



CHRISTOPHER REEVE
PARALYSIS FOUNDATION

**WAITING FOR MEDICARE:
EXPERIENCES OF UNINSURED PEOPLE WITH DISABILITIES
IN THE TWO-YEAR WAITING PERIOD FOR MEDICARE**

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ABSTRACT: While most of the 40 million Americans covered under Medicare are age 65 and older, nearly 6 million qualify because of severe and permanent disabilities. Unlike older Americans, who typically enroll and become eligible for coverage within months of turning age 65, disabled beneficiaries must wait two years before their coverage takes effect. Many who are in the waiting period face enormous problems. In this study, researchers talked to these individuals in focus groups and through in-depth telephone interviews. Participants reported skipping medications, putting off needed care, feeling depressed and anxious about the future, and believing they were not in control of their own lives. To alleviate their plight, the researchers recommend that Congress eliminate the waiting period, expand Medicaid eligibility, and subsidize COBRA insurance coverage. Beneficiaries also need better, more consistent information regarding their options for accessing health care and coverage.

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EXECUTIVE SUMMARY

Medicare plays a vital role in providing decent, appropriate, and affordable health care coverage to more than 40 million beneficiaries. The vast majority of Americans with Medicare are age 65 and older, who typically enroll and become eligible for coverage within three or four months of turning age 65. However, the same is not true for the nearly six million people under age 65 who qualify for Medicare because of a severe and permanent disability. Federal law requires these individuals to wait two years after they receive Social Security Disability Insurance (SSDI) before their Medicare coverage takes effect.

There are growing indications that many individuals in the waiting period face enormous difficulties obtaining needed health care, and that as many as one-third may be uninsured.¹ The Commonwealth Fund and the Christopher Reeve Paralysis Foundation commissioned this study to gain insight into the experiences of people with disabilities under age 65 in the Medicare two-year waiting period. This study included two focus groups in Atlanta, Georgia, in February 2004, followed by nine in-depth telephone interviews in March and April 2004 with participants nationwide. Participants had an array of disabilities, including spinal cord injury, multiple sclerosis, cardiovascular disease, diabetes, several cancer, bipolar mood disorder, severe depression, HIV/ AIDS and obsessive compulsive disorder (OCD). Many had both physical and mental conditions. While several Atlanta, Georgia focus group participants are enrolled in Medicaid, most participants in this study are without any health insurance during the two-year waiting period.

Insights from the focus group and interview participants provide a powerful commentary on the lives of people with disabilities attempting to make it through the Medicare two-year waiting period. Participants speak candidly about how lack of coverage during the waiting period often acts as an insurmountable barrier to the care and services they require. They speak of foregoing care; stopping medications and therapy; feeling depressed and anxious about the future; and feeling less independent and in control over their own lives. For most, just trying to survive and get their most basic human and health care needs met is a never-ending job. Specific insights from the focus groups include:

- **Participants say the Medicare two-year waiting period impedes their ability to live full lives.** Most believe that without health coverage and Medicare, they cannot return to work, regain mobility, participate in their

communities, and stop depending on family members and friends for their basic needs. Rather, they live constrained lives, fearful of their next health crisis.

- **Most participants access health care sporadically, at best.** Despite their many health care needs—everything from chemotherapy, to physical therapy, to mental health services—most participants seem to receive minimal care because they often cannot afford to pay for services out-of-pocket, and feel they must avoid incurring costs whenever they can. Many tell of skipping medications, doing only limited physical therapy or none at all, putting off doctor visits or diagnostic tests, or not seeing their mental health provider.
- **Many participants suffer irrevocable physical and mental deterioration during the waiting period.** Foregoing doctor’s visits, treatments, medications, and rehabilitation therapy has resulted in irrevocable damage to their physical and mental health. Others talk about the stress and worry of being uninsured with a disability, and how that has affected their overall well being.
- **While many want to return to work, they are unable to do so.** One striking insight of this study is the degree to which participants see Medicare’s two-year waiting period as a barrier to work. Only two out of 21 study participants work; the others expect to return to work in the future, but do not see how, given their current state. Many feel they need better access to health services before considering working again.
- **Many participants lost their Medicaid coverage when they received SSDI benefits.** Participants found themselves in a Catch-22. When they received a small increase in cash benefits, they lost health benefits through Medicaid. Some with incomes below the poverty line never even met their state’s Medicaid eligibility criteria.
- **Lack of knowledge about Medicare, the two-year waiting period, and other health coverage options is a problem for most participants in this study.** Many fear that if they return to work, they will lose both SSDI and their Medicare coverage once it starts. Most are confused about Medicare and the types of services it will cover once they enroll. While some participants are aware of federal work incentives they could use to return to work and retain both their SSDI and Medicare coverage, much of what they heard was incomplete or inaccurate, and few report having used these incentives. Even the most persistent

participants in this study say they have no information resources for health coverage and are unable to get their questions answered.

- **Since many cannot qualify for Medicare or Medicaid, private insurance is their only option, yet they believe it is out of reach.** Most participants see private health insurance as unaffordable. At some point, many had private insurance—usually when they had a job—and recall not worrying about how to pay for their employer-based insurance. Some used COBRA to maintain their private insurance for the short period after they left their jobs, but found it too expensive to continue for the full period allowed under the statute.¹ Some also worry that they could no longer qualify for private insurance because their pre-existing conditions would either make them ineligible or such coverage would be extremely costly.
- **Finally, all participants want the Medicare two-year waiting period eliminated.** Most perceive the two-year rule as an unnecessary barrier between them and the health care system. They have strong emotions about the waiting period—they feel it is “punitive” and “does more damage than good.” They feel their lives are put on hold while they wait for health coverage and believe this is fundamentally unfair. They see their health deteriorating and returning to work becoming increasingly impossible.

To learn more about these and other insights from this study, please refer to the full report of findings.

¹ The Consolidated Omnibus Budget Reconciliation Act (COBRA), which passed in 1985, allows most workers leaving employer-sponsored group coverage to buy into that coverage for up to 18 months. But, they must pay 102 percent of the premiums. Additionally, COBRA permits those in the Medicare waiting period to continue paying for private coverage for up to 29 months. But to do this, they must pay premiums of 102 percent for the first 18 months, and premiums of up to 150 percent for any additional months they maintain such coverage (i.e., for months 19 through 29).

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INTRODUCTION

Medicare plays a vital role in providing decent, appropriate, and affordable health care coverage to more than 40 million beneficiaries. Most Americans with Medicare are age 65 and older who typically enroll and begin coverage within three or four months of turning age 65. For these beneficiaries, the enrollment process is short and simple. However, the same is not true for nearly six million people under age 65 who qualify for Medicare because of a severe and permanent disability. Federal law requires these individuals to wait two years after they begin receiving Social Security Disability Insurance (SSDI) before their Medicare coverage takes effect. A principal reason Congress imposed the two-year waiting period was to “help to keep program costs within reasonable bounds.”²

From February to April 2004, The Commonwealth Fund and the Christopher Reeve Paralysis Foundation sponsored two focus groups and nine in-depth interviews with individuals with disabilities in the Medicare two-year waiting period to learn about their experiences including: the impact of the waiting period on their health and independence, access to health insurance and health care, and prospects for employment. The focus groups and interviews included individuals who are within, or had only recently completed, the two-year waiting period to gain the freshest perspective on the barriers to receiving health care and living independent, productive lives. The participants have a wide array of disabilities, including both physical and mental impairments, and most are currently uninsured. (See Appendix A for a description of characteristics of participants.)

More Americans with disabilities can lead active, healthy, and productive lifestyles than ever before. Advances in the law, education, health care, and technology make this increasingly possible for millions. In enacting the Americans with Disabilities Act in 1990, Congress declared that: “The Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.” Today, Medicare is already playing a vital role in making certain that millions of Americans of all ages with disabilities have access to appropriate and affordable health care they often need to help achieve these goals in their own lives. This becomes self-evident when one recognizes that:

² U.S. House of Representatives, Committee on Ways and Means, *Social Security Amendments of 1971*, House Report No. 92-231, May 26, 1971, p. 67 and Senate Committee on Finance, Senate Report No. 92-1230, Sept. 26, 1972, p. 178.

