

W H I T E P A P E R

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Financing Health Care for Women with Disabilities

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*Prepared for the
FISA Foundation*

RAND Health

The research described in this report was conducted within RAND Health for the FISA Foundation.

ISBN: 0-8330-3470-7

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Published 2003 by RAND
1700 Main Street, P.O. Box 2138, Santa Monica, CA 90407-2138
1200 South Hayes Street, Arlington, VA 22202-5050
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Preface

Women with disabilities, a large and growing segment of the U.S. population, are as a group underserved in primary health care services that are appropriate to their needs. To date, few (if any) formal studies have been done examining the short-term costs or long-term benefits of providing specialized care for these women. This paper describes the major financial issues affecting access to appropriate primary health care for women with disabilities. The assessment is based on a review of the published literature, supplemented by key stakeholder interviews, and covers issues that are relevant at the national level and in southwestern Pennsylvania specifically. The findings and recommendations should be of interest to public and private decisionmakers seeking to improve access to health care for women with disabilities.

Conducted under the auspices of the Magee-RAND Women's Health Initiative, this work was made possible by a grant from the FISA Foundation in Pittsburgh, Pennsylvania, as part of its Women with Disabilities Access to Health Care Initiative.

FISA Foundation

This study has been conducted through a grant from the FISA Foundation. The Foundation's mission is to support nonprofit organizations in southwestern Pennsylvania that foster full community participation of adults and children with disabilities or that address the health needs of women and girls. The FISA Foundation has funded 11 projects in Pittsburgh through an initiative designed to improve access to health care for women with disabilities. Among the projects currently underway are an accessible primary care clinic, home-based preventive gynecologic health screenings for women with multiple sclerosis, sexual violence information and support services for women with disabilities, adaptive parenting resources, a Web-based guide for referrals to appropriate, accessible health care services, disability awareness training for hospital employees, and pre- and post-natal support for pregnant women who are disabled.

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RAND Health

Staffed by more than 100 experts in health economics, quality measurement, and other fields, RAND Health is the largest private health care research organization in the United States. It has been at the forefront of emerging health care issues for more than four decades. The work of the Magee-RAND Women's Health Initiative is conducted as part of the RAND-University of Pittsburgh Health Institute located at RAND's Pittsburgh office.

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Magee-RAND Women's Health Initiative

The Magee-RAND Women's Health Initiative, a collaboration between RAND and the Magee-Womens Research Institute, conducts research to improve the quality of and access to health care services for women in southwestern Pennsylvania and works to replicate successful models of women's health care in real-world settings.

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Executive Summary

Elimination of health disparities through improved access to care for underserved populations is a top priority on the nation's health care agenda. Nevertheless, women with disabilities continue to be underserved in having access to primary health care services that are appropriate to their needs. While these needs are well documented, what are less understood are the financial and other barriers that may impede provision of and access to health care services for this large and growing segment of the population. To gain a better understanding of the health care barriers women with disabilities face, the FISA Foundation in Pittsburgh, Pennsylvania, commissioned RAND to assess what is known about the key financial issues affecting access to appropriate primary health care for women with disabilities and to recommend strategies for effectively addressing these issues.

Our assessment is based on a review of the research literature and other published sources, supplemented by interviews with women with disabilities, policymakers, physicians, insurers, and representatives from coordinated care plans. We also conducted two focus groups with women with disabilities in the Pittsburgh area. This paper describing our key findings and recommendations is intended to inform national, state, and local policymakers and other leaders seeking to eliminate health disparities and improve quality of care for women with disabilities.

Women with Disabilities: Who Are They and What Are Their Health Care Needs?

An estimated 27 million American women are living with disabilities, defined by the World Health Organization¹ as "any impairment, activity limitation, or participation restriction that substantially affects one or more life activities." Some 17 percent of U.S. women between the ages of 16 and 64 currently report at least one major activity limitation. This paper focuses primarily on women with physical/sensory disabilities under the age of 65, who constitute approximately 15 percent of the

¹See World Health Organization (2001).

women in this age group in Pittsburgh and the rest of Allegheny County, Pennsylvania.

Demographic Characteristics of Women with Disabilities

Women with disabilities share a number of important demographic characteristics that can impact their utilization of and ability to pay for health care. More women with disabilities than without disabilities live in poverty, with incomes below the mean for both women without disabilities and men with disabilities. Many also belong to ethnic or minority groups that are traditionally underserved by the health care system. Native-American and black women overall have higher disability rates. Twenty-six percent of women with disabilities live in rural areas, where unemployment rates are higher than in other more populous areas, and the annual incomes of women with disabilities are lower on average than the incomes of women without disabilities. Inaccessible public transportation and decreased access to specialty care centers compound the health care challenges facing women with disabilities.

Special Health Care Needs of Women with Disabilities

Although people with disabilities consume more health care services than the general population, they still have many unmet needs for care. Women with disabilities, like all women, require routine preventive care, including regular medical and gynecological checkups, mammograms, and reproductive care. However, their disabilities frequently result in underutilization of the most routine preventive care services. The standard equipment made available for many routine exams is often not adequate for women with disabilities, who may need specially designed chairs or tables in order to be examined. In addition, women with disabilities often have complex health needs that require them to receive care from at least one clinical specialist, and many may require care from multiple specialists and social service providers. Providers usually spend far more time delivering otherwise routine primary care services to these patients with special needs.

For all the reasons just stated, to ensure the best possible outcomes, women with disabilities require coordinated and continuous care including active follow-up, proper equipment, and adequately trained health care practitioners and other service providers. Effective models for

providing such care do exist and they may be applicable to this population.

Non-Financial Barriers to Health Care

Women with disabilities often face non-financial barriers that can prevent them from accessing the care they should have even if financing is readily available. Physical barriers, such as a lack of specialized examination equipment and inadequate transportation and support services, are common problems. In addition, women who were interviewed for this study said that they had difficulty in finding physicians who understand all of their health care needs, including their need for general preventive care, as well as the special needs related to their particular disability.

How Is the Delivery of Health Care for Women with Disabilities Provided and Covered?

As expected, women with disabilities who do not have insurance coverage have greater difficulty receiving appropriate health care than women with disabilities who do have coverage. However, even those with insurance face significant challenges in paying for certain services.

Health Insurance Coverage

Almost all women with disabilities have medical insurance; the fraction with no insurance is lower than it is for women without disabilities. Women with disabilities obtain public insurance primarily through two programs: Medicare, which covers people in the Social Security Disability Insurance (SSDI) Program, and Medicaid, which covers people in the Supplemental Security Income (SSI) Program.

SSDI provides benefits for any person meeting the Social Security definition of disability and who has worked and contributed to Social Security or who has been a dependent of someone who has worked and contributed to Social Security. After a person becomes eligible for SSDI, there is a two-year waiting period for Medicare. Consequently, many individuals with disabilities initially face a gap in medical insurance coverage. More than five million people under the age of 65 have Medicare through SSDI, and approximately 41 percent of them are women.

About 6.6 million individuals with disabilities receive Medicaid through the SSI program, accounting for about one-fourth of all Medicaid beneficiaries. SSI provides benefits to persons who are poor and have a qualifying disability, whether or not they have ever worked.

Medicare does not cover outpatient pharmaceuticals and only pays for specialized care, such as attendant care services and equipment, under limited conditions. Thirty-six percent of Medicare-eligible women with disabilities have supplementary Medicaid coverage, which covers many services not covered by Medicare. Fewer people obtain supplemental coverage through their employers' plans or Medigap plans.²

In addition to Medicare and Medicaid, some women with disabilities can pay for their health care needs through *The Ticket to Work and Work Incentives Improvement Act of 1999* (Public Law 106-170), which allows people with disabilities to retain their public insurance status while they are working. Many of the women we interviewed also rely on philanthropic organizations, such as the National Multiple Sclerosis Society, to fill the gaps in their insurance coverage, including costs for special equipment or home modifications.

Managed Care

Increasingly, women with disabilities are enrolled in Medicaid managed care plans, primarily health maintenance organizations (HMOs). Approximately 40 percent of men and women with less-severe disabilities and 28 percent of men and women with severe disabilities are enrolled in HMOs, with the majority in traditional Medicaid programs.³ In Pennsylvania, the Medicaid managed care program is HealthChoices,

²A Medigap plan is a second insurance plan designed to supplement Medicare (i.e., it helps to pay for those items that Medicare does not cover, such as deductibles, copays, and supplementary benefits).

³Definitions of degrees of severity vary with the data source. According to Jans and Stoddard (1999), the Survey of Income and Program Participation (SIPP) defines an individual with a severe disability as having one of the following conditions: unable to perform at least one functional activity; needing personal assistance with an activity of daily living or instrumental activity of daily living; uses a wheelchair or other walking assistance device (such as a cane, crutches, or walker) on a long-term basis; has a developmental disability or Alzheimer's disease; is unable to do housework; or who receives federal disability benefits or is between the ages of 16 and 67 but is unable to work. SIPP defines those with a non-severe (or less severe) disability as all other individuals with a disability that does meet the criteria of a severe disability.

also an HMO; in southwestern Pennsylvania, one-third of all Medicaid enrollees in the three HealthChoices plans are SSI recipients.

The few attempts that have been made to compare specific types of health care programs for women and people in general with disabilities suggest that access and quality of care vary across plans based on the type of care required. Preventive health services for women with disabilities in managed care programs appear to be better than such services in non-HMO plans. As a group, people in private and Medicare managed care programs are more likely to report a usual source of care and less likely to have delayed receiving care due to cost. However, many women with disabilities express concerns about managed care programs, including limitations in provider choice, difficulty in accessing specialty care when needed, and lack of information about the various options for care.

Specialized Health Care Programs for Women with Disabilities

A number of programs specifically targeting people with disabilities have arisen recently in recognition of the greater role that coordinated care programs have played for this population. Several of these programs are funded as Medicaid managed care programs, but with a unique focus on individuals with disabilities. A common thread in the programs is an initial needs assessment that allows the development of coordination-of-care plans specific to the needs of individual members.

Other hospital-based programs provide a mixture of primary gynecologic care and social services in addition to women's health screening services. Their goal is to be funded, as other hospital departments are, through traditional insurance-based reimbursements.

Still other programs are not housed at hospitals but are affiliated with local hospitals that can provide specialty care if needed. A key element of these programs is the provision of care in the home of the person with disabilities, thus eliminating transportation barriers.

Finally, most people with disabilities would qualify for the special disease-management programs frequently offered by private managed care plans for patients with chronic medical needs. These programs typically provide special benefits, such as transportation assistance, some durable medical equipment coverage, and home health care.

Given the high start-up costs, it is unlikely that short-term cost savings can be achieved with these specialized programs; the more immediate effect is an improvement in health care quality. However, at least one such program has shown that an investment in better primary care can pay off in lower costs for specialized care later.

What Are the Financial Barriers to Health Care for Women with Disabilities?

Women with disabilities between the ages of 18 and 44 have almost 2.5 times the yearly health care expenditures of women who are not disabled; women between the ages of 45 and 64 have more than three times the average yearly expenditures. Clearly, having an adequate way to finance health care is extremely important.

Health care is usually paid for through employer- or government-sponsored insurance. Health plans competing for employer and government contracts try to hold their costs down. Those plans will pay for coordinated care programs only if savings resulting from more appropriate care offset the additional costs of establishing these programs, or if the employer and government payers are willing to cover higher costs associated with better care. Currently, financial support for specialized programs targeting people with disabilities has come from a few state Medicaid programs and, secondarily, private philanthropy. However, the quality and cost outcomes for usual care versus coordinated care programs are unknown.

Even women with disabilities who have insurance coverage face significant financial barriers to accessing the care they require. Many report delays in obtaining in-home attendant care and inadequate coverage for essential services, such as prescription medications, physical therapy, durable medical equipment, and programs that would facilitate the back-to-work transition. It may be that the most important limitation results from the failure of current reimbursement methods to adequately take into account the additional time and equipment needed to provide even routine care for women with disabilities. As a result, there are few specialized programs for these women, and most of them must rely on private philanthropy or subsidies from other activities within the same institution to supplement insurance payments. Unless risk-adjusted payments that reflect the higher treatment costs for women with disabilities are widely adopted, these programs are likely to remain small.

Policy Recommendations

While the health care financing system explicitly reimburses for specialty care for a disabling condition, it ignores the substantial added equipment and staffing needed to provide appropriate general health care. New approaches for financing health care for women with disabilities should be considered, along with a careful assessment of the cumulative cost effects of those new approaches on federal Medicare and Medicaid budgets.

Based on our findings and analysis, our key recommendations are as follows:

- Payers should create incentives for tailoring case management to women with physical disabilities.
- States should consider adopting coordinated programs for women with disabilities who are covered by Medicaid.
- Medicare should review its methods for risk-adjusting both fee-for-service and capitation payment rates to ensure that the rates reflect the higher costs of primary care for women with disabilities.
- Medicare should also consider covering the coordinated care programs developed by some states for Medicaid recipients, while sharing costs with those states for individuals enrolled in both programs.
- Improved physician training, education, and sensitivity to disability issues are required to enhance the quality of primary care provided to women with disabilities.
- Coverage should be extended to services that typically are not covered by payers but can be shown to be cost-effective for women with disabilities.

