

**UNDERSTANDING THE HEALTH-CARE NEEDS
AND EXPERIENCES OF PEOPLE WITH DISABILITIES**

Findings from a 2003 Survey

DECEMBER 2003



THE HENRY J. KAISER FAMILY FOUNDATION

Authors

Kristina Hanson
Tricia Neuman
Molly Voris

Acknowledgements

The authors wish to thank David Dutwin and Melissa Herrmann of International Communications Research, Inc. (ICR); and Judy Kasper, Henry Claypool, and Bob Williams for their assistance with this survey. They also wish to thank Diane Rowland, Barbara Lyons, and Risa Elias of the Kaiser Family Foundation.

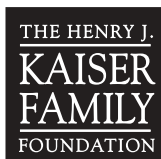
The Henry J. Kaiser Family Foundation

is an independent, national health philanthropy dedicated to providing information and analysis on health issues to policymakers, the media, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.

**UNDERSTANDING THE HEALTH-CARE NEEDS AND
EXPERIENCES OF PEOPLE WITH DISABILITIES**

Findings from a 2003 Survey

DECEMBER 2003



THE HENRY J. KAISER FAMILY FOUNDATION

Table of Contents

Introduction.....1

Survey Methods.....3

Survey Findings

 Section 1: Overview of Sample..... 4

 Section 2: Sources of Support and Assistance..... 7

 Section 3: Health Care and Coverage..... 9

 Section 4: Problems with Access to Care..... 12

 Section 5: Cost-Related Barriers to Care..... 14

 Section 6: Worries, Policy Priorities, and Politics..... 19

Conclusions and Policy Implications.....22

Survey Methods

The data presented in this report are based on a national, telephone survey of 1,505 non-elderly adults ages 18-64 with permanent physical and/or mental disabilities. The sample was drawn from a nationally representative survey of households to identify individuals with disabilities. Households were contacted through random-digit dialing and screened between June 19, 2002, and January 28, 2003, and the survey interviews were conducted between January 9 and February 11, 2003. International Communications Research, Inc. (ICR), conducted the fieldwork and the survey instrument was developed by a team of researchers at ICR and The Henry J. Kaiser Family Foundation.

A central goal of this study was to describe the health-care experiences of non-elderly adults across a broad array of disability types and sources of health insurance. The questions in the screener instrument were designed to capture two groups of individuals between ages 18-64: 1) those receiving disability payments through either the Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) programs; and 2) those who consider themselves as having a mental or physical disability, but who are not receiving payments from either program. These questions were asked again for validation purposes when the households were recontacted for complete interviews. The survey instrument included items on respondents' disabling conditions, health-care utilization, health insurance, access to care, cost burdens, employment status and history, and basic demographic characteristics.

In collecting the sample, 33,357 households were contacted, 3,687 of which were identified as including a household member with a disability. As with any survey, when households were recontacted for complete interviews, a number of those identified in the initial screening process were deemed invalid due to the respondent no longer meeting the inclusion criteria, having moved out of the residence, death, or other reasons. Among those not ruled out in this way, the response rate was 67.3%.¹ The sample excludes people with disabilities living in institutions and non-English speakers. Proxy interviews were conducted with 168 respondents (11% of the total sample) on behalf of those whose disabilities or health status prevented them from completing the interview themselves.

Demographic data were used to post-stratify the sampling weights to Census data.² The tables in this paper present weighted data so that the estimates are representative of the national population of people ages 18-64 who are living with a disability, according to the criteria used in this study.

To analyze the sample by source of insurance, respondents were assigned to one of the following mutually exclusive insurance groups: Medicaid only, Medicare only, Medicaid and Medicare ("dual eligibles"), Medicare and private, private only, some other source, and uninsured. Given that many people have multiple sources of insurance to help fill the gaps in their primary source of coverage, these categories were derived in order to test the impact of different sources of coverage—both alone and in combination with others—on access to care. The analyses in this report include bivariate and multivariate models.

For about 25% of all cases, data on health insurance coverage were missing or invalid. Regression-based imputation was used to assign coverage to these individuals, using models that included SSI/SSDI participation and selected demographic and health-related indicators.³

Survey Findings

Section 1: Overview of Sample

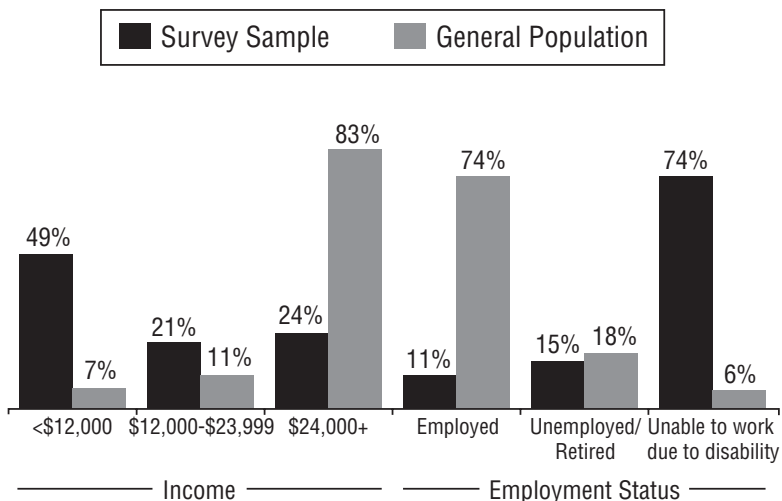
People with disabilities are at significant socio-economic and health-related disadvantages when compared to the non-elderly U. S. population as a whole. Relative to the general, non-elderly adult population, those with mental and/or physical disabilities in this sample have lower incomes and are far less likely to be employed (Exhibit 1). As might be expected, they are also much more likely than the general adult population to say their health status is fair or poor, and to report limitations in their activities of daily living, such as bathing and preparing meals (Exhibit 2). More than half of the overall sample has difficulty with at least one basic task, such as showering and bathing, getting in or out of a bed or chair, and taking medicines at the right time. By contrast, fewer than 1% of all non-elderly adults in the general population have such difficulties.

A large majority (80%) of the sample described here became disabled in adulthood, 9% were either born with their disability or became disabled before the age of 1, and the remaining 10% became disabled before turning 18 (Exhibit 3). The number of different disabilities reported by this population speaks to the array of health-care services and other sources of support people with disabilities often need. Most of the people in the survey sample (61%) report having only a physical disability, 15% report having only a mental disability, and the remaining 24% report having both physical and mental disabilities (Exhibit 4).

The specific conditions and diagnoses reported by the sample include a wide range of congenital conditions, injuries, neurological disorders, and psychiatric illnesses. Injury-related disorders were the most common (reported by 18% of the sample), including traumatic brain injury, spinal-cord injuries often resulting in paraplegia or quadriplegia, and other injuries to the neck and back. Next most commonly reported were psychiatric disorders such as schizophrenia, bipolar disorder, and depression, which account for 14% of the main disabling conditions in the sample. Compounding the fundamental challenges associated with these diagnoses, more than two-thirds of the sample says they often feel depressed. These groups alone demonstrate the diversity of the disabled population in terms of their health-care needs, reliance on equipment and other sources of support, and ability to navigate the health-care system independently.