- Without Medicare, most of these individuals would almost assuredly be “uninsurable” and they, as well as many of their families, would be forced to go without any health coverage.
- Medicare helps pay for a broad array of preventive care, rehabilitation, mental health services, home health, and durable medical equipment essential to the health and independence of such beneficiaries.
- Accessing these services and supports is crucial to enabling millions to avoid far more costly hospitalization and long-term institutionalization.
- It also can enable many Americans with disabilities to return to work.

But, as this study amply illustrates, the Medicare two-year waiting period creates tremendous barriers for many under age 65 trying to obtain needed health care, assistive devices, and other services at a time when many need it the most: after becoming severely disabled or seriously ill.

BASIC FACTS ON MEDICARE AND AMERICANS WITH DISABILITIES UNDER AGE 65

Disability is a subject you may read about, but not think about—actually happening to you. But, a 20-year-old worker has a 30 percent chance of becoming disabled before reaching retirement age.³

To fully understand the study’s findings, consider the following:

Medicare and Working Age People with Disabilities

According to the 2000 Census, there are approximately 33.1 million working age people with disabilities between ages 16 and 64 in the U.S.⁴ Of this, six million—or one in five—are currently enrolled in Medicare. About five million of these individuals are covered by Medicare because they became severely and permanently disabled while working, and receive SSDI payments. The remainder have Medicare because they are the disabled spouses, widows, or widowers of current or deceased Medicare beneficiaries; the dependent, disabled adult children of current or deceased Medicare beneficiaries who have had severe and permanent disabilities since childhood; or people with end-stage renal disease.

³ Social Security Administration, *Social Security Protection If You Become Disabled*, available at <http://www.ssa.gov/dibplan/index.htm>.

⁴ U.S. Census Bureau, *Disability Status: 2000*, available at <http://www.census.gov/prod/2003pubs/c2kbr-17.pdf>.

The Link Between SSDI and Medicare

SSDI is partial wage replacement income for workers who have paid into the Social Security system for six to 10 years, depending on their age, and become too disabled to work based on SSA rules. The average SSDI monthly benefit is about \$864.⁵ In 1972, Congress extended Medicare benefits to these workers after a two-year waiting period.

The Process

To understand the impact the waiting period can have on such individuals' health and well-being, you must first understand the strict criteria and timelines that must be met before they can obtain and begin Medicare coverage.

- A worker must meet the Social Security's Disability Standard. For an adult to be considered disabled, the SSA must determine that the individual cannot engage in any "substantial, gainful activity" because of a physical or mental impairment that is expected to result in death or to continue for at least 12 months.
- Once such a worker has been certified as having a severe and permanent disability, they must wait five months before receiving their first SSDI check.
- After the person receives their first SSDI payment, they must wait an additional two years before their Medicare coverage actually goes into effect.

Exceptions to the Waiting Period

The Medicare two-year waiting period requirements apply to almost all of these individuals, with two exceptions: In 1972, when Congress first extended Medicare benefits to workers who became disabled before reaching age 65 and created the two-year requirement, it established a separate three-month waiting period for those with end-stage renal disease. In 2000, the Congress passed legislation that now enables people with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease) to enroll in Medicare upon diagnosis. Member of Congress passed both measures because they believed the health of the affected individuals warranted more timely access to Medicare coverage.

⁵ Social Security Administration, SSDI statistics, Table 5. DI benefits, by type of beneficiary April 2003 to April 2004, available at http://www.ssa.gov/policy/docs/statcomps/oasdi_monthly/2004-04/table5.html.

This study focuses exclusively on how the waiting period has affected the lives and futures of 21 people with disabilities under age 65—all of whom are currently on SSDI. While not a true representative sample, those that participated comprise an appropriate cross section of the entire SSDI population. For this reason, it might be helpful to consider the following:

General Characteristics

About six million people are on SSDI: most are men, age 50 or over. But, about 2.1 million are age 49 or younger, and one-third of this group is age 39 or younger; many of whom might return to work if afforded access to necessary health care and related services. Over 70 percent of those on SSDI also has one of the following four primary conditions: mental illness (28.1%), musculoskeletal system and connective tissue conditions (23.9%), circulatory system conditions (10.1%), and nervous system and sense organs conditions (9.6%).⁶ About 59 percent of those on SSDI say they are in fair or poor health.⁷

Of the 1.2 million people with disabilities under age 65 in the waiting period in 2002, virtually all are unemployed and non-self-sufficient. By the time they obtain Medicare coverage after the two years end, most (77%) are poor or nearly poor. Nearly half (45%) have incomes below the poverty line. About 400,000 or one-third of all these individuals likely were uninsured. About 40 percent were enrolled in Medicaid. Another 25 percent to 33 percent may have at least some private insurance coverage either under COBRA or their spouse's employer-based health plan.⁸

As many as 2.3 million working-age people with severe disabilities were uninsured in 2000.⁹ An estimated 400,000 of those people—or 17 percent—is someone who is on SSDI and waiting for their Medicare coverage to take effect.¹⁰ No study,

⁶ Social Security Administration, *Annual Statistical Report on the Social Security Disability Insurance Program, 2002*, August 2003, available at http://www.ssa.gov/policy/docs/statcomps/di_asr/2002/index.html.

⁷ Betsy Briesacher et al., *Medicare's Disabled Beneficiaries: The Forgotten Population in the Debate over Drug Benefits* (New York: The Commonwealth Fund, September 2003), available at http://www.cmwf.org/publications/publications_show.htm?doc_id=221529.

⁸ Stacy Berg Dale and James M. Verdier, *Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs* (New York: The Commonwealth Fund, July 2003), available at http://www.cmwf.org/publications/publications_show.htm?doc_id=221569.

⁹ Based on an analysis of the Medical Expenditure Panel Survey (MEPS 2000) conducted for the Henry J. Kaiser Family Foundation by Johns Hopkins University and cited in *Understanding the Health Care Needs and Experiences of People with Disabilities: Findings from a 2003 Survey*, by Kristina Hanson, Tricia Neuman and Molly Voris for the Kaiser Family Foundation, available at <http://www.kff.org/medicare/121203package.cfm>.

¹⁰ Dale, *Elimination of Medicare's Waiting Period*, 2003.

other than this one, has been conducted that focuses specifically on the experiences of people with disabilities on SSDI who are uninsured during the waiting period. But a 2003 national telephone survey of 1,505 nonelderly adults ages 18 to 64 with permanent physical and/or mental disabilities, found that those who were uninsured face enormous barriers in accessing needed health care, and, as a result, postpone or forego it completely.¹¹

DETAILED FINDINGS

WAITING FOR MEDICARE: AN UPHILL BATTLE

Although participants in this study have a variety of disabilities, they have much in common: chaos and uncertainty rule their lives. Only two participants are currently working; the others have had to leave employment behind indefinitely because of physical or mental limitations. Uncertain as to how they will feel day-to-day, regular employment is currently not an option. For most, money is running out and they are barely able to make ends meet on their SSDI payments alone. The majority are without any form of health insurance, yet require regular supervision and care from doctors and typically take several different prescription medications. Paying for food and rent is difficult. Paying for critical medications, doctor's visits, and rehabilitation therapy—and, in a few cases, completing a round of chemo or radiation therapy—is often out of the question. Several have accumulated mounting debt from health expenditures that they are unable to pay. Because of their physical and mental conditions, their abilities to drive, sleep, and even think clearly are sometimes inhibited. As a result of these factors, both mental and physical fatigue, depression, and worries about the future have set in for most.

“You have to put your life back together. . . . You’re just trying to stay alive. I don’t understand what is up with these two years. I’m a cancer patient. I didn’t stub my toe.”