Future Research Needs

Increased resources should be dedicated to research on health care for women with disabilities, especially now that people with disabilities are living longer and have more active lives than in the past. Much more information is needed about the health care needs of women with disabilities, the costs and outcomes of various care approaches, and the

best ways of organizing and financing the care of women with disabilities.

A more standardized definition of disability that is consistent across national datasets as well as across data collected by payers is needed so that the demographics and needs of this population can be better understood.

Better data are needed for women with disabilities, in particular longitudinal data for assessing long-run costs and health outcomes.

Research areas that warrant more attention include the following:

Prevention/Health Care Needs

- The cost-effectiveness of preventive care specialized to the needs of women with disabilities in reducing acute care visits and hospitalizations.
- The presence of secondary conditions, including behavioral or mental health conditions such as depression, and the impact those secondary conditions have on health care for women with disabilities.
- The impact of disability on pregnancy and reproductive health.
- The effect of the aging process on the disabilities that women have.
- The general and specialized health care needs of specific subpopulations with disabilities, including women with certain types of disabilities, women in certain socioeconomic groups, women living in specific geographic areas, and women representing diverse ethnic and cultural backgrounds.

Clinical Interventions

- The cost-effectiveness and quality of coordinated care programs, and how access to those programs affects one's ability to work and general quality of life.
- How new approaches for coordinated/integrated/specialized care for specific populations with disabilities might be developed and tested.

Health Care Financing and Policy

- Health outcomes and costs under specific payer arrangements.
- The impact of Medicaid managed care on outcomes for women with disabilities.
- How women who were disabled during childhood finance health care differently from those who acquired disabilities during adulthood.
- Designs for potential new reimbursement methods and cost modeling (e.g., development and application of new risk-adjustment techniques).
- The costs and benefits of model programs and assessment of their potential for broader implementation.

Acknowledgments

The authors would like to acknowledge Harold Alan Pincus, MD, Director, and Donna J. Keyser, PhD, Associate Director of the RAND-University of Pittsburgh Health Institute; Sarah Hudson Scholle, DPh, Co-Director of the Magee-RAND Women's Health Initiative; and Katherine D. Seelman, PhD, Associate Dean for Disability Programs and Professor of Rehabilitation Science and Technology, School of Health and Rehabilitation Science, University of Pittsburgh, for their important contributions to this paper.

We would also like to thank Dee Delaney, Executive Director, FISA Foundation; Patti Campbell, CRC, LPC, Professional Disability Consultant; Nora Dougherty, Director of Communications, FISA Foundation; Sheila Fisher, Co-Chair, FISA Foundation, Grant Review Committee; Carolyn Hoffman, PhD, Assistant Professor, Department of Special Education and Clinical Services, Indiana University of Pennsylvania; Molly Sauereisen, FISA Foundation Board Member; and other members of the FISA Foundation Board of Directors for their many useful comments. Melinda Beeuwkes Buntin, PhD, Health Economist at RAND, also provided numerous helpful suggestions in her review of this paper.

Finally, we acknowledge with appreciation the many others who contributed to this effort through their participation in our interviews and focus groups or who offered guidance during the course of our work.

The statements made and views expressed in this paper are solely those of the authors.

1. Introduction

Elimination of health disparities through improved access to care for underserved populations, including people with disabilities, is a top priority on the U.S. health care agenda. Nevertheless, women with disabilities, a large and growing segment of the nation's population, continue to be underserved in having access to primary health care services that are appropriate to their needs. While these needs are well documented, what are less understood are the financial and other barriers that may impede provision of and access to health care services for this population. To date, there have been few (if any) formal studies specifically examining the short-term costs or long-term benefits of providing specialized care for women with disabilities. As a result, informed and effective national and state policymaking designed to eliminate health disparities and improve quality of care for these women has been difficult to achieve.

To gain a better understanding of the health care barriers women with disabilities face, the FISA Foundation in Pittsburgh, Pennsylvania, commissioned RAND to synthesize and analyze what is known about the key financial issues affecting access to appropriate primary health care for women with disabilities and to provide a framework for thinking about ways to address these issues.¹ This paper presents our key findings and recommendations from this analysis. Our assessment is based on a review of the literature and supplementary interviews with women with disabilities, policymakers, physicians, payers, and coordinated care plan representatives.

As part of the interview process, RAND developed a set of key questions using a standard protocol. We conducted two focus groups and individual interviews with women with disabilities who were identified through local community-based agencies in Pittsburgh. Other interviewees included representatives of major insurers in southwestern Pennsylvania, current and former policymakers at Medicare, representatives of the Agency for Health Care Quality and Research, local

¹This paper covers issues that are relevant at the national level and that are relevant to southwestern Pennsylvania, specifically Pittsburgh and the rest of Allegheny County.

policymakers, and several national and local experts in the field of disability research and policy. We also interviewed representatives of coordinated care plans as well as health care providers serving women with disabilities from a wide range of disciplines including primary care, neurology, rehabilitative medicine, obstetrics/gynecology, and physical therapy.

In Chapter 2, we begin by describing the target population of women with disabilities and their specialized health care needs, and the manner in which they typically pay for the health care they receive. Chapter 3 explains how the delivery of health care for women with disabilities is currently financed and organized through health plans and describes the few existing tailored health care programs for this population. Chapter 4 describes the major financial barriers associated with the current health care delivery system. In conclusion, Chapter 5 suggests steps for removing these barriers and further research that would be useful for informing the policymaking process regarding health care for women with disabilities.

2. Women with Disabilities: Who Are They and What Are Their Health Care Needs?

An estimated 27 million American women are living with disabilities, and this number is steadily increasing. Although definitions of disability vary considerably (see Appendix A), in general, women with disabilities fall into three overlapping categories: (1) women with physical and sensory disabilities, such as cerebral palsy, multiple sclerosis, and vision and/or hearing impairments; (2) women with mental illness and/or cognitive disabilities, such as mental retardation; and (3) women with disabilities secondary to chronic medical conditions, such as diabetes. The term *disability* is used to describe “any impairment, activity limitation, or participation restriction that substantially affects one or more life activities” (World Health Organization, 2001). According to data from the 2000 Census, more than 17 percent of U.S. women between the ages of 16 and 64 currently report some type of disability.¹

This paper focuses primarily on adult women with physical and sensory disabilities under the age of 65. In Allegheny County, Pennsylvania, approximately 15 percent of women between the ages of 16 and 64 have some type of disability, including limitations on self-care or employment.² In addition, some of these women may also have secondary health care problems associated with their disability and/or may have severe functional limitations. Although the topic of women who are chronically ill and living in long-term care facilities, such as nursing homes, is important, this report does not address issues related to those women.

¹This percentage includes women with physical, sensory, mental, activity, and employment limitations. In general, estimates vary according to data source. Jans and Stoddard (1999), based on data from the National Health Interview Survey (see Appendix A), estimated that 14 percent of women between the ages of 18 and 64 report at least one major activity limitation. One of the greatest challenges in the field of disability is working across the various definitions of disability. As a result, interpretation of disability can vary, further complicating development of appropriate services for this population.

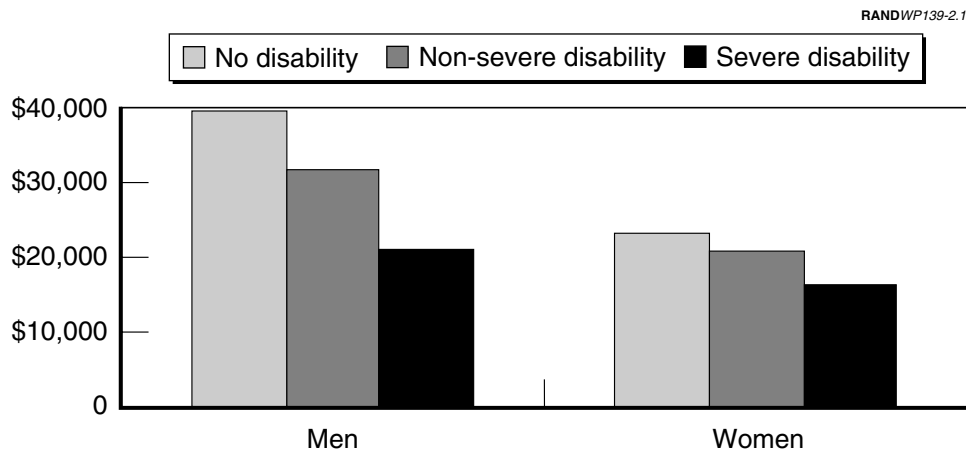
²This percentage is based on data from the 2000 U.S. Census (see Appendix A for more information).

Demographic Characteristics of Women with Disabilities

In addition to disability, this population of women shares a number of important demographic characteristics that can impact their utilization of and ability to finance health care. The information presented in this section was obtained from 2000 U.S. Census data and other published studies cited here.

To begin, a greater percentage of women with disabilities live in poverty than women without disabilities. Women with disabilities have mean incomes below those of women without disabilities and men with disabilities (see Figure 2.1).

Many women with disabilities also belong to special populations that are already traditionally underserved by the health care system. As shown in Figures 2.2 and 2.3, Native-American, black, and Hispanic women, for example, all have higher rates of disability than other women (Jans and Stoddard, 1999; Bradsher, 1996; Spas and Seekens, 1998; Glenn, 2001). African-American and Hispanic women with disabilities are also less likely to have insurance or report a usual source of care (Cornelius and Altman, 1995).

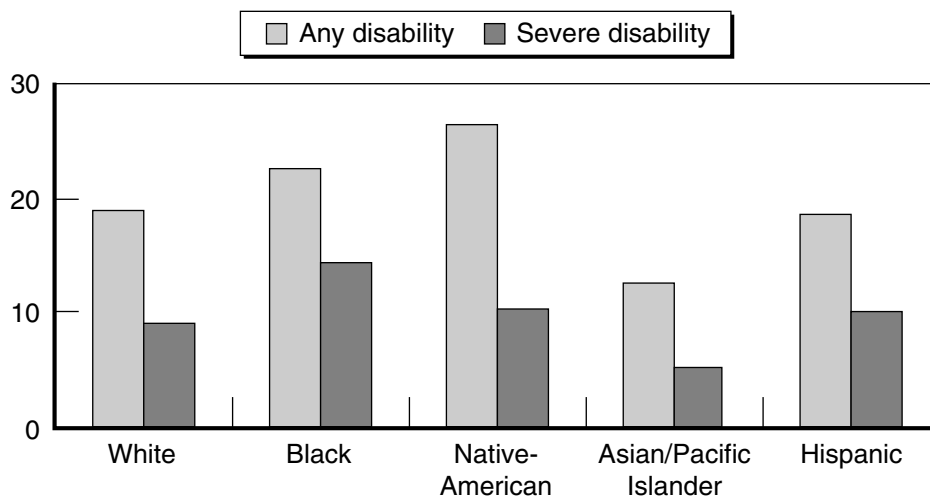


SOURCE: McNeil (2000).

NOTE: Uses the 1996 Survey of Income and Program Participation (see Appendix A).

Figure 2.1—Mean Annual Income for People with Disabilities Age 21–64 in the United States, 1997

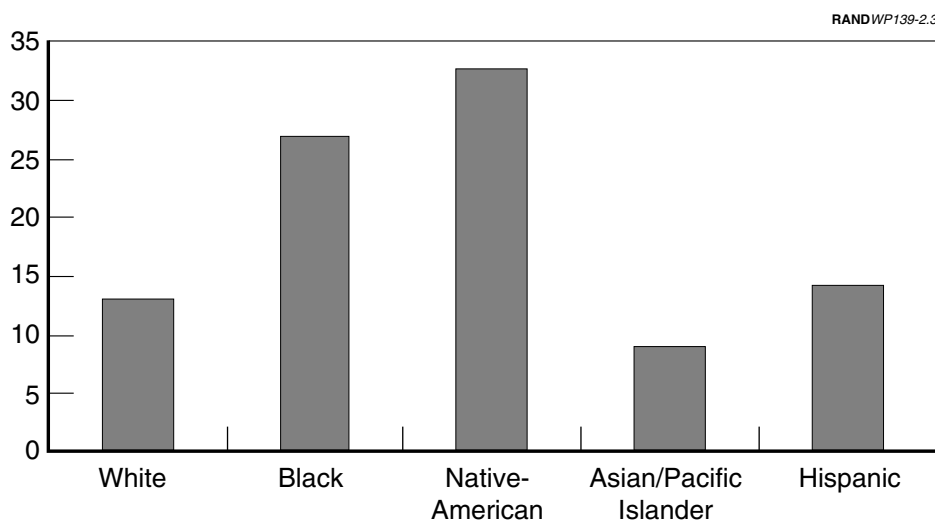
RANDWP139-2.2



SOURCE: McNeil (1997).

NOTE: See Survey of Income and Program Participation inclusion criteria in Appendix A.

