Breaking Down Barriers to Health Care for Women with Disabilities

A White Paper from a National Summit

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A White Paper and Action Plan from a National Summit

Table of Contents

Appendices

1. Introduction

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 3 years.

A 69 year-old woman is recovering from a stroke which has left her paralyzed in the right arm and leg. She has always had regular check-ups in the past, but now wonders how she is going to climb onto an exam table for a breast exam, or stand for mammography. (Case studies from Breast Health Access for Women with Disabilities www.bhawd.org)

Of the more than 140 million women living in the United States today, an estimated over 28 million of them—one in five—have disabilities with which they were born or acquired. Disability is not the same thing as illness, and many women with disabilities can, and do lead otherwise healthy lives. However, disabilities can present a broad array of challenges for women—including challenges in access to health care services and programs to maintain good health.

As has been suggested in the evocative title of a recent publication, accessibility to good health care and services means more than ramps. It means better informed health care providers who are better educated about and trained to meet the full range of health care needs of women with disabilities—and not just focus on the disability itself. It means equipment and facilities that are accessible for women with disabilities, preserving their dignity and independence. It also means policies and programs that can help overcome attitudes and prejudices that, unfortunately, continue to reinforce the stigma associated with disability.

The Office on Disability and the Office on Women's Health, both part of the U.S. Department of Health and Human Services, recognized that good health is a prerequisite for contributing, independent and self-directed lives in the community for women with disabilities, the hallmark of the President's New Freedom Initiative. They recognized that, without good health, employment and education, community engagement and family life all can be compromised. Thus, on December 6, 2004, the two Offices convened a national Summit, Breaking Down Barriers to Health Care for Women with Disabilities, that was co-sponsored by the Interagency Committee on Disability Research at the U.S. Department of Education, and coordinated by the National Center for Policy Research for Women and Families.

In her opening remarks to those attending, Dr. Margaret Giannini, MD, FAAP, Director of the Office on Disability, stated "In his Freedom Initiative, President Bush stated 'My administration is committed to tearing down the barriers to equality faced by many of the 54 million Americans with disabilities.'" She urged participants to identify ways to do just that when it comes to the health and wellbeing of women with disabilities.

The summit explored ways in which health care professionals and health care facilities can overcome barriers to the best possible care for women with disabilities. It featured promising effective programs and new paradigms for approaching the health of women with disabilities that have helped improve access and, ultimately, quality of care including projects that focus on educating health care professionals. The summit, attended by 50 participants including representatives from provider associations, legal experts, advocates, health care providers, government officials, and researchers, featured national experts who explored issues and highlighted these promising practices. (See the participant list in the Appendix B.) The goal of the summit was to develop an action plan that can be used during the next few years to make progress in improving access to healthcare for women with disabilities.

This white paper not only summarizes the conference deliberations, but also delineates that plan of action. Biographies of presenters, contact information for participants, as well as the full text of each presentation, are found in the appendices to this white paper. The morning portion of the summit was webcast live and is available on the Office on Disability website http://www.hhs.gov/od" . A recording can be accessed online by accessing the “women’s issues” section of the website and clicking on “audio webcast”. A limited number of DVDs of the Summit are available on request from the Office on Disability on a first-come, first-served basis for persons with blindness or limited vision.

2. Framing the Issues: What Do We Know?

Four experts provided Summit participants with a portrait of the challenges to accessing health care faced by many women with disabilities.

- Jo Ann Thierry, PhD, (Centers for Disease Control and Prevention) offered an overview of current research knowledge related to health care access for women with disabilities.

- Margaret Turk, MD, (State University of New York Upstate Medical Center), described health care provider issues related to serving women with disabilities and suggested ways to improve provider preparation and continuing education to meet these women's needs.

- Judith Panko-Reis, MA, MS, (Rehabilitation Institute of Chicago) discussed the role of the Americans with Disabilities Act can and must continue to play in improving access to care.

- Sharman Word Dennis, MEd, (Rose Inc.), described the additional health care access problems faced, in particular, by women of color with disabilities.

A summary of the presentations follows. The full text and/or copies of the PowerPoint slides that accompanied the presentations can be found in Appendix A.

Identifying Barriers to Health Care: the Current Research

JoAnn Thierry, PhD, MSW
Centers for Disease Control and Prevention

Background

In recent years, women's health has emerged as a prominent public health priority. Research focused on women's health has led to valuable information about how and why certain diseases affect women disproportionately, predominantly, or differently than men. It has also led to a better understanding of the differential health risks faced by particular subpopulations of women, such as those who are members of racial and ethnic minority groups. Yet despite the increased awareness of women's health, research to date has not adequately addressed the health concerns of women with disabilities. In general terms, disability refers to "limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks or roles". There are approximately 26 million women living with disabilities in the United States. Estimates of the prevalence of disability among women range from 16% to 18% depending on the definitions used.

Barriers

Women with disabilities face substantial barriers that limit their access to healthcare services including physical, attitudinal, and policy barriers; lack of information about how disability affects health; limited finances; and insufficient personal assistance.

Recent studies suggest that women with disabilities encounter many of the same health problems as women who are not disabled, yet they consistently report poorer health. These findings also identify disparities between women with and without disabilities on a number of leading health indicators. Data was presented that summarized selected disparities including access to healthcare, provision of clinical preventive services, overweight and obesity, and physical activity.

Conclusions

The public health community has begun to recognize and address the health concerns of women with disabilities. However, increased efforts are needed to improve collaboration among women with disabilities, and federal, state and local organizations to identify short and long-term strategies for reducing health disparities among this population of women.

Barriers to Health Care for Women with Disabilities: Education of Healthcare Providers

Margaret A. Turk, MD
SUNY Upstate Medical University

Background

There are approximately 26 million women with disabilities in the U.S.. These numbers are increasing as improved medical care helps more people survive serious illness and injury that result in permanent disabilities. Women with disabilities are among the most economically disadvantaged, and this increases their risk of health problems. As a group, they have lower socioeconomic status, less education, and are less likely to be married. Millions of people with disabilities have contact with healthcare providers every year, including physicians, physician assistants, nurse practitioners, nurses, therapists (e.g. physical, occupational, speech/language), psychologists, social service providers, and technicians (e.g. phlebotomy, respiratory, radiology).

