

## **Briefing: Examining Medicare's Two-Year Waiting Period for Individuals with Disabilities October 18, 2004**

---

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

[START RECORDING]

**ED HOWARD:** The Alliance for Health Reform, and I wanted to welcome you on the behalf of Senator Jay Rockefeller, our Chairman, Bill Frist, our Vice-Chairman and the rest of the Board and Alliance to this session on one of Medicare's more obscure rules, that you have to wait two years after you start getting Social Security cash disability benefits before you can get covered by Medicare. We got started with the Alliance a dozen years ago. Senator Rockefeller used to say that one of our main goals was to make everybody in Washington understand the difference between Medicare and Medicaid. We're almost there. That modest goal, I dare say, we've made some progress one, but we haven't yet completed it. But today we're going to go beyond that. We're going to try to make sense of how four different titles of the Social Security Act, including Medicare and Medicaid work together, or don't, to offer an income and healthcare safety net to Americans with disabilities. It's going to be confusing at times. Stay with us. We have some very good explainers with us today. It's vital to the well-being of over a million vulnerable people in this country. We're very pleased to have as partners in today's briefing the Commonwealth Fund, one of America's leading health philanthropies, and especially pleased to have with us Barbara Cooper, who is the Senior Program Officer at the Fund for its project, Medicare's Future, and who's been doing incredible

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

health policy analysis work in this town and New York and elsewhere for many years. Barbara, if you want to say something on behalf of the Fund?—

**BARBARA COOPER:** Yes. On behalf of the Commonwealth Fund, I want to join Ed in welcoming you to this session on the Medicare two-year waiting period. A representative of the Christopher Reeve Paralysis Foundation was hoping to be here with us today, up here. You can understand why it was impossible for her to be here, but she wanted me to mention that.

The two-year waiting period has been characterized by some people as cruel and unusual punishment. Briefly, for those of you who may not know, if someone becomes so severely disabled that they cannot work for at least a year—they get cancer, MS, suffer a spinal-cord injury, for example—they may be able to receive benefits from Social Security Disability Insurance, and just as Medicare and Social Security eligibility were linked originally for the elderly, they're linked here, but with a little glitch. If someone is eligible for Social Security Disability they are eligible for Medicare. However, once they're deemed eligible, they have to wait five months to get disability payments. They have to wait two years and five months to get Medicare. It's not like they might not need healthcare. And to mix metaphors a little bit, they suffer double jeopardy. In a number of cases, their Social Security

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Disability payments push them above the Medicaid eligibility limit, so they lose their Medicaid, and they wait two years for Medicare. Now there's terrific policy. So, our panelists today will tell you why Congress did this back in 1972 when it added Medicare coverage for the disabled, and what it means for the people who are waiting.

Thanks very much, Barbara. A couple of logistical items that those of you who have been to Alliance briefings before will know about. You'll find a good variety of materials on this topic in your packet, including where we have them, the slide presentations that the speakers will be using so you can follow along. By the end of today, you'll be able to view a webcast of this on [kaisernetwork.org](http://kaisernetwork.org) and within a couple of days you'll have a transcript of this session both there and on the Alliance website at [allhealth.org](http://allhealth.org). A couple of pieces of paper in the packet I want to call your attention to: the green question card. At the end of the formal presentations, if you want to write a question on that card and hold it up, you'll get a chance to, and we'll try to get to as many of those as we can. There are also floor mics that you can use to actually ask the question. That's how you can be sure it will be asked in the way you want it with no editing in-between. The blue form is an evaluation form. If you will fill that out to help us improve these sessions as we go along, it will be very helpful and we would appreciate it very much.

<sup>1</sup> [kaisernetwork.org](http://kaisernetwork.org) makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Now, as I said, we have some outstanding speakers to help us grapple with this complicated rule and its often not very desirable consequences. I'm not going to waste our time or your speakers' time by giving the kinds of introductions they deserve, but you can read about them in the biographical sketches in your materials. Let me just start with very brief introductions, first, for Jim Verdier. Jim is going to start off the speaking line-up for us today. He brings to this discussion of disability policy a background that very few people in this country can match. He's run the Indiana Medicaid program, taught at the Kennedy School of Government at Harvard, served on the Congressional Staff, both in the Senate and the House side. He's been the CBO Director of Tax Analysis for a number of years. His day job these days is as a Senior Fellow at Mathematica Policy Research here in town, where he works mainly on Medicaid and Medicare issues and state health policy. He's the author of a couple of papers that really shed as much light on this topic as I have run across, so we're very happy, Jim, that you could join us today, and look forward to your presentation.

Thank you very much for that great introduction. Let's turn this thing on. Okay, it works. As Ed mentioned, there is in your packet a policy brief we did, issue brief for Commonwealth a little over a year ago, and that goes into detail on the coverage and cost implications of eliminating the

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

two-year waiting period. I'm going to be talking a little bit today about the cost implications, both for Medicare and Medicaid of eliminating the waiting period, and say a little bit about how those estimates would be affected by the Medicare Modernization Act when it goes into effect in 2006, and then also say a little bit about the House and Senate waiting-period legislation that was introduced in this Congress, and a little bit about the last time that this issue was on the Congressional agenda back in 2000 when the two-year waiting period was eliminated for those with ALS, Lou Gehrig's Disease. Also, as Ed indicated, say a word or two at the outset about how this policy came to be, and that's not on my slides, but it is covered in the issue brief. Briefly, this came in at the same time in 1972 that Medicare coverage of people with disabilities under 65 was initiated. At that time there was just a three-year waiting period for those with end-stage renal disease, and then the longer waiting period for others. What it said in the committee reports for the two bills—and they're quoted in the issue brief—is that the purposes of the two-year waiting period were three-fold: one, there was a concern about what the costs might be of the waiting period. There was a concern about displacement of private insurance, and then finally there was a concern that Medicare coverage be limited to people whose disabilities have proven to be "severe and long-lasting". And I'll come back at the end to the extent to

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

which those concerns still apply today.

The fiscal impact of eliminating the waiting period—and these are 2002 estimates—are about just under 1.3 million people on SSDI in the waiting-period in 2002. About 40 percent of them were covered by state Medicaid programs. If Medicare covered everybody in the waiting period in 2002, we estimated that Medicare costs would go up by about \$8.7 billion, and that Medicaid costs would go down by \$4.3 billion, because Medicare would take over many of the costs for hospital care and physician care that Medicaid would otherwise cover for people in the waiting period. A final point—and you might flip to the next slide, where this is shown in graphical form—since the federal government pays about 57 percent of the cost of Medicaid, there would also be some additional savings in the federal Medicaid budget as a result of shifting dual-eligibles, shifting people with disabilities from Medicaid to Medicare, so that would reduce the net federal costs to \$6.2 billion and the Medicaid savings, the state dollar savings would be about 1.8 billion. These estimates are laid out in elaborate detail in an appendix that Stacy Dale, my colleague, and I prepared that's also on the Commonwealth website.

