

# Uncovering The Health Challenges Facing People With Disabilities: The Role Of Health Insurance

Findings from a 2003 national survey of people with disabilities highlight barriers to care among the uninsured and those with gaps in coverage.

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**ABSTRACT:** Americans with disabilities have wide-ranging health care needs and face serious challenges in the health care system. This 2003 survey of 1,505 nonelderly adults with disabilities finds relatively large shares of people with disabilities reporting cost-related barriers to care. The study also reveals marked differences in cost-related experiences both between those with and without health insurance and across sources of coverage. These findings suggest the need for additional research, along with policies to provide health insurance to people with disabilities who lack coverage, to fill gaps in coverage among those with Medicare and private insurance, and to maintain coverage for Medicaid enrollees amid rising costs and state budget shortfalls.

PEOPLE WITH DISABILITIES face serious challenges because of their often substantial health care needs, their reliance on a wide range of services and supports, and their often low and fixed incomes.<sup>1</sup> Despite these challenges and the need to navigate a complex system of public and private sources of health care coverage and assistance, little is known about the services and supports people with disabilities need to live independently in the community, the extent to which their needs are being met by the health care system, and how this varies by source of insurance and other personal characteristics.

This paper examines the role of health insurance for people with disabilities,

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with a particular emphasis on Medicare and Medicaid. Together, these two programs provide coverage to more than ten million nonelderly people (under age sixty-five) living with disabilities.<sup>2</sup> Given the size of the population affected, the substantial commitment in public dollars, and the challenges inherent in living with a disability, it is especially important to understand how well these programs are meeting people's needs and the extent to which gaps in coverage create barriers to needed care.

A number of existing data sets shed light on the challenges people with disabilities face, in terms of the public programs they rely on for health insurance and other forms of assistance, their health care needs, and financial circumstances. However, these data are often restricted to specific subgroups of people with disabilities, defined either by disability type or by a single source of insurance coverage, or are focused primarily on measures other than the extent to which various health programs are meeting the needs of this heterogeneous population.<sup>3</sup>

For instance, the Medicare Current Beneficiary Survey (MCBS) includes detailed data on the health care needs, coverage status, and living situations of all Medicare beneficiaries, including nonelderly beneficiaries living with disabilities. However, because the survey by definition excludes those not enrolled in Medicare, it does not address the question of how those with other sources of insurance compare along these dimensions. The Disability Supplement to the National Health Interview Survey (NHIS-D), one of the most comprehensive efforts to identify people with disabilities and their patterns of health care use, continues to provide important information but was conducted almost ten years ago.

In addition to survey data, administrative data—such as Social Security data on the numbers of disabled people receiving income support through the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs—provide another source of information about people with disabilities.<sup>4</sup> However, these resources are generally limited to data on basic demographic characteristics and disability benefits, not health coverage, spending, and outcomes.<sup>5</sup> Conversely, national Medicare and state Medicaid data reflect use and health care payments made by these programs but include no information on other payers, out-of-pocket costs, access measures, or barriers to care.

These data sources, while valuable, leave a number of questions unanswered. In an effort to address some of these gaps, this 2003 survey takes a comprehensive look at the health-related characteristics of people with a broad range of disabilities and provides information on how use, costs, and access vary by source of coverage. This paper highlights key survey findings, including the diversity of this population, the major health care challenges they face, how their experiences vary by insurance type, and the extent to which specific sources of coverage are associated with access- and cost-related problems. The paper concludes with a discussion of the range of policy options that could be considered in an effort to address the challenges we identify.

## Study Methods

The data presented in this paper are based on a national telephone survey of 1,505 nonelderly people ages 18–64 with permanent physical disabilities, mental disabilities, or both. The sample was drawn from a nationally representative survey of households to identify people with disabilities. Households were contacted through random-digit dialing and screened between 19 June 2002 and 28 January 2003, and interviews were conducted between 9 January and 11 February 2003. International Communications Research (ICR) conducted the fieldwork. The survey instrument was developed by team of researchers at ICR and the Henry J. Kaiser Family Foundation, in consultation with academic disability experts and others at the Social Security Administration.

There are multiple approaches to defining *disability* for research purposes. However, because a central goal of this study was to describe the health care experiences of nonelderly adults across a broad array of disability types and sources of coverage, the questions were designed to capture two groups of people ages 18–64: (1) those receiving disability payments through either SSI or SSDI; 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 contacted again for full interviews. The survey instrument included items on respondents' disabling conditions, health care use, health insurance, access to care, cost burdens, employment status and history, and basic demographic characteristics.

