

**THE ROLE OF HEALTH COVERAGE FOR
PEOPLE WITH DISABILITIES:**

**Findings from 12 Focus Groups with
People with Disabilities**

Prepared by

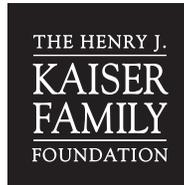
**Michael Perry and Adrienne Dulio
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and

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The Henry J. Kaiser Family Foundation**

August 2003

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Executive Summary

The Henry J. Kaiser Family Foundation commissioned Lake, Snell, Perry, and Associates, Inc., to conduct focus groups on the role of health insurance coverage in the lives of people with disabilities under age 65. This study included 12 focus groups conducted in May and June 2002 in 5 cities: Austin, Texas; Hartford, Connecticut; Los Angeles, California; Missoula, Montana; and New Orleans, Louisiana.

The groups were designed to capture a range of perspectives in terms of both health insurance and specific disabilities. The perspectives of individuals with Medicaid, Medicare, dual coverage (both Medicaid and Medicare), private insurance, and no insurance coverage at all were represented. In addition, people with varying degrees of physical, developmental, and mental impairment participated in the study. In some cases, members of their family or others who assist them attended as well.

The participants were recruited with the assistance of local caseworkers, support groups, local chapters of disability-specific organizations, group homes, and advocates for people with disabilities. As this approach likely gathered individuals who are more connected to the system in terms of obtaining the services and supports they need, it should be noted that the experiences described below are not necessarily representative of all people living with disabilities.

Included among the 98 participants in all of these groups were:

- A 47-year-old woman with **bipolar disorder** and **no health insurance** in New Orleans, LA, who goes to a free clinic for her medications.
- A 20-year-old with **cerebral palsy** enrolled in **Medicaid** who lives at home with his parents in Austin, TX, but relies on a personal care assistant who comes six days a week and helps him “have a normal life.”
- A 49-year-old **Medicare** beneficiary in New Orleans, LA, diagnosed with both **depression and paranoid schizophrenia**, frustrated by the lack of coverage for more intensive visits with his mental-health provider.
- A former competitive skier who is now **quadriplegic due to a spinal cord injury** from a car accident. Living in Missoula, MT, and enrolled in **both Medicare and Medicaid**, he has had significant problems getting the equipment and physical therapy he needs to get by.
- A 19-year-old boy with **cerebral palsy** in Hartford, CT, who has **private health insurance coverage** through his mother’s employer, but worries about losing his current doctors and coverage when he is ready to leave home for college.

Although the health-care system at large often poses challenges for the general population, the insights from these focus groups offer the unique perspectives of relatively frequent users of health-care services with multiple and complex needs. These individuals talk about their experiences with the specific health-care services, prescription medications, daily assistance, and equipment they need to live.

Health Insurance and People with Disabilities

- **Medicaid** covers approximately 8 million people under age 65 who qualify for the program based on disability, including those with physical disabilities, sensory impairments, mental retardation or developmental disabilities, and mental illness. Medicaid covers physician care, behavioral health and long-term support services, and prescription drugs—and is often the only source of assistance with the costs of institutional or community-based long-term care services. Medicaid requires individuals to meet income and asset criteria in order to qualify for coverage.
- **Medicare** covers over 5 million people under age 65 who qualify on the basis of a total and permanent disability after having received disability payments through the Social Security Disability Insurance (SSDI) program for two years. Non-elderly Medicare beneficiaries with disabilities have the same set of benefits as do seniors on Medicare, including physician and hospital care, behavioral health, durable medical equipment, physical therapy, and home health. The traditional Medicare benefits package does not include prescription drug coverage or long-term care.
- **Dual coverage through Medicaid and Medicare** is currently available to over 2 million people under age 65, accounting for about one-third of all “dual enrollees.” Beneficiaries with dual coverage may rely on Medicaid to fill in many of Medicare’s gaps, including prescription drug coverage and long-term care. These benefits are often especially significant for people with disabilities.
- **Private insurance** is available to many people with disabilities through either their own employer (previous or current) or through the employer of a spouse or parent. Individuals may also purchase private policies on their own in the absence of employer-sponsored coverage. Although private insurance typically covers a wide range of services—with the exception of long-term care—many employers are shifting costs onto enrollees in the form of higher coinsurance or limits on benefits.