Figure 2.2—Percent of U.S. Adult Women with Disabilities, by Race and Severity



RANDWP139-2.3

SOURCE: 2000 U.S. Census.

NOTE: See Census Data inclusion criteria in Appendix A.

Figure 2.3—Percent of Women in Allegheny County with Disabilities, by Race

Twenty-six percent of women with disabilities, most notably those who are Native-American, live in rural areas where unemployment rates are higher than in other areas and where the annual incomes of women with

disabilities are lower on average than the incomes of women without disabilities (Szalda-Petree, Seekens, and Innes, 1999). Inaccessible public transportation and decreased access to specialty care centers compound the health care challenges facing this special group of women (Spas and Seekens, 1998).

Special Health Care Needs of Women with Disabilities

According to a national survey conducted by the Center for Research on Women with Disabilities at the Baylor College of Medicine (Nosek et al., 1997), women and people overall with disabilities consume a larger share of health care services than the general population. Women with physical disabilities are more likely to have used both primary care providers and specialists within a one-year period than women without disabilities. Significantly, during the 12 months preceding the national survey, more women with disabilities also used public health clinics, rehabilitation hospitals, and emergency rooms (Nosek et al., 1997). However, these women still have many unmet needs for care.

Like all women, those with disabilities require routine preventive care, including regular medical and gynecological checkups, mammograms, and reproductive care. Although these women may be more likely to visit a physician for general health care concerns, their disabilities may result in underutilization of many routine preventive gynecological services (Nosek and Howland, 1997). Many women with disabilities have difficulty receiving mammograms and gynecological examinations due to limited accessibility and problems with being properly positioned for an exam because of limitations with the examining table and equipment. As a result, women with disabilities are significantly less likely to receive pelvic exams on a regular basis, and women with severe functional limitations are even less likely to receive regular pelvic exams (Kirschner et al., 1998). In addition, women with disabilities may need more specialized counseling on contraception and sexuality than other women, making it more likely that the counseling they receive may be inadequate (Beckmann et al., 1989). Overall, women with disabilities have lower rates of preventive care services than women without disabilities.

In addition to their need for specialized preventive gynecological care, women with disabilities often have complex health needs that require care from at least one clinical specialist, and many may need care from multiple specialists and social service providers who are knowledgeable

about their needs (Ziring, 1988). These needs include but are not limited to the following:

- Specialized treatment for secondary conditions (e.g., joint pain, bowel and bladder dysfunction, and sexual dysfunction) resulting from their disability or other common co-morbid illnesses, such as osteoporosis, cardiovascular disease, urinary tract infections, and pressure ulcers (Coyle, 2000; Turk, 1997; Nosek, 1996).
- Prescription medications, including experimental drugs and orphan drugs that are not widely available. *Experimental drugs* include those currently undergoing trials to test their efficacy and safety, such as rolipram for multiple sclerosis. *Orphan drugs*, such as abetimus for kidney complications from lupus, can be experimental or approved by the Food and Drug Administration, but companies are able to receive special governmental benefits to further their development.
- Maintenance physical therapy, including during pregnancy.
- Special transportation services or assistance in getting to medical appointments.
- Mental health care for behavioral conditions (e.g., depression and/or emotional or sexual abuse from caregivers) (Fuhrer et al., 1993; Young et al., 1997).
- Educational support, durable medical equipment or other assistive devices, and special adaptations of the home environment and/or in-home care to maximize the capacity for independent living.

Not unlike the needs of other people with chronic conditions, the complex health care needs of women with disabilities are ongoing, and the mix and intensity of those needs may change over time. Women who develop disabilities during adulthood may be faced with having to find a new provider who is sensitive to their specific health care needs and new challenges in employment that may affect their existing health care coverage. In addition, at various stages of their life spans, women with disabilities may have different needs requiring specialized care. For example, pregnancy may result in added stress on a woman's body, such as back pain, that may further restrict mobility (Kristiansson, Scardsudd, and von Schoultz, 1996) and require additional physical therapy.

As a woman ages, she may have further unique needs. Disability rates increase with age, and the disabling condition itself may progress, resulting in ever more complex secondary conditions requiring special

interventions. Therefore, even women who have lived with disabilities throughout their lives require more specialized health care as they begin to age.

For all the reasons just stated, to ensure the best possible outcomes, women with disabilities require coordinated and continuous care including active follow-up, proper equipment, and adequately trained health care practitioners and other service providers. Effective models for providing such chronic care do exist, and they may be applicable to this population.³

Non-Financial Barriers to Health Care

Women with disabilities often face non-financial barriers that can deter them from accessing the care they should have even if financing is readily available. As discussed in the next chapter, financial barriers can further deter access, and standard financing mechanisms rarely cover the added services that women with disabilities need to overcome non-financial barriers to accessing care.

Physical barriers are a major category of non-financial barriers. Physicians' offices and hospitals still have physical barriers despite the requirements of the Americans with Disabilities Act. For example, Kaiser Permanente in Oakland, California, recently settled a class-action lawsuit filed specifically because of lack of access within its facilities for people with disabilities (Kaiser Permanente California News Bureau, 2001).

Women who were interviewed for this study cited physical barriers within physicians' offices and hospitals as being particularly challenging. For example, many facilities do not have the type of specialized examination equipment (e.g., Welner tables and specially designed mammography chairs) that women with disabilities require for less painful and more accurate examinations. In a national survey of women with physical disabilities conducted by the Center for Research on Women with Disabilities, difficulties related to positioning their bodies on an examination table and during mammography exams were cited as the most common reasons for women with disabilities deferring routine preventive exams (Nosek et al., 1997). Lack of support staff to aid in patient transfer and inadequate transportation and support services in

³See Improving Chronic Illness Care (n.d.).

order to keep health care appointments with specialists and/or physicians of choice were also cited as common problems by the women interviewed for this study.

Women who were interviewed for this study also expressed difficulty in finding physicians who understand all of their health care needs, including their needs for general preventive care and the special needs related to their particular disability. Clearly, a number of physicians, technicians, and other health care employees are sensitive to the issues of those with disabilities and are comfortable with women who may have difficulty in communicating. Nevertheless, women with disabilities continue to report that some physicians deny them service if they cannot, for example, mount an examination table without assistance, or even refuse to see them solely because of their disability, both of which cases are in violation of the Americans with Disabilities Act.

3. How Is Health Care for Women with Disabilities Covered?

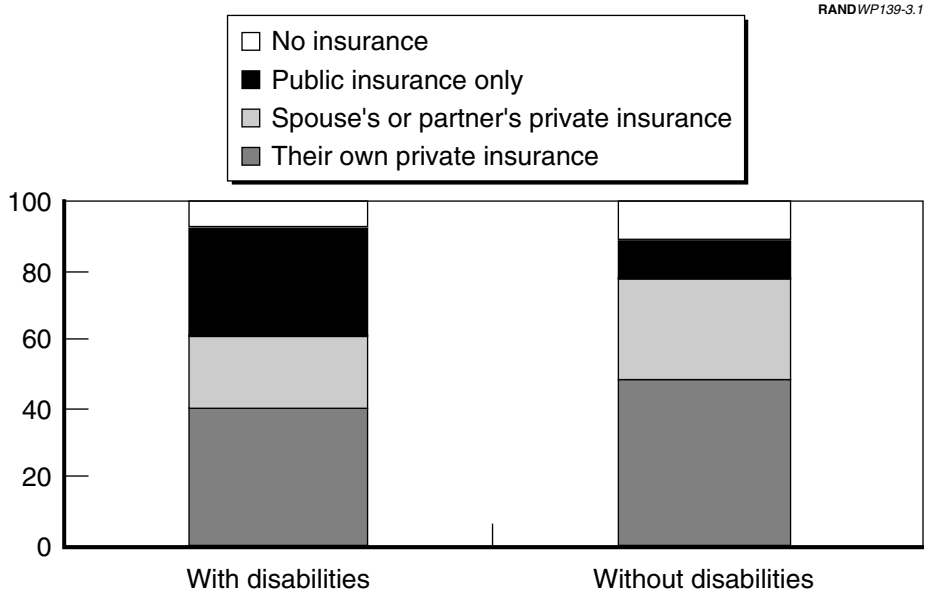
Health care for women with disabilities and payment for that care are provided through a number of means—private and public insurance coverage, managed care plans, and specialized health care programs.

Health Insurance Coverage

Among women who receive care, women with disabilities are somewhat more likely to have insurance than women without disabilities (see Figure 3.1). Fewer women with disabilities than women without disabilities have private insurance because they are less likely to be employed (see Figure 3.2) and therefore are less likely to be eligible for private insurance through the workplace. About 20 percent of women with disabilities have part-time jobs, but often those jobs do not provide private insurance coverage (Altman, 2001). However, as Figure 3.1 illustrates, public insurance more than makes up the difference between the percentage of women with disabilities who have private insurance coverage and women without disabilities who have private coverage.

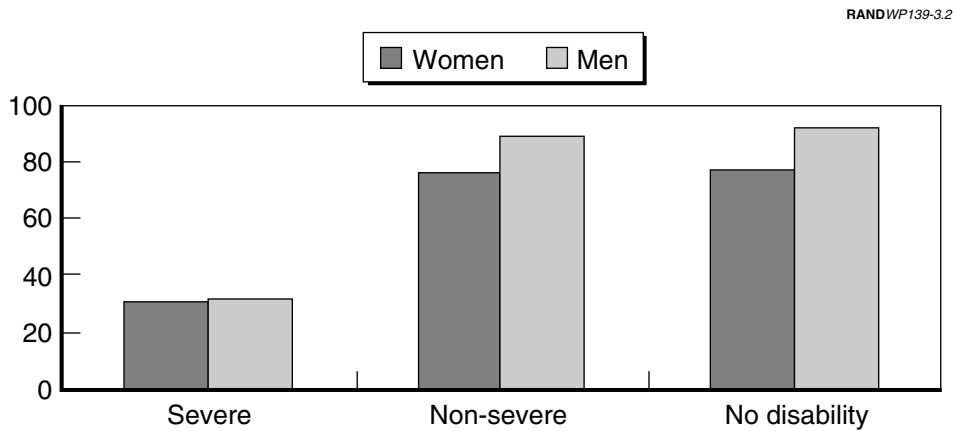
Women with disabilities are also less likely to be married and have insurance from a spouse. Only 50 percent of women with disabilities are married versus 64 percent of women without disabilities (Jans and Stoddard, 1999). Given that marriage usually is linked with greater rates of insurance for women in general, the predominantly single status of women with disabilities represents a significant cause of underinsurance (Nosek, Grabois, and Howland, 2002).

As expected, women with disabilities who do not have insurance have greater difficulty receiving appropriate health care than those with coverage. Data from the National Health Interview Survey Disability Supplement (see Appendix A) reveal that almost 18 percent of working-age adults with disabilities and who are without insurance report delaying care because of the cost of that care (Meyer and Zeller, 1999). However, even women *with* insurance face significant challenges in financing some of their care.



SOURCE: Altman and Taylor (2001).
 NOTE: Includes all women age 18 and over with any limitations. Uses Medical Expenditure Panel Survey data (see Appendix A).

Figure 3.1—Types of Insurance Coverage for Women with and Without Disabilities



SOURCE: McNeil (2000).
 NOTE: Uses the 1997 Survey of Income and Program Participation (see Appendix A).

Figure 3.2—Percent of U.S. Men and Women Employed, by Level of Disability

Medicare and Medicaid

Women with disabilities obtain public insurance primarily through two programs: Social Security Disability Insurance (SSDI)/Medicare¹ and Supplemental Security Income (SSI)/Medicaid.² SSDI benefits are paid to any person who meets the Social Security definition of disability and who has worked and contributed to Social Security or who has been a dependent of someone who has worked and contributed to Social Security.³ In March 2003, monthly benefits under the SSDI program averaged \$836 for disabled workers (Social Security Administration, 2003a). More than five million people under the age of 65 have Medicare through SSDI, and approximately 41 percent of those people are women (Health Care Financing Administration, 2000a).⁴

There is a two-year waiting period for Medicare coverage that begins after SSDI is received (SSDI takes approximately five months to receive after initial eligibility has been established). According to interviews conducted for this study, the resulting lapses in coverage present a

¹Medicare is a federally administered program available for persons over age 65, those with end-stage renal disease, and those with disabilities through the SSDI insurance program. It is divided into two parts. Part A includes inpatient and hospice care, limited-skilled nursing facility care, and home health care coverage. Part B includes outpatient care and physician office visits as well as certain diagnostic tests and procedures, limited ambulance transportation, home health care supplies, and durable medical equipment. This paper focuses on Medicare as it relates to coverage for people with disabilities. For a more detailed description of coverage features and limitations of Medicare, refer to www.cmms.gov.

