of such research. The Director should also request that the Scientific Management Review Board determine how best to integrate disability and health disparity research into the

portfolios of the institutes and centers, and recommend any organizational changes that might be required to achieve this goal.³⁹⁰

RECOMMENDATION:

The Agency for Healthcare Research and Quality (AHRQ), within its mandate to undertake research on priority populations, should promote research that clearly identifies the various barriers encountered by people with disabilities when seeking health care. Such research would help disability health policy researchers and other stakeholders to assemble an accurate picture of, for example, the extent to which health care technologies, facilities, and equipment remain inaccessible to people with various disabilities,³⁹¹ and bolster efforts to effect change.

RECOMMENDATION:

The Secretary of the U.S. Department of Health and Human Services (HHS) should require substantive evidence of compliance with Title V of the Social Security Act's Section 504 nondiscrimination provision from every state that receives funding under the Maternal and Child Services (MCH) Block Grant program.

States that receive MCH Block Grant funding should link their responsibility for ensuring disability nondiscrimination in Title V programs, as expressly incorporated in the statute, with their existing reporting requirements. For example, currently required information on the number of maternal and child-health-related providers licensed in the state in a year should incorporate information on the degree to which those providers have received training in the accessibility needs of children with disabilities. Currently required information on the proportion of women who did not receive prenatal care during the first trimester of pregnancy should include information on whether the mother had a disability along with currently collected information about her racial and ethnic group. Moreover, indicators specific to the structural and programmatic accessibility of maternal and child care providers in Title V programs should be systematically incorporated in the annual audits.

RECOMMENDATION:

State Medicaid agencies and health maintenance organizations (HMOs) should notify enrollees with disabilities of their Federal accessibility rights, as well as the right to auxiliary aids where necessary, either for effective notice or to provide equal benefit from the service in question, as established in Section 504.³⁹² State Medicaid agencies and HMOs that receive Federal financial assistance must acknowledge and act on their own generally greater financial and administrative capacity (compared with individual health care providers) to set policies and procedures that will inform, provide incentives, monitor, and enforce accessibility requirements among the providers that deliver health care services.³⁹³

RECOMMENDATION:

State Medicaid agencies that accept matching Federal monies must ensure that all Medicaid enrollees, including enrollees with disabilities, receive equal access to all aspects of the health care delivery system. Regulations enacted under Title XIX of the Social Security Act place ultimate responsibility for access to health care with the states. Each state is required to have a state Medicaid plan that “must ensure that all services covered under the State plan are available and accessible to enrollees of MCOs [managed care organizations], PIHPs [prepaid inpatient health plans], and PAHPs [prepaid ambulatory health plans].”³⁹⁴ The plans must include mechanisms to monitor and collect information about the extent of structural and programmatic access problems.

The continuing presence of structural and programmatic barriers within the multiple levels of state Medicaid health care systems is an ongoing violation of the Medicaid program regulations and greatly contributes to the health care disparities experienced by people with disabilities. A state system may begin with Medicaid enrollment and extend to making health care appointments, as well as to actual health care examinations and treatment.

CHAPTER 4. **Assessment of Key Federal Efforts That Promote Health for People with Disabilities**

A. Introduction

The Federal Government undertakes and supports significant public health, biomedical, and social science research, and provides funding for health care services and other activities, such as public education and professional training, through a complex array of programs. Various Federal agencies lead and support interagency collaborations that define the future direction of health, health care, and health disparities research. Chapter 3 of this report outlines the legal framework for the key Government agencies, departments, and centers that engage in these activities, and presents recommendations for including or increasing attention to people with disabilities based on the legislative scheme.

This chapter examines the extent to which people with disabilities are included in the recent activities of these key agencies, departments, and centers as they relate to health, health care, health promotion, disparities research, data collection, professional education, and other related activities. This chapter also presents a brief summary of the Federal Government's level of effort related to health disparities research and program development for people with disabilities. The chapter concludes with recommendations for guiding reform that will improve and promote health, access to health care and health promotion programs and activities, professional education, and necessary research such as data collection.

The following is a discussion of the key Federal agencies concerned with health and disability: the Department of Health and Human Services (HHS), the National Institutes of Health (NIH), other relevant Federal and allied agencies, and lead agencies for identifying future health policy research.

1. Department of Health and Human Services

The Federal Government devotes approximately 20 percent of the annual Federal budget to health care and is the largest insurer of people with disabilities. The HHS is the lead Federal agency for health care, health research, professional training, and health promotion and disease prevention. Within HHS, the Centers for Medicare & Medicaid Services (CMS), with a 2008 budget of \$606.9 billion, oversee the two largest programs that provide health care insurance for people with disabilities, as well as the State Children's Health Insurance Program (SCHIP), which also serves certain children with disabilities. Six additional HHS agencies engage in activities such as research, public education, program development, and interagency collaboration related to health, health care, health disparities, and outcomes of concern either to the broad population of people with disabilities or to subsets of that population. These agencies are the Administration for Children and Families (ACF) (2008 budget of \$47.4 billion); the National Institutes of Health (NIH) (2008 budget \$29.5 billion); the Health Resources and Services Administration (HRSA) (2008 budget of \$6.9 billion); the Centers for Disease Control and Prevention (CDC) (2008 budget of \$6.5 billion); the Substance Abuse and Mental Health Services Administration (SAMHSA) (2008 budget of \$3.4 billion); and the Agency for Healthcare Research and Quality (AHRQ) (2008 budget of \$335 million).

2. National Institutes of Health

NIH, composed of 27 institutes and centers, is the primary Federal agency for conducting and supporting medical research. Among its centers and institutes, at least 12 have supported one or more research, education, health promotion, or other projects that relate to health issues and problems experienced by certain subgroups of people with disabilities. Some agencies have specifically included in their mission statement, strategic plan, or both a reference to disability as a population demographic whose members experience health disparities. However, while these agencies have undertaken important projects, the overall effort is quite limited when compared with agency funding levels and other research commitments.

3. *Other Relevant Agencies and Offices*

Also included within HHS are the Office on Disability and the Office of the Surgeon General, which report directly to the Secretary of HHS.³⁹⁵

The National Institute on Disability and Rehabilitation Research (NIDRR) (2008 budget of \$106.7 million), in the U.S. Department of Education (ED), also includes a programmatic focus on the health concerns of people with disabilities and has provided funding for research and program development in this area.

The Institute of Medicine (IOM) of the National Academy of Sciences, an independent agency, has also undertaken significant research on topics including health and disability, technology and rehabilitation, and aging and long-term care. In collaboration with and supported by various Federal agencies, IOM carries out research that informs health care policy development. The activities of IOM are included in this report because the agency serves a crucial advisory role to Federal agencies concerned with matters of health and health policy.

4. *Lead Agencies for Identifying Future Health Policy Research*

In addition to undertaking and sponsoring research, several Federal agencies, including CDC and the Interagency Committee on Disability Research (ICDR), have taken the lead in identifying future public health research needs and initiating Federal collaboration on health disparities research.³⁹⁶

B. Overview of Key Federal Efforts That Promote Health for People with Disabilities

The overview and discussion of key Federal efforts to promote health for people with disabilities includes a description of each agency or initiative's overarching mission and goals, and a brief summary of its primary activities related to people with disabilities. (The Medicare, Medicaid, and SCHIP programs, along with related recommendations, are discussed in detail in chapter 3.)

1. Administration for Children and Families

The Administration for Children and Families (ACF) is responsible for Federal programs that promote the economic and social well-being of families, children, individuals, and communities. The Administration on Developmental Disabilities (ADD), within the ACF, is responsible for implementing the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (discussed in chapter 3). The [DD Act](#) requires ADD to ensure that people with developmental disabilities and their families receive the services and supports they need and are able to participate in planning and designing those services. The DD Act identifies eight areas of emphasis for ADD programs, including health, and specifically mandates that University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) be established. As discussed in chapter 3, UCEDDs undertake interdisciplinary training, community service, and research and information dissemination activities. Currently, ADD funds 68 UCEDDs—at least one in every state and territory—with a total budget of approximately \$33 million.

Preservice and continuing education training programs may include family support; personal assistance services; clinical, health, and prevention services; and other direct services. During 2006, for example, 4,279 people were trained in interdisciplinary settings across a variety of disciplines, including pediatrics, special and regular education, psychology, nutrition, and nursing. UCEDD staff also offer expertise and services to individuals with developmental disabilities, family members of these individuals, professionals, and others. According to a 2006 report of UCEDD program activities, more than 524,000 individuals in the community gained knowledge and skills related to the health care needs of people with disabilities, and more than 665,000 people with disabilities benefited from health-related activities supported by UCEDDs.³⁹⁷

2. Health Resources and Services Administration

The Health Resources and Services Administration (HRSA) is the primary Federal agency for improving access to health care services for people who are uninsured, underserved, isolated, or medically vulnerable. Its program goals include improving

access to health care, health outcomes and the quality of health care; eliminating health disparities; improving the public health and health care systems; and enhancing the ability of the health care system to respond to public health emergencies. HRSA grantees provide health care to uninsured people, people living with HIV/AIDS, pregnant women, mothers, and children. They also train health professionals and improve systems of care in rural communities. HRSA distributed approximately 90 percent of its FY 2007 \$6.4 billion budget in grants to states and territories, public and private health care providers, health professions training programs, and other organizations. The following are HRSA's primary areas of activity.

- Providing support to nearly 3,600 health center sites serving about 12.5 million people
- Funding care and treatment services for an estimated 533,000 people living with HIV/AIDS
- Assisting health care organizations, states, and communities, including rural and border areas, in improving services to women and children
- Overseeing the national system that allocates organs, tissue, and blood stem cells for transplant.
- Working with academic health centers and other training programs to enhance the diversity and distribution of the nation's health care workforce
- Implementing comprehensive systems of services in communities to meet the many needs of children and youth with special health care needs and their families
- Participating in global health initiatives such as the President's Emergency Plan for AIDS Relief

Within HRSA, bureaus and divisions whose programs and activities specifically concern people with disabilities include the Maternal and Child Health Bureau (MCHB), the Division of Services for Children with Special Health Needs (DSCSHN), and the Division of Research, Training and Education. In addition, HRSA operates the Health Center

Program, which provides comprehensive, culturally competent primary health care services to medically underserved communities and vulnerable populations.

a. Maternal and Child Health Bureau

The Maternal and Child Health Bureau (MCHB) is charged with promoting and improving the health of pregnant women, infants, children, adolescents, and their families. This work includes women of reproductive age, fathers, and children with special health care needs. MCHB administered seven major programs in FY 2007, with a total budget of \$838.2 million. MCHB undertakes programs mandated for children with special health care needs established under Title V of the Social Security Act, one of the largest Federal block grant programs. Approximately a million children with special health care needs receive care through Title V programs; this represents about half of American children with severe disabilities and 20 percent of those with chronic health conditions.³⁹⁸ MCHB also makes discretionary grants to more than 900 maternal and child health programs.

b. Division of Services for Children with Special Health Needs

The Division of Services for Children with Special Health Needs (DSCSHN) supports the development and implementation of comprehensive, culturally competent, coordinated systems of care for the estimated 18 million American children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally. The division works to achieve the systems outcomes set forth in “Healthy People 2010,” outcomes intended to break down barriers to community inclusion for people with disabilities. The following programmatic areas are included.

- Family Professional Partnerships/Cultural Competence—supports grants to implement Family to Family Health Care Information and Education Centers for Families of Children with Special Health Care Needs in every state, in keeping with the Family Opportunity Act of 2005.

- Medical Home—promotes access to care for children and youth with special health care needs and their families, improves continuity and quality of care, and ensures comprehensive, coordinated care.
- Health Insurance and Financing—focuses on strategies to improve access to adequate health insurance. Nearly 1 in 10 children with special health care needs have no health insurance, while others are underinsured and experience gaps in coverage for key services, including mental health, ancillary therapies, home health care, and durable medical equipment.
- Early and Continuous Screening—has the goal of placing all infants identified with hearing loss in early intervention programs by the age of 6 months.
- Community Integrated Services—facilitates the development of community-based systems of service for children and youth with special health care needs and their families, and promotes the goal of breaking down barriers to community inclusion for people with disabilities and special health care needs.
- Transition to Adult Health Care—supports statewide grants and a National Resource Center that provides information and resources to prepare youth to make the transition to adulthood, including moving from the pediatric to the adult health care system.

In addition, the Division of Services for Children with Special Health Care Needs supports initiatives on certain special populations and issues, including improving and advancing state-based service systems for traumatic brain injury (TBI) survivors and their families, and improving access to care for children and youth with epilepsy, especially those living in medically underserved and rural areas, and those who belong to racial and ethnic minority populations.

MCHB is also charged with establishing a program for genetic disease testing, counseling, information development and dissemination, and grants related to hemophilia, sickle cell disease, and other genetic disorders. In February 2008, MCHB

published the “National Survey of Children with Special Health Care Needs Chart Book 2005–2006.”³⁹⁹

c. Division of Research, Training and Education

The Division of Research, Training and Education is one of five divisions of HRSA’s Maternal and Child Health Bureau. Within the division, the Maternal and Child Health Leadership Education in Neurodevelopmental Disabilities (LEND) program trains individuals from a wide variety of professional disciplines to improve the health of children who have, or are at risk of developing, neurodevelopmental or other related disabilities, such as intellectual and developmental disabilities. Interdisciplinary faculty and trainees include audiologists, dentists, family members, health administrators, nurses, nutritionists, occupational therapists, physical therapists, physicians, psychologists, social workers, special education professionals, and speech and language pathologists.

d. Primary Health Care: The Health Center Program

HRSA-supported health centers provide comprehensive health care services to medically underserved communities and vulnerable populations, including low-income populations, people who are uninsured, those with limited English proficiency, migrant and seasonal farm workers, individuals and families experiencing homelessness, and those living in public housing. Approximately 40 percent of patients served in 2006 were uninsured. Nearly 829,000 individuals served that year experienced homelessness, and more than 129,000 were residents of public housing. Twenty-three percent of patients who received health care from the centers were African American, and 36 percent were Hispanic/Latino. HRSA also funds programs and services provided by designated health centers that are operated by tribal organizations.⁴⁰⁰

While HRSA does not explicitly target people with disabilities for health care services through designated health centers, the groups identified as the intended beneficiaries are likely to experience a greater level of disability than does the general population. Therefore, while HRSA’s Health Center Program neither targets individuals with

disabilities for health care services nor collects disability status data on those it serves, it is reasonable to assume that a proportion of the individuals who receive services from health centers experience disability.

3. *Centers for Disease Control and Prevention*

The Centers for Disease Control and Prevention (CDC) promotes health and quality of life by preventing and controlling disease, injury, and disability. CDC works with partners to monitor health, detect and investigate health problems, conduct research, develop public policies, and promote healthy behaviors. Several centers within CDC either sponsor or conduct research concerning health, health care, health status, and health disparities for people with disabilities. These include the National Center for Health Statistics (NCHS), the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), the National Center on Birth Defects and Developmental Disabilities (NCBDDD), and the Office on Disability and Health within NCBDDD.

a. National Center for Health Statistics

The National Center for Health Statistics (NCHS) is the principal Federal health statistics agency. (See chapter 5 for a discussion of health data collection.)

b. National Center for Chronic Disease Prevention and Health Promotion

The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) conducts and supports research on chronic diseases and health promotion programs, and monitors population health through surveys, including the Behavioral Risk Factor Surveillance System (BRFSS), which has tracked health conditions and risk behaviors in the United States annually since 1984. (See chapter 5 for a discussion of the BRFSS and people with disabilities.)

NCCDPHP has provided funding for an important research undertaking for people with disabilities: the Rochester Prevention Research Center (RPRC) at the University of Rochester, which is developing a national center of excellence for health promotion and disease prevention research in people who are deaf or hard of hearing. The RPRC

works to promote health and prevent disease in the deaf or hard-of-hearing population primarily through community-participatory research. Specific activities include identification and prioritization of the deaf or hard-of-hearing community's health needs, development of effective and inclusive interventions, accessible communication and dissemination of the center's findings, and evaluation of the center to ensure meaningful contributions to the health of local, state, national, and international deaf or hard-of-hearing populations.

c. Office of Disability and Health—National Center on Birth Defects and Developmental Disabilities

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) promotes the health of babies, children, and adults.⁴⁰¹ NCBDDD's activities include identifying the causes of and preventing birth defects and disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities. The Disability and Health Team, within the center's Division of Human Development and Disability, focuses on promoting the health of people with disabilities through projects and programs that build the capacity of organizations to improve health and prevent morbidity. In recent years, the team has moved away from focusing on disability prevention and toward promoting secondary illness and disease prevention for people with disabilities, consistent with the goals of "Healthy People 2010" and the Surgeon General's "Call to Action." Currently, the Disability and Health Team is funding 16 state projects aimed at integrating awareness of disability health disparities into public health programs and activities. Core activities of these projects include analyzing BRFSS data for their respective states, creating and implementing strategic plans, and establishing and maintaining an advisory committee.⁴⁰² The Disability and Health Team has also recently undertaken eight research projects that include a major emphasis on health promotion and disease prevention for women with disabilities.⁴⁰³

The following are examples of projects of CDC and the Office of Health and Disability.

- Promoting Health & Functioning in Persons with Serious Mental Illness (SMI)—a project funded by CDC and undertaken by Dartmouth College to evaluate a novel program that may offer a practical approach to improving health, independent functioning, and longevity in persons with SMI.
- Telehealth: Automated Phone Followup for People with Mobility Impairments—a project funded by CDC and undertaken by the Boston Medical Center to develop and evaluate an automated, telephone-based screening, referral, and educational behavioral intervention system with the long-term objective of promoting health by preventing secondary conditions and decreasing their severity among older patients with mobility impairments who are wheelchair users.
- A qualitative study to explore the barriers to breast cancer screening for women with physical disabilities. As a result of the study, CDC developed and tested the Right to Know Campaign—a family of health promotion materials (posters, MP3 recordings, flyers, ads, and a tip sheet) designed to increase awareness of breast cancer among women with physical disabilities and to encourage these women to be screened.

The Disability and Health Team also supports the American Association for Disability and Health, the National Resource Center on Spina Bifida housed within the [Spina Bifida Association of America](#), and the National Center on Physical Activity and Disability (NCPAD), which is operated jointly by the University of Illinois at Chicago's Department of Disability and Human Development, the Rehabilitation Institute of Chicago, and the National Center on Accessibility at Indiana University. Established through a CDC award in 1999, the Indiana University center is a national clearinghouse to gather, organize, and consolidate existing information; to synthesize resources on physical activity for people with disabilities; and to facilitate dissemination to consumers, practitioners, and disability and service organizations.

In addition to core programs, the team is responsible for nearly \$18 million to support several congressionally mandated programs, including the Amputee Coalition of

America, the Special Olympics, and the Christopher and Dana Reeve Paralysis Resource Center. The team has also hosted training opportunities for developing a cadre of public health professionals who will ultimately work in the field of disability and health. In addition, the team is working to integrate the needs of people with disabilities into emergency planning and preparedness activities to ensure that they will not be excluded from shelters and that they are included in evacuation planning and procedures.

d. National Center for Environmental Health

The National Center for Environmental Health (NCEH) is responsible for a national program to maintain and improve health and promote a healthy environment by preventing premature death and avoidable illness and disability caused by noninfectious, nonoccupational environmental and related factors. The center recognizes that health issues are related to land use, and therefore, a major initiative of the NCEH is designing and building healthy places. NCEH stipulates that health relates to land use and includes accessibility for people with disabilities and older persons as well as aspects of the community environment that influence residents' level of physical activity. NCEH has funded the University of Michigan at Ann Arbor to study the effects of the built environment and the progression of disability among older adults.

4. Substance Abuse and Mental Health Services Administration

This mission of the Substance Abuse and Mental Health Services Administration (SAMHSA) is to build resilience and facilitate recovery for people with or at risk for substance abuse and mental illness. SAMHSA envisions "A Life in the Community for Everyone." This vision is based on the premise that people of all ages who have, or are at risk for, mental or substance use disorders should have the opportunity for a fulfilling life that includes a job, an education, a home, and meaningful personal relationships with friends and family. The agency administers competitive and block grant programs, and undertakes data collection, evaluation, and technical assistance activities. With a fiscal year 2007 budget of nearly \$3.3 billion, SAMHSA funds and administers grant programs and contracts that support state and community efforts to expand and

enhance prevention and early intervention programs, and to improve the quality, availability, and range of substance abuse treatment, mental health, and recovery support services in local communities, where people can be served most effectively. Programs are carried out by the Center for Mental Health Services (CMHS), the Center for Substance Abuse Prevention (CSAP), the Center for Substance Abuse Treatment (CSAT), and the Office of Applied Studies.

a. Center for Mental Health Services

The Center for Mental Health Services (CMHS) applies scientifically established findings and practice-based knowledge in the prevention and treatment of mental disorders; improves access, reduces barriers, and promotes high-quality effective programs and services for people who have or are at risk for these disorders, and for their families and communities; and promotes an improved state of mental health in the nation, as well as the rehabilitation of people with mental disorders.

b. Center for Substance Abuse Prevention

The Center for Substance Abuse Prevention (CSAP) provides national leadership in the development of policies, programs, and services to prevent the onset of illegal drug, underage alcohol, and tobacco use; disseminates substance abuse prevention practices; and builds the capacity of states, communities, and other organizations to apply prevention knowledge effectively.

c. Center for Substance Abuse Treatment

The mission of the Center for Substance Abuse Treatment (CSAT) is to bring effective alcohol and drug treatment to every community. CSAT provides national leadership to expand the availability of effective treatment and recovery services for alcohol and drug problems; and to improve access, reduce barriers, and promote high-quality effective treatment and recovery services for people with alcohol and drug problems, abuse, or addiction, and for their families and communities.

d. Office of Applied Studies

The Office of Applied Studies (OAS) collects, analyzes, and disseminates national data on behavioral health practices and issues. OAS is responsible for the annual National Survey on Drug Use and Health, the Drug Abuse Warning Network, and the Drug and Alcohol Services Information System, among other studies.

OAS also provides access to the National Registry of Evidence-based Programs and Practices (NREPP), a searchable online registry of mental health and substance abuse interventions that have been rated by independent reviewers. The purpose of this registry is to help the public find approaches to preventing and treating mental and substance use disorders that have been scientifically tested and that can be readily disseminated to the field.

5. Agency for Healthcare Research and Quality

The Agency for Healthcare Research and Quality (AHRQ) is the health services research arm of HHS. The agency supports research in major areas of health care, including quality improvement and patient safety, outcomes and effectiveness of care, clinical practice and technology assessment, health care organization and delivery systems, primary care, including preventive services), and health care costs and sources of payment.

AHRQ conducts and supports health services research, both within the agency and in academic institutions, hospitals, physicians' offices, health care systems, and other settings across the country. The agency is also a major source of funding and technical assistance for health services research and research training at U.S. universities and other institutions.

a. Priority Populations

AHRQ is also charged with carrying out research, evaluations, and demonstration projects with respect to health care for "priority populations," including low-income groups, minority groups, women, children, the elderly and "individuals with special

health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.” The AHRQ Office for Priority Populations Research coordinates, supports, manages, and conducts health services research on these populations. AHRQ describes its disability-related research as follows:

AHRQ-supported research brings evidence on what works—and what does not work—in health care delivery to people impaired by disabling illness or injury. Findings from AHRQ research can help public policymakers, program administrators, and other health care leaders develop policies and programs to improve health services for people with disabilities as well as determine eligibility for benefits under Medicare, Social Security, and other publicly financed programs and private health plans.⁴⁰⁴

b. National Healthcare Disparities Report

In 2003, AHRQ began publishing an annual “National Healthcare Disparities Report” (NHDR), describes the quality of and access to care for multiple subgroups across the United States; the NHDR is a source of information for tracking progress over time. The first report, released in 2003, included a chapter entitled “Disparities in Health and Health Care,” which recognized that disability and chronic disease are not synonymous and that people with disabilities typically confront two generic problems in health care: access to care and coordination of care. The use of the word “access” in the context of this chapter refers to physical, cognitive, communication, or other barriers. In subsequent NHDRs, information about people with disabilities is included in a chapter entitled “Priority Populations” under the heading “Individuals with Special Health Care Needs,” which includes people with disabilities, people who need chronic or end-of-life care, and children with special health care needs. The 2004 NHDR highlights children with special health care needs, while the 2005 and 2006 reports present data on quality and access for younger and elderly Medicare beneficiaries with disabilities, as well as for children with special health care needs.

In the 2007 NHDR, AHRQ broadened the definition of disability and focused on the impact on individuals with disabilities of delayed care; inappropriate medication use by older people; and exercise and weight management for obese adults with disabilities.

c. Related Research

The following are recent and current disability-related research topics supported by AHRQ.

- Use of risky or ineffective medicines by seniors with disabilities
- Depression among people with diabetes
- The relationship of age, ethnicity, and living arrangements on the use of assistive devices by people with mobility disabilities
- Increasing chronic disability care management programs in Medicaid managed care plans
- Health disparities experienced by women with disabilities
- The impact of lack of health care in rural areas for people with disabilities
- Ways to improve the health care experiences of people who are blind or have vision impairments
- Creating an evidence base for vision rehabilitation
- How health insurance status affects people with disabilities
- Translating and adapting the Consumer Assessment Healthcare Providers and Systems (CAHPS) survey to collect information in American Sign Language (ASL) from deaf people about their health care experiences
- Measuring the business case for disability care coordination from the perspective of Medicaid by showing that the additional expenses of paying for care coordination are offset in the form of reduced total program expenditures

AHRQ also oversees the Medical Expenditure Panel Survey (MEPS), a set of large-scale surveys of families and individuals, their medical providers, and employers across the United States. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage. (See chapter 5 for a discussion of MEPS.)

6. Office on Disability

The HHS Office on Disability was created in October 2002 in response to the New Freedom Initiative, which established seven areas of emphasis for people with disabilities, including community integration, education, employment, health, housing, technology, and transportation. The Office on Disability focuses its efforts on these seven domains. The Director of the Office reports to the Secretary of HHS and serves as an advisor on HHS activities related to disabilities.

The Office on Disability is charged with serving as the focal point within HHS for the implementation and coordination of policies, programs, and special initiatives related to disability, both within the department and with other Federal agencies. The office is also responsible for increasing interactions among programs within HHS and with Federal, state, community, and private sector partners, and for supporting initiatives that remove barriers that prevent people with disabilities from participating in their communities.

Activity highlights for 2008 included the following:

- Collaboration with the Surgeon General to develop and publish a document concerning closing the gaps in services for infants and young children with hearing loss
- Management of the “I Can Do It; You Can Do It” program, which promotes physical fitness and healthy diets among children and youth with disabilities
- Promotion of the Surgeon General’s “Call to Action To Improve the Health and Wellness of Persons with Disabilities” through management of four working groups that are increasing attention to disability in the media, entertainment industries, medical trade organizations, health care providers, and employers
- Distribution of the “Call to Action” at numerous conferences and meetings
- Ensuring that people with disabilities are included in the development of electronic and personal health records planning activities
- Ensuring that emergency preparedness plans include the needs of people with disabilities

To further implement the goals of the “Call to Action,” the Office on Disability convened a meeting of leading experts in health care, education, and Government to address the need to include training programs in medical, nursing, and dental curriculums that are directly related to persons with disabilities and to forge an action plan to ensure that all health programs offer consistent health care access for people with disabilities.

Participants identified actions for moving forward, including incorporating disability into core competencies using universal design; developing methods for electronic information exchange and dissemination; and identifying opportunities for accreditation support.

Through partnerships with the U.S. Department of Education, the Administration on Developmental Disabilities, the Social Security Administration, the Substance Abuse and Mental Health Services Administration, and the Georgetown University Center for Child and Human Development, the Office on Disability is working toward an integrated approach to address the needs of people with co-occurring disabilities.⁴⁰⁵

7. *Office of the Surgeon General*

The Surgeon General serves as the nation’s chief health educator by providing the public with scientific information on how to improve health and reduce the risk of illness and injury. The Surgeon General reports to the Assistant Secretary for Health, who is the principal advisor to the Secretary of HHS on public health and scientific issues. The Office of the Surgeon General oversees the operations of the 6,000-member Commissioned Corps of the U.S. Public Health Service.

The Surgeon General is charged with various duties, including protecting and advancing health by educating the public and advocating for effective disease prevention and health promotion programs and activities. He or she is also charged with providing leadership in promoting special health initiatives, such as tobacco- and HIV-prevention efforts, with other Government and non-Government entities, and elevating the quality of public health practice in the professional disciplines through the advancement of appropriate standards and research priorities. Public health priorities of the Office of the

Surgeon General include disease prevention, limiting health disparities, public health preparedness, and improving health literacy.

Reports issued by the Surgeon General focus attention on important public health issues such as the adverse health consequences of smoking; the report on the smoking issue triggered nationwide efforts to prevent tobacco use and generated major public health initiatives. The Surgeon General has produced several critical reports that focus attention on health and health care disparities experienced by people with disabilities, including people with intellectual and developmental disabilities, and that emphasized the centrality of health to the quality of life. Included are the 2005 “Call to Action,” the 2002 report entitled “[Closing the Gap: A National Blueprint To Improve the Health of Persons with Mental Retardation](#),” “Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation,” and “Oral Health in America: A Report of the Surgeon General,” which underscores the many oral and systemic diseases and conditions that impair health in older adults and the role of oral health in the quality of life and life expectancy of individuals with disabilities. These reports describe the particular challenges to health and well-being faced by persons of all ages with disabilities and place their health among the public health issues that should be at the forefront of research, service delivery, financing, training and education, and health care policy. The reports also establish the principle that good health is necessary for people with disabilities to work, learn, and engage with their families and communities.

“Call to Action,” “Closing the Gap,” and “Oral Health in America” firmly establish that the health and wellness of people with disabilities is a matter of public health concern. Further, they call for better approaches to identifying, acquiring, and utilizing new knowledge, new technologies, and new systems of services that emphasize a team approach and partnerships with people with disabilities. These publications identify the need for “health care providers who see and treat the whole person, educators willing to teach about disability, a public that sees beyond the disability to the whole person, and a community that provides accessible health and wellness services for persons with disabilities.”⁴⁰⁶ “Call to Action” specifically identifies challenges that must be overcome

to realize the principle that, with good health, people with disabilities have the freedom to work, learn, and engage actively with their families and their communities.

Challenges are present in all aspects of health care and service delivery for persons with disabilities. They include such concerns as an inadequately trained and educated health care and services workforce and a health care and health promotion service system that is limited in accessibility or availability to persons with disabilities.

8. “Healthy People 2010”

“Healthy People 2010” is the Federal Government’s statement of national health objectives, designed to identify the most significant preventable threats to health, and to establish national goals for reducing these threats. This report is designed to increase the quality and years of healthy life, and to eliminate disparities in the burden of disease. People with disabilities are represented in 207 of the 467 objectives that span 21 of the 28 “Healthy People 2010” focus areas. However, when “Healthy People 2010” was implemented, data on people with disabilities were available for only 88 of the 207 objectives.

The statement’s Focus Area 6, Disability and Secondary Conditions, contains 13 objectives to promote the health and well-being of children and adults with disabilities across their lifespan. It introduces the concept of “healthy people with disabilities.”⁴⁰⁷ For the first time in national public health parlance, disability is considered in relation to fitness and health, rather than solely as an outcome of illness or disease. The stated goal of Focus Area 6 is to “Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population.” Within Focus Area 6, Objective 6–1 states that “Disability is a demographic descriptor rather than a health outcome” and that

[d]isability can be viewed as a universal phenomenon everyone experiences at some time. Disability also can be viewed as representing a minority of the population, in that people with disabilities may be less visible, undercounted, and underserved. As a potentially underserved group, people with disabilities would be expected to experience disadvantages in health and well-being compared with the general population. People with disabilities may experience

lack of access to health services and medical care, and may be considered at increased risk for various conditions.⁴⁰⁸

“Healthy People 2010” also contains 10 vision objectives. While most of these objectives are concerned with prevention and treatment of vision impairments, Focus Area 28, Objective 10, addresses the need for vision rehabilitation. This objective aims to “increase the use of vision rehabilitation services and adaptive devices by people with vision impairments.”⁴⁰⁹

The objectives for disability and secondary conditions seek to eliminate disparities between people with and without disabilities by addressing health disparities among specific populations of people with disabilities. “Healthy People 2010” undertook a midcourse review that revealed some preliminary information on the extent to which objectives are being met. For example, for Focus Area 6, the midcourse review provides new data comparing populations within the disability community that address both quality of life and health disparities. Disparities are documented between people who have disabilities and those who do not, as well as among subgroups based on education, income, gender, and ethnicity. Improvements are shown in several areas, including an increase in inclusion of people with disabilities in national and state surveillance, a reduction of the number of adults with disabilities living in congregate care facilities, and an increase in the number of children with disabilities included in regular education programs. However, according to the midcourse review, this improvement cannot be attributed to any particular programmatic intervention. Implementation and enforcement of Federal disability rights laws, improved public awareness of disability generally, and an increase in accessibility, including to public transportation, may be contributing factors.⁴¹⁰

9. National Institute on Disability and Rehabilitation Research

The National Institute on Disability and Rehabilitation Research (NIDRR), operating in concert with the Rehabilitation Services Administration (RSA) and the Office of Special Education Programs (OSEP), conducts research and related activities that foster full inclusion, social integration, employment, and independent living among individuals with

disabilities. With a fiscal year 2007 budget of \$106.7 million, NIDRR supports disability research, demonstration projects, and related activities. NIDRR undertakes core research in areas such as employment, health and function, technology for access and function, knowledge dissemination and utilization, independent living and community integration, and other related areas. Most of NIDRR's research related to health, health care, and health disparities for people with disabilities is conducted within the health and function core priority area.

NIDRR's 2005–2009 strategic plan spells out the agency's mission for that period regarding health and function. Recognizing that functional ability reflects the complex interaction between individuals and the environment in which they live, NIDRR supports research at both the individual and systems levels. Individual-level research focuses on development and testing of new interventions that improve functional and health outcomes for people with disabilities. At the systems level, NIDRR-supported research focuses on the organization and delivery of health care and medical rehabilitation services.⁴¹¹

a. Health and Function

NIDRR's research focus for health and function emphasizes the challenges people with disabilities encounter in obtaining individual health care, services, and supports. Research topics include medical rehabilitation, health and wellness programs, service delivery, short- and long-term interventions, systems research, and new and emerging disabilities. NIDRR has specifically emphasized support for projects concerned with health and health care disparities among individuals with disabilities.

Recent past and current multiyear research grants specifically address health disparities and people with disabilities. For example, the Health Disparities Project, a 5-year initiative launched by the Oregon Health and Science University (OHSU) in 2008, will include review and synthesis of existing health and health care access information for people with disabilities. The initiative will use Medical Expenditure Survey data to analyze systemic, environmental, and individual factors that relate to health care access

among people with certain disabilities, and to identify models of health outcomes. An earlier project undertaken by OHSU is identifying strategies to overcome barriers that impede access by people with disabilities to routine health care, such as exercise, nutrition, pain management, and complementary and alternative therapies that promote health and wellness. The same project is developing improved measurement tools to assess the health and well-being of people with disabilities regardless of functional ability. A third OHSU project is developing a group therapy intervention to address the specific needs of women with physical disabilities who experience depressive symptoms.

Additional projects relate to health, function, fitness, and independent living for individuals with disabilities. The following projects relate to prevention and health promotion.

- The University of Illinois, Chicago, has undertaken a 5-year project concerning access to recreational opportunities, physical fitness, and endurance of people with disabilities. The university's other projects include one that aims to reduce obesity and obesity-related secondary conditions among adolescents with disabilities.
- George Mason University has undertaken a 4-year project to develop and validate health service quality indicators for people with disabilities enrolled in managed Medicaid programs.
- Marquette University and partners undertook a 5-year research project to evaluate accessible medical instrumentation.
- Georgia Institute of Technology conducted research on the way wheeled mobility is conceptualized and understood.
- Northwestern University undertook a 5-year project to address the need to improve the delivery of health services for people with disabilities by evaluating the impact of Medicare's inpatient rehabilitation facilities prospective payment

system and by identifying the impact of comorbidity on patients' classification and reimbursement.

NIDRR also enters into interagency agreements with various agencies, including HRSA, to promote certain aspects of health care delivery, and it supports substantial research in the area of traumatic brain injury, and burn and stroke treatment and recovery.

NIDRR-supported research has resulted in published articles on topics including the following:

- Recognizing and responding to the health disparities of people with disabilities
- Health and health care access for people with intellectual disabilities
- Access barriers to substance abuse treatment for persons with disabilities
- Translating policy principles into practice to improve health care access for adults with intellectual disabilities
- Understanding health outcomes for people with spinal cord injury
- Physical and social environmental factors that influence health and participation outcomes for chronically ill adults

b. Interagency Committee on Disability Research

The Director of NIDRR chairs the Interagency Committee on Disability Research (ICDR), which facilitates the exchange of information on disability and rehabilitation research activities among its member Federal agencies on topics including assistive technology and universal design; medical rehabilitation; data and statistics; employment; and community participation. The ICDR identifies emerging research areas; assesses gaps and duplications in existing research; and makes recommendations to strengthen the Federal research agenda.

10. National Institutes of Health

With its 27 institutes and centers, NIH is the primary Federal agency for conducting and supporting medical research. The National Center on Minority Health and Health Disparities (NCMHD) is the primary center in NIH that promotes minority health and that leads, coordinates, and supports activities intended to eliminate health disparities for racial and ethnic minority groups. NCMHD's mission does not include health disparities experienced by people with disabilities. (See chapter 3 for a discussion of the legislation that established NCMHD.) However, at least 12 other institutes and centers within NIH are engaged in various levels of research that promotes health and reduces health disparities for certain groups of people with disabilities. (Agencies are presented alphabetically.)

a. National Cancer Institute

The National Cancer Institute (NCI) is the Federal Government's primary agency for cancer research and training. NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs concerning the cause, diagnosis, prevention, and treatment of cancer. It also supports education and training in fundamental sciences and clinical disciplines, and research projects on cancer control, a national network of cancer centers, and the collection and dissemination of information on cancer.

NCI oversees the Center to Reduce Cancer Health Disparities (CRCHD), which engages in collaborative research studies with NCI and other NIH institutes and centers to promote research and training in cancer health disparities and to identify new and innovative scientific opportunities to improve cancer outcomes. While health disparities for people with disabilities do not appear to be a focus of the CRCHD, there is modest indication that NCI and CRCHD recognize that the disability community experiences health disparities. For example, in his opening remarks during a 2007 Cancer Health Disparities Summit, NCI's Director, Dr. John Niederhuber, said, "Health disparities are about unacceptable inequalities in health outcomes that are experienced by certain groups. Racial and ethnic minorities, residents of rural areas, women, children, the

elderly, and people with disabilities all experience disproportionate burdens of disease, including cancer.”⁴¹² NCI has supported several research projects on health disparities that affect certain subpopulations of the disability community, including the following:

- A research grant awarded to the Susan G. Komen Breast Cancer Foundation for a pilot study to develop and test a method to identify women of screening age with physical and sensory disabilities, and a questionnaire to identify amenable-to-change barriers in screening mammography for these women⁴¹³
- A research grant on the effects of disability on the diagnosis of breast cancer; awarded to the University of Texas Medical Center, Galveston
- A program to expand the number of cancer education training videos available to people who are deaf in San Diego, California, and to test dissemination strategies designed to take the program nationwide, including developing national partnerships with deaf ministries; awarded to the University of California, San Diego.
- An immersion project to train 10 medical students from the University of California, San Diego, in basic American Sign Language (ASL), Deaf culture awareness, and medical terminology in ASL, with a focus on cancer-related issues; awarded to the University of California, San Diego

b. National Eye Institute

The National Eye Institute (NEI) conducts and supports research and helps prevent and treat eye diseases and other vision disorders. NEI supports vision research through research grants and training awards to universities, medical centers, and other institutions, and conducts laboratory and patient-oriented research. NEI is the lead Federal agency for the vision chapter in “Healthy People 2010,” and it recognizes the importance of access to vision rehabilitation services for people who are blind or have vision impairments. NEI’s 1999–2003 strategic plan includes a national plan for low-vision and blindness rehabilitation, with program goals such as developing devices, environmental modifications, and rehabilitation strategies to minimize the impact of

vision impairment in everyday life and reduce societal limitations for individuals with vision impairments. The plan states

. . . NEI is working on a project to educate eye health care professionals about the issues of vision rehabilitation. The NEI is developing a pilot program to enhance referrals of individuals with low vision to vision rehabilitation services. The primary purpose of the program is to increase patient referrals from eye care professionals to qualified vision rehabilitation services.⁴¹⁴

NEI's commitment to establishing sound scientific evidence about the effectiveness of vision rehabilitation is particularly important because of the high prevalence of vision impairments in the United States, as well as the role vision rehabilitation plays in supporting the health and independence of people who are blind or have vision impairments. Acting on this commitment, the Institute supported various projects including the following:

- University of Alabama at Birmingham—a project to lead randomized clinical trials on the effectiveness of low-vision rehabilitation services for adults with vision impairments who seek them. One goal of the project was to provide information that could assist the Centers for Medicare & Medicaid Services (CMS) in formulating policy on coverage of these services.
- University of Minnesota, Twin Cities—a project to develop a computer-based design tool in which environments could be simulated with sufficient accuracy to predict the visibility of key landmarks and obstacles, such as steps or benches, under differing lighting conditions. The long-term goal was to create tools to enable the design of safe environments for people with vision impairments.

c. National Human Genome Research Institute

The National Human Genome Research Institute (NHGRI) began as the National Center for Human Genome Research (NCHGR), which was established in 1989 to carry out the role of the National Institutes of Health (NIH) in the International Human Genome Project (HGP).

NHGRI has funded a 3-year project at the University of Illinois at Chicago designed to explore the areas in which medical genetic advising is, or is not, informed by the lived experience of persons with genetic or prenatally diagnosable disabilities.

d. National Institute on Aging

The National Institute on Aging (NIA) researches the biomedical, social, and behavioral aspects of the aging process; the prevention of age-related diseases; and the promotion of a better quality of life for older people. NIA funds research and training at universities, medical centers, and other institutions, and conducts basic and clinical intramural research. NIA recognizes that older adults experience health disparities and that research is needed to understand the causes of these disparities and how they relate to social, economic, and health system factors. While one of NIA's goals is to reduce the incidence of disease and disability among older people, the work of the agency also relates to health, health care, and health disparities experienced by people with disabilities generally because many older people have acquired various chronic, long-term hearing, vision, and mobility impairments and, therefore, are likely to experience disparities in secondary health conditions. NIA is exploring important interrelationships among socioeconomic status, race-ethnicity, and health, as well as biodemographic approaches to aging and health. Outcomes of these research endeavors may be generalizable to the broader disability community over time.

e. National Institute on Alcohol Abuse and Alcoholism

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) conducts research focused on improving the treatment and prevention of alcoholism and alcohol problems to reduce health, social, and economic consequences that may include, for example, personal health costs, the cost of medical care and treatment, and loss of productivity. The institute's vision includes increasing the understanding of normal and abnormal biological functions and behavior relating to alcohol use, and improving the diagnosis, prevention, and treatment of alcohol use disorders. Enhancing quality health care is also a key aspect of the institute's vision. NIAAA apparently does not specifically investigate alcohol use among people with disabilities, but the institute does have an

initiative related to alcohol use among people who are aging. This group will likely include a high percentage of individuals who have other limiting impairments. Further, overuse of alcohol can increase the probability of developing diabetes, heart disease, and other conditions that can lead to disability. Thus, NIAAA is included among the NIH institutes that engage in activities related to health and disability.

f. National Institute of Child Health and Human Development

The National Institute of Child Health and Human Development (NICHD) conducts and supports research on all stages of human development, from preconception to adulthood, to better understand the health of children, adults, families, and communities. The institute has supported research projects such as the following:

- University of California, San Francisco—a project to study a diverse sample of families raising youth who are both medically fragile and developmentally disabled, to describe the challenges in the transition to adulthood and to discover how services, programs, and resources available through schools affect family planning and decision making for the transition, including the health care transition
- Oregon Health and Science University—a project to test the efficacy of a health promotion intervention for people with intellectual disabilities

g. National Institute of Dental and Craniofacial Research

The National Institute of Dental and Craniofacial Research (NIDCR) leads a national research program designed to understand, treat, and ultimately prevent infectious and inherited craniofacial-oral-dental diseases and disorders. NIDCR performs and supports basic and clinical research, conducts and funds research training and career development programs, coordinates and assists relevant research and research-related activities among other sectors of the research community, and promotes the transfer of knowledge. The institute has developed a strategic plan to eliminate oral, dental, and craniofacial health disparities; this plan is the foundation for addressing persistent

national inequalities in oral health. NIDCR broadly defines “health disparities” and the factors with which they are associated.

The complex nature of American society is mirrored in the complex meaning of health disparities. We are interpreting the term to refer to the diminished health status of population subgroups defined by demographic factors such as age and socioeconomic status (SES), geography, disability status, and behavioral lifestyles. Health disparities associated with any one or more of these factors reflect the diversity of the U.S. population by gender and age, racial or ethnic identity, educational attainment, income (measured by money and other forms of wealth), location of residence (regional and metropolitan area), disability status, and sexual orientation.⁴¹⁵

NIDCR has developed and published a series of important booklets on providing dental care for people with developmental disabilities. A document entitled “An Introduction to Practical Oral Care for People with Developmental Disabilities” is available on the NIDCR Web site, and other documents in the series can be accessed or ordered there, including the following: “Practical Oral Care for People with Autism,” “Practical Oral Care for People with Cerebral Palsy,” “Practical Oral Care for People with Down Syndrome,” and “Practical Oral Care for People with Mental Retardation.”⁴¹⁶ The institute also has a caregiver’s guide to everyday dental care for people with disabilities that can be accessed online, and it offers continuing education credit and certification for the completion of an examination concerning health challenges and strategies for practical oral health care for people with developmental disabilities. NIDCR also makes available online a health care provider’s guide to wheelchair transfer and an extensive list of additional resources for providing oral care for people with developmental disabilities.⁴¹⁷

In 2008, NIDCR launched a clinical research initiative to improve the oral health of special needs populations, which could include epidemiologic and behavioral studies and patient-oriented research. The institute has funded the University of California, San Francisco, to investigate oral health disparities in children with disabilities.

h. National Institute of Diabetes and Digestive and Kidney Diseases

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD) conducts and supports research on the diseases of internal medicine and related subspecialty fields, as well as many basic science disciplines. NIDDKD has funded the University of Montana to undertake several projects intended to test the reliability and validity of various methods to assess the dietary intake of adults with significant cognitive impairments living in the community.

i. National Institute on Deafness and Other Communication Disorders

The National Institute on Deafness and Other Communication Disorders (NIDOC) conducts and supports biomedical and behavioral research and research training about the processes of hearing, balance, smell, taste, voice, speech, and language. NIDOC has funded a project at the Virginia Commonwealth University, which identifies, analyzes, and addresses the ethical and social implications from advances due to the Human Genome Project.

j. National Institute of Environmental Health Sciences

The National Institute of Environmental Health Sciences (NIEHS) undertakes activities to reduce illness and disability by understanding how the environment influences the development and progression of human disease. NIEHS emphasizes basic science, disease-oriented research, global environmental health, and multidisciplinary training for researchers. NIEHS also makes available information on major health topics that are related to or affected by environmental exposures, uses research outcomes to influence public health interventions and policies, and helps health professionals diagnose and treat people with conditions and diseases influenced by environmental agents. The institute supports research centers that address health issues such as breast cancer and the environment, children's environmental health, population health, and health disparities.

NIEHS has funded a longitudinal study using community-based participatory research to improve access to the built environment for persons with mobility disabilities. The

project involves partnerships between the University of Illinois at Chicago, the Illinois Americans with Disabilities Act Project, the Chicago-based American Planning Association, and the Urban Transportation Planning Center at the University of Illinois at Chicago. The study involves the development of a health empowerment zone that includes training initiatives with fitness and recreation facilities, grocery stores, the regional transportation authority, and local planning and zoning boards. Interventions include disability awareness and accessibility training for fitness facility, grocery store, and mass transit staff; recommending barrier removal options to store and facility owners; recommending strategies for improving community accessibility; and a health marketing incentive campaign. The primary outcome is a model program for improving access to the built environment, resulting in improved health and reduction of secondary conditions among people with mobility disabilities.⁴¹⁸

k. National Institute of Mental Health

The National Institute of Mental Health (NIMH) is the lead Federal agency for research on the mind, brain, and related behavior. NIMH's strategic plan calls for deepening and expanding personalized intervention research, specifically calling for a comprehensive health care perspective through studies that take into account illnesses that co-occur with mental disorders (for example, heart disease and substance abuse) or that address the effects of taking multiple prescribed medications.⁴¹⁹ NIMH has funded Johns Hopkins University and partners to test the effectiveness of an intervention to help people with serious mental illness who are overweight or obese to lose weight and keep it off. The institute has also funded the Technical Assistance Institute for Intellectual Disabilities in Dexter, Oregon, to develop an interactive computer-based CD-ROM HIV/AIDS prevention curriculum for adult women with mild intellectual disabilities.

l. National Institute of Nursing Research

The National Institute of Nursing Research (NINR) supports clinical and basic research to establish a scientific basis for the care of individuals across their lifespan. Research focuses on health promotion and disease prevention, quality of life, health disparities, and end-of-life care.

NINR supports research that will, among other things, “elucidate mechanisms underlying disparities and design interventions to eliminate them, with particular attention to issues of geography—rural and remote settings—minority status, underserved populations, and persons whose chronic or temporary disabilities limit their access to care.”⁴²⁰ The institute recently awarded a grant to the University of Texas at Austin to examine how white and Hispanic women between the ages of 55 and 75 developed mobility impairments, and to study the impact of their disabilities on their lives. The goal of the research is to help prepare the health care system to address the age-related issues faced by people with disabilities and to understand the reasons for health disparities within the study group.

11. Allied Initiatives That Promote Health, Health Care, and Wellness for People with Disabilities

a. Institute of Medicine

The Institute of Medicine (IOM), established in 1970 under the charter of the National Academy of Sciences,⁴²¹ provides independent, objective, evidence-based advice to policy makers, health professionals, the private sector, and the public. A nonprofit organization, IOM works outside the framework of Government to ensure scientifically informed analysis and independent guidance.

The overarching critique of the health care system that emanated from the IOM’s 1996 Quality Initiative bears directly on the health and health care experiences of people with disabilities. The initiative, which aimed to assess and improve the quality of health care provided in the United States, documented the depth and breadth of problems in the system. In its first phase, it reported that “the burden of harm conveyed by the collective impact of all of our health care quality problems is staggering.”⁴²² It defined the scope and nature of the problem as one of overuse, misuse, and underuse of health care services. In the second phase of the initiative, IOM set forth a vision for the way in which the health care system and related public policy must undergo a radical transformation to close the chasm between high-quality care and the care that is generally provided in practice. Reports released during this phase, including “To Err Is Human: Building a

“Safer Health System” in 1999 and “Crossing the Quality Chasm: A New Health System for the 21st Century” in 2001, “stressed that reform around the margins is inadequate to address system ills.”⁴²³

In response, IOM set forth six goals for improvement that are widely accepted by the health care community and that have specific resonance for people with disabilities.

- Safety—avoiding injuries to patients from care that is intended to help them
- Effectiveness—providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit
- Patient-centered care—providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions
- Timeliness—reducing waits and sometimes harmful delays for those who receive and those who give care
- Efficiency—avoiding waste, including waste of equipment, supplies, ideas, and energy
- Equitable care—providing care that does not vary in quality because of personal characteristics such as geographical location or socioeconomic status

IOM has published other important reports that relate to health and health care for people with disabilities, including “Disability in America: Toward a National Agenda for Prevention” (1991); “Enabling America: Assessing the Role of Rehabilitation Science and Engineering” (1997); “Improving the Quality of Long-Term Care” (2000); “The Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs” (2002); “Workshop on Disability in America—An Update” (2005); “A New Look—Summary and Background Papers” (2006); and “The Future of Disability in America” (2007). In “The Future of Disability in America,” IOM firmly establishes disability as a demographic indicator rather than just the outcome of disease processes;

this is a sea change in how the agency understands the relationship of disability to health.

IOM has also devoted significant resources to investigating health disparities among racial and ethnic minorities, poor people, and other disadvantaged groups in the United States. In a 2006 report, “Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business,” IOM examined the extent to which NIH has achieved a primary goal of the Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525)—“to ensure that NIH health disparities research is conducted as an integrated and inclusive field of study, rather than as an aggregate of independent research activities occurring in separate research domains.”⁴²⁴ The report assesses how well the “NIH Strategic Plan and Budget To Reduce and Ultimately Eliminate Health Disparities” provides necessary guidance and recommends ways to improve oversight and coordination of these research efforts.⁴²⁵

IOM reports:

In Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business, the Institute of Medicine assesses NIH’s response to the 2000 law, focusing on the development and implementation of the Strategic Plan across NIH Institutes and Centers. The report examines the Strategic Plan for fiscal years 2002–2006 and the Plan for 2004–2008. Twenty-seven Institutes and Centers (ICs), along with two NIH Offices, developed individual plans as part of the 2002–2006 NIH-wide Strategic Plan. These units are conducting and planning valuable health disparities research. At the same time, the impact of this work is being mitigated by a lack of coordination and limited strategic planning. In short, when it comes to addressing health disparities and fulfilling the promise of the 2000 law, NIH’s business is unfinished.⁴²⁶

While the Minority Health and Health Disparities Research and Education Act aims primarily to address health disparities among racial and ethnic minorities—and indeed that is the interpretation of the act by most NIH institutes, centers, and offices—IOM makes the following recommendation in response to NIH’s implementation plan.

National Center on Minority Health and Health Disparities [NCMHD] should consider the designation of additional health disparity groups based on an

informed process and developed criteria. It should promote development of, and access to, a registry of diseases and conditions for which disparities exist with regard to race, ethnicity, socioeconomic status, geographic locale, and other designated health disparity populations.⁴²⁷

By recommending that NCMHD consider designating additional health disparity groups for study, IOM recognizes that health disparities affect other groups in addition to racial and ethnic minorities, and makes the case for including research on health disparities experienced by people with disabilities.