Exhibit 1

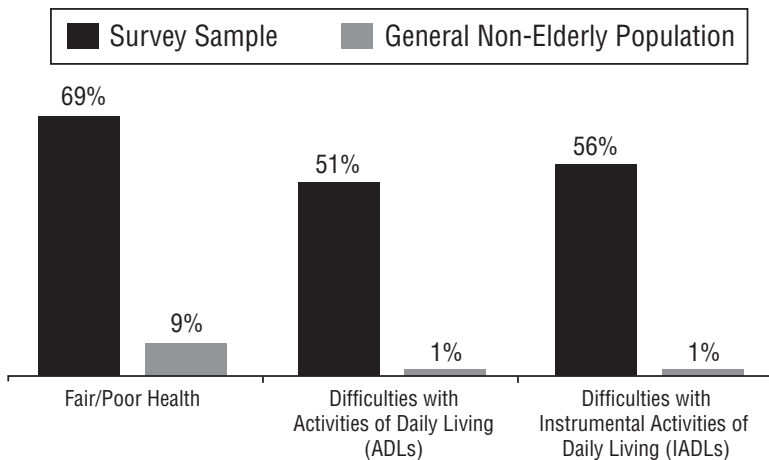
**Survey Sample vs. General Non-Elderly U.S. Population,
by Income and Employment Status**



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003; Income: Current Population Survey, 2001; Employment: National Health Interview Survey, 2001.

Exhibit 2

**Survey Sample vs. General Non-Elderly U.S. Population,
by Health Status and Functional Limitations**

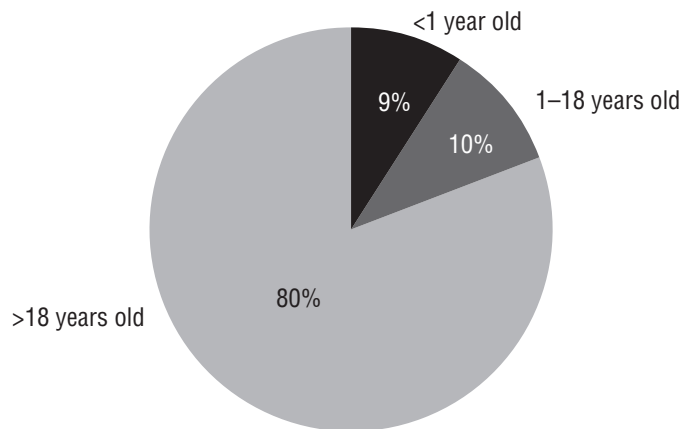


Note: Limitations in ADLs defined as difficulties with bathing, showering, or getting in or out of a bed or chair. Limitations in IADLs defined as difficulties with taking one's medicines at the right time or preparing meals.

SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003; National Health Interview Survey, 2001.

Exhibit 3

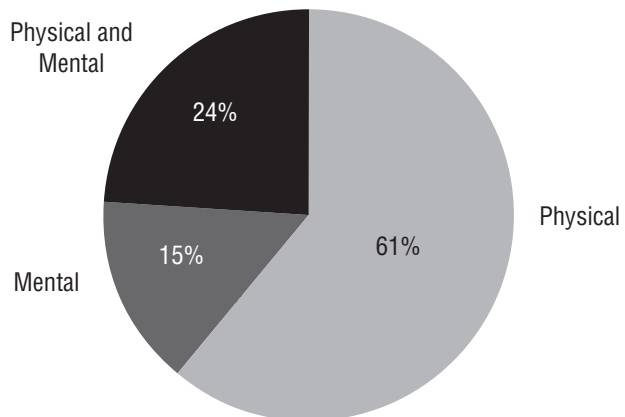
Age of Disability Onset Among Non-Elderly People with Disabilities



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 4

Disability Type Among Non-Elderly People with Disabilities



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Section 2: Sources of Support and Assistance

Family members and friends are an important source of support for people with disabilities, with more than two-thirds of the sample relying on family and friends for assistance with daily activities (Exhibit 5). By contrast, only 8% turn to professional sources of assistance, such as home-health aides and personal assistants. Equipment also plays a critical role in the lives of many people with disabilities, with 45% of those with a physical disability relying on some form of equipment, such as motorized wheelchairs, to help them manage their basic needs at home and/or work. Despite these various sources of support, 42% of the sample reported falling while getting in or out of bed or a chair because no one was available to help (not shown).

Many people in the sample also receive more formal assistance through a range of public programs that help manage their disabilities. Three-quarters (76%) of the sample receive income support payments through Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI), programs that serve as pathways to health insurance through Medicaid and Medicare, respectively.⁴ Nearly a quarter (24%) of respondents receive Food Stamps and 13% get help with transportation, with substantially smaller shares relying on veterans' benefits programs and programs that assist with rent or housing and job training (Exhibit 6).

Along with facilitating basic activities of daily living, the ability to rely on various forms of assistance likely plays a critical role in physical mobility and social interaction among people with disabilities. While clearly facing substantial health-care needs and functional limitations, the majority of those in the sample report having talked with friends or relatives on the telephone in the previous month (91%), left the house for a meal or to run errands (81%), or gotten together for a social occasion (74%) (Exhibit 7).

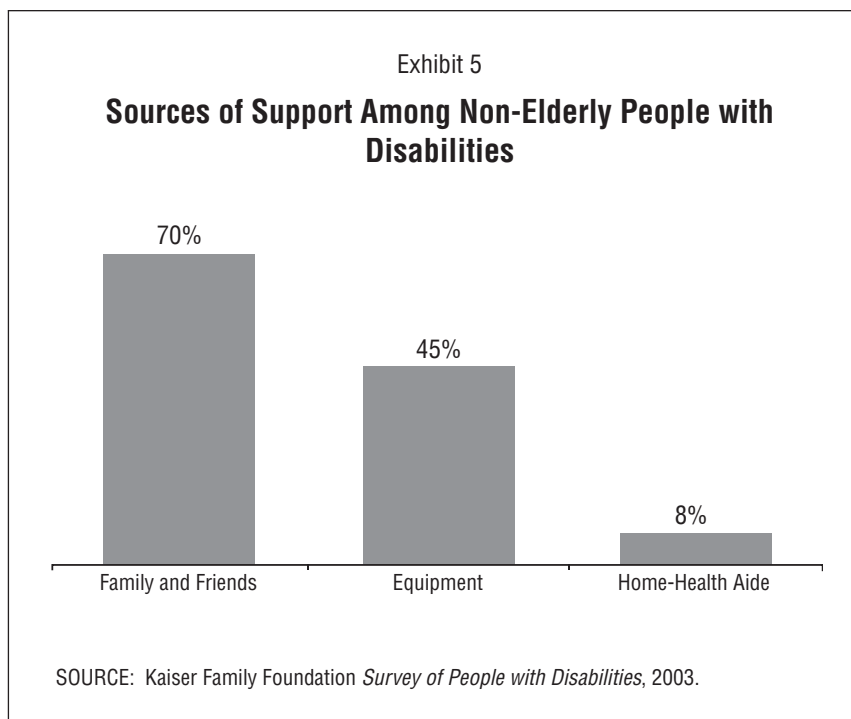
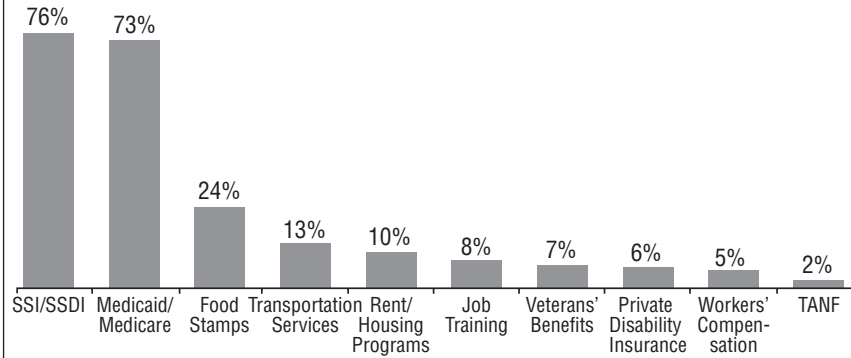