Barriers

Currently no educational requirements exist in any health care provider certification that attend to the significant and specialized needs of persons with disabilities. Three areas of education must be considered: attitudes, knowledge and skills. Healthcare providers acknowledge a lack of knowledge and skills in providing care to women with disabilities. However, it is not clear to what extent they acknowledge issues surrounding negative attitudes toward people with disabilities. Research indicates that health care providers' attitudes toward people with disabilities are generally negative, although they vary depending on type of disability, age, and gender. The literature supports the positive effects of contact, experience, and education on providers' attitudes toward people with disabilities.

With respect to knowledge and skills, existing curricula fulfill broad requirements, and issues specific to women with disabilities can get lost in the larger picture of undergraduate, graduate, and continuing education. Curricular reform requires prioritization of many topics competing for attention. Providers often find it difficult to approach someone with a disability, let alone examine them. Communication is now a significant competency in medical education. For exams, skills are required for positioning, transfers, general exams, and gynecologic exams.

Providers often find that while caring for women with disabilities is more time-consuming than is care for women without disabilities, public and private insurer reimbursement rates remain the same as for other patients. This poses some potential disincentive for providers to work with women with disabilities or to extend services beyond those directly related to their disabilities.

Conclusions

Despite the current lack of educational requirements, there are successful programs to address provider attitudes, knowledge and skills, such as the curriculum being developed by the Association of Professors of Gynecology and Obstetrics. Kaiser Permanente also has a long-standing provider education program aimed at improving competency in caring for people with disabilities. There is also on-going research in this area. A program through the American Medical Students Association, supported by the American Medical Women's Association, is surveying students about what they actually learn about health care for women with disabilities. The American College of Obstetricians and Gynecologists will soon publish a paper based on their research identifying these issues.

It Takes More than Ramps to Solve the Crisis of Healthcare for People with Disabilities

Judith Panko Reis, MA, MS
Rehabilitation Institute of Chicago

Background

It Takes More than Ramps to Solve the Crisis of Healthcare for People with Disabilities, a policy paper published in September 2004, examines how the U.S. healthcare system is not structured to provide safe patient-centered care to people with disabilities It highlights gaps between safe, patient-centered care and the reality people with disabilities experience; explores the role of the ADA to improve access to health care; and recommends ways to bridge the gaps. Major findings of the policy paper recognize that:

People with disabilities use healthcare services at a higher rate than people without disabilities, yet commonly express dissatisfaction with their healthcare. They are susceptible to disparities in health care, and experience widespread lack of appropriate accommodations.

The roots of shortfalls in quality of care and safety include inadequate training of clinicians, poor executive oversight to enforce the ADA, limited funds and few financial incentives.

Healthcare institutions have the moral and legal responsibility to take action to improve healthcare delivery for people with disabilities in a safe, patient-centered, and culturally competent way.

Barriers

Little agreement exists among both providers and consumers about the precise meaning of the concept of accommodation for persons with disabilities. When health care providers neither understand nor implement the requirements of the Americans with Disabilities Act, they place themselves and their institutions at liability risk; they place their patients with disabilities in jeopardy of not being able to gain access to necessary care and services. Examples of the failure to make reasonable accommodations include such matters as not having an interpreter on staff or not asking a family member of a deaf or hearing impaired patient to provide interpreter services during an examination; examining a patient in her wheelchair instead of on an exam table; or having a security guard rather than a member of the clinical staff transfer a woman from her wheelchair to an exam table. Persons with disabilities, themselves, often are unaware what they can do to promote equity in their care as required under the Americans with Disabilities Act. Thus, education for both providers and persons with disabilities would benefit both in the healthcare setting.

However, combined state and federal ADA implementation efforts and community advocacy have led to useful guidelines and model projects under the Medicaid program that are working to benefit persons with disabilities. Center for Medicare and Medicaid Services (CMS) Guidelines for Medicaid Managed Care today reflect the ADA. While not enforceable guidelines, they help by providing examples of how to make accommodations for persons with disabilities. Disability rights advocates won a landmark, ADA-based class action suit against Kaiser Permanente of California in 2000. A similar class action suit against Washington Hospital Center in DC was filed in 2003.

Conclusions

Federal and state enforcement of the ADA and private litigation have spurred important, albeit modest reforms in healthcare services for persons with disabilities. However, many challenges remain, including that most hospitals, large facilities and medical provider offices have not provided more than architectural accessibility. Also, many private office-base medical \ have little awareness of the requirements of the ADA, including their obligation to determine if a patient with a disability requires an accommodation and to provide that accommodation if possible.

Women of Color with Disabilities: Triple Jeopardy

Sharman Word Dennis, MEd
Rose, Inc.

Background

Women with disabilities report limited access to important health care services. Barriers include insufficient numbers of obstetrical care providers with knowledge about specific disabilities, a dearth of accessible mammography and pelvic exam equipment, and a lack of adequate fertility control services and sexual health information for women with disabilities. All too often, women of color with disabilities experience the impact of a "triple jeopardy": race, gender, and disability, when it comes to gaining access to appropriate needed health care services. In addition to coping with issues related directly to their disabilities, minority women also have to negotiate economic, social, and cultural factors that can hurt their health. Disparities in educational resources, lower wage jobs, and higher unemployment rates found in some minority groups are barriers to high-quality, affordable, and accessible healthcare.

Barriers

Women of color with disabilities use fewer health services and continue to suffer more from premature death, disease, and secondary disabilities. Some barriers to care affect women with disabilities of all races, such as policies that deny services to women who cannot easily get up onto exam tables, or that let doctors refuse to see women with disabilities. For women of color with disabilities, especially dark skin color or those who speak with an accent, additional barriers exist such as a lack of communication, validation and respect. Women of color are more likely to lack insurance and therefore are often unable to receive adequate services. Studies reporting on disparities in access to healthcare among women of different racial and ethnic origins in the U.S. have been summarized in reports by the Agency for Healthcare Quality and Research.

Conclusions

Women of color with disabilities must identify health care providers who are accepting of all people: people of color and those with disabilities. Medical students and other providers need to be trained to meet the needs of this population. While it is important to enforce legislation, we also must work to change attitudes. We need to create a paradigm shift within society for total acceptance and inclusion of people with disabilities and people of color.

3. Promising Practices

Summit participants next learned of promising programs that can be adopted and adapted to improve access to health care and services for women with disabilities.

- Dr. Kristi Kirschner, MD, Medical Director of the Center for Women with Disabilities at the Rehabilitation Institute of Chicago , who shared information about her Center and the lessons learned from its more than a decade of service.