So what's the impact of the Medicare Modernization Act on that? If the Medicare take-over of prescription drug coverage for dual-eligibles that goes into effect in 2006 had in fact been in place in 2002 when we did these estimates, the

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Medicaid costs for prescription drugs for people with disabilities in the waiting period, we estimated in 2002 were about \$1.3 billion. If the Medicare Modernization Act had been in place at that point, that \$1.3 billion of costs would have been shifted from Medicaid to Medicare, if the waiting-period were eliminated, and that would bring the new Medicare costs to about 10 billion as opposed to 8.7, and reduced the remaining Medicaid costs to about 2 billion from the 3.3 billion that we estimated. That would happen in 2006 as well. The estimates would be different because lots of other things have changed during that period of time, but the magnitudes would be about the same as what we estimated for 2002.

What about the claw-back? I assume that anybody who works with states and Medicaid programs knows what the claw-back is, but it's a way of requiring the states to pay back to the federal government a large part of the savings that states would otherwise see when Medicare takes over prescription drug costs in 2006. It's actually a separate financial transaction. It doesn't directly affect the program costs while they're going on. It's a settle up kind of thing, although the payments are made every quarter or every month, I believe. The way that the formula for the claw-back works, a lot of the additional savings that I just described from Medicare taking over all costs, including drug costs if the waiting-period were eliminated would be largely taken back from states as a result

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

of the claw-back. So that \$1.3 billion in savings probably would not occur as long as the claw-back is in effect in its current form.

A couple of words about the waiting-period legislation: You see up on the slide there that Representative Gene Green from Texas introduced a bill to eliminate the waiting period early in the current Congress, had 27 cosponsors, then subsequently Representative Andrews from New Jersey introduced a bill to waive the waiting-period for those with no health insurance coverage. Representative Rogers from Alabama introduced a bill that would waive it for people who are terminally ill, then most recently, Representative Green introduced a bill, essentially the same as the bill that Senator Bingaman introduced in the Senate fairly recently as well to phase out the waiting-period over ten years, and eliminate it for those with life-threatening conditions. There's one additional House bill that I missed when I put the slide together - that's HR5116. That was introduced by Representative Pallone, and that would waive the waiting period for those who have advanced-stage cancer. Almost all of these bills, their sponsors and their cosponsors are Democrats. Representative Rogers is a Republican. But I took look back at the legislation that was passed in 2000 to eliminate the waiting-period for those with ALS, Lou Gehrig's Disease, and that was introduced in the Senate by Senator Toricelli, a

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Democrat, but out of the 28 cosponsors, 12 of them were Republicans, including some fairly conservative Republicans. Jesse Helms was a cosponsor, for example. In the House, the similar legislation, or identical legislation was introduced by Representative Lois Capps from California. She's a Democrat, but there were approximately 282 cosponsors for that bill, so it had very wide bipartisan support in both houses back in 2000.

So just to summarize and to say a little bit about where the original reasons for waiting-period now stand in light of what's happened over the last 30 years. There really has been with the exceptions that I noted, very little change and little examination of this policy. The original reasons appear, at least to me, a bit less compelling than they might have appeared in 1972. There are certainly extra Medicare costs, and they're not insignificant, but they are offset substantially by Medicaid Savings, since so many of the people in the waiting-period are now covered by Medicaid. The disabilities of those in the waiting period certainly do appear to be long-lasting. There are fewer than one percent of people who go on SSDI who lose their SSDI coverage because their condition improved within the two years that they're in the waiting period. We estimated that perhaps four percent of the people in the waiting period died while they were in the waiting period waiting for their Medicare coverage. There has

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

been subsequent estimates done by Jerry Riley of the Social Security Administration using a somewhat better data set than we have that indicates as many as twelve percent of the disabled workers in the waiting period died during the two years that they're waiting for Medicare.

The last concern was for the potential displacement of private insurance. That appears fairly limited, maybe a quarter or a third of the people in the waiting period have some form of private insurance. Often times, COBRA coverage from their former employer or coverage from their spouse's employer. That's pretty expensive. It's 102 percent of the premium for the first 18 months, and 150 percent of the employer premium for another 11 months for those in the waiting period. That's a lot of money, and it's a burden on employers as well as on employees, because even though the premiums are high, they don't cover the full costs of the healthcare that people in the waiting-period need, so it is a burden on employers and insurers as well during that period, and eliminating the waiting period would alleviate that burden. So, in conclusion, the elimination would help a high-risk, high-need group of the uninsured. It would provide some needed fiscal relief to states, and it would ease financial burdens on those who are privately insured and on their employers. Thank you.

Thank you very much, Jim. Turn now to Henry Claypool.

Henry Claypool knows about disability policy. He's a principal

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

at Advancing Independence, modernizing Medicare and Medicaid, which is a forum where he focuses on making sure the Americans with Disabilities Act actually works for people with disabilities. He was a senior advisor to the head of what is now called the Centers for Medicare and Medicaid Services, and was key to HHS's response to the Supreme Court's Olmstead decision. Some of you may have been at the briefing we did a while back on the fifth anniversary of that decision. It involved the states' response and the federal government's response to the Americans with Disabilities Act. Henry Claypool knows the world of disability from the other end of the telescope as well, as someone who's had to grapple with the major disability and healthcare programs as a participant and as a potential participant. Henry, thanks for being with us, and it's your turn.

**HENRY CLAYPOOL:** Thank you, and good afternoon. As you can tell, I'm here, but part of my voice isn't. I refer you to the report if you don't get something that I say, and there will be a chance to ask questions, also.

I'd like to start with really some of the very basics. Let's begin with Social Security Disability Insurance. It's a program that is intended to be a partial replacement for earned income for workers that become disabled. Let's then look at the criteria that Social Security will use to determine whether or not one is eligible for this SSDI program, the Social Security

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Disability Insurance program. First of all, a person must meet their rather strict criteria for having a disability. That's significant. It's not easy, and many of the participants that we interviewed had a rough time with the process that Social Security put them through, as they said, while they were determining whether or not they were eligible for the SSDI program. Once the Social Security Administration has determined eligibility, individuals have to wait five months before individuals receive their first check. So after those five months, they begin to receive some modest income and then their two-year waiting-period kicks in, so again you see, we're looking at 29 months that people are going without quite a bit. Often times, it's health insurance, and certainly they're going without some of the earned income that they're accustomed to. That's a basic definition for moving towards Medicare once one meets the SSDI criteria. And you saw earlier that a number of people in 2002 that were actually in the waiting period were around 1.3 million, so it's a rather significant population that's really waiting for Medicare, something we can't forget.

Once those individuals actually begin to receive Medicare, we know a little bit about them. We know that three out of four of them are actually poor. We also know that one in three of them remains uninsured during that waiting period before they get their Medicare. So these are significant factors when we look at a population of people that's basically

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

going without resources.