Exhibit 6

Public Services and Assistance Received by Non-Elderly People with Disabilities

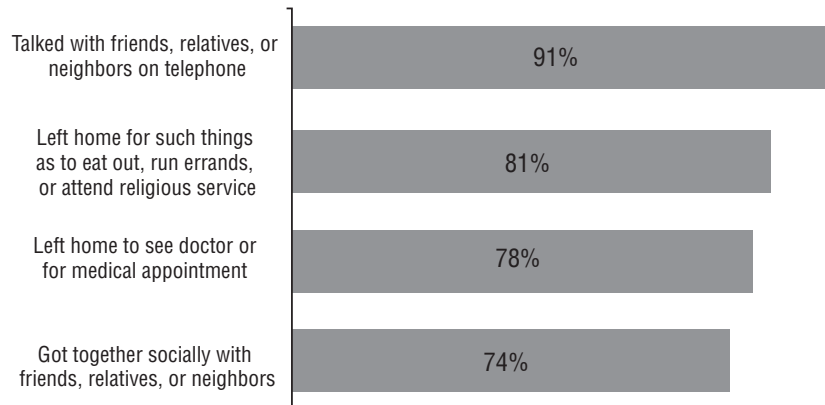


SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 7

Social Activity/Interaction Among Non-Elderly People with Disabilities

Percent reporting having done the following within the past month:



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Section 3: Health Care and Coverage

Not surprisingly, many people with disabilities use the health-care system frequently, with more than half (57%) having seen a physician four or more times in the six months prior to the survey, and 18% reporting two or more visits to the emergency room in the past six months (Exhibit 8). In addition, nearly 9 out of 10 of those in the sample report using at least one prescription medication on a regular basis. As might be expected, these utilization rates are higher than they are for the general non-elderly adult population.⁵

While those with disabilities in the sample are relatively heavy users of health-care services, they are less likely than the general population to receive preventive services and receive these services considerably less frequently than is generally recommended.⁶ Less than half of all female respondents reported having a mammogram in the past year and only about a third of all men reported having a prostate exam over the same period (Exhibit 8). Despite the importance of routine dental care, only 41% reported having a dental exam in the past year. These findings suggest that many in this population may be seeking out services pertaining to their disability-related needs to the exclusion of other health-care services such as preventive care.

Among those in this survey sample, the vast majority (95%) has some form of health insurance. This high rate of coverage is due partly to enrollment in SSI and SSDI, which are linked to eligibility for health insurance through Medicaid and Medicare, as described above. However, even among those with disabilities, this sample includes a disproportionate share with insurance, most likely due to the definition of disability used in this survey, which was designed primarily to analyze the role of health insurance.⁷

Looking at the three leading sources of health insurance within this sample, 44% are covered by Medicaid (including the 14% with both Medicaid and Medicare known as “dual eligibles”), 43% by Medicare (again, including the dual eligibles and another 14% with private supplemental coverage), and 33% by some form of private coverage (Exhibit 9). When sorted into mutually exclusive groups, almost a third (30%) of respondents rely solely on Medicaid, 15% have Medicare as their only source of coverage, and 19% rely on private health insurance alone. In sum, roughly two-thirds of the sample relies on a single source of insurance coverage and about one-third reports multiple sources of coverage.

The populations covered by different sources of coverage vary along several dimensions.⁸ In terms of disability type, for example, Medicaid was more likely than other sources of insurance to serve people with mental disabilities (Exhibit 10). More than half (53%) of those with only Medicaid have a mental disability, either alone, or in conjunction with a physical disability. By contrast, less than a third of those on Medicare (either alone or with private coverage) have a mental disability, similar to the population covered only by private coverage.

People with disabilities are more likely than adults in the general population to have lower incomes across the board, with about half (49%) of the survey sample reporting an annual income of \$12,000 or less (Exhibit 11). Medicaid is especially likely to serve poorer beneficiaries, simply by virtue of the program’s income and asset eligibility criteria. In this sample, more than three-quarters (77%) of the Medicaid population and almost three-quarters (74%) of those enrolled in both Medicaid and Medicare report an annual income of \$12,000 or less. Excluding dual eligibles, fewer than a third (31%) with Medicare fall in this income group and an even smaller share of those with private coverage alone (13%) do so. Not surprisingly given the connection to an employer and/or the ability to afford such a policy on one’s own, more than half (60%) with private coverage alone reports incomes of \$24,000 or more per year.

With Medicaid serving many of those with the lowest incomes and private insurance covering primarily those at the higher end of the income spectrum, the uninsured population is comprised disproportionately of the near-poor, or those with incomes just above the poverty line. Those with incomes in this range may face the greatest challenges in terms of access to health-care services and high out-of-pocket costs.