²Medicaid is a joint federal and state administered program. Although states have some discretion in determining levels of eligibility, in general Medicaid includes, but is not limited to, coverage for low-income families with children meeting some of a state's low-income assistance program requirements, children of Medicaid-eligible pregnant women, women and children younger than age 19 (starting in 2002) who are at or below 133 percent of the federal poverty level. However, state thresholds can vary to include a higher percentage of the federal poverty level, recipients of foster or adoption care, low-income Medicare beneficiaries, and persons with disabilities under the SSI program. In addition, states can include several other categories of coverage under Medicaid. This paper focuses on Medicaid as it relates to coverage for people with disabilities. For a more detailed description of the coverage features and limitations of Medicaid, see www.cmms.gov.

³The Social Security definition of disability includes any person who cannot work as he or she had previously done and who cannot make adjustments to his or her work due to a medical condition. The disability must be expected to last at least one year or to result in death. For more information, see the Social Security Administration Web site at www.ssa.gov.

⁴Average per capita monthly expenditures for physical health services in the SSI population in Pennsylvania with Medicaid coverage only was \$429 in 2001 (Pennsylvania Department of Public Welfare, 2002b).

significant financial challenge for women with disabilities. Interim solutions, such as coverage through COBRA (which allows previously employed women to elect to continue to pay for private insurance) or private purchase of insurance, are frequently not an option due to the limited income provided through SSDI.

Women with disabilities can also receive coverage through Medicaid under SSI, which provides benefits to individuals who are poor and disabled whether or not they have worked in the past. In most states, those who are receiving SSI payments are automatically enrolled in Medicaid. To receive such coverage, a woman must meet the Social Security Administration's (SSA) definition of disability and fall below minimum income requirements. Eligibility for SSI is not dependent on prior work status and does not require a waiting period. In Pennsylvania, the monthly SSI payment in 2003 is \$579 for an individual living independently (Social Security Administration, 2003b). About 6.6 million individuals with disabilities receive Medicaid through the SSI program, totaling about one-fourth of all Medicaid beneficiaries. Expenditures for this group, however, are about 44 percent of total Medicaid expenditures.

These public insurance programs, especially Medicare, that cover many women with disabilities do not include some services these women need. For example, Medicare does not cover outpatient pharmaceuticals and pays for attendant care services and equipment only under limited conditions. The mean expenditure for prescription drug coverage for people under age 65 who are covered by Medicare was \$1,241 in 1998. Given these high expenditures, Medicare recipients must supplement their drug coverage, in particular, through a variety of mechanisms. The most common mechanism to supplement drug coverage that is used by people with disabilities is Medicaid, which covers many of the services not covered by Medicare (Health Care Financing Administration, 2000b). This coverage includes state-sponsored pharmaceutical assistance, such as the Qualified Medicare Beneficiary and Specified Medicare Beneficiary Plus programs.

Thirty-six percent of individuals with disabilities have supplementary Medicaid coverage, but relatively few of them obtain supplemental coverage through employer plans or Medigap plans.⁵ In fact, very few states offer guaranteed access to Medigap plans for the under-65

⁵Medigap plans are specifically designed to supplement Medicare coverage.

Medicare population with disabilities. Overall, this population is more likely to be part of a minority group, poor, have serious health conditions, and experience problems accessing care than others in the elderly Medicare population (The Henry J. Kaiser Foundation, 1999). Lack of access to supplemental employer and Medigap coverage significantly increases out-of-pocket expenditures for this population; people lacking supplemental pharmaceutical coverage had a mean out-of-pocket expenditure of \$499 in 1998 (Briesacher et al., 2002).

In Pennsylvania, a Medicaid-funded waiver program covers attendant care services for eligible individuals with incomes up to 300 percent of the SSI eligibility limit (\$1,656 as of January 2003) and no more than \$2,000 in additional resources (Pennsylvania Department of Public Welfare, 2002b). Others may receive funding through Act 150, a state-funded program that does not have the income and resource requirements of the Medicaid waiver, but may require an income-based copayment. Both Medicaid waiver and Act 150 funds are allocated to public and private agencies throughout Pennsylvania that help foster independent living in the home setting for persons with disabilities. Services that these agencies provide include in-home care and assistance with daily activities such as bathing, dressing, shopping, and travel. These services differ from traditional homemaker services in several ways—they are available 24 hours a day; they are longer term; and they are controlled by the recipient, who makes decisions about hiring and service usage. To qualify, an individual must be between the ages of 18 and 59, be mentally alert, have a physical disability expected to last at least 12 months, and be eligible for nursing facility services. The average wait for eligibility determination is approximately two months.

Other Public Insurance

In addition to the more traditional ways of obtaining Medicare and Medicaid, some women with disabilities can pay for their health care needs through The Ticket to Work Initiative. *The Ticket to Work and Work Incentives Improvement Act (TWWIA)*, passed in 1999, allows people with disabilities to retain their public insurance status while they are working. This program, administered by the SSA, allows individuals with SSDI to retain Medicare for up to eight-and-a-half years and individuals with SSI to retain Medicaid coverage while working. Pennsylvania initiated the TWWIA in January 2002 as the Medical Assistance for Workers with Disabilities Program. To be eligible for this program, an enrollee's income

must be less than 250 percent of poverty level and his or her countable resources worth less than \$10,000. Enrollees must be employed and also meet the SSA functional definition of disability. Those who are eligible must contribute 5 percent of their income for medical assistance.

Available data through December 2002 showed that 1,325 people were enrolled in the program in Pennsylvania (Webster, 2002).

Private Philanthropy

Many of the women we interviewed rely on philanthropic organizations to fill the gaps in their insurance coverage, including covering the costs for special equipment or home modifications. For many women, this source of funding is more accessible than public funding and enables them to circumvent the bureaucratic red tape of the insurance system. In Pittsburgh, for example, the Multiple Sclerosis Society offers a financial assistance program for items not covered by insurance, such as durable medical equipment, incontinence supplies, equipment repairs, and rolling safety walkers (Mageras, 2001). We were unable to find data indicating how many women rely on private philanthropy or what fraction of their health care costs are financed this way.

Managed Care

Increasingly, more women with disabilities are enrolled in managed care plans, primarily health maintenance organizations (HMOs). HMOs in particular limit enrollees' choices of health care providers and exercise some control over access, especially to referral care. Approximately 40 percent of men and women with less severe disabilities and 28 percent with severe disabilities are enrolled in HMOs. These rates are well below the rates for the general non-aged (under age 65) population because HMOs enroll relatively few Medicare participants.⁶ Managed care has

⁶Definitions of degrees of severity vary with the data source. According to Jans and Stoddard (1999), the Survey of Income and Program Participation (SIPP) defines an individual with a severe disability as having one of the following conditions: unable to perform at least one functional activity; needing personal assistance with an activity of daily living or instrumental activity of daily living; uses a wheelchair or other walking assistance device (such as a cane, crutches, or walker) on a long-term basis; has a developmental disability or Alzheimer's disease; is unable to do housework; or who receives federal disability benefits or is between the ages of 16 and 67 but is unable to work. SIPP defines those with a non-severe (or less severe) disability as all other individuals with a disability that does meet the criteria of a severe disability.

played an increasingly larger role for those with disabilities covered by Medicaid. However, less than 10 percent of the Medicare population with disabilities is enrolled in managed care programs, which is a lower percentage than the percentage of elderly Medicare enrollees in these plans (Murray and Eppig, 2002b). One of the more attractive aspects of the managed care option is coverage of the cost of pharmaceuticals, although many of these programs have recently scaled back their drug benefits (Murray and Eppig, 2002a). The role of managed care would expand quickly for women with disabilities if those plans that scaled back their drug benefits came up with a new pharmaceutical benefit.

As of December 1998, more than 1.6 million people with disabilities were enrolled in Medicaid managed care programs nationwide (most of them HMOs), or about 27 percent of all of those people with disabilities who receive coverage through Medicaid. The majority of those enrollees were in mainstream Medicaid programs that are not designed primarily for people with disabilities (Regenstein, Schroer, and Myer, 2000). However, 11 Medicaid programs specifically target the elderly and/or people with disabilities (Rawlings-Sekunda, 2002). Some states, such as Massachusetts, Minnesota, and Wisconsin, have special programs designed specifically for people with disabilities, but these are not statewide programs (see Appendix B).

Pennsylvania's Medicaid Managed Care Program

In Pennsylvania, the Medicaid managed care program is HealthChoices, an HMO. HealthChoices will be implemented statewide by 2006. Initially, only residents of eastern Pennsylvania qualified for the program, but it has been expanded to include other areas of the state, including the area surrounding Pittsburgh. HealthChoices enrollees in southwest Pennsylvania have three options: the University of Pittsburgh Medical Center (UPMC)/Best Health Plan, the Three Rivers/MedPLUS+ Health Plan, and the Gateway Health Plan (Regenstein and Schroer, 1998; Pennsylvania Department of Public Welfare, 2002b).

HealthChoices Southwest (the regional HealthChoices program of southwestern Pennsylvania) estimates that it will cover almost 500,000 member months in 2003 for SSI recipients (approximately 41,666 people with disabilities, 85 percent of whom are in Allegheny County). This number represents one-third of the Medicaid population in the region. In comparing the numbers of enrollees for each of the three HealthChoices

options (see Figure 3.3), the UPMC/Best Health Plan had the largest percentage (38 percent) of people enrolled in HealthChoices based on SSI eligibility.

The state requires all programs under HealthChoices to establish Special Needs Units with special case management and disease management programs. Eligible patients may either contact the plan directly to receive special needs services or they may be identified as individuals in need of those services through member services or provider referrals. Physical disabilities are not a separate category specifically targeted for special case management, although many people who use this option do have disabilities as well as other chronic conditions.

Under HealthChoices, Pennsylvania also offers a special service through which an individual in the southwest region of the state with a disabling condition may qualify to choose a specialist as his or her primary care provider. Certain services, such as durable medical equipment and home health services, are available but require pre-approval (Pennsylvania Department of Public Welfare, 2000). Pennsylvania also requires that all managed care plans must be accessible for persons with physical and sensory disabilities (*The Pennsylvania Code*, 2002). An example would be the availability of providers who can communicate with people with sensory disabilities.

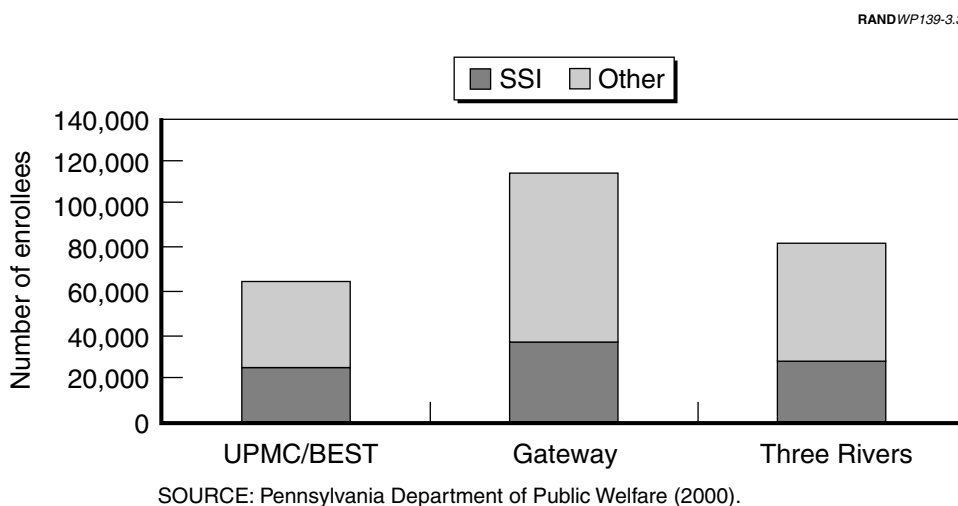


Figure 3.3—Number of HealthChoices Enrollees by HealthChoices Option, Southwest Pennsylvania, as of December 1999

Adequacy of Care for Women with Disabilities in Managed Care Programs

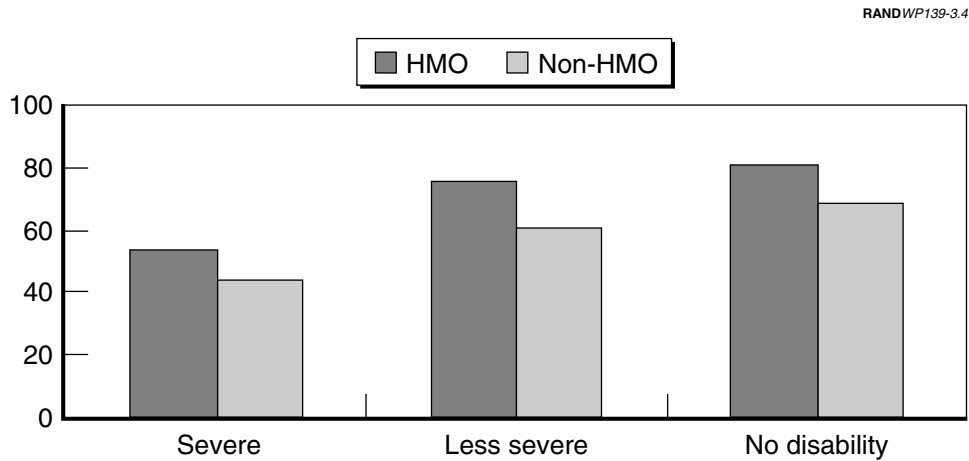
As a group, people in private and Medicare managed care programs are more likely to have a usual source of care. This group is also less likely to have delayed seeking care due to cost (Burden et al., 1999).