Participant with cancer,
Glen Rose, Texas

This section describes what the two-year waiting period has meant to these participants. It begins by documenting experiences with the SSDI application process, a self-described “nightmare” to many; followed by their daily struggles—difficult, often painful, choices are made between “living and surviving.” Finally, it focuses on these individuals’ access to doctors and specialists, rehabilitation therapy, prescription medications, and assistive devices (e.g., wheelchairs or nebulizers).

¹¹ Hanson et al., *Experiences of People with Disabilities*, 2003.

Frustration from the Start: Applying for SSDI

Most individuals describe applying for SSDI as a trying, difficult process. A few admittedly received assistance from capable, sympathetic case workers, and recall their experience positively. But the majority of participants describe the application process in negative terms, such as a “hassle” or a “nightmare.” Participants blame Social Services for its backlog, bureaucracy, ensuing “runarounds,” and (unnecessarily) lengthy and complex paperwork.

“I think there ought to be an easier way of working with Social Security.”

Participant with diabetes
and cardiovascular disease,
Towson, Md.

One participant in Pflugerville, Texas, with multiple sclerosis recalls, “I kept calling because I wasn’t hearing anything. It was just at a standstill. I said, ‘Can I at least get a letter from the Social Security saying that I’m disabled, so I can keep my [health coverage under] COBRA, so I can keep my medicine?’ He said they couldn’t do that because that would be admitting that I was disabled, and that’s what the hearing is for.”

Most faced difficulty obtaining information and assistance from the local Social Security office where they applied. Individuals note how caseworkers did not return their phone calls, and if they did, it was weeks later. One participant explains: “I mean, you almost get the feeling that if you call once too many, they’re going to punish you. . . . One time, it took over a month for them to return our call. . . . They’re not very pleasant people there to start with. . . .” Many say they were denied SSDI at least once before they were able to get it, and that they are unclear why they were denied.

Why the Wait?

Given the uphill battle participants like this one describe, beginning with the application process for SSDI /Medicare, followed by the ensuing physical and mental deterioration from “going without” for two years (or more), it is not surprising that participants express strong negative feelings about the waiting period. First and foremost, participants are puzzled by it—Why wait two years? Then sentiments turn to resentment and anger.

Not one participant understands the rationale behind the two-year waiting period, nor has it been explained to them during the application process. “Why is the two years there?” asks one participant with transverse myelitis in East Syracuse, New York. “That’s an historical question. Who put that in the legislation or what bureaucrat thought that was a good idea and why? That isn’t there just by accident; somebody chose that, and what’s the rationale?”

They also question having to wait when they have been paying into the system in the first place—it’s their own investment that is being denied them. A Medicaid enrollee with a spinal cord injury, in Atlanta, Georgia, says, “I mean they’ve been taking it straight out of your check, how come they can’t [give it] back? And when you need it, you’ve got to wait two years, you’ve got to wait when you’ve been putting [money] in.”

Many find the two-year wait especially perplexing because they believe it will cost the government more in the long run. According to one participant with multiple sclerosis in Pflugerville, Texas: “What’s occurring, is these people are becoming sicker, whereas, if they were able to get the care they needed right away, or as needed, they wouldn’t have as many severe cases as what they get.” Other participants believe the government is “just waiting for other people to die.” They believe their battle is with the government; more so than with their medical condition.

Making Choices and “Going Without”

Once individuals are approved for SSDI and receive their first disability check five months later, their two-year wait for Medicare coverage begins in earnest. Nearly all say they are forced to pay out-of-pocket for most services and almost all prescription medication; put off doctor’s visits, or visit much less frequently, or not at all (some opting to use the emergency room instead); and, in many cases, forego necessary medications, tests, and rehabilitation therapy. Because of lack of coverage, these individuals say they access services sporadically at best, and inconsistent care is taking a toll on their health.

Participants say mainly why they often receive insufficient and/or inconsistent care is that they cannot afford to do otherwise. Most say their SSDI checks are wholly inadequate to begin to cover their numerous health needs and medical costs they must pay out-of-pocket during the waiting period. One participant from Towson, Maryland, with diabetes and cardiovascular disease, points out how inadequate SSDI payments force

“[After three denials and two appeals,] the judge proceeds to tell me that I have to wait 25 months. I went, ‘More?’ He says, ‘Yes, five months, plus 25 months.’ I said, ‘That’s 30 months?’ He says, ‘That’s the law. That’s the rule.’ I said, ‘But you guys are behind a year on processing my paperwork, and you’re going to penalize me?’ The judge said to my attorney that perhaps she needed to explain the rules to me. I said, ‘What do you mean, rules?’ because I was getting a little unruly I said, ‘I don’t understand.’ I don’t really think the system benefits us like it was meant to benefit us.”

Uninsured participant with multiple sclerosis, Pflugerville, Texas

“Well, maybe you won’t live long enough for us to have to pay that benefit on you. . . . The government is supposed to be for the people, and this law is definitely not for the people.”

Participant with pancreatic cancer, Glen Rose, Texas

most of them into making choices: “The biggest problem is the money we have coming in, \$1,500 a month. My rent is \$947 a month, so there is no money left over. Then, sometimes you make a decision. . . . Well, maybe I don’t get this prescription filled because there is no money to pay for it.”

As a result, participants say that during the two-year waiting period, they are forced to “make choices,” often painful, untenable ones, between food, rent, and other essential items, and receiving the health care they require. A participant with pancreatic cancer, in Glen Rose, Texas explains, “I have to take a pancreatic enzyme because I don’t produce any enzymes to digest my food, and that’s \$90 a month. So when I can’t get that on [the] Indigent [Care Program], then I have to decide whether to eat or take the enzymes. If I take the enzymes and don’t eat, they’ll tear my stomach up. If I eat without the enzymes, I can’t digest the food. It’s another Catch-22. It is not optional.”

Maggie’s Story

Maggie,★ age 57, lives in Texas and has multiple sclerosis (MS) and rheumatoid arthritis. She had to wait more than four years for her Medicare to start, having been repeatedly denied SSDI, and was then told she would have to wait an additional two years after that. Her thoughts: “I think they need to look at the system and realize that some people can wait the two years, but some can’t. They need to have a provision in there, where it’s good for either situation.”

During the waiting period, Maggie was uninsured. Early on, she stopped taking some of her medications “cold turkey.” One is to keep her MS “at bay,” yet it costs roughly \$1500/month. “My MS medicine, the Copaxin, didn’t keep my MS in remission, but it kept it real slow. I wasn’t progressing, and it was just very slow. It was like heaven sent,” she recalls. She says she also foregoes other medications and blood work, and spaces critical doctor’s visits in order to keep health expenses manageable. Maggie plays what she calls “Russian roulette” with her health.

I have to go down my list of medications and choose which pills I can take and which ones I can’t. . . . Some months, I have a little extra money and I can take it, and other months I can’t. . . . I’ve just been picking and choosing. . . . I haven’t done myself any favors by doing that, but you have to do what you’ve got to do.

The result, her doctors tell her, is that her MS is now progressing rapidly. “I went for my bone density [test] the other day, and I got chewed out by the technician because she says, ‘You know you can’t get better if you don’t take your medicines.’” “I said, ‘I take what I can afford to take.’”

She also suffers from related bone density loss. This, in turn, has led to bouts of acid reflux, which has meant additional medications, and she now has high blood pressure and chronic pain.

* Names have been changed to protect privacy.

Participants point out that the biggest barriers to becoming healthier, more independent, and returning to work are “going without” the following services:

Lack of Access to Doctors and Specialists

Many in the study say they require regular care and constant supervision by doctors and specialists. Some depend on life-saving treatments (like chemo and radiation therapy) and other critical procedures like routine blood work and CAT scans. However, because they do not have health insurance, they must pay out-of-pocket for doctor’s visits. For this reason, many delay or just go without care.

Others choose to carefully space their visits; some cutting them by more than half.