- Florita Maiki, MA, of the Breast Health Access for Women with Disabilities in Berkeley, CA described the challenges and opportunities experienced by her program focused on individualized breast health services for women with disabilities.

- Dr. Jennifer Potter, MD, of both the Beth Israel Deaconess Medical Center, and the Association of Professors of Gynecology and Obstetrics Women's Health Learning Competencies program, discussed efforts to develop and implement new curricula in women's health—including the health of women with disabilities—for both undergraduate and postgraduate medical education.

A summary of the presentations follows. The full text and/or copies of the PowerPoint slides that accompanied the presentations can be found in Appendix A.

Women with Disabilities Center, Rehabilitation Institute of Chicago

Dr. Kristi Kirschner, MD, Medical Director
Center for Women with Disabilities, Rehabilitation Institute of Chicago

Program Description

The Women with Disabilities Center at the Rehabilitation Institute of Chicago (RIC) was established in 1991. The Center's mission focuses on empowerment:

The Center is dedicated to providing services that empower women and girls with disabilities to practice self-determination in achieving emotional and physical wellness. To meet this goal, the Center provides services free of charge centered on advocacy, support, education and combating the inherent isolation of women and teenage girls with disabilities.

The Center provides a range of services—all of which are accessible. The clinic provides not only physical access, but also accessible examination tables that were developed under the guidance of Dr. Amie Jackson, who created the first accessible reproductive health clinic for women with disabilities in the country. The Center both provides basic reproductive health services on-site, and has also facilitated relationships within the community for mammography and colonoscopy services. The program also has accessible prenatal care services, available through its sister hospital, Northwestern University Medical Center.

Their wide-ranging support services include:

- Library and information center
- Referral network
- Weekly peer support groups
- Individual consultation
- Parenting support
- Domestic Violence Program
- Teen Mentoring Program

Educational activities include:

- Seminars for the community—at least 3 times per year, full day
- In-service training opportunities
- Health care provider education
- Newsletter—Resourceful Woman—published once or twice per year

The Women with Disabilities Center conducts research and evaluation projects in such areas as provider attitudes and knowledge about people with genetic disabilities. Advocacy is also an important aspect of the Center's work. At the level of the individual, Center staff works to educate patients about their rights; at the community level, staff educates about and advocates for accessible health services. They participate in many task forces and committees to insure that the issues of women with disabilities are represented.

Lessons Learned

The Center represents a collaboration between women with disabilities and RIC staff, a factor that contributes to its significant success. Women with disabilities have been included in the development of the Center from its inception. Today, women with disabilities represent one of the driving forces behind the ongoing work of the Center.

The Center's ultimate aim is to make the provision of services through such a separate health care providing entity unnecessary. To that end, the Center developed an educational video, funded by the federal National Institute on Disability and Rehabilitation Research that focuses on the provision of health services for women with disabilities is directed toward practicing health care providers to identify ways in which they, too, can provide client-centered care for women with disabilities.

The Center's work clearly shows, however, that strong financial and community-based support is necessary to provide comprehensive services. Most of the non-medical services provided by the Center are funded through donations and grants.

Breast Health Access for Women with Disabilities

Florita Maiki, MA
Alta Bates Summit Medical Center, Rehabilitation Services Department, Berkeley, California

Program Description

The Breast Health Access for Women with Disabilities (BHAWD) program is an award winning program that was established in 1995 and began providing free clinical services in 1997. The program has four main goals:

Reduce barriers that prevent many women with disabilities from obtaining early cancer detection services
Develop alternative protocols and techniques for clinical care
Increase awareness and sensitivity as well as enhanced material knowledge through publications and educational seminars
Identify public policy issues in order to facilitate effective changes in state and national programs

The program is the product of a collaboration among women with disabilities, breast cancer survivors, Independent Living Centers, and the Alta Bates Breast Center and Physical Rehabilitation Department at the Alta Bates Summit Medical Center. The program seeks to ensure that women with disabilities receive breast and reproductive health information and all appropriate health care, diagnostic, and screening services, and that policy initiatives are inclusive for women with disabilities. To help achieve that goal, women with disabilities are involved in planning, implementation and evaluation of the programs and services provided by BHAWD.

The program also conducts research on screening rates and the prevalence of barriers to screening and other women's health-related services for women with disabilities; it also provides, ongoing outreach and education to diverse, populations (e.g. cognitively impaired, aging, deaf/hard of hearing) to help improve their access to and knowledge of needed care and services. Educational tools have been developed and set in place, such as an education module for women with cognitive and developmental disabilities, and a health care provider manual, *Breast Health and Beyond for Women with Disabilities: A Provider's Guide to the Examination and Screening of Women with Disabilities*. The BHAWD program also developed the first American Society of Radiologic Technologists accredited mammography training modules in California that include cultural competency, as well as positioning techniques specific to women with different types of disabilities.

The BHAWD program also provides training and accessibility assessments for medical providers and clinic personnel in clinical health care settings. A pilot project to assess the accessibility of mammography facilities developed a three-part Mammography

Accessibility Assessment instrument designed to evaluate the accessibility of an individual mammography facility and its equipment.

BHAWD's clinical services provide BHAWD's clinical services include free clinical breast exams, provided by a nurse practitioner. They have accessible exam rooms equipped with multi-positioning exam tables. Attendant services and assistance with transfer are made available to all patients. They also provide BSE education to our patients. They make referrals to mammography facilities that can accommodate most women. Consumer clinic forms are available in alternative formats, such as Braille, audio tapes, large print and disk format. They also provide a women's educational preparedness/wellness program in client settings, such as to women in board and care homes.