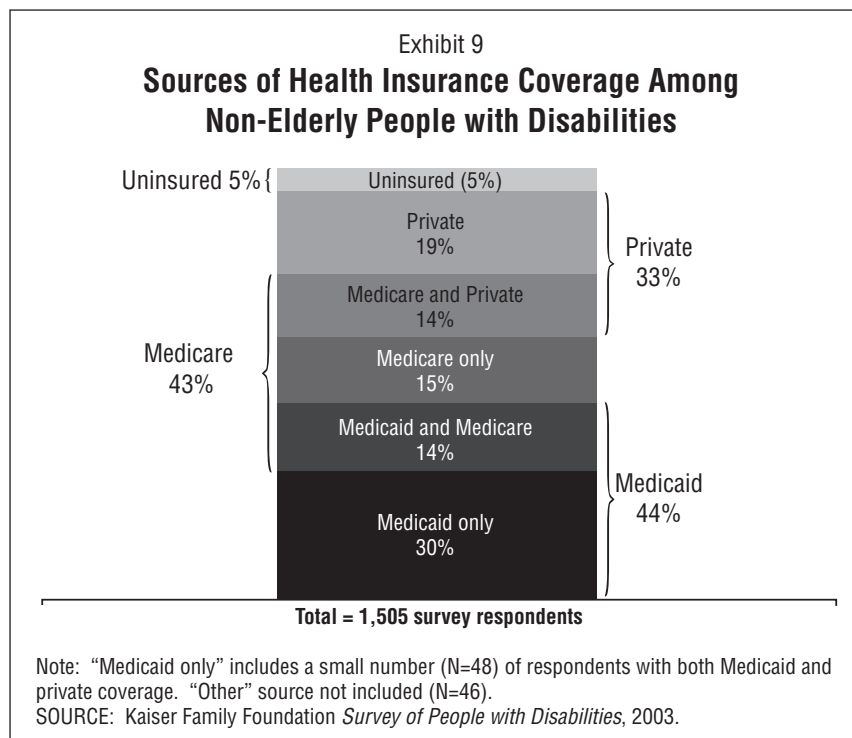
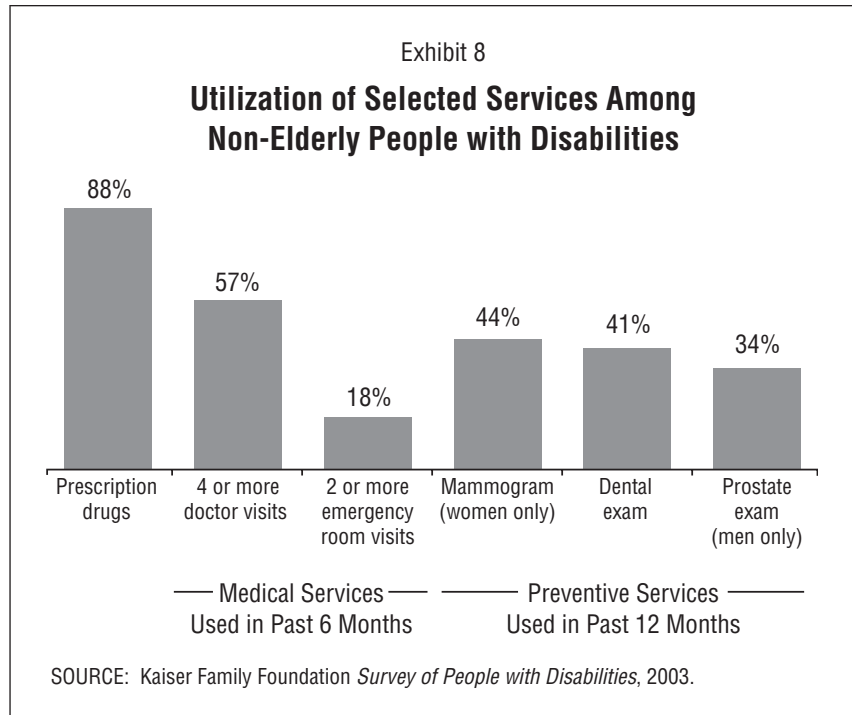
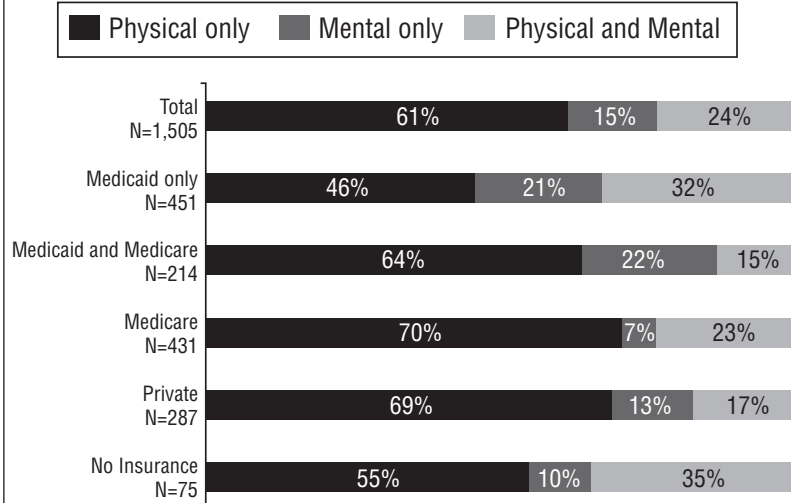


Exhibit 10

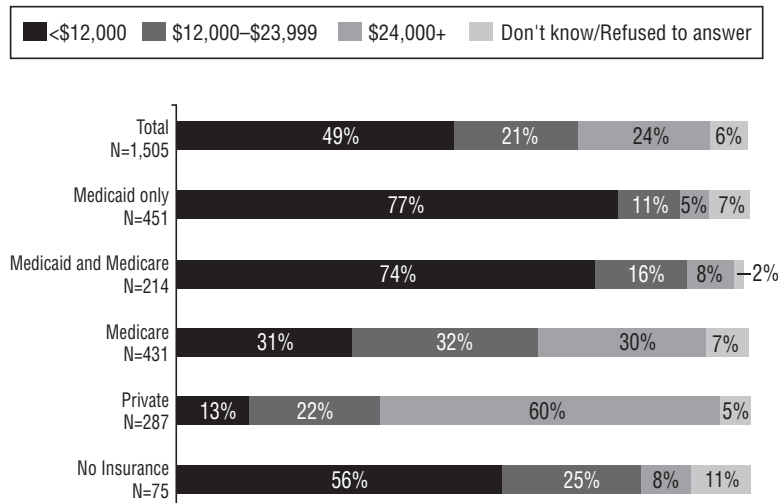
Source of Health Insurance Among Non-Elderly People with Disabilities, by Disability Type



Note: Numbers may not add to 100% (1,505) due to rounding, imputation, and weighting; "Medicare" includes respondents with Medicare only and Medicare and private coverage; "Medicaid only" includes a small number (N=48) of respondents with both Medicaid and private coverage. "Other" source not included (N=46).
 SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 11

Source of Health Insurance Among Non-Elderly People with Disabilities, by Income



Note: Numbers may not add to 100% (1,505) due to rounding, imputation, and weighting; "Medicare" includes respondents with Medicare only and Medicare and private coverage; "Medicaid only" includes a small number (N=48) of respondents with both Medicaid and private coverage. "Don't know" responses included due to share of respondents not disclosing income. "Other" source not included (N=46).
 SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Section 4: Problems with Access to Care

This survey also explored the extent to which people with disabilities face challenges in terms of navigating the health-care system and getting needed services. For instance, while only a small share (15%) of survey respondents say they have no regular doctor, one in four reports having had trouble finding a doctor who understands their disability (Exhibit 12). These problems are especially prevalent among those without any health insurance. More than two-thirds (69%) of the uninsured report having no regular doctor and more than a third (35%) say they have trouble finding a doctor who understands their disability. Among those with health insurance of any type, smaller shares reported such difficulties (Exhibit 13).