To complicate matters, many participants are required to see more than one doctor on a regular (sometimes weekly) basis—often their primary care doctor, a specialist, and a physical or mental health therapist. During the two-year waiting period, this regimen becomes impossible for most. A participant with bipolar disorder in Towson, Maryland recalls, “Well, of course, I would go to my regular family doctor, and I would also go to a psychiatrist. I was going to him for a while. Depending on how I felt, it was either once a week, or once every other week. When the [COBRA] insurance stopped, a 45-minute session with a psychiatrist cost \$120 to \$145. I can’t even think about spending that kind of money.”

“I made them space my visits. Instead of coming in every month, I said, I have to come in every three or four months. They said, ‘OK,’ and if I had any problems, they’d just give me my prescriptions.”

Participant with multiple sclerosis,
Pflugerville, Texas

Participants talk openly about their physical deterioration that can ensue as a result of skipped tests and doctor's appointments. According to one, "If I ache, I would go to the doctor. But when you can't afford to go to that doctor, then you still ache, you know." But the consequences of not having critical tests run can be more severe. According to one participant with pancreatic cancer in Glen Rose, Texas: "I have to have labs run on [my Coumadin levels] because the way he explained it, it's like rat poison. If that Coumadin level gets too high, it's deadly."

Several participants with various cancers choose to forego regular blood work, which can potentially mean not catching the recurrence of their cancers in time to begin a successful course of treatment. Two, in particular, have chosen to stop their chemo and radiation therapy because they cannot afford it.

Going Without Rehabilitation Therapy

For some participants, especially those with spinal cord injuries, rehabilitation therapy is vital. In fact, they say it is paramount to their ability to regain movement and long-term independence. Much like the services highlighted above, however, they say that rehabilitation therapy is unaffordable without health insurance. An uninsured participant with quadriplegia in

"The doctor told me that . . . I needed therapy so I would get out of this chair . . . because that way, my muscles will start moving again, but now I have to wait two years."

Participant with spinal cord injury,
Atlanta, Ga.

Atlanta, Georgia, makes the following point: "I need range of motion every day, you know. I need to come back and get out of the pool. I need to come back and get into the weight room. But without insurance, some things, you can't pay out of pocket for medication and therapy."

Many express the same fears about the future. A Medicaid enrollee with a spinal cord injury, from Atlanta, Georgia, says, "When my therapy got cut off . . . I lost a lot of range of motion. I had problems with my shoulder . . . [with more] therapy, there would be a lot more things I could do. . . ."

Lack of Access to Medical Equipment

Most of the participants (all from Atlanta, Georgia, with spinal cord injuries) who require wheelchairs, were also Medicaid enrollees during the two-year waiting period. Nevertheless, these individuals expressed deep frustration with what they saw as inadequate equipment coverage under Medicaid. Most of their complaints include out-of-date equipment, difficulty obtaining coverage for repairs and

replacement pieces, and the need to pay out-of-pocket for equipment improvements. For example, one participant has been unable to replace an old, malfunctioning manual wheelchair because Medicaid deems this chair adequate for his needs. Another recalls needing repairs to his wheelchair, which getting Medicaid to cover he likens to “pulling teeth.” Still, others say Medicaid will not pay for any repairs.

Just as with access to physical or rehabilitation therapy, participants explain that not having access to an appropriate, well-functioning wheelchair or other equipment, limits their ability to move about their home and community. It also puts them at greater risk for falls, sprained muscles, and other injuries. One reason that these participants would like their Medicare coverage to begin much sooner, is so they can obtain equipment and supplies they need to function as independently as they can.

Going Without Prescription Medications

By far the most common experience of “going without” during the two-year waiting period concerns prescription medications. Participants talk at length about the number of medications they have been prescribed, and the out-of-pocket expenses they have incurred as a result. Because of the expense, most participants recount tales of stopping some prescription medications altogether, and/or scaling back on others. A few participants report having gone without needed medications for months, or even years. In some cases, individuals are choosing between, and in one case, sharing medications. According to a participant from East Syracuse, New York, with transverse myelitis, “Each day, I was on four [medications] for depression; one was to help with the tightness of the muscles. . . . I ran out of that around three months ago.”

One participating couple, both of whom have diabetes (as well as other physical and mental disabilities), has resorted to sharing diabetes medications at times, because they have difficulty paying for both prescriptions. The wife explains, “His diabetes got worse. So I stopped the [drug] and, basically, I just lied to him and told him mine was fine. So I haven’t been on that. . . . I just stopped taking that so he could take his because, actually, I was sharing what he was getting from the VA [Veteran’s Administration] for a little while.”

According to these participants, the results of stopping or scaling back medications can be devastating. The longer they go without, they say, the greater the toll on

their minds and bodies. For example, one participant with pancreatic cancer in Glen Rose, Texas, who stopped taking her blood thinner despite her doctor telling her “it was not an option,” knows her decision might mean “inviting the blood clots back in.”

Those with mental illness have trouble making it through the day without their medications. This participant with bipolar disorder and obsessive-compulsive disorder (OCD) in Towson, Maryland, says:

I just stopped taking the medication for the OCD and the bipolar disorder. [It's] hard to get through a day. It still is, and I've been off of it for quite a while . . . when the insurance was no more, there is no way I could afford those kinds of medications, and I would just do the best I could to get through the day. . . . It's hard, because I would have—I still have—mood swings, and some of my mood swings would last for weeks, some for days. I would go through a period, after I stopped taking the medication, where I would sit on a sofa and I would feel the mood swings go up and down within a matter of minutes. You get this feeling of euphoria, then drop, then euphoria, then drop. It was just constant for, maybe, an hour until I thought I was going to lose my mind.

It should be noted that recent reforms to Medicare include prescription drug coverage. This may mean that individuals in this study waiting for Medicare, and currently lacking prescription drug coverage, could obtain this coverage when their Medicare takes effect.

LACK OF KNOWLEDGE ABOUT SSDI, THE TWO-YEAR WAITING PERIOD, AND MEDICARE

Compounding these obstacles to better health and increased independence is the confusion all participants share with regard to SSDI, the two-year waiting period, what Medicare does, and does not cover, and a host of other related matters. The following sections describe these issues in greater detail.

Participants Are in the Dark About SSDI and Other Programs

Many participants are unclear about SSDI, its purposes, how they came to be on it, and how SSDI relates to programs like Supplemental Security Income (SSI), Medicare, and Medicaid. Some of this is likely due to the fact that many apply for SSDI within weeks or

months of acquiring their disability—a traumatic experience for most. As a consequence, many participants often paid little attention to what they were signing up for.

Some are still as perplexed by the two-year waiting period as when first told about it at the time of application. A few participants are even uncertain when their wait even began, and thus, when Medicare will kick in. One participant makes clear how this can happen:

When the diagnosis was actually given in July for pancreatic cancer, I didn't understand and I was so sick—you have to understand that I never expected this, so I didn't understand how Medicaid or Medicare, Social Security goes. I just assumed that when I was accepted under the Social Security, that I would receive health care. But that's not how it worked.

Participants Are Unsure and Confused About Their Medicare Benefits

Similarly, most participants are uninformed about Medicare and its benefits, and, therefore, lack a working understanding of what that coverage will mean to them after their two-year waiting period ends.

Overall, these participants believe Medicare will be a change for the better, affording them security they do not currently enjoy. According to one participant in East Syracuse, New York, who has been struggling with transverse myelitis since childhood, “I think that I wouldn't be afraid to go see a doctor now, once that kicks in. If I would have another urinary tract problem, or something like that, I would definitely go see the doctor more quickly than I would now. So it would probably be easier and quicker to treat something.”

“It's like they don't tell us the whole story. They just tell us a little bit of this, and a little bit of that. They don't tell us the truth about the whole story.”

Participant with HIV/AIDS,
Atlanta, Ga.