The Mammography Accessibility Initiative includes:

- Adapted protocols
- Training- e.g. staff, technologists
- State wide Advisory committee to look at larger policy issues
- Accessibility Assessment
- Programs to increase awareness and education (articles, conferences)

Lessons Learned

To help facilities (and providers) become more accessible and sensitive to the healthcare needs of women with disabilities, programs and providers should:

- Emphasize that women with disabilities are women first
- Include the larger comprehensive topic of accessibility in all education and outreach activities and strategies
- Create flexibility within the program and its components to accommodate innovation and creativity
- Seek and include input from women with disabilities in all aspects by focus groups, etc.
- Provide necessary accommodations to individual women
- Modify clinical and scheduling protocols—use or revise BHAWD's clinical protocols
- Acquire additional information and skills—encourage professional associations to include wellness and disability in their conferences, curriculum, etc.
- Set up communication and collaboration with referring services- mammography, x-ray, lab, etc.
- Integrate disability awareness education into staff in services and meetings
- Include access and disability education into goals and outcomes into quality improvement plans
- Purchase accessible equipment—lifts, scales

- Work in partnership with family members, board and care providers, and administrators when providing services to women with cognitive developmental disabilities - collaborate, collaborate, collaborate
- Consult women with disabilities to determine appropriate images and language of outreach and educational materials
- Work in partnership with community-based groups, breast health and women's health advocates and agencies and women's state funded organizations
- Create an advisory committee that includes women of color and younger women with disabilities

APGO/WHEO Women's Health Care Competencies for Medical Students

Jennifer Potter, MD
Beth Israel Deaconess Medical Center
Boston, MA

Program Description

The Women's Health Care Competencies Project of the Association of Professors of Gynecologists and Obstetricians (APGO) and the Women's Health Education Office (WHEO) is a curricular tool that can provide needed professional education for health care providers on caring for women with disabilities. The project is intended to ensure the iinclusion of gender-specific information and materials in medical education, since gender plays a key role in both the promotion of wellness and the prevention and treatment of health conditions. medical students, regardless of their planned specialty following graduation, must know how to care appropriately for female patients based on a female, rather than male model of health care. Despite increasing recognition of the importance of gender differences, undergraduate medical curriculum reform has been slow.

The project focused on two key goals

- To identify women's health care competencies for medical students, and
- To develop a tool to evaluate, improve, and integrate these competencies into undergraduate medical education. A similar tool developed for undergraduate medical education, may be readily adapted to postgraduate (residency) medical education and continuing medical education.

The project began in November 2000 with a large interdisciplinary retreat of women's health experts who developed a pamphlet entitled "Women's Health Care Competencies for Medical Students." "Competency" is defined as the basic knowledge, skills, and attitudes trainees need to develop in order to provide appropriate preventive care and treatment to women. Eight core competencies were identified:

Explain sex and gender differences in normal development and pathophysiology
Effectively communicate demonstrating awareness of gender and cultural differences
Perform a sex, gender, and age appropriate physical exam
Discuss the impact of gender-based societal and cultural roles on health care
Identify and assist victims of physical, emotional and sexual violence and abuse
Assess and counsel women for sex- and gender-appropriate reduction of risk
Access and critically evaluate new information and adopt best practices of sex and gender differences in health and disease
Discuss the impact of healthcare delivery systems on populations and individuals

In 2001, a list of learning objectives was developed for two of the eight core competencies. For each learning objective, an appropriate level of competence, evaluation method, and pertinent references were assigned. This phase of the project was a collaborative effort of the APGO Undergraduate Medical Education Committee (UMEC), the Professional Education Working Group of the National Centers of Excellence in Women's Health (NCoE), and the WHEO Multidisciplinary Task Force.

In 2003, an interdisciplinary group of women's health experts gathered again to develop learning objectives for each of the other six competencies, and in 2004 they completed our finished product, an on-line Curriculum Builder, that can be accessed at www.apgo.org/wheocomp.

WHEO has presented this work at various meetings, including a semi-annual NCoE conference, American Medical Women's Association (AMWA) meeting, CREOG/APGO meeting, the Association of American Medical Colleges (AAMC) annual meeting, VCU School of Medicine Women's Health Conference, and the International Association of Medical Science Educators meeting Their next step will be to publicize an RFA for Demonstration Projects (funded by the Ford Foundation), in April, 2005. Information will be available soon at www.apgo.org.

An additional feature of the Curriculum Builder is the ability for anyone to save curricula on the web site and access other saved curricula as well, in effect creating a free library of on-line curricula that address different topics. The intent is to provide a useful template that will help medical educators identify and incorporate key sex and gender information into curricula easily and efficiently.

4. Vision Statement

Following the Summit presentations, Summit participants began the process of developing an Action Plan to guide program and policy development over the two years following the Summit. As a first step in that process, participants brainstormed a series of statement—culminating in an overarching Summit vision statement of what, in community-based practice, is meant by full access to health care for women with disabilities.

The vision statement, once developed, served as a springboard for creative deliberations that led to the Action Plan, presented by Summit participants to both the Office on Disability and Office on Women's Health, to inform future work at all levels of government, in health provider education, and in communities nationwide.

- All providers and their staff will be educated on how to care for people with disabilities, and their facilities will be built using the principles of universal design, accessible to all.

- Quality improvement will be based on evidence-based practice, and will be fundamental to the system.

- Health care system personnel will reflect the diversity of the general population, and the quality and quantity of care will not be affected by race, health status, gender or other individual characteristics.

- People will increasingly take responsibility for their own health and well-being.

5. Action Plan

The Action Plan, developed by conference participants in dynamic exploratory dialogues during the conference, makes a series of recommendations to address the health care challenges faced by women with disabilities. It was based on the brainstorming of the summit's four working groups, which developed effective goals and strategies for addressing key barriers. Each work group addressed a different topic area:

- Americans with Disabilities Act (ADA) and access issues
- Financing issues
- Health promotion
- Provider education.

Critically, participants focused on developing goals that would be achievable in one to two years. A planning grid guided each work group to define the current situation, key stakeholders, resources needed, objectives that need to be achieved to reach the goal, and first steps to immediately get the process going. This section delineates the two-year-focused action plan that resulted from deliberations by each of the work groups and later agreed upon by all Summit participants.

Americans with Disabilities Act (ADA) and Access Issues

While women with disabilities need accessible equipment in the healthcare setting, this need has not yet been either widely recognized or adopted. Hospital and medical facility accreditation bodies do not consistently consider accessibility issues. .

The goal is to ensure that accessible equipment is available on a routine basis in health care providers' offices, hospitals, and hospital-based and other outpatient clinics and programs. Particular emphasis should be placed on the availability of accessible mammography services.

Objectives:

- Convene a meeting of stakeholders involved in accrediting facilities to develop effective strategies.
- Explore modification of the Food and Drug Administration standards for approval of medical devices to include accessibility issues.
- Assist the Department of Justice in developing model policies for settlements and disseminating results.
- Showcase trendsetters and model practices as a means of sharing information---create a gold standard for disability competence.