As the sample was collected, 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 contacted again for complete interviews, a number of those identified in the initial screening process were deemed invalid because the respondent no longer met the inclusion criteria, had moved out of the residence, had died, or some other reason. Among those not ruled out in this way, the response rate was 67.3 percent.<sup>6</sup> The sample excludes people with disabilities living in institutions and non-English speakers. Proxy interviews were conducted with 168 respondents (11 percent of the total sample) on behalf of those whose disabilities or health status prevented them from completing the interviews themselves.

Demographic data were used to poststratify the sampling weights to census data.<sup>7</sup> The exhibits in this paper present weighted data so that the estimates are representative of the national population of people ages 18–64 who are disabled according to the criteria we used.

Respondents were assigned to one of the following insurance groups: Medicaid only, Medicare only, Medicaid and Medicare (“dual eligibles”), Medicare and private, private only, some other source, and uninsured.<sup>8</sup> Given that many people have multiple sources of insurance to help fill the gaps in their primary coverage, these categories were derived to test the impact of different sources of coverage, both alone and in combination with other sources. For about 25 percent of all cases,

data on health coverage were missing or invalid. Regression-based imputation was used to assign coverage to these people, using models that included SSI/SSDI participation and selected demographic and health-related indicators.<sup>9</sup>

Our analyses include bivariate and multivariate models. Bivariate relationship testing across categorical variables and sources of insurance employed analysis of covariance (ANCOVA) models, using a Bonferroni adjustment to account for multiple tests of significance. Multivariate models contained two waves of logistic regression designed to measure factors associated with access problems and cost-related barriers to care.<sup>10</sup> The first separated source of insurance into dummy variables using those with only private coverage as the comparison group. The second used single dichotomous variables defined by pairs of insurance types to allow for specific comparisons other than those provided by the dummy variable analysis. This approach facilitated additional comparisons—for example, between people with Medicare and no supplemental coverage and those with both Medicare and Medicaid. Whereas the first approach included all respondents, the models used in the second approach were limited to those in each insurance group.

This survey could be used to address additional policy-relevant issues, including variations in health care experiences across sources of disability assistance, such as SSI and SSDI. However, such issues are beyond the scope of this analysis, which was designed primarily to explore the role of insurance in the lives of people with disabilities. In addition, as stated above, source of coverage was imputed for 25 percent of the sample because of apparent uncertainty among these respondents concerning their coverage. Given the strong link between enrollment in disability-benefits programs and health insurance through Medicaid and Medicare, exploring the role of disability benefits in the outcomes of interest here would require a different analytical approach from the one we took.

## Study Findings

People with disabilities face serious socioeconomic and health-related disadvantages compared with the nonelderly U.S. population as a whole. Relative to the general nonelderly adult population, people with mental or physical disabilities (or both) in this sample have lower incomes and are older, disproportionately likely to be female, much less likely to be employed, and in much poorer health (Exhibit 1). Because of these characteristics and their baseline disabling conditions, people with disabilities tend to have many more limitations in their basic daily activities and are much more likely to use the health care system intensively.

■ **Health care needs.** People with disabilities have an extremely wide range of health care needs and personal circumstances (Exhibit 2). A large majority (80 percent) of the sample described here became disabled in adulthood, 9 percent either were born with their disability or became disabled before age one, and the remaining 10 percent became disabled before turning eighteen.

The number of different disabilities reported by this population speaks to the

**EXHIBIT 1**  
**Overview Of Survey Sample And U.S. General Nonelderly Population, By Selected Demographics, 2001 And 2003**

	Survey sample (%) (N = 1,505)	U.S. nonelderly adult population (%)
<b>Income</b>		
<\$9,000	35	5
\$9,000-\$11,999	14	2
\$12,000-\$17,999	13	5
\$18,000-\$23,999	8	6
\$24,000 or more	24	83
<b>Race/ethnicity</b>		
White	72	72
African American	14	12
Hispanic	6	12
Other	6	5
<b>Age</b>		
18-34	14	38
35-44	18	26
45-54	33	22
55-64	34	14
<b>Sex</b>		
Male	44	49
Female	56	51
<b>Region</b>		
Northeast	17	19
Midwest	23	24
South	39	36
West	21	21
<b>Employment status</b>		
Employed	11	74
Unemployed	11	15
Unable to work because of disability	74	6
Retired	4	3
<b>Health status</b>		
Poor	35	2
Fair	34	7
Good	19	23
Very good/excellent	11	68

**SOURCES:** Kaiser Disability Survey, 2003; National Health Interview Survey, 2001; and Current Population Survey (CPS), 2001 (income).