Of course, the report has significant findings, and you'll find them in detail, but I'll give a brief overview of some of what we found during the interviews of our individuals. We conducted focus groups, two of them in Atlanta with primarily individuals with spinal cord injury, some folks with HIV, and then we did some in-depth interviews with individuals across the country. They of course, informed the report. One of the things we found is that paying for food and paying rent were quite difficult for those individuals that were on Social Security Disability and in the two-year waiting-period. Of those issues besides rent and food, they had great difficulty, obviously, paying for their medications, doctors' visits, and any of the therapy that they might want to access to help deal with some of the side-effects of their disability. Often times in the early stages of a disability, you need to learn certain things to become more independent or maintain your independence, and we heard quite clearly from individuals that this was something that they were ill-equipped to deal with and didn't have the resources. This quickly led to frustration. In the two-year waiting-period, people really felt like this was a big hassle, and a real nightmare. These are words that were used by the people that we interviewed.

They also talked about getting the run-around. It's unfortunate that people who need help the most have to go

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

through this type of process to secure some of the resources that they need, and one of the quotes, it's very brief: "I think there ought to be an easier way to work with Social Security." So obviously, Social Security is the place that you begin in applying for your benefits. You're looking forward to getting health insurance. Not many individuals know that the agency that runs the Medicare program really doesn't have much to do with the Social Security Administration anymore, and as a consequence, people are really confused and frustrated. One of the things that comes to mind for these individuals is why the wait? They have these negative feelings about waiting two years. It's understandable. It moves beyond frustrations, really, in terms of resentment and anger, and I think we can all understand why. You're dealing with something and you're not getting the resources you need. Many of the individuals that we've interviewed feel like they've paid in, and rightfully so, to the Social Security program, through their paychecks and their benefits, and their earnings as when they were employed, and now they're wondering where those benefits are that they've already paid for.

So this frustration really takes on a number of shapes and forms, and here's another quote from one of the people that we interviewed: "What's occurring is that these people are becoming sicker, whereas if they were able to get the care that they needed right away, or as they needed, they wouldn't have

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

as severe cases as what they get." So obviously, I think the person's telling us rather clearly that if we make people wait two years, or 29 months that we're actually going to see people deteriorate, and need more in the way of services once they actually receive their health insurance. So, now that they're not receiving health insurance, these individuals have the problem of making choices and basically going without.

So while in this waiting-period, their out-of-pocket payments for prescription drugs are really the number one issue that we heard about, and I'll touch again on that later. We had numerous reports of people putting off doctor visits, or seeing them less frequently, and in many cases, we had individuals foregoing necessary medications, tests, and the rehab therapy that they were looking for. So, back to, I'm paying this money out-of-pocket now to purchase some of the health insurance or the related services I need, and the biggest problem is—another quote—"The biggest problem is the money we have coming in is about \$15,000 a month, my rent is \$945 a month, and so there's no money left over."

**ED HOWARD:** Fifteen hundred.

**HENRY CLAYPOOL:** Excuse me. Did I give them 15,000?

**BARBARA COOPER:** Yeah.

**HENRY CLAYPOOL:** Wow! I wish—

**ED HOWARD:** Sounds like a friendly amendment.

**HENRY CLAYPOOL:** Yeah, they want to hear about this

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

also. Then sometimes you may need to make the decision: Well, maybe I don't need to get this prescription filled because there's no money to pay for it. So people are actually just skipping doctor's visits, prescriptions, etc. And we come back to the issue again of making choices. We heard people about deciding whether they were going to pay for food or rent, and obviously they're struggling to get their healthcare needs. So again, the lack of access affects doctors and specialists. You want to make sure that people see them, but unfortunately they can't during the two-year waiting-period in most cases, unless they're paying for it out-of-pocket. We heard from the individuals with spinal-cord injuries in the focus groups that they really relied on the rehab therapy because they believed that this would lead them to greater independence and allow them to return to a lifestyle that they were more accustomed to. Unfortunately, they don't have any health insurance to cover that while they're in the two-year waiting-period. Access to medical equipment was another issue that they raised. People need this to maintain their independence, and again, to be involved in their communities, and one of the larger issues that came up was people want to go back to work, but if you don't have the equipment to help you get there, obviously, you're going to have real trouble.

Prescription medications: Well, now Medicare is going to have a prescription drug benefit. How will that affect

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

people? That's hopefully something that we'll know after 2006, but again, they're still subject to the two-year waiting-period, so prescription medications will still be an issue for many of the folks that we interviewed.

Just looking toward the future, individuals really have quite a bit of fears and despair over their circumstance. They're concerned that they're not going to be able to make it, that they're not going to live through this two-year waiting-period. And that came through quite clearly. Here's another quote from one of our participants: "I do understand that if I do not receive healthcare 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 taking care of me. There's a side of me that does, but there's that carnal side of me that freaks out, going, 'Oh, my God, how am I going to do this?' I don't have any answers, and I have lots of questions." So these are real issues, and people are struggling mightily with them. One of the issues that comes up again is people wanting to get back to work. How are folks going to be able to return to work if they continue to get sicker? That was one of the things that they asked us about. We obviously didn't have too many answers. It's interesting. We had a piece of legislation at the end of 1999 that was signed into law, the Ticket to Work, and Work Incentives Improvements Act, which actually extended Medicare

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

coverage for eight and a half years once someone returns to work. Unfortunately, you have to go through the two-year waiting-period, begin to receive Medicare, and then guess what? Then you can go back to work and begin to receive eight and a half years of Medicare coverage. So we have a disconnection here in the nation's policies regarding Medicare and how it's going to cover people with disabilities.

Quickly, I'd like to go over three of the recommendations that are included in the report. There are about eight of them, and some of them concern Medicaid, but just to keep this clear, we're focusing in this presentation on the Medicare program.

One is, Congress should take immediate action to enact legislation that eliminates the current Medicare two-year waiting-period and brings Medicare coverage concurrent with that of SSDI.

A second recommendation: Congress also should consider subsidizing the purchase of private health insurance during the waiting period on a sliding basis.

Third, accurate information and benefits counseling assistance on how incentives can be used to return to work or to obtain health coverage during the waiting period should be made available through the same methods identified in this report. So you can look to the report and find out the other recommendations. I urge you to read them. I hope you find it

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

most informative. Thanks.

**ED HOWARD:** Thank you Henry. Can I just ask a clarifying question? You mentioned the test of disability itself to qualify for SSDI cash benefits that triggers the waiting period. There's a work requirement, too, is there not, similar to the work requirement for old-age benefits?

Yes. The work requirements vary, depending on age, but typically if you are thirty or forty years of age, you need to have about forty working quarters, or ten years. Other individuals, if they're younger, would look towards maybe a six-year history when Social Security is deciding whether or not an individual has paid into the system enough to qualify for SSDI. There are exceptions and many of you know there are always exceptions with Social Security, SSDI, SSI, Medicare and Medicaid, and the report touches on some of those exceptions.