Key Stakeholders:

- HHS - Office on Disability, Office of Developmental Disabilities, Office on Women's Health Centers of Excellence, Center for Medicare and Medicaid Services, Food and Drug Administration, Office for Civil Rights
- Women with disabilities and their families
- Joint Commission on Accreditation of Healthcare Organizations
- Commission on Accreditation of Rehabilitation Facilities
- American Hospital Association
- Department of Justice
- Department of Transportation

Needed Resources:

None noted

Next Steps:

Create internet-based resources with the assistance of HHS and the National Research Center for Women and Families in compliance with 508 standards.

Financing Issues

Discrepancies exist in the public and private healthcare insurance systems that work at a disadvantage to persons with disability; for example, providers may not receive reimbursement commensurate with the additional time they may be required to take when serving patients with disabilities. Under Medicaid, unless an individual state seeks a waiver from the Centers for Medicare and Medicaid Services, providers are reimbursed at fixed rates set by state Medicaid agencies. Due to generally low Medicaid reimbursement rates for treating individuals with disabilities, such individuals may have trouble receiving medical care. As a result, their conditions may deteriorate, secondary health problems may arise, and care may be more protracted, intensive and expensive. All too often, institution-based long-term care may become necessary, with a current estimated cost of $45 billion for persons with disability. A customer-driven, individualized system of community-based care that is responsive to individual needs has been demonstrated to provide better, less expensive care.

The goal is to redirect Medicaid financing from institution-based to improve health care outcomes for women with disabilities, a goal being supported by new community-based Medicaid-supported initiatives implemented in response to President Bush's New Freedom Initiative.

Objectives:

- Develop new models through a Centers for Medicare and Medicaid Services (CMS) demonstration project to learn how to change the system to make it more cost effective while maintaining independence and self-directed health management within the health care delivery system.
- Reduce existing inequities in reimbursement for medical professionals' time, case management, and medical and technological equipment.
- Reduce the reimbursement paperwork burden for providers.

Key Stakeholders:

- Women with disabilities and their families
- Health care providers
- CMS and other providers of healthcare benefits
- Federal and State Medicaid agencies
- Health departments
- Community-based service providers
- Foundations
- Employers

Needed Resources:

- Enhanced federal support
- Non-governmental funding supports (e.g. foundations)
- Public and Private Partnerships and collaborations
- Participants for demonstration project (entities to apply in a State)

Next Steps:

- Develop workgroup and establish a timeline
- Conduct research review on public and private financing issues
- Develop a concept paper
- Explore with CMS interest in supporting a demonstration project
- Raise consciousness and trust relationships with advocates, legislators, private and public, foundations, academia, and constituents

Health Promotion

Gaps exist in the current body of knowledge related to the health care needs of women with disabilities. Current data sets, such as that maintained by the National Center for Medical Rehabilitation Research, contain little data specifically focused on women with disabilities. There is a need to address the health issues of all women with disabilities, including those with cognitive, sensory, and physical disabilities. A few organizations, such as the Association of University Centers on Disabilities, Alta Bates Summit Medical Center, among others have conducted research on women with disabilities, but more information is needed.

The short-term goal is to produce a White Paper on Health Promotion for Women with Disabilities across the Lifespan. This document would address the current state of health promotion and needs of women with disabilities and would be distributed to health care providers, policymakers, government agencies, and consumer groups.

Objectives:

- Establish white paper workgroup—with representatives from all stakeholder organizations and offices.
- Convene a workgroup meeting within 2 months of the project initiation to identify roles in researching and writing the White Paper.
- Write, revise, and seek approval for publication of the White Paper within 6 months of the implementation of the work group.

Key Stakeholders:

- Professional organizations – American Medical Association, American Academy of Pediatrics, National Medical Association, American Academy of Physical Medicine and Rehabilitation, National Association of Community Health Centers, Association of Women's Health, Obstetric, and Neonatal Nurses, American Public Health Association, American Spinal Injury Association, Association of Academic Physiatrists
- Women with disabilities and their families
- Disability and women's health policy experts
- Consumer groups—Multiple Sclerosis groups, American Association of People with Disabilities, ARC, United Cerebral Palsy, Down Syndrome Association, National Spinal Cord Association, Brain Injury Association , Through the Looking Glass, AARP, National Health Council, United Spinal Association
- Federal Agencies: National Council on Disability, HHS Office on Disability and Office on Women's Health, National Institute on Disability and Rehabilitation Research, US Department of Education

Needed Resources:

- Interdepartmental and interagency partnerships
- Champion/spokesperson

Next Steps:

- Identify a group to take ownership of the development of the White Paper, using channels already established by the HHS Office on Disability and Office on Women's Health interagency agreement.
- Delineate the mechanisms under which the White Paper will be developed, reviewed, edited, and, ultimately, cleared and published, including such matters as funding and editorial responsibility.
- Establish a timeline for development and ultimate publication of the White Paper.

Provider Education

A broad curriculum for undergraduate, graduate, or continuing medical or for allied health education for disabilities issues is not currently available. Practitioners express a lack of confidence in their ability to treat women with disabilities. There are a variety of local curriculum programs, and there is a national curriculum program addressing women's health issues more broadly. Communication is limited among providers and across disciplines on disabilities issues. In mid-2005, the Surgeon General will be issuing a Call to Action on the health and wellness needs of persons with disabilities which will enhance interest in this issue area.

The goal is for all health care provider training programs, including continuing education programs, to address the care of women with disabilities in areas of competencies involving attitudes, knowledge, and skills.

Objectives:
- Establish a resource center through a competitive process similar to that used to select the Research and Training Centers of the HHS Office on Women's Health Centers for Excellence. The resource center would collect and disseminate all existing educational resources for all types of providers and for all levels of training.
- Obtain support from relevant groups by writing journal articles, making convention presentations, etc. All participants in this meeting will participate. Take advantage of the Surgeon General's Call to Action as a springboard to generate interest.
- Seek public and private resources to advance curricula development with the aim of modifying provider behavior and improving safety and outcomes.

Key Stakeholders:
- Women with disabilities and their families
- Independent living centers
- Health educators across the range of disciplines, and across levels of education
- Professional organizations – key physician, nurse, OT/PT associations
- Hospital associations, practice management companies
- Risk managers and malpractice insurance carriers
- Women's groups
- Disability and women's health experts
- Joint Accreditation Commission for Healthcare Organizations, National Committee for Quality Assurance and other quality standard setters

Needed Resources:
- Web site as locus for materials dissemination
- Journal articles, conference presentations
- Support from professional organizations
- Support from public and private entities
- A leader of the effort to coordinate the group

Next Steps:

- Kristi Kirschner (Rehabilitation Institute of Chicago) will summarize current resources and forward that information to the National Research Center for Women and Families and the HHS Office on Disability for circulation to conference participants to begin the process of assembling existing resources.
- Establish a formalized work group to lead this effort.
- Establish a timeline.