12. Examples of Federal Agency Leadership in Identifying Health Disparities Research Needs for People with Disabilities

Against this complex backdrop, some interagency collaboration holds promise for increasing Federal agency attention to health disparities research for people with disabilities. For example, CDC produced a 2006 report entitled “Advancing the Nation’s Health: A Guide to Public Health Research Needs, 2006–2015,” which identifies research areas that should be addressed during the next decade by CDC and its partners, including a chapter on health disparities experienced by people with disabilities.⁴²⁸ The Federal Collaboration on Health Disparities Research (FCHDR), a collaboration of Federal agencies working to find solutions to eliminate health disparities through research, began operations in 2006 to explore, coordinate, and support innovative health disparities research and identify priorities for cross-agency collaboration. The Interagency Committee on Disability Research (ICDR) co-leads the FCHDR. The ICDR, led by the National Institute on Disability Research Rehabilitation, is charged with promoting coordination and cooperation among Federal departments and agencies conducting rehabilitation research programs.

A number of agencies have undertaken important and even groundbreaking research, which underscores the need for further investigation into the reasons why people with disabilities experience health and health care disparities, problems accessing health care, and health inequalities, and why people with disabilities participate less than others in prevention programs.

C. A Summary of Key Federal Health Disparities Initiatives for People with Disabilities

A 2006 ICDR study identified 119 Federal research projects or programs dealing with health disparities. In nearly all the projects and programs, the concept of people with disabilities as a group was either absent or unstated. Further, the leading Federal center on health disparities research—the National Center on Minority Health and Health Disparities—focuses primarily on health disparities within racial and ethnic minority populations, and only to a lesser extent on the other demographic groups. Thus far, people with disabilities have not been included in the work of the NCMHD.

While research is indeed quite limited on health disparities for people with disabilities, several Federal agencies have supported such research and related initiatives, including CDC, the Agency for Healthcare Research and Quality (AHRQ), the National Institute on Disability Rehabilitation Research (NIDRR), and the National Institute of Dental and Craniofacial Research (NIDCR). The National Institute of Mental Health (NIMH) and the National Institute on Nursing Research (NINR) also have undertaken several projects. For example, CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDHP) has supported the Rochester Prevention Research Center (RPRC) at the University of Rochester, which is developing a national center of excellence for health promotion and disease prevention research in people who are deaf or hard of hearing. The Disability and Health Team at the National Center on Birth Defects and Developmental Disabilities (NCBDDD) has asserted significant leadership by funding programs in 16 states to increase recognition within the public health community of health disparities experienced by people with disabilities. NCBDDD team also has undertaken eight research projects with a major emphasis on health promotion and disease prevention for women with disabilities. In addition, the team supports the National Center on Physical Activity and Disability (NCPAD) at the University of Illinois, Chicago, which serves as a national clearinghouse on physical activity for people with disabilities.

AHRQ carries out research under its “priority populations” program, which includes people with disabilities and individuals with special health care needs. The agency produces the “National Healthcare Disparities Report,” which includes a section on people with disabilities. Some examples of recent AHRQ health and health care disparities research include health disparities experienced by women with disabilities, depression among people with diabetes, ways to improve the health care experiences of people who are blind or have vision impairments, and translating and adapting the Consumer Assessment of Healthcare Providers and Systems (CAHPS) ambulatory care survey to collect information in American Sign Language (ASL) about the health care experiences of people who are deaf.

In recent years, NIDRR has conducted substantial research related to health, health care, and health disparities for people with disabilities within its health and function core priority area. For example, the Health Disparities Project, a 5-year initiative launched by the Oregon Health and Science University (OHSU) in 2008, will review and synthesize health and health care access information for people with disabilities and will use NCBDDD Medical Expenditure Panel Survey (MEPS) data to analyze systemic, environmental, and individual factors that relate to health care access among people with certain disabilities and to determine models of health outcomes. An earlier project undertaken by OHSU is identifying strategies to overcome barriers that impede access by people with disabilities to routine health care, such as exercise, nutrition, pain management, and complementary and alternative therapies that promote health and wellness. The same project is developing improved measurement tools to assess the health and well-being of people with disabilities regardless of functional ability. A third OHSU project is developing a group therapy intervention to address the specific needs of women with physical disabilities who experience symptoms of depression.

Several NIH institutes and centers include people with disabilities as a unique disparity population and undertake related research. Specifically, the National Institute of Dental and Craniofacial Research (NIDCR) broadly defines health disparities to include disability status and has developed and published a series of booklets on providing

dental care for people with developmental disabilities. In 2008, NIDCR launched a clinical research initiative to improve the oral health of special needs populations, and the institute has funded the University of California, San Francisco, to investigate oral health disparities in children with disabilities.

The National Institute of Nursing Research (NINR), which supports clinical and basic research, focuses on health promotion, disease prevention, and health disparities, and identifies people with disabilities as a health disparity population. In 2008, NINR awarded a grant to the University of Texas at Austin to examine how white and Hispanic women between the ages of 55 and 75 developed mobility impairments and the impact of their disabilities on their lives. The goal of the research is to help prepare the health care system to address the age-related issues faced by people with disabilities and to understand the reasons for health disparities within the study group.

D. Summary of Recent and Current Federal Efforts in Health Promotion and Disease Prevention for Women with Disabilities, People Who Are Blind or Have Vision Impairments, People Who Are Deaf or Hard of Hearing, and People with Intellectual and Developmental Disabilities

1. Women with Disabilities

AHRQ, CDC, NIDRR, the National Cancer Institute (NCI), and the National Institute of Mental Health (NIMH) have undertaken or supported recent research related to health disparities experienced by women with disabilities. CDC has undertaken a qualitative study to explore the barriers to breast cancer screening for women with disabilities and has developed and is testing the Right to Know campaign. NIDRR has supported research to develop group therapy interventions for women with physical disabilities who experience symptoms of depression. NCI supported research for a pilot study to develop and test methods of identifying women of screening age with physical and sensory disabilities, as well as a questionnaire to identify barriers in screening mammography for these women. NCI also funded a study on the effects of disability on

the diagnosis of breast cancer. NIMH has funded HIV/AIDS prevention curriculums for women with intellectual disabilities.

2. *People Who Are Blind or Have Vision Impairments*

AHRQ has supported research on methods to improve the health care experiences of people who are blind or have vision impairments and on creating an evidence base for vision rehabilitation. The National Eye Institute (NEI) supported a randomized clinical trial on the effectiveness of low vision rehabilitation services for adults with vision impairments. One goal of the project was to provide information that could assist the Centers for Medicare & Medicaid Services (CMS) in formulating policy on coverage of these services.

3. *People Who Are Deaf or Hard of Hearing*

AHRQ, NCI, and CDC have supported research projects related to people who are deaf or hard of hearing. AHRQ has supported research on translating and adapting the Consumer Assessment of Healthcare Providers and Systems (CAHPS) ambulatory care survey to collect information in ASL about health care experiences from people who are deaf. NCI has funded a program to expand the number of cancer education training videos available to the Deaf community in San Diego, California, and an immersion project to train 10 medical students from the University of California, San Diego, in basic ASL, Deaf culture awareness, and medical terminology in ASL, with a focus on cancer-related issues. CDC has provided funding for the Rochester Prevention Research Center (RPRC) at the University of Rochester, which is developing a national center of excellence for health promotion and disease prevention research in persons who are deaf or hard of hearing.

4. *People with Intellectual and Developmental Disabilities*

In addition to programs of the Administration for Children and Families and the Health Resources and Services Administration (HRSA)—University Centers for Excellence in Developmental Disabilities (UCEDDs) and Leadership Education in Neurodevelopmental Disabilities (LEND)—the following Federal initiatives also promote

health for people with intellectual and developmental disabilities. The National Institute of Mental and Craniofacial Research (NIDCR) has identified people with disabilities as a disparities population, has developed and published a series of important booklets on providing dental care for people with developmental disabilities, and has funded an oral health disparities research project at the University of California, San Francisco. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has funded projects intended to test the reliability and validity of various methods to assess the dietary intake of adults with significant cognitive impairments living in the community. The National Institute of Child Health and Human Development (NICHD) has supported the University of California, San Francisco, in its exploration of transition in a diverse sample of families raising youth who are both medically fragile and developmentally disabled. The research investigates how services, programs, and resources available through schools affect family planning and decision making. NICHD has also supported Oregon Health and Science University to test the efficacy of a health promotion intervention for people with intellectual disabilities.

5. Effectiveness of Federal Efforts at Health Promotion and Disease Prevention for People with Disabilities

Although it is difficult to determine with any certainty the effectiveness of Federal efforts at disease prevention and health promotion for people with disabilities, particularly in terms of reduced health disparities or improved health status, the midcourse review for “Healthy People 2010” reported some related progress. At that time, new data had become available on several key indicators since “Healthy People 2010” was launched in 2000. People with disabilities are currently represented in 207 of the 467 objectives that span 21 of 28 “Healthy People 2010” focus areas. However, when “Healthy People 2010” was implemented, data on people with disabilities were available for only 88 of those 207 objectives. “Healthy People 2010” undertook a midcourse review that revealed some preliminary information on the extent to which objectives are being met. For example, in Focus Area 6, “Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the US population,” the midcourse review provides new data comparing

populations within the disability community that address both quality of life and health disparities. Disparities are documented between people who have disabilities and those who do not, as well as among subgroups based on education, income, gender, and ethnicity. Improvements are shown in several areas, including an increase in inclusion of people with disabilities in national and state surveillance, a reduction of the number of adults with disabilities living in congregate care facilities, and an increase in the number of children with disabilities included in regular education programs. However, according to the midcourse review, the explanation for this improvement cannot be attributed to any particular programmatic intervention. The review suggests that implementation and enforcement of Federal disability rights laws, improved public awareness of disability, and increased accessibility, including public transportation, may be contributing factors.

While data may be limited on the effectiveness of the Federal effort at health promotion and disease prevention for people with disabilities, it would be important not to overlook other influences that have effectively increased attention to these issues in recent years. In addition to the redefinition of disability that appears in “Healthy People 2010,” reports issued by the Surgeon General—including “Closing the Gap” and “Call to Action”—as well as the 2007 IOM report “The Future of Disability in America,” have helped to sound a clarion call for attention to disability status as a bona fide demographic indicator and on the specific health and health care needs of people with disabilities.

E. Conclusion and Recommendations

The extensive network of Federal programs that provide health care and prevention services to people with disabilities (e.g., Medicare, Medicaid, SCHIP, Title V) serves as a critically important safety net for many, including children and adults with disabilities. Some other HHS agencies and programs, such as MCHD’s LEND program, have established unique health delivery models for certain people with disabilities. However, health disparities research has been limited.

The Federal biomedical research effort has historic roots in a philosophy of disability and disease prevention, and most current biomedical research still aims to achieve

these goals. However, a recent shift has taken place that acknowledges the fact that some people living with disabilities experience poorer health than the general population and that research is required to understand the causes of these health disparities. While this shift is in evidence in Focus Area 6 of “Healthy People 2010” and in seminal reports by the Surgeon General and the IOM, people with disabilities are still largely excluded from the major Federal health disparities research initiatives. As a result, there has been limited investigation that illuminates the reasons for health disparities in this population. Moreover, almost no resources have been devoted to exploring the extent to which barriers in the built environment and the lack of accommodation in health care delivery settings (e.g., sign language interpreters, accessible examination equipment, additional time for examinations, and consultations for complex health matters) contributes to health disparities experienced by people with disabilities.

Against this backdrop, a few Federal agencies have supported and undertaken groundbreaking and innovative research and projects aimed at understanding the causes of health disparities among people with disabilities. These projects promote health and wellness within specific populations, and acknowledge and explore the role that environmental factors play in health and health outcomes for people with disabilities. While it is too soon for these programs to report improved health outcomes for people with disabilities, they are an important, although modest, beginning. Further, several Federal interagency collaborations hold some promise for increasing the visibility of health issues for people with disabilities in future Federal research initiatives, provided they receive adequate funding.

RECOMMENDATION:

Congress should amend the Minority Health and Health Disparities Research and Education Act to broaden the definition of “health disparity population” found in 42 U.S.C. § 287c-31(d) to encompass “populations for which there is a significant disparity in the quality, outcomes, cost, or use of health care services or access to or satisfaction with such services as compared to the general population,” as specified in 42 U.S.C. § 299a-1(d). This will enable people with disabilities to be

included in the health and health care disparities research, program development, professional training, health promotion, and clinical interventions conducted and supported by the National Center on Minority Health and Health Disparities, as well as other Federal agencies that are currently engaged in health disparities research and activities on behalf of racial and ethnic minorities and other geographic and population groups.

RECOMMENDATION:

Congress should create and fund an Office of Disability and Health in the Office of the Director at the Centers for Disease Control and Prevention to mandate and oversee integration of disability issues into all CDC programs.

RECOMMENDATION:

Congress should increase funding for the Interagency Committee on Disability Research of the National Institute on Disability and Rehabilitation Research in order to (1) vest it with sufficient resources and authority to fulfill its mandated research coordination role and (2) expand its role to include collaboration with other agencies, including Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), and the Department of Health and Human Services (HHS) Office on Disability, to identify research areas related to health, health care, and health disparities that lend themselves to interagency collaboration.

RECOMMENDATION:

Federal agencies concerned with disability and health—including the Department of Health and Human Services (HHS), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the National Institute for Disability and Rehabilitation Research (NIDRR), and the Access Board—should develop mechanisms to undertake research that investigates the economic and systemic implications, as well as the impact of barriers to health care access, on people with disabilities, and the potential for enhanced efficiency and cost savings through improved access.⁴²⁹

RECOMMENDATION:

The Health Resources and Services Administration (HRSA) should designate people with disabilities or subgroups of the population as medically underserved populations. Such a designation will open opportunities for physicians, physician assistants, and dentists who choose to provide health care services for a significant number of patients with disabilities in their practices to apply for Federal student loan forgiveness.⁴³⁰

RECOMMENDATION:

The Institute of Medicine (IOM) of the National Academies of Science should include the topic of health disparities experienced by people with disabilities in its workshops and roundtables on health disparities. IOM should expand on recommendations presented in its 2006 report critiquing the National Institutes of Health (NIH) interagency disparity activities to include a recommendation that disability health disparities be acknowledged as a national problem. The IOM should also urge the development programs and strategies to reduce health disparities for people with disabilities.

RECOMMENDATION:

The U.S. Surgeon General should lead an effort with other Federal agencies concerned with health care quality for people with disabilities—including the Department of Health and Human Services (HHS) Office of Disability, the Centers for Medicare & Medicaid Services (CMS), the National Institute on Disability and Rehabilitation Research (NIDRR), the Agency for Healthcare Research and Quality (AHRQ), the Access Board, and the Administration for Children and Families (ACF)—in a joint project that will establish principles of universal design for health care facilities and programs. Goals and objectives should be established and key stakeholder actions identified. Drawing on the well-established principles of universal design for the built environment, this collaboration should bring together Federal agency experts, disability and health policy researchers, leading disability and health practitioners (e.g., physicians who specialize in caring for women with

disabilities, people who are deaf or hard of hearing, and people with intellectual and developmental disabilities, as well as vision rehabilitation experts), and people with disabilities to participate in the process. The Surgeon General should publish a report of findings that builds on previous publications, such as “Call to Action To Improve the Health and Wellness of Persons with Disabilities,” “Closing the Gap: A National Blueprint To Improve the Health of Persons with Mental Retardation,” and “Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation.”

CHAPTER 5. **Availability and Accuracy of Federal Health Data Concerning Americans with Disabilities**

Shaping health research goals and health care policy and programs so that the specific needs of people with disabilities are identified and included depends significantly on current and accurate health data. This chapter reports on progress toward meeting this goal.

A. Use of Databases by Sponsoring Agencies To Understand the Health Care Experience of People with Disabilities

Although no dataset currently meets all information needs, several surveys have either the current ability or the strong potential to provide much of the data necessary to assess health care utilization and the treatment experience. The sponsoring agencies have used the data for some evaluation of health care utilization by people with disabilities, but they have not produced analyses to the fullest extent possible.

1. *Availability of Information*

Most of the major datasets enable some identification of people with disabilities; some datasets include multiple indicators. The Medical Expenditure Panel Survey (MEPS), National Health Interview Survey (NHIS), Behavioral Risk Factor Surveillance System (BRFSS), American Community Survey (ACS), and Medicare Current Beneficiary Survey (MCBS) all use indicators of activity limitation. In its core component, asked of all respondents, BRFSS uses one broad question that asks whether any activities are limited because of physical, mental, or emotional problems; a second question asks about the use of assistive devices. MEPS and NHIS use a question that includes several activities that comprise the Activities of Daily Living (ADL) scale, and another question that puts together in a single phrase some of the components of the Instrumental Activities of Daily Living (IADL) scale. A similar question is optional in BRFSS. ACS contains four questions about activity limitations: one about cognitive limitations, one about walking or climbing stairs, one about the ADLs of bathing or

dressings, and one about doing errands outside the home alone. Two additional questions ask separately about hearing and vision impairment. Additional questions in MEPS, NHIS, BRFSS, and MCBS ask about the presence of a health condition that limits work, other daily activities, or social activities (for BRFSS it is an optional question, that is not regularly used). There is no disability indicator in the CAHPS core survey module; the disability questions are part of the optional supplemental questions list. Despite Federal agency oversight and technical support, the costs of conducting a BRFSS or CAHPS is borne by the state or private organizations that have questions or data needs that these surveys can address. Both BRFSS and CAHPS are structured to collect a core of data common across all administrations of the survey, but also enable questions that can meet state or local or other very specific needs, to be added at the state or private agency's expense.

The same basic health care information that is collected for people without disabilities is also available for people with disabilities in the MEPS, NHIS, and BRFSS datasets. The presence of a disability question in the core components of these surveys means that distributions for people with disabilities can be developed. For all respondents, information is available about whether there is a usual source of care and whether there is insurance to pay for the care. The surveys also collect information on whether a person has had a regular checkup and a mammogram, Pap test, or prostate-specific antigen (PSA) screen. Data are also collected on exercise, obesity, and smoking, and whether the respondent's physician has talked about these issues. All respondents are asked if they have ever had to delay, postpone, or go without care.

Satisfaction with the health care provider and the health care delivery experience is not asked directly in NHIS, MEPS, or BRFSS. Satisfaction information is available through the Medicare Current Beneficiary Survey (MCBS), which does enable a comparison of Medicare beneficiaries with disabilities to beneficiaries without disabilities. Another source of data on satisfaction and aspects of patient treatment in the health care encounter is the Health Plan Survey 4.0 of CAHPS. The satisfaction questions are part of the core survey; however, there is no disability question in the core.

2. Data Utilization

All the agencies that sponsor large surveys release reports derived from their data. Most issue a summary report that consists of tables that cross demographic characteristics by the other health and health care indicators on which they have data. Some of these reports are complete documents that can be obtained in print or downloaded from the agency's Web site. In other cases (for example, much of the BRFSS), the information is available as downloadable individual tables in HTML format or PDF files. Agencies also issue shorter reports of analyses by agency researchers on specific subtopics. Since the agencies make the data available for other researchers, they sometimes provide, on the agency Web site, a list of links to these external publications.

Regular agency summary reports use race, ethnicity, gender, and age as the main demographic categories for which health and health care experience are presented. They may also use income, health insurance type, or education. Where there is a disability variable, it is generally used as an outcome variable, not one of the demographic characteristics. The NHIS summary report produced annually by NCHS contains tables with activity limitations and ADL and IADL limitations as an outcome variable crossed with the demographic variables. However, for the table describing levels of health care access by demographic characteristic (table 15 in the 2006 report), disability is not one of the characteristics.⁴³¹ The AHRQ reports of MEPS data do not report data findings by disability, even though the data exist to do so. CDC makes the data from the BRFSS available through the Web Enabled Analysis Tool (WEAT), which helps users create their own tables from BRFSS data. WEAT options do not include the disability questions, so users cannot create tables that cross disability with other BRFSS questions. The only statistic available is the simple distribution of answers to the disability question. CDC issues a brief report entitled "At a Glance," in which it describes disability as a health outcome, not as a population group, and states that the BRFSS can be used to

Determine high-priority health issues, detect emerging health issues, and identify populations at highest risk for illness, disability, and death, by analyzing data according to respondents' age, sex, education, income, and race/ethnicity.⁴³²

CAHPS does not include the disability question as a core question; so its regular report contains no indication of how people with disabilities rate their health care experience. No published reports were located that used data from the supplemental questions to examine the assessment of their health care by people with disabilities. Before CAHPS released its question module, People With Disability Impairments (PWMI), one publication used CAHPS with specially developed and tested questions for people with physical disabilities.⁴³³

While the sponsoring agencies generally do not use disability as a population characteristic in their regular reporting, disability is used in targeted reports and smaller focused analyses produced from the data. In some instances, a researcher from the Federal agency is the author of the report; in other instances, it is an external researcher. (See table 1, appendix C, for a list of selected publications that have used the datasets for analysis of health care utilization and experiences of people with disabilities.). One example of a special report is the large report on the health and wellness of people with disabilities that NCHS released in July 2008⁴³⁴ based on the NHIS. AHRQ's "National Healthcare Disparities Report 2007" also included three tables that addressed health care behavior for people with disabilities.⁴³⁵

B. Gaps in and Problems with Data Sources' Ability or Utilization for Providing Information About the Health Care Experiences of People with Disabilities

Even though the several datasets, if considered as a group, can provide useful and appropriate information, serious gaps remain. The following are the most significant gaps and problems.

- Absence of data from patients about the delivery of care including physical access, programmatic access, and communication access

- Absence of data from providers about their ability and preparation to provide health care to people with disabilities that is structured for physical, programmatic, and communication access
- Absence of information about providers' disability cultural competence
- Survey sampling frames that do not include persons living in group quarters, and samples that are too small to study the circumstance of subgroups of people with disabilities
- Data collection methods that exclude people who are deaf, have other communication disabilities, or who do not have telephones
- Regular agency reporting of health care utilization, health care experience, and health and wellness behavior that does not report on people with disabilities as a population group and does not report on these health care issues for people with disabilities crossed by other demographic characteristics (such as race or gender)
- consistent, reliable, and valid indicator for disability that is a part of the core demographic questions in all surveys
- Consistent, reliable, and valid survey questions to identify people with intellectual, cognitive, or psychiatric disabilities.

1. *Absence of Information About Physical Access, Programmatic Access, and Communication Access*

NHIS, MEPS, BRFSS, and ACS—the surveys with the best prospects of being usefully generalized nationwide—do not ask questions that can provide information about physical, programmatic, or communication access for people with disabilities. For example, a question in MEPS that asks why people go without or delay care is not structured to allow respondents to indicate that delay was due to problems of access. Respondents are offered a set of possible reasons (e.g., cost, insurance coverage, could not take time from work, or could not find child care), but the categories do not include a reason related to physical or programmatic access barriers.

The only survey that explicitly asks about physical, programmatic, and communication access to the provider's office is CAHPS, and these questions are in optional CAHPS supplemental item sets. The set for People with Mobility Impairments includes questions about accessible exam tables, scales, and restrooms; coverage of mobility equipment and repair through a health plan; physician attention to pain and fatigue; and access to speech and physical therapy. Other adult supplemental items to CAHPS, beyond the three activity limitation questions similar to those in NHIS, include questions about access to mental health care, doctor's understanding of how a chronic health condition affects day-to-day life, coverage for medical equipment and home health care, need for and availability of an interpreter (including a sign language interpreter), and willingness of the physician to engage in joint decision making. Two additional efforts are underway to develop and field test additional CAHPS survey items for coordination of care⁴³⁶ and to develop and test a version of CAHPS for use with people who are deaf.⁴³⁷ Other aspects of health care utilization and experience—such as the provider's ability to offer alternative formats for people with vision impairment, willingness additional time, or efforts to provide other access—are not addressed by any of the major data sources.

2. Absence of Data on the Nation's Health Care Providers That Can Profile Their Ability and Preparation to Deliver Accessible Health Care

There is no regularly conducted, nationally representative survey of health care providers that can provide information about the accessibility of the health care system to people with disabilities. Currently, there is no way to estimate from Federal data what percentage of physicians' offices have height-adjustable exam tables. Surveys of patients with disabilities may allow estimates of the percentage who were examined on a table or received a mammogram, but surveys cannot determine the percentage of doctors who were able or willing to provide accessible care, since patients may all have seen the same few doctors who did provide accessibility.

To date, accessibility surveys of physicians have been small or local.⁴³⁸ Mail surveys have suffered from low response rates. Iezzoni and O'Day report that their plan to

systematically interview physicians and visit practice sites in a large, multisite health care provider was aborted because they could not obtain cooperation from the provider.⁴³⁹ They were able to speak with a convenience sample of approximately 20 people who were physicians, nurses, or office staff from a couple of practices. There have been some small-scale efforts to survey health plans and rate the accessibility of health care settings, using a site visit or self-administered instrument with assessment tools that include attention to architecture; equipment; office procedures for arranging, conducting, and completing medical encounters; and methods of communicating with patients.⁴⁴⁰ These efforts are important and worthy, and they can serve as models for larger, more nationally representative data collection efforts. However, such efforts are no substitute for a national profile of health care providers or for regular data collection to quantify current status and progress over time.

3. *Absence of Information About Providers' Disability Cultural Competence*

The Surgeon General's report "Call to Action To Improve the Health and Wellness of Persons with Disabilities" identifies the issue of disability cultural competence, noting that

. . . many physicians have had limited experience during medical training in treating patients with disabilities. As a result, many are unable to meet the full range of health care needs presented by a person with a particular disabling condition, much less to evaluate and treat that individual in a culturally appropriate and sensitive manner.⁴⁴¹

While the issue is defined, its prevalence is not empirically measured, nor is there detailed information to point out areas most in need of attention or to allow monitoring of change in response to remedial strategies. No survey explicitly collects information about a provider's competence to provide care to someone with a disability.

Several surveys (MEPS, CAHPS, and MCBS) regularly ask respondents whether they feel respected by their physicians, whether their health care providers provide information about care in an understandable manner, and whether the patient's views are taken into consideration in the process of selecting a course of action for health

conditions. These questions, combined with the ability to determine which respondents are people with disabilities, provide indirect information about the disability cultural competence of health care providers. However, these questions do not tap the kinds of health care experiences described in qualitative interviews with people with disabilities⁴⁴² or the problems described in the Washington Hospital Center lawsuit.⁴⁴³

4. *Survey Sampling Frames That Do Not Include People Living in Group Quarters*

Most of the major health surveys do not include people living in institutional settings. Thus, information from people of all ages who reside in a group setting is missing from national assessments. And these individuals are more likely to have having disabilities. Among the group quarters usually not included in surveys are nursing homes, board and care homes, adult group homes, group foster homes, juvenile residential facilities, state schools or other residential settings for young people with intellectual disabilities, and prisons (data indicate that a substantial percentage of prisoners have psychiatric or cognitive disabilities).⁴⁴⁴ The sampling frames of NHIS, MEPS, and BRFSS are constructed to represent the noninstitutionalized U.S. population. The community sample of MCBS is a sample of Medicare beneficiaries living in noninstitutional settings. There is a sample of Medicare beneficiaries living in nursing homes; however, facility staff complete the survey on behalf of these individuals, thus limiting the range of information that can be collected. MCBS surveys only people who have health care coverage under Medicare, so people with private coverage, Medicaid, or no health care coverage are not included in the survey.

Until recently, the American Community Survey (ACS) also sampled only people in noninstitutional settings. However, starting in 2006, ACS included people living in group quarters, including prison, in the sample. The ACS has implemented a data collection strategy that includes a self-administered interview, telephone interview, or in-person interview (including use of a proxy), offering the possibility that respondents whose disabilities might affect inclusion in a survey with a single data collection technique will be surveyed. The ACS does not, however, ask questions about health care; so its utility

is restricted as a means of monitoring the health care experience of people with disabilities.

5. *Sample Sizes Too Small To Allow Analysis of Subgroups of People with Disabilities*

The strength of several of the national datasets is that they have large samples and provide data that represent the U.S. population. NHIS and MEPS use a complex random sampling design with an oversample of racial and ethnic minority groups to facilitate analysis of population subgroups. Despite relatively large numbers of respondents, the samples are too small to allow detailed analysis of people with low prevalence impairments. Only the NHIS-D, conducted in 1994 as a special supplement to the NHIS survey, with a followback survey of people with disabilities who were identified via the main survey, offered a larger sample of people with disabilities in the context of a regular national survey. BRFSS and CAHPS depend on state and private sector partners, who decide to mount the survey and which questions to use. Several states have used the BRFSS supplemental questions regarding the health care experience of people with disabilities. However, the resulting information, is generalizable only at the state and not at the national level.

CAHPS presents a sampling frame problem similar to that of BRFSS; samples may only represent the population for the location where the disability questions are utilized. While CAHPS has approximately 100,000 respondents each year, it does not offer a representative national sample. The CAHPS dataset is built from surveys conducted by state Medicaid plans, commercial insurance plans, and Medicare. The tie to the Healthcare Effectiveness Data and Information Set (HEDIS) means that a large number of the commercial plans are now using the CAHPS instrument and submitting the resulting data for inclusion in the national dataset. CAHPS contains a large number of surveys of people with some kind of health care coverage, but it is not a random sample of the U.S. population.

6. *Data Collection Methods Exclude Some People with Disabilities*

Some of the large surveys are conducted in person, using computer-assisted personal interviewing (NHIS, MEPS, MCBS, ACS in part); some are telephone interviews (BRFSS, ACS in part, CAHPS in part); and some are self-administered forms, filled out by respondents (ACS, CAHPS). Each of these collection methods may work for some people with disabilities and not for others. A particular problem is the reliable collection of information from people who are deaf. While self-administered surveys do not exclude people who deaf who are English-literate, both telephone and in-person surveys are problematic. Not only is there the obvious exclusion of people who cannot hear and speak on the telephone, but there is also the problem of translation. ASL is not the same as English. Translating an in-person survey into ASL should receive care equal to that given to translating the survey into Spanish. To date, this has not been widely done. However, CDC has funded the National Center for Deaf Health Research at the University of Rochester Medical Center to adapt the BRFSS (and the Youth Risk Behavior Surveillance System, a school-based survey) to ASL and English-based sign language, add deaf-specific questions, and administer the survey.⁴⁴⁵

7. *Agencies Do Not Include Disability As a Population Characteristic in Their Regular Reporting of Health Information, Health Care Utilization, or Health Care Experience*

Even where the datasets contain questions that allow researchers to identify people with disabilities, the sponsoring agency regularly reporting on such topics as health disparities, primary and preventive care received, and factors associated with problematic care do not report this information for people with disabilities. As a consequence, information is not readily available to state public health agencies or others interested in tracking the access to care and the quality of care received by people with disabilities. When agencies report about the health care experience of demographic groups across two categories (e.g., Hispanic men and Hispanic women), they do not use disability as one of the demographic subcategories. Other researchers have used the data for analyses using disability as a population characteristic and found health disparities for the benchmarks used for other groups (e.g., smoking, obesity,

alcohol dependence, lack of exercise). Disparities also have been found in delay or postponement of care, satisfaction with care, and receipt of some preventive care (e.g., mammograms and Pap tests). Despite the fact that people with disabilities are considered a priority population for AHRQ's health disparities monitoring, disability is not included as a population demographic in either the annual NHIS report or the standard MEPS report.

8. *There Is No Consistent Definition of Disability Across All the Surveys*

All the major health surveys are now using an activity limitation framework that separates ability to work from the indicator of disability, but the way in which they implement this indicator varies. There is movement toward a single consistent set of questions based on the American Community Survey (ACS) disability questions. According to congressional testimony by Susan E. Dudley of the Office of Management and Budget, the ACS disability questions have been adopted by the Bureau of Labor Statistics for the Current Population Survey (CPS) and by the National Crime Victimization Survey (NCVS); work is also under way with NCHS to incorporate a version of the ACS questions into the NHIS.⁴⁴⁶ In a separate effort, AHRQ convened a work group to develop a question or brief set of questions that could be consistently used across surveys to indicate disability. The recommendation from this task force was a variable with three categories: no disability, basic actions difficulties, and complex activity limitations. This disability variable was built from several activity limitation questions, particularly those that use elements of ADL and IADL. The AHRQ "National Healthcare Disparities Report 2007"⁴⁴⁷ and "Disability and Health in the United States, 2001–2005"⁴⁴⁸ by the National Center for Health Statistics use this disability variable. The three categories are defined as follows:

- Basic actions difficulties: limitations in mobility or other basic person-level functioning
- Complex activity limitations: limitations, in interaction with the environment, in ability to participate in community life
- No disability: neither basic nor complex activity difficulties or limitations

Perhaps the joint project described by Dudley will bring further convergence for the indicator of disability. However, the two questions in BRFSS are not specific enough to allow the AHRQ formulation to be created from the BRFSS survey data, nor are the two questions similar to the set in ACS. Beyond that, when there is interest in studying subgroups of people with disabilities, the survey questions do a poor job of identifying and distinguishing people with intellectual disabilities and people with psychiatric disabilities.

9. *Availability and Accuracy of Federal Health Data Concerning Access to Wellness and Prevention Services and Their Relative Long-Term Costs and Benefits for Americans with Disabilities*

The wellness and prevention services tracked by the Federal Government as benchmarks for the general U.S. population include screening for conditions and behaviors that place people at risk for serious health problems and measures of the receipt of preventive medical services, screenings, and examinations. The indicators tracked for “Healthy People 2010,” along with several additional indicators collected regularly in the major health surveys include the following:

- Health risk behaviors/indicators: smoking, obesity, excessive alcohol use, high cholesterol, hypertension, and lack of exercise
- Preventive medical exams, screenings, and services: general physical exam, Pap test, mammogram, PSA test, flu shot, colonoscopy, cholesterol test, and doctor discussion and referral for services for smoking cessation, weight loss, exercise, alcohol treatment, and dietary and drug treatment for cholesterol

“Healthy People 2010” includes objectives for people with disabilities for the top 10 health indicators. The top 10 list is health care access, immunization, overweight and obesity, physical activity, tobacco use, mental health, substance use, sexual behavior, injury, and environmental quality.⁴⁴⁹ Data are not regularly collected on sexual behavior, injury, and environmental quality for people with disabilities. However, health care access, immunization, physical activity, obesity, substance use, and tobacco use can be tracked using the NHIS, MEPS, and BRFSS datasets, all of which include a disability question in their cores. While the data collected using these three surveys can identify people with

disabilities (the exact wording of the disability questions vary), the regular reporting of health and wellness benchmarks by the sponsoring agency does not present the status of people with disabilities on these indicators. Thus, health and wellness can be tracked using some of the same indicators that are used for people without disabilities, but since this information is not regularly included in the agency reports, it is not easily available in public documents. (The impact of the data collection methodology on data quality and accuracy, and the manner in which sponsoring agencies use and report on the health and wellness indicators, is described in more depth in the previous section, as part of the discussion of variables and datasets, generally.)

Beyond the examination of whether the standard health and wellness indicators are collected for people with and without disabilities is the issue of whether the indicators applicable to the general population are sufficient to track wellness and prevention for people with disabilities. Chapter 6 of “Healthy People 2010,” titled Disability and Secondary Conditions, lists additional objectives, including the following:

- Objective 6-10: Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.
- Objective 6-11: Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.
- Objective 6-12: Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

CAHPS has the potential to address objective 6-11 through its supplemental questions. The other two objectives cannot currently be tracked via the major datasets.

Not only is there no regular measurement of facility characteristics associated with access, but there are no regular sources of data to measure participation in wellness programs such as exercise classes, smoking cessation programs, or self-help or AA-type groups for substance abuse. Surveys also do not ask people with disabilities

about their experiences with access or environmental barriers that may affect participation in wellness programs or activities at home, in school, or in the community. The potential to assess the long-term costs and benefits of access to wellness and prevention programs requires (1) consistent, appropriate measures over time and (2) research that documents costs and the link between wellness or prevention programs and health benefits for people with disabilities.

Agreement on an indicator of disability, and use of that indicator in every major health survey over time will produce over time the ability to track for people with disabilities the prevalence of the wellness and prevention benchmarks used nationally for the noninstitutionalized population. As indicated above, no single indicator of disability is currently used in all surveys, but ongoing activities suggest progress toward this goal. Once a consistent definition is in place, it will require a number of years of data before it will be possible to assess long-term prevalence rates for the wellness and prevention benchmarks.

In their discussion of methodology for assessing the long-term costs and benefits of health prevention interventions, Stone and colleagues⁴⁵⁰ note that intervention costs are commonly incurred at the beginning of an intervention, with the benefits spread out into the future. The financial costs of implementing the program are not difficult to identify; the economic costs (e.g., opportunity costs) are somewhat more difficult to calculate. However, the calculation of long-term benefits for people with disabilities from participation in wellness and prevention programs depends on the presence of studies that have measured outcomes. Currently, few studies measure the outcomes of interventions for smoking cessation, increased mammography screening, exercise, or other programs for people with disabilities. Nor do studies show whether the participation of people with disabilities in programs for broader populations were affected by access issues. If the outcomes of, for example, increasing exercise or reducing tobacco use are the same for people with disabilities as for people without disabilities, we can use the same estimates about increased longevity or fewer days of restricted activity that are used to estimate long-term benefits for the general population. However, if interactions with disabilities cause different outcome rates on these

indicators, separate long-term benefits should be calculated. A clear understanding of impact will require further research on the outcomes of health and wellness programs that include people with disabilities.

C. Conclusion and Recommendations

There is good news, but challenges remain with respect to the availability and accuracy of data to monitor the health status, health care utilization, and health care delivery experiences of people with disabilities. There appears to be progress in the development and use of a consistent indicator of disability, and there are a number of recent reports on health in which disability is used as a population variable. Attention and acknowledgement of the importance of collecting data about the health care experience of people with disabilities is growing, and some promising research is under way to develop survey questions that will gather previously unmeasured information about the health care experience of people with disabilities. Moreover, some surveys are developing and implementing data collection methods that will result in the inclusion of people with disabilities who were previously excluded from surveys.

Important challenges remain, however. For example, questions about the health care delivery experience should be moved from the optional supplemental parts of surveys to the regularly asked core. The number of surveys that do not exclude people in group quarters or without telephones from samples should be expanded, and better survey indicators for people with cognitive, intellectual, and psychiatric disabilities should be developed. Methods should be designed to ensure that sponsoring agency reports include disability as a population variable in data analysis and the reporting of survey findings. Also, a means should be developed for collecting information about health care providers with respect to physical, programmatic, and communication access to health care, including information from the providers themselves.

RECOMMENDATION:

A regularly conducted national survey of physicians and other health care providers should be developed. Such a survey could begin with Medicare and Medicaid

providers, because they receive Federal financing for their services. However, the ultimate goal would be to have a nationally representative sample of all providers. Information should be collected from providers on (1) demonstrated physical accessibility, (2) demonstrated capacity to provide programmatic accessibility, (3) level of knowledge and confidence in treating patients with disabilities, and (4) disability training and cultural competency of office staff. (See chapter 5.)

RECOMMENDATION:

Ongoing research activities must continue to develop a valid and reliable set of survey questions that identify people with disabilities, and these questions must be included in all regularly conducted national surveys. The standardized questions should be included in the core of all surveys, but surveys that already contain additional data items should continue to use them, to permit more detailed and nuanced analyses. Specifically:

- Behavioral Risk Factor Surveillance System (BRFSS) should include the standardized question set in its core (substituted for the two questions currently in its core).
- The Consumer Assessment of Healthcare Providers and Systems (CAHPS) should add the standardized disability questions to its core.
- The Medicare Beneficiary Survey (MCBS) has a number of disability indicator questions, but they should be part of the standardized set.

RECOMMENDATION:

Reliable and valid questions that can identify people with intellectual and mental health disabilities should be developed and regularly used in major surveys. In addition, the major national surveys should develop and use, on a regular basis, questions that identify, in separate categories, people who are blind, vision-impaired, deaf, or hard of hearing. Such questions should be asked of all respondents, not just those over 40 years of age, as is currently the case for

questions concerning vision loss in Module 4 of the Behavioral Risk Factor Surveillance System (BRFSS).

RECOMMENDATION:

Surveys that ask questions about access and utilization of care should provide answer options that enable respondents to indicate disability-related problems with access. For example, the reasons for delaying or going without care should include options about physician office equipment and other accessibility issues, and about physician disability competence and acceptance of patients with disabilities. Questions that can provide data with respect to policies for eligibility for use of public health programs and benefits are also needed.

RECOMMENDATION:

The Agency for Healthcare Research and Quality (AHRQ) and the National Center for Health Statistics (NCHS) should include people with disabilities as one of the population groups in the tables that comprise the annual reports derived from the Medical Expenditure Panel Survey (MEPS) and National Health Interview Survey (NHIS) datasets. Data on people with disabilities should be crossed with the health care access indicators, and reporting should provide dual demographic status and access (e.g., access data for disability/gender; disability/race/ethnicity groupings).

RECOMMENDATION:

Federal support is imperative for research to investigate the outcome of wellness and prevention programs and services for people with disabilities, and attention is needed in other wellness/prevention research to ensure that people with disabilities have access to such programs and services (with appropriate data collected about their experiences and outcomes).

RECOMMENDATION:

Incentives and directives are needed to increase the use of the existing optional disability modules or supplemental questions in the national surveys, especially for the Behavioral Risk Factor Surveillance System (BRFSS), the Medical Expenditure

Panel Survey (MEPS), the National Health Interview Survey (NHIS), and possibly the Consumer Assessment of Healthcare Providers and Systems (CAHPS). States should be directed to use the modules or questions on a periodic basis; funds as an incentive to implement should be offered to support their use.

RECOMMENDATION:

Modules that ask about specific disability access issues should be developed. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Mobility Impairment module is a good example, but the module should be applicable more broadly and in more surveys. This would provide an alternative to mounting a national special survey. However, a survey such as the National Health Interview Survey-D (NHIS-D) should be conducted at a minimum once every 10 years.

RECOMMENDATION:

Survey sampling and data collection should be designed to include people living in institutional settings and group quarters, especially in community-based group quarters. Surveys should be conducted in a manner that does not exclude people who do not communicate by telephone or do not have telephones. Translations for American Sign Language (ASL) should be made for the major surveys to ensure the inclusion of people who use ASL as their primary language.

RECOMMENDATION:

Federal agencies that undertake health research for people with disabilities, such as the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), and the Administration for Children and Families (ACF), should undertake studies that document the extent to which the health care needs of women with disabilities, people who are deaf or hard of hearing, people with intellectual and developmental disabilities, and people who are blind or have vision impairments are being met. Such studies should use outcome-oriented approaches and will provide a foundation for developing crosscutting, universal quality-of-care guidelines.

CHAPTER 6. **Summit on Health Care for People with Disabilities**

A. Overview

NCD envisioned a summit on health care for people with disabilities as a critical component of the research effort on the state of health care for people with disabilities. Convened in Chicago April 7–8, 2008, the Summit on Health Care for People with Disabilities brought together health care experts, opinion leaders, Federal agency and disability community representatives, researchers, funders, and practitioners to discuss barriers to health and health care for people with disabilities and to create a strategic action plan that will begin to address the problems.

The summit participants considered a series of recommendations for reform derived from seminal reports issued by the Institute of Medicine, the Surgeon General of the United States, and leading health policy researchers. They identified strategic actions that should be taken to move forward the reform agenda and ranked the recommendations based on the extent to which some goals are achievable in the near term.

Summit participants identified overarching strategic principles for advancing reforms that included defining a vision of health care that will meet the needs of people with disabilities; riding the wave of health service and facility growth; driving system-level change; changing hearts and minds; reframing the issues to reflect patient-centered care and universal design solutions; and increasing health care professional capacity and competency. Specifically, participants identified the following strategic actions that hold significant potential to achieve meaningful results in the near term.

- Securing Federal agency or congressional support to establish a Technical Assistance Center for Health Care Improvement for People with Disabilities
- Gaining active support from the Joint Commission to bring accessibility and universal design principles into the medical facility survey accreditation process

- Gaining commitment and active engagement from a committed core group of people who will advocate for accreditation standards that require disability awareness and competence in the medical school curriculum

Two top-tier recommendations were identified:

- Health care facilities, services, and programs must be accessible according to Federal and state standards and guidelines, and should actively promote principles of universal design both in the built environment, for diagnostic, examination, and other medical equipment—in fact, for all aspects of care delivery.
- Congress should establish a publicly funded system of technical assistance centers from which states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on defined standards of care and related practical resources for ensuring full access to health care services for people with disabilities.

While important education took place among the participants—and themes, ideas, and strategic action plans that hold great potential emerged throughout the summit—the meeting was only a starting point. Ongoing discussion and the involvement of additional stakeholders is urgently needed. The summit outcomes can be used as a road map by the disability community, policymakers, and health care professionals and researchers to continue a focused dialogue that will influence the direction of reform and the substance of the policy discourse going forward.

B. Planning Process

Before the summit convened, a multidisciplinary organizing committee engaged in extensive discussion to develop summit objectives, process, and logistics. Planning focused on bringing together approximately 25 influential and strategic decision makers from across the health care system and the community of people with disabilities. The

summit was designed as a 1½-day interactive working meeting to engage in a dialog with senior leadership from multiple relevant constituencies.

The summit sought to include the shared wisdom of the public and private sectors, the health care provider community, Government agencies, disability rights and advocacy groups, and people with disabilities. Individuals representing each of these constituencies were invited to participate. Summit attendees represented a continuum of expertise on health care access issues faced by people with disabilities. The group included (1) experts deeply familiar with broad health and health care access issues for people with disabilities; (2) expert authorities on a focused access issue, such as architectural or communication access; and (3) those who were somewhat unfamiliar with disability access issues but held expertise in a sector highly relevant to the summit's goals, such as health care organization accreditation or professional education. In some cases, participants represented more than one community. (See appendix B for a list of participants.)

C. Structure

Summit organizers opened the meeting with a discussion of the overall NCD research project and the summit's purpose, goals, and rationale. Throughout the meeting, participants met in a mix of large and small discussion groups in which facilitation techniques were used to elicit their views and achieve consensus concerning priority recommendations and strategic action plans.

A variety of experts provided high-level introductions to health care access issues affecting people with disabilities. Topics included (1) key health care access issues for people with disabilities in general and for specific populations, such as women with disabilities, people who are deaf or hard of hearing, people who are blind or who have vision impairments, and people who have intellectual and developmental disabilities; (2) universal design principles in health care; (3) the status of Federal directives on access, accommodation, and accountability; and (4) disability definitions, data collection, and disparity initiatives.

Before the summit, organizers defined five “Priority Recommendations for Reform and Stakeholder Actions” for discussion by the participants. The five recommendations were chosen from the 2007 Institute of Medicine (IOM) report “The Future of Disability in America,” the 2005 “Surgeon General’s Call to Action to Improve Health and Wellness of Persons with Disabilities,” and other reports and publications concerning health and health care for people with disabilities. Summit organizers considered the scope of recommendations made by these seminal reports and selected the recommendations that could potentially yield identifiable objectives and outcomes. The recommendations were selected on the basis of their projected impact, feasibility, and alignment with summit participants’ spheres of influence. Recommendations that were considered too broad or unwieldy were set aside in favor of more promising alternatives. The planning process and the summit itself emphasized identifying achievable goals.

Priority recommendations:

- Federal agencies should adopt a uniform disability monitoring system for identifying access barriers, quality measures and outcomes, and health and health care disparities.
- Health care facilities, services, and programs must be accessible according to Federal and state standards and guidelines, and should actively promote principles of universal design in the built environment, for diagnostic, exam, and other medical equipment—in fact, for all aspects of care delivery.
- All health care provider training programs should have a disability competency requirement that produces student comprehension and understanding of the principles of accessibility, accommodation, cultural competency, and awareness of community and other resources for people with disabilities.
- Congress should establish a publicly funded system of technical assistance centers from which states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on

defined standards of care and related practical resources for ensuring full access to health care services for people with disabilities.

- Key stakeholders must ensure that these and other critical issues concerning health and health care for people with disabilities are fully integrated into “Healthy People 2020” deliberations taking place during 2008 and 2009, and into the final publication. (See appendix E for additional recommendations and potential stakeholder actions.)

Participants were organized into two facilitated roundtable discussion groups that identified three priority recommendations from the list of five. The full group reconvened, roundtables outlined their respective priorities and action plans, and ideas were merged.

At the close of day 1, summit conveners prepared a synthesis of results and developed a single priority plan. On day 2, participants deliberated the priority plan, agreed to a set of final recommendations, and set priorities for action. Summit conveners closed the meeting by encouraging action and collective accountability, and they sought commitments from participants to begin working on specific tasks. Organizers sent a postsummit summary letter to participants in order to reinforce the work of the summit and maintain and direct momentum going forward. (For additional details on the summit process, see appendix F.)

D. Summit Proceedings

1. Charge and Goals

Summit organizers set the stage for the meeting with impassioned opening remarks that described the dramatic life changes for people with disabilities that have been achieved since the enactment of the Americans with Disabilities Act (ADA). Although these changes are evident and effective in areas such as architectural accessibility, transportation, and telecommunications, similar advances are not yet apparent in health care. Issues of cultural competency, health disparity, and health literacy dominate the national health care agenda and reflect an appropriately placed concern for economic

and sociocultural barriers to care. However, issues of concern to people with disabilities, such as physical and communication barriers to care, remain unchanged for the most part.

From the time the IOM released its first report on people with disabilities, in 1991, to its most recent publication in 2007, numerous high-profile reports have explicitly identified barriers to health care for people with disabilities and offered extensive recommendations for improvement.⁴⁵¹ Yet for all the reports and recommendations, there has been little action and little change.

Determined not to dispatch another report to the shelves, summit conveners challenged participants to lead a sea change forward. Participants were asked to examine the following questions:

- Why haven't we been successful in enacting the recommendations of past reports?
- Why haven't we witnessed a sea change?
- What prevents us from moving forward?

Summit conveners sought engagement and meaningful discussion from participants and encouraged them to identify practical implementation steps for the most promising and readily achievable recommendations.

One of the charges of the summit, in addition to examining the health care status of the overall population of people with disabilities, was to examine specific groups within the larger population, specifically, women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, people with other communication disabilities, and people with intellectual and developmental disabilities. Summit presentations and discussions specifically addressed these populations.

2. Framing the Issues: Content Presentations

The content presentations provided introductory material on topics relevant to disparities in health and health care for people with disabilities. The four topical sessions addressed the following issues:

- a. *Health Status of People with Disabilities and Key Health Care Access Issues*
- b. *Specific Health and Health Care Issues*
 - Women with disabilities
 - People who are blind or have vision impairments
 - People with intellectual and developmental disabilities
 - People who are deaf or hard of hearing
- c. *Universal Design Principles in Health Care*
- d. *Role of the Federal Government*
 - Absence of Federal directives to states on access, accommodation, and accountability
 - Definitions, data collection, and disparity initiatives

3. Forensic Inquiry

Over the past few decades, significant strides have been made in improving the health status of Americans. Despite these improvements, people with disabilities continue to experience a disproportionate burden of poor health compared with the general population. Elimination of health disparities through improved access to care for underserved populations is a top priority on the nation's health care agenda, yet people with disabilities remain disconnected from its fiery momentum. Why is this so?

By leading participants through a form of failure analysis, summit conveners posed a series of thought-provoking questions, listed below, that spurred discussion about why

access to health care for people with disabilities had not improved to any significant extent.

- Why aren't more health care organizations breaking down the barriers to access for people with disabilities?
- Why is it so difficult to get accessibility principles adopted in the health care setting?
- Why are people with disabilities so difficult to get on the radar screen of health care organizations?
- Why have all the existing reports and recommendations on health care access led to so few actions and results?

While participants found no clear causal factors that accounted for these failures, a number of contributory and interrelated factors emerged that informed the group's thinking and discussion.

4. Contributing Factors

a. Core Attitudes

A participant from the disability community stated:

Most people who do not have disabilities look at someone with a disability, and they don't believe we can live a fulfilling, productive, and happy life. They don't believe that. And that creates a gulf. And unless you can bridge that gulf, it will always be there.

Misconceptions about people with disabilities impede access to health care services. Health needs are frequently interpreted only in reference to the individual's disability and not in regard to broader health issues. This form of diagnostic myopia goes beyond stigma and stereotyping, and limits access to appropriate quality care. In particular, it can lead to underutilization of health promotion and preventive services. For example, several summit participants related stories about health care providers who did not

screen people with disabilities for nutritional status, tobacco or alcohol use, sexually transmitted disease, cancer, or domestic violence.

Another participant said:

My son is 25 years old, identified at 18 months old with muscular dystrophy. He is also legally blind, has signs of autism and depression. People can't imagine he can do anything. And yet, I see him as a wonderful, loving person who makes an enormous contribution to my family and our community; that piece is almost never discussed when we talk about health care and developmental disability.

False assumptions and stereotypes about those who have a disability are often the root causes behind the pervasive and systemic barriers people with disabilities experience in the health care delivery system. One participant told a particularly wrenching story about a deaf patient who was waiting for the results of a biopsy, to learn whether he had prostate cancer. Before he was given a diagnosis, and without a sign language interpreter present, the physician handed him a note that said, "Prostate cancer—testicles removed. Radiation if necessary. Depends on bone scan." This note comprised the entire communication about this man's medical condition, treatment options, and possible prognosis until family members intervened and insisted on appropriate communication.

Summit participants discussed how basic health care needs are often neglected by health care practitioners because they operate in a culture that frequently devalues life with a disability and that finds it difficult to understand that people with disabilities can live lives that have meaning and quality. For example, many health professionals hold myths about the sexuality of people with intellectual disabilities. Not only do they sometimes mistakenly think that women with intellectual and developmental disabilities are asexual, but they subscribe to an attitudinal bias pervasive in the health care community that argues that such women should not be sexual. As a result, health care providers sometimes fail to consider reproductive needs or conduct basic health screenings.

Another participant told this story:

I was three years old when I had polio. Throughout my life, and even today, it's amazing how often people are amazed at what I do. We simply don't have an image in this country of what disabled people can be. We are blazing a trail. Now, what's too bad is that when we see a doctor, to this day we continue to blaze that trail over and over again. Even when things work, you come to the next person and you get to blaze it all over again. I guess I've gotten to the point where I accept the fact that to the end of my time I will be doing this. But sooner or later we've got to find a way to let people know what the expectations really ought to be.

b. System Failure

Patient-centered care—defined by the Institute of Medicine as care that is respectful of and responsive to individual patient preferences, needs, and values⁴⁵²—is a key ingredient of health care quality. But looking at health care quality from the patient's perspective is fairly new, and it is only recently that patient-centered principles have dominated health care conversations.