Overall, managed care has been fairly effective in reducing expenditures for care for persons with disabilities (Ireys, Thornton, and McKay, 2002). One study of persons with disabilities who had enrolled in a voluntary Medicaid managed care program in Ohio found that expenditures and utilization decreased substantially after enrollment. Inpatient care, outpatient services, such as emergency department visits, and prescription medications had the largest decreases in costs (Cebul et al., 2000).

Although a fair amount of information is available that supports the finding that managed care has been successful in reducing expenditures, less information is available on how managed care affects the quality of care for women with disabilities. Overall, access and quality of care appear to vary across plans based on the type of care required.

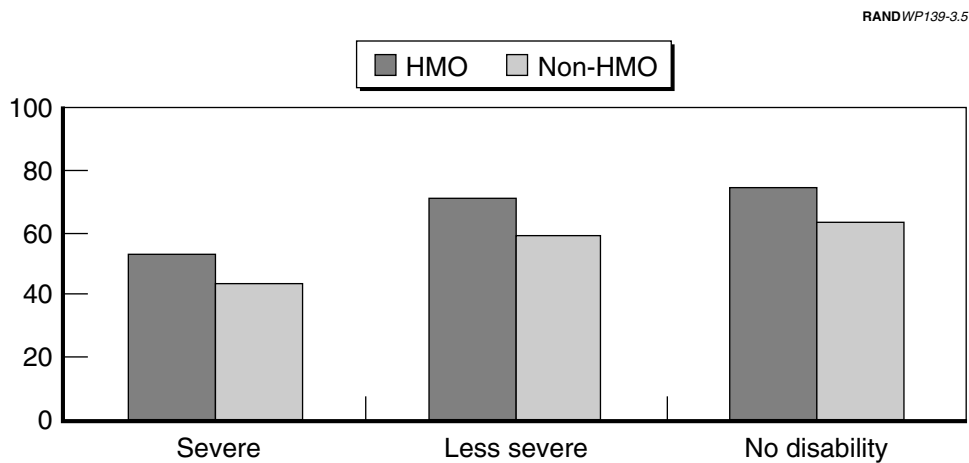
Preventive health services for women with disabilities in managed care programs appear to be better than preventive health services in non-HMO plans. More women in HMOs report having had a pap smear and/or mammogram in the previous two years than women in non-HMO health plans (see Figures 3.4 and 3.5). Similarly, women enrolled in Medicare managed care programs were more likely to receive these two basic preventive care measures (Beatty, Jones, and Dhont, 2001).

Scant data are available on the ability of managed care plans to provide for the special health care needs of women with disabilities, including provision of special medications, physical therapy, and referrals to specialists with the requisite expertise or equipment for addressing primary health concerns. Although many managed care plans include prescription coverage for standard medications, special medications are less likely to be covered. In a 1996 study of multiple sclerosis patients, managed care plan physicians were less likely than those in fee-for-service plans to recommend interferon, a relatively experimental and expensive drug that is nevertheless recommended as being efficacious (Nosek, Grabois, and Howland, 2002).



SOURCE: Beatty, Jones, and Dhont (2001).

Figure 3.4—Percent of Women Reporting Having Had a Pap Smear in the Previous Two Years, by Type of Insurance Coverage and Level of Disability



SOURCE: Beatty, Jones, and Dhont (2001).

Figure 3.5—Percent of Women Reporting Having Had a Mammogram in the Previous Two Years, by Type of Insurance Coverage and Level of Disability

In general, the few studies that have been done on managed care plans providing for the special health care needs of women with disabilities have shown wide variations in satisfaction with those plans, particularly satisfaction with coverage of special health care needs and provider choice. Persons with disabilities in Medicare managed care plans are more likely to report having had difficulties with access to service and

have lower levels of satisfaction with health plans overall as well as for specific subcategories of plan performance such as accessibility and provider rating than other Medicare managed care enrollees (Cox, Langwell, and Eckert, 2001).

According to a survey conducted by The National Rehabilitation Hospital Center for Health and Disability Research, more people with cerebral palsy, multiple sclerosis, and spinal cord injury in fee-for-service plans believe they are able to obtain the doctor they want than those in managed care plans. In addition, people in fee-for-service plans report that their doctor is more likely to be knowledgeable about their specific disability and more likely to have physically accessible facilities (National Rehabilitation Hospital Center for Health and Disability Research, 2001).

In our interviews with women in Pittsburgh with disabilities, many of those women expressed concerns about managed care programs, including limitations in provider choice, difficulty in accessing specialty care when needed, and lack of information about the various options for care. These concerns were greatest for women with previous long-standing relationships with their providers. Other studies have shown that opinions on managed care programs are mixed, with some studies finding comparable levels of satisfaction among people enrolled in managed care versus people enrolled in fee-for-service plans (O'Day et al., 2001).

Specialized Health Care Programs for Women with Disabilities

A number of programs specifically targeting people with disabilities have arisen recently in recognition of the important role that coordinated care programs have had in providing health care to this population. For purposes of this study, we profiled programs that are funded publicly, funded privately, and funded through a mix of traditional insurance reimbursement and supplemental private coverage. These programs were identified through our research and interviews with experts in the field of disability research. Most of the programs, with the exception of programs in Boston and Wisconsin, have not been formally evaluated in terms of quality or cost. A more detailed description of these programs is provided in Appendix B.

Public Programs

Three of the programs profiled in Appendix D—Boston Community Medical Group/Community Medical Alliance, Wisconsin I-Care, and Minnesota AXIS—are funded as Medicaid managed care programs with a unique focus on individuals with disabilities, but they do not specifically target women. All three of these state-funded programs are based on private-public partnerships of one form or another. Each program conducts an initial needs assessment that allows coordination of care specific to the needs of an individual member. Because these programs are part of the Medicaid system, the pharmaceutical benefits available through Medicaid continue to be available to enrolled members.

The oldest of the three programs, the Boston Community Medical Alliance, which later merged with Boston's Neighborhood Health Program, has data illustrating recent cost savings as compared with traditional Medicaid fee-for-service plans. Rates of hospitalization from complications such as decubitus (pressure) ulcers, for example, were found to have decreased in the capitated program as compared with the traditional fee-for-service Medicaid program (Master et al., 1996). A key element of this program's success is its integration of health services and the close involvement of a nurse practitioner who makes home visits as a part of routine care.

Hospital-Based Programs

Three hospital-based programs profiled in Appendix B are the Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago, the Comprehensive Healthcare Center for Women with Physical Disabilities at Magee-Womens Hospital of the University of Pittsburgh Medical Center Health System, and the SSM Rehabilitation Institute Women's Outpatient Wellness Center in St. Louis, Missouri. The latter two programs are both less than two years old as of this writing. Although the Magee program was fortunate to have initial start-up funding through the FISA Foundation and the Eden Hall Foundation, a common goal of these hospital-based programs is that they are funded, as other hospital departments are, through traditional insurance-based reimbursements.

Because women with disabilities often have needs that require extended office visit times, it is unclear if the funding available to these specialized

programs can cover all of the costs involved in the care of these women, including extra physician time. However, because these programs exist as part of large hospitals, their primary goal is to establish high-quality care as part of the larger institutional mission. Each program provides a mix of primary gynecologic care and social services and women's health-screening services, such as pap smears and mammograms. The programs are able to provide specialized care in one central location and expedited referrals to specialists if needed.

A fourth program, the Alameda Breast Health Access Center, is housed at the Alta Bates Summit Rehabilitation Center in Berkeley, California. This program specifically targets breast health care by providing free breast exams and accessible mammogram services for women with disabilities. The program is funded through foundations, but mammogram services, when covered, are billed through insurers.

Other Programs

Two of the programs profiled in Appendix D are not housed at hospitals but have affiliations with local hospitals that can provide specialty care if needed. Those programs are ACCESS at the Anixter Center in Chicago (affiliated with Schwab Rehabilitation Hospital) and the National Multiple Sclerosis (MS) Society Allegheny District Chapter Home-Based Health Maintenance Program for Women with Multiple Sclerosis (affiliated with the Pittsburgh-based Magee-Womens Hospital program).

ACCESS is financed through insurance reimbursement, but the program also provides care for people without coverage through a grant providing pharmaceutical funding and a sliding-scale payment option. The MS Society program is funded through grants from the Komen Pittsburgh Race for the Cure and the FISA Foundation. A key element of these two programs is provision of care in the home of the person with disabilities, which eliminates the transportation barriers that women with disabilities might otherwise face.

Lowering costs may be difficult in specialized programs such as those highlighted in this section. New programs have high start-up costs, such as the cost of purchasing equipment specifically designed for women with disabilities, including specially designed scales for wheelchair patients and accessible examination tables. In addition, many of these programs provide care to an underserved population with needs that have been largely overlooked in the past. Expanding access to such a

population will result in initially high costs. However, it is conceivable that coordinated care programs may lower health care costs in the long run. For example, over time, the provision of more effective outpatient preventive care could reduce costs associated with avoidable acute care, as was the case with the public Boston Community Medical Alliance Program discussed earlier, which lowered costs by reducing complications, such as pressure ulcers, thus avoiding hospitalizations.

Finally, most people with disabilities would qualify for special disease-management programs developed by many private managed care plans for patients with chronic medical needs. As part of such programs, the two largest private health plans in Allegheny County—UPMC and Highmark—offer case management that coordinates services for individuals with special needs, including disabilities. At Highmark, for example, individuals can receive special case management if they qualify through certain screening diagnoses (such as diagnoses for AIDS, major trauma, heart failure, or end-stage renal disease), through referrals from primary medical providers, and through member self-referral. In many instances, these case management programs provide special benefits, such as transportation assistance, some durable medical equipment coverage, and home health care (Feterroff, 2002; Docimo, 2002).

4. What Are the Financial Barriers to Health Care for Women with Disabilities?

Barriers to preventive health care services for women with disabilities may be caused by the financing mechanisms paying for that care. Because women with disabilities have special health care needs, it is not surprising that they have overall higher levels of medical expenditures. Women with disabilities between the ages of 18 and 44 have almost 2.5 times the yearly medical expenditures as women without disabilities, and women with disabilities between the ages of 45 and 64 have more than three times the average yearly medical expenditures as women without disabilities (Jans and Stoddard, 1999). Clearly, having an adequate way to finance health care is extremely important to these women.

Financial Barriers Facing Health Care Purchasers and Health Plans

The ultimate payer for health care is usually an employer or a government agency, either through contracts with health plans or by directly paying providers to cover the charges they bill. Women with disabilities incur high costs associated with their care, but payers often have little discretion in covering them. Employers cannot discriminate on the grounds of health in offering medical benefits, and governments must cover everyone who meets the criteria for eligibility.

In a study of two firms' employees, people with disabilities were found to be more likely to choose indemnity (fee-for-service) plans than were other employees. In general, those choosing fee-for-service plans had higher expenditures than those choosing managed care plans because the fee-for-service group had worse health than the managed care group. In other words, the fee-for-service plans experienced *adverse selection* (i.e., they enroll fewer healthy individuals than they would have without the program) among people with disabilities. Unless employers appropriately adjust the premiums they pay to various health plans to reflect the differences in the health care needs of their enrollees, the plans

that employees with disabilities find most attractive will suffer financial losses (Ozminkowski et al., 2000).

Unless employer or government payers are willing to pay more for better health care for the women with disabilities whom they cover, coordinated care programs for these women must offset additional facility and staffing costs with savings resulting from more appropriate care. Otherwise, a health plan that invests in a tailored program may experience cost increases if more women with disabilities enroll in the plan to take advantage of the coordinated care program. The health plan would see its costs rise overall because of adverse selection. If women with disabilities do not constitute a large percentage of a health plan's enrolled population, it may be more efficient for the plan to develop a single case management system targeting all chronic disease patients rather than developing individualized programs.

The quality and cost outcomes of general versus individualized programs are unknown. Based on our interviews for this study, purchasers and health plans do not appear to be tracking access or quality for people with the most severe disabilities, presumably because the group is relatively small.

Currently, financial support for specialized programs targeting people with disabilities has come from a few state Medicaid programs and, secondarily, private philanthropy. Because Medicaid serves a relatively high-cost population, including a disproportionate share of women with disabilities, states may have more incentives to seek lower-cost and innovative alternatives to improve quality. Little information exists about the costs and health outcomes of state programs tailored to women with disabilities. Other payers, particularly those in the private sector, may benefit from additional data from the state programs about the needs of this population and whether coordinated programs pay for themselves in the long run.

With the exception of a few states, such as Minnesota and Wisconsin, which fund specific programs targeting persons with disabilities as part of their Medicaid services, payers do not distinguish between women with disabilities and other women when they design benefits. This lack of differentiation between women with and without disabilities has consequences both for women with disabilities and for the providers who treat them.