When it comes to finding a doctor who accepts their insurance, 17% of the sample reports having had such problems, with higher rates reported among those covered by Medicaid—both with (23%) and without (22%) Medicare as a supplement (Exhibit 14). When multivariate analyses were used to examine the relationship between source of coverage and access problems, the results were somewhat mixed, with insurance appearing to play less of a role than is suggested in the bivariate analyses detailed above.

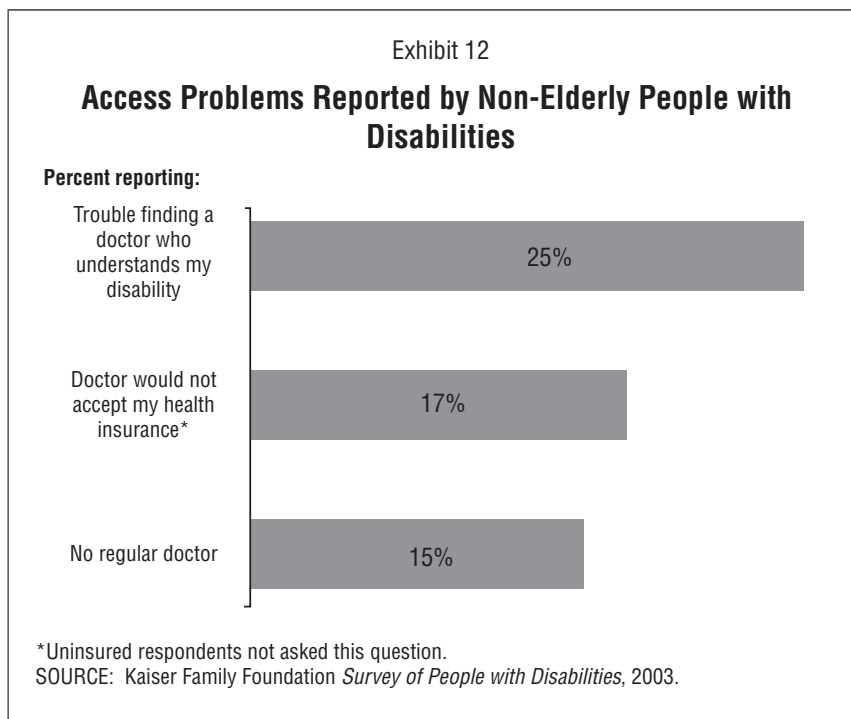
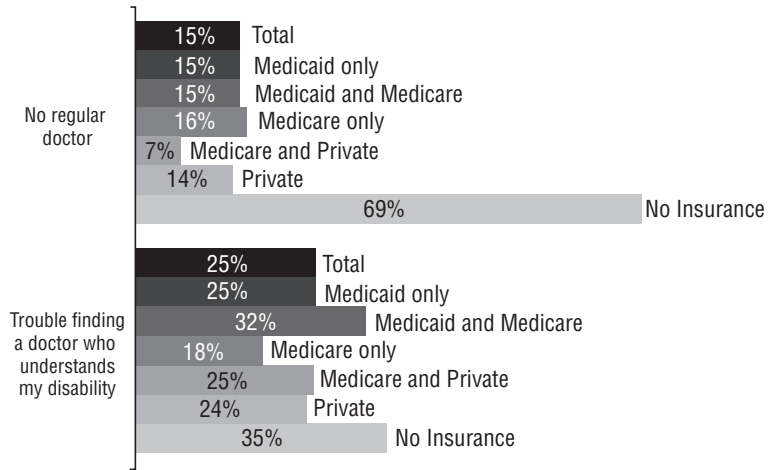


Exhibit 13

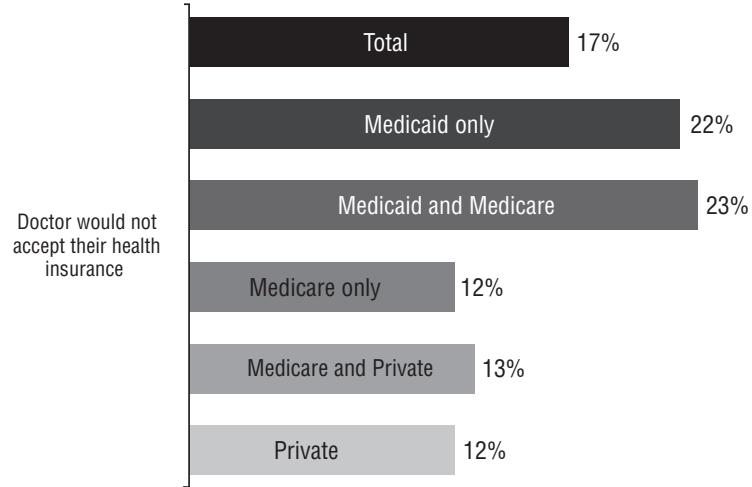
Access Problems Among Non-Elderly People with Disabilities, by Source of Health Insurance



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 14

Percent of Non-Elderly People with Disabilities Reporting Doctor Would Not Accept Their Health Insurance, by Source of Health Insurance



Note: Uninsured respondents not asked this question.

SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Section 5: Cost-Related Barriers to Care

For many people with disabilities, health-care costs are a major concern. Overall, prescription drugs and dental care are the two most commonly named services or benefits causing cost problems, cited as a serious problem by 32% and 29% of the sample, respectively (Exhibit 15). In addition, 21% of those who use equipment to manage their disabilities say they have serious difficulties paying for it, and 17% of those with a mental disability said the cost of mental-health services is a serious problem for them.

Cost-related problems vary by source of health insurance coverage. Respondents with Medicare (and no supplemental coverage) are more likely to report cost-related concerns than are those covered by Medicaid. While almost a quarter (24%) of those with Medicaid alone cite paying for prescription drugs as a serious problem, more than half (52%) of those enrolled only in Medicare report such problems (Exhibit 16). Similarly, only 12% of those with only Medicaid coverage who use home-care services report problems paying for this type of care, compared with 60% of home-care users enrolled in Medicare.

Problems paying for selected services have significant implications for the services and products that people with disabilities receive. For example, nearly half (46%) of those in the sample report going without necessary items such as equipment and eyeglasses due to cost (Exhibit 17). Significant shares of this sample also report having postponed care due to cost (37%) and having skipped doses of a prescription medication, split pills, or gone without filling a prescription in order to save money (36%). This latter finding echoes previous work, which demonstrated that seniors on Medicare struggle with paying for their prescription medicines, with almost a quarter (22%) estimated to skip doses or split pills due to cost.⁹

The consequences of not being able to afford various health-care products and services also vary by source of coverage. Those without health insurance altogether are at a substantial disadvantage when it comes to being able to pay for selected services. And, when compared to the rest of the sample, those without insurance are more likely to take significant measures to cut costs. Two-thirds of the uninsured report having postponed care and gone without necessities due to cost and almost as many say that they split pills, skipped doses, or did not fill a prescription to save money (Exhibits 18 and 19).

