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**Medicare, Health Reform, and the Challenges for People with
Disabilities
Kaiser Family Foundation
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TRICIA NEUMAN: Good morning. I'm really, really pleased to welcome you to this briefing on Medicare, health reform, and challenges facing people with disabilities. I'm Tricia Neuman. I'm a Vice President here at the Kaiser Family Foundation and I direct our Medicare Policy Project. I'm so glad to see you here. It's quite fitting that we are here in the Barbara Jordan Conference Center named for a beloved member of the Kaiser Family Foundation Board of Trustees.

As you may know, Barbara Jordan was one of the most inspiring political figures of the 20th century but what you may not know is that Barbara spent years of her trailblazing career in a wheelchair living with a disability. So for so many reasons, the foundation is so happy to be hosting this briefing here in this room.

We've actually had many, many interesting briefings in this room as you probably know and often on what we might consider hot health policy issues that are front and center in the policy debate but other times, we like to shine a very bright light on issues and people that sometimes don't get the attention that we feel they deserve in the policy arena. That's what today's all about. That's why we're all here.

So we will focus specifically on the 8 million people on Medicare who are under age 65 and on Medicare because of a

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permanent disability. All too often, as you know, when we're talking about Medicare, we tend to talk about seniors but people with disabilities on Medicare who are younger than age 65 now account for 17-percent of the Medicare population. That's about one in five. So it's time to focus more attention on this population.

Just to give a little bit of background of the 47 million people on Medicare, as I said 8 million people are younger than age 65. Well how do they get on Medicare? I bet you most people in this room actually know the answer to that question but just to remind us all to get on Medicare, an individual not only has to qualify for social security disability insurance but also has to have received social security disability insurance payments for 24 months.

When you put that on top of the five months that people often wait to go on social security disability that means 29 months waiting for Medicare. I suspect we'll be hearing about what people call the waiting period for Medicare.

We want to talk about this population because, as a group, they differ very much from the elderly population on Medicare. They tend to have lower incomes. About a third live on incomes below the poverty level. That's about \$10,000 for an individual.

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About two-thirds live on incomes below 150-percent of poverty. That's just \$15,000 for an individual. They're a substantially lower income as a group than the elderly.

People with disabilities on Medicare also tend to be in poorer health than seniors. They have more chronic conditions. They more frequently report living with pain, sadness, and depression. Their supplemental insurance situation is quite different.

Forty-percent of all people on Medicare who are younger than age 65 rely on Medicaid as a supplement to Medicare. Medicaid helps fill in the gaps, pay premiums and cost sharing and pays for services and supports that Medicare does not cover. So policies that affect Medicare and Medicaid profoundly affect this population but of course many people do not have Medicaid. That's something we're going to talk about.

So at this point, I would like to turn this morning's program over to another trailblazer, Judy Woodruff who will moderate the discussion and introduce our panelists. Over the years, we have come to rely on Judy as she has covered politics and policy at CNN, NBS, and the News Hour, keeping us all a lot smarter and we thank you for that but even more importantly for today, Judy has a longstanding personal and professional interest in policies affecting people with disabilities and has dedicated much of her career speaking clearly and

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compassionately about the issues and challenges facing this population both on the air and off.

On the air, I just want to acknowledge a recent segment that you did on the 20th anniversary of the Americans with Disabilities Act, which was very important and we thank you for that. So without further adieu, Judy on behalf of the foundation, we are so happy that you're here. We are grateful for your coming and I turn over the morning to you [Applause].

JUDY WOODRUFF: Thank you so much Tricia. I am delighted to be here. There's not much going on in the world of news today as you probably know. So it was easy to get away but seriously I am truly delighted to be here. I'm so thrilled that Kaiser is hosting this forum this morning. I'm really happy to see a number of familiar faces around the room for a number of reasons. I'm glad that I'm here.

I suppose now that one could say that you could say now that health care reform is passed and it's behind us, what's the point of continuing to talk about health care reform but the reality is, of course, that it does continue to be in the news. It is a topic of heated political debate. We hear about it every day several times a day. We know there are efforts underway to repeal all or part of it. There are is talk about reforms that were left out of it.