Despite some progress, participants agreed that tremendous gaps exist in the adoption of patient-centered practices. The system remains focused on illness rather than people and on short-term fixes rather than long-term relationships. Neither strategy serves people well. The fundamental inability of the system to respond to individual needs and the fact that the system thrives on its very impersonal nature are primary cause of the failures of health care quality as a whole. The experiences of people with disabilities showcase the impact of these system weaknesses.

c. System Complexity

Various participants noted that the U.S. health care system is often called a nonsystem. It is characterized as complex, fragmented, entrenched, and deeply layered, and any form of transformation must cut across these diverse elements. Despite all the reports and recommendations, no sweeping change in access or quality of health care has taken place for people with disabilities. It is extraordinarily difficult to influence the complexity of forces that shape health care, how it is delivered, who gets it, and how

well it works. As long as the health care system continues to be layered in complexity, health disparities experienced by people with disabilities will also remain unchanged.

d. Data Challenges

Participants discussed the impact of poor disability data on funding and health care service delivery. No single operational definition of disability exists, nor does a consistent system for measuring the prevalence of disability or its impact on health. The current monitoring system is not sufficient to provide the basic data needed to measure and monitor disability.

People with disabilities are represented in 207 of the 467 objectives that span 21 of the 28 “Healthy People 2010” focus areas. However, data on people with disabilities are available for only 88 of those 207 objectives.⁴⁵³ In the absence of data, appropriate programs cannot be planned, outcomes cannot be evaluated, and the causes of disparities cannot be identified and reduced.

As one participant observed:

We know that people with disabilities experience disparities in health and health care. But we know nothing about why the disparity exists. Are people not receiving services because of a stigmatized attitude on the part of the physician or because the patient preferred not to have the service? Available data sets are not designed to capture such aspects of care.

When women with disabilities under age 65 were diagnosed with early stage breast cancer, they were much less likely than the general population to receive breast-conserving cancer surgery. They were much more likely to be treated with mastectomies. It could be the patient’s preference, but it could be other factors as well. We just don’t know.

Several participants noted that current Federal data collection efforts amass a significant amount of information on impairment, activity, and participation limitations. However, national public health data sets do not collect information on environmental factors that have an impact on health, such as whether people use wheelchairs or augmentative communication devices, or whether they have access to public

transportation to get to the doctor. Further, data are not collected on access modifications or adaptations in private homes, or programmatic accessibility in health care settings. Little is known about the extent to which these and other environmental factors contribute to the overall health status of people with disabilities.

e. Strategy Limitations

Participants discussed the lack of impact of efforts, such as litigation, to bring about necessary systemic change in health care access for people with disabilities. One participant observed that some perceive the ADA as the only tool available to address the issues, when in fact it is only one instrument, and a blunt one at that. Several people questioned whether other strategies have been used effectively, such as standards setting and monitoring by private accreditation entities or better training of health care professionals.

One person observed that significant gains had been made within the institutions by the milestone settlement of *Metzler v. Kaiser Permanente* (2001) and the Washington Hospital Center settlement with the Department of Justice (2005). She went on to ask, “Where are the others?” The ADA was an effective tool in these cases, but other institutions did not follow suit. The majority of health care delivery in the United States takes place in private offices and small clinics, where there is little or no ADA implementation or enforcement. Several people suggested that it is unlikely that the ADA can effectively reach the levels and layers of health care being provided in small offices and clinics around the nation. One participant questioned whether the ADA as a blunt tool is capable of “changing the hearts and minds of an entire sector of society.”

f. Attention Overload

Human attention is becoming a scarce resource in health care environments. Fiscal constraint, workforce shortages, pay-for-performance, and emergency department overcrowding are just a few of the current demands on the system. In an environment saturated with complexity, chaos, and time demands, issues vie for their share of

attention. One summit participant noted, “If it’s not on their radar as an important issue, then all other issues swamp it.”

Another participant said:

You’ve got to get people’s attention. The inertia of ignorance is more powerful than I ever suspected. People in health care are so focused on life and death issues, on overloaded caregivers, on limited resources with so many competing interests. Until that ignorance is overcome or you get their attention by a lawsuit or Department of Justice investigation, it’s tough to get these issues to the top of their to-do pile. It will always be “that’s a good thing to do” but it will never quite rise to the surface until there is some sort of accountability demanded.

g. Culture and Curriculum

One participant told the story of a recent mammogram. Through experience, she knows it takes two technicians to position her effectively, but only one was available that day. The single technician said, “I’ve been doing this for years. Let’s give it a try.” The participant replied, “No, let’s not!” There was general agreement that the stories people with disabilities can tell about providers who do not respect their wishes or trust them to know their own needs are virtually unlimited. Another participant said there are “really, really horrific stories out there about people with disabilities not getting their needs met.” And a third participant, a member of the medical community, asked, “Where is the culture of humility?” Provider training is key to changing attitudes and practices, and “cultural humility warrants greater emphasis in medical training.”

All health care providers should be better educated about disability and appropriate health care, but current curriculums that address these issues are very limited in professional training programs. Physicians, nurses, and other providers therefore have little awareness of the challenges involved in living with a disability or knowledge about how to provide culturally appropriate care and accommodations.

From a training perspective, health care professionals must understand that disability touches everyone’s life, through birth, accident, disease, or aging, or through

relationships with others. Health care providers, including physicians, nurses or allied health professionals, and others, are the heart of our health care system. However, when they have not been trained to address the needs of a major segment of the population, serious problems arise for people with disabilities. Providers should learn to recognize the knowledge gap and seek information from patients or from other sources. Historically, however, medicine is a profession that operates on the adage that “the doctor knows best,” which fosters a culture in which the physician leads and others dutifully follow. This scenario tends to be more pronounced when people with significant disabilities are involved. Quality experts have identified this mindset as a major barrier to reducing medical errors and improving the quality of medical care overall.

Various participants acknowledged that common problems—including lack of awareness, indifference to informed consent, disregard for the patient’s best interest, and unwillingness to provide for accommodations—seriously undermined efforts to ensure quality care and eliminate health disparities for people with disabilities.

h. Untapped Possibilities

Many groups have a mutual interest in expanding health care access to underserved populations. However, several participants questioned whether the disability community has adequately leveraged these potential partners for a common cause. One individual encouraged the group to avoid treating disability issues as silos. “Your issues are shared by others. The more you can be seen as a part of a full-court press, the more likely you are to succeed.” This participant stressed, and others agreed, that collaboration is necessary to create win-win scenarios.

Participants observed that other populations affected by health disparities have just as much stake in health care access as do people with disabilities, which suggests an opportunity to achieve critical mass. If disability issues are isolated and unique, however, they risk being viewed as nominal, making success more difficult to achieve. Various participants asked which partners the disability community had failed to embrace and which partners should be approached.

Some participants cautioned against this approach and questioned whether disability concerns might be either diluted or absorbed by aligning with other affinity groups.

5. *Priority Recommendations for Reform and Stakeholder Action*

Participants discussed the following five priority recommendations for reform, derived from leading reports on health care for people with disabilities. They identified the recommendations that they thought should be the highest priorities; eliminated those that were overly broad, overly ambitious, or too complex; revised or added to the recommendations; and generated specific action steps to advance the goals.

- Federal agencies should adopt a uniform disability monitoring system to identify access barriers, quality measures and outcomes, and health and health care disparities.
- Health care facilities, services, and programs must be accessible according to Federal and state standards and guidelines, and should actively promote principles of universal design in the built environment, for diagnostic, examination, and other medical equipment—in fact, for all aspects of care delivery.
- All health care provider training programs must have a disability competency requirement that produces student comprehension and understanding of the principles of accessibility, accommodation, cultural competency, and awareness of community and other resources for people with disabilities.
- Congress must establish a publicly funded system of technical assistance centers from which states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on universally defined standards of care and related practical resources for ensuring full access to health care services for people with disabilities.
- Key stakeholders must ensure that these and other critical issues concerning health and health care for people with disabilities are fully integrated into the

The group concluded that all the recommendations were relevant and critical, and none of the five should be eliminated from the broader agenda. One participant compared the recommendation to a three-legged stool; no recommendations can be removed without the entire stool falling. While all five recommendations must be addressed, the participants focused on those that were most likely to be achieved sooner rather than later, referring to them as “low-hanging fruit.” Rather than trying to tackle the broad issues posed by the five recommendations, the group felt a more effective proposition would be to identify priorities, then narrow down and create action steps for two or three of them.

After considerable discussion, the group came to a consensus on two top-tier and three second-tier recommendations. Two additional recommendations were identified and are reported as well. Because of time limitations, the group identified strategies and action steps only for the top-tier recommendations.

a. Summit Participants’ Top-Tier Recommendation #1

Health care facilities, services, and programs must be accessible according to Federal and state standards and guidelines, and must actively promote principles of universal design in the built environment—for diagnostic, exam, and other medical equipment—and for all aspects of care delivery.

- **Rationale**

People with disabilities face numerous barriers to receiving adequate health care. Barriers can range from physically inaccessible health care provider locations, to exam and diagnostic equipment that cannot be adjusted for a range of patient function, to a failure to modify office policies or practices to accommodate the communication and accommodation needs of patients with various disabilities.

A participant related the following story illustrating the pervasive problems with programmatic access inherent in health care settings. The individual—an active, vigorous man who is functionally paraplegic and uses a wheelchair—experiences the effects of post-polio syndrome and uses a noninvasive ventilator when he lies supine. A computerized tomography (CT) scan showed an ill-defined pelvic lesion, and he was referred for an outpatient magnetic resonance imaging (MRI) followup. His internist ordered the MRI and noted that he must use his ventilator when lying flat.

Unquestionably, this situation is novel and unique; further, the medical community is generally not familiar with the use of ventilators outside the acute care context. This individual's MRI required that staff understand the problem and integrate and coordinate appropriate services, which unfortunately did not take place in a timely manner. Nine months later, the man finally had an MRI using an MRI-compatible ventilator. By that time, the lesion had more than doubled in size and was found to be malignant. The participant who shared the story, a member of the medical community, summed up the anecdote by saying, "What has happened here? This is much more than disability access. This is patient safety. This is quality of care. This is a delayed diagnosis."

While Federal laws, such as the ADA, as well as many state laws, prohibit discrimination on the basis of disability and clearly apply to health care facilities and services, enforcement efforts have failed to bring about needed systemic change in health care access for people with disabilities.

- **Accessibility and Universal Design**

Substantive discussion took place over how to make the best use of accessibility mandates and universal design principles in health care environments. Participants emphasized the importance of a two-pronged approach for achieving access to health care facilities. Facilities must first implement the legally mandated accessibility requirements in the ADA and relevant regulations. Health care facilities and programs should also adopt and promote universal design principles as a means of initiating systemic changes in institutional attitudes and behaviors.

Some participants saw the potential for universal design to move health care facilities beyond strict physical access and compliance with standards and guidelines to a values-based framework of inclusiveness. The potential exists to go far beyond just the letter to the spirit of the law and to create truly inclusive environments, but the will to do so must be present. Participants discussed the fact that compliance with universal design principles is not easily measured and is not regulated. ADA accessibility guidelines will likely represent the minimum requirement, or the floor of what must be provided, because adherence to the guidelines can be measured and evaluated. Universal design principles could subsequently be added. Several participants expressed concern that universal design would be interpreted as a one-size-fits-all approach rather than an adaptable solution to various accommodation and design challenges in the health care context. Participants discussed methods and strategies for working with health care facilities to get the best of universal design and the ADA.

Participants also discussed current health care design movements. One participant encouraged efforts to conceptually meld three contemporary approaches—universal design, design for sustainability, and design for safety—into the design of health care facilities. Participants encouraged interaction with the American Institute of Architects (AIA) and its “Guidelines for Design and Construction of Health Care Facilities” (2006). The group expressed enthusiasm for hitching disability accessibility and accommodation onto the relatively new drive for social sustainability (which includes universal design). One person noted, “Green movement seminars are hot in the architectural world. Can we approach them and get onto their agenda? Can they include something on disabilities? To the extent that we can talk about ourselves in their terms, the door will be open for us.”

A thoughtful dialogue took place on the challenge of balancing the prescriptive and measurable standards of the ADA and the broader vision and values of universal design. Participants offered the following:

- When the Joint Commission required health care organizations to establish an ethics mechanism, the committee did not specify that an ethics committee or an

ethics consultant was required. Rather, the Joint Commission required an ethics mechanism; it was up to the organization to determine which mechanism.

- ADA specifications for wheelchair lifts meet certain use requirements. However, in the spirit of inclusiveness, facilities should purchase the lift that is most useful to the greatest number of people. This would include newer lifts that can accommodate larger scooters and power wheelchairs, as well as conventional wheelchairs.

Inaccessible medical equipment, a major barrier to quality health care for people with disabilities, was a consistent theme at the summit. Discussion focused on the development of technical criteria for such equipment. The merits of performance and technical standards were compared: a performance standard would specify, for example, that a patient room must be accessible or universally designed, whereas a technical standard would specify that the door must provide a 32-inch clearance opening. While the performance standard can be interpreted in different ways, the technical provision is without ambiguity and is measurable, but participants also questioned whether that is the best method for improving access and fostering meaningful inclusion.

Participants observed that the rapid pace of change in health care is a major factor to consider in the debate between performance and technical standards. Technical standards can impede advancements in health care, as they are quickly outpaced by emerging technologies. By comparison, performance standards, which rely on laying a foundation of best practices, are potentially more durable.

Alternatively, one participant suggested involving the Food and Drug Administration (FDA) in the issue of accessible medical equipment. Since the agency is responsible for approving and regulating medical equipment, exploring methods to incorporate accessibility standards into the FDA review process could advance the development of such standards.

- **Changing Context**

In “Crossing the Quality Chasm” (2001), IOM advanced six aims for transforming the U.S. health care system. The values—safe, effective, patient-centered, timely, efficient, and equitable—mesh neatly with universal design principles. Merging the IOM aims with universal design principles would enable people with and without disabilities to benefit from the underlying values while experiencing person-centered health care. One participant said:

We think of people with disabilities as a narrowly defined population when in fact they are not. Roughly 85 percent of people over the age of 85 experience age-related hearing loss, and arthritis is the single most disabling condition in adults, so when we talk about people with disabilities, the numbers are huge. And I would hate for the message to come out of our group that we’re talking about a narrow community of disabled people. . . . This really has to do with everyone. It’s all-inclusive. It’s everybody. It’s you. It’s your parent, if it’s not you yet.

Another participant talked about the issue of universality. Communication is a significant issue for all patients, including people who are deaf or hard of hearing, and this issue intersects with issues of poverty, literacy, and ethnicity. The need for effective communication is not specific to people with disabilities but universal to all patients.

Various participants discussed the fact that disability is a universal phenomenon. Most people will experience physical changes and challenges at some point in their lives, and almost certainly will as they age. The attraction of universal design is that it encompasses human variation and ability, thus helping to shift the view of people with disability from a narrow, specialized community with unique needs to a broader community with common needs and values. One participant said, “It is a mistake to think we can solve this whole problem each in our own little way.”

- **Role for the Joint Commission**

The Joint Commission (JC), through the provision of health care accreditation and related services that support performance improvement in health care organizations, is

in a key position to influence the pace at which health care facilities accept and adopt accessibility standards and principles of universal design. The JC employs numerous mechanisms to educate health care organizations about best practices, and it can bring about ADA compliance by developing accreditation standards for accessibility, patient accommodation, and universal design.

The JC establishes standards for 96 percent of U.S. hospital beds and monitors compliance, thereby ensuring that it has an influential voice in the hospital industry. Because the majority of hospitals use JC accreditation to establish Medicare certification, hospitals readily engage in JC-sponsored educational programs and disseminate JC materials in order to maintain certification. JC accreditation penetration, however, is not as deep in long-term for ambulatory care settings, and therefore the commission has less influence in these markets. A participant from the medical community spoke of JC's ripple effect. "It is a sea change any time JC endorses an issue. It doesn't matter if JC's influence is concentrated on hospitals, because physicians work in hospitals. And then they go to their outpatient settings, clinics, or long-term care facilities, and they bring the new practices with them. They don't compartmentalize. When JC issued new pain standards for hospitals, pain management improved in every care setting."

Another participant advised against using standards as a first step. He suggested a process that begins by educating organizations and surveyors on deficiencies and best practices. In this approach, the JC could serve as a major communication vehicle. The adoption of a standard could follow and an agreement on technical content could be garnered.

One participant made the point that

[w]hether it is standards or the law, organizations will act in order to be in compliance. They will act without thinking. And we're not going to have quality and safe care for everyone unless people think about what they're doing. Health care is complex and requires thinking. Check-off sheets can't substitute for thinking, and thinking is the key to patient-centered care. So what we're

trying to do is get people to think about what they're doing in the context of the values we've endorsed around health care. That's bigger than a standard.

Another participant from the medical community offered the following example: Consensus on adding cultural competency to medical school curriculums was percolating for a few years, and then the Liaison Committee on Medical Education (LCME) inserted a simple standard on cultural competency into the accreditation process.⁴⁵⁴ Suddenly there was an explosion of best practices, curriculums, seminars at meetings—all due to the new standard. From this participant's view, standards are the catalysts that drive action, even in a landscape that is amenable to taking action but has not yet done so.

- **New Models of Health Care Delivery**

Participants discussed increasing use of models of care delivery, such as mobile mammography, telehealth monitoring and consultation, home dialysis and home chemotherapy, and a resurgence of house call medicine. On the positive side, home care environments effectively solve some of the routine barriers to health care faced by people with disabilities (e.g., transportation, fatigue, inaccessibility). On the cautionary side, disability communities must be involved in developing access guidelines and standards now, as these delivery models emerge. One participant warned that language in guidelines and standards must explicitly target equipment and devices used in the home. If the language says “all aspects of health care delivery,” it will inevitably be interpreted to mean hospitals and clinics but not the home.

Others recommended laying the groundwork for Federal regulation of telehealth and telemedicine applications specifically. Various participants suggested that DOJ should define what “accessible” means in a telehealth environment, and the Access Board should develop technical criteria. DOJ might also need to address other civil rights issues now, before the technology becomes ubiquitous in mainstream medicine.

- **Build the Business Case**

Participants noted that hospital leadership is generally receptive to hearing the business case on accessibility. When accessibility issues intersect with workplace or patient safety issues, and a positive return on investment can be projected, hospital administrators tend to be open and interested.

Specific discussion took place about the attention that has been given to the health and safety risks among health care workers. For example, nursing staff, by the very nature of their work, are particularly vulnerable to the hazards of back injuries. It is estimated that annually 12 percent of nurses leave the profession because of back injuries, and more than 52 percent complain of chronic back pain.⁴⁵⁵ The extent of injury among the nursing workforce is particularly distressing in the context of the current nursing shortage.

Several participants spoke about how providing appropriate patient lift and transfer equipment, along with processes to support their use, is an effective strategy hospitals can use to reduce the risk of injury. Not only does the equipment decrease injury to nurses (reducing work-related compensation claims, staff turnover, and lost productivity), it improves the safety and quality of patient care delivery.⁴⁵⁶

In another example, hands-free paper towel dispensers create accessibility for a segment of the population with mobility limitations. At the same time, these dispensers reduce the chance of cross-contamination and thus facilitate improved infection control.

- **Involving People with Disabilities**

Several participants brought up the need for people with disabilities and their families to be involved in the design process of health care facilities and medical equipment.

- **Insurance Industry**

Participants considered the role of third-party payers. Dysfunctional reimbursement methods have a profound effect on the will or ability of providers to create accessible

environments of care. However, driving insurance industry change was beyond the scope of the summit.

- **Scope of the Problem**

Concerns were raised about the enduring and pervasive lack of implementation, monitoring, and enforcement of the ADA in health care delivery. One person described it this way:

JC has not adopted the ADA standards or guidelines as a basis for accreditation of its facilities. CMS has not adopted the ADA or Section 504 of the 1973 Rehabilitation Act as a mechanism for determining allocation of Federal funds to the states. Although companies that contract with states to provide health care are required to comply with the ADA and other civil rights laws, as a practical matter there is no implementation and no monitoring and no enforcement. It's a challenge to think about how to make that work.

- **Goal-Specific Strategies**

- Use ADA accessibility guidelines as a minimum standard but aspire to universal design principles in the spirit of the direction reform should take.
- Align health care access for people with disabilities with the Institute of Medicine's six aims for improving the health care system.
- Begin to shift the context of disability away from an accessibility and civil rights issue toward a patient safety and quality of care issue.
- Capitalize on the Joint Commission's significant reach into health care organizations.
- Partner closely with the Joint Commission in educating organizations and surveyors on accessibility and universal design principles.
- Think and act systemically.

- **Specific Action Steps**

- Develop a best practices guide to help providers (a) recognize that universal design goes beyond ADA requirements and (b) understand methods of implementing and evaluating universal design principles in health care settings. In this guide, profile organizations that have implemented best practices, including their methods and outcomes.
- Submit a scholarly article to the Joint Commission *Journal on Quality and Patient Safety* that aligns health care access for people with disabilities with the six IOM aims for a transformed health care system.

- **Identified Stakeholders**

- Centers for Medicare & Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Joint Commission (JC)
- Access Board
- Department of Justice (DOJ)
- Disability and health care policy advocates and researchers

b. Summit Participants' Top-Tier Recommendation #2

Congress must establish a publicly funded system of technical assistance through which states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on defined standards of care and related practical resources for ensuring full access to health care services for people with disabilities.

- **Rationale**

The participants defined a number of barriers that prevent readily available, accessible equipment from being acquired and used in health care settings. Health care providers

sometimes hesitate to implement accessible solutions if they do not have knowledge about where to find resources, think it is too time-consuming to learn how to use an accommodation, or think that the accommodation is too complex to master. When sufficient information is not readily obtainable, providers often either give up or reinvent solutions rather than seek existing technologies and ideas.

Substantial information is available on assistive technology, accessible medical equipment, accessible built environments, and universal design principles for health care settings. But the information is fragmented, poorly disseminated, and hard to find. Health care providers, the public, and people with disabilities need a better road map to access it. A technical assistance system would provide an expert road map to information and resources.

A comprehensive center of technical assistance would improve access to health care by making this information readily and proactively available to health care providers, people with disabilities, and other key stakeholders. One participant from the disability community said, “I think a lot of people don’t know you can get better care and should get better care. If we had a repository, a technical assistance center for health care, people could find information, program access tips, policies, whatever.”

- **Structure and Function**

Summit participants fully endorsed the need to make some form of technical assistance available to health care providers who are seeking information on accessibility, accommodations such as sign language interpreters, best practices, or universal design principles. Participants considered various models for providing technical assistance and deliberated which would be most effective in serving the health care industry.

A number of federally funded models of technical assistance exist. A national network of Disability and Business Technical Assistance Centers (DBTAC: ADA Centers) has been established to provide information, referral, resources, and training, with an emphasis on businesses and employers. The DBTAC Centers are set up as a regional model,

whereas the summit participants favored a national center that included a virtual approach for health care.

The precise role and function of a national technical assistance center for health care Access requires refinement and stakeholder input; such a center could build on existing expertise and resources, but participants suggested a number of potential core activities:

- Provision of national technical assistance through an interactive Web site and Webinars
- Listserv, email, and toll-free telephone support
- Provision of training at health care provider national conferences
- Provision of onsite training at hospitals and clinics
- Assistance to hospitals and clinics to identify and address barriers
- Review and critique of accessible medical devices
- Analysis of novel approaches
- Development of model policies and procedures
- Compilation of best practices
- Assistance to patients and providers on the growing use of technology, software, Web services, and multimedia inpatient care programs
- Development of materials that are important for increasing access to health care systems

- **Strategy**

The group agreed that any initiative to establish a technical assistance center for health care would require Federal support and that the center did not necessarily have to reside in the National Institute on Disability and Rehabilitation Research (NIDRR) but could fit well with any number of Federal disability programs. One person suggested

that the only way to elevate the center to an appropriate level of importance was through congressional legislation. This idea has yet to resonate with Congress, but “the fact is that information is exceedingly difficult to get and physicians, hospitals and other providers must have it if we’re going to deal with these issues.”

One participant suggested investigating the possibility of establishing a Federal interagency agreement to initiate a model technology assistance program, which generated enthusiastic discussion. Another person advised investigating the possibility of expanding responsibilities of the DBTAC: ADA Centers to include a specific health care component.

The physicians attending the summit suggested that providers’ willingness to make accessibility accommodations was positively influenced by access to technical support and professional allies. This fact underscores the importance of involving physicians as stakeholders and reaching out to providers through their professional networks.

- **Resource Anthology**

Participants discussed the breadth of stories that people with disabilities tell about trying to gain access to health care services and the barriers they experience. One participant said, “It seems pretty clear there are some really, really horrific stories of people who did not get care, did not get access. I’m not sure if those stories are widely available so that if you move forward on these issues—you have to be able to say there really is a need for this. There are an awful lot of people who don’t understand this. Not a report—a series of topical stories that people can look through.”

The summit group agreed that an anthology of encounters in health care would make an excellent resource to have available through the technical assistance center. The anthology would serve as a means to educate health care providers and the public about the types and extent of barriers present in everyday health care encounters. An accompanying anthology of best practices in universal design was suggested as a way to offer solutions.

- **Goal-Specific Strategies**

- Explore with appropriate Federal agencies the potential for developing an interagency memorandum of understanding to pursue funding for a Technical Assistance Center for Health Care Access, a model project to improve health care access for people with disabilities. The interagency initiative could be led by any of a number of different agencies such as the Centers for Disease Control and Prevention (CDC) or the Department of Health and Human Services (HHS).
- Partner with organizations that have similar agendas, such as the Job Accommodations Network (JAN), Disability.gov, and the DBTAC national network.

- **Specific Action Steps**

- Define core functions and structure a model for a technical assistance center for health care access. The center will serve as a national clearinghouse and technical assistance center that provides comprehensive information resources and technical assistance services to health care providers, people with disabilities, and other key stakeholders.
- Prepare the groundwork to seek a congressional mandate for a technical assistance center for health care access.
- Gather stories of barriers to health care encountered by people with disabilities to be compiled into an ongoing anthology and made available through the Technical Assistance Center for Health Care Access.
- Gather stories of best practices in universal design in health care settings to be compiled into an ongoing anthology and made available through the Technical Assistance Center for Health Care Access.

- **Identified Stakeholders**

- Centers for Disease Control and Prevention (CDC)

- Department of Health and Human Services (HHS)
- Existing bodies with similar objectives, such as Disability.gov and the Disability and Business Technical Assistance Center (DBTAC) national network
- The health care provider community, through professional associations and professional training programs
- Joint Commission (JC)
- Medical device manufacturers and trade associations
- People with disabilities

(See appendix E for a discussion of lower tier recommendations.)

6. *Overarching Strategies for Moving Forward*

Overarching strategies provide a general framework for moving forward and apply to all recommendations. They appear throughout the report and are summarized here to underscore their importance to the overall goal of improving health care access for people with disabilities.

a. Define the Goal

What defines accessible, effective, and culturally competent health care for people with disabilities? Stakeholders must articulate a clear, widely accepted vision of what such health care means. Only after hospitals, clinics, diagnostic services, physicians' offices, and others understand the goal can they take steps toward making it a reality. When Donald M. Berwick, M.D., president of the Institute for Healthcare Improvement (IHI), described a transformed health care system, he imagined a "place with no needless deaths, pain, waits, helplessness and waste."⁴⁵⁷ Similarly, the disability community must define an inclusive and accessible environment, and communicate that vision consistently and repeatedly.

b. Ride the Wave

Hospital and medical office building construction is undergoing unprecedented growth. Aging buildings, the migration of procedures from hospital to outpatient settings, and most important, the aging baby boomer generation are just a few of the factors feeding this growth. Throughout, a new vision for health environments is emerging: patient-centered well-being is driving the design of services and buildings for the first time. As services and buildings evolve, disability communities must ride the wave by seeking every opportunity to influence best practice in inclusive and accessible designs.

c. Drive System-Level Change

Historically, people with disabilities have improved health care service quality primarily through programs established and managed locally; that is, with a project-by-project approach such as a center in Chicago for women with disabilities or a clinic in Washington, DC, for children who are deaf. Far-reaching, system-wide improvements of consequence to the larger community of people with disabilities have been much harder to achieve. James Reinertsen, M.D., a senior fellow at IHI, compares the challenge to that faced by WWII leaders considering the invasion of Normandy.

It would be one thing to prove at a project level that you could land a boat on the coast of Normandy and unload some troops and weapons. It is quite another thing to commit to a full-scale invasion. We've proved over and over that we can do small projects—to land a boat on the coast. It's now time that we mounted a concerted invasion on a large scale.⁴⁵⁸

d. Change Hearts and Minds

The ADA guaranteed equality of opportunity for people with disabilities in most spheres of community life, yet health care settings and processes in the United States continue to regularly and systematically exclude people with disabilities from quality care. While buildings, medical equipment, and health care delivery processes must change in order to ensure equality of access, transformational change must also take place that obliges a fundamental reframing of core values, habits, and beliefs. As one summit participant explained, it is one thing to mandate access in building standards, but it is quite another

to make acceptance happen in hearts and minds: “You have to start by building sensitivity to the issues and literally create the will to take action.”

e. Reframe the Issues

As the population ages, people with disabilities make up one of the fastest growing segments of society. Examining the issue from a policy perspective, one participant suggested, “Couldn’t we get further faster by universalizing some of these needs rather than just talking from a disability perspective?” While disability rights laws are frequently perceived as focusing on a narrow range of people with specific disabilities, such as those who use wheelchairs or those who are blind or deaf, patient-centered care and patient safety should apply to and encompass everyone. Similarly, principles of universal design respond to the greatest possible range of human needs and characteristics. The athlete who is using crutches temporarily, the parent pushing a child in a stroller, and the older person with a vision impairment each benefits from universal design, which should be a foundational principle for patient-centered care. By reframing the goal from strict accessibility to patient-centered care built on the foundation of universal design, the long-term vision for meaningful reform of health care for people with disabilities comes into focus.

f. Create Capacity

Medical students; nursing, hospital, and clinic staff; and allied health professionals receive little education about the meaning and impact of disability on individuals and society. Most health professionals lack a basic understanding of the health issues people with disabilities face. Effective, accessible, high-quality health care for people with disabilities requires that providers have a deep understanding of disability issues and access to the resources required to accommodate the individual needs of patients, such as sign language interpreters, height-adjustable examination tables, and sufficient time to ensure that examinations and treatments can be carried out appropriately. Training at every level of professional education is an essential element to achieve the goal of such professional competency. Increasing the number of health care professionals in the workforce who possess the required knowledge and capacity to

care for people with disabilities will help spur the critical mass required to achieve the level of systemic change that must occur to improve the quality of care and reduce health disparities for people with disabilities.

E. Conclusion and Recommendations

The 2008 Summit on Health Care for People with Disabilities marks a significant milestone in the movement to improve health and health care for people with disabilities in the United States. Participants made it clear that they perceived the summit as a starting point. While important education took place, and themes, ideas, and strategic action plans that hold great potential emerged throughout the summit, time limitations made it impossible to discuss every issue that affects health care for people with disabilities. Therefore, further discussion and the involvement of additional stakeholders are urgently needed. Meanwhile the summit outcomes can be used as a road map by the disability community, policymakers, and health care professionals and researchers to continue a focused dialogue that will influence the direction and substance of the policy discourse going forward.

The following specific recommendations emanated from the summit.

RECOMMENDATION:

Congress should establish a technical assistance system through which states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on universal standards of care and related practical resources for ensuring full access to culturally competent health care services for people with disabilities.

RECOMMENDATION:

Health care accreditation organizations must play a principal role in ensuring that health care delivery provided to people with disabilities meets basic standards of cultural competency and accessibility. Accreditation bodies should evaluate health

care institutions based on the extent to which the institution meets minimum architectural accessibility in accordance with the ADA Architectural Guidelines (ADAAG); rewards the implementation of universal design principles in health care settings; has established mechanisms to ensuring that programmatic accommodations are provided (e.g., sign language interpreters, height-adjustable examination tables, wheelchair-accessible weight scales, lifting assistance, materials in alternative formats); and has established grievance procedures that ensure people with disabilities can resolve problems they encounter in a timely way.

RECOMMENDATION:

The Association of American Medical Colleges (AAMC) and the Liaison Committee on Medical Education (LCME) should convene a workgroup charged with identifying specific disability competencies that should be required of health care professionals before graduation from medical and residency training programs, and translate these competencies into specific course recommendations that can be adopted by medical training programs. Competencies should include the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with intellectual and developmental disabilities; awareness of language and cultural issues related to the Deaf community; and general awareness of health care issues and concerns of people who are blind or have vision impairments, women with disabilities, and others within the disability community.

CHAPTER 7. **Examples of Effective Health Care, Research, and Related Programs for People with Disabilities**

The programs highlighted in this chapter emphasize health and mental health care and health education and promotion for people with disabilities, including women with disabilities, people with intellectual and developmental disabilities, people who are deaf or hard of hearing, and people who are blind or have vision impairments. Also included are several projects that involve structural innovations that hold some promise for improving health care and health outcomes for people with disabilities.

Most of these programs serve either women or people with specific disabilities in settings where they are the primary beneficiaries, rather than including them in programs that serve a broader population. While some of these programs are located within hospital or medical rehabilitation settings and draw upon the resources of those organizations, in most cases services are still provided specifically for subgroups of people with disabilities rather than being integrated into programs meant for a more diverse population. Further, some programs serve relatively small numbers of people with disabilities, thereby raising the question of how the program or elements of the program can be expanded or replicated effectively in order to provide services to more people across more health care settings. It is likely that these programs serve small numbers of people because funding and staffing are limited. In any event, most people with disabilities do not have access to such services and instead must seek care from traditional providers.

Various key informants and stakeholders have suggested that disability-specific programs represent the best approach to providing health care and related services to people with disabilities because of the extensive structural problems in the health care delivery system, the lack of professional training and awareness about the needs of people with certain disabilities, and other documented barriers to care.⁴⁵⁹ These observations suggest the need for further exploration of methods to apply what has

been learned from these and other programs to increase effective health care services for people with disabilities.

A. People with Physical Disabilities—An Effective Program

1. *AXIS Healthcare, Greater Twin Cities Area, Minnesota*

Contracted by a Minnesota Department of Human Services program called Minnesota Disability Health Options (MnDHO) in 2001, AXIS Healthcare founded UCare Complete for Twin Cities area residents with physical disabilities who are between the ages of 18 and 64. The program combines physician, hospital, home care, nursing home care, home- and community-based services, and other care into one coordinated care system that maximizes independence while providing person-centered and person-directed services. The plan was designed because people with disabilities who participated in the Medicaid program in the target counties were experiencing poor access to health care services, were unable to obtain accommodations in health care settings, and found that few health care providers understood their particular needs. This plan covers only people with physical or mobility disabilities—who are often unable to obtain appropriate services in conventional health care settings.

UCare Complete applies the coordinated care approach by addressing the specific needs of more than 1,000 adults with physical disabilities who have voluntarily enrolled in the program, up from 200 in 2004. Each participant works one on one with a nurse to develop an individualized care plan. Examples of services designed to meet individual needs include prearranged personal assistance to undergo diagnostic procedures or to use an exam table, and home or work visits instead of office visits to avoid accessibility problems. A panel of people with disabilities provides ongoing feedback about the program's design and implementation.

Consumers report high levels of satisfaction with the program. In the first year following the switch from noncoordinated services to UCare Complete from noncoordinated services, 81.3 percent of consumers reported that UCare services provided better managed care than previous services, and 74.6 percent reported an improvement in the

availability of experts to answer their questions. These and other gains in consumer satisfaction saw additional increases over the following 2 years.⁴⁶⁰ One man, an AXIS member since 2001, says that AXIS is “like a family. We all know each other by name; we’re not just a number. You have a team—the nurse, the social worker, and the person who can approve what’s needed—and you’re all on the same page.”⁴⁶¹

After studying UCare Complete, researchers concluded that care coordination for people with disabilities can achieve the national health objectives expressed in “Healthy People 2010” to close the gap in access to care for people with severe disabilities. Access to disability-competent providers is enhanced through delivery system design, clinician support, self-management support, and clinical information systems. Enrollees become more knowledgeable about the importance of primary and preventive care, and report more productive interactions with their physicians.⁴⁶²

Further, UCare Complete holds the important promise of cost-effectiveness. Coordinated health care can be more efficient and effective than the piecemeal care that is typical of noncoordinated systems. AXIS and UCare anticipate cost savings by serving the comprehensive health needs of individuals.⁴⁶³

B. People with Developmental Disabilities—Effective Programs

1. *South Dakota Rosebud Developmental Clinic, Sioux Falls, South Dakota*

The South Dakota Rosebud Developmental Clinic operates in conjunction with the Sanford School of Medicine at the University of South Dakota in Sioux Falls, South Dakota. The program was organized 18 years ago to identify children from birth through 5 years of age on the Rosebud Reservation who are at risk for developmental disabilities, provide immediate care through early intervention, and refer them to additional medical services provided by local agencies and facilities.

Native Americans continue to experience significant health disparities compared with the general population.⁴⁶⁴ Before the clinic was established, children and parents on the Rosebud Reservation were without local specialists to diagnose and evaluate

developmental disabilities. The clinic operates by sending local staff to the reservation to perform developmental screenings. High-risk children who are identified are referred to the clinic for further evaluation and treatment. Once a month, a team of professionals (psychologist, physical/occupational therapist, speech therapist) and two or three graduate students perform full evaluations for children who are referred to the clinic. Staff members use specific, standardized evaluation methods (e.g., testing motor skills, communication skills, and cognitive/adaptive skills) that allow for flexibility and familial involvement. Children may also see a nutritionist, a developmental physician/pediatrician, and a geneticist at the clinic. After evaluation, an Individual Service Plan (ISP) is created and services are scheduled for eligible children.⁴⁶⁵

The Rosebud Clinic has been so successful that the model has been duplicated on both the Cheyenne River and Pine Ridge Reservations. Clinics at each of these locations provide services to approximately 8 to 10 children each month. Staff conduct monthly conference calls to prepare for the upcoming clinics.⁴⁶⁶

The Rosebud Developmental Clinic was initially funded with a 3-year pilot grant from the State Department of Education and the Bureau of Indian Affairs. Eventually, the Rosebud Tribe assumed funding responsibilities. Similar models are being used in the Cheyenne River and Pine Ridge clinics to achieve sustainability. The clinics use satisfaction surveys to gather and evaluate feedback about the quality and effectiveness of services from families and team members.⁴⁶⁷

2. *Premier HealthCare—YAI/National Institute for People with Disabilities Network, New York*

Premier HealthCare, an agency in the YAI/NIPD (National Institute for People with Disabilities) network,⁴⁶⁸ provides specialty health care practices for individuals with developmental, physical, and learning disabilities throughout New York City. The medical facility provides an integrated medical home for its patients. Premier offers the advantages of both a small group practice and a large academic medical center.⁴⁶⁹

The 11-year-old agency is staffed by doctors and professionals who have extensive training in working with people with disabilities. Premier HealthCare sees 8,000 to 10,000 patients each year, with an average of 100,000 patient visits. Because people with developmental disabilities experience higher rates of secondary conditions than the general population, Premier's comprehensive care clinic practice provides for patients not only to be seen by a primary care physician but to have immediate access to specialists offering a variety of services (e.g., dental, social work, and nutrition).

Premier also conducts various outreach projects, particularly with the Latino population. The agency holds an annual Latino Health Care conference conducted in Spanish that provides technical and emotional support to this traditionally underserved population. Overall, Premier HealthCare is empowering patients and family members by providing a community of support and understanding.

Premier HealthCare receives funding predominantly through Medicaid and minimally through Medicare. Patient surveys are conducted to evaluate customer satisfaction, and quality improvement plans are an integral part of each discipline to ensure progressive growth and modification of outdated standards.

3. *Center for Development and Disability, University of New Mexico, Albuquerque*

A University Center for Excellence in Developmental Disabilities (UCEDD), the Center for Development and Disability (CDD) at the University of New Mexico in Albuquerque is a statewide organization established in 1990 that provides a variety of person- and family-centered health care services for individuals with disabilities, especially developmental disabilities. CDD works for the full community inclusion of people with disabilities and their families by engaging individuals in making life choices, partnering with communities to build resources, and improving systems of care.

CDD's approximately 140 employees serve people of all ages with developmental disabilities, autism, and physical and mental health disabilities throughout New Mexico. This work is guided by four central values: (1) cultural and linguistic diversity;

(2) inclusion and accessibility for all individuals; (3) partnerships and collaboration that encourage capacity-building; and (4) innovative, interdisciplinary, and research-based practice.⁴⁷⁰ These values are applied through CDD's work in four areas: interdisciplinary training, information dissemination, direct service and technical assistance, and applied research. Many programs draw on more than one of these areas. CDD's diverse work includes coordinating a statewide disability and health alliance, building community groups, running conferences and leadership trainings, and maintaining the most comprehensive disability resources collection in New Mexico. An array of technical assistance and trainings are offered, including at-home online trainings for people with disabilities. These initiatives strive to provide consumers with education that integrates the knowledge, skills, values, and methods of distinct disciplines such as medicine, nursing, physical and occupational therapy, speech therapy, social work, psychology, nutrition, family services, special education, and education administration.⁴⁷¹

Preventive strategies are an important part of mental health, family support, and early childhood care efforts. Other direct services for children include care for youngsters who have deafness and blindness; autism screening and support; case management and service coordination for medically fragile children; family consultations; home visitations and trainings for families with children at risk for developmental delays; and trainings for health care professionals, educators, families, and people with disabilities about caring for patients, students, family members, and themselves. CDD also provides supplemental services to Native American children with developmental disabilities and special needs (motor, speech and language, cognitive, and medical), including evaluation, diagnosis, referral, and some therapy.

In fiscal year 2008, CDD provided clinical services for 1,784 people, many of whom received services multiple times, for a total of 24,968 service visits. CDD also presented 387 trainings on a range of topics related to developmental disabilities, with a total of 17,314 participants, a number that represents more than a 100 percent increase from 2007. The center also responded to 2,433 technical assistance requests to schools and agencies, reaching more than 17,300 participants. The CDD Resource Center

responded to more than 5,200 requests for information, and the Information Center provided referrals and answered questions for more than 2,862 individuals.⁴⁷²

As a University Center for Excellence in Developmental Disabilities Education, Research and Services, CDD receives its primary funding from the Administration on Developmental Disabilities. State, Federal, and private grants make up the rest of the funding.

CDD evaluates its work through client satisfaction feedback and outcome measures, typically assessed with surveys. Oversight comes from state agencies and advocacy organizations, as well as an in-house Consumer Advisory Board that reviews programs and works to improve them. CDD submits annual evaluation data to the Administration on Developmental Disabilities. The following are examples from the 2008 annual report.

- 88 percent of respondents to a survey on Self-Directed Family Support users—a program that develops self-directed plans and budgets for families of children with developmental disabilities—indicated that they were satisfied with the program overall; 68 percent reported they were highly satisfied.
- 75 percent of pediatric residents reported increased knowledge and skills in disability-related issues.
- 75 percent of Medicaid users and potential users reported increasing their understanding of how to access services.⁴⁷³

4. *Westchester Institute for Human Development, Valhalla, New York*

A University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD), the Westchester Institute for Human Development (WIHD) is a UCEDD in Valhalla, New York. A former affiliate of the Westchester Medical Center, WIHD became an independent nonprofit organization in 2005. Today, the institute provides coordinated health care to people with disabilities; provides training and technical assistance for people with disabilities, caregivers, family members, and health care professionals; and undertakes research. Operational values include self-

determination, family- and consumer-directed supports, community inclusion, and cultural competence.⁴⁷⁴ WIHD addresses the longstanding health care disparities faced by people with disabilities.

One of WIHD's major roles is the provision of specialized outpatient health care for children and adults with developmental and other disabilities living in the middle and lower Hudson Valley areas of New York State and adjacent regions of Connecticut and New Jersey. Currently, WIHD serves more than 6,000 with developmental and other disabilities in the region. WIHD's health care role includes primary health care services for adults with severe disabilities and complex health problems, as well as specialty health care for both children and adults. WIHD offers a comprehensive, coordinated model of health care provision specifically designed to address the often intensive, complex, and chronic health problems of these individuals. The institute has played a lifelong role in health care for many of its patients and has often been a critical resource, supporting families' ability to care for family members at home, as well as people's successful integration into the community. In parallel with its longstanding specialized health care mission on behalf of children and adults with developmental disabilities and other special health care needs, WIHD has a major professional and community education agenda for professionals in these fields.⁴⁷⁵

WIHD provides consumers with access to medical care, social work, speech pathology, occupational and physical therapies, psychological support, early childhood development, and autism expertise. In addition to formal professional training and experience, many staff members are personally familiar with disability as parents or siblings of people with disabilities. WIHD works to promote the concept that people with disabilities require primary care services and need to be included in health promotion activities. Preventive efforts include the development and dissemination of health promotion programs that highlight health self-management practices, including nutrition, exercise, hygiene, and smoking and drinking cessation. WIHD partners with the Self-Advocacy Association of New York State to promote lifelong self-advocacy and autonomy, and assistive technology that allows people to age in place.

Westchester County contracts with WIHD to oversee child welfare services for approximately 600 children.⁴⁷⁶ The organization has pioneered an innovative, comprehensive program that serves foster, adoptive, and biological families. WIHD's Children's Advocacy Center is one of only two programs in New York State that provides forensic medical and psychosocial assessments of any child who may have experienced physical or sexual abuse. In addition, WIHD provides service coordination to more than 2,200 families with children up to 3 years of age who have developmental delays, and the institute's Early Childhood Direction Center offers information and referral to families with children ages 3 through 5.

The institute's also offers services that reach communities across the seven-county Hudson Valley region. These include assistive technology programs for school districts and an array of programs for children and families, including the Hudson Valley Regional Center for Autism, applied behavior analysis, emergency preparedness, and transition services for youth entering adulthood. Finally, in conjunction with New York Medical College, WIHD provides training for a range of interdisciplinary professionals through its Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Leadership Education and Developmental Disabilities (LEADD) programs. Its distance learning initiatives reach trainees in the U.S. Virgin Islands and Puerto Rico.

Institute programs are evidence based, and ongoing evaluations are conducted to ensure that high-quality services are provided. WIHD efforts have been featured in a number of publications and conferences.⁴⁷⁷ Further, WIHD has recently implemented an electronic health records system to standardize its data collection and evaluation.

As a UCEDD, WIHD receives funding from the Federal Administration on Developmental Disabilities and the U.S. Bureau of Maternal and Child Health. The New York State Department of Education, Westchester County, and other sources provide additional funding.⁴⁷⁸

C. Women with Disabilities—Effective Programs

1. *Disabled Women’s Health Center, University of Alabama, Spain Rehabilitation Center, Birmingham*

The country’s first gynecological clinic for women with disabilities, the Disabled Women’s Health Center at the University of Alabama’s Spain Rehabilitation Center, in Birmingham, was founded by Dr. Aimee Jackson in 1989 after several women with disabilities patients noted the lack of high-quality, accessible health care. The clinic has provided services to approximately 500 patients who range in age from 17 to 87 and reside in Alabama, Mississippi, Tennessee, and Florida. About 35 to 40 percent of the clinic’s patients are women with spinal cord injuries, and about 20 percent have spina bifida. Some of the women who are served also have other disabilities, including stroke, multiple sclerosis, rheumatism, dwarfism, and scoliosis. The clinic also serves deaf patients.

The clinic operates two afternoons each month, and six appointments are scheduled during each clinic session. Appointments are about 2 hours in length, to allow for thorough examinations and ensure that patients do not have to return for multiple examinations. Examination facilities and equipment are accessible and include height-adjustable examination tables. Women are provided with any assistance they might require to get on and off the examination table, and with positioning to ensure comfort. Clinic staff members understand the impact of specific disabilities on reproductive capacity and other aspects of women health, and they ensure that the individual needs and requirements of each patient are taken into consideration. After examinations staff meet with patients to discuss health care issues and concerns, including sexual function and relationships, and to answer any questions patients may have. Annual screening and diagnostic tests are recommended, including mammograms, if appropriate.

The clinic assesses its effectiveness and quality through annual patient satisfaction surveys that seek feedback from patients on issues such as their level of comfort, satisfaction with accommodations, whether or not they received the information they sought, and whether their questions were answered. The surveys are used to monitor

the clinic's overall operation and to adjust or improve services. Patients are also encouraged to communicate with the clinic staff by phone and email if they have any questions, concerns, or problems.

In addition to providing direct services, clinic staff members respond to questions from other practitioners treating patients with disabilities who are pregnant or have other women's health issues. Staff encourage and assist women with disabilities to be active participants in their own health care. In addition, the center conducts research into health issues for women with disabilities, such as sexual and urological function and menopause. The clinic has recently incorporated a transition program for young adults with disabilities, to help them make the transition from child to adult health services.

The clinic is supported by Medicare, Medicaid, and private health insurance reimbursements and grants for the development of educational materials and research.

2. Breast Health Access for Women with Disabilities, Alta Bates Summit Medical Center, Berkeley, California

Breast Health Access for Women with Disabilities (BHAWD) is the rehabilitation services program of the Alta Bates Summit Medical Center, in Berkeley, California. BHAWD offers an accessible clinic for free breast exams, breast self-examination training, general breast health management education, and mammogram referrals. The program was conceived in 1994, when a Susan G. Komen Breast Cancer Foundation grant funded a town hall meeting to explore the difficulties women with disabilities encounter in accessing breast health services. After the meeting and subsequent conferences, the program was initiated in 1995; clinical services began in 1997. Alta Bates staff, women with disabilities, and breast cancer survivors spearheaded BHAWD in response to a gap in women's health services, including breast health. At the time, women with disabilities were ignored in cancer publications, breast health programs, and most public health research. In fact, staff members reported encounters with many women who had never had a mammogram or clinical breast exam.⁴⁷⁹

The BHAWD staff includes a manager, administrative assistant, education/outreach specialist, and nurse practitioner. BHAWD provides clinic services twice a month and reports approximately 110 patient visits annually. The clinic provides accessible clinical breast exams, breast self-examination education, and mammogram referrals for women 20 years of age and older who are blind or have vision impairments, who are deaf, or who have physical or developmental disabilities.⁴⁸⁰ Various accommodations are provided, including ASL interpreters, height-adjustable and accessible exam tables, and reimbursement for personal assistance services when women bring their own attendants to a clinic visit.

Drawing on its clinical experience, BHAWD developed the country's first protocols for adapted breast screening services and created trainings for physicians and other care providers, such as the Women Be Healthy program for women with cognitive disabilities. In addition, the group has produced several publications and a nationally distributed DVD on mammography training. These activities are in keeping with the organization's long-term goal of empowering women to be their own advocates and encouraging other health care providers to adopt its clinical component.

Within the Alta Bates Summit Medical Center, the group leads trainings for all staff. As a result, schedulers in that medical system now give women with disabilities additional appointment time, and everyone who calls for an appointment is asked if she requires accommodations. The program manager estimates that more than 2,500 members of the California Association of Radiology Technology and at least 700 mammography technicians have attended BHAWD trainings.⁴⁸¹ BHAWD also distributes its materials to community medical centers and assisted living facilities, as well as at conferences.

BHAWD administers client satisfaction surveys for all trainings, media materials, and clinical services. Clinic users and people who participate in trainings report high levels of satisfaction. In data collected from women with disabilities who used the breast health clinic in 2007, 100 percent of consumers rated the care they received during their visit as either "Good" (18 percent) or "Very Good" (82 percent).⁴⁸² All said they were likely to recommend the clinic to others; the majority (77 percent) rated the likelihood as "Very

Good.” They rated BHAWD staff members either “Good” or “Very Good.” Surveys from mammography technicians who attended four of BHAWD’s continuing education conferences in 2006 and 2007 rated the conference as either “Very Good” or “Good,” with 67 percent rating their training as “Very Good” and almost one-third rating their training as “Good.”⁴⁸³

One client stated:

I find all of them to be very approachable . . . ; my speech impairment is never a problem. I always have a good experience with the BHAWD clinic. They’re much more thorough than any other practitioner I’ve had. I like going—I feel that it’s one place where I can get the appropriate attention. They are more receptive, very professional yet very welcoming and warm. They know you by name. It’s very personalized. The care is personal and client-specific. They have wonderful disability awareness. They know the community that they serve.⁴⁸⁴

BHAWD has been supported with grants from a dozen private foundations, and the Alta Bates Summit Medical Center also provides direct support in the form of rent, telephones, and development and graphic design assistance.

3. *Women with Disabilities Center, Rehabilitation Institute of Chicago*

Founded in 1991, the Women with Disabilities Center (WWDC) of the Rehabilitation Institute of Chicago (RIC) was the country’s first community-based health resource center for women with disabilities. WWDC shares staff and space with RIC, which is known nationally for its expertise in physical medicine. The center provides a variety of direct services to women with disabilities and also educates the medical community about the needs of this population. WWDC promotes the safety and dignity of women and girls with disabilities, with the aim of helping them practice self-determination in achieving lifelong physical and emotional wellness.⁴⁸⁵ The center was launched by a group of women with disabilities, including WWDC’s current director, who believed that they were not receiving necessary health care services.

Partnering with Northwestern University's Prentice Hospital, WWDC refers women with disabilities to a team of physicians, nurses, and occupational therapists who are familiar with disabilities and who provide specialized care. This team provides basic reproductive services, including pelvic exams, mammograms, and family planning, which are frequently unavailable for women with disabilities from traditional health care providers.

WWDC recognizes that health care for women with disabilities involves more than clinical services; other direct services are also sometimes needed. For example, WWDC offers free, confidential domestic violence support and information through RIC's Domestic Violence Services Program. The Mentor Program pairs teenage girls and adult women with disabilities and funds regular activities. WWDC also offers a weekly support group that allows women with disabilities to discuss personal and health issues. This group encourages relationships that combat the danger of social isolation and fosters ongoing friendships.