State Medicaid programs, and Medicare, pay a *capitated payment* to individual managed care plans, which involves a single sum for all the care a patient receives over a set period of time. Programs use varying approaches to help adjust payments for the higher costs associated with caring for women with disabilities. These include risk-adjustment systems that factor in higher costs in determining the payment these programs receive for each individual with a disability. The term *carve-outs* refers to the practice of managed care plans contracting out a segment of care to a traditional fee-for-service provider. Many states contract out some services, such as behavioral health and pharmaceutical care, payments for which are made outside of the capitation fee. Other states use risk-adjustment systems in which the amount paid per beneficiary is adjusted based on either prior diagnosis or average expenditures. According to a recent review of state Medicaid managed care programs, 31 of 36 programs use some type of carve-out process for persons with disabilities (Regenstein and Schroer, 1998).

Thirty-one states also adjust their rates for Medicaid managed care recipients who are Supplemental Security Income eligible. Some states also use other methods to adjust payments, such as prior average resource use and diagnostic-related groups. As of 1998, only two states, Nebraska and Tennessee, had plans in place to retrospectively reimburse managed care plans for the higher costs associated with having a larger number of enrollees with disabilities—the so-called adverse selection mentioned earlier (Regenstein and Schroer, 1998). At that time, 19 states did not risk-adjust Medicaid capitation rates; 12 states and Medicare used a health-based risk-adjustment system. About half of the states simply limited the total financial loss that health plans could suffer in their Medicaid contracts (Palsbo and Post, 2001). The states absorb losses that exceed these limits.

Some states use the recently developed Chronic Illness and Disability Payment System (Kronick et al., 2000) to adjust managed care payments for the higher costs of care associated with people with disabilities. Unless this kind of payment system is more widely adopted, the number of specialized programs that meet the needs of women with disabilities is likely to remain small.

Medicare adjusts payments to managed care plans for a core set of conditions, including disabilities, which may be more costly to Medicare managed care plans. Capitation rates are currently calculated based on whether diagnosed conditions are identified during a prior inpatient

hospitalization. Beginning January 2004, Medicare will also adjust rates based on diagnoses made in the outpatient setting. As a result of this phased-in rate adjustment, capitation rates for a woman with a disability in a Medicare managed care plan will not differ based on whether the condition was identified in the inpatient or outpatient environment. By not differentiating between settings, physicians will not have incentives to capture the higher payment rate by hospitalizing patients for conditions that could otherwise be treated in ambulatory settings (Health Care Financing Administration, 2000b). Through this change, overall higher costs associated with care may be better covered.

Some advocates in the field of disability policy are concerned that carve-outs may be more likely to encourage disparate treatment if people with disabilities are treated separately from the rest of the population. Risk adjustment helps eliminate this problem but creates the added challenge of appropriately considering the costs associated for care for people with disabilities. Depending on the criteria used to make these adjustments, such systems will have varying success in predicting costs (Batavia and DeJong, 2001).

Financial Barriers Facing Women with Disabilities

Many women with disabilities face significant financial barriers to accessing the care they require. Compared with the general population, women with disabilities are more likely to have some type of insurance. However, as discussed previously, there are a number of important limitations in insurance coverage for these women. Such limitations include delays in obtaining Medicare coverage, delays in obtaining in-home attendant care, lack of affordability of unskilled care, and inadequate coverage for essential services, such as prescription medications, physical therapy during pregnancy and maintenance therapy, durable medical equipment, and services that facilitate the back-to-work transition.

Poor information about how to maneuver through the health care payment process is another significant barrier identified by the women we interviewed for this study. Although many payers have grievance options as well as means of petitioning for specialized care, these options are not always well publicized and often take a great deal of time and effort to understand. Women who are less familiar with the grievance

system or who are less able to expend the effort to learn about the system may not know how to appeal for these special benefits.

It may be that the most significant limitation in insurance coverage results from reimbursement systems that ignore the special requirements associated with providing appropriate care for women with disabilities. Although the benefits in greater comfort and health accruing to women who have access to knowledgeable providers with the proper facilities and staff have not been carefully measured, those benefits are undoubtedly sizable. The absence of these benefits can be attributed to the failure of reimbursement methods to take into account the special needs of women with disabilities.

Financial Barriers Facing Providers

Inadequate reimbursement is a major disincentive facing providers of health care for women with disabilities, and inadequate reimbursement pertains to nearly every aspect of providing appropriate services for this population.

Most health insurers employ fee-for-service payments to reimburse providers for services. For example, standard payments are made for a gynecologic examination and for each associated diagnostic test (e.g., a pap smear). Hospitals may receive a payment for each day of care or for each admission, with the payment level set according to the diagnosis or the type of care (e.g., intensive care). Fee-for-service reimbursements are usually made with the presumption that for any given service some patients will cost more and some will cost less than the fee-for-service payment allows, but that providers will be reimbursed adequately for all their patients.

However, under this system, providers who see a greater number of complex-care patients (with higher costs for the same services) will be underpaid overall, and providers who see patients needing more-straightforward care will be overpaid. For example, Medicare bases its payments on a Resource-Based Relative Value Scale that measures the average relative resource use for all patients who receive a particular clinical service. This system is intended to adjust for the complexity of a visit, but does not allow billing to be adjusted based on associated diagnoses, such as diagnoses for disabilities. Reimbursement rates are formulated based on resources expended on a visit for an "average patient," and therefore do not account for the additional time that may be

needed for a woman with a disability. For example, an otherwise non-complex gynecologic visit may take much longer to complete for a woman with a disability and may involve non-physician assistants to aid in transfer and examination support. These added costs are difficult to factor into routine billing. Further, many private health plans employ a simpler system that is less sensitive to differences among patients than is the Medicare system.

Alternatively, insurers may employ capitation payments made to providers. HMOs receive capitation payments for their enrollees (from payers such as Medicaid), and HMOs may, in turn, pay providers in the same way or make fee-for-service payments, usually with financial incentives for controlling costs. Like fee-for-service payments, capitation payments are designed to cover average costs and assume that providers will have a mix of patients, with some costing more and others costing less than the average amount. However, fee-for-service payments increase when the number of services provided increases, whereas capitation payments do not. As discussed previously, advanced capitation systems risk-adjust payments based on the patient's health-related characteristics (e.g., age, gender, chronic diseases) so that providers are not penalized for treating more complex patients. However, many programs do not have such systems in place.

As discussed earlier, primary care for women with disabilities is more costly than primary care for women without disabilities because it requires extended office time, specialized accessible medical equipment, or involvement by other nontraditional primary care providers (DeJong, 1997). Typical fee-for-service and capitation reimbursement methods do not cover these additional resources. In addition, physicians cannot bill for other related services often needed by these women, such as medical advice provided over the phone when transportation is not available.

Many physicians interviewed for this study have spent extended periods of time contesting managed care plans' reviews of their treatment decisions and coordinating equipment needs and/or arranging special services for their patients. The payments they received did not cover this added time. Consistent with medical ethics, physicians will see their share of women with disabilities, but they may prefer not to specialize in treating these women. Acquiring sufficient office space and specialized equipment (e.g., Welner exam tables, scales that accommodate wheelchairs), making appropriate office modifications, and maintaining adequate support staff to assist in exams is not economically feasible for

physicians if they have only a limited number of patients with disabilities. At the same time, the “limited number” of such patients may be due to the lack of these accessible features.

Reimbursement is even more inadequate for providers who specialize in caring for women with disabilities. These providers have the necessary equipment and staffing, and they build expertise in caring for this population. However, they cannot cover their higher costs from most insurance payments and few women with disabilities have the means to pay for even basic care themselves. Therefore, as shown by Appendix B, few programs are offered for women with disabilities, and most of those programs must rely on private philanthropy or subsidies from other activities in the same institution to supplement insurance payments.

There are some circumstances in which providers may find it economically advantageous to offer specialized preventive care for women with disabilities even though the payments do not cover their costs. For example, a hospital may want to offer this care as a loss leader if more women with disabilities are induced to choose the hospital for specialized outpatient or inpatient services that earn the hospital a “profit.” Alternatively, women without insurance might decrease their utilization of high-cost, uncompensated care (e.g., emergency or inpatient care). We are unaware of any evidence indicating whether preventive care for women with disabilities might be a loss leader. Because most of these women have insurance, it seems unlikely that savings in uncompensated care would be sufficient to cover the costs of a preventive-care program. Finally, any provider that accepts full financial responsibility for a patient’s care will invest in tailored preventive services if they prevent other, more costly types of care. As we discussed earlier, there is some evidence that appropriate preventive care can decrease the need for other types of care and, on net, save money. However, few providers bear the full financial risk of their patients’ care.

Women with disabilities face many challenges in paying for their medical care. The services they need for physical functioning (e.g., appropriate wheelchairs and transportation) are often not well covered by either private or public insurers, erecting a further barrier to care, particularly because these women are less able to supplement inadequate coverage given their comparatively low incomes. The financial barriers to care for women with disabilities also extend beyond the individual patient to disincentives that may exist among payers and providers. Removing the barriers to health care services for women with disabilities will require a

multifaceted strategy that includes financing the services these women need for optimal health and functioning and developing an efficient delivery system that is tailored to their needs.

5. Findings, Policy Recommendations, and Future Research Needs

Findings

Care for women with disabilities tends to be heavily weighted toward treating specific problems related to the disabilities those women have, often at the expense of ignoring the broader scope of their health needs as women. Those needs include prevention (especially as it relates to female-specific cancer screening and general medical screening), sexual and reproductive health, vulnerability to behavioral health problems and abuse, and unique daily living needs.

The health care financing system explicitly reimburses for specialty care for a disabling condition, but it ignores the added equipment and staffing needed to provide appropriate general health care. Therefore, even though women with disabilities use a greater amount of health care than do women without disabilities, they still have many unmet needs. Providing health care to meet these needs will be even more costly than it is now if more effective approaches to case management are not developed.

Although further research is needed to understand how best to finance health care for women with disabilities, some potentially useful financing strategies can be identified. It is important to recognize, however, that various approaches to financing health care may work for women with various levels and types of disability. Moreover, the cumulative effects of various financing arrangements on federal Medicare and Medicaid budgets must be carefully assessed to determine the best mix of coverage and services for women with disabilities.

Policy Recommendations

Based on our findings and analysis, our key recommendations are as follows:

- Payers should create incentives for providers to tailor case management to women with physical disabilities, thus enabling improved access to and coordination of care. Tailored case management would also better assist women who need nonstandard equipment and specialized services. Although a number of health care programs already have case management systems in place, many of the women who would benefit most from the services these systems provide are unaware of their existence. Therefore, more effective marketing of existing case management services is also required.
- States should consider adopting coordinated programs for women with disabilities who are covered by Medicaid. More data are needed to determine whether the few existing programs are cost-effective (i.e., display a desirable combination of high quality and affordable cost). Many programs may not be cost-effective initially, but they may improve the quality of care for this population of women and therefore control costs in the long run.
- Medicare should review the adequacy of its methods for risk-adjusting both fee-for-service and capitation payment rates for women with disabilities. Medicare was designed for the population over age 65, many of whom have functional limitations because of chronic disease. But people with more severe limitations from permanent disabilities who are under age 65 and who have Medicare coverage may create higher costs for those providers that are equipped and staffed to serve this population. Medicare reimbursement is particularly important for women with disabilities because so many of these women qualify for that reimbursement. Moreover, private insurers often adopt Medicare payment innovations; therefore, refinement of Medicare payment procedures is likely to benefit women with disabilities who are covered by private insurance.
- Medicare should also consider covering the coordinated-care programs developed by some states for Medicaid recipients and sharing costs with the states for individuals enrolled in both programs.
- Greater physician support is needed to improve the quality of care for women with disabilities. This support includes training and educating providers about the special health needs of women with disabilities and about the proper equipment needed for this

population. This education process should begin in medical school and should include a disability-awareness training component that recognizes cultural and ethnic differences among these women.

- Payers should extend coverage to include services typically not covered but that have been shown to be cost-effective for women with disabilities. Women interviewed for this study cited examples of such services, such as home modifications and maintenance physical therapy, which can increase their level of activity and reduce subsequent injury and hospitalizations. Further study is needed to evaluate the impact that expanding coverage of such services may have on improved functioning of women with disabilities and health care cost savings in the long term.

Areas for Future Research

A great deal of prior research has focused on issues regarding persons with disabilities as a general group rather than targeting gender-specific issues. Increased resources should be dedicated to research on women with disabilities, especially now that people with disabilities are living longer and have more active lives than in the past.

A more standardized definition of disability that is consistent across national datasets and across data collected by payers is needed so that the demographics and needs of women with disabilities can be more fully understood. Better data are needed on women with disabilities, in particular longitudinal data for assessing long-run costs and health outcomes.

More research is also needed that distinguishes among women with primary physical disabilities, mental health disabilities, and disabilities that are solely secondary to chronic conditions and the aging process.