Multivariate analyses designed to examine the relationship between health insurance and cost-related access problems confirm the importance of insurance for people with disabilities (Exhibit 20). For instance, those without any source of health insurance coverage were approximately four times as likely to have postponed care due to cost than were people with health insurance. And, the uninsured were about three times more likely than those with insurance to go without needed supplies or forgo medicine due to cost.

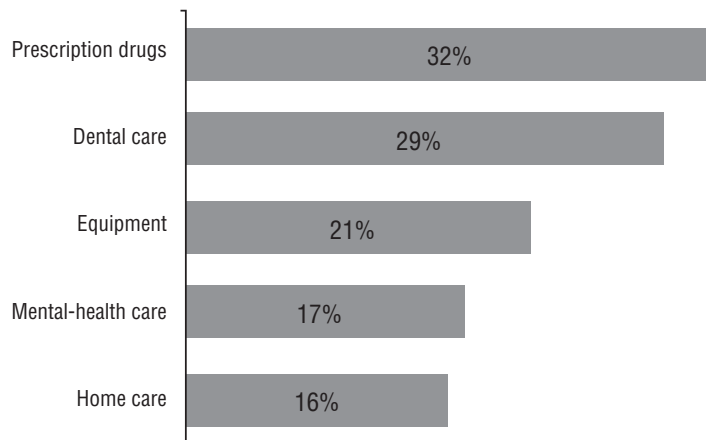
Respondents with Medicare as their only source of coverage were more than 12 times as likely to have postponed care and were more than 7 times as likely to have forgone taking medications due to cost than were those enrolled only in Medicaid, underscoring the significant financial protections provided by the Medicaid program, as well as the substantial gap created by Medicare's lack of a prescription drug benefit. In general, those relying solely on Medicare fared worse than did people with private coverage as well.

Those with some form of supplemental coverage are at a substantial advantage in terms of cost-related access measures when compared to those without such additional assistance. Medicare beneficiaries without supplemental coverage through either a private source or Medicaid were significantly more likely to report cost-related access problems on each of the three cost-related outcome measures tested here. Those relying solely on Medicare were over six times more likely than were those with supplemental coverage through either Medicaid or a private source to postpone care due to cost. They were also about five times as likely as those with private supplemental coverage—and about three times as likely as those with both Medicare and Medicaid—to go without health-care necessities due to cost. Taken together, these findings shed significant light on the role of health insurance and the ways in which access to needed services may vary dramatically by source of coverage.

Exhibit 15

Problems Paying for Selected Health-Care Services Among Non-Elderly People with Disabilities

Percent reporting serious problems paying for the following services in the past 12 months:



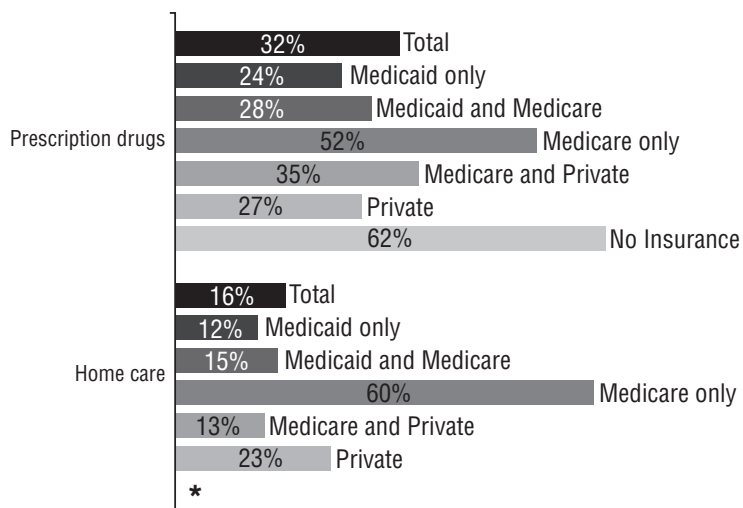
NOTE: Data on prescription drugs, equipment, and home care reflect responses of users of those products/services only; data on mental health reflect responses of people with mental disabilities.

SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 16

Problems Paying for Selected Services Among Non-Elderly People with Disabilities, by Source of Health Insurance

Percent reporting serious problems paying for the following services in the past 12 months:



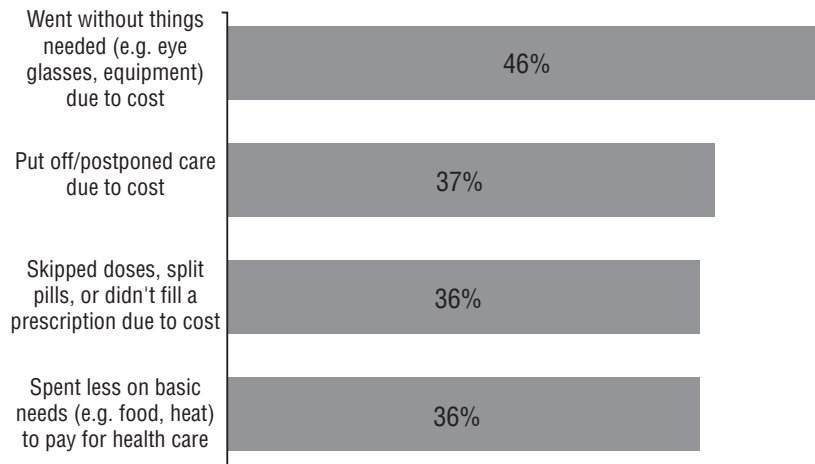
* Data not presented because of insufficient sample size.

Note: Data reflect responses of users of these products/services only.

SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 17

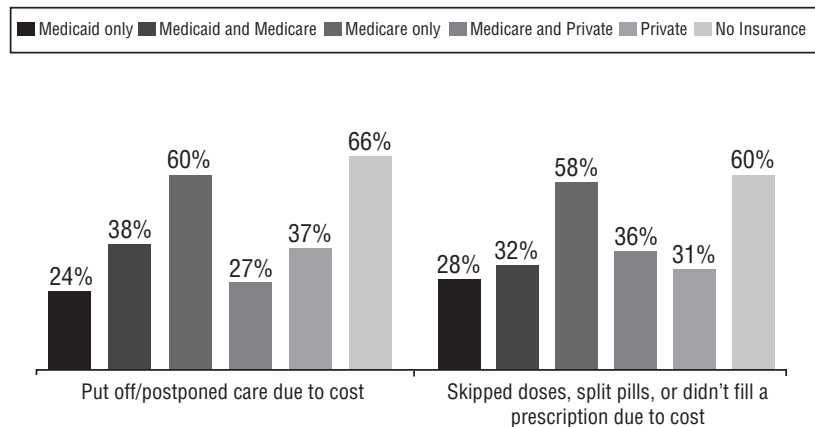
Cost-Related Barriers to Care Among Non-Elderly People with Disabilities



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 18

Postponing Care and Skipping Doses of Needed Medication, by Source of Health Insurance