**ED HOWARD:** Thank you very much. Finally we're going to hear from Lorne Fox. Lorne Fox is here today as kind of a reality check for those of us who operate inside of the Beltway, usually. Two years ago today, if I read your biographical information right, Lorne suffered a seizure that it turned out was connected to brain tumors. His condition has left him with a substantial disability, and he's been trying to make the safety net programs that are supposed to help with healthcare and income work ever since. Social Security has determined that he qualifies for Disability cash benefits, but

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

now he's waiting. He'll have to wait a total of two years to qualify for Medicare coverage, and he's agreed to share with us his experience today, including the harrowing experience of getting her today from Texas. Lorne, thank you so much for joining us and sharing your information.

**LORNE FOX:** And thank you for having me. How's everybody? Good. It's good to be here. I'm nervous as hell, but you'll help me through that, I'm sure. Next slide, please. That's me, and that's why I'm here. Next slide, please.

That's me. Good looking fellow, ain't he? Things I did before cancer. I did anything and everything. I never had to take any medications at all. I was health, active. If you hitched me to a barn, I could move it. I trained in many different areas. Ever since—remember what Superman looked like when he found his Kryptonite? That's what this has done to me. If I ever found out, or ever had to find out in a certain way that I was indeed mortal, this has surely done it to me.

I started having seizures in my sleep, and went to the doctor. I had insurance at the time with the company I was with. When I would have a seizure in my sleep, I would wake up, but it was a very groggy type of consciousness, and once I fell back to sleep, I was down. I would sleep through my alarm clock, and I was late to work, almost daily. I ended up losing my job because I was late for work so many times. I had told my supervisor, who was a wonderful fellow, that I was having

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

seizures in my sleep, and he sent me to the doctor. Well, the doctor I had is a good doctor, but her physician's assistant sent me for an MRI, and they scanned me from the neck down. I and I asked her at the time, telling her, "I'm just a simple fellow, but don't most seizures originate in the brain?"

Well, about a month later, I was on another job, and I was working quite hard. I was working third shift, getting off at seven a.m. I got off of work and it was a filthy factory job, but the pay was good. It was quite good. I walked into the bathroom, and I ripped a paper towel off the wall and I blew my nose and had a seizure. These aren't the grand mal type seizures, they're what's called a focal seizure. It started in my hand, and started working up my arm, and it felt like I was getting shocked. I didn't know if there was some weird bug biting me, so I lifted my sleeve up, and that ain't a bug, because it kept going up my arm. It went up into the side of my face, and my arm was thrashing pretty wildly and the muscles in the side of my face are twitching, and my neck is contracting. It scared the hell out of me, because it was the first one I'd had while I was awake.

I walked out to my vehicle and I called somebody, because they ran an ambulance transport, and these companies are territorial, so she couldn't help me. So I called 911. I went into the office to call, and my supervisor was sitting at his desk, and I told him I just had a stroke or a seizure, I'm

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

not really sure what it is. He said, "How do you know?" I couldn't even move my left arm afterwards. It hangs, just hangs there useless. I threw my arm up on his desk with my right hand, and pulled some pushpins out of his bulletin board and stabbed them into my arm, grinning the whole time. I could not feel it at all. So, he called 911 pretty quick.

They took me to the hospital, and I called my family back in Texas. I was in Pennsylvania at the time. I called my family and called my mom and dad and sister and everybody, and told them where I was and what was going on. They did scan after scan, and they took more blood than I thought I had. As it ended up, a few hours later a doctor woke me up and told me I had tumors in my brain. Here's good news. He sent me upstairs. They checked me in. Now, I hope I don't disgust anyone too bad, or offend anyone by saying this, but I really don't ever want to have my prostate checked again. What a horrible experience. They checked me everywhere to see if this was a cancer that had come loose from somewhere else and enlarged and started growing. Nope.

It was a Grade 3 out of 4, an astrocytoma, and I went through two surgeries. Next slide, please. That was just my discharge papers. Next slide, please. Forgot to say that, sorry. My surgery on the 23<sup>rd</sup> of October, last year went pretty well. Next slide, please. That's me in the ICU after the first surgery. Woke up crying like a baby, bawling my eyes out from

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

the anesthetic. Not too good of stuff. It had quite an effect. I have quite a scar here on my head. [Makes knocking sound.] Hear that? That's where the meat did not grow back over my skull. That's not a plate, that's just my skull with skin over it. I went through two months of radiation. Well, let me go back. Next slide, please. Morphine. That's what it does, and I had to get a shot of morphine every hour, because it really hurts like hell to have your head ripped open. Next slide, please. And that's what my head looks like. That was after my second surgery. They had to go back in because, the first shot was in the ICU after my first surgery. That night, I had seizures again in the ICU, and once I got to see my doctor the following day, I told him I thought this would take the seizures away, and they went back in, went and looked again, and said, "You've got two more tumors in there." I thought, but didn't say, "You couldn't see them while my head was open?" Because that piece of my skull that you see there is roughly about the size of my fist, and the whole thing from one end of the incision to the other, that whole piece of my skull was laying on the table somewhere. You could probably see a good bit of my brain. Anyway, one week later, to the day, on the 30<sup>th</sup>, I had another surgery, and that's what I looked like after that one. Next slide, please.

My disability assessment form. Believe it or not, I was accepted right away. I guess one of the reasons is down there

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

under diagnosis, where it says, primary, which tells you it was an anoplastic astrocytoma in the parietal lobe of my brain, which does control movement, and secondary, seizure disorder. I still have seizures.

I went through two months of radiation and I don't recommend it, just to try it. I gained 60 pounds in two months. You don't even see anyone that's very pregnant do that. I was on steroids to keep the swelling down in my brain and I literally blew up like a toad. My clothes didn't fit; I had to wear sweats everywhere. The people at my church were pretty friendly about me showing up in sweatpants in a sweatshirt, but since I had lost my income, that was all I could afford, and those on sale. Next slide, please. My prescriptions—I went through a chromosome study with the last of my money and the Andy Anderson Cancer Center in Houston to determine what form of chemotherapy would be best for my body, because I'd heard so many horror stories about people, their organs and bone marrow being destroyed by chemotherapy, so they did a chromosome study with the little piece of brain that was with the tumor, and we decided on an oral form of chemotherapy called Temodar. With the Temodar, I was able to eat, didn't lose any weight at all. I mean, I took off the weight I had gained from the radiation and the steroids, but Temodar was a wonderful, wonderful acquisition, but for 2 pills, the average cost per month was \$3550. The Zofran, which was the anti-nausea medication that I