WWDC's outreach component educates members of the area health care community about disability-specific issues and needs. This prong of WWDC's program also partners with Northwestern University to improve the accessibility of mammography providers. In addition, WWDC organizes two free educational seminars each year for health care providers and others concerned with health care for people with disabilities; produces educational publications that are distributed to the broader medical community; and provides technical assistance, information, and advice on treatment and care for individuals with disabilities to diverse health care providers regionally and nationally.

In 2007, 384 women with disabilities used WWDC's clinical services. The center responded to 1,560 general requests for information, and the domestic violence program responded to 214 calls for assistance. Within the domestic violence program, 36 women who are survivors of domestic violence volunteered with the program and helped provide 19 trainings for an estimated 620 shelter workers. Thirty young women and teens participated in the Mentor Program as either mentors or mentees, and the

support group, with 10 members, met 100 times. WWDC staff made 830 educational and advocacy presentations to service providers, clinicians, and students, and the center's newsletter reached roughly 8,000 individuals and organizations.⁴⁸⁶

Today, the center is supported primarily by grants from the State of Illinois, which conducts quality monitoring; RIC provides in-kind support. WWDC conducts general satisfaction surveys for most of its programs. Pre- and postsurveys are conducted for the Mentor Program.⁴⁸⁷

4. *Center for Women with Disabilities, Magee-Women's Hospital, University of Pittsburgh Medical Center*

The Center for Women with Disabilities, Magee-Women's Hospital, at the University of Pittsburgh Medical Center (UPMC), offers comprehensive, patient-centered care that integrates accessibility and accommodation for women with physical disabilities. The center provides preventive medical services for women with disabilities, and also refers patients to other culturally competent physicians who operate in accessible facilities and can provide appropriate accommodations. The center also offers educational programs for youth and their parents and caretakers, and works with the UPMC's other centers to develop and improve system-wide accessibility and services. Founded in December 2001, the program was pioneered by a group of 15 to 20 women with disabilities who recognized their community's need for accessible, comprehensive, and respectful health care for women with disabilities.

Staffed by an obstetrician/gynecologist and an internist, the center provides clinical care to women with disabilities two afternoons each week. The clinic conducts annual physical exams, Pap tests, and mammograms, as well as ultrasound tests, as needed. Four appointments are scheduled each afternoon when the clinic is open. The schedule allows ample time for staff to assist women to undress and dress, get onto and off of examination tables, and get positioned. The center uses accessible equipment, including wheelchair-accessible weight scales, height-adjustable and otherwise universally accessible exam tables, patient lifts, and padded hydraulic stirrups for comfort.⁴⁸⁸ The clinic provides services to 250 to 300 women with physical disabilities

each year. Patients range in age from 18 to more than 90 years, reside in diverse geographic locations, and have a variety of disabilities, including arthritis and osteoporosis. About 70 new patients are seen each year, according to data from 2007.⁴⁸⁹

The center's staff—nominated in 2008 for an “outstanding UPMC staff” award—have remained consistent over time, which is both a function and an outcome of high morale. Training and limited staff turnover ensure high-quality service. According to the center's director of Ambulatory/Outpatient care, one of the clinicians noted that the center “never makes a patient feel like she is a burden.” The staff tries to make patients feel like “they have all the time in the world” for them.⁴⁹⁰

In addition to health care, the center offers educational programs about sexuality and disability, including a program on socialization for teens with disabilities: Social You, Sexual You. The center also works with the University of Pittsburgh's hospital-wide Disability Resource Center and the university-wide Center for Assistive Technology. These groups aim to improve overall accessibility, expand clinical services for people with disabilities, and train staff to work with this population.

The center relies on a continuous evaluation process to ensure the best quality of service. Patients and caretakers receive evaluation forms after each appointment. These evaluations include questions about the ease of making appointments, personal comfort, respect and dignity, staff communication, the clarity of take-home health instructions, and general satisfaction. The director reports that most evaluations are very positive.⁴⁹¹ Additional evaluation comes from a small committee of the women who founded the center, who meet bimonthly to discuss general disability topics, and to identify and address any issues and problems.

The center is funded primarily by the State of Pennsylvania, public and private insurers, and grants. Because insurance reimbursements often fall short of the cost of health for people with disabilities, grants and state funds are essential for sustaining the program.

5. *Health Promotion Campaign for Women with Physical Limitations, Center for Research on Women with Disabilities, Baylor College of Medicine, Houston*

Between 2005 and 2007, members of the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine in Houston, Texas, initiated the Health Promotion Campaign for Women with Physical Limitations. Funded by a grant from the Houston Endowment, this program was an outreach effort directed at women with physical disabilities, care providers, and friends and family members. In an effort to inform and “empower women with physical disabilities to improve their health and wellness,” CROWD staff and faculty developed educational materials and a website, and attended health fairs in the Houston region.⁴⁹² CROWD’s efforts in the area of health promotion grew out of a recognition that disability adds another dimension to the problem of health disparities. People with disabilities face a number of disparities compared with the general population, including overall poor quality care, poor general health information, and low rates of health insurance.⁴⁹³ CROWD saw that such challenges are further compounded for women with disabilities, because their general reproductive health needs are often ignored by health care providers.

Through its Health Promotion Campaign, CROWD engaged these challenges with a series of health promotion materials entitled “Removing Health Disparities for Women with Physical Disabilities.” Available in both Spanish and English, the promotion materials include topical newsletters (e.g., “Depression” and “Physical Activities”), motivational and inspirational posters, press releases, and other relevant data. The current CROWD Web site was designed to serve as a domestic and international clearinghouse for these materials, which can be downloaded and reproduced at no cost. CROWD staff and faculty distributed the promotion materials to 13 health fairs in the Houston area. CROWD staff estimate that they reached 14,913 women with physical disabilities, care providers, and others using this tactic.⁴⁹⁴

While the initial funding for the project has ended, project staff think that the impact of CROWD’s Health Promotion Campaign is ongoing. The Web site continues to receive roughly 7,000 visits each month, and it is being maintained and updated.⁴⁹⁵ The center

uses the promotion materials to supplement other programs. For example, revised versions of the original materials have been used to train volunteers in the Department of Health and Human Services (HHS) projects and in Christopher Reeve Foundation workshops for women with paralysis. One person who regularly uses these materials to facilitate workshops said:

I thought it was great information in a format easy to understand and follow for the participants. The material was grouped together very well. . . . It told the women that every woman is the expert on her own body. . . . It is about acknowledging your disability, honoring it, and being an advocate for yourself.⁴⁹⁶

Finally, the campaign has helped CROWD staff and faculty develop a better understanding of the health care service gaps that women with disabilities face. As a result, they are now working toward the creation of a wellness counseling center that would use the information on the Web site in workshops, counseling, and new Internet applications.

D. People Who Are Blind or Have Vision Impairments—Effective Programs

1. *Blindness Support Services, Inc., Riverside, California*

Blindness Support Services (BSS), in Riverside, California, was established in 1992 to provide innovative approaches to assist residents who are blind or have vision impairments in Riverside, San Bernardino, Orange, San Diego, and Los Angeles counties in southern California to achieve independence and self-reliance.⁴⁹⁷ BSS provides services to approximately 600 clients a year in three age ranges: children (birth–5), adults (18–55), and seniors (55+).⁴⁹⁸

BSS creates an Individual Service Plan (ISP) for each client to maximize his or her ability to take advantage of the agency's services. Specifically, the agency offers vision rehabilitation, which includes orientation and mobility, independent living skills, and

acquisition and use of adaptive technology. BSS also provides talking watches, clocks, scales, and other devices that help people live independently.

In addition to vision rehabilitation, BSS provides various health care services. The Health and Wellness Plan was designed to address the problems that arise from the lack of healthy eating habits among individuals with blindness and vision impairments. BSS offers exercise plans tailored to the needs of the community and presents lectures on healthy eating. BSS's partnership with Riverside County Regional Medical Center provides a family practice resident with the opportunity to work with BSS to learn how to address the various needs of patients who have vision impairments.

BSS also specializes in working with child care centers to include children who are blind or have vision impairments. The overall goal of this initiative is to ensure that each child care center or facility possesses the capacity to serve children with vision impairments.⁴⁹⁹

BSS receives funding through public and private agencies, and city and county governments.

2. LightHouse for the Blind and Visually Impaired, San Francisco

The LightHouse for the Blind and Visually Impaired, San Francisco, is the largest agency providing direct service, advocacy, and information to the blind and visually impaired community of northern California.⁵⁰⁰ Since 1902, the LightHouse has offered solutions to living with vision loss.

Through the LightHouse Client Services Program, individuals who are blind or have vision impairments receive orientation to LightHouse services, assessment of their rehabilitation needs, enrollment as a client, support services, and case management. Social workers and low vision specialists staff the program in San Francisco and in Marin and Humboldt/Del Norte Counties.

The LightHouse provides a wide variety of services, including vision rehabilitation—a process whereby people who have experienced vision loss learn new ways to approach tasks. Rehabilitation may include orientation and mobility, adaptive technology, and independent living. The agency’s comprehensive intake process ensures that clients people will not only receive appropriate services from the LightHouse, but will be referred to any additional services in the community that might be beneficial.

The Vision Loss Resource Center (VLRC) provides information to individuals experiencing vision loss, their families and friends, and professionals in the field. Among the resources available through VLRC is an adaptive technology and health seminar, which provides an audio transcript and information handouts of presentations on adaptive equipment, including accessible tools for glucose monitoring, weight management, healthy food preparation, and exercise equipment that aids in maintaining health.

The LightHouse’s Low Vision Clinic operates in collaboration with the University of California, Berkeley School of Optometry, which offers low vision evaluations. The clinic assists clients by recommending various strategies and techniques that will maximize residual functional vision. The clinic prescribes appropriate adaptive devices that will help them to regain functional independent living skills.⁵⁰¹

After they have received services, clients fill out a customer satisfaction survey to determine outcomes and areas for improvement. In 2007, 209 clients identified specific goals and participated in programs and services that assisted them to reach those goals. Over 90 percent of them reached their vision rehabilitation goals, according to customer satisfaction surveys.⁵⁰²

The LightHouse supports programs through individual and corporate donations, including bequests, LightHouse Enterprises, return on investments, and Government grants and contracts.

E. People Who Are Deaf or Hard of Hearing—Effective Programs

1. Deaf Access Program, Mt. Sinai Hospital, Sinai Health Systems, Chicago

The Deaf Access Program (DAP) of Mt. Sinai Hospital, in Chicago, offers a comprehensive program of medical and mental health services for children and adults who are deaf. DAP is sensitive to both the language and culture of the Deaf community and is strengthened by a program manager who is deaf, three physicians who are fluent in American Sign Language (ASL), three ASL staff interpreters, and three mental health therapists who are also fluent in ASL. This program meets a specific and critical need within the Chicago Deaf community, because people who are deaf have historically found it difficult to obtain appropriate health and mental health care because of substantial communication barriers.⁵⁰³

An estimated 50,000 people who are deaf or hard of hearing live in the metropolitan Chicago area. DAP currently serves approximately 1,300 patients and provides full communication access to medical, mental health, and support services. In addition to interpreting for patients in clinical settings, ASL interpreters travel to affiliated clinics in the Chicago area and provide interpreter services. DAP also coordinates the deployment of outside interpreters, as needed, to ensure that deaf patients have access to effective and appropriate communication during health care visits.⁵⁰⁴

Sinai offers a wide range of psychiatric and behavioral health services for adults and children who are deaf or hard of hearing. These services include diagnostic interviews, psychiatric evaluations, psychological testing, crisis intervention, individual and family therapy, parenting support and intervention services, and consultations. DAP's psychiatry and behavioral health staff, including two clinical therapists and a psychologist, are fluent in ASL and well versed in Deaf culture. Sinai Health Systems pay for the cost of Sinai's staff ASL interpreters.

DAP is using innovative techniques to address problem areas in the field. After many certified interpreters left hospitals to join Video Relay Service interpreter call centers, the Deaf Access Program began experimenting with the use of video remote

interpreters (VRIs) to provide interpreting services to patients in after-hours emergency situations. DAP staff think that patient wait time for interpreter services will be cut substantially and satisfaction will improve with the use of VRIs. Ultimately, DAP hopes to share its interpreters with hospitals throughout the Chicago area, using the VRI service.⁵⁰⁵

Sinai was the first hospital in the United States to offer a videophone booth in the lobby for deaf or hard-of-hearing patients who use ASL. The videophone booths enable communication between these patients and the hearing community by connecting the caller to a nationwide network of live ASL interpreters who facilitate conversations with hearing individuals.

The DAP has undertaken significant research in collaboration with Advocate Illinois Masonic Medical Center. With a grant from the Michael Reese Health Trust, DAP undertook a face-to-face survey of the Deaf community on issues such as doctor visits, communication problems, barriers to access, and physician and staff knowledge of the Deaf community.⁵⁰⁶

2. Deaf and Hard-of-Hearing Program, Advocate Illinois Masonic Medical Center, Chicago

The Deaf and Hard-of-Hearing Program at Advocate Illinois Masonic Medical Center, in Chicago, began more than 25 years ago. The program provides mental health services and prevention education, and reaches more than 500 people who are deaf in Chicago's six-county region and beyond. During 2007, approximately 100 patients received mental health services each month; the annual total of contacts was 3,400.

Some of these contacts were made through telepsychiatry services using interactive videoconferencing, which allows deaf patients to take advantage of certain specialized services that are otherwise inaccessible. In 2007, video technology linked the program's culturally and linguistically competent providers with patients from geographically dispersed points of access in a total of 500 telepsychiatry encounters.

In addition to mental health services, the program engages in prevention education that is understandable and usable by people who are deaf. Since most people who are deaf are not fluent in English, they may find it difficult to understand certain written materials and spoken presentations. Signed videotape or digitalized information is an effective alternative to convey health promotion information. Therefore, the program team is developing a library of video pamphlets featuring deaf actors, who present signed narration as well as vignettes and graphics, and apply a storytelling approach that reflects the information-sharing style common in ASL. These videos have been incorporated into various education initiatives that are available on the program's Web site.⁵⁰⁷ The program features health education pamphlets presented in streaming video on a variety of topics, including HIV/AIDS, sexually transmitted diseases, breast health, and diabetes. Also available are interactive screenings for depression, anxiety, and risk of heart attack, as well as programs for smoking cessation and depression management.

3. *Metropolitan Hospital Consortium, Communication Services for the Deaf of Minnesota, Minneapolis*

The Metropolitan Hospital Consortium, one of the Communication Services for the Deaf of Minnesota, in Minneapolis, was established in November 2005 to provide the 26 member health facilities located in the greater Twin Cities area ASL interpreter services in emergency situations.⁵⁰⁸

The consortium was created to provide interpreter services for members of the Deaf community who have traditionally faced significant problems gaining access to health care when unplanned situations arise and prescheduling of an interpreter has not been possible. Interpreters must meet certain qualification requirements.⁵⁰⁹ Under the consortium's operational contract, ASL interpreters are paid to be listed on a reserved 24/7 on-call schedule, allowing them to respond immediately when a need arises at a member facility. The consortium operates three shifts per day with three interpreters on call for each shift. The consortium guarantees that an interpreter will arrive at a facility within 2 hours; 95 percent of the time, the consortium is able to send an interpreter within 1 hour.⁵¹⁰

The consortium monitors and conducts quality improvement of its services by maintaining daily printouts containing all call information to ensure adequate arrival times. Consortium representatives meet monthly to discuss any issues that may have arisen and to identify methods for improvement. Monthly meetings include a joint session with members of the Deaf or hard-of-hearing community to ensure that their feedback is incorporated into the evaluation and quality improvement process. Members of the interpreter pool also meet monthly, to discuss pertinent issues and identify any solutions. This communication process allows all stakeholders to have an ongoing voice in the system. As a result, hospital representatives are less concerned about the potential for litigation if a patient who is deaf comes to the emergency room for service; members of the Deaf community know they will have an interpreter in an emergency; and interpreters have a manageable workload and receive fair compensation.⁵¹¹

The consortium's monthly operating costs are about \$22,500. Each of the 26 members pays \$433 a month to ensure that emergency interpreting services will be available. The remaining cost is divided proportionately among the members on the basis of the actual services they use in a given month.⁵¹²

4. *CATIE Center, the College of St. Catherine Interpreter Education Program, St. Paul/Minneapolis*

The Collaboration for the Advancement of Teaching Interpreter Excellence, known as the CATIE Center, is one of six centers working in partnership as the National Consortium of Interpreter Education Centers (NCIEC).⁵¹³ Created in 2005, the CATIE Center serves a 10-state region and has a primary focus of identifying effective practices in interpreting in the health care field.⁵¹⁴

The center's goal is to significantly increase the number of qualified interpreters in the field, while providing resources and opportunities that are accessible to interpreters of all backgrounds and experiences. Program members plan to create an online curriculum that can be used by both interpreter education programs and individuals who want to update their skills. The CATIE Center and NCIEC have developed a Web site,

www.medicalinterpreting.org, that provides a variety of useful resources, including CD-ROMs, DVDs, and links to relevant information.⁵¹⁵

The CATIE Center has helped define some boundaries for interpreters in the health care setting, and these boundaries have to illuminate the role that interpreters can and should play in these settings. The center's work has revealed a lack of interpreter education for Spanish-speakers.⁵¹⁶ Additional research has revealed that interpreters often lack a common medical vocabulary and medical knowledge, which can hamper their ability to function adequately in medical situations.⁵¹⁷

The CATIE Center and NCIEC are funded through 2010 by a Department of Education Rehabilitation Services Administration grant.

5. *Deaf Wellness Center, University of Rochester Medical Center, Rochester, New York*

The Deaf Wellness Center (DWC) is a program of the Department of Psychiatry at the University of Rochester Medical Center, Rochester, New York. The DWC has five full-time staff members who are fluent in ASL and a number of trainees who engage in clinical services, teaching, and research activities that pertain to mental health, health care, sign language interpreting, and other topics that affect the lives of people who are deaf or hard of hearing.⁵¹⁸ The center seeks to improve the quality of life of persons for whom hearing loss is a significant aspect of their identity or experience in the world.⁵¹⁹

In the area of clinical services, DWC physicians perform individual and group psychiatric assessments. The center conducts 2,000 to 3,000 units of service annually; approximately 100 patients are actively participating in care at a given time. The DWC provides evaluation and psychotherapy services to individuals of any age, couples, and families. Several psychotherapy groups conducted by the DWC are composed entirely of people who are deaf, and meetings are conducted by therapists who are fluent in ASL. The DWC also conducts psychiatric evaluations and provides consultation and forensic evaluation services to courts and Government on topics related to deafness, mental health, and health care.

The DWC seeks to play a leading role in advancing scholarship in the identification, manifestations, and treatment of psychological and medical disorders that affect people who are deaf or hard of hearing. The center has undertaken a variety of federally funded research projects, including “Toward Equity,” a multiproject mental health research program funded by the National Institute on Disability and Rehabilitation Research; “Optimization and Dissemination of Proven Reforms in Interpreter Education,” sponsored by the National Center for Deaf Health Research; and “Strong Connections,” a videoconference-based sign language interpreter service for remote health care settings.

The DWC’s teaching program covers general topics relating to deafness and mental health. The Program for Deaf Trainees recruits medical interns who are deaf to work with both deaf and hearing patients (in partnership with sign language interpreters as necessary) at Strong Behavioral Health and Rochester Psychiatric Center. By the time they graduate, these students acquired skills and experience in providing mental health services to deaf and hearing patients.

6. *National Technical Institute for the Deaf, Rochester Institute of Technology, Rochester, New York*

The National Technical Institute for the Deaf (NTID) in Rochester, New York, is one of eight colleges of the Rochester Institute of Technology. The mission of NTID is to provide deaf students with outstanding technical training. The student body consists of 1,350 undergraduate students who are deaf or hard of hearing, approximately 130 hearing students who are taking ASL courses, and approximately 110 students enrolled in master’s degree programs preparing them to be teachers of children and adults who are deaf.⁵²⁰

NTID provides a variety of medical and counseling services for students. Students have access to doctors and nurses who are familiar with basic ASL and to a full-time interpreter. NTIS offers mental health counseling, and three ASL interpreters work with staff psychologists. The school offers a monthly eye clinic, a hearing aid shop, and on-campus audiology and hearing aid services.⁵²¹ Mental health services are available 24

hours a day. In 2007, 148 deaf or hard-of-hearing students were seen for these services, with responses to 57 emergency calls.⁵²²

Additionally, NTID offers services to the greater Rochester community. A substance and alcohol intervention program offers support groups and communicates with the judicial system on behalf of people who are deaf who face legal, medical, or mental health problems.

The International Center for Hearing & Speech Research (ICHSR) is a collaboration of NTID and other universities that focuses on age-related hearing loss, with the ultimate goal of preventing and reversing hearing loss at any age.⁵²³ The center received its third 5-year competitive program project grant from the National Institute on Aging (NIA) of the National Institutes of Health (NIH).

F. Children with Disabilities—A Practice with Potential

1. *State Buy-In: The Family Opportunity Act*

The Family Opportunity Act (FOA) allows families with a child who meets the Supplemental Security Income (SSI) disability criteria and have an income under 300 percent of the Federal poverty level (FPL) to buy in to Medicaid for that child. Since the enactment of FOA in 2006, Illinois, Iowa, Louisiana, North Dakota, Ohio, Pennsylvania, and Vermont have established buy-in programs.

This program serves as a national model for innovative policies that can contribute to reducing the number of children with disabilities who still receive inadequate health care.

G. Professional Education—A Practice with Potential

1. *Disability Standardized Patient Exercise for Medical Students, Tufts University Medical School, Medford, Massachusetts*

The Tufts University Medical School: Disability Standardized Patient Exercise for Medical Students, begun in 2001 with a grant from the Massachusetts State Developmental

Disabilities Council, targets third- and fourth-year medical students. The program is now required, and about 170 students participate. The goal of the program is to introduce an individual with a mobility disability who is seeking care for a health problem that is not disability-related. For example, a paid patient-educator who is a wheelchair user discusses her health concern, shoulder pain. She reports living an active life with family and friends. The goals of the exercise are to help students develop a comfort level working with a patient with a disability, dispel stereotypes about disability, and encourage students to learn how to differentiate between disability-related and other medical problems. The program is fully embedded in the medical school.

H. Conclusion and Recommendations

On examining the programs presented in this chapter, it becomes evident that the people with disabilities do not need extraordinary health care services or settings. In fact, these programs embody basic characteristics that all people hope will be available to them when they need health care services. These include health care providers who are familiar with the specific issues and needs of the individuals they care for, adequate time for thorough examinations and discussions between physician and patient, access to appropriate equipment and support services, and provider capacity to coordinate care and consult with specialty services when they are needed.

Advancing these principles presents many of the same challenges health policy advocates have encountered in broader national health care reform discussions. The universally important elements of exemplary health care—defined by IOM as *safe, effective, patient-centered, timely, efficient, and equitable*—should be available for everyone, including people with disabilities.

In serving people with disabilities, the basic challenge is to find ways to achieve these universal elements within the current fragmented system of health care delivery. As a practical matter, individuals within the disability population require specific accommodations in health care settings. However, the accommodations are not necessarily defined by primary diagnosis. For example, children with developmental

disabilities may also have mobility impairments and use wheelchairs, and people who are blind may also have arthritis or fibromyalgia. To avoid oversimplification by compartmentalizing the care needs of people according to diagnostic category, some health policy researchers argue that identifying universal crosscutting areas of quality of care and provider competency should be the starting point. As one leading health researcher put it, “At the core, the global dimensions of health care, if not patients’ particular experiences, are universal.”⁵²⁴

The health programs identified in this report provide high-quality services for the relatively small number of people who have access to them. The majority of people with disabilities, however, receive primary health care from providers who are not necessarily well equipped to provide culturally competent care. The appeal of developing and disseminating crosscutting guidelines is that they hold some promise for improving care not only for greater numbers of people with disabilities, who may never have access to the kind of specialized care featured in this chapter, but for everyone. This strategy builds on the experiences of these programs to bring information about the elements of culturally competent care to a wider practitioner audience.

Federal agencies, including AHRQ, are well situated to lead an effort to develop such guidelines in concert with knowledgeable health policy researchers, people with disabilities, and health care providers. Other agencies within HHS, such as CDC, could provide leadership on developing methods to advertise, promote, and widely disseminate the guidelines to the public health and health care community. Resources should be identified that will pay for, or help defray costs of, certain services and equipment (for example, ASL interpreters and height-adjustable examination tables), and strategies should be identified for resolving key issues such as additional provider payment for extra time spent caring for patients with disabilities.

In addition to the guidelines project, certain discrete, well-developed components of some of the reported programs lend themselves to being replicated and disseminated. Federal agencies involved in health care for people with disabilities should follow the lead of these programs and disseminate information their efficacy.

RECOMMENDATION:

Federal agencies improving access to appropriate and effective health care for people with disabilities—including the Agency for Healthcare Research and Quality (AHRQ), the National Institute on Disability and Rehabilitation Research (NIDRR), the Administration for Children and Families (ACF), and the Centers for Disease Control and Prevention (CDC)—should establish an interagency collaboration to produce guidelines that identify universal and crosscutting elements of quality measures that will drive delivery of health care in general and also for diverse people with disabilities. This endeavor should be undertaken in collaboration with agency experts, other disability and health policy researchers, leading disability and health practitioners (e.g., physicians who specialize in caring for women with disabilities, people who are deaf or hard of hearing, people with intellectual and developmental disabilities, as well as vision rehabilitation experts), and people with disabilities. The guidelines should be disseminated widely and promoted in medical education programs and among practitioners.

RECOMMENDATION:

Federal agencies—including the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and the Department of Health and Human Services (HHS) Office of Disability—should collect and disseminate information about models for improving access to care for people with disabilities.

RECOMMENDATION:

The Centers for Medicare & Medicaid Services (CMS) should identify and support methods for providing coordinated primary health care to people with certain disabilities or multiple disabilities (e.g., mobility and developmental disabilities) in home or community settings rather than the offices of health care providers, in order to resolve some of the most pressing accessibility, accommodation, and transportation problems identified as barriers to care. The Minnesota UCARE Complete program could serve as a model to guide these deliberations.

RECOMMENDATION:

Federal agencies concerned with health care quality for people with disabilities—including the Agency for Healthcare Research and Quality (AHRQ), the National Institute on Disability and Rehabilitation Research (NIDRR), and the Access Board—should develop a best practices guide to help providers (a) recognize that universal design goes beyond Americans with Disabilities Act (ADA) requirements and (b) understand methods of implementing and evaluating universal design principles in health care settings. This guide should also profile organizations that have implemented best practices, including their methods and outcomes.

RECOMMENDATION:

The Registry of Interpreters for the Deaf should consider creating a specialist certification for medical and mental health interpreting. Such a certification should be developed in collaboration with the organizations that are currently providing medical training for interpreters, organizations of people who are deaf, and individuals who are deaf or hard of hearing.

RECOMMENDATION:

Radiology technician training and certification programs should adopt key elements of the training program that the Breast Health Access for Women with Disabilities (BHAWD) has created and implemented for helping radiology technicians learn techniques for performing mammograms on women with diverse disabilities. All training programs should incorporate these key elements into training curriculums and licensing examinations.

CHAPTER 8. Findings and Recommendations

A. Findings Responding to the Research Questions

1. *What are the key Federal efforts that promote health care for Americans with disabilities, including wellness and prevention services? How effective are these efforts?*

The extensive network of Federal programs that provide health care and prevention services to people with disabilities—including Medicare, Medicaid, the State Children’s Health Insurance Program (SCHIP), and Title V of the Social Security Act—serve as a critically important safety net. Medicaid serves 8 million people with disabilities who lack any other source of care and 6 million low-income Medicare beneficiaries who are elderly and have disabilities. The program has become the “largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities.”⁵²⁵ SCHIP provides critical assistance to eligible families that include children with disabilities, yet it is difficult to say how many children with disabilities are covered under SCHIP because there is no requirement that state programs collect or maintain such information. Title V of the Social Security Act establishes federally funded public health programs intended to provide comprehensive services for mothers and children. Title V is the only Federal program that consistently provides all four possible levels of services: (1) direct health care; (2) enabling services such as transportation, translation, and health education; (3) preventive services such as newborn screening, immunization, and oral health; and (4) infrastructure-building services such as needs assessment, policy development, and information systems support.⁵²⁶ States must document how many children have special health needs in the state and how services will be received, along with infant mortality and child and maternal health statistics according to such categories as county, race, and ethnic group.⁵²⁷

The Developmental Disabilities Assistance and Bill of Rights Act⁵²⁸ (DD Act) established the University Centers for Excellence in Developmental Disabilities (UCEDDs). The UCEDDs have a broad research mandate to conduct basic or applied research,

evaluation, or public policy analyses in “areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.”⁵²⁹ The UCEDDs also provide coordinated and multidisciplinary direct health care. In 2006, more than 524,000 people in the community gained knowledge and skills related to the health care needs of individuals with disabilities, and more than 665,000 people with disabilities benefited from health-related activities supported by UCEDDs.⁵³⁰

The UCEDDs serve as models because they have been consistently funded over a period of more than 4 decades and thoughtfully embedded within an entire network of grant programs. Accessible health care is recognized as one of the key elements through which people with developmental disabilities will achieve independence, inclusion, and community integration.

Health care insurance availability, affordability, and coverage for important benefits—including medications, long-term care, durable medical equipment, mental health, rehabilitative and specialty care, and care coordination—are key issues for people with disabilities. Access to appropriate, affordable care and required equipment, medications, and supports affects the health status of people with disabilities, as well as their participation in disease prevention and health promotion programs. Both Medicare and Medicaid beneficiaries have reported difficulties obtaining the care and services they require. With higher copayments, Medicare beneficiaries with disabilities report significant cost-related problems, including forgoing needed equipment, postponing care, and paying for long-term care. Further, Medicare imposes a 2-year waiting period for coverage for individuals who are under age 65 who become eligible for the program when they receive Social Security Disability Insurance (SSDI). While cost-sharing is lower under Medicaid, people with disabilities who are covered by the program report, among a number of problems, difficulties finding physicians who will accept Medicaid payments, and this compromise access to care for people who have low incomes. Seventy-eight percent of Medicaid beneficiaries with disabilities qualify for Medicaid because they meet the income and asset limitations required to be eligible for Supplemental Security Income (SSI).⁵³¹ For many of these low-income beneficiaries,

however, essential health care services—including dental and vision care, medical supplies, and durable medical equipment—may be out of reach financially, even with low cost-sharing under Medicaid.

2. *Are accurate health data available concerning Americans with disabilities?*

Although no dataset currently meets all information needs, several surveys have either the current ability or the strong potential to provide many of the data necessary to assess health care utilization and the treatment experience. The sponsoring agencies have used the data for some evaluation of health care utilization by people with disabilities, but they have not produced analyses to the fullest extent possible. Some progress is apparent in the development and use of a consistent indicator of disability, and a number of recent reports on health include disability as a population variable. Public acknowledgement of, and attention to, the importance of collecting data about the health care experiences of people with disabilities is growing, and some promising research is under way to develop survey questions that will gather information not previously measured about these experiences. Moreover, some surveys are being developed that will collect data on people with disabilities, who were previously excluded.

Important challenges remain, however, that currently limit the availability of accurate health data concerning Americans with disabilities. For example, questions about the health care delivery experience should be moved from the optional supplemental parts of surveys to the regularly asked core in order to ensure that this information is collected. The number of surveys that do not exclude people in group quarters or without telephones from samples should be expanded, and better survey indicators for people with cognitive, intellectual, and psychiatric disabilities should be developed. Methods should be designed to ensure that sponsoring agency reports include disability as a population variable in data analysis and the reporting of survey findings. Also, a means should be developed for collecting information about health care providers with respect to physical, programmatic, and communication access to health care, including information from the providers themselves.

3. *What are the access barriers to health care for people with disabilities, including barriers to wellness and prevention services?*

Many people with disabilities have some type of health insurance, and publicly financed health insurance provides an important safety net. However, a significant number of individuals with chronic health conditions remain uninsured. Lack of health insurance coverage is one of the most critical barriers to health care for people with disabilities. During the period 2001–2005, about 19 percent of adults with a basic actions difficulty and 17 percent of those with a complex activity limitation reported being uninsured. Twenty-eight percent of people with emotional disabilities reported being uninsured, the highest rate among people with disabilities, followed by 20 percent of people who are blind or have vision impairments or who are deaf or hard of hearing.⁵³² One notable administrative barrier to coverage is Medicare’s 2-year waiting period for coverage for individuals who are under age 65 and become eligible for the program when they receive SSDI. Nearly half of all uninsured nonelderly adults report having a chronic condition, and of these, almost half forgo medical care or prescription drugs because of the cost.⁵³³

Among barriers that affect the quality of care that people with disabilities receive, lack of disability competency and awareness among health care providers ranks high among focus group participants and in other participatory research.⁵³⁴ Without appropriate training and awareness, health care providers hold incorrect assumptions and stereotypes about people with various disabilities, which can affect every aspect of care and result in inadequate and inappropriate care. Research has revealed, for example, that some providers incorrectly assume that people with disabilities do not have a good quality of life; that people with developmental disabilities do not feel pain and, therefore, do not require anesthesia; that people who are deaf have cognitive deficits because they may not be fluent in standard English; and that women with disabilities do not require reproductive counseling and care because they are not sexually active. Beyond undermining quality of care, such humiliating and frustrating encounters with health care providers can damage patient-provider trust and deter people with disabilities from seeking care.

People with disabilities also encounter structural barriers to health care, including inadequate transportation, lack of architectural accessibility in the facilities and offices of health care providers, and lack of accessible exam and diagnostic equipment. For many people with mobility disabilities, access to examination and diagnostic equipment such as mammogram machines can be difficult or impossible if the equipment is not height-adjustable. Medical office staff members often are not trained to provide lifting assistance and are unwilling to lift patients onto inaccessible examination tables. Some patients do not wish to be lifted, out of fear that they will be dropped or injured.

Communication barriers, including a lack of sign language interpreters for people who are deaf or significantly hard of hearing are frequently cited as problems that prevent access to care or reduce the quality of care. People who are blind or have vision impairments report that medical providers sometimes do not speak to them directly and do not provide prescription information, return-appointment dates, or other health care instructions in formats that are accessible; nor do they offer to read the information. Diabetes care training can be difficult to obtain for people who are blind or have vision disabilities, because some diabetes care professionals are not aware of blood glucose testing and other equipment that provides an audio output of readings. People with developmental disabilities also report difficulty communicating with some health care providers: during standard office visits, too little time may be available for discussion of complex health issues or the appropriate presentation of information so that people with developmental disabilities can understand what is being said, participate in their health care decisions, and become informed about wellness and prevention.

In general, research is limited that identifies barriers to participation in wellness and prevention services by people with disabilities. However, factors such as having both health insurance and a regular source of health care predicted whether or not women with disabilities received all types of clinical preventive services.⁵³⁵ Similarly, in a study comparing prevention procedure rates of Medicare beneficiaries with disabilities, level of disability played an important role: Women with the most significant disabilities reported fewer Pap tests and mammograms compared with those who did not have disabilities.

Research suggests that measurement of weight, electrocardiograms, and inquiries about smoking habits occurred less frequently for women with disabilities than for women of similar age without disabilities. Although it is not clear why someone with a more significant disability might participate less in wellness and prevention services and programs, factors such as inadequate transportation, inaccessible medical facilities and diagnostic equipment, inaccessible exercise equipment, and lack of disability cultural competency on the part of health care providers likely play a part.

Studies suggest that people who are deaf or hard of hearing experience specific barriers to participating in prevention programs, may have limited access to appropriate and accessible information about health promotion activities, and may not understand why such programs and activities are important. In particular, adults who are deaf tend to have less health literacy compared with the hearing population. Focus group research has shown that women who are deaf have unique linguistic and cultural issues that affect their health and their health care experiences. Participants were unaware of the need to assess health risks through prevention and diagnostic screening procedures, including those for cardiovascular disease. Some participants also lacked knowledge and information about screening and diagnostic procedures for breast and cervical cancer, as well as the purpose and importance of treatments such as surgery.⁵³⁶ However, when people who are deaf or hard of hearing have access to deaf-friendly medical organizations (i.e., organizations in which methods for effective communication such as ASL interpreters and assistive listening devices are readily available and providers understand cultural aspects of deafness), screening rates for colorectal, cervical, and breast cancer were similar to rates for the general population.⁵³⁷

Although people who are blind or have vision impairments experience overweight and obesity at a higher rate than the general population, most health maintenance programs emphasizing weight management and fitness are not structured to accommodate them. Likewise, diabetes education and care management do not always reach people who have vision impairments and diabetes. People who have vision impairments are less

physically active and are generally in poorer physical condition than people who do not have vision impairments⁵³⁸ Various factors contribute to inactivity and overweight among people who have vision impairments, including difficulties obtaining and preparing fresh foods, lack of transportation, inaccessible exercise equipment, and the inaccessibility of the pedestrian environment.⁵³⁹ However, little effort has been made to promote health and weight management for people who are blind or have vision impairments. The lack of tailored programs and accessible exercise equipment prevents people who have vision impairments from participating in exercise programs that could lead to weight loss.⁵⁴⁰ People who are blind or have vision impairments encounter numerous problems using standard exercise equipment, including inaccessible display screens, tactile buttons, and control labels. Recreation facilities are also often inaccessible.

Adults with intellectual and developmental disabilities are more likely to lead sedentary lives, and more often report being in fair or poor health than adults without disabilities.⁵⁴¹ However, research is limited on issues related to health promotion for people with intellectual and developmental disabilities.⁵⁴² In one national study, family practice and internal medicine physicians indicated that they conduct fewer health promotion activities for patients with physical disabilities than for patients who do not have disabilities.⁵⁴³ It is therefore particularly difficult for people with intellectual and developmental disabilities who also have physical disabilities to gain access to health promotion services.

4. *What are the unique access barriers to health care for women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities?*

Women with disabilities report that financial concerns and inadequate health insurance are the primary reasons they cannot obtain needed services.⁵⁴⁴ Among women who do not have disabilities, slightly over 75 percent had private insurance, compared with almost 62 percent of women with basic actions difficulty and only about 49 percent of women with complex activity limitations.⁵⁴⁵ Depending on level of disability, between 15

and 18 percent of women with disabilities between the ages of 18 and 64 years have no health care coverage at all.⁵⁴⁶

Even when a woman with disabilities has health insurance, her plan may not adequately cover required prescriptions, physical or occupational therapy, durable and expendable medical equipment and supplies, assistive devices, or personal assistance services. Women with disabilities that included three or more functional limitations were more likely to report being unable to get general medical and dental care, prescriptions, or eyeglasses, regardless of age group, compared with women who do not have disabilities. Women with disabilities also report problems with access to prevention services.⁵⁴⁷

Social misperceptions and stereotypes about disability can make it difficult for women with disabilities to obtain information, medical care, and services to ensure that their reproductive needs are met. Structural barriers to receiving adequate and informed reproductive care include limited professional training and competency of primary care and reproductive care specialists; inadequate or no health insurance coverage for visits to specialists; poor physical access to usable and adapted or specialized examination and diagnostic equipment; and negative or discriminatory provider attitudes.⁵⁴⁸

Communicating effectively in health care settings presents complex challenges for people who are deaf or hard of hearing. Research has revealed that deaf and hard-of-hearing patients identify similar problems related to communication that compromise health care, including “medication errors and misdiagnoses, problems during surgery and anesthesia, missed and delayed appointments, and less complete and accurate information than other patients receive.”⁵⁴⁹ Most health care practitioners have little understanding of how people with hearing loss communicate or how to communicate effectively with them. This lack of awareness directly affects the quality of health care these practitioners are able to provide. People who are deaf or hard of hearing frequently report that health care providers rarely use appropriate and effective methods of communication. Problems begin when an individual attempts to schedule an appointment with a health care provider and continue during office visits, diagnostic

procedures, emergency room visits, hospitalizations, and even in hospice care. Most health care practitioners are unaware that many people who are deaf or significantly hard of hearing communicate using technologies including text messaging, faxing, email, and TTY devices, and some practitioners are uncomfortable using these technologies to communicate with patients. Further, most practitioners have complex menu-driven voice message systems that make it difficult for relay operators to type the options to the caller before the connection times out.⁵⁵⁰ Thus, people who are deaf or hard of hearing are sometimes unable to make appointments with their health care providers or communicate directly with them. Deaf focus group participants indicated that communication is most effective when they have the opportunity to work with medically experienced, certified ASL interpreters. However, these interpreters are often not available.⁵⁵¹

Participants in one focus group reported that health care providers and their staff did not know how to relate appropriately to people who are blind or have vision impairments. They indicated that some health care providers are uncomfortable communicating with such patients. For example, providers frequently speak to a companion who is sighted rather than speaking directly to the person who is seeking medical care.

Other barriers to care include lack of public transportation in suburban and rural areas, difficulty scheduling rides, and difficulty relying on paratransit to get to appointments on time. Barriers in the facilities of health care providers include lack of appropriate, accessible signage using Braille and raised letters. Many people who are blind or have vision impairments and who also have diabetes report that diabetes care professionals are poorly equipped to serve them appropriately. Professionals rarely understand the need for information in an accessible format. Health care providers are generally unaware of speech-output devices that enable people who have vision impairments to measure their blood sugar and blood pressure and read prescription dose instructions independently.

For people who are blind or have vision impairments, access to vision rehabilitation services is limited, in part because of eligibility definitions. Even people who are eligible

for services may not know that they are available or may find the cost of these services prohibitive. Further, too few vision care specialists, including ophthalmologists and optometrists, refer eligible people who have vision impairments to vision rehabilitation services.

Studies have shown that people with intellectual and developmental disabilities—as well as the families, caregivers, and advocates who help them to get care—face extraordinary barriers to preserving health and getting health care when they need it.

They feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs. They struggle with unwieldy payment structures that were designed decades ago when people with [intellectual and developmental disabilities] often died in childhood or lived out their lives in residential institutions.⁵⁵²

About 70 percent of Medicare beneficiaries with intellectual and developmental disabilities are also enrolled in Medicaid.⁵⁵³ Because Medicaid includes both mandatory and optional services, certain critical services such as dental care and certain prescription drug coverage may not be available to people with intellectual and developmental disabilities.⁵⁵⁴ Medicaid managed care programs can be poorly equipped to meet the needs of people with disabilities, including people with intellectual and developmental disabilities.⁵⁵⁵ Potential problem areas include inadequate care coordination, limited access to specialists, limited consumer choice, and inadequate risk adjustment for capitation rates.⁵⁵⁶ Medical providers lack training and experience in treating individuals with intellectual and developmental disabilities. Some providers are uncomfortable providing care or are unwilling to serve patients with these disabilities. Patient education materials are often written in ways that people with intellectual disabilities cannot understand, making follow-through less likely. Incorrect assumptions and stereotypes about people with intellectual and developmental disabilities, coupled with limited scientific knowledge about appropriate standards of care, further contribute to ongoing health problems. Negative experiences with health care providers deter

people with intellectual and developmental disabilities, along with their families and caregivers, from seeking care.

Many children with intellectual and developmental disabilities receive medical care managed through an interdependent and complicated system that may include the involvement of medical, educational, vocational, and social services. The transition from this multilayered system to adult health care is fraught with difficulties for many. At a minimum, people with intellectual and developmental disabilities require a primary care physician who can focus on providing adult care. Even at this stage, health systems may fail to support the transition process, and young adults and their families can find themselves without appropriate care. Problems include primary care physicians who are not trained to provide needed care and insurance schemes that do not adequately compensate health care providers for the time required to provide care and care coordination. Further, insurance plans can limit access to the few specialty providers who are familiar with the care needs of young adults with intellectual and developmental disabilities. Finally, environmental factors such as poverty, inadequate and inaccessible housing, unemployment, and poor transportation contribute to the poor health status of people with intellectual and developmental disabilities and limit access to necessary medical care and mental health services for them and their families.⁵⁵⁷

5. *What programs initiated by the public and private sectors have improved access to coverage and care for Americans with disabilities?*

The following are examples of such programs.

a. AXIS Healthcare, Twin Cities area, Minnesota

Contracted by a Minnesota Department of Human Services program called Minnesota Disability Health Options (MnDHO) in 2001, AXIS Healthcare founded UCare Complete for people with physical disabilities, ages 18 to 64, who reside in the Greater Twin Cities area. The program combines physician, hospital, home care, nursing home care, home- and community-based services, and other care into one coordinated care system that maximizes independence while providing person-centered and person-directed

services. The plan was designed because people with disabilities who participated in the Medicaid program in the target counties were experiencing poor access to health care services, were unable to obtain accommodations in health care settings, and found that few health care providers understood their particular needs.

b. South Dakota Rosebud Developmental Clinic, Sioux Falls

The South Dakota Rosebud Developmental Clinic operates in conjunction with the Sanford School of Medicine at the University of South Dakota in Sioux Falls, South Dakota. The program was organized 18 years ago to identify children from birth through 5 years of age on the Rosebud Reservation who are at risk for developmental disabilities, provide immediate care through early intervention, and refer them to additional medical services provided by local agencies and facilities.

Native Americans continue to experience significant health disparities compared with the general population.⁵⁵⁸ Before the clinic was established, children and parents on the Rosebud Reservation were without local specialists to diagnose and evaluate developmental disabilities. The clinic operates by sending local staff to the reservation to perform developmental screenings. High-risk children are referred to the clinic for further evaluation and treatment. Once a month, a team of professionals (psychologist, physical/occupational therapist, speech therapist) and two or three graduate students performs full evaluations for children who are referred to the clinic. Staff members use specific, standardized evaluation methods (e.g., testing motor skills, communication skills, and cognitive/adaptive skills) that allow for flexibility and familial involvement. The children can also see a nutritionist, a developmental physician/pediatrician, and a geneticist. After evaluation, an Individual Service Plan (ISP) is created, and services are scheduled for eligible children.⁵⁵⁹

c. Premier HealthCare—YAI/National Institute for People with Disabilities Network, New York

Premier HealthCare, an agency in the YAI/National Institute for People with Disabilities (NIPD) network,⁵⁶⁰ provides specialty health care for individuals with developmental,

physical, and learning disabilities in New York City. The medical facility provides an integrated medical home for its patients. Premier offers the advantages of both a small group practice and a large academic medical center.⁵⁶¹

d. Center for Development and Disability—University of New Mexico, Albuquerque

A University Center for Excellence in Developmental Disabilities, the Center for Development and Disability (CDD) at the University of New Mexico in Albuquerque is a statewide organization established in 1990 that provides a variety of person- and family-centered health care services for individuals with disabilities, especially developmental disabilities. CDD works for the full community inclusion of people with disabilities and their families by engaging individuals in making life choices, partnering with communities to build resources, and improving systems of care.

e. Westchester Institute for Human Development, Valhalla, New York

A University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD), the Westchester Institute for Human Development (WIHD) is located in Valhalla, New York. A former affiliate of the Westchester Medical Center, WIHD became an independent nonprofit organization in 2005. Today, the institute provides coordinated health care to people with disabilities; provides training and technical assistance for people with disabilities, caregivers, family members, and health care professionals; and undertakes research. Operational values include self-determination, family- and consumer-directed supports, community inclusion, and cultural competence.⁵⁶² WIHD works to address the longstanding health care disparities faced by people with disabilities.

f. Disabled Women’s Health Center, University of Alabama, Spain Rehabilitation Center, Birmingham, Alabama

The country’s first gynecological clinic for women with disabilities, the Disabled Women’s Health Center at the University of Alabama, Spain Rehabilitation Center, in Birmingham, Alabama, was founded by Dr. Aimee Jackson in 1989, after several

women with disabilities who were patients at the Spain Rehabilitation Center noted the lack of high-quality, accessible health care. The clinic has provided services to approximately 500 patients who range in age from 17 to 87 years and reside in Alabama, Mississippi, Tennessee, and Florida. About 35 to 40 percent of the clinic's patients are women with spinal cord injuries, and about 20 percent have spina bifida. Women who are served also have other disabilities, including stroke, multiple sclerosis, rheumatism, dwarfism, and scoliosis. The clinic also serves patients who are deaf.

g. Breast Health Access for Women with Disabilities, Alta Bates Summit Medical Center, Berkeley, California

A program of rehabilitation services of the Alta Bates Summit Medical Center in Berkeley, California, Breast Health Access for Women with Disabilities (BHAWD) offers an accessible clinic for free breast exams, breast self-examination training, general breast health management education, and mammogram referrals. The program was initiated in 1995, and clinical services began in 1997. Alta Bates staff, women with disabilities, and breast cancer survivors spearheaded BHAWD because they recognized the gap in women's health services, including breast health. At the time, women with disabilities were ignored in cancer publications, breast health programs, and most public health research.

Drawing on its clinical experience, BHAWD developed the country's first protocols for adapted breast screening services and created trainings for physicians and other care providers, such as a Women Be Healthy program for women with cognitive disabilities. In addition, the group has produced several publications and a nationally distributed DVD on mammography training.

h. Women with Disabilities Center, Rehabilitation Institute of Chicago

Founded in 1991, the Women with Disabilities Center (WWDC) of the Rehabilitation Institute of Chicago (RIC) was the country's first community-based health resource center for women with disabilities. WWDC shares staff and space with RIC, which is known nationally for its expertise in physical medicine. The center provides a variety of

direct services to women with disabilities and also educates the medical community about the needs of this population. WWDC promotes the safety and dignity of women and girls with disabilities, with the aim of helping them practice self-determination in achieving lifelong physical and emotional wellness.⁵⁶³

Partnering with Northwestern University's Prentice Hospital, WWDC refers women with disabilities to a team of physicians, nurses, and occupational therapists who are familiar with disabilities and can provide specialized care. The team provides basic reproductive services—including pelvic exams, mammograms, and family planning—which are traditionally unavailable for women with disabilities. WWDC also offers free, confidential domestic violence support and information through RIC's Domestic Violence Services Program.

i. Center for Women with Disabilities, Magee-Women's Hospital, University of Pittsburgh Medical Center

Founded in December 2001, the Center for Women with Disabilities, Magee-Women's Hospital, University of Pittsburgh Medical Center (UPMC) offers comprehensive, patient-centered care that integrates accessibility and accommodation for women with physical disabilities. The center provides preventive medical services for women with disabilities and also refers patients to other culturally competent physicians who operate in accessible facilities and can provide appropriate accommodations. The center also offers educational programs for youth and their parents and caretakers, and works with UPMC's other centers to develop and improve system-wide accessibility and services.

j. Health Promotion Campaign for Women with Physical Limitations, Center for Research on Women with Disabilities, Baylor College of Medicine, Houston, Texas

Between 2005 and 2007, members of the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine in Houston, Texas, initiated the Health Promotion Campaign for Women with Physical Limitations. Funded by a grant from the Houston Endowment, this program was an outreach effort directed at women with physical disabilities, care providers, and friends and family members. In an effort to

inform and “empower women with physical disabilities to improve their health and wellness,” CROWD staff and faculty developed educational materials and a website, and attended health fairs in the Houston region.⁵⁶⁴ CROWD’s efforts in the area of health promotion grew out of the recognition that disability adds a new dimension to the problem of health disparities. People with disabilities face a number of disparities relative to the general population, including overall poor quality care, poor general health information, and low rates of health insurance.⁵⁶⁵ CROWD saw that such challenges are further compounded for women with disabilities because their general reproductive health needs are often ignored by health care providers.

k. Blindness Support Services, Inc., Riverside, California

Blindness Support Services (BSS), in Riverside, California, was established in 1992 to provide innovative approaches to assist people who are blind or have vision impairments and who are residents of Riverside, San Bernardino, Orange, San Diego, and Los Angeles counties in southern California to achieve independence and self-reliance.⁵⁶⁶ In addition to vision rehabilitation, BSS provides various health care services. The Health and Wellness Plan was designed to address the problems that arise from the lack of healthy eating habits among individuals with blindness and vision impairments. BSS offers exercise plans tailored to the needs of the community and presents lectures on healthy eating. BSS’s partnership with Riverside County Regional Medical Center provides a family practices resident the opportunity to work with BSS to learn how to address the various needs of patients with vision impairments.

l. LightHouse for the Blind and Visually Impaired, San Francisco

The LightHouse for the Blind and Visually Impaired, in San Francisco, is the largest agency providing direct services, advocacy, and information to the blind and visually impaired community of northern California.⁵⁶⁷ The Vision Loss Resource Center (VLRC) of the LightHouse offers an adaptive technology and health seminar that provides an audio transcript and information handouts of presentations on adaptive equipment, including accessible tools for glucose monitoring, weight management, healthy food preparation, and exercise equipment that aids in maintaining health.