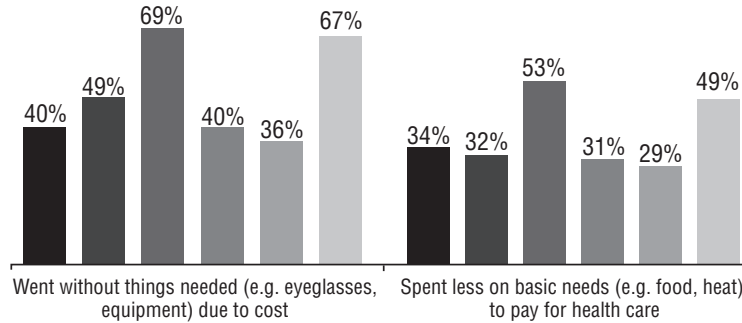


SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 19

Going Without Necessary Health-Care Supplies and Spending Less on Other Basic Needs, by Source of Health Insurance

■ Medicaid only ■ Medicaid and Medicare ■ Medicare only ■ Medicare and Private ■ Private ■ No Insurance



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 20

Relationship Between Health Insurance and Cost-Related Barriers to Care

(Odds ratios based on multivariate logistic analysis)

	Postponed Care Due to Cost	Went Without Needed Equipment and Items Due to Cost	Skipped Doses or Split Pills Due to Cost
Insured (reference) – Uninsured	4.10**	2.60**	3.13**
Private (reference) – Medicare only – Medicaid only	2.63** 0.24**	4.27** —	2.64* —
Medicaid (reference) – Medicare only	12.63**	4.26**	7.33**
Medicare and Medicaid (reference) – Medicare only	6.28**	2.98**	5.92**
Medicare and Private (reference) – Medicare only	6.79**	4.88**	4.00**

NOTE: *p< 0.05; **p<0.001. Contact authors for more detailed specifications of the models.
SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Section 6: Worries, Policy Priorities, and Politics

Given the significant challenges facing people with disabilities—in terms of managing both their health-care needs and the routines of daily living—it is not surprising that many report a number of worries and concerns. For instance, although many people with disabilities currently rely upon a range of programs for assistance, more than half (56%) of respondents in this survey are concerned about losing these benefits and almost as large a share (54%) feel that they might have difficulty paying for basic needs like food and rent (Exhibit 21). While getting a job and earning an income could help to alleviate these concerns, more than a third (36%) of respondents fear that getting a job would mean losing their health insurance, highlighting one of the difficult tradeoffs involved in qualifying for assistance through disability-related public programs. In general, because SSI and SSDI—the primary pathways to health insurance under Medicaid and Medicare for people with disabilities—require that those eligible be totally and permanently disabled, it can often be difficult to hold even a low-wage job on a part-time basis and qualify for either program.

Adults with disabilities also worry about how they will manage as they and their family members grow older. Close to half (45%) say they are concerned that they will become too much of a burden on their family, while nearly a quarter (23%) are worried they will have to go into a nursing home.

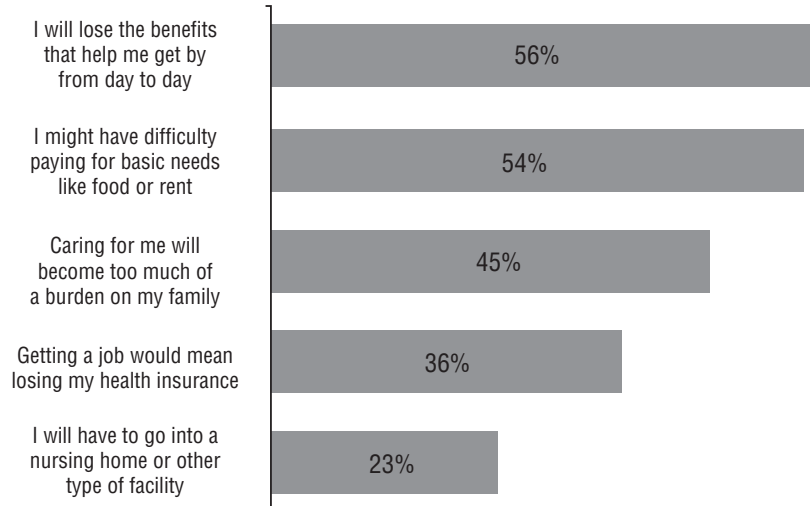
Reflecting their awareness of and frustrations with the options available to people with disabilities, those in the sample hold strong views about how the government should address the shortcomings of various programs. For instance, improving prescription drug coverage was cited by more than 4 in 10 respondents as the most important policy priority for people with disabilities, with more than a quarter (26%) arguing that the top priority should be to help people work while keeping their disability benefits (Exhibit 22). Other policy priorities included making it easier for people to apply for disability benefits, cited by 14% of the sample; helping with the cost of home care, personal assistance, and equipment (11%); and improving transportation services (5%).

As might be expected, these views and priorities varied considerably as a function of respondents' source of coverage. Those relying only on Medicare for their health insurance, for example, were significantly more likely than were those with other sources of coverage to report prescription drug coverage as a top priority, reflecting the absence of a drug benefit in the current Medicare benefit package (Exhibit 23). The most common top priority among those without insurance altogether was making it easier for people with disabilities to apply for benefits, cited by more than a third (34%) of this group.

Exhibit 21

Worries and Concerns Among Non-Elderly People with Disabilities

Percent reporting having the following worries and concerns:

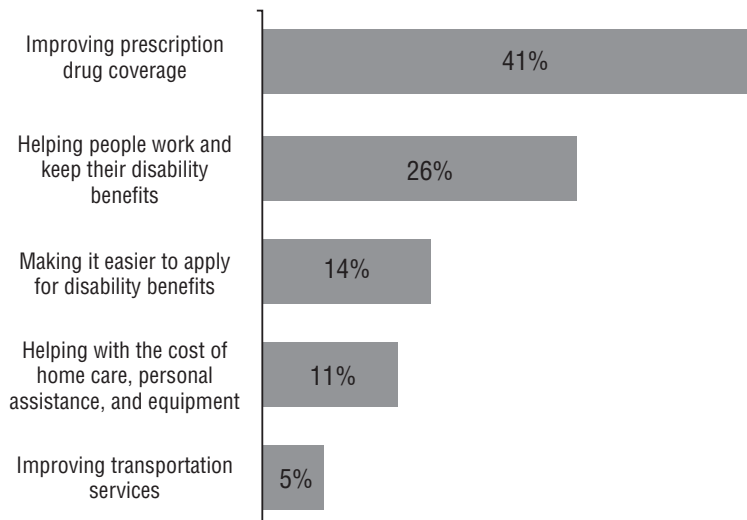


SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 22

Disability-Related Policy Priorities Among Non-Elderly People with Disabilities

Percent reporting the following as the most important disability-related issue for government to address:



NOTE: Data reflect those citing more than one policy priority.