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

had to take was \$32 a pill, and I had to take that twice a day. My anti-seizure medications I have stopped for the last eight months because I can't afford them. I had to wean myself off of them very slowly. I haven't been to a doctor since February. Once I moved back to Texas it was a rather rude awakening to find out that Texas is ranked 49<sup>th</sup> out of 50 when it comes to healthcare. When I was in Pennsylvania, I would pay \$169.60, take a receipt into the Department of Human Services office and they would reactivate what's called the Pennsylvania Access Card. My MRIs, blood work, prescriptions, even dental, everything was covered. It was just like paying a premium. Back then, I thought that was a lot of money, because I was getting about \$779 a month. It takes a big piece out, if you owe 200 bucks a month. That's a lot to me. Then it was. Now it would be so acceptable. In fact, the doctor wants \$384 just to schedule an appointment for the neurologist, and that's before he even says hello. I'm trying my best to get by everyday with the love of my family, and having to put all of my faith in the Lord. I'm waiting and waiting, and even once I get my Medicare, I still don't know how I'm going to afford prescriptions, at least until 2006. From what Jim said, the number can be all the way up to 12 percent of those that die in the waiting period. If the waiting period is designed to help people die off, they're getting there. But I assume it's to see if they're truly disabled. With the piece of my brain that's missing, my

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

left hand is—no offense to anyone, I tell people it's retarded now. I can't feel from about the middle of my middle finger, over. I hook a finger trying to put a hand in my pocket. I can't feel anything that's small in my pocket. My index finger and my thumb, and my middle finger work pretty well, but my ring finger and my pinkie, just trying to put them together, they're stupid now; they don't quite mind for a while. I can't do the work I used to do because I was a welder, and a machinist, and I don't want to have to baby-sit my hand to keep it from getting ripped up or disfigured. I'm here on behalf of a lot of people, and 1.3 million folks, that was a lot of phone calls to make—just kidding. I can't get Medicaid in Texas because the children that I love so dearly are not mine biologically. I can't even get Food Stamps. I can definitely get prescription coverage. We're looking for immediate qualifying, and I understand that something has just been introduced, or passed? Introduced, for those in Stage 3 and 4 cancer? Well, I got Grade 3, I'm close enough! No waiting period for benefits would be wonderful, as long as there was some type of prescription coverage there, for those like me. I don't really need to go see a doctor every month. It would be nice to go get my blood checked, to have an MRI to see how I'm doing, because I have no idea how the hell I'm doing, and I'm in this for the long run. They told me at first that I would live five months, and I just about—well, I lost it. Five months

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

isn't long enough to do anything. Five months isn't long enough to qualify. I've got kids that I love dearly, and I will see them have grandchildren. I told that doctor that told me I was going to live five months that I was going to outlive his grandkids, and I mean to. I don't plan on dying until about five minutes after the Grim Reaper, but I'm going to need some help in the process. Thanks. [Applause.]

**ED HOWARD:** Thank you so much, Lorne. Jim laid out the principal, and you personified it. It's a program that's designed to help you with cash benefits. Making sure you don't qualify for in this case, Food Stamps, by putting you over the income limit.

We have the opportunity now for you to be part of this discussion. You can see that we have microphones for you to ask questions. Bob, I wonder if I could ask you to defer. I've asked Bruce Leslie, who is the health policy advisor to Senator Bingaman, who's one of the principal sponsors of legislation relating to this topic, to bring us up to date on the difference between introduced and enacted and what the prospects are for this kind of legislation, if not in the lame duck, in the coming session.

Thanks. My name is Bruce Leslie with Senator Jeff Bingaman. First of all, I wanted to thank everybody who's here. I want to thank the Alliance for having this briefing on this very important issue, an unbelievably powerful issue, and the

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Commonwealth Fund and the Christopher Reeve Foundation. And Henry for working on the report, and Barbara, and Jim's comments. And Lorne Fox. I've been coming to Alliance briefings for years, and I've not heard anyone as powerful in a briefing.

One of the things I just wanted to say was, after my boss introduced this bill—and this is one of those bills that really came from the grass roots. It was people like yourself in our state who had come to town hall meetings and talked about their disabilities, and we've introduced the bill to eliminate the waiting period. We're hearing from people across this country on this issue, unbelievable stories like yourself, on diseases that I've never heard of, illnesses that you know, I had never fathomed. So I just wanted to thank everybody first.

So we have introduced the bill and will be reintroducing next year. There's a pending bill by Congressman Greene. There are other bills like Congressman Pallone's. But one thing I wanted to highlight, too, and sort of ask people where they are coming from is in respect to the waiting period, I'm finding out there's really three waiting-periods, because it's not just the two-year waiting-period that you get from Medicare and the five months before you get your SSDI, but it's also this whole issue of this determination process. I wanted to ask the panel if they could comment on that. There's a GAO report that the Finance Committee, Senator Grassley and Senator

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Baucus requested on if you're denied, a determination, the length of time it then takes to get an appeal. Anyway, I would like to talk through those three waiting periods so people can understand. The period is longer than 29 months, it's years.

**HENRY CLAYPOOL:** I can begin with some clarification, because Ed had to ask a question, so I think I should really make this more clear. Once the individual does apply, Social Security is really going to look at whether the individual that's applying for benefits is likely to die, or whether their disability is going to continue for at least twelve months, and during that time they aren't capable of work. So there are a number of factors that the Social Security Administration is considering when they do their disability determination, and that can result in—as a matter of fact, I think it's common now for people to be denied on the initial application to move to a reconsideration, which is the next step. You ask the field office of Social Security for a reconsideration of your initial application. That's done at a fairly low level in terms of the Social Security Administration, and after that, you have the opportunity to ask an Administrative Law Judge to make a decision about the reconsideration if you've been denied there. The timeframes are extraordinarily long. If you get to a denial of your reconsideration and you apply for a hearing with an Administrative Law Judge, it can vary from six months to three to four years just in waiting for this hearing to determine

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

whether or not you actually have a disability. So Jeff's question is a good one. It's unfortunate, but I think the Social Security Commissioner has actually introduced some reforms in SSA to speed up the determination process because the Agency understands how long people have to wait for this determination. I hope that answers some of the questions.

**JAMES M. VERDIER:** Just a footnote on the Medicaid part of the process: There are probably about two-thirds of the states that sort of automatically accept the Social Security Administration determination of disability. Some of those states, maybe ten or so, require a separate application, but they'll accept the underlying determination of disability. There are about a dozen states that have historically had a separate disability standard from the one that SSI uses, so they'll make their own separate determination, so that can impose additional delays and complications and hurdles in the process.

**JENNIFER RELICK:** Hi. My name is Jennifer Rellick. I would like to ask if from a policy perspective there has yet been much research about the non-Medicaid, non-Medicare costs associated with this waiting period? Mr. Fox has elaborated that his kids need him, and there is a cost associated with a parent not having enough money to take care of their kids. There's a cost associated to society when someone can't get back on their feet and go to work again. It seems to me that

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

this may be a little bit shortsighted to only take into consideration the direct cost [inaudible] by having this waiting-period.

**JAMES M. VERDIER:** I don't. We certainly looked for those kinds of additional costs to the extent that we could quantify them when we did our report, but the costs that we could identify and quantify were fairly complex to come up with as it is, and we knew those other costs were out there for exactly the reasons you describe, but we couldn't find any good information that would enable us to quantify them.

**ED HOWARD:** Can I help with a follow-up maybe? Jim, I noticed that in the report that you did for Commonwealth last year, you pointed out that the Ticket to Work legislation, as passed back in 1999 authorizes the Social Security Administration to do some demonstrations of ways to get people back to work more quickly, including presumably manipulating the two-year waiting-period. Is there any interest in using that demonstration authority that you know of?