In contrast to the participants noted above, a small minority of individuals fear that Medicare will mean *less*, not more coverage. Medicaid enrollees envision still having to rely on Medicaid for prescriptions.¹² One former Medicare enrollee with HIV/AIDS in Atlanta, Georgia, recalls his coverage negatively: “When I had Medicare, what good was it? I had to pay for the prescriptions. Plus, if you need equipment, you have to pay for

¹² It is important to keep in mind that although these conversations took place after the passage of the Medicare Prescription Drug, Improvement and Modernization Act (MMA) of 2003, the majority of participants were unaware of the new prescription drug benefits entitled to people with disabilities.

that. . . .” In addition, a few individuals worry that the monthly deductions and co-pays will be too costly to handle.

Many Wonder Why They Can’t Get Both Medicaid and SSDI

Many have questions and concerns about why a person’s eligibility for SSI and Medicaid often ends when they begin to receive SSDI. They are either unaware of such rules, or believe they are unfair.¹³ Most do not seem to know that the change in income when they receive SSDI may push them over the financial limits for other programs. One Atlanta, Georgia participant with a spinal cord injury explains both her surprise and frustration this way:

At first, I was hoping I could get both [SSDI and Medicaid], but they said, “No, one is stopping and the other, starting.” I said, “Well, okay, cool, [SSDI]’s still more, right?” Fine. But no one let me know that, all of a sudden, at the end of January, your Medicaid is now over. It’s cancelled . . . that’s why I’m here today. It was as of January 31st, and I had some very necessary doctor’s appointments February 5th that I was told I’d have to pay for. So that’s my confusion.

Many simply want accurate information about eligibility and income-related rules for the different programs, and how each affects the other, so they can avoid potential pitfalls and get on with their lives. Another participant with a spinal cord injury in Atlanta, Georgia, says he would like information about how things affect your benefits, such as your income and going to school.

Notably, some participants are potentially eligible for Medicaid benefits, but have no idea they could qualify, even if their monthly income exceeds the normal limits.¹⁴ Furthermore, most participants do not seem to know who or what to ask to find out more about this option.

¹³ As noted, it can take five months or more once a person applies for SSDI before he or she starts receiving the cash benefit. During this interregnum, many individuals are low-income enough to receive SSI and/or Medicaid coverage. But, once a person’s SSDI payments begin—depending on the amount received—it might make that person slightly “over-income” to still be eligible for SSI or Medicaid.

¹⁴ Some participants seem to have a vague sense that even if their monthly income exceeds the amount that would ordinarily qualify for Medicaid, the large out-of-pocket medical expenses they pay might make them eligible, nonetheless. Some individuals may be able to qualify for Medicaid even when “over-income” by being a “medically-needy” person. In fact, 35 states and the District of Columbia currently have a Medicaid “medically-needy” program in place that enables individuals to subtract their medical expenses from their income, so their income, minus medical expenses, falls below a state-established “medically-needy” income limit (MNIL).

Participants Hunger for Information, but Sources Are Few and Inconsistent

Many participants want to know more about resources in their community that could help them access and pay for health care, prescription drugs, and other services and supports. Says one participant with a spinal cord injury in Atlanta, Georgia, “I’d like to know more about exactly what’s covered. I’m sure there are things that might be covered that I’m not aware of, or some programs out there that are offered that I’ve not been told about, and some things that might help to improve me.” But, several say they have no one or nowhere to turn to learn of these resources. “Social workers really don’t know anything about how it works,” says one Medicaid enrollee participant in Atlanta, Georgia, with a spinal cord injury.

Generally, most participants receive only snippets of information when it comes to accessing insurance, free clinics, and affordable health care. Some have proven resourceful on their own, or received help while still in the hospital, and are able to muddle through. A handful of participants use the Internet regularly to search for information, cheaper medications, and government programs and grants. A few who have applied in the past for government programs, like food stamps and Medicaid, are slightly more equipped to ferret out information. One Atlanta, Georgia, individual, a dual Medicare/Medicaid enrollee, in an HIV/AIDS support network, says he receives an e-mail newsletter from the local HIV/AIDS organization. Yet, these individuals are unique, and even the answers they are able to find are reportedly insufficient.

ENDURING THE WAIT

So how do these participants survive the two-year waiting period? Given their testimonies, uninsured participants—those who cannot afford private insurance, yet have a little too much income to qualify for Medicaid, in many instances—appear to experience the most difficulty staying healthy during the two-year wait. Most of these individuals must invariably get by with some combination of living one day at a time, assertiveness, faith, and sheer luck. This section describes the alternative approaches participants consider, then either use or abandon, to navigate an incredibly trying time in their lives, essentially, on their own.

“The way I read it, I’m going to have to pay for Medicare, \$66 a month, out of my Social Security check, and I can’t afford that.”

Medicaid enrollee with
HIV/AIDS,
Atlanta, Ga.

Private Health Insurance: Attractive, But Not an Option

One of the initial ways individuals in this situation try to weather the storm is by maintaining the employer-based insurance they had while working. None of the

participants were financially able to do this for the full 29-month timeframe allowed under COBRA. That said, however, it is important to note that most still believe that having Medicare or private health insurance (if affordable) would improve their access to health care and provide them the security they currently lack.

Participants believe they would receive “much better care” from doctors than they do currently. Says one participant with transverse myelitis in East Syracuse, New York, “I always thought that’s true. If I had gone to a private doctor, I think I would have gotten much better care, although it would have cost \$100 a visit.”

Despite these feelings, most, if not all, participants say private health insurance is just too expensive. A handful of participants enjoyed employer-sponsored health insurance while working, and some benefited from COBRA afterward, until it became too expensive. A participant with diabetes in Towson, Maryland, says, “I had to pay my wife’s [COBRA], too, but I [eventually] paid only hers, and gave up mine. You’ve got to make a lot of choices.” A few others tried to access private health insurance, but the premiums and co-pays proved too high. But most have not even attempted to secure private health insurance, believing they cannot afford it or qualify (pre-existing conditions mean denial or a lengthy wait).

Left to Sink or Swim

While some participants depend on family and others to meet many basic needs, and some can tap into other support networks, when it comes to finding programs and affordable care, they are on their own. One participant with a spinal cord injury in Atlanta, Georgia, says the advice many get from the health care system on how to survive the two-year waiting period is simply, “try not to get sick for two years.”

“We’re not supposed [to get sick], she said, ‘try not to get sick.’ None of us tried to become disabled.”

Medicaid enrollee with
a spinal cord injury,
Atlanta, Ga.

With nowhere to turn for assistance, many participants are left with little choice but to be their own advocates. Participants for the most part are resourceful—some were able to find help through networks such as the American Cancer Society, the Multiple Sclerosis Society, and various HIV/AIDS organizations. A few were able to find programs, often through pharmaceutical companies, that provide free or lower-cost medications.

Another key to survival, insist some participants, is assertiveness—not taking “no” for an answer. One particular individual has been fighting with a hospital for almost a year

to arrange a payment plan she can handle for past stays. Another participant, a Medicaid enrollee with a spinal cord injury in Atlanta, Georgia, feels similarly about having the right attitude and having to stay on top of things when it concerns his health:

You have to keep pushing, and pushing, and pushing. If you keep pushing, you'll get what you want. It took me almost a year to get shower care, but I just kept pushing, and pushing, and pushing, and telling them, 'I want this. I've got to have this.' It took that long to get one, but I finally got one. . . . You have [to be aggressive] to keep connections.

FEARS AND DESPAIR CLOUD PARTICIPANTS' FUTURE OUTLOOK

Participants speak candidly about the results of “going without” these and other much-needed services during the two-year waiting period. In addition to the physical deterioration noted earlier, depression and anxiety about the future are also common among all participants in this study. For many, inherent in their depression and fears about the future is a lack of independence and control over their lives, including their struggle to return to work. The following section lays out each of these issues in more detail.

Depression and Anxiety About the Future

In addition to their primary disability, many participants also suffer from mild to severe depression. Not working (for the most part), barely able to make ends meet on SSDI, unable to pay for health care out-of-pocket, and, in many cases, struggling to make it through the day, most participants express a deep sense of sadness.