Overall Findings

Participants were generally highly appreciative of their health coverage. In particular, many spoke of the role that Medicaid plays in providing critical services not otherwise covered by Medicare or private insurance. Others, primarily those with Medicare and private insurance, were grateful for the choice of providers available to them. At the same time, because their needs are more complicated than those of most other consumers, they also identified ways in which programs such as Medicaid and Medicare could be improved to help them lead independent and productive lives. Participants would value changes in health-insurance programs that would allow them to work, support their families, and leave their homes. At the same time, they are fearful of policy changes that would jeopardize their health coverage.

Many of the participants in these groups—including many with severe disabilities—report feeling generally satisfied with their quality of life and access to basic health-care services. At the same time, many describe a fear of losing their disability benefits if they try to work or live more independent lives. As one participant in Los Angeles described her situation:

“[I] worry sometimes that I’ll make too much money and then I’ll be cut off from my benefits with SSI... . If they cut my SSI somewhat, maybe they don’t cut me off completely but I’ll have money from the job and it will balance out either way.”

Given the complexity of their needs—in terms of both health care and assistance with basic activities of daily living—the concerns of many participants were often very dependent on having stable and reliable sources of health insurance and disability benefits. In addition, the diversity of needs among people with disabilities paints a complex picture of the ability of Medicaid, Medicare, and private insurance to serve this population effectively. While a specific program may work best for one group of participants, it may be inadequate for others. The strengths and limitations of specific sources of coverage include the following:

- **Medicaid plays a critical role for many low-income participants with conditions such as severe mental illnesses and spinal cord injuries who are often dependent on prescription medications and personal assistance services.** By offering a wide array of services and charging relatively low co-payments, the program is able to meet the needs of many individuals with complex and serious conditions. Several of the participants feel especially appreciative of Medicaid:

“Through... Medicaid, I get all my medications paid for. I have the opportunity to gain resources like certain doctors and certain institutions.”

“I have asthma medicine and [it] is really expensive, so I just recently got approved for a machine and I got into this program where I call, and they take Medicare and Medicaid, so they deliver my medication to me now so that I can take my breathing treatment and stuff.”

“I have a worker right now who comes in every day and he does pretty good. He gets me up and gets me dressed and sometimes he goes to church with me. Sometimes he goes everywhere with me...”

Many are frustrated by some of the limits on coverage or the inability to find providers, however. For example, some enrollees have experienced difficulty finding a provider who will accept Medicaid; found strict limits on their access to durable medical equipment, personal care attendants, and physical therapy; or been unable to get a medication they needed because it was not on the formulary. A woman on Medicaid living with cerebral palsy in Hartford has had a mixed experience on the program and is frustrated that the equipment Medicaid covers is not sufficient to help her get around on her own:

“One, as far as doctors’ appointments and hospitalizations, yes, I am very happy they cover it all and I can see pretty much anyone I want. But, on the other hand, as far as

equipment, because I walk... a little bit, like around the room and down the hallway, they won't pick up certain things like a power chair because they pick up a manual chair."

Medicaid enrollees are concerned about the future, and feel that their coverage is very much dependent on them limiting their independence. For instance, some fear they would become ineligible if they decided to get married or go to work, particularly since many employers would not be able to offer them coverage. As a man enrolled in Medi-Cal in Los Angeles and suffering from back problems described it:

"I could handle a job and make a whole lot more money... but then I'll lose my Medi-Cal. Since I'm having so many physical problems, my bills in the last year to doctors are way up there over \$10,000 to \$15,000."

■ **Medicare enrollees enjoy access to a wide array of providers and many feel they receive better-quality care because they have Medicare.** They are also appreciative of what they end up paying out-of-pocket relative to what they might without the program. As two Medicare beneficiaries living in Austin, Texas, phrased it:

"Well, one good thing I like about Medicare is that... it has a deductible that is all you have to pay except for 20 percent of the doctor's bill. And, the expense of the hospital is thousands of dollars more than what you have to pay through Medicare."