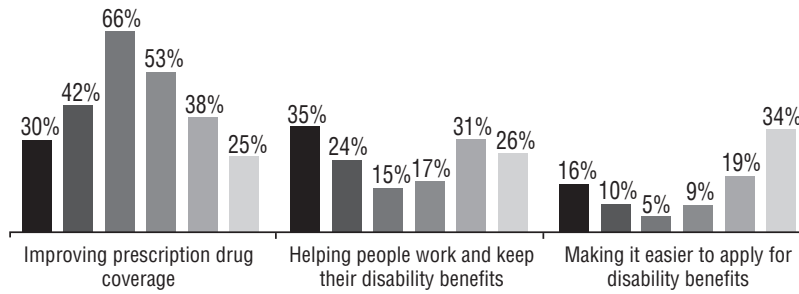
SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Exhibit 23

Disability-Related Policy Priorities Among Non-Elderly People with Disabilities, by Source of Health Insurance

■ Medicaid only ■ Medicaid and Medicare ■ Medicare only ■ Medicare and Private ■ Private ■ No Insurance

Percent reporting the following as the most important disability-related issue for government to address:



SOURCE: Kaiser Family Foundation *Survey of People with Disabilities*, 2003.

Conclusions and Policy Implications

Adults living with disabilities face considerable challenges in the health-care system. Those interviewed for this survey have wide-ranging disabling conditions and substantial health-care needs, along with high rates of functional and cognitive limitations. For many, these needs are compounded by low or modest incomes that often translate into financial barriers to the medical care and supports they need.

Although most people with disabilities do have some form of health insurance coverage, those who are both uninsured and disabled are at a particular disadvantage in the current health-care system. They are more likely than others to forgo or delay getting necessary care, including the prescription drugs and preventive services that would reduce their future need for health-care services. These findings underscore the importance of additional research that identifies those who fall within this group in terms of their health-care needs, income levels, and employment status, while also suggesting the need to provide health insurance coverage for small, but particularly vulnerable subsets of adults with disabilities.

The findings from this survey also demonstrate that all sources of insurance are not created equal in meeting the needs of people with disabilities. Private insurance is often perceived as the most generous source of coverage, generally serving those with higher incomes. However, even those with private coverage often have significant problems paying for various services due in part to high cost-sharing requirements and the lack of coverage of specific services often needed by people with disabilities, such as personal assistance services.

Medicaid appears to shield low-income adults with disabilities from cost-related problems when compared to those with Medicare or private insurance. This is most likely due to the scope of benefits covered under Medicaid and the program's low cost-sharing obligations. Despite Medicaid's relative generosity, however, specific Medicaid benefits do vary considerably by state. Further research is needed to assess the extent of this variation and its effects on beneficiaries with disabilities nationwide. In addition, in the face of rising costs and budget shortfalls, states are currently looking for ways of slowing growth in program spending, such as curtailing benefits, increasing cost-sharing requirements, and restricting eligibility. In sum, this survey confirms both the success of Medicaid in assisting people with disabilities and the potential consequences of budget-driven cutbacks.¹⁰

Medicare provides a critical source of insurance for under-65 adults with disabilities who might otherwise face significant obstacles to affordable health insurance. However, even among non-elderly people with disabilities, Medicare is available only to those who have already been enrolled in the SSDI program for two years. In addition, beneficiaries who rely on Medicare as their sole source of coverage are far more likely than those with either Medicaid or private insurance to delay care, go without needed equipment, and forgo medicines due to costs. They are also more likely than others who have supplemental coverage to report cost-related problems. The new Medicare drug benefit is likely to help those who cannot afford their medications—particularly if designed to cover the unique drug-related needs of Medicare's non-elderly beneficiaries, including those with modest incomes.¹¹ Beyond pharmaceuticals, a careful reexamination of Medicare's benefit package and coverage limits could help to reduce the large share of beneficiaries who report significant problems paying for other services such as mental-health care, dental care, equipment, and home-health services.¹²

In conclusion, the findings from this survey highlight the diverse needs of non-elderly adults with disabilities, while also demonstrating the need for significant improvements in the health-care coverage available to this population. Along with extending coverage to particularly disadvantaged groups of people with disabilities without insurance altogether, future policy debates should focus on strengthening the coverage currently offered through both public and private sources of insurance to improve health care and quality of life for Americans with disabilities.

NOTES

¹ A number of methods were used to maximize the overall response rate, including eight or more call attempts per telephone number, locating techniques for invalid phone numbers, and refusal conversion attempts. The study used the American Association of Public Opinion Research's RR3 response rate formula, which is defined as completed interviews (n=1,505) divided by completed interviews, refusals, non-contacts, and an estimated proportion of unknown contacts.

² Because a central goal of this research was to examine the experiences of individuals covered under Medicare and Medicaid as well as other sources of health coverage, the definition of disability used to create the sample differs from those used in other surveys, such as the Current Population Survey or the National Health Interview Survey.

³ For a more complete discussion of the methods involved in the imputation process, contact the authors.

⁴ SSI is a cash-assistance program for low-income people who are totally and permanently disabled, as determined by the Social Security Administration. Those who are eligible for SSI automatically qualify for Medicaid, although some states have the authority to impose more restrictive eligibility criteria. SSDI is a federal program for people with disabilities with a work history, but without regard to income. People qualify for SSDI if they have a permanent disability that prevents them from engaging in substantial gainful activity and if they have contributed to Social Security for a specified period of time. The SSDI program is financed by Social Security taxes and the amount of the disability payment is based on the individual's earnings record. Enrollees are eligible for Medicare 24 months after they first enroll in SSDI.

⁵ Medical Expenditure Panel Survey website: <http://www.meps.ahrq.gov>

⁶ Recommendations for mammogram use from Centers for Disease Control, www.cdc.gov/cancer/nbccedp/info_bc.htm.

⁷ The National Health Interview Survey on Disability (NHIS-D) estimates that 16% of the non-elderly adult population was uninsured in 1994-1995.

⁸ Foote, Sandra M., and Christopher Hogan. "Disability Profile and Health-Care Costs of Medicare Beneficiaries Under Age 65." *Health Affairs* 20 (November/December 2001): 242-253.

⁹ Safran, Dana G., et al. "Prescription Drug Coverage and Seniors: How Well Are States Closing the Gap?" *Health Affairs Web Exclusive* (July 2002): W253-W268.

¹⁰ *States Respond to Fiscal Pressure: State Medicaid Spending Growth and Cost Containment in Fiscal Years 2003 and 2004*— Results from a 50-State Survey. Report prepared for the Kaiser Commission on Medicaid and the Uninsured, September 2003.

¹¹ Briesacher, Becky, and Bruce Stuart. *Medicare's Disabled Beneficiaries: The Forgotten Population in the Debate Over Drug Benefits*. Report prepared for The Henry J. Kaiser Family Foundation and The Commonwealth Fund, September 2002.

¹² Eichner, June, and David Blumenthal, editors. *Medicare in the 21st Century: Building a Better Chronic Care System*. Washington, DC: National Academy of Social Insurance, January 2003.



The Henry J. Kaiser Family Foundation
2400 Sand Hill Road
Menlo Park, CA 94025
(650) 854-9400 Fax: (650) 854-4800

Washington Office:
1330 G Street NW
Washington, DC 20005
(202) 347-5270 Fax: (202) 347-5274
www.kff.org

Additional copies of this publication (#6106) are available on the
Kaiser Family Foundation's website at www.kff.org.