**NOTES:** Data within categories might not add to 100 percent because of rounding and missing data. Missing data are generally more prevalent with respect to income. Income in this sample is based on income from individual and spouse, whereas the CPS uses a broader definition that includes income from others in the household as well.

array of health care services and other sources of support that people with disabilities often need. Most of the people in the sample (61 percent) reported having a physical disability, 15 percent reported having a mental disability, and 24 percent reported having both physical and mental disabilities.

The specific conditions and diagnoses reported include a wide range of congen-

**EXHIBIT 2**  
**Disability Attributes, Sources Of Support, And Use Of Health Care Services, By Health Status, 2003**

Disability attribute	Total	Health status	
		Fair/poor	Good/very good/excellent
<b>Age of disability onset (years)</b>			
<1****	9%	5%	20%
1-18****	10	7	17
>18****	80	88	63
<b>Disability type</b>			
Physical	61	62	60
Mental****	15	11	25
Physical and mental****	24	28	15
<b>Activities of daily living</b>			
Difficulty showering****	35	41	21
Difficulty dressing****	34	39	22
Difficulty getting in/out of bed/chair****	41	48	25
Difficulty taking Rx at right time**	28	29	24
Difficulty preparing meals****	49	55	37
Often feel depressed**	70	78	52
<b>Sources of support</b>			
Family/friends**	70%	71%	65%
Home health aide	8	8	6
Equipment (among those with a physical disability)****	45	48	35
<b>Use of health care</b>			
<b>Been to doctor in past 6 months</b>			
Haven't been to doctor****	8%	5%	14%
1-3 times****	33	29	43
4+ times****	57	63	42
<b>Been to emergency room in past 6 months</b>			
Haven't been to emergency room****	66	62	75
1 time	15	16	15
2 or more times****	18	22	10
<b>Preventive health services in past 12 months</b>			
Mammogram	44	46	41
Dental exam****	41	35	53
Prostate exam	34	37	29
<b>Regular prescription use (mean number of drugs "taking these days")****</b>			
	5.8	6.8	3.4

**SOURCE:** Kaiser Disability Survey, 2003.

**NOTE:** Individual categories might not add to 100 percent because of rounding or missing data.

\*\* $p < .05$  \*\*\*\* $p < .001$

ital conditions, injuries, neurological disorders, and psychiatric illnesses. Injury-related disorders were the most commonly reported (affecting 18 percent 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 percent of the main disabling conditions in the sample. These groups alone demonstrate the diversity of the disabled population in health care needs, reliance on equipment and other sources of support, and ability to navigate the health care system independently.

While a majority of the sample reported being satisfied with their current quality of life, respondents also described substantial challenges performing many basic tasks of daily living (Exhibit 2). About half reported difficulties preparing meals, and more than a third reported having difficulty with other basic tasks, such as getting in or out of a bed or chair, showering and bathing, dressing, and taking medicines at the right time. Those respondents who reported being in fair or poor health were more likely than their healthier counterparts to have difficulties with each of these activities. Compounding these basic functional challenges, more than two-thirds of the sample said that they often feel depressed.

Family members and friends are an important source of support for people with disabilities, with almost three-quarters of the sample relying on family and friends for assistance with daily activities. By contrast, fewer than one in ten 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 percent of those with a physical disability relying on some form of equipment, such as motorized wheelchairs, to help them manage their basic needs.