Adding to feelings of depression are feelings of hopelessness and anxiety about the future. One participant with pancreatic cancer in Glen Rose, Texas, expresses the anxiety and frustration of many when she says:

I do understand that if I do not receive health care, I'm compromising my health at this point. And I'm not far along enough in this cancer to drop medical care, unless I'm willing to put all my faith in God and know that He's going to take care of me. There's a side of me that does, but there's that carnal side of me that's freaking out, going, 'Oh, my God. How am I going to do this?' I don't have any answers. I have lots of questions.

Independence and Control

The depression many participants experience during the two-year waiting period mostly stems from what they see as a lack of overall independence and control over their lives.

Although these two points are not necessarily Medicare-related, and Medicare cannot directly address them, they are still very important to consider as they overlap with, and complicate the myriad concerns people with disabilities are forced to confront during the waiting period.

Many participants depend heavily on family and caregivers to fulfill a number of their basic needs, including transportation, paying medical bills, and sometimes “just getting through the day.” One participant in Towson, Maryland, with diabetes, says, “I don’t really want to sound like I’m depressed, but I really don’t have any independence. I really depend on my wife for just about everything—for my meals and taking care of me, and I just sit and listen to talk shows or radio shows. I really don’t like television that much. I don’t have any money to do anything. Sometimes, I do get depressed and I really don’t feel independent at all.”

An uninsured participant with bipolar mood disorder also confirms what many others are feeling when she says, “I don’t have any control at all. Whatever is dealt to me, it’s forced on me, and I have to accept it. I have to. I have no recourse. I have to do, what I have to do. There is no luxury of saying, ‘Well, I really don’t feel well, and I really don’t want to do this today.’”

Returning to Work

Many participants believe employment, whether it is full- or part-time, is an important key to increasing their independence and control over their own lives. Among a total of 21 participants, only two are currently employed, and their outlook on life seems markedly more positive than that of their unemployed counterparts. Of note, most link their concerns about returning to work directly to the Medicare waiting period. Specifically, they believe that because they are currently uninsured, they are in poorer health and unable to work. They believe that if they had their Medicare coverage, they could obtain the doctor visits they need and not worry so much about hospitalizations. Since most are doing without medical services most of the time, they perceive their health is deteriorating, and that as a consequence, returning to work anytime soon will be difficult to impossible. Thus, most see the Medicare waiting period as a barrier to returning to work and obtaining a job.

But, those who do manage to return to work find it liberating. An uninsured (but employed) participant in Atlanta, Georgia, with a spinal cord injury was asked to rate her current level of independence on a scale of one to 10. She says, “Right now, because I am working, I have a lot of control over what goes on, so I would give it a seven.” In stark

contrast, a participant in East Syracuse, New York, who has had transverse myelitis since childhood, sees little prospect of working. “I feel pretty much trapped,” he says. “I can’t do anything to try and mitigate the symptoms of my disability right now. I can’t try and really get a job to get off of disability because of the symptoms.”

Most participants express hope about returning to at least part-time employment in the future. One Medicaid enrollee in Atlanta, Georgia, says, “Two years is too far for me to be thinking about [Medicare]. . . . I don’t plan to even need it. I plan to be working. I plan to be able to tell disability ‘good-bye’. That’s my plan, that’s what I still hope for.” Many of the participants with physical disabilities are working to get to a place where they are able to seek employment again. But these are the same individuals who say they are unable to obtain the therapy or devices they feel they need to be as independent and self-sufficient as possible.

Many participants with mental health concerns, such as bipolar mood disorder and severe depression, face many of the same barriers to returning to work, and some that are unique, as well. One participant in Towson, Maryland, who stopped taking her medications almost two years ago, reflects, “I would like to be able to work, but it’s just, it’s hard because you never know—when you get up in the morning, when you’re bipolar, you never know what the day is going to bring. . . . It’s just hard to function because you don’t know what’s going to happen next.”

Many of these individuals—while expressing a strong desire to return to work—are also fearful of the possible negative consequences of doing so. Many participants say they are aware of federal work incentives, but their knowledge of how these incentives could enable them to work is limited and often incorrect.¹⁵ As a result, they are generally unwilling to risk trying to return to work for fear that they will end up losing benefits.

POLICY IMPLICATIONS AND RECOMMENDATIONS

What can be done to lessen the toll that the waiting period is having on the health and independence of people with disabilities?

The recommendations outlined below are meant to lessen the adverse impact the current Medicare two-year waiting period has on people with disabilities in two distinct and very necessary ways. Some of the recommendations identify steps that can and should be taken to ameliorate the effects that the requirement has on the lives and futures of

¹⁵ Provisions, known as federal work incentives, exist in federal law, which can enable people with disabilities to work and retain their cash and/or health coverage benefits under certain circumstances.

people with disabilities, as it exists today. Ultimately, however, to do justice to this vital endeavor, the current waiting period must be eliminated and replaced with a single, concurrent five-month waiting period for both SSDI and Medicare.

Ways to Modify the Medicare Two-Year Waiting Period

Ample evidence shows that the Medicare two-year waiting period requirement is producing a range of unintended, harmful, and often irreversible effects on the health, independence, and self-sufficiency of people with disabilities on SSDI.

There are three basic methods that the Medicare waiting period requirement can be eased or eliminated, and bills have been introduced in this Congress using each one:

1. Eliminating the two-year waiting period all at one time.¹⁶

To accomplish this, Congress could reduce the current waiting period requirement from two years to five months. With this approach, Medicare coverage would begin within five months of someone becoming severely and permanently disabled. This would, in turn, mean that applicants for SSDI would have to wait the same relatively brief period of time for both their cash disability payments and Medicare coverage to begin simultaneously.

On the positive side, this most likely would have several major effects. First and foremost, it would significantly reduce the likelihood of those on SSDI becoming uninsured or under-insured for any period of time. It also likely would reduce the high out-of-pocket costs that further impoverish and place enormous stress on the lives of many new SSDI beneficiaries at the time they can least afford them. It may make COBRA coverage a more affordable option for some. And, last but not least, it would go a long way toward ensuring that SSDI beneficiaries have the continuity of insurance coverage they need to enhance their health, independence, and future prospects, as much as possible.

Eliminating, or significantly reducing the current two-year waiting period in one fell swoop has certain downsides to it, as well. Chief among these, of course, involves the costs of doing so. As previously noted, Dale and Verdier have estimated the costs of eliminating the waiting period to be about \$8.7 billion at 2002 program levels (pre-prescription drug benefit). This would only represent

¹⁶ U.S. Representative Gene Green of Texas has introduced a bill to accomplish this aim: H.R.104, the “Medicare Disability Eligibility Improvement Act of 2003,” would completely eliminate the two-year waiting period 90 days after enactment.

about a 3.4 percent increase in total Medicare costs. Additionally, some of these new costs would be offset by an estimated \$2.5 billion reduction in federal Medicaid expenditures for those on SSDI who go on to Medicaid during the waiting period. It also would save states—most of which are still dealing with severe budget deficits—an estimated \$1.8 billion per year.¹⁷ But, given concerns over Medicare’s rising costs and its continued solvency, such new costs are not likely to be considered insignificant, least of all by Congress.

A second concern that may arise regardless of whether the current waiting period is eliminated all at once, or phased out over several years, is that doing so may increase the number of people who will apply for SSDI. Individuals who have a severe disability, but might have been deterred from applying by the fear of losing any health coverage during the waiting period, may represent some increase. A greater percentage of the increase, however, would likely be on the part of individuals who may be “less disabled” and apply for SSDI in order to receive Medicare coverage in a relatively short period of time.