The LightHouse's Low Vision Clinic operates in collaboration with the University of California, Berkeley, School of Optometry, which offers low vision evaluations. The clinic assists clients by recommending various strategies and techniques for maximizing residual functional vision and by prescribing appropriate adaptive devices that will assist them to regain functional independent living skills.⁵⁶⁸

m. Deaf Access Program, Mt. Sinai Hospital, Sinai Health Systems, Chicago

The Deaf Access Program (DAP) of Mt. Sinai Hospital, in Chicago, offers a comprehensive program that provides medical and mental health services for children and adults who are deaf. DAP is sensitive to the language and culture of the Deaf community and is strengthened by having a program manager who is deaf, in addition to three physicians who are fluent in ASL, three ASL interpreters on staff, and three mental health therapists who are also fluent in ASL. This program meets a specific and critical need within the Chicago Deaf community, where historically, people who are deaf have found it difficult to obtain appropriate health and mental health care because of substantial communication barriers.⁵⁶⁹

With an estimated 50,000 people who are deaf or hard of hearing living in the metropolitan Chicago area, the DAP serves approximately 1,300 patients and provides full communication access to medical, mental health, and support services. In addition to interpreting for patients in clinical settings, ASL interpreters travel to affiliated clinics in the Chicago area and provide interpreter services. DAP also coordinates the deployment of outside interpreters, as needed, to ensure that deaf patients have access to effective and appropriate communication during health care visits.

n. Deaf and Hard-of-Hearing Program, Advocate Illinois Masonic Medical Center, Chicago

The Deaf and Hard-of-Hearing Program at Advocate Illinois Masonic Medical Center, in Chicago, was established more than 25 years ago. The program provides mental health services and prevention education, and reaches more than 500 people who are deaf in Chicago's six-county region and beyond. During 2007, approximately 100 patients

received mental health services each month, with a total of 3,400 contacts for the year. In addition to mental health services, the program engages in prevention education that is understandable and usable by people who are deaf. The program features health education pamphlets presented in streaming video on a variety of topics, including HIV/AIDS, sexually transmitted diseases, breast health, and diabetes. Also available are interactive screenings for depression, anxiety, and risk of heart attack, as well as programs for smoking cessation and depression management.

o. Metropolitan Hospital Consortium, Communication Services for the Deaf of Minnesota, Minneapolis

The Metropolitan Hospital Consortium, one of the Communication Services for the Deaf of Minnesota, in Minneapolis, was established in November 2005 to provide the 26 member health facilities in the greater Twin Cities area with ASL interpreter services in emergency situations. Under the consortium's operational contract, ASL interpreters are paid to be listed on a reserved 24/7 on-call schedule, allowing them to respond immediately when a need arises at a member facility. The consortium operates three shifts per day, with three interpreters on call for each shift. The consortium guarantees that an interpreter will arrive at a facility within 2 hours; 95 percent of the time, the consortium is able to send an interpreter arrives within 1 hour.

p. CATIE Center, the College of St. Catherine Interpreter Education Program, St. Paul/Minneapolis

The Collaboration for the Advancement of Teaching Interpreter Excellence, known as the CATIE Center, is one of six centers working in partnership as the National Consortium of Interpreter Education Centers (NCIEC).⁵⁷⁰ Created in 2005, the CATIE Center serves a 10-state region and has a primary focus of identifying effective practices in interpreting in the health care field.⁵⁷¹ The center's goal is to significantly increase the number of qualified interpreters in the field, while providing resources and opportunities that are accessible to interpreters of all backgrounds and experiences.

q. Deaf Wellness Center, University of Rochester Medical Center, Rochester, New York

The Deaf Wellness Center (DWC) is a program of the Department of Psychiatry at the University of Rochester Medical Center, University of Rochester, Rochester, New York. DWC physicians perform individual and group psychiatric assessments. The center conducts 2,000 to 3,000 units of service annually, and approximately 100 patients are actively participating in care at a given time. DWC provides evaluation and psychotherapy services to individuals of any age, couples, and families. DWC has five full-time staff members who are fluent in ASL and a number of trainees who engage in clinical services, teaching, and research activities that pertain to mental health, health care, sign language interpreting, and other topics that affect the lives of people who are deaf or hard of hearing.⁵⁷²

r. State Buy-In: The Family Opportunity Act

The Family Opportunity Act (FOA) allows families with a child who meets the Supplemental Security Income (SSI) disability criteria and that have an income under 300 percent of the Federal poverty level (FPL) to buy in to Medicaid for that child. Since the enactment of FOA in 2006, Illinois, Iowa, Louisiana, North Dakota, Ohio, Pennsylvania, and Vermont have established buy-in programs. These programs serve as a national model for innovative policies that can contribute to reducing the number of children with disabilities who still receive inadequate health care.

s. Disability Standardized Patient Exercise for Medical Students, Tufts University Medical School, Medford, Massachusetts

The Disability Standardized Patient Exercise for Medical Students, at Tufts University Medical School, in Medford, Massachusetts, targets third- and fourth-year medical students. The program is now required, and about 170 students participate. The goal of the program is to introduce an individual with a mobility disability who is seeking care for a health problem that is not disability-related. For example, a paid patient-educator who is a wheelchair user discusses her health concern, shoulder pain. She reports living an active life with family and friends. The goals of the exercise are to help students develop

a comfort level working with a patient with a disability, dispel stereotypes about disability, and encourage students to learn how to differentiate between disability-related and other medical problems. The program is fully embedded in the medical school.

6. *What are key disparities and gaps in third-party coverage of the types of programs and services most needed by Americans with disabilities, particularly women with disabilities, people who are deaf or hard of hearing, people who are blind or have vision impairments, and people with intellectual and developmental disabilities?*

Lack of comprehensive insurance coverage and excessive out-of-pocket costs rank high among disparities and gaps in third-party coverage for the types of services and programs most needed by Americans with disabilities. For example, Medicare contains significant gaps in coverage benefits for items or services that can be both expensive and particularly important for maintaining function and independence. Medicare does not pay for long-term care services at home or in an institution, routine dental care and dentures, routine vision care or eyeglasses, and hearing exams and hearing aids. These notable gaps in coverage may result in significant out-of-pocket expenses to meet medical, equipment, and long-term care needs for some people with disabilities.⁵⁷³ Both Medicare and Medicaid beneficiaries have reported difficulties obtaining the care and services they require. With higher copayments, Medicare beneficiaries with disabilities report significant cost-related problems, including forgoing needed equipment, postponing care, and paying for long-term care. While cost-sharing is lower under Medicaid, people with disabilities covered by the program report, among various problems, difficulties finding physicians who will accept Medicaid payments, which compromise access to care for people who have low incomes. One national survey found that health insurance is inadequate for more than one in three people with disabilities; these individuals reported delaying care, skipping medication, or going without needed equipment because of cost.⁵⁷⁴ Further, neither private nor public insurance plans reimburse health care providers for ASL interpreters or cover the cost of vision rehabilitation for people who are blind or who have vision impairments.

For those who have employer-sponsored group health insurance, plans often do not provide adequate benefits for people with disabilities.⁵⁷⁵ For example, private insurance plans increasingly limit annual payments for durable medical equipment such as wheelchairs, crutches, braces, and ventilators, regardless of medical necessity, and at a level that makes the individual's out-of-pocket costs for higher priced items such as motorized wheelchairs prohibitively expensive.⁵⁷⁶ Many private insurance plans limit mental health services and prescription drugs, which are generally restricted to medications on approved lists, or formularies.⁵⁷⁷ For families who have a child with intellectual and developmental disabilities and complex medical problems, private insurance does not provide for adequate reimbursement to health care providers for key services such as specialty care and care coordination.⁵⁷⁸

Purchasing individual private insurance is rarely an option for people with disabilities because it is unaffordable or because they are denied coverage outright on the basis of disability. While group plans may not exclude an individual with a disability from coverage, no such prohibition exists for individual private insurance.⁵⁷⁹ In addition to paying more for an individual plan than they would for a group plan, purchasers are often charged premiums that are higher than those charged to individuals without disabilities.⁵⁸⁰ One study examined the availability of individual health insurance coverage for hypothetical individuals with minor and major health problems. The study found that these hypothetical individuals were unable to obtain coverage at the standard rate 90 percent of the time, and benefit restrictions and premium surcharges were imposed on the applications that were accepted.⁵⁸¹

7. How can the extensive recommendations identified in studies conducted by the Institute of Medicine and others be advanced?

Participants in NCD's Health Care Summit for People with Disabilities considered a series of recommendations for reform derived from seminal reports issued by the Institute of Medicine (IOM), the Surgeon General of the United States, and leading health policy researchers. The summit participants undertook a failure analysis exercise, identified strategic actions that should be taken, and ranked the

recommendations according to the extent to which some goals are achievable in the near term.

Participants identified the following factors that interrelate and contribute to the failure of health care institutions.

- Core attitudes—misconceptions that impede access by people with disabilities to health care services
- System failure—despite some progress, tremendous gaps in the adoption of patient-centered practices
- System complexity—a health care system that is overly complex, fragmented, entrenched, and deeply layered, requiring any form of transformation to cut across multiple diverse elements
- Data challenges—a monitoring system that is insufficient to provide the basic data needed to measure and monitor disability
- Strategy limitations—lack of systemic impact of efforts, such as litigation, to bring about needed change; limited attempts to use standards setting and monitoring by private accreditation entities; and inadequate training of health care professionals
- Attention overload—an environment saturated with complexity, chaos, and time demands, forcing issues to vie for their share of attention
- Culture and curriculums—lack of health care providers' awareness of the challenges involved in living with a disability or knowledge about how to provide culturally appropriate care and accommodations
- Untapped possibilities—lack of partnering with other groups that share a mutual interest in expanding health care access to underserved populations

Summit participants identified the following strategic actions that hold significant potential to achieve meaningful results in the near future.

- Securing Federal agency or congressional support to establish a Technical Assistance Center for Health Care Improvement for People with Disabilities
- Gaining active support from the Joint Commission to bring accessibility and universal design principles into the medical facility survey accreditation process
- Gaining commitment and active engagement from a core of committed individuals who will advocate for accreditation standards that require disability awareness and competence in the medical school curriculum

8. *Are accurate health data available concerning access to wellness and prevention services and their relative long-term costs and benefits for Americans with disabilities?*

The wellness and prevention services tracked by the Federal Government as benchmarks for the general U.S. population include screening for conditions and behaviors that place people at risk for serious health problems and measures of the delivery of preventive medical services, screenings, and examinations. The indicators tracked for “Healthy People 2010,” along with several additional indicators collected regularly in the major health surveys, include the following:

- Health risk behaviors/indicators: smoking, obesity, excessive alcohol use, high cholesterol, hypertension, and lack of exercise
- Preventive medical exams, screenings, and services: general physical exam, Pap test, mammogram, PSA test, flu shot, colonoscopy, cholesterol test, and doctor discussion and referral for services for smoking cessation, weight loss, exercise, alcohol treatment, and dietary and drug treatment for cholesterol

“Healthy People 2010” includes objectives for people with disabilities for the top 10 health indicators. The top 10 list is health care access, immunization, overweight and obesity, physical activity, tobacco use, mental health, substance use, sexual behavior, injury, and environmental quality. Data are not regularly collected on sexual behavior, injury, or environmental quality for people with disabilities. However, health care access, immunization, physical activity, obesity, substance use, and tobacco use can be tracked

using the National Health Interview Survey (NHIS), Medical Expenditure Panel Survey (MEPS), and Behavioral Risk Factor Surveillance System (BRFSS) datasets, all of which have disability questions in their cores. While the data collected using these three surveys can identify people with disabilities (the exact wording of the disability questions varies), the regular reporting of health and wellness benchmarks by the sponsoring agency does not present the status of people with disabilities on these indicators. Thus, health and wellness can be tracked using some of the same indicators that are used for people without disabilities, but since this information is not regularly included in the agency reports, it is not easily available in public documents.

Beyond the examination of whether the standard health and wellness indicators are collected (for people with and without disabilities) is the issue of whether the indicators applicable to the general population are sufficient to track wellness and prevention for people with disabilities. Chapter 6 of “Healthy People 2010,” entitled “Disability and Secondary Conditions,” lists additional objectives, among them the following three:

- Objective 6-10: Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.
- Objective 6-11: Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.
- Objective 6-12: Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

The Consumer Assessment of Health Providers and Systems (CAHPS) survey has the potential to address Objective 6-11 through its supplemental questions. The other two objectives, 6-10 and 6-12, cannot currently be tracked via the major datasets.

There is no regular measurement of facility characteristics associated with access; neither are there regular sources of data to measure participation in wellness programs such as exercise classes, smoking cessation programs, or self-help or AA-type groups

for substance abuse. Surveys do not ask people with disabilities about their experiences with access or environmental barriers that may affect participation in wellness programs or activities at home, in school, or in the community.

Assessing long-term costs and benefits of access to wellness and prevention programs requires (1) consistent appropriate measures over time and (2) research that documents costs and the link between wellness or prevention programs and health benefits for people with disabilities. Agreement on an indicator of disability and use of that indicator in every major health survey will produce over time the ability to track for people with disabilities the prevalence of the wellness and prevention benchmarks used nationally for the noninstitutionalized population. Currently, no single indicator of disability is used in all surveys, but ongoing activities suggest progress toward this goal. Once a consistent definition is in place, data will have to be collected for a number of years before it will be possible to assess long-term prevalence rates for wellness and prevention measures.

Intervention costs are commonly incurred at the beginning of an intervention, with the benefits spread out into the future.⁵⁸² The financial costs of implementing a program are not difficult to identify; the economic costs (e.g., opportunity costs) are somewhat more difficult to calculate. The calculation of long-term benefits for people with disabilities from participation in wellness and prevention programs depends on the existence of studies that have measured outcomes. Currently, few studies measure the outcomes of interventions for smoking cessation, increased mammography screening, exercise, or other programs for people with disabilities. Nor do studies show whether the participation of people with disabilities in programs for broader populations were affected by access issues. If the outcomes of, for example, increasing exercise or reducing tobacco use are the same for people with disabilities as for people without disabilities, we can use the same estimates about increased longevity or fewer days of restricted activity that are used to estimate long-term benefits for the general population. However, if interactions with disabilities cause different outcome rates on these indicators, separate long-term benefits should be calculated. A clear understanding of

impact will require further research on the outcomes of health and wellness programs that include people with disabilities.

9. *How effective are Federal efforts at health promotion and disease prevention (public health) as they affect Americans with disabilities, particularly women with disabilities, and people who are blind or have vision impairments, people who are deaf or hard of hearing, and people with intellectual and developmental disabilities?*

Although it is difficult to determine with any certainty the effectiveness of Federal efforts at disease prevention and health promotion for people with disabilities, particularly in terms of reduced health disparities or improved health status, the midcourse review for “Healthy People 2010” reported some related progress. At that time, new data had become available on several key indicators since “Healthy People 2010” was launched in 2000. People with disabilities are currently represented in 207 of the 467 objectives that span 21 of 28 “Healthy People 2010” focus areas. However, when “Healthy People 2010” was implemented, data on people with disabilities were available for only 88 of those 207 objectives. “Healthy People 2010” undertook a midcourse review that revealed some preliminary information on the extent to which objectives are being met. For example, in Focus Area 6, “Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the US population,” the midcourse review provides new data comparing populations within the disability community that address both quality of life and health disparities. Disparities are documented between people who have disabilities and those who do not, as well as among subgroups based on education, income, gender, and ethnicity. Improvements are shown in several areas, including an increase in inclusion of people with disabilities in national and state surveillance, a reduction of the number of adults with disabilities living in congregate care facilities, and an increase in the number of children with disabilities included in regular education programs. However, according to the midcourse review, the explanation for this improvement cannot be attributed to any particular programmatic intervention. The review suggests that implementation and enforcement of Federal disability rights laws, improved public awareness of disability, and increased accessibility, including public transportation, may be contributing factors.

At the same time, some relatively recent Federal efforts at health promotion and disease prevention for people with disabilities may produce results that can be measured in the future. For example, the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the National Cancer Institute (NCI), and the National Institute of Mental Health (NIMH) have undertaken or supported research related to health promotion and disease prevention as they apply to women with disabilities. CDC has undertaken a qualitative study to explore the barriers to breast cancer screening for women with disabilities, and has developed and is testing the Right to Know campaign. NCI supported research for a pilot study to develop and test methods of identifying women of screening age with physical and sensory disabilities, as well as a questionnaire to identify barriers in screening mammography for these women. NCI also funded a study on the effects of disability on the diagnosis of breast cancer. NIMH has funded HIV/AIDS prevention curriculums for women with intellectual disabilities.

AHRQ has supported research on methods to improve the health care experiences of people who are blind or have vision impairments and efforts to create an evidence base for vision rehabilitation. The National Eye Institute (NEI) supported a randomized clinical trial on the effectiveness of low vision rehabilitation services for adults who have vision impairments. One goal of the project was to provide information that could assist the Centers for Medicare & Medicaid Services (CMS) in formulating policy on coverage of these services, which help people with vision loss to follow disease prevention and health promotion regimens.

AHRQ, NCI, and CDC have supported research projects related to people who are deaf or hard of hearing. AHRQ has supported research on translating and adapting the Consumer Assessment of Healthcare Providers and Systems (CAHPS) ambulatory care survey to collect information in ASL about health care experiences from people who are deaf. NCI has funded a program to expand the number of cancer education training videos available to the Deaf community in San Diego, California, and an immersion project to train 10 medical students from the University of California, San Diego, in basic

ASL, Deaf culture awareness, and medical terminology in ASL, with a focus on cancer-related issues. CDC has provided funding for the Rochester Prevention Research Center (RPRC) at the University of Rochester, which is developing a national center of excellence for health promotion and disease prevention research in persons who are deaf or hard of hearing.

In addition to programs of the Administration for Children and Families (ACF) and the Health Resources and Services Administration (HRSA) (e.g., UCEDDs and LENDs), the following Federal initiatives also promote health for people with intellectual and developmental disabilities. The National Institute of Dental and Craniofacial Research (NIDCR) has identified people with disabilities as a disparities population, has developed and published a series of important booklets on providing oral disease prevention and routine dental care for people with developmental disabilities, and has funded an oral health disparities research project at the University of California, San Francisco. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD) has funded projects to test the reliability and validity of various methods to assess the dietary intake of adults with significant cognitive impairments living in the community. The National Institute of Child Health and Human Development (NICHD) has supported Oregon Health and Science University to test the efficacy of a health promotion intervention for people with intellectual disabilities.

10. What are the long-term costs and benefits of third-party coverage of programs and services most needed by Americans with disabilities?

The payment structure for health care services in the United States is based on third-party payers, either through private insurance or through public programs, including Medicare, Medicaid, SCHIP, and Title V of the Social Security Act. Health care services are so costly that it is not feasible to assume that those without a third-party payer can afford to pay out of pocket. For the 45.7 million Americans without health insurance, this means mostly going without care until health problems are urgent.⁵⁸³ In these circumstances, providers may never be adequately compensated for the care provided, and individuals may find themselves struggling with large health care-related debt.⁵⁸⁴

For people with disabilities, as for most Americans, assessments about the impact of the third-party payment structure on long-term costs and benefits are wrapped up with the larger national policy debate about how best to finance health care so that it meets the two objectives of enabling everyone to access appropriate quality care and controlling the rapid rise of health care expenditures.

People with disabilities rely heavily on health insurance. However, data from the 2001–2005 NHIS indicate that about 19 percent of adults with a basic actions difficulties and 17 percent of those with a complex activity limitations reported being uninsured. Twenty-eight percent of people with emotional disabilities reported being uninsured, the highest rate among people with disabilities, followed by 20 percent of people who are blind or have vision impairments or who are deaf or hard of hearing.⁵⁸⁵ Those who are without insurance or who are inadequately insured often delay care or go without care. Both circumstances can raise costs in the long run, both to the health care system and to individual patients. While not intrinsic to the concept of third-party payment, the current structure permits the denial of coverage on the basis of health status or prior health events. This structure also has developed a reimbursement system geared to the expenses of acute medical care, which leaves people with chronic conditions and the costs of chronic care less well covered. The costs of durable medical equipment and other assistive devices—which often are not considered “medical”—sometimes fall outside the insurance coverage umbrella.

For people with disabilities to realize health insurance benefits that are similar to those for people without disabilities, third-party coverage will have to include some specific services and supports, such as care coordination, access to specialty providers, rehabilitative services, prescription drugs, durable medical equipment, and assistive technologies. Third-party reimbursement also should be able to accommodate the need for longer appointments, assistance with communication (e.g., sign language interpreters), and other modifications to ensure equitable quality in health care for people with disabilities.

Currently, no body of research demonstrates with any certainty the long-term costs and benefits of third-party health care coverage that incorporates the services most needed by people with disabilities. The best that can be offered is a hypothesis for future research: Better third-party coverage of people with disabilities and the services they need will result in longer, healthier lives; improved overall health status; greater productivity and community participation; and decreased utilization of high-cost care for conditions that benefit from earlier intervention.

B. Required Elements for Access to Health Care for People with Disabilities

The extensive network of Federal programs that provide health care and prevention services to people with disabilities (e.g., Medicare, Medicaid, SCHIP, and Title V) serves as a critically important safety net, but many people with disabilities still do not have health insurance, and for many who do, coverage, services, and benefits are often inadequate. These problems have been extensively documented, discussed, and debated among health policy research institutions, in the disability community, and among policymakers. Many of the structural problems are an artifact of the historical and political evolution of health care policy in the United States and lie at the heart of the ongoing national debate about health care reform. However, little attention has been paid to the role these agencies should play to ensure that the Federally supported health care for people with disabilities is provided in a culturally competent manner, in accessible facilities, and with appropriate accommodations.

For people with disabilities, access to health care includes critical dimensions in addition to health care insurance and payment for services. While coverage is one fundamental component of access, another dimension has to do with barriers people with disabilities encounter when they seek health care services and with the capacity of health care systems to ensure accessibility and provide accommodations.

While little research documents the barriers that people with disabilities encounter when they seek care, sufficient evidence has been collected through focus groups and other

forms of participatory research to conclude that problems such as poor architectural accessibility, lack of accessible examination equipment, and limited accommodations in health care settings deter some people from seeking care and can result in inadequate and ineffective care.

Section 504 of the 1973 Rehabilitation Act prohibits discrimination on the basis of disability by recipients of Federal financial assistance. The law requires recipients to evaluate their programs and services to ensure that people with disabilities have adequate access and receive appropriate accommodations so they can participate in and benefit from the program or service. Yet the largest Federal programs that provide health insurance or pay for health care services for people with disabilities through transfer of Federal funds to the states have done little to ensure that states take steps to protect the rights of people with disabilities who receive such federally funded health care. Although Federal agencies may require written assurances that states do not enter into contracts with entities that violate disability rights laws, the agencies do not require that procedures be established for collecting information on the extent of compliance in the systems that provide care. In the absence of such Federal requirements as a condition of receiving funds, states simply pass on their nondiscrimination obligations in contracts with health care organizations, which, in turn, pass the obligations on to the health care providers with whom they contract for services.

Nowhere along the way is a recipient of Federal funds required to report to the entity that provides funding the extent of accessibility of health provider facilities or institutional capacity to accommodate patients with disabilities. Without such a monitoring mechanism, recipients of Federal funds along the health care delivery chain may be unaware of what is required or may have little motivation to remove barriers and provide accommodations. In the absence of a requirement to show their level of accessibility and capacity to accommodate patients with disabilities, it is unlikely that health care providers will seek out or receive information about tax credits available for purchasing accessible equipment or removing architectural barriers.⁵⁸⁶

HHS has provided guidance to states on implementation and enforcement of the ADA and Section 504 but has not established any mechanisms for monitoring states' actions. Funding is not tied to any requirement that states report on progress to ensure compliance by health care providers.⁵⁸⁷ This weakness in Federal health care oversight for people with disabilities has received little public attention and does not appear to be a priority of any Federal agency that has a substantial role in researching, assessing, or directly providing health care for people with disabilities.⁵⁸⁸ For some people with disabilities, the twin dimensions of health care access—adequate insurance coverage and benefits, and health care facility and programmatic accessibility—are inextricably entwined. Yet Federal agencies involved with health care for people with disabilities have not acted affirmatively to elevate attention to, and spur action on, the architectural and programmatic elements.

C. Health and Health Disparities Research

Like Federal health care policy, the health research landscape reflects the legacy of historical priorities and perceptions of disability. Dissonance is evident in the research goals and objectives of key agencies of HHS and NIH, between the longstanding public health goal of eliminating disability and disease and the emerging view fostered by the Surgeon General's report "Call to Action" and Focus Area 6 in "Healthy People 2010." The emerging view, for the first time in public health parlance, defines disability as a demographic characteristic. Much of the Federal effort remains focused on disability and disease prevention rather than on improving access to and quality of health care for people with disabilities, reducing their incidence of secondary health problems, and promoting healthy living. Further, it is very difficult to accurately determine the extent of the overall Federal research effort aimed at addressing health disparities and promoting health and wellness for people with disabilities. This problem stems from the fact that no single Federal agency collects and catalogues health, health disparities, and health promotion research for people with disabilities conducted across all the agencies that have a role in health. The research that can be identified appears poorly integrated into overall health disparities and health promotion research, and too little funding is available to spur a coherent investigative strategy.

In its 2007 report “The Future of Disability in America,” IOM supports this observation with respect to disability research. According to IOM, since its report “Enabling America” was published in 1997,

. . . many of the same problems of limited visibility and poor coordination continue to characterize the organization and funding of federal disability research. The enterprise is still substantially underfunded, given the individual and population impact of disability in America, which will grow as the population of those most at risk of disability increases substantially in the next 30 years.⁵⁸⁹

As evidenced by the disability-specific research topics supported by various agencies (summarized in chapter 4), little attention has been devoted to conducting research on the environmental barriers to health care people with disabilities encounter, the capacity of health care providers to accommodate people with diverse disabilities, the barriers health care providers perceive in providing such care, and the development of successful models for addressing these deficiencies.

D. Federal Agency Political and Structural Issues

The IOM has noted specific structural problems in Federal agency disability research that NCD has also observed in its study of health-related research for people with disabilities. These problems functionally impede the development of a unified, coherent plan for research and program development. Specifically, the level of funding and research is wholly inadequate to inform policy and planning for the growing number of people who will acquire disabilities with age and for the overall future impact of disability on society. Within the Federal research community, commitment to disability health disparities and health promotion research is lacking and coordination mechanisms are weak. The ICDR is underfunded and lacks the authority and gravitas to carry out its coordination functions adequately. CDC’s Disability and Health Team, which has been a leader in health promotion and disease prevention for people with disabilities, is embedded in the National Center on Birth Defects and Developmental Disabilities (NCBDDD), rather than residing at a level within CDC that would vest the unit with more authority and potentially generate greater funding. AHRQ is one of the few agencies with a congressional mandate to conduct

health research and disseminate research findings for people with disabilities, who are included in the agency's focus on priority populations, but so far its level of effort on disability topics other than treatment for specific impairments has been modest. In part, this may be attributable to its exceptionally broad and ambitious mission and limited funding, but it is also likely to be a function of internal priority setting. Further, the agency has no authority to require adoption of recommendations or standards that are identified through sponsored research, which dilutes its practical capacity to influence the actions, policies, and practices of various target audiences. The HHS Office on Disability performs a useful crosscutting educational and collaborative role but appears to be underfunded and is not vested with any tools that could enhance its capacity for impact. Finally, the limited research recently supported by some NIH centers and institutes, while valuable and even groundbreaking in some instances, lacks coordination and a coherent unifying vision.

E. Professional Training and Education

The absence of professional training on disability competency issues is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care. This deficit is widely acknowledged in numerous studies, focus groups, and journal articles (see chapter 1), and by the Surgeon General in the “Closing the Gap” and “Call to Action” reports. NCD’s study of Federal efforts to promote health, health care, wellness, and disease prevention identified very few initiatives that acknowledge and attempt to address the absence of professional training on disability competence. The training opportunities in the field of developmental disabilities, established by the DD Act, are notable. However, researchers and advocates note that most people with developmental disabilities receive care from practitioners who have not had such training and who are often unaware of the related issues and needs. Such knowledge deficits among practitioners are the result of the lack of disability competency training by medical and other professional and allied health institutions.

While disability awareness courses are increasing in medical schools, these courses are often optional and lack stable funding.⁵⁹⁰ Moreover, disability competency is not a core requirement for accreditation for most professional training institutions, and

disability competency training is not required for hospitals that receive Federal funds for student internships and residency programs. Such knowledge is generally not required of applicants who seek a medical or other professional license.⁵⁹¹

Federal agencies, including HRSA and many of the NIH centers and institutes, offer medical and other professional health education loan forgiveness programs when a young health care professional agrees to work with designated underserved populations or in underserved geographic areas. However, these agencies have not identified people with disabilities or subgroups of people with disabilities as underserved health care populations. Therefore, recent health care graduates cannot benefit from the loan forgiveness program if they work in health care settings that serve substantial numbers of people with disabilities.

Acknowledging the dearth of professional education, the HHS Office on Disability convened a meeting in spring 2008 that brought together experts to discuss strategies for solutions. Examples of Federal grant making in this area include an award by the National Cancer Institute to increase medical students' awareness of health issues of people who are deaf or hard of hearing and a National Eye Institute (NEI) grant for a project to educate eye health care professionals about the issues of vision rehabilitation. A few previous Federal grants, including some from NIDRR, have addressed the problem. However, these limited Federal efforts do not constitute a coherent or committed response to the need for student training by medical and other professional schools.

F. Federal Legislative Mandates and Funding

Disability programs—either specifically mandated and adequately funded by Federal legislation, or adequately funded by specific appropriations and carried out by Federal agencies—are most likely to foster awareness on a given subject, gain enough leverage to achieve some of the desired outcomes, and ensure long-term continuity. One example is the combined impact of the 67 University Centers of Excellence on Developmental Disabilities (UCEDDs) and the 35 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. The national network of UCEDDs is authorized

under the DD Act, and their core funding is administered by the Administration on Developmental Disabilities (ADD). Each state has at least one UCEDD, and there are LENDs operating in 29 states. The impact of such a sustained and ongoing operation is reflected in a given year in the number of clinical services provided to individuals with disabilities and their families. For example, in 2006, the UCEDDs and LENDs provided clinical services for 146,484 people with developmental disabilities. Among those, minority populations who are typically underserved received services at a higher rate than their proportion of the national population.⁵⁹² While it is likely that individuals who received these services benefited from a high standard of interdisciplinary care and care coordination, most people with intellectual and developmental disabilities continue to experience significant health and health care problems, and difficulty obtaining appropriate care. The UCEDD infrastructure, however, provides an important foundation on which future models of knowledge, capacity-building, and care can be designed.

Unlike the UCEDDs, LENDs, and other programs operating with a legislative mandate, much of the remaining disability and health research (including health disparities research undertaken by agencies such as NIDRR) has been supported with 1- to 5-year grants that have little or no long-term continuity. Although disability health care is a core research area for NIDRR, specific research in this area is subject to fluctuating internal priorities. For example, in 2007, a 5-year NIDRR grant ended for the Rehabilitation Engineering Research Center on Accessible Medical Instrumentation, undertaken by Marquette University and partners—and a continuation project is not planned.⁵⁹³ Inaccessible diagnostic and medical examination equipment is a primary barrier to health care for people with certain disabilities, and this Marquette project identified preliminary metrics that could inform accessible design for medical equipment. However, according to its draft strategic plan for 2010–2014, NIDRR intends to emphasize employment research; this indicates that funding may not be available for Marquette's to continue its unique research.⁵⁹⁴ Unfortunately, changing agency interests, among other factors, can disrupt and dilute the impact of work undertaken during initial funding cycles and ensure that problems remain unsolved.

The Minority Health and Health Disparities Research Act, which established the Center on Minority Health and Health Disparities (NCMHD) sets forth specific conditions that must be met for a group to be considered a disparity population. The legislation that established the center specifies that minority groups are to be given priority consideration, thus directing the focus of health disparities research toward racial and ethnic minority populations, and only to a lesser extent on the other demographic groups. Thus far, people with disabilities have not been included in the work of the NCMHD. Consequently, people with disabilities are in a Catch-22 situation. The 2004–2006 report of the Interagency Committee on Disability Research (ICDR) states, “Little is known about health disparities within and across disability conditions or between people with disabilities and those without, and support for further exploration is needed.”⁵⁹⁵ More research evidence is clearly required to show the extent of health disparities that people with disabilities experience, but they are not fully included as a population category in the nation’s primary research effort.

In 2003, NIH and other Federal agency partners established eight Centers for Population Health and Health Disparities. For the purpose of the centers, “health disparity” is defined as “differences in the incidence, prevalence, mortality, and burden of diseases, and other adverse health conditions that exist among specific population groups in the United States.”⁵⁹⁶ Initially, study populations included only low-income whites, African Americans, Latinos, and older people, and people with disabilities were not explicitly included. This created additional hurdles to their inclusion in the disparities research being undertaken by some of the nation’s most renowned research institutions.

While NCMHD and other Federal agencies do not recognize disability status as a population demographic, several Federal agencies explicitly include disability status, along with other population groups, in their definitions of disparity populations, either in accordance with their mission statements or in response to legislative directives. For example, the National Institute of Dental and Craniofacial Research (NIDCR) interprets health disparities expansively, acknowledging disability as a population subgroup defined by demographic factors; NIDCR also accounts for social and environmental influences.⁵⁹⁷

Other agencies have either a legislative directive or a funding appropriation that explains their involvement. For example, the Health Care Research and Quality Act of 1999, which established AHRQ, defines health care research priority populations to include low-income groups, minority groups, women, children, the elderly, and individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.

While these agencies unquestionably have undertaken important initiatives that include people with disabilities, the overall effort is very modest relative to the need and compared with the level of Federal research on behalf of other disparity groups. There is no assurance that agencies without an express mandate will continue to conduct disability health disparities research in the future. Realistically, research continuity exists only for Federal agencies and programs that have a congressional mandate and funding. In the absence of a legislative directive and an ongoing source of program funds, people with disabilities must depend on champions within the various agencies and centers.

The lack of consistency in defining health disparity populations creates some confusion and sends mixed messages about whether disability status should be acknowledged as a bona fide population demographic, and impedes a unified research approach to disability health disparities. Faced with this dilemma, the disability community, for the most part, has been forced to argue its own case for acceptance as a legitimate health disparities population worthy of research resources, whereas the health disparities experiences of other groups and populations have been widely acknowledged and are benefiting from the ongoing investment in research.

G. Interagency Collaborations

Against this complex backdrop, several interagency collaborations hold promise for increasing Federal agency attention to health disparities research for people with disabilities. For example, CDC produced a 2006 report, “Advancing the Nation’s Health: A Guide to Public Health Research Needs, 2006–2015,” which identifies research areas

that should be addressed during the next decade by CDC and its numerous partners. The report includes a chapter on health disparities experienced by people with disabilities. This chapter states:

An estimated 24 million persons experience significant disabilities due to impairments, including cerebral palsy, rheumatoid arthritis, spina bifida, developmental disorders, inherited blood disorders, vision loss, and spinal cord injury. . . . Information is lacking regarding the course of these disabling conditions and related secondary conditions (e.g., obesity and depression resulting from loss of mobility and independence) as persons move through different stages of life; the 24 million persons currently affected by severe disabilities represent the first generation of such persons to have lived into middle or old age. Understanding and preventing poor health in this population and identifying comprehensive health care practices will have a significant impact on health-care resources. Knowledge of the course and impact of illness on disabled populations will help in the development of health promotion interventions and the reduction of health disparities.⁵⁹⁸

The Federal Collaboration on Health Disparities Research (FCHDR), a collaboration of Federal agencies working to eliminate health disparities through research, began operations in 2006 to explore, coordinate, and support innovative health disparities research and identify priorities for cross-agency collaboration. The Interagency Committee on Disability Research (ICDR) is co-leading the FCHDR. The ICDR, led by NIDRR, promotes coordination and cooperation among Federal departments and agencies conducting rehabilitation research programs. As co-leader, ICDR is positioned to influence the direction of the work undertaken by the coalition and to encourage inclusion of health disparities concerns of people with disabilities.⁵⁹⁹ Unfortunately, limited funding and staffing have prevented ICDR from fulfilling its research coordination role in the past and may hamper it from exerting sufficient influence on this process to generate the desired outcomes.⁶⁰⁰

H. List of Recommendations

The recommendations presented in previous chapters have been organized into four primary subject matter categories and are listed in this section. This organizational structure facilitates the presentation of recommendations as they relate to specific

problems identified by the study. The categories are (1) research; (2) professional education, training, and technical assistance; (3) monitoring, oversight, and accountability; and (4) improving systemic access to health care services and programs. Recommendations are directed to Congress, the Administration, professional medical and accreditation organizations, states, standards-setting bodies, health care organizations, the health and disability policy and research community, the disability community, and others. Each recommendation is followed by a reference to the chapter in which it first appears.

1. Research

RECOMMENDATION #1.1:

Congress should amend the Minority Health and Health Disparities Research and Education Act to broaden the definition of “health disparity population” found in 42 U.S.C. § 287c-31(d) to encompass “populations for which there is a significant disparity in the quality, outcomes, cost, or use of health care services or access to or satisfaction with such services as compared to the general population,” as specified in 42 U.S.C. § 299a-1(d). This will enable people with disabilities to be included in the health and health care disparities research, program development, professional training, health promotion, and clinical interventions conducted and supported by the National Center on Minority Health and Health Disparities, as well as other Federal agencies that are currently engaged in health disparities research and activities on behalf of racial and ethnic minorities and other geographic and population groups. (See chapter 4.)

RECOMMENDATION #1.2:

Congress should increase funding for the Interagency Committee on Disability Research of the National Institute on Disability and Rehabilitation Research in order to (1) vest it with sufficient resources and authority to fulfill its mandated research coordination role and (2) expand its role to include collaboration with other agencies, including Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), and the Department of

Health and Human Services (HHS) Office on Disability, to identify research areas related to health, health care, and health disparities that lend themselves to interagency collaboration. (See chapter 4.)

RECOMMENDATION #1.3:

The Director of the National Institutes of Health (NIH) should require that institutes and centers within NIH that conduct health disparities research include people with disabilities as a demographic population for the purpose of such research. The Director should also request that the Scientific Management Review Board determine how best to integrate disability and health disparity research into the portfolios of the institutes and centers, and recommend any organizational changes that might be required to achieve this goal. (See chapter 3.)

RECOMMENDATION #1.4:

The Agency for Healthcare Research and Quality (AHRQ), within its mandate to undertake research on priority populations, should promote research that clearly identifies the various barriers encountered by people with disabilities when seeking health care. Such research would help disability health policy researchers and other stakeholders to assemble an accurate picture of, for example, the extent to which health care technologies, facilities, and equipment remain inaccessible to people with various disabilities, and bolster efforts to effect change. (See chapter 3.)

RECOMMENDATION #1.5:

Federal agencies concerned with disability and health—including the Department of Health and Human Services (HHS), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the National Institute for Disability and Rehabilitation Research (NIDRR), and the Access Board—should develop mechanisms to undertake research that investigates the economic and systemic implications, as well as the impact of barriers to health care access, on people with disabilities, and the potential for enhanced efficiency and cost savings through improved access. (See chapter 4.)

Recommendation #1.6:

The U.S. Surgeon General should lead an effort with other Federal agencies concerned with health care quality for people with disabilities—including the Department of Health and Human Services (HHS) Office of Disability, the Centers for Medicare & Medicaid Services (CMS), the National Institute on Disability and Rehabilitation Research (NIDRR), the Agency for Healthcare Research and Quality (AHRQ), the Access Board, and the Administration for Children and Families (ACF)—in a joint project that will establish principles of universal design for health care facilities and programs. Goals and objectives should be established and key stakeholder actions identified. Drawing on the well-established principles of universal design for the built environment, this collaboration should bring together Federal agency experts, disability and health policy researchers, leading disability and health practitioners (e.g., physicians who specialize in caring for women with disabilities, people who are deaf or hard of hearing, and people with intellectual and developmental disabilities, as well as vision rehabilitation experts), and people with disabilities to participate in the process. The Surgeon General should publish a report of findings that builds on previous publications, such as “Call to Action To Improve the Health and Wellness of Persons with Disabilities,” “Closing the Gap: A National Blueprint To Improve the Health of Persons with Mental Retardation,” and “Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation.” (See chapter 4.)

Recommendation #1.7:

Federal agencies that undertake health research for people with disabilities, such as the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), and the Administration for Children and Families (ACF), should undertake studies that document the extent to which the health care needs of women with disabilities, people who are deaf or hard of hearing, people with intellectual and developmental disabilities, and people who are blind or have vision impairments are being met. Such studies should use

outcome-oriented approaches and will provide a foundation for developing crosscutting, universal quality-of-care guidelines. (See chapter 5.)

Recommendation #1.8:

A regularly conducted national survey of physicians and other health care providers should be developed. Such a survey could begin with Medicare and Medicaid providers, because they receive Federal financing for their services. However, the ultimate goal would be to have a nationally representative sample of all providers. Information should be collected from providers on (1) demonstrated physical accessibility, (2) demonstrated capacity to provide programmatic accessibility, (3) level of knowledge and confidence in treating patients with disabilities, and (4) disability training and cultural competency of office staff. (See chapter 5.)

Recommendation #1.9:

Ongoing research activities must continue to develop a valid and reliable set of survey questions that identify people with disabilities, and these questions must be included in all regularly conducted national surveys. The standardized questions should be included in the core of all surveys, but surveys that already contain additional data items should continue to use them, to permit more detailed and nuanced analyses. Specifically:

- Behavioral Risk Factor Surveillance System (BRFSS) should include the standardized question set in its core (substituted for the two questions currently in its core).
- The Consumer Assessment of Healthcare Providers and Systems (CAHPS) should add the standardized disability questions to its core.
- The Medicare Beneficiary Survey (MCBS) has a number of disability indicator questions, but they should be part of the standardized set. (See chapter 5.)

Recommendation #1.10:

Reliable and valid questions that can identify people with intellectual and mental health disabilities should be developed and regularly used in major surveys. In addition, the major national surveys should develop and use, on a regular basis, questions that identify, in separate categories, people who are blind, vision-impaired, deaf, or hard of hearing. Such questions should be asked of all respondents, not just those over 40 years of age, as is currently the case for questions concerning vision loss in Module 4 of the Behavioral Risk Factor Surveillance System (BRFSS). (See chapter 5.)

Recommendation #1.11:

Surveys that ask questions about access and utilization of care should provide answer options that enable respondents to indicate disability-related problems with access. For example, the reasons for delaying or going without care should include options about physician office equipment and other accessibility issues, and about physician disability competence and acceptance of patients with disabilities. Questions that can provide data with respect to policies for eligibility for use of public health programs and benefits are also needed. (See chapter 6.)

Recommendation #1.12:

The Agency for Healthcare Research and Quality (AHRQ) and the National Center for Health Statistics (NCHS) should include people with disabilities as one of the population groups in the tables that comprise the annual reports derived from the Medical Expenditure Panel Survey (MEPS) and National Health Interview Survey (NHIS) datasets. Data on people with disabilities should be crossed with the health care access indicators, and reporting should provide dual demographic status and access (e.g., access data for disability/gender; disability/race/ethnicity groupings). (See chapter 5.)

Recommendation #1.13:

Federal support is imperative for research to investigate the outcome of wellness and prevention programs and services for people with disabilities, and attention is

needed in other wellness/prevention research to ensure that people with disabilities have access to such programs and services (with appropriate data collected about their experiences and outcomes). (See chapter 5.)

Recommendation #1.14:

Incentives and directives are needed to increase the use of the existing optional disability modules or supplemental questions in the national surveys, especially for the Behavioral Risk Factor Surveillance System (BRFSS), the Medical Expenditure Panel Survey (MEPS), the National Health Interview Survey (NHIS), and possibly the Consumer Assessment of Healthcare Providers and Systems (CAHPS). States should be directed to use the modules or questions on a periodic basis; funds as an incentive to implement should be offered to support their use. (See chapter 5.)

Recommendation #1.15:

Modules that ask about specific disability access issues should be developed. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Mobility Impairment module is a good example, but the module should be applicable more broadly and in more surveys. This would provide an alternative to mounting a national special survey. However, a survey such as the National Health Interview Survey-D (NHIS-D) should be conducted at a minimum once every 10 years. (See chapter 5.)

Recommendation #1.16:

Survey sampling and data collection should be designed to include people living in institutional settings and group quarters, especially in community-based group quarters. Surveys should be conducted in a manner that does not exclude people who do not communicate by telephone or do not have telephones. Translations for American Sign Language (ASL) should be made for the major surveys to ensure the inclusion of people who use ASL as their primary language. (See chapter 5.)

Recommendation #1.17:

Federal agencies concerned with improving access to appropriate and effective health care for people with disabilities—including the Agency for Healthcare

Research and Quality (AHRQ), the National Institute on Disability and Rehabilitation Research (NIDRR), the Administration for Children and Families (ACF), and the Centers for Disease Control and Prevention (CDC)—should establish an interagency collaboration to produce guidelines that identify universal and crosscutting elements of quality measures that will drive delivery of health care in general and also for diverse people with disabilities. This endeavor should be undertaken in collaboration with agency experts, disability and health policy researchers, leading disability and health practitioners (e.g., physicians who specialize in caring for women with disabilities, people who are deaf or hard of hearing, or people with intellectual and developmental disabilities, as well as vision rehabilitation experts), and people with disabilities. The guidelines should be disseminated widely and promoted in medical education programs and among practitioners. (See chapter 7.)

Recommendation #1.18:

The Institute of Medicine (IOM) of the National Academies of Science should include the topic of health disparities experienced by people with disabilities in its workshops and roundtables on health disparities. IOM should expand on recommendations presented in its 2006 report critiquing the National Institutes of Health (NIH) interagency disparity activities to include a recommendation that disability health disparities be acknowledged as a national problem. IOM should also urge the development of programs and strategies to reduce health disparities for people with disabilities. (See chapter 4.)

2. *Professional Education, Training, and Technical Assistance*

Recommendation #2.1:

Congress should establish a technical assistance system through which states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on universal standards of care and related practical resources for ensuring full access to culturally competent health care services for people with disabilities. (See chapter 6.)

Recommendation #2.2:

Agencies of the Federal Government, including the institutes and centers of the National Institutes of Health (NIH) that are involved in providing Federal grants and Federal loans, including loan forgiveness programs for medical education, should require that medical training institutions whose students receive support include in their training curriculums material that ensures that graduates will possess disability knowledge, cultural competency, and a basic capacity to work effectively with people with disabilities. (See chapter 1.)

Recommendation #2.3:

The Health Resources and Services Administration (HRSA) should designate people with disabilities or subgroups of the population as medically underserved populations. Such a designation will open opportunities for physicians, physician assistants, and dentists who choose to provide health care services for a significant number of patients with disabilities in their practices to apply for Federal student loan forgiveness. (See chapter 4.)

Recommendation #2.4:

Federal agencies concerned with health care quality for people with disabilities—including the Agency for Healthcare Research and Quality (AHRQ), the National Institute on Disability and Rehabilitation Research (NIDRR), and the Access Board—should develop a best practices guide to help providers (a) recognize that universal design goes beyond Americans with Disabilities Act (ADA) requirements and (b) understand methods of implementing and evaluating universal design principles in health care settings. This guide should also profile organizations that have implemented best practices, including their methods and outcomes. (See chapter 7.)

Recommendation #2.5:

Federal agencies—including the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and the Department of Health and Human Services (HHS) Office of Disability—should

collect and disseminate information about models for improving access to care for people with disabilities. (See chapter 7.)

Recommendation #2.6:

The Association of American Medical Colleges (AAMC) and the Liaison Committee on Medical Education (LCME) should convene a workgroup charged with identifying specific disability competencies that should be required of health care professionals before graduation from medical and residency training programs, and translate these competencies into specific course recommendations that can be adopted by medical training programs. Competencies should include the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with intellectual and developmental disabilities; awareness of language and cultural issues related to the Deaf community; and general awareness of health care issues and concerns of people who are blind or have vision impairments, women with disabilities, and others within the disability community. (See chapter 6.)

Recommendation #2.7:

The Registry of Interpreters for the Deaf should consider creating a specialist certification for medical and mental health interpreting. Such a certification should be developed in collaboration with the organizations that are currently providing medical training for interpreters, with organizations of people who are deaf, and with individuals who are deaf or hard of hearing. (See chapter 7.)

Recommendation #2.8:

Radiology technician training and certification programs should adopt key elements of the training program that the Breast Health Access for Women with Disabilities (BHAWD) has created and implemented for helping radiology technicians learn techniques for performing mammograms on women with diverse disabilities. All training programs should incorporate these key elements into training curriculums and licensing examinations. (See chapter 7.)

3. *Monitoring, Oversight, and Accountability*

Recommendation #3.1:

The U.S. Department of Justice (DOJ) must step up monitoring and enforcement of the Americans with Disabilities Act (ADA) and Section 504 of the 1973 Rehabilitation Act for health care facilities and programs. DOJ must focus additional resources on compliance monitoring and investigation of Title III complaints concerning programmatic access violations of the ADA and Section 504 by health care providers. (See chapter 1.)

Recommendation #3.2:

Congress should direct the Department of Health and Human Services (HHS) to identify performance standards that must be included as a condition of receiving Federal financial assistance to ensure that states, health plans, managed care organizations, and health care providers who receive Federal health care funds under Medicaid, the State Children's Health Insurance Program (SCHIP), and other Federal programs that pay for health care for people with disabilities meet the minimum requirements of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that they possess sufficient cultural competency to provide effective health care to people with disabilities. (See chapter 1.)

Recommendation #3.3:

Congress should create and fund an Office of Disability and Health in the Office of the Director at the Centers for Disease Control and Prevention (CDC) to mandate and oversee integration of disability issues into all CDC programs. (See chapter 4.)

Recommendation #3.4:

The Secretary of the U.S. Department of Health and Human Services (HHS) should require substantive evidence of compliance with Title V of the Social Security Act's Section 504 nondiscrimination provision from every state that receives funding under the Maternal and Child Health Services (MCH) Block Grant program.

States that receive Maternal and Child Health Services Block Grant (MCH Block Grant) funding should link their responsibility for ensuring disability nondiscrimination in Title V programs, as expressly incorporated in the statute, with their existing reporting requirements. For example, currently required information on the number of maternal and child-health-related providers licensed in the state in a year should incorporate information on the degree to which those providers have received training in the accessibility needs of children with disabilities. Currently required information on the proportion of women who did not receive prenatal care during the first trimester of pregnancy should include information on whether the mother had a disability along with currently collected information about her racial and ethnic group. Moreover, indicators specific to the structural and programmatic accessibility of maternal and child care providers in Title V programs should be systematically incorporated in the annual audits. (See chapter 3.)

Recommendation #3.5:

The Department of Health and Human Services (HHS), the U.S. Department of Justice (DOJ), the Centers for Medicare & Medicaid Services (CMS), and the U.S. Access Board should enter into an interagency agreement to identify and adopt performance standards to ensure that states, health plans, managed care organizations, and health care providers who receive Federal health care funds under Medicaid, the State Children's Health Insurance Program (SCHIP), and other federally funded health care programs meet the minimum requirements of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that they possess sufficient cultural competency to provide effective health care for people with disabilities. Such methods could include a Federal contractual requirement that states, health plans, and providers collect and submit data concerning architectural and programmatic accessibility, capacity to accommodate patients with disabilities, and a showing of cultural competency and disability awareness. Such a contractual obligation should also include regular monitoring mechanisms. (See chapter 1.)

Recommendation #3.6:

State Medicaid agencies that accept matching Federal monies must ensure that all Medicaid enrollees, including enrollees with disabilities, receive equal access to all aspects of the health care delivery system. Regulations enacted under Title XIX of the Social Security Act place ultimate responsibility for access to health care with the states. Each state is required to have a state Medicaid plan that “must ensure that all services covered under the State plan are available and accessible to enrollees of MCOs [managed care organizations], PIHPs [prepaid inpatient health plans], and PAHPs [prepaid ambulatory health plans].” The plans must include mechanisms to monitor and collect information about the extent of structural and programmatic access problems.

The continuing presence of structural and programmatic barriers within the multiple levels of a state’s Medicaid health care system is an ongoing violation of the Medicaid program regulations and greatly contributes to the health care disparities experienced by people with disabilities. The state system may begin with Medicaid enrollment and extend to making health care appointments, as well as to actual health care examinations and treatment. (See chapter 3.)

Recommendation #3.7:

State Medicaid agencies and health maintenance organizations (HMOs) should notify enrollees with disabilities of their Federal accessibility rights, as well as the right to auxiliary aids where necessary, either for effective notice or to provide equal benefit from the service in question, as established in Section 504. State Medicaid agencies and HMOs that receive Federal financial assistance must acknowledge and act on their own generally greater financial and administrative capacity (compared with individual health care providers) to set policies and procedures that will inform, provide incentives, monitor, and enforce accessibility requirements among the providers that deliver health care services. (See chapter 3.)

State Medicaid agencies and health maintenance organizations (HMOs) should notify enrollees with disabilities of their Federal accessibility rights, as well as the

right to auxiliary aids where necessary, either for effective notice or to provide equal benefit from the service in question, as established in Section 504. State Medicaid agencies and HMOs that receive Federal financial assistance must acknowledge and act on their own generally greater financial and administrative capacity (compared with individual health care providers) to set policies and procedures that will inform, provide incentives, monitor, and enforce accessibility requirements among the providers that deliver health care services. (See chapter 3.)

Recommendation #3.8:

States should develop mechanisms whereby health insurers, managed care organizations, and other health plans provide assurances that the health care providers (e.g., hospitals, clinics, diagnostic centers, provider offices, and laboratories) with whom they contract for Medicaid and other federally funded health care services provide physical and programmatic access for people with disabilities. Such mechanisms could include annual physical and programmatic access surveys of providers and adherence to other performance standards by health care providers that would be required to renew health service delivery contracts. Failure to provide the required information to appropriate state agencies should result in contract termination. (See chapter 1.)

Recommendation #3.9:

Health care accreditation organizations must play a primary role in ensuring that health care delivery provided to people with disabilities meets basic standards of cultural competency and accessibility. Accreditation bodies should evaluate health care institutions on the basis of the extent to which they meet minimum architectural accessibility in accordance with the Americans with Disabilities Act (ADA) Architectural Guidelines (ADAAG); reward the implementation of universal design principles in health care settings; have established mechanisms for ensuring that programmatic accommodations are provided (e.g., sign language interpreters, height-adjustable examination tables, wheelchair-accessible weight

scales, lifting assistance, and materials in alternative formats); and have established grievance procedures that ensure that people with disabilities can resolve problems in a timely way. (See chapter 6.)

4. *Improving Systemic Access to Health Care Services and Programs*

Recommendation #4.1:

Congress should ensure that reform of the health care system in the United States responds to the basic needs of people with disabilities by making certain that health care coverage is available and affordable to all people with disabilities without pre-existing condition limitations. Benefits made available through either private or public coverage, or a combination, must include access to appropriate prescription medications, specialty care, care coordination, durable medical equipment and assistive devices, and long-term care services. Any co-insurance payments must be affordable and annual or lifetime limits on these key benefits must not be permitted. Health care reform efforts must also take into account the fact that achieving health care equity for people with disabilities also includes the additional dimensions of physical and programmatic accessibility and health provider disability cultural competency. Some key elements of these additional dimensions can include the need for more time for medical visits for some people with disabilities, methods that ensure effective communication including provision of sign language interpreters and educational and instructional materials in accessible formats, and accessible diagnostic and other common medical office equipment such as height-adjustable exam tables and wheelchair accessible weight scales. To the extent possible, methods must be established to ensure that these essential elements are readily available when health care is delivered. Examples of possible methods to ensure they are provided include reimbursement for sign language interpreters by public and private insurers, new tax credits or other tax benefits that help offset costs, equipment sharing, and other schemes that create incentives for health care providers to acquire necessary equipment and services that are needed by patients with disabilities. (See chapter 1.)