Not surprisingly, many people with disabilities use the health care system frequently: 90 percent reported having seen a physician in the six months prior to the survey, and one-third reported a visit to the emergency room in the past six months. In addition, nearly 90 percent reported using at least one prescription drug regularly. As might be expected, these use rates are higher than they are for the general adult population.<sup>11</sup> People in fair or poor health are especially likely to use services frequently: Almost two-thirds of this group reported seeing a physician four or more times in the previous six months, compared with slightly more than 40 percent of those who consider themselves in better health. While those with disabilities are relatively heavy users of health care services, they receive these services much less frequently than is generally recommended.<sup>12</sup>

■ **Health insurance coverage.** Previous research has documented the importance of health insurance in facilitating access to health care.<sup>13</sup> Thus, it is especially critical to examine the role of coverage in the context of people with complex service needs, such as those with disabilities. In our sample, 95 percent have some form of health insurance. This high rate of coverage is partly attributable to the links between enrollment in disability benefit programs such as SSI and SSDI and eligibility for health insurance through Medicaid and Medicare, respectively. However, even among those with disabilities, this sample includes a disproportionate share with insurance, most likely because of the definition of *disability* we used, which was de-

signed to facilitate analysis of the role of health insurance.<sup>14</sup>

Looking at the three leading sources of health insurance in this sample, 44 percent are covered by Medicaid (including the 14 percent with both Medicaid and Medicare), 43 percent by Medicare (including 14 percent with Medicaid known as “dual eligibles” and another 14 percent with private supplemental coverage), and 33 percent by some form of private coverage (Exhibit 3). Roughly two-thirds rely on a single source of insurance coverage, and about one-third have reported multiple sources of coverage. When the sample is sorted into mutually exclusive groups, 30 percent rely solely on Medicaid, 15 percent have Medicare as their only source of coverage, and 19 percent rely on private health insurance alone.

The populations covered by different sources of coverage vary along several dimensions.<sup>15</sup> In terms of disability type, for example, Medicaid was more likely than other sources of insurance to serve people with mental disabilities. More than half (53 percent) 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

### EXHIBIT 3 Disability Type, Income, Race, Sex, And Health Status, By Source Of Health Insurance, 2003

	Total	Medicaid only (A)	Medicare only (B)	Medicaid and Medicare (C)	Medicare and private (D)	Private only (E)	Other source only (F)	No insurance (G)
Sample size	N = 1,505 (100%)	n = 451 (30%)	n = 225 (15%)	n = 214 (14%)	n = 206 (14%)	n = 287 (19%)	n = 46 (3%)	n = 75 (5%)
Disability type								
Physical	61%	46% <sup>B,C,D,E</sup>	69%	64%	71%	69%	70%	55%
Mental	15	21 <sup>B,d,e,g</sup>	9 <sup>C</sup>	22 <sup>D,g</sup>	5	13	11	9
Both	24	32 <sup>C,E</sup>	21	15 <sup>g</sup>	24	17 <sup>g</sup>	20	35
Income								
<\$12,000	49	77 <sup>B,D,E,F,G</sup>	44 <sup>C,D,E</sup>	74 <sup>D,E,F</sup>	18 <sup>f,G</sup>	13 <sup>f,G</sup>	37	56
\$12,000-\$24,000	21	11 <sup>B,D,e,g</sup>	38 <sup>C,E</sup>	16	26	22	28	25
>\$24,000	24	5 <sup>D,E,F</sup>	13 <sup>D,E</sup>	8 <sup>D,E,f</sup>	49 <sup>e,f,G</sup>	60 <sup>F,G</sup>	33 <sup>g</sup>	8
Race								
White	72	66 <sup>D,E</sup>	77	74 <sup>e</sup>	80 <sup>g</sup>	88 <sup>G</sup>	69	64
African American	14	18 <sup>E</sup>	16 <sup>e</sup>	16 <sup>e</sup>	13	3 <sup>f,g</sup>	24	21
Hispanic	6	13 <sup>B,C,D,E,f</sup>	4	1	2	5	*	8
Sex								
Male	44	30 <sup>B,C,E,F</sup>	61 <sup>D,e</sup>	52	42	45	69	52
Health status								
Fair/poor	69	67 <sup>b</sup>	79 <sup>c,e</sup>	66	74	64	65	73

**SOURCE:** Kaiser Disability Survey, 2003.

**NOTES:** Individual categories might not add to 100 percent (or 1,505) because of rounding, missing data, or imputation. The result in each cell was compared individually to every other result in the same row (that is, across insurance types). Superscript letters indicate whether the given value is significantly different from each of the values in the same row, in the columns indicated by the letters. Uppercase letters denote significance level of  $p < .001$ ; lowercase letters denote  $p < .05$ . Significance results are reported only once. So, for example, if a result in column A is significantly different from a result in column E, the letter E (upper- or lowercase depending on the  $p$  value) will appear alongside the result in column A, but the letter A will not appear alongside the result in column E.