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Just this morning, we read in the news that there are plans by health insurance companies to raise premiums on some Americans, which these companies say is directly a result of the requirements in the new law. All this is one more reason that it is so important to have this conversation that we're having this morning. The topic that we are focused on is a very particular, and I know you know, an important one as Tricia just said, the challenges that remain for the millions and millions of Americans with disabilities.

I do have a special interest in this subject because our older son, who is now 28 years old, has permanent disabilities related to a brain injury, in Jeffrey's case, the result of a surgical mistake when he was 16 years old. So for the last 12 years, he's used a wheelchair. He has not had the use of one of his arms. He has one eye closed. He has speech impairments, severe loss of short-term memory and so a complex set of disabilities. I've come to understand that Jeffrey's no different than anyone else with disabilities.

Every individual with disabilities is unique. Their set of disabilities is unique and that's what makes what we are talking about today as challenging and as complicated as it is and so urgent for us to address what we are going to be talking about. Jeffrey does need help with pretty much all of his activities of daily living. He did manage to graduate from

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college this year after eight-and-a-half years of hard work, which thrilled us. He is now living in an all-too-rare and wonderful community for people with disabilities.

He will always be our family hero but even with our resources, two employed parents with insurance coverage, access to excellent medical care, access to excellent therapy options, the path for Jeffrey has been a crooked one, a nonstop series of questions, judgment calls, relentless advocacy for what Jeffrey needs and at this point, no prospect of a paying job putting Jeffrey in the category of the vast majority of people with disabilities, as many as 70-percent who have abilities but who are unemployed.

So we are acutely aware of what Jeffrey would face if his economic circumstances were any different and we worry a lot about what he faces when we're no longer around.

So this is a topic of great interest, of vital interest to me and I'm especially glad to be here with this outstanding panel who you are going to hear from. I'm going to introduce them. They're going to take turns speaking. I'm going to ask them some questions and then we're going to take questions from you in the audience for, we hope for the last 20 or 30 minutes of our time.

First off, we are especially pleased to hear from Jeff Crowley. He is the second person you're going to hear from him

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second but I'm going to introduce him first. He is the second from your right. He works at the White House as the Director of the Office of National AIDS Policy and as Senior Advisor to the President on disability policy. In that role, he is responsible for coordinating disability and health policy for the President's Domestic Policy Council.

Next to him, Joe Baker, who is President of the Medicare Rights Center. Most recently, he was a Deputy Secretary for Health and Human Services for the state of New York. Next to Joe Baker, Elizabeth Priaulx. Elizabeth is the senior disability legal specialist for the National Disability Rights Network.

This is a membership organization for the nationwide protection and advocacy systems. These are, as I'm sure all of you know, congressionally mandated agencies that provide legal advocacy and representation to individuals with disabilities. Finally, I want to introduce Juliette Cubanski.

She is on the right. She is the Associate Director of the Medicare Policy Project here at the Kaiser Family Foundation. She's the co-author of the study that is the basis of what we are here to talk about, Kaiser's new study of how Medicare meets the needs of its younger disabled beneficiaries.

So Juliette is going to kick it off this morning. She's going to present the results of her findings and then we

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are going to hear from the others. I will call on them in turn. So Juliette Cubanski, the floor is yours [Applause].

JULIETTE CUBANSKI: Thank you very much Judy. Thanks as well to all of you here today. As Judy said, I'm Juliette Cubanski, Associate Director of the Medicare Policy Project here at the Kaiser Family Foundation. Before I get any further into my remarks, I would like to acknowledge my colleagues here at Kaiser without whom these results would not have seen the light of day, Tricia Neuman and Anthony D'Amico.

I'm presenting results from a survey conducted by the Kaiser Family Foundation in 2008 of non-elderly people with disabilities and seniors on Medicare. We obtained data from the Centers for Medicare and Medicaid Services to identify and survey people on Medicare with an oversample of the under 65 population.