"Well, I really like my Medicare. I have had it for 10 years. I mean, so many doctors take it. Although it is hard to find a psychiatrist that will take it, but it doesn't pay much. Then I have this other one that supplements it. But the Medicare is just, it is government. It is excellent, and I am able to stay on it."

However, many also cite gaps in their Medicare coverage, particularly in terms of prescription drugs, that cause them to pay large sums out-of-pocket or do without important services. Some, but not all of these enrollees have found ways to get medications from other sources, such as free clinics or state-subsidized programs offering lower-cost medications. Those with Medicare also cite problems with access to preventive services and paying for mental-health care, which requires higher coinsurance than do other Medicare services under Part B (50% vs. 20%).

The need for better access to psychiatric services was acutely felt by a Medicare beneficiary with schizophrenia living in New Orleans:

"I really feel if the government in some way could provide more counseling services to those who need it either at no cost or low cost, it would really be beneficial. It would stop people from going back into the hospital for possible suicide intervention."

Due to these gaps, many Medicare enrollees would like Medicaid coverage as well.

■ **Dual enrollees who have both Medicaid and Medicare are often able to fill many of the gaps in each of these programs. Although benefits vary by state to some extent, dual enrollees are often spared the high out-of-pocket costs that come with gaps in Medicare, with many**

referring to this combination of programs as optimal. Two participants with both Medicare and Medicaid coverage in Los Angeles, appreciated how the services covered by each program complement one another:

“It depends on what I need. If I’m in a hospital, Medicare takes care of it and then Medi-Cal covers what Medicare doesn’t take care of. It’s a catch-all.”

“They do work hand in hand, Medi-Cal and Medicare... [Medi-Cal] pays for all the things that you need once you get out of the hospital. While you are in the hospital, it’s best to have the other one because it covers more than the other one does.”

At the same time, another dual enrollee expressed some frustration with the lack of coordination between the two programs:

“When they’re done correctly, when the filing and stuff is done correctly, they complement each other quite well, so that’s good, when you do all the paperwork correctly. But, there’s so much paperwork and stuff that it’s not very attractive to doctors and hospitals and things like that. I constantly hear complaints, ‘Oh, we can’t do that anymore because it takes so long and we’re not being reimbursed and it’s just a giant headache.’ I’m like, ‘Whatever. Do you take it or not?’ I don’t want to hear their life story. I just want to know whether I’m going to be able to get my health care taken care of and move on.”

In many ways, however, the dual enrollees sound very much like the Medicaid enrollees in this study, only with less trouble finding providers who will accept their coverage. For instance, many are frustrated by their inability to obtain medications not on their formulary, insufficient coverage of durable medical equipment, inadequate access to mental-health providers, and limited coverage of personal-care services. However, despite being frustrated and/or confused about how the two programs work together, dual enrollees generally sound more satisfied than many other enrollees in this study.

■ **Those with private coverage—often through a spouse or parent’s employer—generally feel they have access to an extensive array of providers and high-quality care. However, many of these enrollees appear worried about rising costs, and many are already paying large co-payments and high premiums.** Just like Medicaid and Medicare enrollees, those with private insurance do face some limits on coverage of durable medical equipment, as well as services such as mental-health care and physical therapy. This is especially critical to those with disabilities that call for specialty care. There is also often substantial confusion about what is covered and what is not. As some of the privately insured participants put it:

“I’ve been able to access doctors when I’ve needed to, including specialists... I was handed a list and was able to find one.”

“Basically, I think I’m okay because my health [insurance] has a network and when I first moved to California, I called the network and I found a good doctor. So far, that doctor has led me to other doctors I need.”

“I guess it’s the deductible. You have to pay the first \$1,000 in a given year. I guess that’s what it is instead of just a co-pay. I guess the thing that bothers me is that you just don’t know and I guess it’s just so hard to figure out what’s actually covered, in terms of how much is covered.”