\*Sample was too small to generate statistically significant estimates.

those on Medicare (either alone or with private coverage) have a mental disability, similar to the population covered by private coverage only.

Although people with disabilities are more likely than adults in the general population to have lower incomes across the board, Medicaid is especially likely to serve poorer beneficiaries, simply because of the program's income and asset eligibility criteria. In this sample, 77 percent of the Medicaid population and 74 percent of those enrolled in both Medicaid and Medicare reported annual incomes of \$12,000 or less. Fewer than half (44 percent) with Medicare alone fall into this income group, and even smaller shares of those with Medicare and private coverage and private coverage alone do so. Not surprisingly, given the connection to an employer or the ability to afford such a policy on one's own, 60 percent of those with private coverage alone reported incomes of \$24,000 or more per year.

Relative to Medicaid, which serves many of those with the lowest incomes, the uninsured population is composed disproportionately of the near-poor, or those with incomes just above the federal poverty level. Those in this income range could face the greatest challenges in access and out-of-pocket costs.

■ **Access problems and cost-related barriers.** Because utilization patterns are driven by multiple factors—including health care needs, people's care-seeking behavior, and the affordability of care—this survey also explored the extent to which people with disabilities face challenges in paying for care, navigating the health care system, and getting needed services.

Although the majority of survey respondents said that they have a regular doctor, one in four reported having had trouble finding a doctor who understands their disability (Exhibit 4). The uninsured were also more likely than those with health insurance to say they have no regular doctor and to report trouble finding a doctor who understands their disability. When it comes to finding a doctor who accepts their insurance, 17 percent of the sample reported this problem, with higher rates reported among those covered by Medicaid.

Overall, prescription drugs and dental care are the services or benefits most commonly named as causing cost problems, cited as a serious problem by 32 percent and 29 percent of the sample, respectively. In addition, 21 percent of those who use equipment to manage their disabilities said that they have serious difficulties paying for such equipment, and 17 percent of those with a mental disability said that the cost of mental health services was a serious problem. The affordability of these services has direct implications for the care people with disabilities receive. Sizable shares of this sample reported having postponed care (37 percent) or gone without necessary items such as equipment and eyeglasses (46 percent) because of cost. In addition, 36 percent of the overall sample reported having skipped medication doses, split pills, or gone without filling a prescription altogether to save money. Previous work has shown that seniors on Medicare struggle with paying for their prescription medicines as well, with 22 percent estimated to skip doses or split pills.<sup>16</sup>

**EXHIBIT 4**  
**Access Problems And Cost-Related Barriers To Care, By Source Of Coverage, 2003**

Access problems	Total	Medicaid only (A)	Medicare only (B)	Medicaid and Medicare (C)	Medicare and private (D)	Private only (E)	No insurance (F)
No regular doctor	15%	15% <sup>d</sup>	16%	15%	7% <sup>F</sup>	14% <sup>f</sup>	69%
Trouble finding a doctor who understands disability	25	25	18 <sup>c,f</sup>	32	25	24	35
Doctor would not accept health insurance	17	22 <sup>e</sup>	12	23	13	12	-1
<b>Cost-related barriers</b>							
Serious problems paying for							
Physician visits	22	15 <sup>B,F</sup>	31 <sup>C,F</sup>	12 <sup>e,F</sup>	21 <sup>F</sup>	24 <sup>F</sup>	64
Hospital care	15	7 <sup>B,d,e,F</sup>	26 <sup>C,F</sup>	8 <sup>F</sup>	14 <sup>F</sup>	16 <sup>F</sup>	49
Prescription drugs <sup>2</sup>	32	24 <sup>B,F</sup>	52 <sup>C,d,E</sup>	28 <sup>F</sup>	35 <sup>f</sup>	27 <sup>F</sup>	62
Equipment <sup>2</sup>	21	10 <sup>b,d</sup>	18	11	18 <sup>e</sup>	9	11
Home care <sup>2</sup>	16	12 <sup>b,f</sup>	60 <sup>c</sup>	15 <sup>f</sup>	13	23	*
Mental health <sup>2</sup>	17	14 <sup>d</sup>	26 <sup>d</sup>	10	5 <sup>E</sup>	25	36
Dental care	29	27	47 <sup>c,d,e</sup>	26	20	24	43
Put off/postponed care	37	24 <sup>B,c,e,F</sup>	60 <sup>C,D,E</sup>	38 <sup>F</sup>	27 <sup>F</sup>	37 <sup>F</sup>	66
Went without things needed (such as glasses, equipment)	46	40 <sup>B,F</sup>	69 <sup>C,D,E</sup>	49 <sup>f</sup>	40 <sup>F</sup>	36 <sup>F</sup>	67
Skipped doses, split pills, or didn't fill a prescription in past year	36	28 <sup>B,F</sup>	58 <sup>C,D,E</sup>	32 <sup>F</sup>	36 <sup>f</sup>	31 <sup>F</sup>	60
Spent less on basic needs (food/heat)	36	34 <sup>B</sup>	53 <sup>C,D,E</sup>	32	31	29 <sup>f</sup>	49