Not that I know of. I know they've got some demonstrations underway, but I don't know whether they are specifically linked to the waiting period. Back a year or so ago when we looked, we couldn't find any. Maybe Henry knows of some subsequent to that.

**HENRY CLAYPOOL:** Actually, I have done some work with the Social Security Administration, and they have looked at

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

waiving the two-year waiting-period in a demonstration just to simply test the question of what would happen if we didn't make people wait two years. But they don't have a demonstration designed or anywhere close to actually running a demonstration.

**ED HOWARD:** If there's anybody here from SSA, or if you know of anything in addition to that, and you could provide it, we'll make sure it gets posted on our website.

**BARBARA COOPER:** I was wondering if Henry, you knew of specific examples where the two-year wait really made a person deteriorate so much that they couldn't go back to work, where if they had gotten healthcare, maybe they could have?

**HENRY CLAYPOOL:** Yeah. We heard from a few individuals when we were in Atlanta, and in one case, a wheelchair user who was recently injured, a positive story. She was continuing to work even while she was doing her rehabilitation, and uninsured, hoping to regain her employer-sponsored health insurance. We also had two other individuals in one other focus group that talked about how their bodies had deteriorated because they had foregone the rehab therapy that they needed and they felt like they really weren't able to go back to work now. And I think beyond the physical, it really takes an emotional and psychological toll on individuals, leading them to a sense of hopelessness and really decreasing the likelihood of their returning to work, so it's a large problem, and hopefully one that we can address one day.

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**ED HOWARD:** Take your time. Let me remind you that you do have the green question cards, as well, so feel free to fill them out and hold them up.

**BOB GRISS:** My name is Bob Griss. I'm the Director of the Center on Disability and Health and a frequent attender of these Alliance Health Reform session. I think this is a very unusual session, because we get both the policy analysis and the personal experience on the same panel. I would like to suggest that in the future that there is some reality to policy debates by inviting an appropriate consumer representative who really can illustrate the experiences of the policies. Henry gave a lot of examples from focus groups, but we usually discount as anecdotes about how delayed healthcare could actually interfere with rehabilitation and could ultimately increase the costs that get paid by Medicare. But unfortunately as Jim has just acknowledged, those anecdotes are not incorporated in most of the research. The members of Congress who have voted against eliminating the two-year waiting-period justify it by saying that the costs would be prohibitive. I can't tell you how many times we hear that complaint. And even Jim's cost assessment now is based on what it would cost if the two-year waiting-period was eliminated for everybody. And yet the bills that you've recognized here are saying how about we eliminate it for the one-third people who have no insurance at all? We don't see a cost estimate for that. So my feeling is

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

that the healthcare debate is actually a very distorted set of options that are often presented, and we really need to look at real people and see how the cost estimates are taken into account, because so often we dismiss as impractical the costs when they don't have to be as high as eliminating it for everyone. Because as Ed pointed out, we're talking about people who have had to meet the work requirement in order to qualify and who also have had to prove that they were disabled by their medical condition. So I think this is a very important panel, and I appreciate it.

**ED HOWARD:** Thank you, Bob. We have some questions that have come forward on cards, but go ahead, Brigitte, Eric. And we've got somebody over here. Sorry. The light has blinded me.

**FEMALE SPEAKER:** Do you want me to go first?

**ED HOWARD:** Yeah.

**FEMALE SPEAKER:** Mine's really brief. It's just a question for Jim. But first let me say thank you to you, Ed, and the Alliance and Henry and all the rest of you on the panel, Barbara, for being here. And Lorne, most importantly for you, for coming here all this way. My question is, on your slides--this will show the wonkie in me, because I'm interested in trying to pass this thing--You talked about the fiscal impact on Page 2, the second slide. You showed a bullet at the bottom that said the federal government paid 57 percent of Medicaid, so the net cost would be 6.2. On the next page, am I correct,

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

that you don't have a bullet like that? Because you went up to ten, and then Medicaid costs down to two. But wouldn't it be less, even though it made them that, if you did the same example that you did on the other page?

**JAMES M. VERDIER:** What I was doing on the first slide there that Slide 2 was actually doing some of the arithmetic that you have to do in your head. If you look at just the three parallel bar graphs there. . .

**FEMALE SPEAKER:** So you're telling me if I would have calculated this in my brain, I would have figured this out?

**JAMES M. VERDIER:** Yeah.

**FEMALE SPEAKER:** Okay, I just wanted to make sure that it was appropriate to do that. Basically, the ten doesn't include the savings from the 57 percent federal government's contribution.

**JAMES M. VERDIER:** No, it does not, and we further threw you off by rounding some of the numbers.

**FEMALE SPEAKER:** That's okay, because I wanted—because I'm hopeful that the number is less. I don't think in the grand scheme of things, although in this day and time we have to pay for everything that's an [inaudible] tax-cutting. But that means that that number's not so big and maybe we could accomplish it.

**JAMES M. VERDIER:** Yeah. No, if you start with the 8.7 billion, which is the total additional costs to the Medicare

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

program, but then you subtract from that the federal savings that would occur to the Medicaid part of the budget, and in the budget as a whole you would subtract those from Medicaid, even though it was in the Medicare budget, you don't subtract them.

**FEMALE SPEAKER:** That's helpful, because if we do it the way Mr. Bingaman wants to do it, it would be even less. Thanks.

**ED HOWARD:** Yes, go right ahead.

**DONALD MANNY:** This question is for Mr. Fox, and it's more off-topic, so I apologize to the rest of the panel.

**ED HOWARD:** Would you like to identify yourself, Sir.

**DONALD MANNY:** Donald Manny with the American Legion. Mr. Fox, I tried to catch the date of your discharge while it was up on the screen for a very short time. My eyesight isn't that good. But if you were discharge within—you seem to have been discharged from the Air Force approximately two years ago.

**LORNE FOX:** Yes, Sir.

**DONALD MANNY:** If it can be shown by a preponderance of medical evidence to include an expert medical opinion that your condition had its onset in or within one year following discharge, then you are statutorily entitled to VA healthcare for your problem, and depending upon your level of disability, all your healthcare. So, I don't know if you're aware of this, but there's a good possibility you could shift this whole thing from one government agency to another.

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**LORNE FOX:** That's definitely good news. I spoke with a VA service officer while I was still in Pennsylvania, and I had a very hard time getting my records, because I actually separated from active duty back in 1997 and was on inactive reserve until May of 2002.

**DONALD MANNY:** Well, I don't know much about—I've heard of astrocytoma. If it's a slow-growing cancer that started way back when, and if you can get a doctor to state that, you may still get into the VA.

**LORNE FOX:** They told me what different symptoms and signs were, and I had those for years. It would be like a camera flash, but it would feel like I just got a really good shock.