Appendices

Appendix A: Presentations

Sharman Word Dennis, MEd

Kristi Kirschner, MD

Florita Maiki, MA

Judith Panko-Reis, MA, MS

Jennifer Potter, MD

JoAnn Thierry, PhD, MA

Margaret Turk, M.D.

Identifying Barriers to Health Care

JoAnn Thierry, Ph.D.
Centers for Disease Control and Prevention

Slide 1 – Title

In recent years, women's health has emerged as a prominent public health priority. Research focused on women's health has led to valuable information about how and why certain diseases affect women disproportionately, predominantly, or differently than men. It has also led to a better understanding of the differential health risks faced by particular subpopulations of women, such as those who are members of racial and ethnic minority groups. Yet despite the increased awareness of women's health, research to date has not adequately addressed the health concerns of women with disabilities (Thierry & Cyril, 2004).

Although there is a growing interest in women's health, research addressing the health of women with disabilities is a new and emerging field. Only within the past decade has an increasing number of researchers begun to examine the health of women with disabilities and address topics such as access to care, health care utilization, and the prevention of secondary conditions (Vines & Shackelford, 1996; Turk, Geremski, Rosenbaum. 1997; Stuifbergen & Roberts, 1997; Iezzoni, McCarthy, Davis, & Siebans, 2000; Turk, Rosenbaum, Scandale, 2001; Rimmer & Liu, 2001; White, Figoni, Froehlich, Marquis, 2001; Coyle & Santiago, 2002). And for the first time objectives on the public health needs of people with disabilities, including disabled women, are reflected in *Healthy People 2010* (U.S. Department of Health and Human Services (HHS), 2000).

Slide 2 – Definition of Disability

In general terms, disability refers to "limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks or roles" (IOM).[8] Commonly accepted measures of disability have focused on functional limitations, activity limitations, and work limitations. These definitions allow for the inclusion of people with many disabling conditions including sensory, cognitive, emotional, or physical impairments, and various chronic health conditions. However, use of these multiple definitions has resulted in varying prevalence estimates of disability in women.

Slide 3 – Prevalence of Disability Among Women with FLs

For example, estimates from the National Health Interview Survey-Disability Supplement indicate that 16% of women 18 years of age or older have at least one functional limitation.[2] The prevalence of having at least one functional limitation increases with age from 6% for women 18-44 years to 40% for women 65 years or older. In comparison, state-based estimates from the Behavioral Risk Factor Surveillance System suggest the overall prevalence of disability among women is 18%. [9]

Appendix B: Presenter biographies

Sharman Word Dennis, MEd, the founder and CEO of ROSE, Inc, has worked with youth for more than thirty years. She has completed postgraduate studies in special education from George Washington University, a masters of arts in education, specializing in special education from George Washington University, and a bachelor of arts in education from Emmanuel College in Boston, Massachusetts. Ms. Dennis is considered one of the foremost experts on persons with Developmental Disabilities, Mental Retardation, other special needs and EPSDT. She has served as an adjunct professor at Howard University in the School of Education, the University of the District of Columbia and George Washington University.

Ms. Dennis was instrumental in developing and providing oversight for the DC Early Intervention Program for infants and toddlers with special needs. She has served on numerous committees in the District of Columbia that focus on the needs of persons with disabilities.

Ms. Dennis has managed programs with limited resources as well as programs with million dollar budgets. She is knowledgeable of barriers to institutional growth and expansion. Much of her work involves the development of needs assessments and evaluative processes. She has years of experience in facilitating groups and managing interpersonal relationships by bringing together key stakeholders and being aware of turf issues. She has conducted outreach and training activities for the federal government, District government and private sector.

Ms. Dennis' favorite enjoyments are working with children and training about the needs of children and families and to support agencies in serving the needs of children in a cost effective manner.

The Honorable Margaret J. Giannini, MD, FAAP was appointed in 2002, as Director of the Health and Human Services Office on Disability by Secretary Tommy G. Thompson. She serves as advisor to the Secretary on HHS activities relating to disabilities. Prior, Dr. Giannini was appointed by President George W. Bush as the Principal Deputy Assistant Secretary for Aging at the Department of Health and Human Services. From 1981-1992, Dr. Giannini was Deputy Assistant Chief Medical Director for Rehabilitation and Prosthetics at the Department of Veterans Affairs. 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. Dr. Giannini, in 1950, was the first to create the largest facility for mentally retarded and the developmentally disabled for all ages and etiologies 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. 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; received the Wyeth Medical Achievement Award; the Seal of the Inner London Education Authority for Contributions in the Field of Mental Retardation at the House of Parliament London; and the Governor Hugh Carey Citation for Leadership and Medical Contributions to the State of New York; presented the First Honorary Degree by Mercy College Doctor of Humane Letters; the Meritorious Honor Award in Mental Retardation and awarded the Key to the City of Bologna, Italy; received the Bronze Medal Award by the American Academy of Pediatrics; the National Italian-American Foundation Award for Distinguished Achievements in Science and Medicine; "Recognition Plaque' from the City of San Francisco; Seton Award from Seton Hall College, Pittsburgh, PA; the First Presidential Award for Design Excellence from President Reagan; the N. Neal Pike Award for Service to the handicapped from Boston University; the Isabelle and Leonard H. Goldenson Award for Technology Application to Cerebral Palsy; President Reagan's Distinguished Service Award, Committee on Employment of the Handicapped; Silver helmet Award by AMVETS; is in the New York Hall of Fame (AHRC, '98); and was honored by the naming of the "Hon. Margaret J. Giannini, M.D. Physical Rehabilitation Pavilion" in 1997 at Westchester Special School, N.Y. First International Leadership Scholars Award by the University of Maryland, Baltimore, Maryland in recognition for "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. She has served for many years as Chair of the Board of Trustees, the American University of Rome, Italy. She has published extensively and lectured nationally and internationally. Dr. Giannini has most recently edited "Behavioral Neurology in the Elderly," December 2001. She is also a Member of Institute of Medicine.