**SOURCE:** Kaiser Disability Survey, 2003.

**NOTES:** Individual categories might not add to 100 percent because of rounding or missing data. The result in each cell was compared individually to every other result in the same row (that is, across insurance types). Superscript letters indicate whether the given value is significantly different from each of the values in the same row, in the columns indicated by the letters (see Legend at top of table). Capital letters denote significance level of  $p < .001$ ; lower-case letters denote  $p < .05$ . For sample sizes, see Exhibit 3. Significance results are reported only once. So, for example, if a result in column A is significantly different from a result in column E, the letter E (upper- or lowercase depending on the  $p$  value) will appear alongside the result in column A, but the letter A will not appear alongside the result in column E.

<sup>1</sup> Not applicable.

<sup>2</sup> Among those using these services and, for mental health, among those with a mental disability.

\*Sample was too small to generate statistically significant estimates.

Those without health insurance are at a substantial disadvantage when it comes to paying for services. More than half of the uninsured reported serious problems paying for physician visits and prescription drugs, and almost half reported similar problems paying hospital and dental bills. Not surprisingly, when compared with the rest of the sample, people with no insurance whatsoever are more likely to take stringent measures to cut costs. Two-thirds of the uninsured reported having postponed care and gone without necessities because of cost, and almost as many said that they split pills, skipped doses, or did not fill a prescription to save money.

■ **Variations in access problems and cost-related barriers, by source of coverage.** Multivariate analyses designed to examine the relationship between health insurance and selected access problems and cost-related barriers to care confirm the

importance of insurance for people with disabilities (Exhibit 5). For instance, those without any source of health insurance coverage were approximately four times as likely as people with health insurance to have postponed care because of cost. The uninsured were about three times more likely than the insured to go without needed supplies or forgo medicine because of cost.

Level of coverage and financial protection vary considerably by source of insurance. Those with Medicaid as their sole source of coverage were significantly less likely than those with either private coverage or Medicare alone to report postponing care or skipping on medications because of cost. In general, those relying solely on Medicare fared less well than people with private coverage. In addition, respondents with Medicare as their sole source of coverage were more than twelve times as likely to have postponed care and more than seven times as likely to have forgone taking medications because of cost than those enrolled only in Medicaid, which underscores the important financial protections provided by Medicaid.

Among disabled Medicare beneficiaries under age sixty-five, those with some form of supplemental coverage are at a substantial advantage in surmounting cost-related barriers to care. Medicare beneficiaries without supplemental coverage through either a private source or Medicaid were significantly more likely

**EXHIBIT 5**  
**Relationship Between Health Insurance, Access Problems, And Cost-Related Barriers To Care (Odds Ratios), 2003**

Insurance status	Access problems		Cost-related barriers		
	Trouble finding doctor who understands disability	Doctor wouldn't accept insurance	Postponed care because of cost	Went without equipment/items because of cost	Skipped/split pills because of cost
Insured (reference)					
Uninsured	-	-	4.10****	2.60****	3.13****
Private (reference)					
Medicare only	0.434**	-	2.63****	4.27****	2.64**
Medicaid only	0.403**	-	0.24****	-	-
Medicaid (reference)					
Medicare only	-	-	12.63****	4.26****	7.33****
Effect of supplemental coverage for Medicare under-65 disabled					
Medicare + Medicaid (reference)					
Medicare only	0.498**	0.378**	6.28****	2.98****	5.92****
Medicare + private (reference)					
Medicare only	-	-	6.79****	4.88****	4.00****

**SOURCE:** Kaiser Disability Survey, 2003.

**NOTES:** Insurance categories are mutually exclusive. People with Medicare, Medicaid, or private insurance do not have any source of supplemental coverage, unless explicitly noted. More detailed specifications of the models are available from the authors (see Note 9 in text).