- **The uninsured individuals in these groups face many challenges.** Many said they lack a regular doctor or case manager who is overseeing their care, and many say that they go long periods without any health care at all. Although some of these participants have been able to patch together some basic level of care through free clinics and state-sponsored drug subsidy programs; others are cycling on and off Medicaid; and several have tried applying for benefits through Medicaid or Medicare in the past, but have been denied or are currently waiting to be deemed eligible. Many also feel their providers are generally unsympathetic to their situation. The experiences of some of the uninsured participants included the following:

“He [the doctor] said he wouldn’t touch me unless I paid him up front... I paid him \$800 cash.”

“I get some of [my bills paid] through the family benefits clinic, some of them are paid through the workers comp but the other ones I have to pay out of my own pocket.”

“I don’t have insurance. Once in a while, I do go on MAP [Medical Assistance Program] and get their assistance. They just give me MAP for a few months, and they take me off. Then you have got to go back to do all the paperwork again. Sometimes I forget to go back. Sometimes I don’t qualify for whatever reason. They tell me to go to Medicaid, and then Medicaid tells me to go here and there. They have got me running around. So, at this time, I don’t have any insurance.”

While most of those with insurance in these groups are thus generally satisfied with their benefits, others feel it is a constant struggle to see providers and obtain the prescription medications, equipment, home-health services, and mental-health care they need. Many point out that their ability to function independently and live fuller lives is often contingent on being able to rely on specific services and yet that coverage often appears biased toward services geared toward recovery as opposed to maintaining current levels of functioning—putting those with permanent disabilities at a substantial disadvantage.

In some ways, the participants’ biggest concern is that Medicaid, Medicare, and private insurance are often unable to meet the diverse needs of all people with disabilities in terms of health-care needs, functioning levels, goals, and life circumstances. As a result, much of the discussion in the groups focused on the ways in which various sources of health insurance could be changed to serve people with disabilities more effectively in the context of specific services.

Experiences with Specific Services

Not surprisingly, the experiences of the participants in these groups vary not only by their health insurance status, but also by the types and intensity of services they need.

Office Visits. Regardless of their insurance status, many participants have had difficulty forming a close relationship with their primary care providers and specialists. Those with long-standing relationships with their providers seem most satisfied and able to obtain most of the services they need. As a woman in Austin with two children recounted:

“How do you weigh somebody who can’t stand up to know how much weight they’re putting on in their pregnancy? It was just that I had a very creative gynecologist who arranged for me to go down to St. David’s once a month to the heart unit there. They have this huge weighing thing that you can go on in your wheelchair. So, I went on in my chair and then they weighed the chair on its own. Then, each month, I was able to go on it in the chair and they could tell me how much weight I’d put on.”

However, others cite problems with frequent provider turnover, providers’ lack of knowledge about their disability, and—especially among Medicaid enrollees—difficulty finding a provider who will accept their coverage. Some individuals report having to travel far for specialty care due to a lack of providers in their area. Many claim that their providers lack familiarity with their disability, forcing them to seek information about their health-care needs on their own—by word of mouth, on the internet, or through other sources. A Medicare beneficiary with schizophrenia in New Orleans had experienced particular problems with continuity of care:

“... my internist told me that I would have to take this medication for the rest of my life but hopefully by diet and exercise, I was hoping that, you know, it could be discontinued. But you know... I have another doctor now because they’re always changing in these groups. You know they change doctors. But, the last doctor told me I would have to take it for the rest of my life. So that is an expense that I have incurred.”

Prescription Medications. Most participants depend on prescription medications on a daily basis in order to manage their health and maintain basic functioning—as a result, inadequate access to necessary medications can pose major problems for them. Even among those with drug coverage, many say that health plan formularies are barriers to receiving the medications they need and that their providers are not familiar with the combinations of medications they take. Others express frustrations with coverage that includes only generic medications and are concerned about their potential side effects. This was often true among those with private and public coverage alike. A participant with hyperthyroidism explained her coverage this way:

“If there is a generic available, you have to get the generic first. The only time you get the name brand is when there is no generic available. For my prescriptions, for generic I pay \$5 and for name brand I pay \$15. If it is not on the formulary and I want this particular medicine and I want the name brand, I have to pay \$30 and I have to get it especially approved.”