Recommendation #4.2 :

Congress should direct the Centers for Medicare & Medicaid Services (CMS) to establish a mechanism to pay for American Sign Language (ASL) interpreters when they are required for deaf or hard-of-hearing beneficiaries of Medicare, Medicaid, the State Children’s Health Insurance Program (SCHIP), and other federally funded health care to ensure that people who are deaf or hard of hearing who use sign language receive effective services from health care providers—including mental health providers, clinics, hospitals, diagnostic centers, and laboratories—and in other health care settings. (See chapter 1.)

Recommendation #4.3:

Congress should direct the Centers for Medicare & Medicaid Services to identify and implement mechanisms to pay for vision rehabilitation services and assistive devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and Medicare programs or other federally subsidized health care. (See chapter 1.)

Recommendation #4.4:

Congress should amend the Public Health Service Act, which established the Substance Abuse and Mental Health Services Administration (SAMHSA) to include an emphasis on people with disabilities through the following changes:

- Add a directive that identifies people with disabilities. Such a directive could be modeled after the existing directive to work with the National Institutes of Aging, Drug Abuse, Alcohol Abuse and Alcoholism, and Mental Health to “promote and evaluate substance abuse services for older Americans in need of such services, and mental health services for older Americans who are seriously mentally ill.”
- Amend the specific provision that ensures “that services provided with amounts appropriated under this subchapter are provided bilingually, if appropriate” to

include the provision of effective methods of communication for people who are deaf or hard of hearing, including sign language interpreters.

- Include mental health and substance abuse issues of concern to women with disabilities among the identified duties of the associate administrator and the Advisory Committee for Women's Services, which ensure that "the unique needs of minority women, including Native American, Hispanic, African American, and Asian women, are recognized and addressed" in SAMHSA's activities. This should include aspects of substance abuse and mental illness that are (a) unique to or more prevalent among women, or (b) characterized by insufficient services or data involving women. (See chapter 3.)

Recommendation #4.5:

The Centers for Medicare & Medicaid Services (CMS) should establish a mechanism to pay for sign language interpreters when they are required for beneficiaries of Medicare, Medicaid, the State Children's Health Insurance Program (SCHIP), and other federally funded health care, to ensure that people who are deaf or hard of hearing who use sign language receive effective services from health care providers, including mental health providers, clinics, hospitals, diagnostic centers, and laboratories. (See chapter 1.)

Recommendation #4.6:

The Centers for Medicare & Medicaid Services (CMS) should identify and implement mechanisms to pay for vision rehabilitation services and assistive devices for people who are blind or have vision impairments who are beneficiaries of the Medicaid and Medicare programs. (See chapter 1.)

Recommendation #4.7:

The U.S. Department of Health and Human Services (HHS) should direct key Federal agencies charged with health promotion and disease prevention to collaborate and implement methods that ensure that people with disabilities are fully included in health promotion and disease prevention research, program

development, public education, and development of best practices. (See chapter 1.)

Recommendation #4.8:

The Centers for Medicare & Medicaid Services (CMS) should identify and support methods for providing coordinated primary health care to people with certain disabilities and multiple disabilities (for example, mobility or developmental disabilities) in home or community settings rather than the offices of health care providers to resolve some of the most pressing accessibility, accommodation, and transportation problems identified as barriers to care. The Minnesota UCARE Complete program could serve as a model to guide these deliberations. (See chapter 7.)

Recommendation #4.9:

The Centers for Medicare & Medicaid Services (CMS) should update their current definitions of durable medical equipment and medical necessity, which are outdated and give little consideration to increasing an individual's functional status. The current patchwork of both Federal and state health care and private insurance coverage contains barriers and gaps that leave many people with disabilities unable to obtain needed assistive technology. As a starting point, more consistent and coherent Federal eligibility and reimbursement policies are needed. New definitions of medical necessity are needed to ensure that effective assistive technology will be deemed eligible for coverage and reimbursement. (See chapter 1.)

Recommendation #4.10:

States should enact legislation that requires health insurers either to pay for sign language interpreters through employer-based group health insurance plans or to pay directly into a state fund or another mechanism established specifically to cover ASL interpreter expenses for people who are deaf who receive health care services through a private insurance plan. (See chapter 1.)

I. Conclusion

People with disabilities bear a disproportionate burden of poor health compared with the general population and use preventive services at a lower rate than people who do not have disabilities. For many, health care in the United States is not always available or affordable, and gaps in coverage can present insurmountable obstacles to obtaining appropriate care and maintaining good health. Lack of health care provider education and disability cultural awareness and competency also creates significant barriers for people with disabilities when they try to access care. Other common and pervasive barriers to care include health care provider misperceptions and disability stereotypes that can lead to ineffective and inappropriate care, lack of accessible equipment such as common office exam tables, lack of written information provided in accessible alternative formats, and ineffective provider-patient communication when sign language interpreters are not provided or there is not enough time to communicate adequately with a patient who has a speech or cognitive disability. At the same time, social, economic, and cultural factors such as poverty, lack of transportation, and fragmented support services further contribute to poor health and health outcomes for some people with disabilities.

The root causes of these longstanding health and health care inequities involve multiple, complex factors that are embedded in the historical evolution of the nation's health care structure, and the parallel research and public health emphasis on disability prevention and cure. One especially serious outcome of this evolutionary process is a highly fragmented health care delivery system, which is unable to reconcile the competing interests of cost containment and patient-centered care, which is an important tool for achieving culturally competent care for people with disabilities. Another current manifestation of the historic public health emphasis on disability prevention is the slow pace at which the research community has moved in acknowledging disability as a demographic indicator that should be considered in health disparities research. Disability is slowly gaining acceptance and recognition as a bona fide population demographic, thanks in part to the Surgeon General's reports and the leadership of "Healthy People 2010." The Federal Government, however, has yet to

identify disability health disparities as a high research priority or call for a robust, coordinated, multiagency effort to identify the reasons such disparities exist. Although more than a dozen bills on research and funding strategies to improve the health status of groups experiencing health disparities were introduced in the 110th Congress in 2007, not one identified people with disabilities as a group experiencing health disparities rather than as a group whose diagnosis is to be avoided or prevented.

As with any other identifiable minority group whose basic health care needs are not being met, the impact of physical, financial, cultural, socioeconomic, and other environmental barriers on the ability of people with disabilities to obtain needed care must be acknowledged and identified. The health inequities that people with disabilities experience must not be reduced to a matter of individual genetics as researchers continue to explore the interconnections between economic, social, and other environmental factors and individual or minority group health.

Immediate action must be taken where existing research reveals the clear need for such strategies as enhanced health care provider education, greater clinical research, enhanced payment systems, and the removal of policy and procedural barriers and other physical barriers to receiving quality health care services. It is equally critical that accurate and integrated data be collected for people with disabilities to ensure continuing progress in addressing health and health care inequities.

There is no simple solution to the complex and entrenched problems people with disabilities experience when they seek health care. Key elements of any move toward reform must include action by Congress and Federal agencies that have a role in health care. Professional medical associations, organizations of medical educators, accreditation organizations, and the public health community must also turn their attention to the issues. The disability community must continue in its leadership, advocacy, and watchdog roles, and must participate in state and national discussions about health care reform.

APPENDIX A. Key Informant Interviewees and Informational Interviewees

Key Informant Interviewees

Anita Aaron
Executive Director
LightHouse for the Blind and Visually
Impaired
214 Van Ness Ave.
San Francisco, CA 94102
415-694-7348
415-431-1481

Barbara Altman, Ph.D.
Formerly, Special Assistant on Disability
Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
14608 Mellinda Lane
Rockville, MD 20853
301-460-5963

Brian Armour
Health Scientist
Division of Human Development and
Disability
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333
800-232-4636

Steven Barnett, M.D.
Department of Community & Preventive
Medicine
National Center for Deaf Health Research
University of Rochester
P.O. Box 278990
Rochester, NY 14627-8990
866-901-0727 (voice/VRS)

Vincent Campbell, Ph.D.
Associate Director for Science
Disability and Health Team
Division of Human Development and
Disability
CDC/National Center on Birth Defects and
Developmental Disabilities
1600 Clifton Rd.
Mail Stop E-88
Atlanta, GA 30333
404-498-3012

Leighton Chan, M.D., M.P.H.
Chief
[Rehabilitation Medicine Department](#)
NIH Clinical Center
National Institutes of Health
Bethesda, MD
301-496-4733

Tracie Harrison, Ph.D.
Assistant Professor
School of Nursing
The University of Texas at Austin
1700 Red River St.
Austin, TX 78701
512-471-7311
512-471-7913

Teri Hedding
Manager, Deaf Access Program
Sinai Health Systems
1501 S. California Ave.
Chicago, IL 60608
TTY/VP: 773-257-6289
773-257-5125
773-257-2124

Gary Kauffman, M.D.
Director, Deaf Access Program
Mt. Sinai Hospital
1500 S California Ave.
Chicago, IL 60608
773-542-2000

Gloria Krahn, Ph.D., M.P.H.
Director, OIDD
Child Development and Rehabilitation
Center
Oregon Health & Science University
503-494-7410
(Subsequent to her interview, Dr. Krahn
became the Director of the Division of
Human Development and Disability
(DHDD) at the National Center for Birth
Defects and Developmental Disabilities
(NCBDDD) within the Centers for Disease
Control and Prevention.)

Clarissa Kripke, M.D., FAAFP
Associate Clinical Professor
Department of Family and Community
Medicine
University of California, San Francisco
UCSF Family Medical Center, Lakeshore
500 Parnassus Ave.
MU3E, Box 0900
San Francisco, CA 94143
415-353-3253

Linda M. Long, Esq.
Adjunct Clinical Instructor
University of Massachusetts Medical
School
Center for Health Policy Research
222 Maple St.
Shrewsbury, MA 01545
617-686-3054

Bonnie O'Day, Ph.D.
Mathematica Policy Research, Inc.
600 Maryland Ave., SW, Suite 550
Washington, DC 20024-2512
202-484-9220

Janet O'Keefe, Dr. P.H., R.N.
Senior Researcher and Policy Analyst
Aging, Disability and Long-Term Care
RTI International
1278 N Robinson Dr.
Macon, NC 27551
252-257-2433

Susan L. Parish, M.S.W., Ph.D.
Associate Professor School of Social Work
University of North Carolina
Tate-Turner-Kuralt Building
325 Pittsboro St.
CB 3550
Chapel Hill, NC 27599-3550
919-962-6434

Constance Pledger
Executive Director
Interagency Committee on Disability
Research (ICDR)
U.S. Department of Education
550 12th Street, SW., Room 6039,
Potomac Center Plaza (PCP)
Washington, DC 20202-2700
202-245-7480

Brenda Premo
Executive Director
Center on Disability Issues and the Health
Professions
Western University of Health Sciences
309 E. Second St.
Pomona, CA 91766-1854
909-469-5441

Elizabeth Rasch
Staff Scientist
NIH – Mark O. Hatfield Clinical Research
Center
Rehabilitation Medicine Department
Bethesda, MD
301–594–3090

Amy E. Rauworth, M.S., R.C.E.P.
Associate Director, National Center on
Physical Activity and Disability
University of Illinois at Chicago (M/C 626)
1640 W. Roosevelt Rd., Room 607
Chicago, IL 60608
312–355–1584

Harvey A. Schwartz, Ph.D., M.B.A.
Senior Advisor, Priority Populations
Agency for Healthcare Research and
Quality
540 Gaither Rd.
Suite 2050
Rockville, MD 20850
301–427–1552

Arthur M. Sherwood
Science and Technology Director
National Institute on Disability and
Rehabilitation Research (NIDRR)
Office of Special Education and
Rehabilitative Services
400 Maryland Ave., SW.
Washington, DC 20202
202–245–7522

Informational Interviewees

Marty Barnum
Director, Interpreting Operations
Communication Service for the Deaf of
Minnesota
Metropolitan Hospital Consortium
2055 Rice St.
St. Paul, MN 55113
651–487–8879

Steven J. Taylor, Ph.D.
Co-Director
Professor of Cultural Foundations of
Education
Director of the Center on Human Policy
Coordinator of Disability Studies
School of Education
Syracuse University
Syracuse, NY 13244–2280
315–443–3851

JoAnn M. Thierry
Scientific Program Officer
Centers for Disease Control and Prevention
Coordinating Center for Health Promotion
Extramural Research Program Office
4770 Buford Hwy. N.E.
Mailstop K–92
Atlanta, GA 30341
770–488–8253

Kris Vertiz
Director, Deaf Access Program and
Extended Services Dept.
Schwab Rehabilitation Hospital
1401 S. California Blvd.
Chicago, IL
773–522–5869

Shelby Benton
Case Coordinator
Blindness Support Services
3696 Beatty Dr., Suite A
Riverside, CA 92506
951–341–6333

Lynn U. Berman
Senior Media Relations Manager
Premier HealthCare
YAI/National Institute for People with
Disabilities Network
460 West 34th St.
New York, NY 10001-2382
212-273-6199
203-981-6938

Allan Brenner
Executive Director/CEO
The Earle Baum Center
4539 Occidental Rd.
Santa Rosa, CA 95401
707-523-3222

Marco Damiani
Director, Clinical and Family Services
YAI/National Institute for People with
Disabilities
YAI/NIPD Network
460 West 34th St.
New York, NY 10001-2382
212-273-6182

Pam Dodge
Director of Ambulatory/Outpatient Care
University of Pittsburgh Medical Center
Magee Hospital
Center for Women with Disabilities
300 Halket St.
Pittsburgh, PA 15213-3180
412-641-1011

Kenneth Frasse
CEO/Executive Director
Santa Clara Valley Blind Center
101 North Bascom Ave.
San Jose, CA 95128
408-295-4016, ext. 201

Wendy Geringer
Director, Research and Program
Development
Westchester Institute for Human
Development
Cedarwood Hall
Valhalla, NY 10595
914-493-8150

Joyce A. Hunter, Ph.D.
Deputy Director
National Center on Minority Health and
Health Disparities
National Institutes of Health
6707 Democracy Blvd., Suite 800
Bethesda, MD 20892-5465
301-402-1366

Amie Jackson, M.D.
Spain Rehabilitation Center
Disabled Women's Health Center
Chairman, Physical Medicine &
Rehabilitation, University of Alabama
UAB Health System
1802 6th Ave. South
Birmingham, AL 35249
205-934-3330

Richard Laurion
External Liaison and Project Manager
CATIE Center
The College of St. Catherine
2004 Randolph Avenue, #4280
St. Paul, MN 55105
651-690-6973
651-690-6727
Videophone: 140-225-24-13

Jessie Lorenz
Director, Public Policy and Information
LightHouse for the Blind and Visually
Impaired
214 Van Ness Ave.
San Francisco, CA 94102
415-694-7361

Florita Toveg Maiki
Alta Bates Summit Medical Center
(ABSMC)
Manager
Breast Health Access for Women with
Disabilities (BHAWD)
Berkeley, CA 94704
510-204-4522

Cate McClain, M.D.
Director, Center for Development and
Disability
Health Sciences Center
University of New Mexico
2300 Menaul Blvd. NE.
Albuquerque, NM 87107
505-272-3000

Margaret Nosek, Ph.D.
Executive Director
Center on Research on Women with
Disabilities (CROWD)
Department of Physical Medicine and
Rehabilitation
Baylor Medical College
3440 Richmond, Suite B
Houston, TX 77046
1-800-442-7693

Robert Pollard, M.D.
Director, Deaf Wellness Center
University of Rochester Medical Center
300 Crittenden Blvd.
Rochester, NY 14642
585-275-3544

Judith Panko Reis
Director, Women with Disabilities Center (WWDC)
Rehabilitation Institute of Chicago
345 E. Superior St.
Chicago, IL 60611
1-800-883-3931

Dr. Eleanor Rosenfield
Associate Dean, Student & Academic
Services
National Technical Institute for the Deaf
Rochester Institute of Technology
52 Lomb Memorial Dr.
Rochester, NY 14623
TTY/VP: 585-475-6202

Judy Struck, Executive Director
Center for Disabilities
South Dakota Rosebud Developmental
Clinic
Sanford School of Medicine
University of South Dakota
Vermillion, SD 57069
605-357-1468
Kris Vertiz
Director
Deaf Access Program
Schwab Rehabilitation Hospital
1401 S. California Blvd.
Chicago, IL 60608
773-522-5869

APPENDIX B. NCD Health Care Summit Participant List, April 2008

1. James A. Bostrom
Deputy Chief, Disability Rights Section
Civil Rights Division
U.S. Department of Justice
950 Pennsylvania Ave., NW.
Washington, DC 20530
Jim.bostrom@usdoj.gov
2. L. Irene Bowen
Deputy Chief
Disability Rights Section
U.S. Department of Justice
9 Montvale Ct.
Silver Springs, MD 20904
l.irene.bowen@usdoj.gov
3. Rebecca Brashler, L.C.S.W.
Clinical Educator, The Donnelley Family
Disability Ethics Program
Director of Inpatient Care Management
and Family Support
The Rehabilitation Institute of Chicago
345 East Superior St., Room 1378
Chicago, IL 60611
rbrashler@ric.org
4. Mary Lou Breslin
Senior Policy Advisor
Disability Rights Education and Defense
Fund (DREDF)
2212 Sixth St.
Berkeley, CA 94710
www.dredf.org
5. Victoria Ray Carlson
Council Member, National Council on
Disability
Naperville, IL 60564
Victoria79@wowway.com
6. John H. Catlin, FAIA
Partner, LCM Architects
819 South Wabash Ave., Suite 509
Chicago, IL 60605
jcatlin@lcmarchitects.com
7. Carmen A. Cicchetti, M.Ed., M.A.
Business Support Manager
The Donnelley Family Disability Ethics
Program
The Rehabilitation Institute of Chicago
345 East Superior St., Room 1374
Chicago, IL 60611
ccicchetti@ric.org
8. Raymond H. Curry, M.D.
Dean of Education
Northwestern University Feinberg
School of Medicine
303 East Chicago Ave., Ward 4–161
Chicago, IL 60611–3008
rcurry@northwestern.edu
9. Kaylan M. Dunlap
Evan Terry Associates, P.C.
1 Perimeter Park South, Suite 200S
Birmingham, AL 35243
kdunlap@evanterry.com
10. Julia Epstein, Ph.D.
Director, Development and
Communications
Disability Rights Education and Defense
Fund
2212 Sixth St.
Berkeley, CA 94710
jepstein@dredf.org

11. Rick Erdtmann, M.D., M.P.H.
Director, Board on Military and Veterans
Health & the Medical Follow-up
Agency
Institute of Medicine, National
Academies
500 Fifth St., NW.
Washington, DC 20001
rerdtmann@nas.edu
12. Amy Freeland
Consultant, American Foundation for the
Blind
Portage, MI 49024
Amy.L.Freeland@wmich.edu
13. Margaret Giannini, M.D., F.A.A.P.
Director
Health and Human Services Office on
Disability
200 Independence Avenue, SW
Suite 637D
Washington, DC 20201
Lee.watson@hhs.gov
14. Janice Ford Griffin
National Program Director
Community Health Leaders
Robert Wood Johnson Foundation
P.O. Box 2316
Route 1 and College Rd. East
Princeton, NJ 08543
jgriffin@rwjf.org
15. Susan Henderson
Executive Director
Disability Rights Education and Defense
Fund
2212 Sixth St.
Berkeley, CA 94710
shenderson@dredf.org
16. Rosemary B. Hughes, Ph.D.
Senior Research Scientist
Rural Institute—Corbin 52
The University of Montana
Missoula, MT 59802
rhughes@ruralinstitute.umt.edu
17. Lisa I. Iezzoni, M.D., M.Sc.
Professor of Medicine
Harvard Medical School
Associate Director
Institute for Health Policy
Massachusetts General Hospital
50 Staniford St., Room 901B
Boston, MA 02114
liezzoni@partners.org
18. June Isaacson Kailes, M.S.W., L.C.S.W.
Associate Director and Adjunct
Associate Professor
Center for Disability Issues and the
Health Professions
Western University of Health Sciences
309 E. Second St.
Pomona, CA 91766
jik@pacbell.net
19. Kristi L. Kirschner, M.D.
Coleman Foundation Chair in
Rehabilitation Medicine
Director
The Donnelley Family Disability Ethics
Program
The Rehabilitation Institute of Chicago
345 East Superior St., Room 1136
Chicago, IL 60611
kkirschner@ric.org
20. Mitchell Loeb, M.Sc.
Research Fellow
Office of Analysis and Epidemiology
National Center for Health Statistics
3311 Toledo Rd.
Hyattsville, MD 20782
gze1@cdc.gov

21. Nancy Mudrick, Ph.D.
Professor
School of Social Work
College of Human Ecology
Sims Hall, 4th Floor
Syracuse University
Syracuse, NY 13244–1230
mudrick@syr.edu
22. Debjani Mukherjee, Ph.D.
Associate Director
The Donnelley Family Disability Ethics
Program
The Rehabilitation Institute of Chicago
345 East Superior Street, Room 1376
dmukherjee@ric.org
23. Judy Panko Reis, M.A., M.S.
Director
Women with Disabilities Center
The Rehabilitation Institute of Chicago
345 East Superior St., Room 164
Chicago, IL 60611
jreis@ric.org
24. Mark Richert, Esq.
Director, Public Policy
American Foundation for the Blind
Public Policy Center
1660 L Street, NW.
Suite 513
Washington, DC 20036
blemoine@afb.net
25. Teresa Savage, Ph.D., R.N.
Consultant
The Donnelley Family Disability Ethics
Program
The Rehabilitation Institute of Chicago
345 East Superior St., Room 1374
Chicago, IL 60611
tsavage@ric.org
26. Harvey A. Schwartz, Ph.D., M.B.A.
Senior Advisor, Priority Populations
Agency for Healthcare Research and
Quality
540 Gaither Rd.
Suite 2050
Rockville, MD 20850
Harvey.Schwartz@ahrq.hhs.gov
27. Paul M. Schyve, M.D.
Senior Vice President
The Joint Commission
1 Renaissance Boulevard
Oakbrook Terrace, IL 60181
pschyve@jointcommission.org
jbradley@jointcommission.org
28. MaryMargaret Sharp-Pucci, Ph.D.,
M.P.H.
Sharp Health Strategies, LLC
1120 Crestview Dr.
Batavia, IL 60510
mmsp@sharpstrat.com
29. Carolyn Stern, M.D.
CEO, DeafDOC.org
Physician, Rochester School for the
Deaf
Physician, Gallaudet University
58 Eastland Ave.
Rochester, NY 14618
deafdoc@aol.com
30. Sue Swenson
Former Executive Director
ARC of the United States
Bethesda, MD
sue.swenson@gmail.com
31. James L. E. Terry, AIA
CEO, Evan Terry Associates, P.C.
1 Perimeter Park South
Suite 200S
Birmingham, AL 35243
jterry@evanterry.com

32. JoAnn M. Thierry
 Scientific Program Officer
 Centers for Disease Control and
 Prevention
 Coordinating Center for Health
 Promotion
 Extramural Research Program Office
 4770 Buford Highway NE.
 Mailstop K-92
 Atlanta, GA 30341
jxt4@cdc.gov
33. Cynthia Wainscott
 Council Member
 National Council on Disability
 Cartersville, GA 30121
wainscott1@bellsouth.net
34. Silvia Yee
 Staff Attorney
 Disability Rights Education and Defense
 Fund
 2212 Sixth St.
 Berkeley, CA 94710
SYee@dredf.org

Biographical Sketches: NCD Health Care Summit Participants

Jim Bostrom is a deputy section chief in the Disability Rights Section of the Civil Rights Division, U.S. Department of Justice. For more than 30 years Mr. Bostrom has focused on accessibility and accessible design, design and human factors research, design consulting, publication development, and technical assistance.

Mr. Bostrom manages the ADA Design Unit and supervises a team of architects, code specialists, and other professional staff. This unit provides key technical expertise for the Section's Americans with Disabilities Act (ADA) enforcement and technical assistance activities and works closely with attorneys, investigators, and information specialists as well as with businesses and state and local governments. Mr. Bostrom's responsibilities also include managing the popular ADA Web site <http://www.ada.gov>, developing technical assistance materials on accessible design and ADA requirements, and serving as senior technical resource to the Division.

Irene Bowen is deputy chief of the Disability Rights Section, in the Civil Rights Division of the U.S. Department of Justice (DOJ), where she supervises litigation and investigations involving both private and public entities under the Americans with Disabilities Act. She has overseen cases in a variety of areas including physical access, higher education, health care, transportation, and effective communication. She spearheaded the Division's litigation against Laurel Hospital, which established criteria

for video relay services and other approaches to effective communication in hospitals; the settlement agreement with Washington Hospital Center, which addressed physical access to buildings as well as equipment such as exam tables; and settlement agreements with several clinics concerning access to equipment. Ms. Bowen was actively involved in the development of the Americans with Disabilities Act and was a member of the task force that developed DOJ's regulations implementing the statute. As the Assistant Attorney General's representative to the Architectural and Transportation Barriers Compliance Board, she was also a key member of the task force charged with developing the Board's ADA Accessibility Guidelines. Ms. Bowen received her J.D. degree from George Washington University. While in law school, she cofounded the National Center for Law and the Deaf, a legal services and advocacy organization for persons with hearing impairments.

Rebecca Brashler, L.C.S.W., is a clinical educator in the Donnelley Family Disability Ethics Program and the director of Inpatient Care Management and Family Support at The Rehabilitation Institute of Chicago. She received her undergraduate degree from the University of Michigan and her M.S.W. from the University of Maryland with a joint certificate in habilitation from the University of Maryland and Johns Hopkins Medical School/Kennedy Institute. Ms. Brashler is a clinical assistant professor at the Feinberg School of Medicine at Northwestern University with appointments in the Department of Physical Medicine and Rehabilitation and the Department of Medical Humanities and Bioethics. She is also an adjunct faculty member at the University of Chicago's School of Social Service Administration.

Mary Lou Breslin has been a disability rights law and policy advocate for more than 35 years. In 1979 she cofounded the Disability Rights Education and Defense Fund (DREDF), a leading national disability rights law and policy center, and presently serves as senior policy advisor with DREDF, directing the organization's special projects. She has served as a policy consultant, trainer, and lecturer on disability and related civil rights topics. Ms. Breslin taught graduate and undergraduate courses at the University of San Francisco, McLaren School of Business, and the University of California at

Berkeley. For 8 years she served as editor and researcher with the Disability Rights and Independent Living Project of the Regional Oral History Office of the Bancroft Library, UC Berkeley. She has written and published on various disability rights topics, most recently on health care and disability. In 2007 Ms. Breslin was honored for her work to improve health care access for people with disabilities by the Independent Living Resource Center, San Francisco, and the San Francisco Mayor's Office on Disability. She received the prestigious Henry B. Betts award in 2002 for improving the lives of people with disabilities and the Paul A. Hearne Award from the Physical and Mental Disability Rights Committee of the American Bar Association in 2000. Ms. Breslin received her undergraduate degree from the University of Illinois and a graduate degree from the University of San Francisco.

Victoria Ray Carlson is a member of the National Council on Disability. Ms. Carlson is a homemaker with three young girls. She was the executive director of the National Multiple Sclerosis Society, Iowa Chapter. She has worked at the U.S. Departments of Energy and Housing and Urban Development and for Senator Robert Dole in the Republican Leader's Office. In addition, Ms. Carlson was the Iowa Organization Coordinator for Branstad for Governor and worked in the Iowa House of Representatives. Ms. Carlson was also a member of the Iowa Persons with Disabilities Commission.

Jack Catlin is a partner at LCM Architects, Chicago. Mr. Catlin has over 20 years of personal and professional experience with disability-related issues. This expertise has led to his involvement in the development of accessibility codes and standards for city, state, and federal agencies; national and international speaking engagements on accessibility compliance issues; and the development of accessibility compliance plans and consultation for many private and public entities. A licensed architect and member of the American Institute of Architects, Mr. Catlin is the first practicing architect to serve as chair of the U.S. Architectural and Transportation Barriers Compliance Board (Access Board). Mr. Catlin's numerous accessibility presentations include national and

international venues. He has also provided training and accessibility consulting to various private and public entities.

Carmen A. Cicchetti, M.Ed., M.A., is the business support manager for the Donnelley Family Disability Ethics Program at the Rehabilitation Institute of Chicago. Previously, he was the director of research for the Office of the Commissioner of Probation in Boston, Massachusetts. Under his leadership, the department became nationally recognized for its innovation in criminal justice research. It was among the first in the nation to develop a valid and reliable risk/needs assessment tool providing objective data on over 260,000 individuals under supervision, an assessment of their relative risk, and an identification of their specific criminogenic needs, which translated into targeted program development. It was the first to systematically develop a wide spectrum of databases, which provided a rich source for numerous studies, influenced significant evidence-based public policy and legislation, led to innovative supervision techniques, and resulted in the first-in-the-nation scientifically valid court staffing formula. Mr. Cicchetti received his undergraduate degree in classics from Loyola University, Chicago, an M.Ed. in counseling from Xavier University in Cincinnati, an M.Div. from the Jesuit School of Theology, Chicago, and an M.A. in community social psychology from Boston College.

Raymond H. Curry, M.D., F.A.C.P., is Dean for Education and Professor of Medicine and Medical Education at Northwestern University Feinberg School of Medicine. Dr. Curry oversees all aspects of undergraduate, graduate, and continuing medical education at Northwestern. In directing graduate medical education throughout the Northwestern system he also serves as president of the McGaw Medical Center of Northwestern University.

A native of Lexington, Kentucky, he is a graduate of the University of Kentucky and of the Washington University School of Medicine in St. Louis. He completed residency training in internal medicine at Northwestern McGaw. A general internist, Dr. Curry is board certified in internal medicine and is currently included in Woodward and White's "Best Doctors in America."

Kaylan Dunlap has served as accessibility specialist specializing in health care with Evan Terry Associates, P.C. for the past 5 years. She is a licensed physical therapist assistant with over 9 years of health care experience in the outpatient rehabilitation and acute care settings, where she was involved with patient care and program development for breast cancer patients and student athletes. Her primary responsibilities with ETA include surveying facilities to identify barriers, preparing reports, quality assurance, project coordination, surveyor training, survey form development, and seminars for organizations such as Kaiser Permanente, Sears/Kmart, Pacific Gas & Electric, J. Paul Getty Museums, and others. Kaylan has developed a special interest in access to health care through her experience as a practitioner as well as her experience with Kaiser Permanente's California facilities.

Julia Epstein is director of communications and development for DREDF and the parent of a child with a disability. Prior to her work with the disability community, Ms. Epstein was a technical writer and editor at PeopleSoft and at Gene Logic. She received a Diplôme Supérieure d'Études Françaises from the Université de Strasbourg, France, in 1972, a B.A. summa cum laude from Washington University in St. Louis in 1973, and M.A. (1976) and Ph.D. (1977) degrees in comparative literature from Cornell University. She has been on the faculties of the College of William and Mary, Drexel University, and Haverford College. At Haverford, where she taught beginning in 1986, she was Barbara Riley Levin Professor of Comparative Literature from 1992 to 1997. Ms. Epstein is the author of "The Iron Pen: Frances Burney and the Politics of Women's Writing" (University of Wisconsin Press, 1989) and "Altered Conditions: Disease, Medicine, and Storytelling" (Routledge, 1995). She is also the coeditor of "Body Guards: The Cultural Politics of Gender Ambiguity" (Routledge, 1991) and "Shaping Losses: Cultural Memory and the Holocaust" (University of Illinois Press, 2001). She has also published several dozen articles on 18th-century literature, legal and medical humanities, and cultural studies.

Frederick (Rick) Erdtmann, M.D., is a graduate of Bucknell University where he received a bachelor of science degree in biology. He attended medical school in

Philadelphia ,where he earned his doctor of medicine degree from Temple University School of Medicine. After completing his internship at the Allentown General Hospital in Allentown, Pennsylvania, he was drafted into the Army and served at Fitzsimons Army Medical Center. He elected to remain on active duty and completed a residency program in General Preventive Medicine at Walter Reed Army Institute of Research in 1975. He is board certified in that medical specialty.

Dr. Erdtmann has had a variety of assignments with the Army Medical Department, including assignments as Chief of the Preventive Medicine Services at Fitzsimons Army Medical Center, Frankfurt Army Medical Center in Germany, and Madigan Army Medical Center. He also served as division surgeon for the Second Infantry Director of the Medical Follow-up Agency and as Office of the Surgeon General, including assignments as chief of the Preventive Medicine Consultant's Division and as director of Health Services. Dr. Erdtmann served as commander of Evans Army Community Hospital from 1995–1997 and as TRICARE lead agent for the Department of Defense Health Service Region 8 from 1996–1997. He later served as deputy chief of staff for clinical operations within DOD's TRICARE Region 1, prior to assuming Hospital Command at Walter Reed Army Medical Center in March 1998. Following that he was assigned to the Office of the Surgeon General as the Deputy Assistant Surgeon General for Force Development.

He holds a master's degree in public health from the University of California at Berkeley and is a graduate of the Industrial College of the Armed Forces. Dr. Erdtmann's special interests include deployment-related medical issues, tropical medicine, and the prevention of communicable diseases. In 2001, following 30 years of commissioned military service, Dr. Erdtmann joined the Institute of Medicine at the National Academies and now serves as director of the Board on Military and Veterans Health and director of the Medical Follow-up Agency.

Amy L. Freeland, M.A., is a certified vision rehabilitation therapist and certified orientation and mobility specialist who is completing coursework for her Ph.D. in Interdisciplinary health sciences at Western Michigan University. Freeland is a fellow

of the National Center for Leadership in Visual Impairment and participates in research, policy, and higher education activities both locally and nationally. Her doctoral studies have allowed her to study health policy economics at the Harvard School of Public Health, and research/program evaluation at Johns Hopkins University's Bloomberg School of Public Health. She has also worked with Pennsylvania College of Optometry in Philadelphia, PA, in the development of a master of public health degree program for blindness clinicians and is currently working as a consultant to the American Foundation for the Blind Public Policy Center in Washington, DC, as a research and policy analyst. Her interests include public health policy; program and training assessments and outcomes; and research to support vision rehabilitation as an integral part of environmental access and healthy living.

Honorable Margaret J. Giannini, M.D., F.A.A.P. was appointed October 1, 2002, as Director of the U.S. Department of Health and Human Service's (HHS) Office on Disability by Secretary Tommy G. Thompson. She serves as advisor to the Secretary on HHS activities relating to disabilities. Prior to becoming Director of the Office on Disability, Dr. Giannini was appointed by President George W. Bush as the Principal Deputy Assistant Secretary for Aging at the HHS. From 1981 to 1992, Dr. Giannini was Deputy Assistant Chief Medical Director for Rehabilitation and Prosthetics at the Department of Veterans Affairs, Washington, DC. There her work focused on technology transfer and assistive technology involving all disabilities. In 1979, President Jimmy Carter appointed Dr. Giannini as the first Director of the National Institute of Handicapped Research, and she was confirmed by the Senate in January of 1980. In 1950, Dr. Giannini created the largest facility for people who have mental retardation and development disability in the United States and the world, which became the first University Center of Excellence on Developmental Disabilities.

Dr. Giannini is the recipient of many national and international awards from various organizations in recognition of her professional and humanitarian services and achievements. Among these, she was saluted by the Association for Pediatric Research; selected "Woman of the Year" for Achievement in Medicine and "Woman-

Doer” by President and Mrs. Lyndon B. Johnson; presented the First Honorary Degree by Mercy College Doctor of Humane Letters; Seton Award from Seton Hall College, Pittsburgh, PA; the First Presidential Award for Design Excellence from President Reagan; President Reagan’s Distinguished Service Award, Committee on Employment of the Handicapped; was honored by the naming of the “Hon. Margaret J. Giannini, M.D. Physical Rehabilitation Pavilion” in 1997 at Westchester Special School, NY, and the First International Leadership Scholars Award by the University of Maryland, Baltimore, in recognition of her work in “International Programs in Rehabilitation and Disability.” Dr. Giannini has served on numerous national and international boards and chaired more than 61 international conferences on rehabilitation and developmental disabilities in many countries, including Israel, Italy, Spain, China, Russia, Argentina, India, and Egypt. She has published extensively and lectured nationally and internationally. Dr. Giannini is also a member of the Institute of Medicine of the National Academy of Sciences and fellow of the American Academy of Pediatrics, and is on the Editorial Board of the American Association on Health and Disability (AAHD) “Disability and Health Journal.” In February 2007, Dr. Giannini received the American Medical Association’s highest award for a public official when she was named “Outstanding Member of the Federal Executive Branch by Presidential Appointment.”

Janice Ford Griffin is the national director of the Robert Wood Johnson Foundation (RWJF) Community Health Leaders (CHL). In this capacity she works to provide recognition for the contributions community health leaders make toward achieving RWJF’s mission and goals, and to enhance their capacity to have more permanent and widespread impact on health problems. CHL conducts a competitive nomination and selection process to identify 10 leaders each year. In addition to enhanced recognition and other support, each leader receives a financial award of \$125,000 to acknowledge their personal accomplishment and to further his/her work. Prior to coming to RWJF, Ms. Griffin was the director of The Compass Project, LLC, a consulting practice that provided technical assistance to a range of clients in the public and private sectors. From 1993 to 2005 Ms. Griffin served as the deputy director of Join Together at Boston University SPH, a national RWJF ad hoc program that is a national resource for

communities working to address substance abuse prevention and treatment. Ms. Griffin also served as the director of drug policy for the City of Houston for Mayor Kathy Whitmire and Mayor Bob Lanier. Ms. Griffin received a B.A. in economics from Fisk University in Nashville, TN.

Susan Henderson is the executive director of the Disability Rights Education and Defense Fund, Inc. (DREDF), a leading national law and policy center dedicated to protecting and furthering the civil rights of people with disabilities. Ms. Henderson has served with DREDF since 1997. Prior to joining DREDF, she was the administrative director at Adams & Broadwell, a public interest law firm specializing in environmental law. For the past 20 years Ms. Henderson has specialized in law firm management and finance.

Ms. Henderson is a member of the Ed Roberts Campus Board, a coalition of seven organizations that came together to develop a universally designed, transit-oriented center to be the home of organizations dedicated to furthering the independent living and disability civil rights movement in the San Francisco Bay Area. She is the president of the board of directors of Community Resources for Science and is the cochair of the Berkeley High School Development Group. Ms. Henderson received her undergraduate degree in anthropology from the University of California at Davis and an MBA degree from California State University, Hayward.

Rosemary B. Hughes, Ph.D., is senior research scientist at the Rural Institute on Disabilities, research associate professor in the Department of Psychology, and faculty affiliate in the Department of Public and Community Health at The University of Montana (UM) in Missoula. She holds a Ph.D. in counseling psychology from the University of Houston. Dr. Hughes is a licensed psychologist with clinical, teaching, and research experience in the field of disability. She has served as principal investigator/co-investigator on more than 15 federally funded research projects addressing the health and well-being of people with disabilities. Dr. Hughes is highly published and has presented nationally and internationally on issues of people with disabilities.

Lisa I. Iezzoni, M.D., M.Sc., is professor of medicine at Harvard Medical School and associate director of the Institute for Health Policy (IHP), Massachusetts General Hospital. She received her degrees in medicine and health policy and management from Harvard University and spent 16 years in the Division of General Medicine and Primary Care at Boston's Beth Israel Deaconess Medical Center before joining the IHP in 2006. Dr. Iezzoni has conducted numerous studies for the Agency for Healthcare Research and Quality, the National Institutes of Health, the Centers for Medicare & Medicaid Services, and private foundations on a variety of topics, including evaluating methods for predicting costs, clinical outcomes, and substandard quality of care. She has published and spoken widely on risk adjustment and has edited *Risk Adjustment for Measuring Health Care Outcomes*, now in its third edition (2003). With a 1996 Investigator Award in Health Policy Research from The Robert Wood Johnson Foundation, Dr. Iezzoni began studying health care quality and health policy issues relating to persons with disabilities. Her book "When Walking Fails" was published in 2003, and "More Than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities," coauthored with Bonnie L. O'Day, appeared in 2006. Dr. Iezzoni serves on the editorial boards of major medical and health services research journals and in 2008 was appointed to the U.S. Department of Health and Human Services Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020. She is a member of the Institute of Medicine of the National Academy of Sciences.

June Isaacson Kailes, M.S.W., L.C.S.W., is associate director and adjunct associate professor of the Center for Disability Issues in the Health Professions, Western University of Health Sciences, Pomona, CA, where she teaches, supervises development of research tools, and designs implementation of research projects and reports. Recognized nationally and internationally, Ms. Kailes is one of the original leaders in the national Independent Living Movement. She consults, writes, and trains on Americans with Disabilities Act (ADA) implementation, advocacy training and skills building, developing and analyzing disability-related public policy, planning barrier free meetings, disability diversity training, reaching the disability market, customer service

and product design, accessible telecommunication, disaster preparedness for people with disabilities, and incorporating universal design and usability principles into existing and new environments.

Ms. Kailes also works as a trainer, writer, researcher, and policy analyst for projects, including the Rehabilitation Research and Training Centers on Aging with a Disability, Managed Care and Disability, Health and Wellness and Disability, and National Center of Physical Activity and Disability. Her extensive writings and publications include “Emergency Evacuation Preparedness: Taking Responsibility For Your Safety,” “A Guide For People with Disabilities and Other Activity Limitations,” “Living and Lasting on Shaky Ground: An Earthquake Preparedness Guide for People with Disabilities” (distributed by California Office of Emergency and Safety), “Be a Savvy Health Care Consumer—Your Life May Depend on It!” “Health, Wellness, and Aging with Disability,” “A Guide to Planning Accessible Meetings,” and “Creating a Disaster-Resistant Infrastructure for People at Risk Including People with Disabilities.” She has also delivered hundreds of keynote addresses, workshops, and seminars. For the last 7 years Ms. Kailes has held a presidential appointment to the United States Access Board. Ms. Kailes earned an M.S.W. from the University of Southern California, Los Angeles, and a B.A. in Psychology from Hofstra University, Hempstead, NY.

Kristi L. Kirschner, M.D., is an attending physician at the Rehabilitation Institute of Chicago (RIC), and associate professor of Physical Medicine and Rehabilitation, and of Medical Humanities and Bioethics at the Northwestern University Feinberg School of Medicine. She is also the medical director for the RIC Women with Disabilities Center (formally the Health Resource Center for Women with Disabilities) and the director of the Donnelley Family Disability Ethics Program. Dr. Kirschner is a graduate of Carleton College and of the University of Chicago Pritzker School of Medicine. She completed her residency in physical medicine and rehabilitation at the Rehabilitation Institute of Chicago/Northwestern McGaw Center for Graduate Medical Education in 1990. She also completed a fellowship in clinical medical ethics at the MacLean Center for Clinical Medical Ethics at the University of Chicago in 1995. She was named RIC’s Coleman

Chair of Rehabilitation Medicine in February of 1996. This chair supports her work in women's health and disability, as well as in disability ethics.

Mitchell Loeb, M.Sc., is a research fellow in the Office of Analysis and Epidemiology at the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention. His research experience includes work in Canada, Norway, and several developing countries in sub-Saharan Africa and Southeast Asia. Prior to arriving at NCHS last fall, he spent 20 years in Norway working at SINTEF, an independent research foundation. While at SINTEF he assisted in carrying out a series of surveys of living conditions among people with disabilities in the southern African region (South Africa, Namibia, Zimbabwe, Malawi, Zambia, and Mozambique). He has also acted as disability data consultant for the Medical Committee Netherlands Vietnam (MCNV) in 2006, where he facilitated workshops intended to formalize a common understanding of disability and harmonize the collection and management of disability data in Vietnam. In 2005 he consulted for the World Bank in Indonesia to supervise disability data collections in support of the Indonesia Poverty Analysis Program. He is currently involved with the Washington Group on Disability Statistics, whose Secretariat is located at NCHS, and the analysis of disability data from a variety of U.S. surveys and linked databases.

Nancy R. Mudrick, Ph.D., M.S.W., is professor in the School of Social Work, College of Human Ecology at Syracuse University. Her Ph.D. is in social policy from the Florence Heller School for Advanced Studies in Social Welfare, Brandeis University. Dr. Mudrick teaches courses in U.S. social welfare policy, workplace policy, mental health policy, research methodology, and program evaluation. Her research focuses on disability policy in the areas of employment, civil rights, and health. Over the past decade, she has worked with the Disability Rights Education and Defense Fund (DREDF) on several projects, among them an evaluation of federal agency enforcement of disability civil rights laws for the National Council on Disability. She is currently working with DREDF on the NCD-funded project on the current state of health care for Americans with disabilities. Dr. Mudrick has published on disability issues, discrimination and civil rights,

and childhood disability. In addition to her work on disability topics, she has directed federally funded child welfare training grants and evaluated demonstration projects of child welfare services. Dr. Mudrick served on the board of directors of the Society for Disability Studies, is a longstanding member of the American Public Health Association Disability Section, and a member of several social work professional organizations. She serves on the editorial board of several journals, some focused on disability and others on social work.

Debjani Mukherjee, Ph.D., is the associate director of the Donnelley Family Disability Ethics Program at the Rehabilitation Institute of Chicago and an assistant professor of Physical Medicine and Rehabilitation and of Medical Humanities and Bioethics at Northwestern University Feinberg School of Medicine. She received her bachelor's degree from Cornell University, and her master's and doctorate in Clinical/Community Psychology from the University of Illinois at Urbana-Champaign. Dr. Mukherjee completed 2 years of postdoctoral fellowship training in Clinical Medical Ethics at the University of Chicago and after her fellowship, she was invited to spend a year in Paris to help start the first center for Clinical Ethics in France, the Centre D'Ethique Clinique at Cochin teaching hospital. For the 2006-2007 academic year, she was a Fulbright Senior Research Scholar affiliated with Calcutta University's Department of Applied Psychology in Kolkata, India. Her research interests include psychosocial adjustment to traumatic brain injury and the cultural contexts of medical decisions and ethical dilemmas posed by neurological impairments.

Judy Panko Reis, M.A., M.S., became head-injured due to a random violent attack while camping in Hawaii. Since then, Ms. Panko Reis has become a wife, mother, and the cofounder and director of the Rehabilitation Institute of Chicago's Women with Disabilities Center (WWDC), the first comprehensive health center in the country run by and for women with disabilities. In 1993, Ms. Panko Reis received \$100,000 as a Robert Wood Johnson Foundation Community Health Leadership awardee in recognition of her education and advocacy work on behalf of disabled women's health issues. She is also editor of "Resourceful Woman," an award-winning newsletter written by, for, and about

women and girls with disabilities. She has published several articles and book chapters on disabled women's issues, including articles on women and traumatic brain injury, as well as sexuality and women with disabilities. She also coauthored "It Takes More than Ramps To Solve the Crisis in Healthcare for People with Disabilities," a report detailing the challenges people with disabilities face in their efforts to access disability-competent health services.

Throughout the past 15 years, Ms. Panko Reis has spoken to local and national audiences about disability, violence, and health care issues. She is a trained domestic violence services advocate and has written articles on the subject and conducted trainings on disability and domestic violence for policymakers and service providers. Ms. Panko Reis earned a B.A. in philosophy from the State University of New York in Geneseo, an M.A. in philosophy from the University of Chicago, and an M.S. in managerial communication from Northwestern University.

Mark Richert, Esq., is an attorney with more than 13 years of public policy and governmental relations experience in the vision loss and disability policy field. Mr. Richert serves as the director of the American Foundation of the Blind's (AFB) Public Policy Center, located in Washington, DC, overseeing the Center's management and the implementation of AFB's public policy and policy research agendas. In addition, he is AFB's primary representative to the U.S. Congress and to federal agencies with responsibility for programs, services, and enforcement of rights of interest to individuals with vision loss. Mr. Richert also plays a key leadership role in the wider disability policy community, serving as a cochair of the Civil Rights and Technology/Telecommunications Task Forces of the 100-plus organizational-member Consortium for Citizens with Disabilities (CCD). He is also a member of the steering committee of the 70-member Independence Through Enhancement of Medicare and Medicaid (ITEM) coalition, an alliance of organizations advocating appropriate coverage for durable medical equipment and related assistive technologies. Prior to joining AFB in July 2005, Mr. Richert served for nearly 4 years as the executive director of the Association for Education and Rehabilitation of the Blind and Visually Impaired, the professional

association in the field of vision loss. He has previously served with AFB in the capacity of Governmental Relations Representative, with the American Council of the Blind as ACB's director of Advocacy Services, and in the legislative affairs arena with National Industries for the Blind. Mr. Richert earned his B.A. in both philosophy and political science from Stetson University, DeLand, FL, and his J.D. from the George Washington University National Law Center. He has been a member of the Florida Bar since 1993.

Teresa Savage, Ph.D., R.N., is a consultant to and former associate director of the Donnelley Family Disability Ethics Program at the Rehabilitation Institute of Chicago. She is also an ethics consultant on the Ethics Consultation Service at RIC. She has worked as a staff nurse in neonatal intensive care at three different medical centers, has been a clinical nurse specialist in pediatric neurology, and has worked for various agencies serving adults and children with disabilities. She was a member of the landmark committee, the Illinois State's Attorney's Task Force on Removal of Life-sustaining Treatment. She also has served on pediatric ethics committees and Institutional Review Boards at the University of Illinois at Chicago (UIC). She was an ethics consultant at Rush-Presbyterian-St. Luke's Medical Center and Misericordia Homes. She earned her Ph.D. in nursing sciences from the University of Illinois at Chicago College of Nursing and completed a 3-year postdoctoral fellowship in primary health care/social ethics through the World Health Organization's Global Health Leadership Office at the UIC College of Nursing. She is a research assistant professor at UIC College of Nursing and is currently co-investigator on a National Institute of Nursing Research-funded study entitled "Life Support Decisions for Extremely Premature Infants." She has conducted studies on informed consent in people with intellectual disabilities and factors affecting parental decision-making regarding life-sustaining treatment for children with severe and profound disabilities. She is also conducting an oral history of the field of nursing ethics. In March, 2006, her book, co-authored with Marcia D. Bosek, "The Ethical Component of Nursing Education: Integrating Ethics into Clinical Experience," was published by Lippincott, Williams, & Wilkins.

Harvey A. Schwartz, Ph.D., M.B.A., is senior advisor for priority populations, Agency for Healthcare Research and Quality (AHRQ). He works with other agency senior advisors to disseminate accomplishments of funded agency projects emphasizing priority populations, collaborates with intramural researchers on projects focused on priority populations, serves as a grant reviewer for the AHRQ Small Grant Program for Conference Support, enhances communications and coordination across the Agency in the area of disabilities activities, and conducts outreach efforts to enhance the success of minority and minority-serving institutions in conducting research on health care disparities. Prior to his service as senior advisor for priority populations, Dr. Schwartz has had a career contributing in various positions at AHRQ, including serving as the agency evaluation officer and deputy director of the past Center for Information Technology. He earned his doctor of philosophy in economics, a master's degree in business administration, and a master's degree in statistics from Columbia University.

Paul M. Schyve, M.D., is the senior vice president of The Joint Commission. From 1989 until 1993, Dr. Schyve was vice president for research and standards, and from 1986 until 1989, he was the director of standards at The Joint Commission. Prior to joining The Joint Commission, Dr. Schyve was the clinical director of the State of Illinois Department of Mental Health and Developmental Disabilities. Dr. Schyve received his undergraduate degree from the University of Rochester, where he was elected to Phi Beta Kappa. He completed his medical education and residency in psychiatry at the University of Rochester, and has subsequently held a variety of professional and academic appointments in the areas of mental health and hospital administration, including director of the Illinois State Psychiatric Institute and Clinical Associate Professor of Psychiatry at the University of Chicago. Dr. Schyve is certified in psychiatry by the American Board of Psychiatry and Neurology and is a Distinguished Life Fellow of the American Psychiatric Association. He is a member of the board of directors of the National Alliance for Health Information Technology, a founding advisor of Consumers Advancing Patient Safety, the chair of the Ethical Force Oversight Body of the Institute of Ethics at the American Medical Association, and a former trustee of the United States Pharmacopeial Convention. He has served on numerous advisory panels for the

Centers for Medicare & Medicaid Services, the Agency for Healthcare Research and Quality, and the Institute of Medicine. Dr. Schyve has published in the areas of psychiatric treatment and research, psychopharmacology, quality assurance, continuous quality improvement, health care accreditation, patient safety, and health care ethics.

MaryMargaret Sharp-Pucci, Ph.D., M.P.H., is the managing member of Sharp Health Strategies LLC, which provides a line of clinical research and analytic services to the health care industry. Dr. Sharp-Pucci is an epidemiologist and senior health care analyst with over 25 years of health care experience. Dr. Sharp-Pucci established and served as executive director of the Center on Clinical Effectiveness at Loyola University Medical Center (LUMC) in Maywood, IL. In this role, she directed the outcomes research program and benchmarking strategy that supported clinical quality improvement. Also at LUMC, she served as associate director of the Burn & Shock Trauma Institute, where she conducted research in rehabilitation outcomes and health services utilization. Dr. Sharp-Pucci is also the former associate director of the Technology Evaluation Center at Blue Cross Blue Shield Association. Her work focused on trauma, wound healing and rehabilitation, and the development of research initiatives in disease management.

She is currently on the faculty of the Niehoff School of Nursing at Loyola University Chicago. Her academic background has included research and teaching affiliations with the Burn and Shock Trauma Institute at Loyola University Medical Center, the University of Virginia Medical College, and the Rehabilitation Institute of Chicago. She is a scientific peer reviewer for the *Journal of Burn Care & Research* and has served as a peer reviewer for a number of federal granting agencies, such as the National Institute of Disability and Rehabilitation Research, the Administration on Developmental Disabilities, and the Rehabilitation Services Administration.

She is an appointee of President George W. Bush to the President's Committee on People with Intellectual Disabilities. She also serves as an appointee of the Medicare Coverage Advisory Panel, and locally she is a member of the Central DuPage Hospital

Institutional Review Board (IRB) in Winfield, IL, a board member for CNS Home Health and Hospice in Carol Stream, IL, a consultant with Home Care Physicians, and is the current president of the board of directors and chairs the Planning & Quality Improvement committee for the Anixter Center, one of the largest providers of rehabilitation and community integration services for people with disabilities in Illinois.