The most potent disincentive for this, of course, is that the SSDI payment that many receive is less than half of what they were able to make while they were working. Furthermore, less than one percent that satisfy current Social Security disability determination criteria, leave the SSDI rolls each year. Thus, the existing disability determination process is highly effective in only allowing those with severe and permanent conditions into the SSDI program. There is no reason to believe that eliminating the waiting period requirement would diminish this or lead to an undue expansion of the rolls. Moreover, effective oversight of the disability determination process could further reduce the possibility of this occurring.

2. Phasing out the two-year waiting period over several years.¹⁸

Congress could reduce and eventually eliminate the two-year waiting period over several years. The major advantage in taking this tact is that it would spread out the costs associated with achieving this goal over several years. It might also permit SSA and Congress to closely monitor any increase in SSDI applications and take needed actions to detect and prevent fraud, abuse, and other unintended consequences.

¹⁷ Dale, [Elimination of Medicare’s Waiting Period](#), 2003.

¹⁸ U.S. Senator Jeff Bingaman of New Mexico has introduced S. 2566, the “Ending the Medicare Disability Waiting Period Act of 2004,” which would phase the requirement out over 10 years.

The chief disadvantage of phasing out the current waiting period, of course, is that it would perpetuate the problems highlighted throughout this report for several more years to come. Many would go uninsured or under-insured for all, or most of the two-year waiting period. Much of their health, independence, and capacity to return to work will no doubt be harmed and undermined into the foreseeable future.

3. Exempting only certain categories of people with severe and permanent disabilities from the waiting period requirement.¹⁹

Congress has taken this approach twice already, in respect to individuals with end-stage renal disease, and most recently, people with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease). A major advantage of this type of incremental reform is that the costs associated with carrying it out are lower than eliminating or phasing out the requirement for all beneficiaries with disabilities under age 65.

But, exempting a relative select few from the two-year waiting period also points to the arbitrary nature of the requirement. Moreover, as with phasing out the waiting period over several years, it will not prevent the requirement from continuing to undermine the health, independence, and economic well-being of many of those who continue to endure the two-year wait for Medicare.

RECOMMENDATION 1. CONGRESS SHOULD TAKE IMMEDIATE ACTION TO ENACT LEGISLATION THAT ELIMINATES THE CURRENT MEDICARE TWO-YEAR WAITING PERIOD AND BEGINS MEDICARE COVERAGE CONCURRENT WITH THAT OF SSDI.

Ways to Make Medicaid More Responsive to the Health Coverage Needs of People on SSDI in the Two-Year Waiting Period

Medicaid has the potential to offer critical “gap-filling” coverage for many who are in the waiting period. Evidence also shows that in order for many on SSDI to enhance their health, independence, and chances of someday returning to work, they need the combined benefits that only Medicare and Medicaid collectively offer.

¹⁹ Two bills have been introduced in the U.S. House of Representatives that would exempt only specific groups of beneficiaries with disabilities from the waiting period requirement. The first, introduced by U.S. Representative Robert Andrews of New Jersey, is H.R.2322, the “Immediate Access to Medicare for the Disabled Act of 2003,” which would waive the waiting period for uninsured individuals who had no coverage 60 days before applying for SSDI. The second, introduced by U.S. Representative Mike Rogers of Alabama, is H.R.3382 (no title), which would eliminate the waiting period only for those under age 65 who are terminally ill.

But, many persons lose their eligibility for Medicaid when they start receiving SSDI (receiving the cash benefit makes their incomes too high to meet Medicaid's eligibility criteria). In addition, by law, SSA must pay a person retroactive benefits for the time between when they first became disabled, and when it makes the determination. Retroactive benefits must be paid for a period of up to 12 months. Payment of these benefits in one lump sum can put those on SSDI "over-income" for Medicaid and similar benefits. This, in turn, means that many can lose their Medicaid coverage and other services.

Medicaid eligibility and other key requirements vary significantly from one state to the next. Some study participants were able to obtain Medicaid coverage. Others with strikingly similar health care needs and income limitations were not. Low-income people with disabilities—including those who are in the two-year waiting period—currently face enormous barriers to obtaining and retaining Medicaid coverage. In most states, a person with a disability must have an income at or below 75 percent of the poverty level (under \$7,000 for an individual annually).²⁰ Additionally, some people with disabilities might qualify for Medicaid as medically-needy in some states, but not others, because different states set vastly different financial criteria.

RECOMMENDATION 2. CONGRESS SHOULD REQUIRE STATES TO MAINTAIN MEDICAID ELIGIBILITY FOR PEOPLE IN THE TWO-YEAR WAITING PERIOD. At a minimum, the Social Security Administration and the Centers for Medicare and Medicaid Services (SSA and CMS) should develop and execute a joint strategy of working with new SSDI beneficiaries, state Medicaid programs, health providers, and others to avoid beneficiaries losing Medicaid because of a lump sum SSDI payment.

RECOMMENDATION 3. CONGRESS SHOULD ESTABLISH CLEAR, CONSISTENT MEDICAID FINANCIAL AND SPEND-DOWN ELIGIBILITY STANDARDS THAT ALL STATES WOULD BE REQUIRED TO FOLLOW.²¹ The net effect: any two individuals with the same low income and financial need for publicly-subsidized health care could get Medicaid coverage, regardless of where they live in the U.S. This could affect all low-income individuals, or it could be targeted to apply only to certain groups of individuals with intense health care needs such as those in the two-year waiting period.

²⁰ Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. 2004 Federal Poverty Guidelines, available at <http://aspe.hhs.gov/poverty/04poverty.shtml>.

²¹ Lynn Etheredge and Judith Moore, "A New Medicaid Program," *Health Affairs* Web Exclusive (August 27, 2003): W3-426-W3-439, available at <http://content.healthaffairs.org/cgi/content/full/hlthaff.w3.426v1/DC1>.

Ways to Make COBRA More Responsive to the Health Coverage Needs of People on SSDI in the Two-Year Waiting Period

COBRA permits people in the waiting period to continue paying for private coverage for up to 29 months. To do this, though, they must pay premiums of 102 percent for the first 18 months, and premiums of up to 150 percent for the remaining months. Some of the study's participants were able to use COBRA to retain the health coverage that was previously offered through their employer. But, those who did so found it cost prohibitive to continue for more than a few months.

In fact, overall, although about 57 percent of non-elderly workers were potentially eligible for COBRA, only 7 percent of unemployed workers had COBRA coverage in 1999. Furthermore, the rate of COBRA coverage among those who enrolled, varied based on income and ranged from 5 percent for low-income adults to 11 percent for those with higher incomes.²² The vast majority of those that go on to SSDI have low to moderate incomes to begin with, and their available resources quickly dwindle once they go on the rolls. So, to the extent that COBRA can provide bridge coverage to some on SSDI during any waiting period that may be established, this is probably most likely to occur by keeping the intervening coverage time frame to a minimum.

RECOMMENDATION 4. CONGRESS ALSO SHOULD CONSIDER SUBSIDIZING THE PURCHASE OF COBRA COVERAGE DURING THE WAITING PERIOD ON A SLIDING-SCALE BASIS.

The Need for Accurate, Up-to-Date Information

Lack of knowledge about Medicare, the two-year waiting period, health coverage options, and ways they can prepare to return to work is a problem for most participants in this study. Most simply don't know where to turn to find answers to basic questions or the critical help they need to weather the waiting period. Therefore, such individuals need clear, current, and readily-accessible information on a wide-range of issues from government and other sources from the point they apply for SSDI and going forward.

At any point in time, as many as 1.5 million people with disabilities will have to grapple with the often harsh consequences of living through, and trying to obtain, vital health care during these two years. It is critical, therefore, that the Social Security Administration (SSA) and the Centers on Medicare and Medicaid Services (CMS) develop and implement an education campaign that equips applicants and persons on SSDI—

²² Families U.S.A., *One in Three: Non-Elderly Americans Without Health Insurance, 2002–2003* (Washington, D.C.: Families U.S.A., June 2004), p. 13, available at http://www.familiesusa.org/site/DocServer/82million_uninsured_report.pdf?docID=3641.

especially those in the waiting period—with information, benefits, counseling assistance on SSDI and Medicare, public and private coverage options, and return-to-work rules and options.