A man with depression in New Orleans was frustrated by the potential side effects of the medication recently prescribed for him:

“Well, there was one medicine that my doctor gave me a long time ago and he said to my mom, ‘Does he hear voices?’ My mom of course said, ‘No, he just has depression.’”

The doctor says, ‘Well, tell me if he hears voices just in case because the pill might cause this effect.’ If I don’t hear voices, then why would you give me a pill that might cause this type of effect?”

Mental-Health Services. Those who use mental-health services are often frustrated by a lack of time with their providers and are concerned that their treatment places too much emphasis on medication. Many participants express a desire for more office visits with their mental-health providers, specifically more time for conventional therapy and help with “coping skills” and other challenges they face in their daily lives—as opposed to merely discussing medication. Many with chronic mental-health conditions described their situation as extremely frustrating. This sentiment was shared by a man with schizophrenia enrolled in Medicare in New Orleans:

“Just to call the psychiatrist is almost impossible. Sometimes it is almost impossible just to talk to the nurse. You have to leave a message. I have found that mainly we have to try to take care of ourselves as much as we can. Sometimes we might rely on other people too much to take care of us. I think that the doctors and everybody don’t know what they are going through, and they can’t relate to it.”

While those without insurance altogether may be able to get medications through free clinics, they are frustrated by their inability to afford more time with mental-health providers. A woman with bipolar disorder in New Orleans described her time with her provider this way:

“Every three months for 15 minutes, and you pick up your medication every month. If I didn’t have that... the only thing that I complain about is that my doctor will change because the doctor moves on, so I wouldn’t have a doctor for more than two or three years. We also see groups, so we are in a group of six people, and they just go down the line whoever came in, but I don’t find that I am neglected. If I am in crisis, there is a number.”

Participants with mental-health needs who are connected to a local service provider seem best able to form strong relationships with mental-health professionals and to receive other social-support services.

Durable Medical Equipment. Participants with a range of insurance sources cite many problems with durable medical equipment coverage, and feel that they must fight for every piece of equipment they need or else pay large sums of their own money for it. There is a general sense among participants that Medicaid, Medicare, and private insurance do not always cover the equipment that is best suited to the individual. Some who need a motorized scooter in order to be fully mobile and able to go about their daily lives, for instance, have found that Medicaid will cover only a manual wheelchair. Others describe having needed new parts for or repairs to their wheelchair that Medicaid will not cover. Participants who rely on equipment generally feel that they—not their insurance program—know best what they need and they feel frustrated by the struggles, long waits, and high out-of-pocket expenses often entailed in obtaining such equipment. A dual enrollee in Austin summarized his situation as follows:

“They don’t cover anything. I don’t understand what the point in getting you a chair is if they’re not going to help you at least sometimes. If it’s not paying for the repairs

outright, maybe they can do something creative like a buy-in program or something. If we all pulled in together, it would be a lot cheaper. Something that they could do because when you're in a motorized chair and something big goes wrong you're just sort of..."

Even those with private coverage had experienced such frustrations with lack of coverage:

"A lot of people are in a position where their disability varies... in some situations, it could be better to have a power chair; others, it would be better to have a manual chair. And, the insurance, anywhere I've seen, be it Medicare or Medicaid or private insurance, will only fund one kind of chair for you. Or repairs on it, like if your last chair purchased was a power chair they won't fix your old manual chair."

Personal Care Assistance. Participants with severely disabling physical conditions such as cerebral palsy and quadriplegia need a great deal of personal care assistance (PCA), which can include daily help with basic functions such as bathing, getting dressed, and eating meals. In talking about this care, many stress the vital role it plays in helping them live full and active lives. Medicare and private insurance generally do not cover this critical service. Although Medicaid does in most states, it is an optional benefit. Many participants enrolled in Medicaid fear cuts in coverage, citing ways in which PCA adds substantially to their quality of life. As one mother put it:

"It's really been good for [my son], it's helped him to be more independent. He's now in an independent living situation and, without PCAs, that would really be difficult because of the meals and having to deal with those kinds of things."