Carolyn Stern, M.D., is a family physician. Deaf from birth, she received her medical degree from Northwestern University. Currently, she teaches medical interpreting to senior level interpreting students and is a physician at Student Health Services at Gallaudet University; a consultant physician at Rochester School for the Deaf; and CEO of www.deafdoc.org, a partnership developed to improve health literacy for the Deaf/Hard of Hearing community. DeafDOC.org provides health-related workshops for the Deaf/Hard of Hearing community and professional development for interpreters to improve their practice in the medical setting, and also consults with health care providers and systems to improve communication access and improve patient-interpreter-physician relationships. She also serves as a role model and consultant to Federal, state, and local organizations, including the National Board of Medical Examiners, The National Center for Deaf Health Research, State Associations of the Deaf, and the Rochester Institute of Technology/ National Technical Institute for the Deaf.

Internationally, she testified before the Ministry of Health and Welfare in Japan, advocating for the rights of Japanese Deaf to become licensed health care professionals. She presented at the Tianjin University of Technology/Pen International: All-China Higher Education Conference on “Healthcare and the Deaf Postsecondary Student: Observations and Educational Impact.” Dr. Stern is actively involved in the Rochester, NY, Community Interpreter Grant Project, providing monthly workshops on human body systems.

Sue Swenson, M.B.A., is the former executive director of The Arc of the United States, the oldest and largest advocacy and service organization for people with intellectual and developmental disabilities. Ms. Swenson has served as The Arc’s assistant executive

director for Membership and Program Services; the executive director of the Joseph P. Kennedy Jr. Foundation; the commissioner of the U.S. Administration on Developmental Disabilities; and education specialist at the University of Minnesota Institute on Community Integration in Minneapolis. She has also served on the Minnesota Governor's Council on Developmental Disabilities and national task forces for the State of Minnesota, Pew Center, and Robert Wood Johnson Foundation (both nationally and in Hennepin County).

As a teacher and trainer on disability policy issues, Ms. Swenson has worked on strategies to form viable and productive partnerships between parents, organizations, professionals, and people with developmental disabilities, specifically in analyzing and developing public policy affecting people with developmental disabilities and in developing organizational strategies. Ms. Swenson is a graduate of the University of Chicago and the University of Minnesota.

James L. E. Terry is CEO of Evan Terry Associates, P.C. (ETA), architecture and planning firm, where he oversees all ADA and access consulting services. He is a licensed architect in AL, AZ, CA, FL, MI, NC, and NY. Evan Terry has performed ADA surveys, architectural access plan reviews, training, and consulting services for all of Kaiser Permanente's California facilities, and medical centers for Stanford University, UCLA, the University of Florida, Tenet Healthcare, HealthSouth, and others. He has also consulted with the U.S. Department of Justice, The U.S. Access Board (ATBCB), The Administrative Office of the U.S. Courts, and The U.S. Congressional Office of Compliance. He has served for 14 years as an instructor on ADA compliance and universal design in the Harvard Graduate School of Design's Executive Education program, and has conducted over 150 seminars and lectures nationwide for corporate and public entities, disability rights groups, AIA national conventions, college and universities, professional organizations, and architectural firms. Mr. Terry serves on the board of directors of the National Association of ADA Coordinators, where he teaches its members how to apply the Title II and III requirements of the ADA. He has written or coauthored 10 books and software programs on ADA facilities compliance and universal

design. He coauthored the book “Beautiful Universal Design” with Cynthia Leibrock, ASID, which has been used by many university programs as a textbook. Currently, he is working with NC State University’s Center for Universal Design to develop a free, Web-based training program for architects and design professionals: “Avoiding the 100 Most Common ADA Errors with Universal Design Solutions.” Also, under his direction, ETA has developed the most efficient and effective facility survey and access barrier removal management systems in use today.

JoAnn M. Thierry, Ph.D., M.S., M.S.W., is a behavioral scientist with the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). She is the scientific advisor for several state health departments and research projects focusing on health promotion and the prevention of secondary conditions. She is responsible for coordinating the health and wellness activities for women with disabilities within the CDC’s Disability and Health program.

Dr. Thierry has been working with people with disabilities for 20 years. After earning her degree in psychology at the State University of New York at Oswego, she completed a master’s degree in counseling and psychological services at the same institution, as well as a master’s degree in social work at Syracuse University. She worked for the Onondaga County Health Department in Syracuse for 7 years, where she provided both direct and indirect social work services to persons with disabilities and initiated programs to prevent secondary conditions. Ms. Thierry obtained her Ph.D. in social work at the University of Georgia. She joined the CDC in 1991. Her research emphasis is on health promotion for women with disabilities.

Cynthia Wainscott is a member of the National Council on Disability. Ms. Wainscott is the immediate past chair of Mental Health America, formerly known as the National Mental Health Association. She was acting president and CEO of Mental Health America in 2006. She served as a member of the Institute of Medicine committee that recently released “Improving the Quality of Health Care for Mental and Substance-Use Conditions,” and is a founding board member of the Campaign for America’s Mental Health.

Silvia Yee is a staff attorney with the Disability Rights Education and Defense Fund (DREDF), a leading national disability rights law and policy center. She was DREDF's first international law fellow and co-editor of "Disability Rights Law and Policy: International and National Perspectives," published by Transnational Publishers in 2002. She is active in DREDF's domestic national litigation and policy areas, including health care reform for people with disabilities. She has worked in private commercial practice and with the Health Law Institute at the University of Alberta in Canada, where she published on the topics of Canadian Health Care Standards and the extent of the nursing profession's legal authority. She received her LL.B. from the University of Alberta, and clerked with the Honorable Justice William Stevenson at the Alberta Court of Appeal. She is particularly interested in issues raised by the comparison of different models of equality and justice underlying disability anti-discrimination laws, and in the applicability to disability discrimination of historically evolving social-psychological theories of prejudice. Ms. Yee came to the United States to pursue graduate studies in musicology at the University of California, Berkeley, after receiving her B.Mus. and M.A. at the University of Alberta.

NCD Health Care Summit

Represented Constituencies

Constituency	Number of Participants
Advocate/Content Expert— Architectural Access	3
Advocate/Content Expert—Communicative & Sensory Access	4
Advocate/Content Expert—Women’s Health Access	5
Disability Rights Organization	6
Federal Sector Policy Development	1
Federal Sector Disability & Health Care Research	3
Federal Sector Disability Rights Enforcement	2
Funding Organization	1
Graduate Medical Education & Clinical Training	5
Health Care Accreditation Organization	1
Health Care Provider	4
Health Policy Development	4
Health Services Research	4

APPENDIX C. **List of Methods Related to Data Collection Assessment and Matrix of Selected Studies and Datasets**

Data Availability Assessment

Instrument Content Elements Considered

- Whether people with disabilities could be identified from variables in the dataset, and the indicators used to identify disability
- Whether the dataset made it possible to use the disability variable as a population characteristic (like race or gender), and whether the disability variable could be crossed with demographic and other health and health behavior variables
- Whether the dataset included data about health behaviors and wellness-related activities, such as exercise, tobacco use, regular medical exams, preventive care such as mammograms, pap tests, prostate tests, or flu shots, and whether a medical provider talked to the patient about health risks from such problems as obesity or alcohol abuse
- Whether the dataset included variables to indicate satisfaction with the health care provider or the health care delivery experience, on the basis of indicators of whether the provider was respectful, gave sufficient time, listened to the patient, provided information that the patient could understand
- Whether the dataset included, in reasons for not getting care or postponing or delaying care, options to indicate that physical, programmatic, or communication access was present or not present
- Whether the dataset asked if respondent had a usual source of care and health insurance coverage for care

Sampling Frame Elements Considered

- Population eligible for the sample, and the impact of stated exclusions on adequate representation of people with disabilities
- Size of the sample, and the impact of size on the ability to study the circumstances of population subgroups, such as people who are deaf or people with disabilities, from racial or ethnic subgroups within the U.S. population

Data Collection Methods Considered

- Method of data collection (telephone, mail, the Web, or in-person interview) and the potential impact of the method on the response rate and inclusion of people with disabilities
- Whether/how data are collected from people with cognitive disabilities or from those who may not be able to communicate via the method utilized with the survey's other respondents
- The time frame for data collection, for example, annually, quarterly, one time only
- The process used to develop the survey instrument, including cognitive testing and field testing

How Dataset Findings Are Reported or Made Available for Public Use

- The types of regular reports issued by the sponsoring agency, with attention to whether disability variables are a part of regular reporting and whether they are used as population characteristics or outcome variables
- The arrangements for other researchers to use the dataset for analysis beyond what the sponsoring agency regularly reports

Table 1.
Matrix of Selected Studies and Datasets Used To Assess Healthcare Access
and Health Disparities of People with Disabilities

Authors (full citations follow)	MEPS	NHIS**	MCBS	BRFSS	CAHPS	Other Survey	Qualitative
AHRQ (2008)	2004						
Altman and Taylor (2001)	1996						
DeJong et al. (2002)	1996						
Liu et al. (2005)	1996						
Newacheck and Kim (2005)	2000						
Olin and Dougherty (2006)	1997–2002						
Parish and Savile (2006)	2000, 2002						
Rasch et al., Part I (2008)	1996–1997						
Rasch et al., Part II (2008)	1996–1997						
Shin and Moon (2008)	2002						
Altman and Bernstein (2008)		2001–2005					
Schoenborn and Heyman (2008)		2000–2006					
Smith (2008)		2006					
lezzoni et al. (2007)			2001				
lezzoni et al. (2002)			1996				
lezzoni et al. (2004)			1996, 1997				
lezzoni et al. (2003)			1996				

Authors (full citations follow)	MEPS	NHIS**	MCBS	BRFSS	CAHPS	Other Survey	Qualitative
Jha et al. (2002)			1998				
Armour et al. (2007)				2004			
Armour et al. (2008)				2004			
Drum et al. (2008)				2004			
Fouts et al. (2000)				MO:1995–1997			
Jamoom et al. (2008)				2000, 2001 (25 states)			
Kinne (2008)				WA:2001, 2003			
Palsbo and Ho (2007)					2001–2004		
Cohen and CFILC (2006)						CA health plans, n=10	
Corbin et al. (2005)						Special Olympics Healthy Athletes Screening Data	
Downs et al. (2004)						Physicians, n=417	
Grabois et al. (1999)						Mail survey of practitioners	
Hanson et al. (2003)						Survey non- elderly, n=1505	
Parish and Ellison-Martin (2007)						NSAF 1997, 1999	

Authors (full citations follow)	MEPS	NHIS**	MCBS	BRFSS	CAHPS	Other Survey	Qualitative
Parish and Huh (2006)						NSAF 1997, 1999	
Drainoni et al. (2006)							Focus groups in MA, n=87
Neri and Kroll (2003)							n=30, ms; cp, spinal cord
Scheer et al. (2003)							n=30, ms; cp, spinal cord

Dataset names: MEPS = Medical Expenditure Panel Survey; NHIS = National Health Interview Survey; MCBS = Medicare Current Beneficiary Survey; BRFSS = Behavioral Risk Factor Surveillance System; CAHPS = Consumer Assessment of Healthcare Providers and Systems (with additions for adults with physical disabilities); NSAF = National Survey of American Families.

**Note re: NHIS: Citations are to regular NHIS only. Papers using 1994 NHIS-D are not included because this is not a continuing source of new information.

Table 1 Full Citations

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APPENDIX D. Key Federal Agency Definitions of Health Disparity

Health disparity is formally defined by several federal agencies. Two prominent definitions that also have influence on public funding streams come from the Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) and from the definition used by the CDC for “Healthy People 2010.” The definition in the Minority Health and Health Disparities Research and Education Act does not explicitly name people with disabilities among the targeted groups; the “Healthy People 2010” statement specifically includes people with disabilities.

From the Minority Health and Health Disparities Research and Education Act, P.L. 106-525, Sect. 101:

(a) In General.—The general purpose of the National Center on Minority Health and Health Disparities (in this subpart referred to as the ‘Center’) is the conduct and support of research, training, dissemination of information, and other programs with respect to minority health conditions and other populations with health disparities.

(c) (3) The term ‘minority group’ has the meaning given the term ‘racial and ethnic minority group’ in section 1707.

(d) Health Disparity Populations.—For purposes of this subpart:

(1) A population is a health disparity population if, as determined by the Director of the Center after consultation with the Director of the Agency for Healthcare Research and Quality, there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.

The definition above does not exclude people with disabilities as a health disparity population; however, the focus of most of the projects associated with this initiative has been disparities experienced by racial or ethnic population groups.

“Healthy People 2010” states that Goal 2 is to—

eliminate health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation.

Implied in the “Healthy People 2010” definition above is that differences in health outcomes and health care access are in comparison to the general population.

Much of the research, whether federally supported or through private foundations or other avenues, examines disparities in the prevalence of selected health conditions (for example, cancers and obesity); the prevalence of risk behaviors (for example, tobacco and alcohol use); the receipt of preventive care (for example, flu shots, mammograms, and annual physical exams); prevalence of coverage for the costs of care; the presence of a usual provider of care; and reasons why needed care was delayed, postponed, or not received. In some cases, disability prevalence—defined by Activities of Daily Living (ADLs) or quality of life measures—has been used as one of the indicators of health disparity, making disability not a population group but an outcome measure.

APPENDIX E. **NCD Health Care Summit Additional Recommendations for Reform and Stakeholder Actions**

Recommendation #1:

Federal agencies engaged in population and health research must include disability measures in every survey that identify not only activity limitations but also environmental barriers to and disparate outcomes in health and health care.

Stakeholder Actions

Congress

Congress should direct and fund the Agency for Healthcare Research and Quality so that it may take the lead in

- Evaluating the evidence base to support the development of clinical practice guidelines, quality goals, and monitoring standards for the prevention and management of secondary health conditions among people with disabilities and for the monitoring and management of people aging with disability
- Evaluating the evidence base about environmental contributors to secondary health conditions
- Identifying research gaps and directions for further research on secondary health conditions and aging with disability

In order to support a program of disability research that is commensurate with the need for better knowledge about all aspects of disability at the individual and the societal levels by increasing the total amount of public funding provided for disability research, Congress should

- Elevate the National Center for Medical Rehabilitation Research to the status of a full institute or freestanding center within the National Institutes of Health with its own budget
- Create an Office of Disability and Health in the Office of the Director at the Centers for Disease Control and Prevention (CDC) to promote the integration of disability issues into all CDC programs and direct development of clinical practice guidelines and standards of care
- Direct the U.S. Department of Education to support the National Institute on Disability and Rehabilitation Research in continuing to upgrade its research review process and grants program administration

The National Center for Health Statistics, the U.S. Census Bureau, and Bureau of Labor Statistics

Federal agencies must adopt a uniform disability monitoring system for identifying access barriers, quality measures and outcomes, and health and health care disparities.

- Government agencies involved in disability monitoring should adopt the International Classification of Functioning, Health and Disability (ICF) as their conceptual framework and should actively promote continued refinements to improve the framework's scope and utility for disability monitoring and research.
- The Interagency Subcommittee on Disability Statistics of the Interagency Committee on Disability Research should coordinate the work of these agencies to develop, test, validate, and implement new measures of disability that correspond to the components of the ICF, consistent with public policy priorities.
- The National Center for Health Statistics, in collaboration with other relevant federal agencies, should continue to improve the scope and quality of data—including longitudinal or panel data—on disability, its causes, and its consequences. These improved data sources should serve as the cornerstone of a new national disability monitoring system.

Recommendation #2:

Health care facilities, services, and programs must be accessible according to Federal and state standards and guidelines and should actively promote principles of universal design in the built environment; for diagnostic, exam, and other medical equipment—in fact, for all aspects of care delivery.

Stakeholder Actions

Congress

Congress must require HHS to ensure that every entity involved in the delivery of health care services meets architectural and programmatic accessibility requirements and fund HHS to

- Develop robust monitoring and oversight mechanisms to ensure that entities including states, professional medical education programs, health plans, managed care organizations, and medical facilities and services that receive federal funding to provide health care services, training, research and that engage in other health-related activities meet minimum architectural and programmatic accessibility standards and guidelines
- Document evidence of accessibility and capacity to provide programmatic access through systematic assessments and reporting between and among contractees and contractors
- Develop incentives and penalties related to achieving the goals

The Joint Commission and Other Accreditation Bodies

- The Joint Commission and other accreditation organizations must require that facilities be accessible according to federal and state standards and guidelines and must actively promote principles of universal design both in the built environment and for diagnostic, exam and other medical equipment.
- Accreditation bodies either should provide ongoing technical assistance to institutions seeking accreditation or contract for training with qualified

organizations. (The CARF standards and the Kaiser Permanente and Washington Hospital settlement policies and training materials and procedures could be used as a starting point.)

- Accreditation bodies should reward the implementation of “universal design” principles in health care settings.

U.S. Department of Justice

The Department of Justice must

- Continue to vigorously pursue and publicize effective settlements and litigation of complaints of accessibility and accommodation violations in major health care institutions
- Issue and widely disseminate guidelines for health care providers that describe expectations for compliance with the accessibility provisions of the Act
- Revisit the applicable ADA regulations and ADA Architectural Guidelines in order to identify gaps where compliance with the law does not ensure accessible health care (for example, the absence of requirements for provision of available useable/accessible medical equipment such as height-adjustable exam tables or limited guidance on what constitutes effective communication in the health care context)

Health Care Professional Organizations

Health care professional organizations must

- Design specific hospital and health care provider standards on disability access in concert with the disability community

State Governments

States must ensure that entities with whom they contract for medical care are accessible and culturally competent to serve people with disabilities. Suggested methods include

- Developing and adopting performance standards for health insurers in order to receive Medicaid reimbursement for providing services to people with disabilities. (One model is “Performance Standards for Medi-Cal Managed Care Organizations Serving People with Disabilities and Chronic Conditions: Recommendations Report,” published by the California Health Care Foundation.)
- Adopting the recommendations found in “Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs,” created and published by the U.S. Department of Health and Human Services, the Health Care Financing Administration, and the Center for Medicaid and State Operations
- Adopting the state of New York’s “Guidelines for Medicaid MCO [Managed Care Organization] Compliance with the Americans with Disabilities Act (ADA)”

Recommendation #3:

All health care provider training programs must have a disability competency requirement that produces student comprehension and understanding of the principles of accessibility, accommodation, cultural competency, and awareness of community and other resources for people with disabilities.

Stakeholder Actions

Medical and Other Professional Schools

Institutions that train physicians, surgeons, dentists, therapists, nurses, and others in the health care field must establish disability competency requirements and take steps to ensure that disability-related information is fully integrated into all aspects of training.

Such steps should

- Include and integrate clinical training and resources about disability concerns throughout the educational process
- Provide clinical training about disability accommodations and the role and value of screening and preventive care for persons with disabilities
- Provide clinical resources and tools for addressing specialized disability issues; such information could be developed, deployed, and updated on a Web site, for example

Health Care Professional Organizations

Health care professional organizations must

- Take the lead to design and implement disability curricula in collaboration with the disability community and educational institutions
- Work with educational institutions to integrate disability curricula into training programs
- Educate professional membership using newsletters, journals, and Web sites

Recommendation #4:

Congress must establish a publicly funded system of technical assistance centers where states, health plans, clinics, hospitals, diagnostic and treatment centers, individual medical practitioners, equipment manufacturers, people with disabilities, and others can easily obtain centralized information on defined standards of care and related practical resources for ensuring full access to health care services for people with disabilities.

Stakeholder Actions

Congress

Congress must take steps to identify and set priorities for intervention by

- Conducting oversight hearings concerning health and health care access, accommodation, cultural competency, and standards of care for individuals with disabilities in order to set priorities for technical assistance
- Enacting legislation that mandates and funds technical assistance and charges appropriate federal agencies with carrying out implementation

Recommendation #5:

Key stakeholders must ensure that these and other critical issues concerning health and health care for people with disabilities are fully integrated into “Healthy People 2020” deliberations taking place during 2008 and 2009, and into the final publication.

Possible specific recommendations for inclusion are timely access to appropriate screening for secondary conditions such as osteoporosis, sleep disorders, hypertension, and lipidemia; assurance of accessible health care facilities and services; readily available methods to ensure effective communication; and coordination of care.

APPENDIX F. **Additional NCD Health Care Summit Information: Summit Agenda, Summary of Oral Content Presentations, and Summit Planning Committee List**

Summit Agenda

2008 Summit on Health Care for People with Disabilities

Rehabilitation Institute of Chicago & Disability Rights Education and Defense Fund

On Behalf of the National Council on Disability

Rehabilitation Institute of Chicago

345 East Superior Street

Chicago, IL 60611

Monday, April 7, 2008

8:00 a.m. – 9:00 a.m. Continental Breakfast Heyworth

9:00 a.m. – 10:00 a.m. **Greetings and Introductions** Heyworth

- Kristi Kirschner, M.D., Coleman Foundation Chair in Rehabilitation Medicine, RIC
- Judy Panko Reis, Director, Women with Disabilities Center, RIC
- Joanne Smith, M.D., CEO, RIC
- Victoria Carlson, Council Member, NCD
- Cynthia Wainscott, Council Member, NCD

Background and Rationale for the Project

- Mary Lou Breslin, Senior Policy Advisor, DREDF

Participant Introductions

Business and Logistics

10:00 a.m. – 10:30 a.m. Overview of Health Status of People with Disabilities and Key Health Care Access Issues and Concerns

- Kristi Kirschner and Judy Panko Reis
 - Coverage
 - Accessibility
 - Programmatic Access
 - Cultural Competency
 - Coordination of Care
- Video Presentation – “Learning to Act in Partnership: Women with Disabilities Speak to Health Professionals”
- Question and Discussion

10:30 a.m. – 10:45 a.m. Break

10:45 a.m. – 11:30 a.m. Overview of Specific Health and Health Care Issues

Women with Disabilities

- Rosemary Hughes, University of Montana
- JoAnn M. Thierry, Centers for Disease Control and Prevention

People with Communications Disabilities

- June Isaacson Kailes, Center for Disability Issues and the Health Professions

People with Developmental Disabilities

- Sue Swensen, former Executive Director, The ARC of the United States

People Who Are Deaf

- Carolyn Stern, MD, Rochester School for the Deaf and Gallaudet University

Questions and Discussion

1:30 a.m. – 12:15 p.m. Facilitated Group Discussion

12:15 p.m. – 1:15 p.m. Lunch

1:15 p.m. – 1:45 p.m. Universal Design Principles in Health Care

Universal Design Principles

- Jim Terry, Evan Terry Associates

Questions and Discussion

1:45 p.m. – 2:15 p.m. Role of Federal Government

Absence of Federal Directives to States on Access, Accommodation, and Accountability

- Silvia Yee, DREDF

Definitions, Data Collection, Disparity Initiatives

- Lisa Iezzoni, MD, Institute for Health Policy, Massachusetts General Hospital and Harvard Medical School

Questions and Discussion

2:15 p.m. – 3:15 p.m. Introduction: Priority Recommendations

Facilitated Group Discussion

3:15 p.m. – 3:30 p.m. Break

3:30 p.m. – 4:30 p.m. Specific Priority Recommendations

Small Group Discussion

4:30 p.m. – 5:00 p.m. Report Back and Discussion

5:00 p.m. Wrap-up/Adjourn

6:00 p.m. Welcome Dinner

Viand Restaurant

Marriott Hotel

Tuesday, April 8, 2008

8:00 a.m. – 9:00 a.m. Continental Breakfast

Heyworth

9:00 a.m. – 9:15 a.m. Reconvene and Check-in

- Kristi Kirschner

9:15 a.m. – 10:30 a.m. Develop Action Plans

10:30 a.m. – 10:45 a.m. Break

10:45 a.m. – 12:00 p.m. Develop Action Plans, continued

12:00 p.m. – 1:00 p.m. Lunch

1:00 p.m. – 2:00 p.m. Reconvene: Participant Feedback and Discussion

2:00 p.m. Adjourn

NCD Health Care Summit

Framing the Issues: Summary of Oral Content Presentations

Health Status of People with Disabilities and Key Health Care Access Issues

Judy Panko Reis, M.A., M.S., Rehabilitation Institute of Chicago

Kristi Kirschner, M.D., Rehabilitation Institute of Chicago

Dr. Kirschner began by relating a case story illustrating the pervasive problems with programmatic access inherent in health care settings. Problems arise not from physical accessibility barriers alone but from layers of access. Programmatic access involves the way in which services are delivered. It requires the coordination of services, an accessibility plan, and a road map for recognizing and accommodating a range of disabilities and issues.

Mike is 60 years old, and had polio as a child. Functionally a paraplegic, he uses a wheelchair. He has been an active, vigorous man who graduated from college, married, and has a son and four grandchildren. He works full-time at a university.

About 10 years ago, he began to experience the effects of post-polio syndrome. He began to use a noninvasive ventilator when he lies flat or sleeps, and he accommodated readily to this change.

This is not a scenario that the health care system embraces; we're comfortable with the acute care use of ventilators and tracheostomies, but not the noninvasive side.

Mike went to a community hospital for a CT which showed an ill-defined pelvic lesion. He was discharged and referred for outpatient MRI followup. His internist orders the MRI, noting he must use his ventilator when lying flat.

This situation is novel; it's unique. It requires integrating and coordinating services, and that didn't happen in a timely manner. Nine months later, he had his MRI with an MRI-

compatible vent. This required having a respiratory therapist present, but he got the scan. By this time, the lesion had more than doubled in size, and a serious malignancy was found.

What has happened here? This is about much more than disability access. This is about patient safety. This is quality of care. This is a delayed diagnosis.

Mike's second MRI wouldn't be a problem because we already worked through the scenario, right? Well, guess what? It was like reinventing the wheel. He came in for his MRI and was sent home. Different staff were on duty, and they decided that an anesthesiologist had to be present. Mike couldn't eat breakfast, in case they had to intubate him, and the anesthesiologist ended up leaving because he wasn't needed. He was treated as if he were an acute care patient, not as someone who chronically uses a ventilator to breathe on his own. These uses are not the same, but health care just doesn't have an in-depth, nuanced understanding of that.

Here's a person dealing with cancer, going through the health care system to get his needs met. It's onerous to begin with. And to have to advocate, fight, and deal with access issues is simply overwhelming.

And it's not just simply a civil rights issue. It is a quality of care issue. It is a patient safety issue. There are so many layers to access that we, in the health care profession, must learn to embrace.

And yet, the population of people with disabilities is not small. Depending on the definition used, it includes 20 percent of the population at any given time. Disability is prevalent among our aging population and people are surviving and growing old with disabilities. We have uncharted territory as the first generation of adults with spina bifida and other disabilities grows old.

Disability is challenging in the sense that it is heterogeneous. It involves acquired, congenital, progressive, static, and invisible disabilities. Some people have physical,

sensory, cognitive, or psychiatric disabilities; some are temporary, and others are permanent. But what they have in common is some limitation in the major activities of daily living resulting from physical or mental impairment.

People with disabilities are not necessarily sick, though many of them are, and they're high users of the health care system. As a rule, they are just as likely to have health insurance as their nondisabled counterparts. It is, however, more likely to be publicly funded insurance, Medicare and Medicaid.

We know there are significant holes in the system. For instance, if you become ill or disabled while you are employed, and need to leave your employment, you are eligible for COBRA. But COBRA is very, very expensive. And the requirements to access Medicare and Medicaid are extensive; there are spend-downs and waiting periods. Pre-existing conditions prevent coverage in many cases, and much needed care—eye-care, assistive technology, or augmentative communication—falls under out-of-pocket expense.

We know that people with disabilities as a rule are poor, employed at lower rates, and more likely to be socially isolated. There are racial disparities, with African Americans and Native Americans having higher rates of disability than other groups. Families report postponing care, skipping or splitting medication doses, and spending less on basics like food and heat in order to pay for health care.

People with disabilities report experiencing significant difficulties with providers. Physician offices and physician attitudes prevent access to needed care. Knowledge of disability is rare. Transportation services are lacking. The barriers are broad and the issues are layered and complex.

Judy Panko Reis was reminded of a comment from a user of the Rehabilitation Institute of Chicago's (RIC) Women with Disabilities Center: "We will know if we have achieved accessibility when people with disabilities do not have to pick up the phone before they

go into the hospital, before they go into the restaurant and ask whether or not we can be accommodated.”

Panko Reis described fish tales, a genre of health care access stories among people with disabilities, originated by summit participant, Lisa Iezzoni, M.D. Fish tales are the stories people tell about the health care barriers they've experienced, each story topping the one before. The big fish and small fish tales raise two questions: (1) How do we define the barriers that block us, as people with disabilities, from getting safe, quality patient-centered health care in U.S. medical offices and hospitals? What are the real barriers? (2) What can we, as health care stakeholders, do about removing these barriers?

Panko-Reis introduced “Learning to Act in Partnership: Women with Disabilities Speak to Health Professionals,” a thought-provoking video produced in partnership between the RIC and Carol Gill, Ph.D., of the University of Illinois at Chicago. The video, an Award in Excellence winner at the 2002 International Disability Film Festival, was conceived by women with disabilities working in partnership with health care providers. The message is grounded in the voices of the women telling their personal health care stories. The video is organized into five sections: access barriers, sexuality and reproductive health, mental health and domestic violence, aging, and public policy.

“Learning to Act in Partnership” introduced the role of cultural competency in disability access, and Dr. Kirschner emphasized that many of the access issues embedded in the health care system relate to understanding disability from a social, medical and cultural context. How do we train health care providers to work with, communicate with, and talk to people with disabilities to know what resources are appropriate and available? Disability is not integrated into medical, nursing, or allied health education curricula. As a result, health care providers lack basic knowledge about disability as a construct, the environmental and medical components of disability, and the range of solutions and approaches that exist.

Dr. Kirschner closed by challenging the group to look deeper into the layered issues of cultural competency, patient safety and coordination of care, while at the same time tackling the barriers posed by the bricks and mortar of the built environment.

Women with Disabilities

Rosemary Hughes, Ph.D., University of Montana

JoAnn M. Thierry, Ph.D., M.S.W., Centers for Disease Control and Prevention

Rosemary Hughes introduced the population of women with disabilities. Of 137 million noninstitutionalized civilian women in the United States, 15.4 percent are reported to have some type of disability. Women with disabilities face compounded barriers to health care stemming from environmental, psychosocial, socioeconomic, and informational contexts.

Hughes focused remarks on two specific and critical areas: depression and interpersonal violence. She described the prevalence of depression among women with disabilities; 51 percent of women interviewed in Hughes' research were found to have clinically significant symptoms of depression. Up to 37 percent of women interviewed reported not having received current treatment (treatment within the past three months), and this was especially true for Latinas with disabilities.

Approximately one in five women with disabilities reside in rural American, and the likelihood of receiving treatment for depression is reduced even further for this population. Rural women with disabilities have been termed "the poorest of the poor" according to an American Psychological Association (APA) task force on rural mental health. Rural women are more likely to lack access to timely and appropriate health care; an ongoing source of care; or access to a female, minority, or specialty physician.

Hughes presented interpersonal violence as a critical public health problem for people with disabilities, and discussed her current project work on the screening and intervention needs of both men and women with disabilities—a complex issue that involves access to health care, domestic violence, and sexual assault services. Hughes

is developing screening methods for people with disabilities that will include questions on physical and sexual abuse, as well as disability-related abuse queries, such as a caretaker refusing support with activities of daily living or withdrawing assistive devices.

Jo Ann Thierry focused her discussion on a series of three studies conducted at the Centers for Disease Control and Prevention (CDC) looking at breast cancer screening, breast and cervical cancer screening for women with disabilities, and health promotion programs for women with disabilities.

All members of the disability community should have access to health promotion, disease prevention, and the direct medical services they need to optimize good health. Yet women with disabilities continue to face substantial barriers that contribute to lack of screening. These include physical, attitudinal, and policy barriers; lack of information about how disability affects health; financial limitations; and inadequate personal assistance.

Attitudinal barriers include both participant and provider attitudes. Interviews and focus groups conducted by the CDC in over seven regions of the United States revealed that many women with disabilities do not realize they are at risk of cancer. Although all women have similar risk factors cancer regardless of disability, not all women with disabilities are aware of this fact. In the CDC studies, women believed they did not need breast or cervical cancer screening because of their disability. In other words, lightning would not strike twice. Thierry described hearing this belief stated over and over again.

The CDC's studies also found that women with disabilities lack the basic knowledge about preventive health care that women in general have. In one study, women with disabilities identified 18 different risk factors for breast cancer, yet in fact only three were established risk factors in the literature. For instance, many women believed that engaging in physical activity caused cancer. These results lead Thierry to conclude that prevention information in the public domain does not effectively reach women with disabilities.

Another problem identified by the CDC's research is that women with disabilities are often so preoccupied with competing health issues that preventive health care is not a priority. In these cases, preventive services represented an additional weight that women could not shoulder at the moment.

During the interviews and focus groups conducted by CDC, Thierry spoke with more than 250 women with a variety of physical disabilities across the United States. Provider attitude and behavior played a prominent role in these discussions. Many women with disabilities find the attitudes of health care providers a barrier to health care. In general, providers are reported to lack sensitivity and understanding of disability and make erroneous assumptions based on disability.

The CDC also conducted focus groups with health care providers, asking them to identify barriers to providing care to women with disabilities. The two most frequent responses were lack of training and lack of reimbursement and time. Physicians felt they did not have sufficient time to provide care and were not appropriately reimbursed for services they did provide.

Women who participated in the CDC studies identified several more barriers to health care. Facilities and equipment were cited as a frequent problem; inaccessible entry doors, examination rooms, restrooms and dressing rooms were not uncommon. Transportation was a significant issue, although the problem was not necessarily a lack of availability but instead an absence of service quality and reliability among paratransit systems. Cancelled rides, late pick-ups, and missed medical appointments were widespread occurrences. Deficiencies in personal assistance posed barriers as well. Resources were often unavailable at the time of the medical appointment, leaving women to fill out forms, dress, or transfer without adequate assistance. And financial limitations did not allow women to purchase needed medication, services, or equipment.

Thierry highlighted effective methods for creating and delivering health promotion messages to women with disabilities. Women with disabilities do not see themselves in the general health promotion materials developed and distributed by the CDC; they

couldn't see themselves in the message. In response, the CDC has developed a new health promotion program encouraging women with disabilities to receive breast cancer screening. The program features four women with disabilities who have survived breast cancer and agreed to share their stories. Summit participant June Isaacson Kailes appears in the campaign, and the RIC Women with Disabilities Center served as the pilot site for the new program, which will launch soon.

Strategies to place good materials into the hands of women with disabilities must be evaluated. Some accounts mentioned that materials designed specifically for women with disabilities, distributed through disability service organizations, still failed to reach the target population. Communication approaches must be assessed, and tactics designed to enhance the effectiveness of dissemination efforts.

Thierry believes the problems can be solved; good preventive health care for people with disabilities can be achieved. She cited three things needed to make this happen. First, women must understand they are at risk for cancer and other health conditions. Secondly, we must have better provider training and education. Physicians must know that women with disabilities should be referred for screening. Third, overall access and accessibility must improve. If women understand they are at risk, and physicians refer, then facilities that are fully accessible are essential. According to Thierry, "We must address the issues from these fronts and we must do it simultaneously in order to be successful."

People with Communication Disabilities

June Isaacson Kailes, M.S.W., L.C.S.W., Western University of Health Sciences

June Isaacson Kailes framed her remarks around universal and overarching issues that affect all disability groups. In reality, the subsets of speech and vision disabilities do not exist cleanly alone. People live with multiple disabilities.

There are specific needs for people with speech disabilities: longer appointments to enhance communication access, staff trained to know how to work with people who use

communication devices, and staff who understand how to use speech-to-speech relay services. In terms of visual issues, alternate formats of printed material are needed that can include Braille, large print, or audio translation. Assistance with orientation to facilities and way-finding is needed. A major concern relates to privacy when printed forms need to be completed in the waiting area. Kailes told of people with visual impairments being asked out loud in a waiting room full of people, “Have you had any sexually transmitted diseases?”

Overarching issues comprise physical, equipment, communication, and attitudinal access. In terms of policy fixes, Kailes suggested, “Couldn’t we get further faster by universalizing some of these needs? And not just talking from a disability perspective.” For example, communication access goes beyond disability groups. It’s a major issue for those with low literacy and other language issues. Surveys that Kailes conducted for managed care organizations indicated that people want information in more than one format—large print, audio. It goes beyond disability accommodation. Medical errors are not solely on the provider side but also due to the lack of good communication access. People with visual disabilities, and others, need medication information in formats they can access—pictures, audio, whatever works.

Kailes told the story of a man who was blind and who was taking the cholesterol medication Zocor. He had pharmacy counseling at the window when he collected his prescription, but was not given access to the patient prescription information, which only came in printed format. This man loved grapefruit and ate a lot of grapefruit every day. People who take certain cholesterol medicines are advised against eating grapefruit or drinking grapefruit juice. He had not received this warning because the information was not available to him in an accessible format, and as a result he developed cirrhosis of the liver. His cirrhosis was not a result of alcohol use; this man only had one drink in his life, and that was at his wedding. His death was completely preventable.

Understanding how attitudes get in the way of health care is important. Sometimes, health care providers come into the room with predetermined attitudes. They make assumptions about the quality of the lives of people with disabilities by assuming that

smoking cigarettes, drinking, and eating poorly, for example, are disability-coping mechanisms. Consequently, they can fail to provide information about the importance of exercise or diet. She also noted that she has observed providers who think that wheelchair users do not require HIV testing, thus assuming incorrectly that they do not engage in behaviors that expose them to the risk of HIV infection.

Critical issues are both clinical and attitudinal, so the focus must be on competency development and training that includes processes, policies and procedures. Much of the problem relates to equipment access, not only how specific equipment should be used, but also the procurement process and information that is needed of patients ahead of a visit or scheduled procedure. More attention also must be paid to the importance of policies that call for the acquisition of health information and education materials in accessible formats; most are not captioned or audio described.

Kailes used the term “quality service accommodation alerts” to describe a method for alerting providers that a scheduled patient requires specific accommodations. She posed the hypothetical questions: “How many times do I have to go to the same provider office where they take me to the exam room without a height-adjustable exam table? I say no, I need an accessible table, then they say they do not have one. I say yes, yes you do . . . in exam rooms 3, 4, and 15! The fatigue that goes on every time we have to remind someone that I need an accessible weight scale, or I am not able to stand, or I need two technicians for a mammogram, or I need transfer assistance.” With the right policies, procedures, and awareness, these problems could be solved.

The biggest sea change in health care, according to Kailes, has emanated from disability rights litigation in health care by the Department of Justice (DOJ) and private attorneys. However, she said, “But you know, in the big picture, the impact has still been pretty small. So, how do we escalate this?”

People with Developmental Disabilities

Sue Swensen, Former Executive Director, ARC of the United States

What is the value of the person with a disability in the community if they have profound or multiple developmental disabilities? Too often in health care, the system teaches us to assess the value of the person being treated before they are ever seen. The CEO with the very best health care plan is allowed access to any specialist in the world. Is it because that person has more value? Sue Swensen said we must question this as a society. Do we really think health care can be distributed according to economic capabilities of the person?

“My son Charlie is 25 years old. He was identified at 18 months old with muscular dystrophy, quadriplegia, legal blindness, and with signs of autism and depression. If I describe him accurately, people can’t imagine he can do anything. I see him as a wonderful, loving person who makes an enormous contribution to my family and our community, yet that piece is almost never discussed when we talk about health care and developmental disability.”

One of the major problems we have in looking at health care and people with disabilities is the insistence on a two-part dichotomous model—the social and medical models of disability. Giving credit to Richard McKeon at the University of Chicago, there are at least four models concerning disability.

First is the medical model, which is how families are introduced to developmental disability. The focus is on “cure” and fixing errors inherent in the individual. Families with autism are now experiencing this judgment much as families with a label of mental retardation did in the 1950s. It runs counter to any concept of disability cultural competence. Medical professionals are not trained to be culturally competent with people with disabilities and disability culture; therefore, a family’s first introduction to disability is medically-oriented.

A second approach is to accommodate an individual's lack of function through a rehabilitation model. Basic functions might be achieved through the rehabilitation model; these might include dressing, feeding, self-care, or communication. The role of rehabilitation often falls short, as families of people with intellectual and developmental disabilities have experienced. Accommodations in support of an individual's innate right to become an adult, make decisions, and direct their own life are often truncated and unavailable. This is a serious issue.

A third outlook on disability is the civil rights approach. Instead of aligning accommodations and supports solely with societal expectations, the rights method asks people what they want to accomplish in their lives and how society can assist. Health care makes a significant contribution and work in support of people's rights. Tremendous health care resources are spent supporting the right of people to redefine and reinvent themselves. Yet this is rarely so for people with disabilities. How much cosmetic or bariatric surgery do the wealthy have the right to purchase? Is that a resource that might otherwise be directed to a person with a disability? Does a person who is born with Down syndrome have a right to unlimited cosmetic surgery because we live in a society where image is more important than anything else? This is a serious question that we do not even consider.

As Swenson said, "Medicaid doesn't allow the recognition of modifiers in its billing structure. This means the person can only be treated for one presenting problem at a time. I assure you when my son goes to any doctor; he has six or seven presenting problems. I frequently have to make other appointments to come back so that each can be addressed. It's easy for me to come back. I have staff and a car. For a mother taking her son on three buses across the city of Chicago, those other five problems are just never going to be treated. And that's a deep flaw in the system."

The fourth method to consider is the social model, where we think not only about the individual and which therapeutic interventions might be given, or the accommodations that could be made, or the rights that are necessary, but we think about the social impact of health care and the social requirements.

Questions are continually generated between the methods or models. For example, between medicine and rehabilitation, I might ask, “Am I provided with accommodations that I need to use health care resources?” Conversely, between rehabilitation and medicine, I might say “Do I have the right health care so that I can optimize the accommodations that are available to me?” Is this even considered a goal of health care? Then on the medicine to rights dimension, you might ask, “Does my health care provider have the right to treat me the way his profession requires him to treat me?” Medical professionals have ethics and requirements, and yet, the way the payment system is structured, these professionals are deeply restrained in what they can do. The problem is inherent in private insurance as well as Medicaid.

The key question is “Is there a system to create a system?” Do we depend on meetings like this to bring together people of good will and great intelligence on an occasional basis to deal with very significant issues that affect millions of Americans? Or do we create a system where focusing on moving forward and addressing common problems from different disciplinary platforms is done on an ongoing basis?

The importance of marketing channels was stressed. Swenson described her market research study of Social Security, which involved analyzing more than 2 million Social Security data points via market segmentation databases. The databases that corporate America, including health care companies, used to design new services were found not to contain any data on people with disabilities. Swenson upheld that Social Security has a responsibility to put that information into the marketing databases, and CDC can make a significant contribution as well.

Swenson encouraged summit participants to use available tools such as the “Montreal Declaration on Intellectual Disability,” created under the auspices of the Pan American Health Organization and now adopted by the World Health Organization (WHO). The language is very clear about supported decision making and limited guardianship and their effects on health care for people with developmental and intellectual disabilities.

People Who Are Deaf

Carolyn Stern M.D., Rochester School for the Deaf and Gallaudet University

Dr. Carolyn Stern shared available statistics about the deaf and hard-of-hearing populations, but pointed to limitations in data and called for better collection efforts. Universal newborn hearing screening programs have helped gather better data but without followup they cannot account for hearing loss developed in later months or years.

According to the best data, roughly 1 in 10, or 30 million, Americans have some degree of hearing loss. In the 2000 census, about 1 in 100 was found to have a profound loss. We clearly know the prevalence of hearing loss increases with age, and more than half of people with hearing loss are over the age of 85 years. The Deaf community, those who use sign language to participate in community life, is estimated between 40,000 and 1.5 million people. Accurate estimates are difficult given the lack of precise data.

The health care status of people who were born deaf or became deaf before acquiring language is very similar to other language minority groups. Not unlike new immigrants, people who are deaf experience poorer health status and fewer physician visits, primarily related to language barriers. In contrast, the health care status of people who are deafened later in life tends to mirror those with chronic disabilities. This group is also in poorer health, has more frequent physician visits due to aging, and yet does not necessarily receive preventive services.

People who are deaf and hard-of-hearing tend to be of lower socioeconomic and educational status. Literacy levels, including health literacy, are lower than the general population. Employment opportunities are limited and often inadequate. The language barrier is critical in the work environment, and preconceived attitudes and prejudice is common. Stern noted, "I can't tell you how many times children who have Deaf parents have been told, 'Oh, it's so wonderful you can interpret for your Mom and Dad so you can take care of them.' And Mom and Dad are 40 and 50 years old and they've been getting along just fine, thank you. It's a critical issue."

For the most part, people who use only sign language as their means of communication tend to have limited contact with hearing culture. Many socialize within Deaf clubs, Deaf organizations, or schools for the Deaf and hard of hearing. People who are deaf have their own norms and culture, different from both the medical model of deafness and the social cultural model of someone who is deafened (but not Deaf). The implication is that people who are deaf tend not to be seen in the general population unless they are mainstreamed into the general population.

Teaching the participants about the nuances of Deaf culture, Dr. Stern described learning about acceptable speaking volume differences between waiting room, physician office, and community voices. Stern learned about out-in-public voices from her sister-in-law who was stunned when her father, who is deaf, used his public speaking voice in the doctor's waiting room. Fellow patients responded with audible surprise when hearing the volume of his voice. These are the cultural things you don't necessarily think about.

A high risk of miscommunication exists when deaf patients must rely on writing back and forth with their health care providers. By signing the simple sentence "he bought a house," Dr. Stern showed the difficulty involved in translating American Sign Language (ASL) into the written word. The complexity of the English language adds even greater challenges, as evident in the word "run." You can run to get something, run up a bill, have a run in your stockings, run out of milk, or have a runny nose. The single word "run" has multiple different signs based on intended meaning.

The intricacies of language are amplified further during medical encounters. "Discharge" is a common word in the health care setting, but is that vaginal discharge, discharge from a wound, or discharge from the hospital? Dr. Stern related the time an interpreter interpreted "cervical" not in relation to the spine (as the doctor had intended), but in relation to female anatomy. The nuances of ASL, the challenges inherent in the English language, and the distinctiveness of medical vocabulary must be considered in every medical situation.

Tremendous diversity exists within the deaf and hard-of-hearing population. Some Deaf people rely more on oral communication or cued speech and tend to belong to organizations such as the Alexander Graham Bell Association, while culturally Deaf people communicate with ASL and gravitate toward the National Association of the Deaf (NAD). People who are late-deafened or hard of hearing tend to be more difficult to define because many do not self-identify as deaf or hard of hearing. They likely were hearing at one time, but lost their hearing as they grew older. As a group, they use a wide range of communication methods.

We cannot limit our discussion to the person with a disability; the whole family is affected by disability. The familial effect is evident in organizations such as Children of Deaf Adults (CODA). Children of deaf adults have both practical and cultural issues. Caught in a cultural middle land, they are not really respected by the hearing community because their parents are deaf and they are not necessarily thought of as deaf by the Deaf community.

The Deaf community can be categorized further by ethnic and foreign language modifiers. Black, Asian, Latino, and Russian people who are deaf are just a few examples of the subset populations. Dr. Stern related the story of a patient who was married, pregnant, a Latina with a strong family and Latino culture. The family issues, Deaf cultural issues, Latino cultural issues, and communication issues came together to create quite a complex encounter.

The primary barrier for people who are deaf and hard of hearing in the health care setting is a given: communication is a barrier. Physicians with deaf patients do not understand communication needs, communication methods, Americans with Disabilities Act (ADA) requirements, cultural competency, or cultural humility. Where is the willingness to ask, “What is it that you need so I can communicate with you best?” rather than expecting that it is possible to know and understand each different culture that crosses your door.

Stern added, “Deaf patients do not understand health information. They are told to get a prescription, take this medication or put a patch on every week. This patient came in with, like, ten patches on him. They told him to put a patch on every week. You’re supposed to remove the first patch before placing the next one, only he didn’t know that. And so, these communication errors continue.”

Often health care providers do not understand the roles of deaf and hearing family members. Family members are frequently called upon to act as Sign Language interpreters in areas where they are clearly not trained or qualified; they do not know medical vocabulary, the medical community, or the structure. Stern has heard of 5- and 6-year-old children asked to interpret that their mom needs a mastectomy. Even when sign language interpreters are present, physicians and sometimes deaf patients themselves do not know how to work effectively with interpreters.

Unfortunately, interpreter costs typically exceed the amount a physician receives in reimbursement for an office visit. Moreover, unlike installing a one-time ramp, interpreting costs are a recurrent expense. Costs can escalate easily even with allowable tax credits. The reimbursement issue plus additional time needed in the appointment represent two strong disincentives for physicians to provide care for deaf and hard-of-hearing patients.

Deaf patients experience multiple barriers to accessing and understanding health information. Ambient knowledge—the type of health information you hear on the radio or overhear in conversation—is not accessible to people who are deaf or hard of hearing. As a result of communication barriers, Deaf patients do not receive health information from their health care providers, either. It is not known where people who are deaf or hard-of-hearing obtain their major health information. Often, they simply do not.

These are systemic problems and challenges, and they require systemic solutions. One element of the solution is education. If we educate now, then we can hopefully prevent problems in the future.

In response to participant queries, Dr. Stern provided information on deaf and hard-of-hearing physicians and allied health providers. Although no one has precise numbers, Stern estimates 30 to 40 physicians who use sign language are in practice in the United States. Additionally, there are physicians who are former Sign Language interpreters. Still, primary care, wellness and mental health resources are all very limited, even in communities like Rochester, NY, which is home to many deaf services. Nationally, very few physicians with disabilities are practicing medicine. Our ability to progress toward more accessible and culturally competent care for people with disabilities depends in part on changing this reality.

Stern's presentation prompted participant discussion on the issue of universality. Communication is a significant issue for all patients, deaf and hearing, and it intersects with issues of poverty, literacy and ethnicity. The need for effective communication is not specific to people with disabilities, but universal to all patients. At the same time, we must be careful to properly frame the meaning of universality or universal design; it cannot work if seen as one size fits all. However, the role of universal design in improving health care access is realistic when defined as adapting the environment or equipment or communication around individual needs.

Universal design principles intersect with the Institute on Medicine's (IOM) strategy on person-centered care. The IOM has identified person-centered care as one of the six aims for improving the health care system. According to the IOM, the individual patient's culture, social context, and specific needs deserve respect, and patients should play an active role in making decisions about their care. The IOM context provides a helpful strategy for improving health care access for people with disabilities. Person-centered care is based on health care providers understanding the individual needs of patients and families, a concept which interlinks well with the principles of adaptable design. "Definitely, you want to ask the person, what's the best way for me to communicate with you?" Stern said.

Universal Design Principles in Health Care

Jim Terry, A.I.A., Evan Terry & Associates

Jim Terry provided a detailed examination of the seven principles of universal design. The first principle is equitable use, meaning the design must be useful and marketable to any group of users. User groups in the health care setting include everyone from patients to nursing students, visitors, and hospital volunteers. Moreover, not only does this principle address use from the perspective of functional role in the health care environment, but also considers need throughout the life span. Equitable use means the environment is available to people with variable abilities and disabilities. Terry said, "The design is seamless. It doesn't call attention to disability. It just works."

For example, we have exam tables that drop down to 18 inches. The table articulates directly with the wheelchair, allowing the user to transfer directly from chair to table. This design reduces risk of injury to patient as well as the caregiver involved in patient transfers. Terry estimates that musculoskeletal injuries incurred while transferring patients account for as much as 50 percent of workers' compensation cases in health care. While an adaptable exam table does much for the dignity, safety, and quality of care delivered to the patient, it also contributes significantly to workplace safety and organizational productivity and reduces nursing turnover.

The second principle of universal design is flexibility of use. The question is whether the design accommodates a wide range of preferences and abilities. A good design will accomplish this flexibility through choice. Universal design is not coming up with a single solution for everyone; the best design offers choices. For instance, one of the facilities designed by Terry's architectural firm featured height-adjustable employee work stations and a work counter with two heights distributed along the length of the counter. Employees can choose to work at either the lower or higher section depending on their unique needs or those of the customer on the opposite side of the counter. The design is functional, ergonomic, comfortable, and adaptable.

The concept of choice and flexible use has positive impact on patient safety. We now have adaptable magnetic resonance imaging (MRI) scanners. The patient can walk in, sit, stand, or recline during the procedure. The imaging procedure adapts to the patient's individual need, instead of the patient adapting to the scanner's fixed capability. We have wheelchair weight scales that fold up against the wall, taking up little space when not in use. The patient can be weighed in the chair and the empty chair weighed once the person transfers to the exam table. Through use of this design, the physician can accurately prescribe medication based on the true weight of the individual versus an estimate. These innovations, which support patient safety and quality of care, are available but used little.

Principle three says the design must be simple and intuitive. Use must be easy to understand regardless of the user's experience, knowledge, language skills, or current concentration level. Principle four is perceptible information. The design must communicate the necessary information effectively to the user regardless of the ambient conditions or user's sensory abilities. For example, patients can be alerted in a pharmacy or waiting room environment with a verbal announcement plus light-emitting diode (LED) signage. The benefits of perceptible information are certainly not limited to people with disabilities; people who are distracted or attending to small children benefit from overlapping audible and visual alerts alongside people who are deaf, hard of hearing, or visually impaired.

The fifth principle of universal design addresses tolerance for error. Does the design minimize the hazards and adverse consequences of accidental or unintended actions? A tolerance for error minimizes any surprise to the user. For example, in California hospital facilities, which must be reinforced with seismic bracing capabilities, the protruding bracing can present a hazard to a person with a vision impairment or to someone who is simply inattentive. Installing a rail along the bracing allows a cane to pick up the presence of the bracing, and also alerts the inattentive individual to the hazard well before he or she reaches it.

Principle six emphasizes low physical effort. The design needs to be efficient and comfortable, causing a minimum of fatigue. Automatic door opening devices and distance from parking to entrance are key examples. Principle seven says to design size and space for approach and use. This principle is met when an individual can approach, reach, manipulate, and use the environment regardless of body size, posture, or mobility.

Responding to questions from participants, Terry noted that the universal design movement is in its very beginning stages, even though the concept initially emerged in 1978 or 1979. Currently, the hospital client response to incorporating universal design principles remains mixed. Generally, motivation such as a civil lawsuit, Department of Justice investigation, or Joint Commission survey is required before a hospital will focus on issues of equitable use. Or an internal champion chooses to lead the movement from within, either because he or she has a disability or because he or she has a relationship with someone with a disability.