\*\*p < .05 \*\*\*\*p < .001

than those having those coverage sources to report problems on each of the three cost-related outcome measures tested here. Those relying solely on Medicare were almost seven times more likely than those with supplemental coverage to postpone care because of 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 because of cost.

When multivariate analyses were used to examine the relationship between source of coverage and access problems not stemming directly from the costs of care, the results were somewhat mixed, with insurance appearing to play less of a role than it does where cost-related barriers to care are concerned.

## **Conclusions And Policy Implications**

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

People who are both uninsured and disabled are at a particular disadvantage. They are more likely than others to forgo or delay getting necessary care, including prescription drugs and preventive services that would reduce their future need for health care. These findings underscore the importance of additional research to identify those who fall within this group in terms of their health care needs, income levels, and employment status, along with their eligibility for and enrollment in programs serving people with disabilities such as SSI and SSDI. In addition, the challenges faced by this group of people with disabilities suggest the need for strategies to improve access to affordable coverage for the relatively small share of adults with disabilities who are also uninsured.

A number of approaches could be pursued to achieve this goal, including relaxing eligibility rules to permit more low-income adults with disabilities to qualify for assistance under Medicaid. Similarly, eliminating the twenty-four-month period during which SSDI beneficiaries must wait before becoming eligible for Medicare would clearly help close gaps in coverage for that particular segment of the uninsured population.<sup>17</sup> In addition to strategies involving public programs, policymakers could expand access to coverage through subsidized high-risk pools or could pursue insurance reforms to overcome well-documented barriers to coverage in the individual market, such as denials of coverage, exclusions for underlying conditions, and high premiums.

These findings also demonstrate that all sources of insurance are not created equal in meeting the needs of this population. Private coverage is often perceived as the most generous source of coverage, generally serving those with higher incomes. However, even those with private coverage often have serious problems paying for various services. By contrast, Medicaid appears to be performing well

in shielding low-income adults with disabilities from cost-related problems compared with people on Medicare or private insurance. This is most likely attributable to the scope of covered benefits under Medicaid and the program's low cost-sharing obligations. Despite Medicaid's relative generosity, however, specific benefits vary considerably by state. Further research is needed to assess the extent of these variations and their effects on disabled beneficiaries around the country. In addition, in the face of rising costs and budget shortfalls, states are looking for ways to slow 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.<sup>18</sup>

Medicare provides a critical source of insurance for adults under age sixty-five with disabilities who might otherwise face serious obstacles to affordable health insurance. However, 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, or forgo medicines because of cost. They are also more likely than others who have supplemental coverage to report cost-related problems. A new Medicare drug benefit would clearly help those who cannot afford their medications—particularly if designed to cover the unique drug-related needs of Medicare's nonelderly beneficiaries.<sup>19</sup> In addition, a careful reexamination of Medicare's benefit package and coverage limits could help to reduce the large share of beneficiaries who report problems paying for other services such as mental health care, dental care, equipment, and home health services.<sup>20</sup>

The findings from this survey highlight the diverse needs of nonelderly adults with disabilities, while also demonstrating the need for important improvements in the health care coverage available to this population. Along with extending coverage to particularly disadvantaged groups of people with disabilities who lack coverage altogether, future policy debates should focus on strengthening the coverage offered through both public and private sources of insurance, to improve health care and the quality of life for Americans with disabilities.

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**NOTES**

1. J.A. Meyer and P.J. Zeller, "Profiles of Disability: Employment and Health Coverage" (Washington: Kaiser Commission on Medicaid and the Uninsured, September 1999); and M.J. Perry, A. Dulio, and K.W. Hanson, "The Role of Health Coverage for People with Disabilities: Findings from Twelve Focus Groups with People with Disabilities" (Menlo Park, Calif.: Lake, Snell, Perry, and Associates and Henry J. Kaiser Foundation, September 2003).
2. J.D. Kasper, Unpublished analysis of 1999 Medicaid Statistical Information System (MSIS) and 1999 Medicare Current Beneficiary Survey (MCBS) for the Kaiser Commission on Medicaid and the Uninsured, November 2002.
3. For examples of analyses specific to individual sources of coverage, see T.A. Coughlin, S.K. Long, and S.