Their concern is that their insurance does not always cover as many PCA hours as they need. This is a big worry for many participants who claim that PCA enables them to live in their own home rather than in a nursing home. Indeed, a few participants in this study have spent time in nursing homes and fear that, if their PCA hours are cut, they will have to return. Lastly, some mention that they have difficulty finding qualified and reliable PCAs due to their being poorly trained and paid.

Physical Therapy. Many participants are frustrated that access to physical therapy so often depends on their ability to show progress and feel that maintaining current levels of functioning is just as important. Many express concerns about the limits that Medicaid, Medicare, and private insurance place on the amount of physical therapy those with disabilities can receive, asserting that Medicaid and Medicare in particular will eliminate their physical therapy sessions if they do not see progress or greater mobility. As one woman in Hartford summed it up:

"[Physical therapy] is another concern because Medicare seems to always switch and suddenly stop it. They say, 'Oh no, you're chronic, we can't help you.' Then, you can apply three weeks later and they say, 'Oh, fine. Let's do twice this week.' So, they don't seem to have any sense in how they evaluate."

Dental Care. Most participants report that their dental coverage is inadequate. Even among those with dental benefits, many claim that only minimal services are covered. In addition, several participants have found it challenging to find a dentist who accepts Medicaid payment

and/or who will see someone with their disability. A woman accompanying her son, a young teenager with obsessive compulsive disorder enrolled in Medicaid, to one of the groups in Missoula, Montana, described the difficulties of finding a dentist who would see them:

“We just had a dentist who wouldn’t even see us, numerous dentists wouldn’t take us.”

Transportation Services. Although Medicaid covers transportation services for travel to and from medical appointments, many have to rely on other forms of public transportation (both services specifically for people with disabilities and public transportation more generally) to get to and from work, run errands, etc. However, many say these services are not easy to use because of advanced-scheduling requirements, geographic limits, and criteria for use—with many living in rural areas describing problems with access to these services. Those who lacked adequate transportation, mostly the uninsured and those with private insurance, feel that improved access to these services would make a large difference in their daily lives. This also proved a problem for those enrolled in Medicaid. As an enrollee in New Orleans with depression put it:

“Well, sometimes the transportation is very slow, but then again, I am not paying for it so I really can’t complain on that point. It is because they have so many people that they have to pick up. Sometimes they will come and pick you up an hour early, and you have to ride around while they pick up everybody else.”

Case Management and Service Coordination. Although many participants are unfamiliar with formal case management services, several have an intermediary, often a family member or peer counselor at an independent living center, who assists with the coordination of their care. Such arrangements seem to work well in some instances but less well in others. Moreover, while some are interested in learning more about professional case managers, others suspect that they would be more concerned with cost management and want to retain control over their own care. Only those with Medicaid who have had reliable access to the same case manager or service coordinator for a year or more seem relatively happy with this service. Others say that high turnover makes it difficult to forge a close relationship with one person over time. Participants who have never used this service find the concept appealing since they often feel alone in managing their care, but worry that their needs may not be most appropriate for this type of service. According to a Medicare beneficiary with schizophrenia living in New Orleans, for example:

“The question before about how do we feel about handling our healthcare and do we need case workers, a lot of it depends on your health. And, with a mental illness, it depends on how well we can function mentally and make decisions for ourselves. You know? I understand there are case workers in facilities but I still feel that, at least in New Orleans, [in] one Metairie area that I’ve heard about, the system is overrun.”

Policy Implications

Gaining a better understanding of the diverse needs of people with disabilities and the extent to which they are being met by the current health-care system will be critical to future improvements in coverage. As discussed above, many people with disabilities acknowledge and appreciate the

coverage they have, which in many cases allows them access to vital services. Participants are acutely aware of how much worse off they would be were they to lose their coverage or have their benefits cut back.