The final sample includes 3,913 beneficiaries, 2,288 of whom are under age 65 and on Medicare because of a permanent disability. The study results were published by *Health Affairs* in an online version in August and were also included in the September print edition and a copy of this article is included in your packets and also available on Kaiser's website.

So I'll start with the good news. A large majority of respondents report that they are satisfied or very satisfied with the Medicare program, eight-one-percent of non-elderly

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Medicare beneficiaries with disabilities and 84-percent of seniors. The fact that these satisfaction rates track rather closely is a positive finding as well as perhaps somewhat surprising in light of the greater access and cost-related problems reported by non-elderly disabled beneficiaries and their greater health needs.

Half of non-elderly people with disabilities on Medicare report being in fair or poor health and living with five or more chronic conditions compared to a quarter of the elderly. Around four in 10 report that they have depression and live with severe or very severe pain compared to one in 10 elderly beneficiaries. We sought to understand more about the experiences of non-elderly people with disabilities on Medicare compared to those seniors.

We found that non-elderly disabled beneficiaries report higher rates of access problems than the elderly. When asked about the past 12 months, a minority of Medicare beneficiaries overall report problems such as inability to get an appointment to see a doctor, lack of transportation, or difficulty finding a doctor who accepts Medicare. These findings suggest that access to care is generally not a problem for most beneficiaries, which is also good news, yet along all of these measures, a greater share of non-elderly beneficiaries with

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disabilities than the elderly report that they experienced a problem.

This includes three times as many disabled than elderly beneficiaries reporting that they have trouble finding a doctor who accepts Medicare. Twelve-percent of the non-elderly disabled compared to just four-percent of seniors. Nearly one-fourth of non-elderly beneficiaries with disabilities also report difficulty finding a dentist and 15-percent say they have trouble finding a doctor who understands their disability or how to treat it.

Differences between non-elderly disabled and elderly beneficiaries are also evident with respect to problems obtaining their prescription medicines even when we looked specifically at those enrolled in Medicare Part D plans and exclude those who lacked drug coverage.

One-third or more of non-elderly Part D enrollees with disabilities were unable to get a prescription medication they were taking because it was not covered by their plan or had to switch to a different medication or had to get prior authorization from their plan before being able to get a medication they take. Each of these experiences was reported by 18-percent or less of elderly beneficiaries enrolled in Part D plans.

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Along with higher rates of access problems, non-elderly disabled beneficiaries also report more cost concerns related to health care. A greater share of the non-elderly report that they spent less on basic needs such as food and heat so that they would have enough money to pay for health care fully, one-third of disabled beneficiaries compared to nine-percent of seniors on Medicare. Similarly, one-third of non-elderly disabled beneficiaries report that they had a major or minor problem paying for health care in the past 12 months compared to 13-percent of elderly beneficiaries.

When we asked about problems paying for specific types of health care services such as doctor visits, prescription drugs, hospital services, and durable medical equipment, more than half of non-elderly beneficiaries with disabilities said they had a problem paying for one or more of these services compared to just under one-fourth of seniors. Forty-six-percent of non-elderly disabled beneficiaries report that they delayed getting a service or did not get it at all because of cost concerns compared to only 16-percent of elderly beneficiaries.

Unfortunately these cost-related delays or not getting items or services beneficiaries felt they needed because of cost, do not come without beneficiaries paying a price in the form of perceived adverse consequences including stress or

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anxiety, physical pain, and the worsening of existing medical conditions.

These consequences appear to strike particularly hard among non-elderly beneficiaries with disabilities. For example, 54-percent of those non-elderly beneficiaries with disabilities who reported delaying or not getting care because of cost concerns said that one of the effects was a significant amount of physical pain compared to 26-percent of the elderly. Nearly three-fourths of the disabled said the effect was a significant amount of stress or anxiety compared to 40-percent of seniors.

Among the non-elderly people with disabilities on Medicare, cost-related problems are reported more frequently by those without any form of supplemental coverage. Supplemental coverage helps fill in Medicare's gaps and benefits and helps pay for Medicare's cost sharing requirements, which means that it plays an especially important role for non-elderly beneficiaries with disabilities in light of their greater cost-related problems overall.

