

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.