Hospitals are somewhat resistant to incorporating universal design principles into new construction, although the issue is generally not one of cost. There is little cost difference between building a facility with universal design features and one without. Not surprisingly, much of the resistance from hospital administrators is directed toward costs related to modifications of existing facilities. Terry sees the issue as one of perspective. "It's more an issue of people wanting to do it, people seeing it as a customer service issue and a civil rights issue, and saying this is what we need to be doing and just going in that direction."

Absence of Federal Directives to States on Access, Accommodation, and Accountability

Sylvia Yee J.D., Disability Rights Education & Defense Fund (DREDF)

Sylvia Yee spoke broadly about federal mandates on access, accommodation, and accountability. Looking back to 1990, when the ADA was enacted, health care

accessibility was really a rallying point. We truly expected the ADA to achieve health care access. So the question is, “why are these problems still here?”

Yee related an analogy to help answer the question. Let’s suppose someone brought in a truckload of gravel, sand, and spread it over the carpet in this room. They gave us each a pair of chopsticks and asked us to clear the floor. How far would we get with this task? What can we do but start picking up the biggest pieces first? Eventually we get to the smallest pieces, the sand and the gravel deeply embedded in the carpet now, and we realize we have the wrong tool. We can’t reach in.

In our health care delivery system, we have entities like Kaiser Permanente in California. They represent the large entities that have hospitals, group clinics, and employed physicians. But then we also have solo physician practices and small group clinics. The majority of outpatient visits—89.3 percent, in fact—take place not in the large Kaiser Permanentes, but in private offices around the nation. These small practitioners are like the pebbles and grains of sand we’re trying to pick up with our chopsticks.

Metzler v. Kaiser Permanente was groundbreaking litigation that challenged the level of health access at Kaiser Permanente facilities throughout California. It was a sweeping settlement that required the removal of architectural barriers, the installation of accessible medical equipment, and the implementation of policies and procedures to improve health access for people with disabilities.

The Kaiser Permanente settlement propelled an unprecedented economy of scale for the entire health care system. As related earlier in Jim Terry’s presentation, accessible exam tables were priced at a premium—roughly \$12,000 each—due to low sales volume. When Kaiser expressed interest in thousands of tables, the price dropped by 75 percent to \$3,000 to \$4,000 a piece. As a result, small practitioners were able to enjoy the cost advantages made possible by Kaiser’s buying power. Yee added, “This is no small thing. This is a great thing.”

The 2001 Kaiser Permanente settlement and the 2005 Washington Hospital Center agreement with the Department of Justice are two innovative cases. But where are the others? How many of these significant lawsuits have there been? You see, we are picking up the biggest pebbles, the big rocks. We are not reaching down to that level of health care where the private visits—the majority of health care visits—are taking place. “The law is just a blunt tool for reaching this level,” Yee noted, “for changing the hearts and minds of an entire sector of society.”

There’s another reason why the ADA has not met our expectation of health care access, and this aspect concerns the complexity of health care itself. U.S. health care is really a system of multiple and deep layers. While each of these layers—professional education, accreditation, coordination of care to name a few—in some way has an obligation under Titles II and III of the ADA to provide accommodation to people with disabilities, the law is really most explicit about physical standards.

Programmatic access does not enjoy the same degree of clarity. We cannot expect the law to specify layers of detail on how a health care facility should receive a person with a disability, communicate information or engage in clinical practice. The law cannot and should not give us these details, but it can be an incentive for system change. Yee concluded, “While this presentation was billed as the absence of federal mandates, I believe there is a federal mandate. It is just that it’s a clearly limited one.”

Definitions, Data Collection, and Disparity Initiatives

Lisa Iezzoni, M.D., M.Sc., Harvard Medical School and Institute for Health Policy

Dr. Lisa Iezzoni affirmed that we have not defined disability. We have no accepted definition of disability and no consistent system for measuring how many people have a disability or what the impact of disability is on health. The current monitoring system is insufficient in providing the basic data we need to measure and monitor disability. And we cannot change what we cannot measure.

The World Health Organization (WHO) worked on a definition of disability for more than 10 years. At one point, WHO eliminated the word “disability” entirely, but eventually compromised by formulating the International Classification of Functioning, Disability and Health (ICF). The ICF uses disability as an umbrella term, which encompasses traditional concepts such as disease, disorder, activity, and participation levels. One of the very innovative pieces of the ICF, however, is the addition of environmental factors. The physical, social, and attitudinal environments are considered in the context of disability and disabling condition. For example, assistive devices like a wheelchair are included in the physical environment, and although the ICF did not define aspects such as poverty and education, these dynamics are included in social factors.

A number of available databases use some but not all constructs found in the ICF. Dr. Iezzoni reviewed these national data sets.

The U.S. Census Bureau captures considerable demographic information, data on physical and sensory impairments, and limitations in activity and participation, such as self-care or working outside the home. Regrettably, census data set falls short with regard to health care information. None of the data on physical impairment or limitation in activity, for instance, can be linked to health care.

Two major data sources are administered through the National Center for Health Statistics—the National Health Interview Survey (NHIS) and the CDC’s Behavioral Risk Factors Surveillance System (BRFSS). Both the NHIS and BRFSS collect considerable data on difficulties in hearing, seeing, lifting, and so on, as well as activities of daily living, such as preparing meals or shopping. Additionally, health services utilization data is captured, particularly data relating to U.S. Preventive Services Taskforce recommendations. These data fall under the Federal Government’s Healthy People decennial health initiatives (e.g., “Healthy People 2010”).

The Medical Expenditure Panel Survey (MEPS) is administered by the Agency on Healthcare Research and Quality (AHRQ). MEPS is a national longitudinal survey that enrolls and tracks individuals and families for a period of 2 years. Data are collected on

specific health services used by survey participants, frequency of use, cost, and payer sources, as well as on cost and scope of health insurance and satisfaction with health care experiences.

The Centers for Medicare & Medicaid Services (CMS) have various mechanisms to collect significant amounts of beneficiary data. Aged beneficiaries represent the greatest share of the Medicare population (85 percent), followed by people under the age of 65 who are eligible due to disability (14 percent) or end-stage renal disease (less than 1 percent). The Medicare Provider Analysis & Review (MEDPAR) file contains claims data for inpatient hospital and skilled nursing facility services. MEDPAR is based on diagnostic and procedural codes, and can track inpatient history and patterns of care over time. A beneficiary panel survey is also conducted annually. The Medicare Current Beneficiary Survey (MCBS) is a nationally representative sample of aged, disabled, and institutionalized beneficiaries. This CMS data set is the most comprehensive source of information on health status, health care use and expenditures, and socioeconomic and demographic characteristics of the entire spectrum of Medicare beneficiaries. MCBS also tracks information about activities of daily living (ADLs), functional status and preventive services.

Taken together, the current data collection efforts amass a significant amount of data on impairment, activity, and participation limitations. But data are limited to one slice of the ICF framework—impairment. We have no information on environmental factors. Whether someone uses a wheelchair or an augmentative communication device, or has low vision, is not collected. We have no systematic data on the physical or programmatic accessibility of homes or health care settings. We have not captured the attributes that really get to the social model of disability.

Dr. Iezzoni summarized her lengthy record of health services research by saying that there are disparities in health care for people with disabilities—but we know nothing about why the disparity exists. Are people not receiving services because of a stigmatized attitude on the part of the physician, or because the patient preferred not to have the service? Available data sets are not designed to capture such aspects of care.

Dr. Iezzoni observed, “When women with disabilities under age 65 were diagnosed with early-stage breast cancer, they were much less likely than the general population to receive breast-conserving cancer surgery. They were much more likely to be treated with mastectomies. It could be the patient’s preference, but it could be other factors as well. We just don’t know.”

In 1999, AHRQ received a congressional mandate to produce annual reports to the nation on prevailing disparities in health care delivery. The annual National Health Care Disparities Report (NHDR) describes disparities in health care associated with race, ethnicity, gender, age, income, geography, and the existence of disability and chronic illness. The report serves a number of purposes, such as demonstrating the validity of concerns regarding disparities in health and documenting whether disparities in care are stable, improving, or declining over time. The 2007 NHDR was recently released and included reports on exercise counseling for obese adults, inappropriate medication use by the elderly, delays in necessary care, and delays in illness and injury care for children with special health care needs.

Dr. Iezzoni expressed her amazement at the relative dearth of information in the 2007 report, considering the scale of priority populations and disparities in existence. But NHDR, which relies on the very databases just described (particularly MEPS and NHIS), is limited by the confines of the available data systems. Aside from inadequate definitions of disability, few reporting measures get at the relationship between individuals and their surrounding environments (i.e., cultural, social, natural, and architectural).

The 2007 IOM report, “The Future of Disability in America”, recommends that all national data collection efforts adopt ICF conceptual framework for defining disability. Additional recommendations advise the National Center for Health Statistics to “improve scope and quality of data on disability and its causes and consequences” and note the need for a national disability monitoring system. The latter two recommendations are nearly identical to those made in the IOM’s 1991 report “Disability in America.” Dr. Iezzoni concluded, “We haven’t gotten far since that time. So little has happened. Unfortunately.”

NCD Health Care Summit Planning Committee, October 2007–April 2008

Mary Lou Breslin

Senior Policy Advisor
Disability Rights Education and Defense
Fund (DREDF)
2212 Sixth Street
Berkeley, CA 94710
510.644.2555

Carmen A. Cicchetti, M.Ed., M.A.

Business Support Manager
The Donnelley Family Disability Ethics
Program
The Rehabilitation Institute of Chicago
345 East Superior Street, Room 1374
Chicago, IL 60611
312.238.1119
ccicchetti@ric.org

Susan Henderson

Executive Director
Disability Rights Education and Defense
Fund (DREDF)
2212 Sixth Street
Berkeley, CA 94710
510.644.2555, ext. 225
shenderson@dredf.org

Lisa I. Iezzoni, M.D., M.Sc.

Professor of Medicine, Harvard Medical
School
Associate Director, Institute for Health
Policy
Massachusetts General Hospital
50 Staniford Street, Room 901B
Boston, MA 02114
617.643.0657
liezzoni@partners.org

Kristi L. Kirschner, M.D.

Coleman Foundation Chair in Rehabilitation
Medicine
Director, The Donnelley Family Disability
Ethics Program
The Rehabilitation Institute of Chicago
345 East Superior Street, Room 1136
Chicago, IL 60611
312.238.4742
kkirschner@ric.org

Nancy Mudrick, Ph.D.

Professor, School of Social Work
College of Human Ecology
Sims Hall, 4th Floor
Syracuse University
Syracuse, NY 13244-1230
315.443.5564
kkirschner@ric.org

Judy Panko Reis, M.A., M.S.

Director, Women with Disabilities Center
The Rehabilitation Institute of Chicago
345 East Superior Street, Room 164
Chicago, IL 60611
312.238.1051
jreis@ric.org

Mary Margaret Sharp-Pucci, Ph.D., M.P.H.

Managing Member
Sharp Health Strategies, LLC
1120 Crestview Drive
Batavia, IL 60510
630.667.8365
mmsp@sharpstrat.com

Silvia Yee, J.D.

Staff Attorney
Disability Rights Education and Defense Fund
2212 Sixth Street
Berkeley, CA 94710
510.644.2555, ext. 234
mmsp@sharpstrat.com

APPENDIX G. **Mission of the National Council on Disability**

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency, composed of 15 members appointed by the President, by and with the consent of the U.S. Senate.

The purpose of the NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, and that empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

To carry out this mandate we gather public and stakeholder input, including that received at our public meetings held around the country; review and evaluate federal programs and legislation; and provide the President, Congress and federal agencies with advice and recommendations.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

Statutory History

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

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¹¹ Activities included (1) a review of the mission statement, strategic plan, annual and other significant reports, and major program goals and objectives for each agency to

determine whether health care disparities for people with disabilities had been identified as an area in which activities would be undertaken; (2) a keyword search of the agency Web sites to identify documents or other information that would reveal an agency's involvement in health care disparity research or other health or health care activities on behalf of people with disabilities that might not be readily apparent in the agency's priority program areas, goals, or objectives; and (3) key informant and informational interviews with certain agency representatives.

¹² The datasets selected for examination were those listed as primary sources for the benchmarks in "Healthy People 2010" and those that contained a large number of health care questions. For these datasets, NCD examined the questionnaires, the documentation, and recent published works that used these datasets. NCD also reviewed reports by others who assessed the potential of Federal datasets, congressional testimony, Government Accountability Office reports, and some Webinar transcripts. Two key assessments are the NCD *Indicators Report* (2008) and the University of California, San Francisco *Disability Data Inventory* (2005). Nine researchers were interviewed who had published papers on health disparities and people with disabilities or other aspects of health care utilization, satisfaction with care, or the health care experience of people with disabilities.

¹³ One or more key leaders in each program were interviewed to determine how the program came into being; what community need is being met; the extent to which the program is stable and fully integrated into a broader organization, if applicable; and how program beneficiaries rate the service they receive. Written evaluations and other related documentation were also obtained for each program that is reported as an effective practice, and in some cases NCD conducted client interviews to gain more insight into the program. Programs that do not meet all these criteria but appear to offer innovative or noteworthy services that meet specific health care needs of people with disabilities or a subgroup of people with disabilities are reported as "practices with potential."

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¹⁹ Altman and Bernstein, in *Disability and Health in the United States*, say, "Basic actions difficulty captures limitations or difficulties in movement and sensory, emotional, or mental functioning that are associated with some health problem. NHIS data do not cover the full range of functional levels for all classes of basic actions..., but the available questions can identify [the following] range of difficulty levels in core areas of functioning: [1] movement (walking, standing, bending or kneeling, reaching overhead, and using the hands and fingers); [2] sensory functioning (the ability of a person to see and hear what is going on around him or her); [3] selected elements of emotional functioning—in particular, feelings that interfere with accomplishing daily activities; [4] Important elements in cognitive functioning, specifically difficulties with remembering or experiencing confusion." p. 5.

²⁰ Altman and Bernstein, in *Disability and Health in the United States*, say, "Complex activity limitation describes limitations or restrictions in a person's ability to participate fully in social role activities such as working or maintaining a household.

Complex activity consists of the tasks and organized activities that, when executed, make up numerous social roles. Complex activity performance requires the execution of a combination of more than one of the basic actions. NHIS obtains information on many (but not all) complex activities that comprise participation in social roles, including the following: [1] difficulties experienced with social and leisure activities, represented in these data by questions about attending movies or sporting events, visiting with friends, pursuing hobbies, or engaging in relaxation activities; [2] perceived ability to work, which is a core aspect of social participation for the majority of the U.S. population and is represented by respondents' self-defined limitations in the kind or amount of work they can do or their inability to work at a job or business; [3] maintaining independence, including self-care and the ability to carry out activities associated with maintaining a household, such as shopping, cooking, and taking care of bills (measures are based on questions concerning ADL and IADL). These are the simplest of the complex activities, but limitations in doing them usually reflect the most severe difficulties in basic actions." p. 8.

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²²⁶ *U.S. Code* 29, sec. 794 (2007).

²²⁷ *U.S. Code* 42, sec. 12101.

²²⁸ *U.S. Code* 42, sec. 12181(7).

²²⁹ Ibid., *U.S. Code* 42, sec. 12181(7)(F).

²³⁰ Title III makes a distinction between the barrier removal standard of “readily achievable” (applicable to facilities that were already occupied as of January 26, 1993) and “readily accessible” (for facilities intended for first occupancy after January 26, 1993). See *U.S. Code* 42, sec. 12182(b)(2)(A)(iv), (v); *U.S. Code* 42, sec. 12183; *Code of Federal Regulations* 28, sec. 36(304); and *Code of Federal Regulations* 28, sec. 401. Alterations to existing facilities made after January 26, 1992 are treated as new construction. See *U.S. Code* 42, sec 12183, and *Code of Federal Regulations* 28, sec. 36(402-405). Entities subject to Section 504 or Title II do not have a lesser barrier removal standard for existing facilities.

²³¹ When a state or local government entity enters a contract with any private entity to provide an aid, benefit, or service of the state or local government, the government entity must ensure that the contractual functions are carried out in compliance with Title II of the ADA. See 28 *Code of Federal Regulations*, sec. 35.102.

²³² See *U.S. Code* 42, sec. 708.

²³³ *U.S. Code* 42, sec. 2182(a).

²³⁴ For the purposes of this chapter, an HMO is any corporate entity that assumes responsibility for providing health care services, either directly or through contractual arrangements with third-party service providers, and receives in exchange a fixed premium for each Medicaid, Medicare, or private insurance enrollee. HMO is thus used as a broad umbrella term that includes managed care organizations that generally undertake a comprehensive risk contract, as well as prepaid ambulatory and inpatient health plans that are paid according to fixed capitation payments or other arrangements. HMOs can be structured in a variety of ways, and it is arguable that a corporate entity that does not actually “own, lease, or lease to, or operate” the professional office of a health care provider or hospital is not directly obligated under Title III.

²³⁵ *U.S. Code* 42, sec. 12182(b)(1)(A)(i).

²³⁶ *U.S. Code* 42, sec. 12182(b)(1)(A)(ii)-(iii).

²³⁷ *U.S. Code* 42, sec. 12182(b)(2)(A)(iii); *Code of Federal Regulations* 28, sec. 36(302). “Undue burden” is defined as “causing significant difficulty or expense.”

²³⁸ “Program or activity” is defined as “a department, agency, special purpose district, or other instrumentality of a state or of a local government; or the entity of such state or local government that distributes such assistance . . .” *U.S. Code* 29, sec. 794(b)(1)(A) and (B). See also *Wolford by Mackey v. Lewis*, 860 FSupp 1123 SDWVa (1994), a prima facie case established against the state of West Virginia for denying meaningful access to Medicaid services when transportation to residential care facility residents was refused even though its provision was reasonable. Moreover, a “program or activity” that receives Federal funds expressly includes “all of the operations of . . . an entire corporation, partnership, or other private organization, or an entire sole proprietorship . . . which is principally engaged in the business of providing . . . health care [or] social services . . . any part of which is extended Federal financial assistance.” *U.S. Code* 29, secs. 794(b)(3)(A)(ii)-794(b)(4).

²³⁹ Medicare and Medicaid payments have been interpreted as Federal financial assistance in virtually every circuit when raised in the context of Section 504 litigation brought against health care entities that receive such payments. See *United States v. Baylor Univ. Med. Ctr.*, 736 F2d 1039, 1042, 5th Cir (1984), *cert denied* 469 U.S. 1189, 105 SC 958 (1985), in which Medicare and Medicaid payments to a hospital’s inpatient and emergency services program constituted Federal financial assistance under Section 504; *Glanz v. Vernick*, 756 FSupp 632 Mass (1991), in which a clinic’s receipt of Medicaid reimbursement brought the clinic’s health care program within Section 504, regardless of whether a particular plaintiff received services paid for through Medicaid; *Zamora-Quezada v. HealthTexas Medical Group of San Antonio*, 34 FSupp2d 433 WD

Tex (1998), in which an HMO's receipt of Medicare funds made all its operations subject to Section 504, not only those services provided to Medicare enrollees; and *Davis v. Flexman* 109 FSupp2d 776, 786 SD Oh (1999), in which a private counseling clinic's receipt of Medicare and Medicaid payments brought it within the scope of Section 504 even if the plaintiff was not a Medicare or Medicaid patient. See also *Sharrow v. Bailey*, 910 FSupp 187, 193 MD Pa (1995); *Patient v. Corbin*, 37 FSupp2d433, 434 ED Va (1998); and *Lesley v. Chie*, 81 FSupp 217, 222 D Mass (2000).

²⁴⁰ *U.S. Code* 42, sec. 12132.

²⁴¹ *Code of Federal Regulations* 45, sec. 84.4(b)(1)(i), (ii), (iii), "Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving Federal Financial Assistance." Federal financial aid recipients are also prohibited from using methods of administration "that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to handicapped persons." See *Code of Federal Regulations* 45, sec. 84.4(b)(4).

²⁴² *Code of Federal Regulations* 28, sec. 35 130(b)(2).

²⁴³ Section 504 gives some additional consideration to a small health care provider (15 or fewer employees) in terms of its obligation to undertake physical alterations in an existing facility. Such Federal financial recipients may refer a person with a disability to another provider if, after consultation with the person seeking its services, the recipient finds that there is no method of making its program or activity, when viewed in its entirety, readily accessibly without making a significant alteration in its existing facilities. See *Code of Federal Regulations* 45, sec. 84.22(c). The referring entity also "has the responsibility of determining that the other provider is in fact accessible and willing to provide the service." *Code of Federal Regulations* 45, PtA, AppA 341. Such entities are also not required to provide auxiliary aids and services unless required by the director of the Department of Health and Human Services. See *Code of Federal Regulations* 45, sec. 84.52(d)(2).

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²⁴⁵ *McInnes-Misenor v. Maine Medical Center*, 211 FSupp2d 256 D Me (2002). See also *Moreno v. G & M Oil Co.*, 88 FSupp2d 1116, 1117-1118 CD Cal (2000), in which the plaintiff did not initiate a class action and could not assert claims against 82 additional stations operated by the defendant based on the rights of other disabled person who may encounter the barriers, since there was no injury to himself concerning the additional locations.

²⁴⁶ See Mary Pat Gallagher, "Jury Awards \$400,000 to Deaf Patient for Denial of Interpreter Services, October 17, 2008, <www.law.com/jsp/law/LawArticleFriendly.jsp?id=1202425326286> (accessed October 31, 2008). As reported, the plaintiff sued her doctor under the ADA, Section 504, and New Jersey's Law Against Discrimination for

refusing to provide her with an interpreter over the course of 20 visits over 20 months during her treatment for lupus. The defendant had claimed that, as a solo practitioner, the estimated interpreter's cost of \$150–\$200 per visit would be an undue hardship when he was only being reimbursed \$49 per visit by plaintiff's insurer, but the plaintiff's attorney introduced tax returns showing that defendant provider earned over \$400,000 a year. The three-week trial took place in New Jersey Superior Court, and the jury ultimately found that the defendant violated the law by failing to provide the plaintiff with an interpreter and retaliating against her for requesting one.

²⁴⁷ *Ibid.*

²⁴⁸ *U.S. Code* 42, sec. 12188(b)(1)(B).

²⁴⁹ See Settlement Agreement: *Metzler et al. v. Kaiser Foundation Health Plan, Inc. et al.* <www.drlegal.org/downloads/cases/metzler/settlement.pdf> (accessed October 31, 2008).

²⁵⁰ See Settlement Agreement Among the United States of America, Plaintiffs Equal Rights Center, Dennis Christopher Butler, Rosemary Ciotti, George Aguehoude, and Marsha Johnson and Washington Hospital Center (Department of Justice Complaint Number 202-16-120). <www.ada.gov/whc.htm> (accessed October 28, 2008).

²⁵¹ See *Gillespie et al. v. Laurel Regional Hospital*, No DKC 05-CV-71 DC MD, Consent Decree (July 14, 2006). <www.washlaw.org/projects/disability_rights/dr_lawsuits.htm> (accessed October 28, 2008).

²⁵² Another approach that has been taken recently with a large Title III entity can be found in a settlement agreement negotiated with the UCSF Medical Center on behalf of San Francisco disability rights activist August Longo. Mr. Longo's attorneys, Lainey Feingold and Linda Dardarian, did not file a lawsuit but rather entered formal talks called "structured negotiations." Under the resulting agreement, the Medical Center has initiated an extensive review of its buildings, policies, and medical equipment, and improved access for people with disabilities, including communication access for patients and visitors who are blind and who have other disabilities. UCSF has hired disability access experts recommended by Mr. Longo's counsel to help the center improve access. See UCSF Medical Center Agreement. <www.lflegal.com/2008/09/ucsf-settlement-agreement> (accessed October 24, 2008).

²⁵³ Donald K. Cherry et al., "National Ambulatory Medical Care Survey: 2006 Summary." *National Health Statistics Reports* 3 (August 6, 2008), p. 1. While the word "ambulatory" can be used medically in the narrow sense of the ability to walk, the NAMCS survey targets the offices of non-Federally employed physicians "who were classified by the American Medical Association (AMA) or the American Osteopathic Association (AOA) as 'office-based, patient care.'" The specialties of anesthesiology, radiology, and pathology were excluded, but visits to private, non-hospital-based clinics and HMOs were included in the scope of the survey. *Ibid.*, p. 7

²⁵⁴ *Ibid.*, pp. 2, 4

²⁵⁵ *Ibid.*

²⁵⁶ *Ibid.*, p. 3. Of the remaining offices, 5.9 percent were owned by another health care corporation, 3.4 percent were owned by another hospital, 2 percent were owned by a medical or academic health center, 1.7 percent were owned by an HMO, and 1.6 percent were owned by a community health center. The remaining 2 percent of offices appeared to be owned by a local government entity or charitable organization, or had left the question unanswered.

²⁵⁷ *Ibid.*

²⁵⁸ 1 FSupp2d 456 ED Penn (1998).

²⁵⁹ The court in *Anderson* referred to the “program accessibility” standard of *Code of Federal Regulations* 28, secs. 35.130(b)(4) and 35.150(a)(1), which requires ADA Title II entities to ensure that their programs are accessible when viewed in their entirety. A “program or activity” is defined in Section 504 as “a department, agency, special purpose district, or other instrumentality of a state or of a local government; or the entity of such state or local government that distributes such assistance.” See *U.S. Code* 29, sec. 794(b)(1)(A) and (B). See also *Wolford by Mackey v. Lewis*, 860 FSupp 1123 SD WV (1994), a prima facie case established against the state of West Virginia for denial of meaningful Medicaid services by refusing residential care facility residents transportation when it was reasonable to do so.

²⁶⁰ 34 FSupp2d 433 WD Texas (1998).

²⁶¹ The court specifically found that the HMO’s receipt of Medicare funds made it a recipient of Federal financial assistance and that all its operations were subject to Section 504, not only those services that were provided to plaintiffs who were Medicare enrollees. See 34 FSupp2d 440 WD Texas (1998).

²⁶² The plaintiffs’ complaint specifically alleged that the HMO had sufficient “control” through its contractual relationships with its medical providers to assert a claim under the ADA concerning the provider’s allegedly discriminatory level of service to disabled enrollees. It was a matter of fact whether the HMO-provider contract included a physician incentive plan and payment scheme that set differential capitated amounts per Medicare enrollees.

²⁶³ *Code of Federal Regulations* 45, sec. 84.52.

²⁶⁴ For example, the HMO is in a better position to implement and coordinate the use of a centralized sign language translator bank or centrally located accessible examining rooms that network providers could book, or to disseminate information about financial incentives and requirements concerning the purchase of accessible exam equipment.

²⁶⁵ *U.S. Code* 41, sec. 426a (1965).

²⁶⁶ Diane Rowland, “Helping Families with Needed Care: Medicaid’s Role for People with Disabilities,” testimony before the U.S. House of Representatives Committee on Energy and Commerce Subcommittee on Health, January 16, 2008.

²⁶⁷ *Ibid.*

²⁶⁸ *U.S. Code* 42, sec. 1396 (d). See also *Code of Federal Regulations* 42, sec. 440.10 et seq.; *Code of Federal Regulations* 42, sec. 491.1-491.11.

²⁶⁹ *U.S. Code* 42, sec. 1396 (d); *U.S. Code* 42, sec. 1396(n). See also *Code of Federal Regulations* 42, sec. 440.60 *et seq.*; *Code of Federal Regulations* 42, sec. 440.90.

²⁷⁰ See *U.S. Code* 42, sec. 1396(a)(17); *Code of Federal Regulations* 42, 440.230. Note that the state is still required to ensure that the amount, duration, and scope of coverage are reasonably sufficient to achieve the purpose of the service, and cannot set arbitrary limits on mandatory services based solely on diagnosis, type of illness, or condition. *Code of Federal Regulations* 42, secs. 440.230(b)-(c).

²⁷¹ Rowland testimony.

²⁷² *Ibid.*

²⁷³ *Ibid.*

²⁷⁴ *Ibid.*

²⁷⁵ Programmatic barriers run the gamut of health care and office policies, procedures, and practices that fail to take account of the access needs of people with disabilities. Such barriers include a lack of height-adjustable exam tables or trained transfer assistance in provider offices, the absence of health information in alternative communication formats, the unavailability of sign language interpretation for provider visits, and the difficulty of obtaining a flexible window for an appointment time or an extended appointment time when required by a patient's transportation or particular impairment.

²⁷⁶ *Code of Federal Regulations* 42, sec. 438.206(a).

²⁷⁷ The regulations do specifically include "whether the location provides physical access for Medicaid enrollees with disabilities" among the list of factors that states will contractually require MCOs, PIHPs, and PAHPs to consider in establishing their provider networks. See *Code of Federal Regulations* 42, sec. 438.206(b)(1)(v).

²⁷⁸ *U.S. Code* 42, sec. 426a (1965).

²⁷⁹ A distinction was made between individuals with end stage renal disease (and later, in a 2001 amendment, those with Lou Gehrig's disease), who immediately became eligible for Medicare coverage upon receiving SSDI payments, and those with other disabilities, who generally became eligible for Medicare after a 24-month waiting period after receiving SSDI. See *U.S. Code* 42, secs. 1382(a) *et seq.* (1972).

²⁸⁰ "Medicare—A Primer," Kaiser Family Foundation.

²⁸¹ *Ibid.*

²⁸² *Ibid.*

²⁸³ HMOs, preferred provider organizations (PPOs), and private fee-for-service (PFFS) plans are all private plans that can take part in Part C.

²⁸⁴ "Medicare—A Primer," Kaiser Family Foundation. Interestingly, the Medicare Payment Advisory Commission recently used July 2006 Medicare enrollment data to find that Federal Medicare payments to private health plans on behalf of Part C enrollees in private fee-for-service plans were higher on average than costs would have

been in the traditional Medicare fee-for-service program. PFFS plans were paid 119 percent of traditional FFS costs before adjustment for enrollee risk, and private health plans were paid 112 percent of traditional FFS costs in the counties where Part C enrollees reside.

²⁸⁵ *U.S. Code* 42, secs. 1395w-101 *et seq.*; and *U.S. Code* 42 sec. 1395w-101-1395w-152.

²⁸⁶ “Medicare—A Primer,” Kaiser Family Foundation, p. 6.

²⁸⁷ For the first \$2,400 in drug costs, the standard benefit package requires enrollees to pay a \$265 deductible and 25 percent coinsurance as well as monthly premiums. Private plans must offer either the standard benefit under Part D or an alternative that is at least “actuarially equivalent.” They may also offer enhanced benefits. Seventy-two percent of Part D beneficiaries are enrolled in stand-alone prescription drug plans, which in 2007 mostly deviated from the standard benefits package by charging copayments instead of 25 percent coinsurance and forgoing a deductible. Medicare Part D beneficiaries who meet certain income and asset limitations may also qualify for a low-income subsidy (LIS) through the Social Security Administration, which will pay for some or all of the Part D monthly premium, annual deductible, and drug copayments. As of January 2007, CMS estimates that 3 million beneficiaries who are eligible for the LIS do not receive it. See “Medicare—A Primer,” pp. 7–8.

²⁸⁸ *U.S. Code* 29, secs. 701 *et seq.*

²⁸⁹ *Code of Federal Regulations* 45, secs. 85.1 *et seq.*

²⁹⁰ SCHIP is codified at *U.S. Code* 42, secs. 1397aa *et seq.*

²⁹¹ “SCHIP 101: What Is the State Children’s Health Insurance Program and How Does It Work?” *FamiliesUSA*, p. 1. <www.familiesusa.org/assets/pdfs/SCHIP-101.pdf> (accessed October 26, 2008).

²⁹² Frequently Asked Questions . . . SCHIP, National Conference of State Legislatures Forum for State Health Policy Leadership, available at <www.ncsl.org/print/health/forum/SCHIPFAQ.pdf> (accessed October 26, 2008).

²⁹³ Medicaid prohibits cost sharing for services provided to children under 18 years, pregnant women, and the medically needy. See “GAO Report to Congressional Requesters, Medicaid, and SCHIP: States’ Premium and Cost Sharing Requirements for Beneficiaries,” March 2004, p. 12. <www.gao.gov/new.items/d04491.pdf> (accessed October 26, 2008).

²⁹⁴ The 18 states that operate separate SCHIP programs are to design a benefit package that offers the same “benchmark coverage” as the benefit coverage offered by the BlueCross/Blue Shield plan in the state, the state employees’ benefits plan, or the HMO with the largest Medicaid enrollment in the state. Alternatively, these states may get Federal approval of an “actuarially equivalent” benefit package or another benefit package that the HSS Secretary must approve. Florida, New York, and Pennsylvania had an existing child health insurance program benefit at the time of SCHIP’s enactment and have the option of continuing to offer this package. See “The Basics: State Children’s Health Insurance Program (SCHIP),” National Health Policy Forum,

George Washington University, March 27, 2007. <www.nhpf.org> (accessed October 26, 2008).

²⁹⁵ “SCHIP 101,” *FamiliesUSA*, p. 2.

²⁹⁶ “NACH State Policy Services Fact Sheet on SCHIP,” National Association of Children’s Hospitals, January 2007. <www.childrenshospitals.net/AM/Template.cfm?Section=Search&template=/CM/HTMLDisplay.cfm&ContentID=32560> (accessed September 29, 2008).

²⁹⁷ State Children’s Health Insurance Program (SCHIP) results available at <www.results.org/website/article.asp?id=1561> (accessed September 29, 2008).

²⁹⁸ Susan L. Parish et al., “Material Hardship Among U.S. Families Raising Children with Disabilities,” *Exceptional Children* (Fall 2008). See also “UNC Study: ‘Chilling’ Hardship Rates Among Families Raising Disabled Children,” *UNC News*, August 18, 2008. <<http://uncnews.unc.edu/content/view/1477/138/>> (accessed July 31, 2009).

²⁹⁹ *Ibid.*

³⁰⁰ See Omnibus Budget Reconciliation Act of 1981, Public Law 5, 97th Congress (August 13, 1981).

³⁰¹ See Omnibus Budget Reconciliation Act of 1989, Public Law 239, 101st Congress (December 19, 1989).

³⁰² *U.S. Code* 42, sec. 702.

³⁰³ In 1989, Congress also authorized 12.75 percent of annual MCH Block Grant appropriations in excess of \$600 million to be set aside for Community Integrated Service System (CISS) projects.

³⁰⁴ “Understanding Title V of the Social Security Act: A Guide to the Provisions of the Federal Maternal and Child Health Block Grant,” Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. <www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf> (accessed October 26, 2008).

³⁰⁵ Title V of the Social Act/SLAITS Survey, *Family Voices*, p. 2. <www.familyvoices.org/pub/hcf/titlev.pdf> (accessed October 26, 2008).

³⁰⁶ *U.S. Code* 42, sec. 706.

³⁰⁷ *U.S. Code* 42, sec. 708.

³⁰⁸ *U.S. Code* 42, sec. 15000 *et seq.*

³⁰⁹ *U.S. Code* 42, sec. 1500.1101(a).

³¹⁰ *U.S. Code* 42, sec. 15001.101(b).

³¹¹ “Fact Sheet, Administration on Developmental Disabilities” (July 22, 2008). <www.acf.hhs.gov/programs/add/Factsheet.html> (accessed October 22, 2008).

³¹² Each state is required to designate at least one legal organization as its protection and advocacy agency. While many of these agencies expressly include “protection and

advocacy” in their names, the national trend over the past few years has been to replace the older phrase with “disability rights,” followed by the name of the state.

³¹³ *U.S. Code* 42, sec. 15000. 101(b)(3)(C).

³¹⁴ New regulations had not been codified under the DD Act of 2000 when this report was written. The Administration on Developmental Disabilities (ADD) reopened (until September 29, 2008) the public comment period on the proposed rule first published in the *Federal Register* on April 10, 2008 (73 FR19708). Previous regulations pertaining to the UAPs were codified at *Code of Federal Regulations* 45, sec. 1388 *et seq.* and should apply to the UCEDDs until such time as they are explicitly replaced by a later set of codified regulations.

³¹⁵ *Code of Federal Regulations* 45, sec. 1388.4(g).

³¹⁶ *Code of Federal Regulations* 45, sec. 1388.4(o).

³¹⁷ *Code of Federal Regulations* 45, sec. 1388.4(k).

³¹⁸ *Code of Federal Regulations* 45, sec. 1388.4(r).

³¹⁹ *Code of Federal Regulations* 45, sec. 1388.5(f).

³²⁰ *Code of Federal Regulations* 45, sec. 1388.6(b)(2).

³²¹ *Code of Federal Regulations* 45, sec. 1388.6(c).

³²² *Code of Federal Regulations* 45, sec. 1388.7(b).

³²³ *Code of Federal Regulations* 45, sec. 1388.7(e).

³²⁴ *Code of Federal Regulations* 45, sec. 1388.7(h).

³²⁵ AHRQ at a Glance. <www.ahrq.gov/about/ataglance.htm> (accessed October 7, 2008). Under Title IX, AHRQ’s primary mission is “to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health system practices, including the prevention of diseases and other health conditions.” See *U.S. Code* 42, sec. 299(b).

³²⁶ *Ibid.* AHRQ at a Glance

³²⁷ *U.S. Code* 42, sec. 299b-2. The director is also to ensure that the Medical Expenditure Panel Survey (MEPS) will identify determinants of health outcomes and functional status of individuals with special health care needs, including individuals with disabilities, and provide reliable national estimates for children and persons with special health care needs through the use of supplements or periodic expansions of the survey. *Ibid.*, sec. 299b-2(b)(1).

³²⁸ *U.S. Code* 42, sec. 299a(e) and (f).

³²⁹ *U.S. Code* 42, sec. 299(c)(1)(B).

³³⁰ *U.S. Code* 42, secs. 299(c)(3) and 299(b)(1).

³³¹ *U.S. Code* 42, secs. 299b-5(a)(3) and (c).

- ³³² *U.S. Code* 42, sec. 299b-6.
- ³³³ See *U.S. Code* 42, sec. 299a(a)(5), which includes research and evaluation activities related to health care technologies, facilities, and equipment in AHRQ's general authority.
- ³³⁴ *U.S. Code* 42, sec. 299a(g).
- ³³⁵ Public Law 525, 106th Congress (November 22, 2000).
- ³³⁶ Public Law 43, 103rd Congress (June 10, 1993).
- ³³⁷ *U.S. Code* 42, sec. 287c-31(1).
- ³³⁸ *U.S. Code* 42, sec. 287c-31(d)(1).
- ³³⁹ *U.S. Code* 42, sec. 287c-31(d)(1) & (2).
- ³⁴⁰ *U.S. Code* 42, sec. 287c-31(d)(3).
- ³⁴¹ *U.S. Code* 42, sec. 299a-1(a)(1). Emphasis added.
- ³⁴² *U.S. Code* 42, sec. 299a-1(c)(1).
- ³⁴³ See *U.S. Code* 42, sec. 287c-32.
- ³⁴⁴ See *U.S. Code* 42, sec. 287c-33.
- ³⁴⁵ Rene Bowser, "Racial Profiling in Health Care: An Institutional Analysis of Medical Treatment Disparities," *Michigan Journal of Race and Law* 7, no. 79 (2001), pp. 125–126.
- ³⁴⁶ Numerous bills introduced in the 2007–2008 110th congressional session proposed further amendments to the MHDREA, such as authorizing the HHS Office of Civil Rights to make public findings of discrimination against health care providers on grounds linked to race or ethnicity. See H.R. 3333, sponsored by Rep. Jesse Jackson, and S. 1576, sponsored by Sen. Edward Kennedy, *Minority Health Improvement and Health Disparity Elimination Act*, sec. 1707(a)(16).
- ³⁴⁷ *U.S. Code* 42, sec. 287c-31(d)(3).
- ³⁴⁸ Public Law 525, 106th Congress (November 22, 2000).
- ³⁴⁹ Vision and Mission, NCMHD. <http://ncmhd.nih.gov/about_ncmhd/mission.asp> (accessed October 7, 2008).
- ³⁵⁰ Lisa Ikemoto, "Deconstructing the Image Repertoire of Women of Color: In the Shadow of Race," *University of California Davis Law Review* 39 (March 2006), pp. 1023, 1041–1042; Rene Bowers, "Racial Bias in Medical Treatment," *Dickinson Law Review* 105 (Spring 2001), p. 365.
- ³⁵¹ *U.S. Code* 29, secs. 760-762. NIDRR's program regulations are contained in *Code of Federal Regulations* 34, secs. 350-359.
- ³⁵² NIDRR's research mandate is conducted externally via the funding of individual research projects and centers of excellence; the majority of NIDRR grantees are universities or providers of rehabilitation or related services.

³⁵³ See *U.S. Code* 29, sec. 763. The ICDR submits annual reports to the president, the Committee on Education and the Workforce of the House of Representatives, and the Senate Committee on Labor and Human Resources; it recommends project and program funding for Federal departments and agencies but does not appear to be funded itself.

³⁵⁴ *West's Federal Administrative Practice* (4th edition), sec.161.

³⁵⁵ The Secretary of HHS may delegate the authority to enter into, modify, or issue approvals for Health Center grants or contracts only to the HRSA central office. See *U.S. Code* 42, sec. 254b(o).

³⁵⁶ Public Law 299, 104th Congress (October 11, 1996).

³⁵⁷ *U.S. Code* 42, sec. 254b(a)(1).

³⁵⁸ *Ibid.*

³⁵⁹ *U.S. Code* 42, sec. 254b(a)(2).

³⁶⁰ *U.S. Code* 42, sec. 300w-7(a)(1).

³⁶¹ *U.S. Code* 42, sec. 254b(3)(A).

³⁶² *U.S. Code* 42, sec. 254b(3)(B)(ii).

³⁶³ *U.S. Code* 42, sec. 299aa.

³⁶⁴ *U.S. Code* 42, sec. 299aa(b).

³⁶⁵ *U.S. Code* 42, sec. 299aa(d)(2).

³⁶⁶ *U.S. Code* 42, sec. 299aa(d).

³⁶⁷ *U.S. Code* 42, sec. 299aa(j).

³⁶⁸ *U.S. Code* 42, sec. 299aa(d)(14).

³⁶⁹ *U.S. Code* 42, sec. 299aa(d)(17).

³⁷⁰ *U.S. Code* 42, sec. 299aa(f).

³⁷¹ *U.S. Code* 42, sec. 299aa(f)(2)(B)(iv).

³⁷² *U.S. Code* 42, sec. 299aa(f)(4).

³⁷³ *U.S. Code* 42, sec. 299aa(f)(2).

³⁷⁴ *U.S. Code* 42, sec. 247b-4.

³⁷⁵ *U.S. Code* 42, sec. 247b-4(a)(2).

³⁷⁶ *U.S. Code* 42, sec. 247b-4(b).

³⁷⁷ *U.S. Code* 42, sec. 247b-4(c).

³⁷⁸ *U.S. Code* 42, sec. 247b-4(c)(5).

³⁷⁹ *U.S. Code* 42, sec. 281.

³⁸⁰ *U.S. Code* 42, sec. 281(d)(2)(A).

³⁸¹ *U.S. Code* 42, sec. 281(c)(2)(A).

³⁸² *U.S. Code* 42, sec. 281(d)(1).

³⁸³ *U.S. Code* 42, sec. 281(e).

³⁸⁴ *U.S. Code* 42, secs. 281(d)(2) and (f)(3).

³⁸⁵ *U.S. Code* 42, sec. 282a.

³⁸⁶ *U.S. Code* 42, sec. 299aa(d)(17).

³⁸⁷ *U.S. Code* 42, sec. 299aa(d)(14).

³⁸⁸ *U.S. Code* 42, sec. 299aa(f)(2)(B)(iv).

³⁸⁹ *U.S. Code* 42, sec. 299aa(f)(4).

³⁹⁰ *U.S. Code* 42, sec. 281(e).

³⁹¹ See *U.S. Code* 42, 299a(a)(5), which includes research and evaluation activities related to health care technologies, facilities, and equipment in AHRQ's general authority.

³⁹² *Code of Federal Regulations* 45, sec. 84.52.

³⁹³ For example, the HMO is in a better position to implement and coordinate the use of a centralized sign language translator bank or centrally located accessible examining rooms that network providers could book, or to disseminate information about financial incentives and requirements concerning the purchase of accessible exam equipment.

³⁹⁴ *Code of Federal Regulations* 42, sec. 438.206(a).

³⁹⁵ Other agencies within HHS, including the Administration on Aging and the Indian Health Service, also engage in substantial activities that relate to health, health care, and health disparities. However, while people with disabilities comprise a subpopulation of the demographic groups these agencies serve, they are not explicitly identified as intended beneficiaries; therefore, the activities of these agencies have not been included in this report.

³⁹⁶ NCD did not investigate Federal agencies concerned with military and veterans' health for this report, because a separate initiative was undertaken on this subject.

³⁹⁷ "Fiscal Year 2006 Performance Highlights, University Centers for Excellence in Developmental Disabilities Education, Research, and Service."

<www.acf.hhs.gov/programs/add/adddocs/program_highlights/UCEDD06.pdf>

(accessed July 15, 2008).

³⁹⁸ "SCHIP-Enrolled Children with Special Health Care Needs: An Assessment of Coordination Efforts Between State SCHIP and Title V Programs," Kaiser Commission on Medicaid and the Uninsured, January 2004, p. iii. <www.kff.org/medicaid/upload/SCHIP-Enrolled-Children-with-Special-Health-Care-Needs.pdf>.

³⁹⁹ "National Survey of Children with Special Health Care Needs Chart Book 2005–2006. <<http://mchb.hrsa.gov/cshcn05/MI/NSCSHCN.pdf>>

- ⁴⁰⁰ Health Resources and Services Administration homepage. <www.hrsa.gov> (accessed July 15, 2008).
- ⁴⁰¹ Institute of Medicine, *The Future of Disability in America*, ch. 10. <http://books.nap.edu/openbook.php?record_id=11898&page=310> (accessed July 15, 2008).
- ⁴⁰² Vincent Campbell, Disability and Health Team, Centers for Disease Control and Prevention, interview, August 28, 2008.
- ⁴⁰³ CDC, Office on Disability and Health. <www.cdc.gov/ncbddd/women/default.htm> (accessed on June 8, 2008); Campbell, personal communication.
- ⁴⁰⁴ “Improving Healthcare Access for Americans with Disabilities,” Agency for Healthcare Research and Quality, Department of Health and Human Services. <www.ahrq.gov/news/focus/focdisab.htm> (accessed March 29, 2008).
- ⁴⁰⁵ Office on Disability, Department of Health and Human Services, draft August 2008 program updates, obtained from Lauren Fokowski, email communication, August 18, 2008.
- ⁴⁰⁶ Richard Carmona, Foreword, “The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities.” <www.surgeongeneral.gov/library/disabilities/calltoaction/forward.html> (accessed February 26, 2009).
- ⁴⁰⁷ Focus Area 6 is co-led by CDC’s Disability and Health Team and the National Institute on Disability and Rehabilitation Research at the Department of Education.
- ⁴⁰⁸ Healthy People 2010, Objectives for Improving Health, Disability, and Secondary Conditions. <www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm#_Toc486927298> (accessed October 10, 2008).
- ⁴⁰⁹ Healthy People 2010, Objectives for Improving Health, Vision, and Hearing. <www.healthypeople.gov/document/HTML/Volume2/28Vision.htm#_Toc489325919> (accessed August 31, 2008).
- ⁴¹⁰ Healthy People 2010 Midcourse Review, Goal 6. <www.healthypeople.gov/data/midcourse> (accessed August 31, 2008).
- ⁴¹¹ In recent years, NIDRR has supported health-related research through (1) Rehabilitation Engineering Research Centers (RERCs), which find and evaluate technologies, products, and methods that support the independence of persons with disabilities and the universal design of environments; (2) Rehabilitation Research and Training Centers (RRTDs) that are operated in collaboration with institutions of higher education or providers of rehabilitation or other appropriate services and serve as centers of national excellence in rehabilitation research; (3) Disability and Rehabilitation Research Products (DRRPs) that emphasize research, demonstration, training, dissemination, utilization, and technical assistance; and (4) Small Business Innovation Research (SBIR) and other initiatives.

- ⁴¹² News story, *NCI Director's Brief*, July 20, 2007, "Confronting Cancer Health Disparities: National Cancer Institute Center to Reduce Cancer Health Disparities." <<http://crchd.cancer.gov/news/news-text/dbrief072007.html>> (accessed August 31, 2008).
- ⁴¹³ Screening Mammography Follow-up for Women with Disabilities, NIH Breast Cancer Surveillance Consortium research grant, Susan G. Komen Breast Cancer Foundation. <<http://breastscreening.cancer.gov/collaboratio> *United States v. Baylor Univ. Med. Ctr.*, 736 F2d 1039, 1042, 5th Cir (1984), *cert denied* 469 US 1189<[ns/grants/039.html](http://www.nih.gov/ncbi/grants/039.html)> (accessed August 12, 2008).
- ⁴¹⁴ National Eye Institute, 1999–2003 Strategic Plan. <www.nei.nih.gov/strategicplanning/np_eyehealth.asp> (accessed August 8, 2008).
- ⁴¹⁵ National Institute of Dental and Craniofacial Research, Strategic Initiatives. <www.nidcr.nih.gov/NR/rdonlyres/932B8B7D-E114-4491-BE85-ABA6F29663AE/0/hdplan.pdf> (accessed August 5, 2008).
- ⁴¹⁶ National Institute of Dental and Craniofacial Research. <www.nidcr.nih.gov/NR/rdonlyres/7DC1215F-D0CC-44EF-8C55-8F5BF37CA024/0/Introduction71907.pdf> (accessed August 31, 2008).
- ⁴¹⁷ National Institute of Dental and Craniofacial Research. <www.nidcr.nih.gov/OralHealth/Topics/DevelopmentalDisabilities/AdditionalResources.htm> (accessed August 31, 2008).
- ⁴¹⁸ Project Description, Health Empowerment Zones for People with Disabilities, National Institute of Environmental Health Services. <www.niehs.nih.gov/research/supported/programs/obe/grantees/chicago.cfm> (accessed August 13, 2008).
- ⁴¹⁹ National Institute of Mental Health. <www.nimh.nih.gov/about/strategic-planning-reports/#strategic-objective3> (accessed August 20, 2008).
- ⁴²⁰ National Institute of Nursing Research. <www.ninr.nih.gov/NR/rdonlyres/E54A777C-FAAA-474A-BDFF-5B85EC8B9E7E/0/StrategicMission.pdf> (accessed July 19, 2008).
- ⁴²¹ The National Academies are the National Academy of Sciences, the National Academy of Engineering, the Institute of Medicine, and the National Research Council. The first three are professional elective bodies; the last is the operating arm of the National Academies. In carrying out its program, IOM adheres to all procedures used by the National Research Council. See <www.iom.edu/Object.File/Master/26/047/DRAFT%20STRATEGIC%20VISION%20JulY%202003%20v5%20sept%2005.pdf> (accessed August 31, 2008).
- ⁴²² "Crossing the Quality Chasm: The IOM Health Care Quality Initiative," Institute of Medicine. <www.iom.edu/CMS/8089.aspx> (accessed August 20, 2008).
- ⁴²³ "Crossing the Quality Chasm: A New Health System for the 21st Century," Institute of Medicine. <www.iom.edu/CMS/8089.aspx> (accessed August 20, 2008).
- ⁴²⁴ "Brief Report: Examining the Health Disparities Research Plan of the National Institute of Health: Unfinished Business," Institute of Medicine.

www.iom.edu/Object.File/Master/35/550/nih%20disparities.pdf>. (accessed August 20, 2008)

⁴²⁵ Ibid.

⁴²⁶ Ibid.

⁴²⁷ Ibid.

⁴²⁸ *Advancing the Nation's Health: A Guide to Public Health Research Needs, 2006–2015*, Department of Health and Human Services, Centers for Disease Control and Prevention, December 2006.

⁴²⁹ Drainoni et al., “Cross-Disability Experiences of Barriers,” p. 114.

⁴³⁰ Advisory Committee on Training in Primary Care Medicine and Dentistry, *The Role of Title VII, Section 747 in Preparing Primary Care Practitioners to Care for the Underserved and Other High Risk Groups and Vulnerable Populations*, 6th annual report to the Secretary of the Department of Health and Human Services and to Congress, 2007.

⁴³¹ P. F. Adams, J. W. Lucas, and P. M. Barnes, “Summary Health Statistics for the U.S. Population: National Health Interview Survey 2006,” *Vital Health Statistics* 10, no. 236 (2006), Table 15.

⁴³² *Health Risks in the United States: Behavioral Risk Factor Surveillance System 2008*, Centers for Disease Control and Prevention and Coordinating Center for Health Promotion, p. 3.

⁴³³ S. E. Palsbo and P-S. Ho, “Consumer Evaluation of a Disability Care Coordination Organization,” *Journal of Health Care for the Poor and Underserved* 18 (2007), pp. 887–901.

⁴³⁴ Altman and Bernstein, *Disability and Health in the United States*.

⁴³⁵ Agency for Healthcare Research and Quality, *National Healthcare Disparities Report, 2007* (Rockville, MD: Department of Health and Human Services, 2008).

⁴³⁶ Susan Palsbo, “Assessment of Health Plans and Providers by People with Activity Limitations” Webinar sponsored by Center for Health Care Strategies, Inc., February 2008. www.chcs.org/publications3960/publications_show.htm?doc_id=669840> (accessed July 18, 2008).

⁴³⁷ The project abstract is available at www.gold.ahrq.gov/GrantDetails.cfm?GrantNumber=K08%20HS15700>.

⁴³⁸ E. W. Grabois, M. A. Nosek, and D. Rossi, “Accessibility of Primary Care Physicians’ Offices for People with Disabilities: An Analysis of Compliance with the Americans with Disabilities Act,” *Archives of Family Medicine* 8 (1999): pp. 44–51; B. Premo, L. Carrothers, and M. Larson-McNeal, “Providing Primary Health Care for People with Physical Disabilities: A Survey of California Physicians,” Center for Disability Issues and the Health Professions, 2002. www.cdihp.org/pdf/ProvPrimeCare.pdf> (accessed July 18, 2008); A. Downs et al., “Wellness Promotion in Persons with Disabilities: Physicians’

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