**DONALD MANNY:** The only way to do it is—and I wouldn't go to the VA directly, I'd go to some accredited Veteran's Service officer, either one in your county or state, or the VFW, or the American Legion, and start the process. Like I said, if it can be tracked back to within one year after discharge, then the whole thing will be taken care of by the VA.

**LORNE FOX:** Sweet!

**ED HOWARD:** Thank you very much for that suggestion. We'll make sure it gets followed up on. Yes, Jeff.

**JEFF CROWLEY:** Jeff Crowley with the Georgetown Health Policy Institute. I wanted to follow-up with something Henry

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

said. He gave two recommendations. I think one was to just end the waiting period, and then the second was to rely on private sector solutions, and I think both could potentially work, so I guess I have a question for all of you that want to respond, is just from political sense, do you ever think one is easier to solve than another, or are there drawbacks from not ending the waiting period, but relying on the private sector?

**ED HOWARD:** Let me just jump in here. I don't know if someone from the Congressional Staff, so I know it wasn't you, asked a similar type of question, what are the advantages and disadvantages of eliminating the 24-month waiting-period, as opposed to federal subsidy of Cobra or similar coverage as was done in the Trade Adjustment bill. What are the political strengths of those two approaches?

**JAMES M. VERDIER:** Yeah, and if there were a subsidy for the COBRA coverage so that the employee, or former employer was not as high as it is now, that would clearly help. That would people keep their COBRA insurance. It is still a fairly substantial cost for employers or their insurance companies, depending on how their premium negotiations work, to cover people with COBRA insurance with substantial and very identifiable and fairly costly disabilities. It's almost from a public policy point of view, I would argue, those kinds of very high-cost for disabilities, which are unpredictable from the point of view of an individual employer and hard for an

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

individual employer, especially a small one to even cover with an insurance policy, and even more so for somebody who's getting an individual insurance policy. So yeah, you can make some progress, I think, by subsidizing COBRA coverage, but in the long run, have these kinds of very costly and unpredictable disabilities covered through a public program like Medicare or Medicaid, where the costs can be spread more broadly, I think is preferable from a public policy point of view, but that's reflecting my own sort of values and experience, and I can see making an argument for stronger reliance on the private sector, and they're not mutually exclusive.

**BARBARA COOPER:** Red Hair

**ED HOWARD:** Henry?

**HENRY CLAYPOOL:** Interesting in our findings was a preference amongst the participants for the private insurance, and we basically believe that's due to the fact that that's what they knew. They were covered by this insurance, so they were covered by this, and they knew they hadn't received public health insurance or medical assistance before, but to just point, maybe it would make real sense to look at the one-third of the uninsured, and make sure they got the insurance, and waive their two-year waiting-period for Medicare, and then also look at individuals that were able to retain employer-based coverage and in some way supplement that cost. Through combination there might be a way of reducing the costs and some

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

of the projections that people might make around wiping out the two-year waiting period, because I know there are some concerns about crowd-out and the whole idea of private insurance competing against Medicare.

**ROBERT DeMIKOLAS** [misspelled?]: Hi, my name is Robert DeMikolas. I'm with the Brain Injury Source of America. Lorne, I want to thank you very much for honest testimony here. You've inspired me to step forward and talk. I represent 5.3 million Americans with brain injuries, which can be quite traumatic. Mine happened in a motor vehicle accident. I can't tell you what happened, in 1980, and I spent some time in a coma and recovery [inaudible]. I also wanted to let you know that October this year is brain injury awareness month, and I brought you some information here before I get to my question. The annual [inaudible] burden of TBI in the United States has been estimated at \$56.3 billion in 1995 dollars. However, human costs of the long-term impairments and disabilities associated with TBI are [inaudible]. Because many TBI disabilities are not conspicuous deficits, they are referred to as the invisible or silent epidemic. These disabilities [inaudible] emotional sensory and motor impairments, often permanently alter a person's ability to maintain quality life experiences and have profound effects on social and family relations. CC estimates that the total population of 5.3 million Americans live with total permanent disability, however, this estimate does not

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

include people with mild TBI who are seen in Emergency Rooms and outpatient [inaudible]. Those who do not receive medical care at all can end up having a problem. The pertinent data is that the leading cause of death among children and young adults. It's estimated that 1.5 million Americans are suffering with TBI. [Inaudible] TBI, 230,000 people are hospitalized and survive. 50,000 people die, but more importantly 80-90,000 people experience the onset of long-term disability. That's a huge amount for Social Security to absorb, and like Lorne I went six and a half years to get my word. It's incredible without insurance, without medical [inaudible] and basically it was day-to-day living. If you want to know, people like myself and my peers not getting care [inaudible] show that the same access to quality care helps decrease the aftereffects and the secondary disabilities. [Inaudible] diagnosed with mental health and mental illnesses diagnoses, and are overmedicated and improperly so. Thank you.

**ED HOWARD:** Thank you very much.

**LORNE FOX:** Thank you.

**ED HOWARD:** Yes, Allen in the back.

**ALLEN GLAD:** Allen Glad, Senator Biden's office. We hear a lot of the TV and radio about privatization of Social Security and privatization of Medicare. Could anybody on the panel explain how the Social Security disabilities system would be integrated into any system of privatization of Medicare or

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Social Security? Has anybody seen any proposals on how that would be done?

**ED HOWARD:** That's a very good question.

**HENRY CLAYPOOL:** I haven't seen anything done, but I would assume that the companies that deal with writing those policies would run as fast as they could from this population, as they are likely to be consuming their income supports for a long period of time. I believe that's why these programs were created, because there's really nobody out there that was going to offer health insurance or an income insurance, like disability insurance to these individuals, so the federal government needed to step in and fill the void. So, it's ironic at a time that we talk about privatization that we sometimes don't make the connection between the population that we're talking about and the actual act of privatizing their income supports or their health insurance.

**ED HOWARD:** Let me follow up, if I can. Joe Neuhaus at Harvard has been saying we're this close to a risk-adjustment device that could be usable in Medicare for a long time now, but now we actually have one that seems to be getting refined as we go along to work somewhat better. What's to prevent payments to private companies in a privatized Medicare choice that they might opt for to be adjusted using these risk-adjustment factors so that the companies don't have such a potential risk? Doesn't that make a lot of sense?

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**BARBARA COOPER:** Yes, in theory, but I think—well I haven't kept up with the latest, but the risk adjustment methods are pretty good on average. They have had more difficulty with risk adjustment for persons with long-standing severe illness. But in theory the privatization of Medicare is involving more private plans like PPOs and HMOs that beneficiaries could enroll in. To date there haven't been that many plans that have specialized in any way in serving the most vulnerable population.

**HENRY CLAYPOOL:** Just one quick point back to an earlier question, from Bruce Wesley. Since Senator Bingaman is so active, I just want to point out that there is actually in New Mexico a thing called a Medicaid buy-in. It was created in Ticket to Work and Working [inaudible] Act. And so, in the State of New Mexico, it's structured in such a way that it really tries to help those individuals that are stuck in the two-year waiting-period participate in the Medicaid program while they're waiting for Medicare coverage to come along. It looks like we need to keep looking towards the State of New Mexico for leadership both maybe in some legislation and in just some data around costs associated with serving these individuals.