RECOMMENDATION 5. CURRENT AND PROSPECTIVE SSDI APPLICANTS NEED CLEAR AND COMPREHENSIVE INFORMATION ON PROGRAM REQUIREMENTS.

Similarly, SSDI beneficiaries need a reliable way to find out how much longer they have to wait for their Medicare coverage. Perhaps a well-publicized method for beneficiaries or their representatives to get such information in a confidential manner could be from 1-800-Medicare or online at www.Medicare.gov.

Beneficiaries need information and benefits counseling assistance about how they might be able to maintain coverage under COBRA or their spouse's plan; or how to obtain alternative coverage/benefits through Medicaid, the Veterans Administration, ADAP, and free or low-cost health clinics, and prescription drug distribution programs. To be effective, such information and assistance should be available through a wide variety of media and other means, including 1-800-Medicare or online at Medicare.gov.

RECOMMENDATION 6. A PARALLEL, CONCERTED EFFORT SHOULD BE MADE TO MAKE THE SAME INFORMATION AND ASSISTANCE WIDELY AVAILABLE THROUGH SSA AND DISABILITY DETERMINATION OFFICES; THE VETERANS ADMINISTRATION; STATE HEALTH INSURANCE ASSISTANCE PROGRAMS (SHIPs); SSA'S BENEFITS PLANNING ASSISTANCE AND OUTREACH (BPAO) PROJECTS; PROTECTION AND ADVOCACY FOR SOCIAL SECURITY BENEFICIARIES (PABSS) PROGRAMS; MEDICAID AGENCIES; HEALTH PROFESSIONALS; AND OTHER SAFETY NET PROVIDERS.

RECOMMENDATION 7. ACCURATE INFORMATION AND BENEFITS COUNSELING ASSISTANCE ON HOW INCENTIVES CAN BE USED TO RETURN TO WORK AND/OR OBTAIN HEALTH COVERAGE DURING THE WAITING PERIOD SHOULD BE MADE AVAILABLE THROUGH THE SAME METHODS RECOMMENDED ABOVE.

Most participants fear that if they return to work, they will lose both SSDI and their Medicare coverage once it becomes effective.

Contrary to the fears of many, those on SSDI are able to work and retain both their cash and health care coverage under some circumstances. Others may be able to use a Plan for Achieving Self Sufficiency (PASS plan) to set aside some of their SSDI payment to help achieve a future work goal. Setting aside funds in a PASS plan for a work-related

goal also can have the added benefit of qualifying the person's monthly income for Medicaid.

Many fear, however, that if they use these incentives and somehow break a rule, they will lose SSDI benefits and future Medicare coverage, as a result. SSA has a number of "early-intervention" projects on the drawing board to try to show new SSDI beneficiaries how they can put these incentives to work without losing their benefits. These projects cannot come soon enough for many.

RECOMMENDATION 8. AS PART OF AN OVERALL STRATEGY TO EDUCATE SSDI APPLICANTS AND NEW BENEFICIARIES AS RECOMMENDED ABOVE, GREAT CARE NEEDS TO BE TAKEN TO ENSURE THAT INDIVIDUALS WHO TAKE ADVANTAGE OF WORK INCENTIVES HAVE SUCCESSFUL EXPERIENCES, RATHER THAN BEING PENALIZED. Applicants and beneficiaries should be able to hear these success stories so they can begin to internalize how they can put such incentives to work in their own lives.

APPENDIX. METHODOLOGY

People with disabilities within the two-year waiting period, or recently having completed it (within the last two years), participated in two focus groups held in Atlanta, Georgia, in February 2004. Individuals were recruited with the help of The Shepherd Center, a catastrophic care hospital in Atlanta, Georgia, for those with spinal cord injuries, acquired brain injuries, multiple sclerosis, and other neuromuscular illnesses and urological problems. Following the two focus groups, nine in-depth telephone interviews were conducted in March and April 2004. These individuals were recruited through nationwide contacts.

These individuals had a wide array of physical and mental disabilities and health conditions, including multiple sclerosis, cardiovascular disease, diabetes, high blood pressure, severe migraines, pancreatic, brain, and breast cancers, a herniated disc, bipolar mood disorder, severe depression, and obsessive compulsive disorder (OCD). While some participants from Atlanta, Georgia were concurrently enrolled in Medicaid, the majority of participants were without any form of health insurance during the two-year waiting period. Uninsured participants were specifically targeted, in order for the groups and interviews to gauge the impact of the waiting period on this particular type of individual. Lastly, all participants currently in the two-year waiting period were required to be receiving Social Service Disability Insurance (SSDI) payments.

Following is a detailed breakout of the focus groups.

Table A-1. Focus Group Breakout

Group	Focus Group Site	Date	Description	Total # of Participants
1	Atlanta, Ga.	2/21	Spinal Cord Injury	6
2	Atlanta, Ga.	2/21	HIV/AIDS & Spinal Cord Injury	6

Table A-2. In-Depth Interview Breakout

Interviewee	Date	Description
Male Towson, Md.	3/18	Cardiovascular disease, diabetes, high blood pressure
Female Towson, Md.	3/18	Bipolar mood disorder, O.C.D., diabetes, migraines
Female Glen Rose, Texas	3/22	Pancreatic cancer
Male Dubuque, Iowa	3/23	Bipolar mood disorder
Male Onalaska, Texas	3/24	Brain cancer
Female Westminster, Md.	3/24	Herniated disc, needs hip replacement, breast cancer
Male East Syracuse, N.Y.	3/25	Transverse myelitis, depression
Female Pflugerville, Texas	4/3	Multiple sclerosis, rheumatoid arthritis
Female Bridgeport, Conn.	4/4	Multiple sclerosis

RELATED PUBLICATIONS

Publications listed below can be found on The Commonwealth Fund's website at www.cmwf.org.

[*How Beneficiaries Fare Under the New Medicare Drug Bill*](#) (June 2004). Marilyn Moon. In this issue brief, the author analyzes the complexities of the Medicare Prescription Drug, Improvement, and Modernization Act, highlighting potential pitfalls for beneficiaries.

[*Medicare's Future: Current Picture, Trends, and Medicare Prescription Drug Improvement & Modernization Act of 2003*](#) (Updated February 2004). Barbara S. Cooper and Sabrina How, The Commonwealth Fund. This chartpack presents an array of PowerPoint slides highlighting recent research and analytical findings on Medicare, including an overview of changes brought about by the Medicare prescription drug bill.

[*Caught in Between: Prescription Drug Coverage of Medicare Beneficiaries Near Poverty*](#) (August 2003). Dennis G. Shea, Bruce C. Stuart, and Becky Briesacher. According to this issue brief, many elderly and disabled Medicare beneficiaries with very modest incomes would see little benefit from prescription drug legislation pending in Congress. The authors say that while both bills would provide significant relief for beneficiaries at lower income levels, premium and cost-sharing subsidies would be phased out for those with only slightly higher incomes.

[*Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs*](#) (July 2003). Stacy Berg Dale and James M. Verdier, Mathematica Policy Research, Inc. According to the authors of this issue brief, eliminating the two-year waiting period for disabled Medicare beneficiaries would allow this vulnerable group of adults to gain immediate access to secure coverage, and would also provide significant fiscal relief to states.

[*Medicare's Disabled Beneficiaries: The Forgotten Population in the Debate over Drug Benefits*](#) (September 2002). Betsy Briesacher, Bruce Stuart, Jalpa Doshi, Sachin Kamal-Bahl, and Dennis Shea. In this report from The Commonwealth Fund and the Henry J. Kaiser Family Foundation, the authors conclude that the 5 million disabled Americans under age 65 who are Medicare-eligible have few options other than Medicaid for obtaining prescription coverage, and that a Medicare drug benefit designed for the elderly will not suffice for the disabled unless their particular needs are assessed and addressed.