At the same time, however, many express frustrations with the current patchwork of programs for people with disabilities in terms of insufficiently generous benefits, administrative and bureaucratic hassles, and health-care providers' lack of familiarity with and sensitivity to their needs. The insights provided by the participants in this series of focus groups may thus inform ongoing debates concerning improvements in Medicaid, Medicare, and private insurance in terms of the following observations:

- **Medicaid plays a critical role in the provision of the range of services often needed by people with disabilities, particularly prescription drugs and the home- and community-based services that often enable people to avoid institutional care.** While Medicaid offers a broad benefit package and relatively low cost-sharing, other sources of coverage such as Medicare and private insurance are less effective in meeting the various needs of this heterogeneous population.
- **The population of people living with disabilities is extremely diverse with respect to individuals' health-care needs, levels of functioning, goals, and life circumstances.** The heterogeneity of this population has significant implications for the ability of Medicaid, Medicare, and private insurance to meet the needs of their enrollees.
- **Many participants find the processing of applying for and enrolling in different programs extremely overwhelming and confusing.** Many have gone through the process of filling out the paperwork and gathering the materials needed for eligibility determination, only to be turned down for reasons that are not always clear to them. Others have found their way onto Medicare or Medicaid by navigating these programs' disability and income criteria, but are still not entirely clear about the benefits that are and are not covered.
- **In many ways, participants with mental-health needs seem to face some of the greatest challenges in navigating the health-care system.** Those with all sources of health insurance describe their time with their mental-health professionals as overly focused on medication management instead of on therapy *per se*. Out-of-pocket expenses are also a problem for those with Medicare and private insurance, making therapy sessions dedicated to discussing issues and acquiring coping skills prohibitive.
- **For many participants—particularly those with mental disabilities—access to prescription medications is critical to managing their daily lives. There is great variation across sources of health insurance in terms of whether medications are covered and, if so, to what extent.** Although those with Medicaid are generally satisfied with their drug coverage, many are increasingly anxious about new limits on the number and types of drugs that are covered. Those with Medicare alone, however, are less fortunate in that they do not have any drug coverage at all.

- **Access to durable medical equipment such as wheelchairs is critical for people with physical disabilities in terms of increasing their mobility and independence at home, in the workplace, and in the community.** Based on the comments of many participants, in order to be meaningful, coverage must include equipment tailored to individuals' needs and repairs of such equipment when necessary.
- **Most participants say their ability to lead active and independent lives is inextricably linked to their access to needed services, medications, and social supports.** At the same time, participants in these groups perceive many of the rules and eligibility criteria as barriers to such independence in terms of employment, living in the community, and decisions about marriage and starting a family. Many cite Medicare's homebound rule, which denies coverage of home-health services to those who leave their homes with the help of another person or a wheelchair, as an example of a disincentive to function independently even when possible. As a Medicare beneficiary in Hartford who is quadriplegic put it:

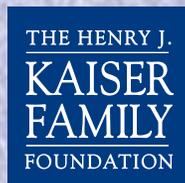
"They sent me this thing... what they determine 'homebound' is. It's that you don't go out on a regular basis and then only with a great deal of difficulty... My provider says, and it's arbitrary... that, if you're homebound, you sit in the damn house. You don't go out unless it's to a doctor. The only time I ever went out was the doctor and a haircut that they knew about. ... You couldn't go out, couldn't go to a movie, couldn't go to dinner, couldn't go and see friends, couldn't go to a party."

Another participant described his situation this way:

"It's like a death sentence because the more you work, the more they take and, so it's almost better if you don't work in some instances. But, I like to be a person that does something with life, not just sits there."

As the comments of the participants in these focus groups demonstrate, people with disabilities make up a diverse population with a wide range of health-care needs and personal circumstances that vary within and across public programs and private sources of coverage. It is also clear that many are greatly appreciative of the coverage they have today. At the same time, they express a wish for the ability to lead more independent lives without risking losing their current benefits.

The experiences described above may assist policymakers considering future changes to public programs such as Medicaid and Medicare by shedding light on the specific needs of people with disabilities. Furthermore, as many payers—public and private alike—look to Medicare as the standard in terms of the benefits they should offer, such decisions about coverage may affect all people with disabilities in that changes to public programs will likely have ripple effects beyond the programs themselves.



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