**ED HOWARD:** Yes, go ahead, Jim?

**JAMES M. VERDIER:** Again, just a footnote on the Medicaid buy-in. Some of my colleagues at Mathematica are doing

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

and have completed summaries of what all the states that are taking advantage of that option are doing, and if anyone is interested, they can give me their card, and I'll give them information on how to link up with that report.

**ED HOWARD:** Excellent. Before we wrap this up, I want to be sure that people remember that they should fill out those blue evaluation forms before we finish up. I want to get this question asked because it does touch on several of the things that we've been talking about in a different way. "Wouldn't it be better," the questioner asks, "for individuals with disabilities to be able to be in Medicaid with personal attendant service and drug coverage now, than in Medicare, even after the drug benefit kicks in?" Henry?

**HENRY CLAYPOOL:** That's a wonderful question, and I think the report goes a way in pointing a direction for us there that obviously the Medicare program offers the type of assistance that people with significant disabilities need, and at least it should wrap around the Medicare program to help these individuals to make sure that they can enjoy community living and return to work. I hope I answered the question. I think it's a yes.

**JAMES M. VERDIER:** Let me again though add a footnote and a caveat. Certainly the Medicaid benefit package has the potential, and in many states is much broader than the Medicare benefit package, not just the prescription drugs, but the

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

personal attendant services and home and community-based services and all others. And there are states that have very broad and very generous Medicaid benefit packages, but as Lorne discovered, living in Pennsylvania and Texas, there are significant differences in the eligibility requirements for getting onto Medicaid as well. In some states, it's very hard and you have to have very low income and fall into relatively narrow eligibility categories, whereas in states like Pennsylvania and many others, the eligibility is much more generous, and the benefit package tends to be more generous in states that have a broader eligibility package as well. So, surely ideally Medicaid is structured to be a better program for people with disabilities, but there is the inevitable state-by-state variation.

**HENRY CLAYPOOL:** And Jim, in the report that the Commonwealth Fund is going to release, there is a recommendation that actually addresses those structural differences, so it would ideally move the program in that direction for these individuals, because we do hear from Lorne and millions of other people about the disparities, especially when they move from state to state.

**ED HOWARD:** I just have one other question of the ones that were submitted in advance that I thought would be useful for people. It actually is something I guess, that Henry touched on, but didn't spend any time on. I wanted to be sure

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

that people don't miss it. The questioner asks if somebody getting SSDI benefits, the cash benefits manages to rehab to the point where he or she can return to work, do they lose their Medicare benefits? That assumes that they've gone through the two-year period and have gotten their Medicare benefits, I guess.

**HENRY CLAYPOOL:** The answer is, it depends. If they have gone through the two-year waiting period, and they're not entitled to the extended eight and a half years of extended eligibility for the Medicare program. The issue is around whether or not the individual is earning SGA, substantial gainful activity. And that is now pegged to increase with inflation, so I believe this year it's \$840 a month. So an individual can actually earn less than that and not compromise their Social Security benefits. They would actually not even be counting a month against their trial work period, which is a whole other issue that I probably shouldn't have raised. Let's just take it and say that it would be a month off of their Medicare eligibility for the eight and a half years. If an individual is earning less than that amount, the Social Security Administration wouldn't look towards that as substantial gainful activity, and it won't count against you.

**ED HOWARD:** But if they were earning more, they would still be able to keep their Medicare for eight and a half years. The law actually extended it about four years. It had

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

been about four and a half years, and now it's eight and a half years. The original proposal was to extend it indefinitely, which seemed to make sense. Jim quoted a figure earlier, I believe, that less than one percent of the individuals actually ever leave the rolls, so the cost is rather modest to extend Medicare eligibility for the duration of that individual's life, because it seems to be a rather rich incentive to return to work because you're still facing a cliff where you lose your benefits after eight and a half years. So we haven't completely relieved the individual of the concern of, Gosh, what am I going to do about my health insurance when these benefits discontinue?

**ED HOWARD:** And, can people keep their Medicare, even if they're eligible for employer-sponsored insurance?

**HENRY CLAYPOOL:** They can.

**LORNE FOX:** So I can get a job making up to \$840 a month, which is more than I am paid on SSDI, and still keep my disability?

**HENRY CLAYPOOL:** Now when we're talking about the Income Support programs, they would actually reduce cash payments. There is a formula they would use to adjust how much you're receiving, but you could indeed earn income without compromising your SSDI payments.

**LORNE FOX:** I tried and this wasn't long ago; it was just in the last months. I went back to work. I got hired

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

making a very good wage considering we live in a very economically depressed area, and I lasted a whole two days. I started having seizures because of the physical labor involved in the job. So, it's humiliating, and I was just in a hell of a funk because it took a lot of the wind out of my sails. I was so excited that I was going to actually go back and do this, and you know, I came to find out, ha, you can't do it yet, and it just hurt. It hurt a lot, and it took me a while to get out of that funk.

**HENRY CLAYPOOL:** And just a quick plug. In the report there's a reference made to a Social Security project, and they have folks that are called BPAO. I'm not going to get this right, but they're basically benefits counselors, and they know the Social Security rules quite well, and their sole purpose is to get out there and help people get information so that they can understand the rules and return to work. So Lorne, maybe we can find somebody in your area that will help navigate some of those earnings issues that you might face in the future.

**LORNE FOX:** Cool. I hope they can pay me to fish and golf.

**JAMES M. VERDIER:** I wanted clarification. If someone returns to work and earns over the substantial gainful activity level, haven't they disqualified themselves as a disabled person, and lose the SSDI benefit? And how quickly does that happen, because otherwise, there would be a lot more people on

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

SSDI who would be employed if they didn't run up against that SGA level, SGA level being—I'm not sure what it is currently, but it's much more than the minimum wage. So you have all the kinds of expenses that Lorne has told us about, and yet you have to make less than minimum wage.

**ED HOWARD:** Henry?

**HENRY CLAYPOOL:** You do have a nine-month trial work period where Social Security will allow you to earn income, and the amount of income that you earn won't be an issue. But you're right, if you earn for nine months more than SGA, you will lose the income support person of your benefit. Hopefully by that time the individual has Medicare and will be able to retain the health insurance component.

**ED HOWARD:** Okay. Well, this has been a moving and very informative session. I want to thank you folks for being a part of that. I want to thank the Commonwealth Fund once again for joining us, both in supporting, and helping to put this program together. I want to thank the Commonwealth staff, Karen Davis and Barbara Cooper. I want to thank the Alliance staff, also. Anne Montgomery has done a wonderful job, also, putting this panel together and helping assemble the speakers. And I want to thank the speakers, Jim and Henry, and especially to Lorne Fox and I ask you to join me in thanking them for a very useful discussion, and one I hope leads to some activity.

[END RECORDING]

<sup>1</sup> kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.