- Kendall, "Health Care Access, Use, and Satisfaction among Disabled Medicaid Beneficiaries," *Health Care Financing Review* (Winter 2002): 115-136; and G.F. Riley, J.D. Lubitz, and N. Zhang, "Patterns of Health Care and Disability for Medicare Beneficiaries under Sixty-five," *Inquiry* (Spring 2003): 71-83.
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, 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 disability payment amounts are based on a person's earnings record.
  5. L.I. Iezzoni, "Using Administrative Data to Study Persons with Disabilities," *Milbank Quarterly* 80, no. 2 (2002): 347-379.
  6. 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, noncontacts, and an estimated proportion of unknown contacts.
  7. Because a central goal of this research was to examine the experiences of people covered by Medicare and Medicaid as well as by other sources, 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.
  8. There are thirty-eight respondents in the "Medicaid-only" group with both Medicaid and private coverage and twenty-three in the Medicaid and Medicare group who have private coverage as well.
  9. For a more complete discussion of the methods involved in the imputation process, contact the authors. Send e-mail to Tricia Neuman, [tneuman@kff.org](mailto:tneuman@kff.org).
  10. Additional independent variables included in the regression models, but not presented here, are disability type (mental, physical, mental and physical) and age of onset, health status and functional status, sources of support, health care use, and demographic information.
  11. Authors' analysis of MEPSnet Household Component, 2000, August 2003, [www.meps.ahrq.gov/mepsnet/HC/MEPSnetHC.asp](http://www.meps.ahrq.gov/mepsnet/HC/MEPSnetHC.asp) (7 November 2003).
  12. For example, see "Screening for Breast Cancer: Recommendations and Rationale," February 2002, [www.ahrq.gov/clinic/3rduspstf/breastcancer/brcanrr.htm](http://www.ahrq.gov/clinic/3rduspstf/breastcancer/brcanrr.htm) (17 October 2003).
  13. J. Hadley, "Sicker and Poorer—The Consequences of Being Uninsured: A Review of the Research on the Relationship between Health Insurance, Medical Care Use, Health, Work, and Income," *Medical Care Research and Review* 60, Supp. (June 2003): 3S-75S.
  14. The National Health Interview Survey on Disability (NHIS-D) estimates that 16 percent of the nonelderly adult population was uninsured in 1994-1995.
  15. S.M. Foote and C. Hogan, "Disability Profile and Health Care Costs of Medicare Beneficiaries under Age Sixty-five," *Health Affairs* (Nov/Dec 2001): 242-253; and Meyer and Zeller, *Profiles of Disability*.
  16. D.G. Safran et al., "Prescription Drug Coverage and Seniors: How Well Are States Closing the Gap?" 31 July 2002, [www.healthaffairs.org/WebExclusives/Safran\\_Web\\_Excl\\_073102.htm](http://www.healthaffairs.org/WebExclusives/Safran_Web_Excl_073102.htm) (27 October 2003).
  17. The number of respondents in the waiting period in the survey sample was not large enough to analyze independently. However, a report recently released by the Commonwealth Fund estimates that 1.2 million nonelderly people with disabilities are enrolled in SSDI, but in the two-year waiting period for Medicare eligibility, as many as 400,000 of them could be uninsured. Commonwealth Fund, *Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs*, July 2003, [www.cmwf.org/programs/medfutur/dale\\_waitingperiod\\_ib\\_660.pdf](http://www.cmwf.org/programs/medfutur/dale_waitingperiod_ib_660.pdf) (17 October 2003).
  18. V. Smith et al., "States Respond to Fiscal Pressure: State Medicaid Spending Growth and Cost Containment" (Washington: Kaiser Commission on Medicaid and the Uninsured, September 2003).
  19. B. Briesacher and B. Stuart, "Medicare's Disabled Beneficiaries: The Forgotten Population in the Debate over Drug Benefits" (Washington: Henry J. Kaiser Family Foundation, September 2002).
  20. J. Eichner and D. Blumenthal, eds., *Medicare in the Twenty-first Century: Building a Better Chronic Care System* (Washington: National Academy of Social Insurance, January 2003).