Wanda Jones, DrPH, is Deputy Assistant Secretary for Health (Women's Health) in the U.S. Department of Health and Human Services and the Director of the Office on Women's Health. Since her selection in 1998, Dr. Jones has focused her efforts on eliminating health disparities for women through a variety of programs and initiatives, including the
HYPERLINK "http://www.4woman.gov/coe/index.htm"
National Centers of Excellence in Women's Health (www.4woman/gov/coe/index.htm), the National Community Centers of Excellence in Women's Health (www.4woman.gov/owh/cCOE/index.htm), the National Women's Health Information Center (www.4woman.gov/index.htm), (1-800-994-WOMAN or TDD: 1-888-220-5446), and the Panel of Experts on Minority Women's Health (www.4woman/gov/owh/minority.htm).

Dr. Jones actively participates in the Department's efforts concerning violence against women, disabilities, and HIV/AIDS. She supports women's health activities outside Washington, D.C., through women's health coordinators assigned to each of the ten regions of the U.S. Public Health Service.

Dr. Jones has long been recognized for her leadership on women's health issues in the federal and state public health communities. Prior to her current position, Dr. Jones was the Associate Director for Women's Health at the Centers for Disease Control and Prevention in Atlanta. A Penn State graduate in medical technology, she has worked in an inner city blood bank and its hematology laboratory; in a small town hospital as its night shift technologist and then as its microbiologist; and for a state public health laboratory as a laboratory improvement consultant. She obtained her doctorate in Public Health Laboratory Practice from the University of North Carolina. Dr. Jones joined CDC in 1987 as an HIV laboratory trainer. In 1990, she became the Assistant Director for Science in the Office of the Associate Director for HIV/AIDS, where she was active in policy issues related to HIV laboratory testing, women and AIDS, HIV vaccine development and healthcare workers.

Kristi L. Kirschner, MD, is an attending physician at the Rehabilitation Institute of Chicago. 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 Center for the Study of Disability Ethics at the Rehabilitation Institute of Chicago.

She received her medical training at the University of Chicago and completed her residency at the Rehabilitation Institute of Chicago 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 has named the Coleman Chair of Rehabilitation Medicine in February of 1996. This chair supports her work in women’s health and disability as well as disability ethics. She is an associate professor of Physical Medicine and Rehabilitation and of Medical Ethics and Humanities at the Northwestern University Feinberg School of Medicine.

Florita Maiki, MA, is the Manager of Breast Health Access for Women with Disabilities (BHAWD) at Alta Bates Summit Medical Center, Rehabilitation Department in Berkeley California. She has been at BHAWD almost six years. Prior, she was the Director of the Multiple Sclerosis Clinic and Research Center at the University of California, San Francisco. Before that she served as Northern California Service Director for the National Multiple Sclerosis Society- Northern California Chapter. Her experience includes 25 years working with people with disabilities, and in women's health in a variety of capacities such as clinic operations and services, program development and evaluation, research, public policy and strategic planning. Florita's interest in healthcare and inequity in healthcare access emerged from her personal and family's experience as immigrants. She is passionate about reducing healthcare disparities through increased education and access to health services.

Judith Panko-Reis, MA, MS Before becoming an advocate for women with disabilities Judith Panko-Reis earned a B.A. in Philosophy from the State University of New York in Geneseo. She later earned her Master's degree in Philosophy from the University of Chicago. In 1991, she graduated from Northwestern University with a Master's of Science in Managerial Communication.

Ms. Panko-Reis became head injured due to a random violent attack while camping in Hawaii several years ago. Since then, she has become a wife, mother and the director for the Women with Disabilities Center of the Rehabilitation Institute of Chicago, the first comprehensive health center run by and for women and teen girls with disabilities in the country. 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 with disabilities. She has published several articles and book chapters on disabled women's issues, including articles on women and traumatic brain injury. Recently she published *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 healthcare issues. She is a trained domestic violence advocate and has written articles on the subject and conducted trainings on disability and domestic violence for policymakers and service providers.

Jennifer Potter, MD, is the Director of the Women's Health Center and Director of Women's Health Education at Beth Israel Deaconess Medical Center in Boston. She attended Harvard Medical School and completed residency in Medicine at the former Deaconess Hospital. She is recognized nationally for her educational contributions in the field of women's health. Her major interests are teaching trainees how to: communicate effectively with diverse patients; perform culturally-sensitive and risk-appropriate breast and pelvic exams; provide comprehensive breast and reproductive care; and assess women’s satisfaction with their sexual lives and address sexual problems that are identified.

JoAnn M. Thierry, PhD, MS, MSW, 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 Disability and Health program.

Dr. Thierry has been working with people with disabilities for twenty years. After earning her degree in Psychology at the State University of New York (SUNY), College 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 seven 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.

Margaret A. Turk, MD, is Professor of Physical Medicine and Rehabilitation at the State University of New York Upstate Medical University at Syracuse, with a joint appointment in the Department of Pediatrics. She is also Medical Director of Rehabilitation Services at St. Camillus Health and Rehabilitation Center. Dr. Turk serves as a Director of the American Board of Physical Medicine and Rehabilitation and as a member of the American Board of Medical Specialties Maintenance of Certification Task Force. In addition to her clinical and administrative responsibilities, Dr. Turk is involved in rehabilitation research and has been funded by CDC over a 10 year period for projects related to secondary conditions of and health promotion for persons with disabilities. Her publications and national and international presentations have been on pediatric rehabilitation, pediatric electrodiagnosis, tone management, adults with cerebral palsy, secondary conditions, health promotion in disability, and the health of women with disabilities. She participates with the NYS DOH Disability Prevention Program Working Group on Secondary Conditions, which she co-chairs. She received The Ohio State University College of Medicine & Public Health Alumnae Achievement Award in 2000, and the United Cerebral Palsy Research and Educational Foundation Isabelle and Leonard Goldenson Technology and Rehabilitation Award in 2004. She has served on the Medical Rehabilitation Research Subcommittee, NICHD, NIH, and was Chairman for two years. She has served on a variety of program planning committees and study groups for CDC, NIH, and NIDRR, and participated in the Institute of Medicine report on rehabilitation science and engineering, Enabling America.

Diana Zuckerman, PhD, is the President of the National Research Center for Women & Families, a nonpartisan, nonprofit organization that uses research information to advocate for programs and policies that will improve the health and safety of women, children, and families.

Dr. Zuckerman received her PhD in psychology from Ohio State University and was a post-doctoral fellow in epidemiology and public health at Yale Medical School. She started her career as a faculty member at Vassar College, then at Yale University, and then was a study director at Harvard, where she conducted research on the life goals and self-images of women at seven liberal arts colleges.