Although research on health care for people with disabilities, including women, has expanded over the past several years, most of the studies we uncovered were of limited scope and depth. Much more information is needed about the health care needs of women with disabilities, the costs and quality of various care approaches, and the best ways of organizing and financing care.

Research areas that warrant more attention include the following:

Prevention/Health Care Needs

- The cost-effectiveness of preventive care specialized to the needs of women with disabilities in reducing acute care visits and hospitalizations.
- The presence of secondary conditions, including behavioral or mental health conditions such as depression, and the impact those secondary conditions have on health care for women with disabilities.
- The impact of disability on pregnancy and reproductive health.
- The effect of the aging process on the disabilities that women have.
- The general and specialized health care needs of specific subpopulations with disabilities, including women with certain types of disabilities, women in certain socioeconomic groups, women living in specific geographic areas, and women representing diverse ethnic and cultural backgrounds.

Clinical Interventions

- The cost-effectiveness and quality of coordinated care programs, and how access to those programs affects one's ability to work and general quality of life.
- How new approaches for coordinated/integrated/specialized care for specific populations with disabilities might be developed and tested.

Health Care Financing and Policy

- Health outcomes and costs under specific payer arrangements.
- The impact of Medicaid managed care on outcomes for women with disabilities.
- How women who were disabled during childhood finance health care differently from those who acquired disabilities during adulthood.
- Designs for potential new reimbursement methods and cost modeling (e.g., development and application of new risk-adjustment techniques).
- The costs and benefits of model programs and assessment of their potential for broader implementation.

A. Definitions of Disability According to Datasets Used in This Study

Several datasets, with differing definitions of disability, are cited in this paper. This appendix provides information on those datasets and their specific criteria for disability.

Survey of Income and Program Participation

The Survey of Income and Program Participation (SIPP) is an ongoing, national panel survey of approximately 21,000 households of non-institutionalized civilians living in the United States. SIPP is sponsored by the U.S. Census Bureau. The same households are interviewed every four months over a period of two-and-a-half to four years. For the SIPP data reported in this paper, disability is defined as a limitation in a functional activity or in a socially defined role or task. This definition includes the following individuals over the age of 15:¹

- People who are long-term users of a wheelchair, cane, crutches, or a walker.
- People who have had difficulty with one or more functional activities, one or more activities of daily living, or one or more instrumental activities of daily living.
- People with a developmental, mental, or emotional disability.
- People over the age of 16 with a condition that has made doing housework difficult.
- People between the ages of 16 and 67 with a work limitation.
- People who receive federal benefits due to an inability to work.
- People with a *severe* disability including those who have one or more functional activity limitation; need assistance with one or more activity of daily living or instrumental activities of daily living; are long-term users of a wheel chair, cane, crutches or walker; are unable to perform housework or are unable to work at a job if between the

¹The definition is from McNeil (1997).

ages of 16 and 67; have a developmental disability or Alzheimer's disease; or receive federal benefits because of their disability.

The National Health Interview Survey and National Health Interview Survey Disability Supplement

The National Health Interview Survey (NHIS) is an ongoing annual survey of approximately 122,000 non-institutionalized civilians. The National Health Interview Survey Disability (NHIS-D) was a supplemental survey on disability conducted in 1994–1995; 107,469 persons, including children, were surveyed. The NHIS is sponsored by the National Center for Health Statistics of the Centers for Disease Control and Prevention. This survey defines disability to include:²

- A limitation of a major activity, such as walking, or a work activity due to a chronic physical, mental, or emotional condition.
- Limitations in activities of daily living, such as getting out of a bed or chair, bathing, showering, using the toilet, dressing, or eating due to a chronic physical, mental, or emotional condition.
- Limitations in instrumental activities of daily living, such as using the telephone, shopping, performing housework, managing money, or preparing meals, due to a chronic physical, mental, or emotional condition.

Census Data

The U.S. Census Bureau of the Department of Commerce collects data every ten years to capture information on all individuals in the United States.³ Census 2000 counted more than 281 million people in the country and collected basic demographic information on each household. In addition, about 17 percent of households received more-detailed questionnaires that included a wide range of questions, such as questions on socioeconomic and disability status. The detailed U.S. Census

²National Center for Health Statistics (2002).

³For more information, see the U.S. Census Bureau Web site at www.census.gov.

questionnaire includes two questions with six subparts to identify people who have a disability. The questions were on the following conditions:⁴

- “Sensory disability”—blindness, deafness, or a severe vision or hearing impairment.
- “Physical disability”—a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying.
- “Mental disability”—a condition lasting six months or more, making it difficult to learn, remember, or concentrate.
- “Self-care disability”—a condition lasting six months or more, making it difficult to dress, bathe, or move around inside the home.
- “Going outside the home disability”—a condition lasting six months or more, making it difficult to leave the home unaccompanied to shop or visit a doctor.
- “Employment disability”—a condition lasting six months or more, making it difficult to work at a particular job or particular place of business.

Medical Expenditure Panel Survey Data

The Medical Expenditure Panel Survey (MEPS) is a national survey that collects data on health care use, expenditures, payment, and insurance coverage for non-institutionalized U.S. citizens.⁵ MEPS is sponsored by the Agency for Healthcare Research and Quality. MEPS consists of four separate components—a household component, a medical provider component, an insurance component, and a nursing home component. The household component collects data from households over a two-and-a-half year period through five rounds of interviews. Included in the MEPS definition of disability are the following items:

- Activities of daily living (ADL), such as bathing; and instrumental activities of daily living (IADL), such as paying bills.
- Physical activity limitations, such as difficulty in walking or climbing stairs.

⁴For more information on questions on disability in the 2000 Census, see the U.S. Census Bureau Web site at <http://www.census.gov/hhes/www/disable/disdef00.html>.

⁵Information in this section is drawn from Altman (2001).

- Activity limitations, such as difficulty in doing paid housework or other work due to an impairment in physical or mental health.
- Any limitation, including those listed above and limitations in social roles due to behavior and cognitive limitations.

B. Specialized Health Care Programs for Women with Disabilities

Boston Community Medical Group/Community Medical Alliance, Boston

Overview: The Boston Community Medical Group/Community Medical Alliance managed care program provides comprehensive services, including case management, for people in Boston with severe disabilities.¹ It is financed by the Massachusetts Medicaid Program and has been in existence in an earlier form since 1970. As of March 2002, 265 patients with severe disabilities, about a third of whom are women, were enrolled in the program. A few years ago, the program merged with Boston's Neighborhood Health Plan (NHP); now all members of the Community Medical Alliance are also officially members of the Neighborhood Health Plan.

- **Target Population:** People with severe physical disabilities; many have cerebral palsy and about half of them have spinal cord injuries. To be eligible for the program, a person must need personal care services.
- **Staffing:** The program is staffed by eight nurse practitioners (not all of whom are full time), two primary care providers (each of whom is half time), and three other physicians who devote a small amount of time to the program, in addition to a social worker, a mental health specialist, and two half-time physical therapists. A durable medical equipment department coordinates equipment needs and conducts a special wheelchair-seating clinic. Some specialty care is contracted out. A mental health consultant helps with outpatient referrals.
- **Funding:** NHP is a state-funded Medicaid managed care program. Some of its members (who are dually eligible) also have Medicare.
- **Services/Coverage:** Home visits, including gynecology visits, are usually staffed by a nurse practitioner. Members are officially

¹Program information is from Shapiro (1998), Glover (2002), and Master et al. (1996).

enrolled in NHP. There is extensive coverage for a broad array of services, including pharmacy services, wheelchair services, primary care, and specialist care. Some services are covered by a general Massachusetts health benefit and, thus, are not covered specifically under NHP. These services include transportation, personal and attendant care, and dental and optometric services.

- **Capitation and Cost Data:** The capitation rate (i.e., the monthly per capita cost) is currently \$2,200 to \$2,400 per member, with average costs of around \$1,800 per member. The number of hospitalization days and the number of medical complications have decreased among members enrolled in the capitated Medicaid plan versus those who are enrolled in traditional fee-for-service Medicaid.

Minnesota Disability Health Options, Minneapolis

Overview: Minnesota Disability Health Options (MnDHO) is a publicly financed managed care program that provides coordinated care for people with disabilities who are covered by Medicaid (and Medicaid/Medicare dual eligibles).² It is owned and operated by the Minnesota Department of Health, UCare Minnesota, and AXIS Healthcare. In existence only since September 2001, the program has (as of 2002) about 60 enrollees, with the goal of attaining 200 to 300 enrollees (Duff, 2002). An earlier pilot program had 40 to 50 enrollees over a two- to three-year period.

- **Target Population:** The target population consists of people with severe disabilities who are eligible for Medicaid or who are dually eligible for Medicaid and Medicare. About 30 percent of enrollees have spinal cord injuries; about 20 percent have cerebral palsy. Enrollment is voluntary.
- **Staffing:** MnDHO is staffed by professionals from a network of five clinics, including one women's clinic. AXIS Healthcare assesses each clinic's accessibility. All clinics seek to achieve full accessibility, including accessibility to mammograms.
- **Funding:** MnDHO is a state-funded Medicaid managed care program.

²For more information on MnDHO, see <http://www.axishealth.com/modelinaction/mndho.html>.

- **Coverage/Services:** Comprehensive services are coordinated by AXIS, with managed care services run by UCare Minnesota, a managed care program. AXIS makes all utilization decisions. Existing provider relationships, including those with specialists, are designed to give patients improved continuity of care. There is a two- to three-month enrollment process, with an initial eight-hour needs assessment, which is submitted to the state. Patients typically are enrolled on the first day of the month following the needs assessment. Coverage includes primary and referral care, transportation, wheelchairs, beds, physical and occupational therapy, some home visits, and mental health care. Pharmaceuticals, a state-covered benefit, are not included.
- **Capitation and Cost Data:** The capitation rate currently is variable and is based on the patient's needs and level of disability as determined by the state after the needs assessment. It varies from \$200 to \$19,000 per member. No cost data are available because the program is so new. However, cost savings are unlikely at this point given that MnDHO is currently covering people with the most severe disabilities.

Independent Care Program, Milwaukee

Overview: The Independent Care (ICare) program is a publicly funded managed care program providing coordinated care for people with disabilities who are covered by Medicaid.³ It is run through a Milwaukee partnership of public and private organizations. The state funds the effort; the Milwaukee Center for Independence and Care Network, Inc., provide social services and coordinated care efforts; and Humana, Inc., is responsible for administration, such as claims processing. A pilot program initiated in 1994 enabled the voluntary enrollment of a select group of disabled individuals with Supplemental Security Income (SSI). Enrollment remains voluntary and is open to any person who contacts ICare. As of late 2001, there were about 4,500 ICare patients (Garber, 2001). A study was conducted in 1996 to assess the effectiveness of ICare across a number of measures, including cost savings, patient satisfaction, and other measures (Human Services Research Institute, 1998).

³Program information is from Human Services Research Institute (1998).

- **Target Population:** The target population consists of people over age 15 with severe disabilities who are eligible for Medicaid through SSI, including individuals with developmental, mental, and physical disabilities.
- **Staffing:** ICare is staffed by a large network of primary care providers in Milwaukee, including, as of 1996, more than 333 primary care physicians, 140 mental health and substance abuse specialists, 29 dentists, 150 pharmacies, 64 transportation providers, 29 home health agencies, and 26 durable medical equipment companies. Many services, such as physical therapy, are contracted out. Physicians receive some continuing medical education, but there is no official quality control program.
- **Funding:** ICare is a state-funded Medicaid managed care program, with a budget of \$17.5 million in 1996. The initial pilot program was funded by the Center for Independence and Humana, Inc. There is no copay.
- **Coverage/Services:** An initial home visit is conducted to assess needs, but otherwise there are no special home visits. The program basically operates like a managed care plan, in which members have a primary care provider who makes referrals and recommends equipment as needed. Members also have a pharmacy benefit with the standard Medicaid formulary. There are also social support services, including transportation.
- **Capitation and Cost Data:** As of 1996, capitation exceeded costs only for people with developmental disabilities. For physical disabilities, the average monthly capitation rate per member was \$529.24, and the average cost per member was \$564.54. The program lost \$2,458,826 in 1994–1996; neither increases in outpatient use nor decreases in inpatient days were evidenced (Human Services Research Institute, 1998). However, according to an ICare founder, the program has recently become profitable, and the average number of inpatient days has decreased (Garber, 2001).

Breast Health Access for Women with Disabilities, Berkeley

Overview: The Breast Health Access for Women with Disabilities program of the Alta Bates Summit Rehabilitation Center provides breast

cancer screening, education, and outreach for women with physical and visual limitations in Alameda and Contra Costa Counties, California.⁴

- **Target Population:** The target population consists of women over age 20.
- **Staffing:** The breast health program is staffed by a specially trained nurse who administers the breast exam.
- **Funding:** Funding is through private foundations; no reimbursement services have yet been initiated.
- **Coverage/Services:** Women receive a free clinical breast exam and education and can be referred to a wheelchair-accessible site for a mammogram, if needed. The program will bill Medicaid, Medicare, and/or private insurance companies as appropriate. Some reimbursement for transportation and attendant care services is also provided.

Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago

Overview: The Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago provides education, community outreach, and comprehensive health care for women with disabilities.⁵

- **Target Population:** The target population consists of women with physical disabilities.
- **Staffing:** The program is staffed approximately one-half day per week by three gynecologists who provide pap smears and oral contraceptive counseling and by one double-boarded internist/rehabilitative medicine specialist. Gynecologists work on a rotating basis.
- **Funding:** Insurance companies are billed for patients' medical services. Coverage includes Medicare, Medicaid, and HMOs that have

⁴Program information is from the Breast Health Access for Women with Disabilities (BHAWD) Web site at <http://www.bhawd.org/sitefiles/index2.html>. BHAWD is a program of the Rehabilitation Services of the Alta Bates Summit Medical Center, Berkeley, California.

⁵Program information is from Kirschner (2001).

a contract with the Rehabilitation Institute of Chicago. The social service network is funded through grants.

- **Coverage/Services:** Medical services, preventive care including gynecologic exams, and psychological services are provided. Specialized examination tables, accessible mammograms, and some coordinated care (e.g., a physiatrist may work with a gynecologist for special needs) are available. The clinic also has a health resource center, offering advocacy and social outreach services and mentorship, which is funded through grants. No specific home visit or transportation services are provided; other services are offered as per-insurance benefits.

The Comprehensive Healthcare Center for Women with Physical Disabilities, Magee-Womens Hospital, University of Pittsburgh Medical Center Health System

Overview: Opened in December 2001 and based at Magee-Womens Hospital, the Comprehensive Healthcare Center for Women with Physical Disabilities provides comprehensive primary and gynecologic care for women with disabilities. As of February 2003, approximately 164 women have been evaluated.⁶

- **Target Population:** The target population consists of women with physical disabilities—most commonly multiple sclerosis, cerebral palsy, spinal cord injury, spina bifida, and muscular dystrophy.
- **Staffing:** The center is staffed by a primary care physician, certified nurse midwife, registered nurse, social worker, and medical assistant. It provides one-half day of care per week, with an average of four one-hour sessions per clinic day.
- **Funding:** Funding is provided by the FISA Foundation, Eden Hall Foundation, and patient billing, with the majority of patients to date covered by Medicare.
- **Coverage/Services:** Women receive a comprehensive needs assessment and are able to obtain primary, gynecologic, and obstetric care and infertility, sexuality, and family planning. Referrals for specialty care are made as needed. On-site mammography and bone

⁶Program information is from Dodge (2001 and 2002).

density screening are available. The clinic also provides social services and a weight management program.

Home-Based Health Maintenance Program for Women with Multiple Sclerosis, National Multiple Sclerosis Society, Allegheny District Chapter, Pittsburgh

Overview: The Home-Based Health Maintenance Program for Women with Multiple Sclerosis provides in-home gynecologic exams, breast exams, and pap smear screening as well as education for women with multiple sclerosis. As of February 2003, 117 home visits were conducted through the program.⁷

- **Target Population:** The target population consists of women with multiple sclerosis.
- **Staffing:** The program is staffed by a program director, a specially trained nurse midwife, and a support person.
- **Funding:** Funding is provided by the FISA Foundation, the Komen Pittsburgh Race for the Cure, and the National Multiple Sclerosis Society. Pap smear and other laboratory tests for patients who qualify are reimbursed through an arrangement with Magee-Womens Hospital and Family Health Council (through Title X funding).
- **Coverage/Services:** The program provides free in-home pelvic exams, breast exams, and pap smears and education about breast self-exams and gynecologic cancers. The nurse midwife schedules follow-up gynecologic exams and mammograms as needed. Transportation can also be arranged.

ACCESS at Anixter Center (formerly Schwab at Anixter Center), Chicago

Overview: ACCESS at Anixter Center is a comprehensive primary health care facility that provides coordinated outpatient services for people in Chicago with disabilities. ACCESS also advocates for the broader disability community. The health care services are based at the Anixter

⁷Program information is from O'Leary (2002) and Mageras (2003).

Center residential unit and are affiliated with the Schwab Rehabilitation Hospital.⁸

- **Target Population:** The target population consists of people with disabilities, including those with dual diagnoses (physical and mental disabilities). About 3,500 patients use the center, with slightly more women than men using the center.
- **Staffing:** ACCESS is staffed by two internists, two psychiatrists, two psychologists, a licensed practical nurse, a case manager, a podiatrist, a medical assistant, and a receptionist.
- **Funding:** Insurance companies are billed for medical services. Many patients are covered by Medicaid and Medicare, fewer by commercial plans. There is also a sliding-scale payment mechanism for those who must pay out of pocket.
- **Coverage/Services:** Medical services, including primary medical care, psychiatry, podiatry, and special services for the deaf, are provided. People who need specialty care are referred to Mt. Sinai Hospital in Chicago; those who need specialty equipment are referred to Schwab Rehabilitation Hospital. There are no home visits, but most people who use the center live nearby. Some support for transportation and pharmaceuticals is available. Most patients pay about \$10 per visit.

Women's Outpatient Wellness Center, St. Louis

Overview: Started in July 2002, the Women's Outpatient Wellness Center program of the SSM Rehabilitation Center in St. Louis operates on patient demand. The center initially operated one day per week, but there are plans to expand operations to two days per week or more if needed. Each patient is estimated to require about one hour of time with the health care provider. A second site was scheduled to be opened in 2003.⁹

- **Target Population:** The target population consists of women with physical disabilities.
- **Staffing:** The center is staffed by a gynecologist and women's health nurse practitioner.

⁸Program information is from Pierce (2002).

⁹Program information is from Allen (2002).

- **Funding:** Funding is currently through Medicare, but the center plans to expand its funding to include all types of insurance and grants for the uninsured.
- **Coverage/Services:** Women receive a comprehensive women's health exam including a pelvic exam, breast exam, lab work, blood work, and mammogram. Because the center is part of a larger rehabilitation operation, referrals to the staff physiatrist and other physicians can occur on site, as needed. Ready access to physical, occupational, and speech therapy and social services is also available. The center plans to provide wheelchair-accessible van service in the near future.

C. Resources for Information on Health Care for Women with Disabilities

ACCESS at Anixter Center
6610 N. Clark Street
Chicago, IL 60626
(773) 973-7900
www.anixter.org¹

Accessibility Development Associates, Inc.
Three Gateway Center, 5th Floor
401 Liberty Avenue
Pittsburgh, PA 15222
(412) 471-4156
www.adaconsults.com

Boston Community Medical Group
1 Boston Medical Center Place
Dowling Building, Suite 5108
Boston, MA 02118
(617) 638-7062

Breast Health Access for Women with Disabilities
Alta Bates Summit Medical Center
Herrick Campus
Rehabilitation Services
2001 Dwight Way, 2nd Floor
Berkeley, CA 94704
(510) 204-4866
www.bhawd.org

¹The Web sites listed in this appendix were valid as of July 2003.

Centers for Disease Control and Prevention
Office on Disability and Health
1600 Clifton Rd.
Atlanta, GA 30333
(770) 488-7150
www.cdc.gov/ncbddd/dh

Center for Research on Women with Disabilities
Department of Physical Medicine and Rehabilitation
Baylor College of Medicine
3440 Richmond Avenue, Suite B
Houston, TX 77046
(713) 960-0505
www.bcm.tmc.edu/crowd

Consumer Health Coalition
650 Smithfield Street
Centre City Tower, Suite 2140
Pittsburgh, PA 15222
(412) 496-0973

The Comprehensive Healthcare Center for Women with Physical
Disabilities
Magee-Womens Hospital of UPMC Health System
300 Halket Street
Pittsburgh, PA 15213
(412) 647-4747
www.magee.edu/ClinicalServices/wwpd/wwpd1.html

FISA Foundation
1001 Liberty Avenue, Suite 650
Pittsburgh, PA 15222
(412) 456-5550
info@fisafoundation.org
www.fisafoundation.org

Health Promotion for Women with Disabilities
Villanova University–College of Nursing
800 Lancaster Avenue
Villanova, PA 19085
(610) 519-6828
www.nursing.villanova.edu/WomenWithDisabilities

Health Resource Center for Women with Disabilities
Rehabilitation Institute of Chicago
345 E. Superior, Room 106
Chicago, IL 60611
(312) 908-7997
www.rehabchicago.org/community/hrcwd.php

Independent Care
101 W. Pleasant Street, Suite 102
Milwaukee, WI 53212
(414) 272-9250

Minnesota Disability Health Options
AXIS Healthcare, LLC
2356 University Avenue West, Suite 405
St. Paul, MN 55114
(651) 641-0887
www.axishealth.com

National Institute on Disability and Rehabilitation Research
400 Maryland Avenue, S.W.
Washington, DC 20202
(202) 205-8134
www.ed.gov/offices/OSERS/NIDRR

National Multiple Sclerosis Society
Allegheny District Chapter
Home-Based Health Maintenance Program for Women with Multiple
Sclerosis
1040 Fifth Avenue
Pittsburgh, PA 15219
(412) 261-6347
www.nmss-pgh.org

National Rehabilitation Hospital Center for Health and Disability
Research
1016 16th Street, N.W.
Suite 400
Washington, DC 20036
(202) 466-1900
www.nrhrehab.org/

National Women's Health Information Center
Office of Women's Health
United States Department of Health and Human Services
200 Independence Avenue, SW, Room 730B
Washington, DC 20201
(202) 690-7650
www.4woman.gov

Pennsylvania Department of Public Welfare
Office of Medical Assistance Programs
Health & Welfare Building, Room 515
Harrisburg, PA 17105
(717) 787-1870
www.dpw.state.pa.us/omap/dpwomap.asp

Pennsylvania Department of Public Welfare
Office of Social Programs
Health & Welfare Building, Room 533
Harrisburg, PA 17105
(717) 787-3438
www.dpw.state.pa.us/osp/dpwosp.asp

Texas Institute for Rehabilitation and Research/
Independent Living Research Utilization at TIRR
2323 South Shepherd, Suite 1000
Houston, TX 77019
(713) 520-0232
www.ilru.org

The University of Montana Rural Institute
52 Corbin Hall
Missoula, MT 59812
(888) 268-2743
www.ruralinstitute.umt.edu

United States Census
4700 Silver Hill Road
Suitland, MD 20746
(301) 763-3242 (disability staff)
www.census.gov

University of California San Francisco
Disability Statistics Center
3333 California Street, Suite 340
San Francisco, CA 94118
(415) 502-5210
www.dsc.ucsf.edu/UCSF/spl.taf

Women's Outpatient Wellness Center
SSM Rehabilitation Hospital
6420 Clayton Road
St. Louis, MO 63117
(314) 768-5300
www.ssmrehab.com

D. Findings from Focus Groups and Interviews with Women with Disabilities

As a part of this project, we conducted focus groups with women with disabilities living in the Pittsburgh area. The two focus groups included seven women identified from a convenience sample provided by a community-based advocacy organization in Pittsburgh. We also performed supplementary interviews with women in the Pittsburgh area who were not present at the focus groups. Interviewees were identified through the FISA Foundation and other local advocacy organizations. Women were queried about their experiences in the health care system, including their experiences with issues related to insurance coverage, provider care (including specialty referrals), prescription drug coverage, and burden of costs.

Some common barriers to receiving health care were identified through the focus groups and interviews:

- Many women both in the focus groups and during the interviews described problems maneuvering through the health care system bureaucracy, especially the bureaucracy surrounding how and where to express grievances.
- Although many women were satisfied with their doctors, some had great difficulty finding a doctor who met their needs. One interviewee felt that her primary doctor was very uncomfortable with any problems related to her disability and often referred her to a specialist when such problems arose. Two of the women interviewed mentioned recurring problems with staff who were not trained to deal with women with disabilities.
- Durable medical equipment was frequently cited as a major out-of-pocket cost. Many women in both the focus groups and interviews had trouble obtaining durable medical equipment; they described the restrictions placed by insurance companies on their acquiring home health equipment and specialized walkers and wheelchairs as prohibitive. Home physical therapy and medications are other costs that were commonly cited.

- Issues related to insurance, such as delays in obtaining Medicare coverage, were also commonly mentioned. One woman who had lost her job stated that she paid \$307 out of a monthly paycheck of \$567 to obtain insurance under COBRA while waiting for Medicare coverage. Some of the women we interviewed were assisted by advocates who helped steer them through the Medicare application process. However, others were not aware that such advocacy support was available or were not aware of any other ways to simplify the Medicare application process.
- Some of the women who participated in the study expressed a general discontent with managed care plans. Restrictions on provider choice and difficulty in traveling to providers or to labs that contracted with certain plans were commonly cited problems.
- One woman mentioned problems related to receiving care during her pregnancy, including difficulty in finding an experienced provider and obtaining physical therapy during pregnancy, which she had to pay for out of pocket.
- Other barriers to receiving care that were cited by women who participated in the study include problems with in-home modifications to encourage independence, limited transportation services, and limited attendant care/unskilled in-home care coverage.

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