For ten years, Dr. Zuckerman worked as a Congressional staffer in the U.S. House of Representatives, working for the Congressional subcommittee that oversees the U.S. Department of Health and Human Services and Department of Education. She was responsible for more than a dozen Congressional investigations and hearings on health, mental health, and other social policy issues. In 1993, she became Director of Policy, Planning, and Legislation for the Center for Mental Health Services of the U.S. Public Health Service. She left to direct the health staff for the U.S. Senate Committee on Veterans Affairs, chaired by Sen. Jay Rockefeller.

After leaving the Senate in 1995, Dr. Zuckerman spent a year as a senior policy adviser in the White House, at the Office of Science and Technology Policy. Since leaving the White House, she has served in leadership positions at non-profit organizations, and has been president of the National Research Center for Women & Families since 1999. (Until recently, the Center was named the National Center for Policy Research for Women & Families). She is the author of Blind Adults in America: Their Lives and Challenges, a report based on the only comprehensive study of legally blind adults in the U.S., which was released at a Congressional policy forum in 2004.

Dr. Zuckerman is a nationally recognized expert on health issues, and has appeared on ABC news, CBS news, NBC news, CNN, Fox News, public television, 20/20, and National Public Radio. She has been quoted in The New York Times, Washington Post, Los Angeles Times, Boston Globe, USA Today, Detroit Free Press, Washington Times, New York Daily News, Newsweek, Time, U.S. News and World Report, and many other newspapers and radio programs. In addition, she writes a monthly research column for Youth Today. She is the author of four books and dozens of articles in academic journals and national newspapers.

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Appendix C: Work Group Members

Provider Education Work Group

Facilitator: Margaret Turk, MD, SUNY Upstate Medical Center

This group will focus on how to ensure providers are equipped to serve patients with disabilities, understand their health care needs, understand the ADA, and learn about community resources.

Ms.	Helena	Berger	American Association of People with Disabilities
Dr.	Veronica	Clarke-Tasker	Black Nurses Association of Greater Washington, DC
Dr.	Sheldon	Horowitz	American Board of Medical Specialties
Dr.	Kristi	Kirschner	Rehabilitation Institute of Chicago
Ms.	Marie-Michèle	Léger	American Academy of Physicians Assistants
Dr.	Jennifer	Potter	Beth Israel Deaconess Medical Center/APGO Women's Health Learning Competencies
Ms.	Melinda	Ray	Association of Women's Health, Obstetric, and Neonatal Nurses
Ms.	Judi	Rogers	Through the Looking Glass
Dr.	Laura	Sessums	Society of General Internal Medicine
Ms.	Chris	Spain	President's Council on Physical Fitness & Sports, HHS
Dr.	Margaret	Turk	Dept. of Physical Medicine and Rehabilitation, SUNY Upstate Medical Center
Ms.	Sunny	Yoder	Association of American Medical Colleges

Health Promotion Work Group

Facilitator: JoAnn Thierry, PhD, Centers for Disease Control and Prevention

This group will focus on identifying challenges to promoting health and wellness for women with disabilities, including consumer and provider attitudes (e.g., knowledge, personal choices, and life style); environmental barriers; health communication; and community support.

Ms.	Laura	Blum	Joint Commission on Accreditation of Healthcare Organizations
Ms.	Judith	Cranford	National Osteoporosis Foundation
Dr.	Bruce	Gans	American Academy of Physical Medicine and Rehabilitation
Dr.	Mary Jo	Goolsby	American Academy of Nurse Practitioners
Ms.	Sandra	Haldane	Indian Health Service, HHS
Dr.	Amie	Jackson	University of Alabama at Birmingham, School of Medicine
Dr.	Wanda	Jones	Office on Women's Health, HHS
Ms.	Sameta "Sam"	Kemp	Lupus Foundation of America
Dr.	Marion	Primas	Bureau of Primary Health Care, HRSA, HHS
Ms.	Jennifer	Sheehy Keller	National Institute on Disability and Rehabilitation Research, US Department of Education
Dr.	JoAnn	Thierry	National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

ADA and Access Issues Work Group

Facilitator: Judith Panko-Reis, MA, MS Rehabilitation Institute of Chicago

This group will focus on accessibility of medical equipment and medical offices; accessibility needs assessments; and transportation.

Dr.	Mindy	Aisen	Veteran's Affairs, Office of Rehabilitation Research and Development
Ms.	Jennifer	Croft	US Food and Drug Administration
Ms.	Joanne	Finegan	CARF, ReMed
Dr.	Jaye	Hefner	Harvard Medical School & Beth Israel Deaconess Medical Center
Ms.	Flora	Maiki	Breast Health Access For Women with Disabilities
Ms.	Kate	Nicholson	Department of Justice, Disability Rights Section
Ms.	Margaret	Nygren	Association of University Centers on Disabilities
Ms.	Judith	Panko-Reis	Women with Disabilities Center, Rehabilitation Institute of Chicago
Ms.	Anne Marie	Pecht	US Department of Justice, Disability Rights Section
Ms.	Lauren	Raskin Ramos	Association of State and Territorial Health Officials
Mr.	Steven	Tingus	National Institute on Disability and Rehabilitation Research, US Department of Education

Financing Issues Work Group

Co-Facilitators: Margaret Giannini, MD, FAAP, Office on Disability, HHS and Dennis Smith, MPA, CMS, Center for Medicaid and State Operations, HHS

This group will focus on reimbursement rates for longer visits; and insurance issues.

Ms.	Angela	Ablorh-Odjidja	National Association of County and City Health Officials
Dr.	Rosaly	Correa	Agency for Healthcare Research and Quality, HHS
Dr.	Margaret	Giannini	Office on Disability, HHS
Dr.	Cassandra	Henderson	National Medical Association, Our Lady of Mercy Medical Center
Ms.	Marian	McCartney	American College of Nurse Midwives
Ms.	Shelia	Newman	New Editions Consulting, Inc.
Ms.	Marcie	Roth	National Association of Spinal Cord Injuries
Dr.	Theresa	San Agustin	National Institute on Disability and Rehabilitation Research, US Department of Education
Dr.	Deborah	Smith	American College of Obstetricians and Gynecologists
Mr.	Dennis	Smith	CMS, Center for Medicaid and State Operations, HHS
Ms.	Sue	Swenson	The Arc of the United States
Dr.	Tom	Tonniges	American Academy of Pediatrics
Dr.	Diana	Zuckerman	National Research Center for Women & Families