Nearly half of those who lack supplemental coverage report that they had a major or minor problem paying health care costs in the last 12 months.

In contrast, among those with some source of supplemental coverage, Medicaid provides the greatest

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protection from cost-related barriers with only one-fourth of those with Medicaid to supplement Medicare reporting major or minor problems paying for care.

Similarly, the experiences of non-elderly Medicare beneficiaries with disabilities varies by source of prescription drug coverage. Among those with no drug coverage, fully six in 10 reported that they delayed or did not get a prescription at some point in 2008 because it was too expensive. Among those with drug coverage, a smaller share of those with VA and employer coverage reported this problem than those with Part D coverage through either a Medicare Advantage drug plan or a standalone drug plan.

In addition to probing for the types of experiences that non-elderly people with disabilities encountered once they became eligible for Medicare, we also asked whether people went without health insurance in the 24-month period leading up to their Medicare eligibility. One-third of non-elderly beneficiaries responded that, in fact, they had gone without health insurance during this time period.

This finding may not be news to those of you here but certainly seems to reinforce longstanding concerns about the waiting period. Other research has shown that when people lack health insurance, they are more likely to delay or forego needed care, which could lead to more serious problems that are

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more difficult and costly to treat. In this way, the 24-month waiting period represents a potentially harmful barrier to health care for people with disabilities.

So it is certainly no surprise that when we ask non-elderly disabled beneficiaries their views about what the government could do to improve the quality of life for people with disabilities, 46-percent said to do away with the 24-month waiting period. An even greater share, 54-percent, said that making it easier to work while maintaining health and disability benefits was important. Forty-four-percent said to improve drug coverage for people with disabilities and 41-percent said to make it easier to apply for disability benefits.

Overall, our survey findings demonstrate the greater access and financial barriers that non-elderly disabled Medicare beneficiaries face compared to elderly beneficiaries. We know Medicare plays a vital role in the lives of non-elderly disabled and elderly beneficiaries alike but we lack a clear understanding of why Medicare does not appear to be working as well for non-elderly people with disabilities as it does for the elderly.

Although our survey was conducted in late 2008, we have little reason to think our findings would be significantly different if we conducted the survey today.

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Nearly two years later, administration officials and others are embarking on implementation of the Affordable Care Act, which has the potential to help people with disabilities with some of the problems documented by our survey, therefore keeping a clear focus on the ways in which the health reform law improves coverage and care for people with disabilities will provide an important test of its impacts. On that somewhat more optimistic note, I'll turn the floor back to Judy. Thank you very much [Applause].

JUDY WOODRUFF: Thank you Juliette. Now we're going to hear responses from our three other panelists and then we're going to talk among ourselves. Jeff Crowley, the floor is yours.

JEFF CROWLEY: Great, thank you Judy and thank you to the Kaiser Family Foundation. It's a pleasure to be here with you today but also thank you for doing this survey. It's one of the things that's important to know about this is just how much we don't really know about what's going on with people with disabilities and Medicare.

So those of us that work in this field, we think we know or we have anecdotal experience but I think this survey is a really important contribution and hopefully it will lead to you and others continuing to do more just to get a sort of factual basis for some things is really important.

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I think you'll hear me repeating Tricia and Juliette a bit but I want to begin with what I think are just some takeaways from the survey. The first is that we just have to recognize upfront that people with disabilities have diverse, sometimes very extensive and often complex needs. This isn't just a program say for people with HIV or people with spinal cord injuries or people with intellectual disabilities. It's for all of these. We're asking for very different things.

They differ in some significant respects from seniors but we probably can't emphasize enough the importance of economic security. They're less economically secure. They're less income, they have fewer assets but they're less likely to have access to supplemental coverage. So that means they have a greatly diminished capacity to pay on their own or supplement when there are gaps in Medicare that we know exist.

I think it's important though when we talk about this and there are challenges. There are gaps in coverage but the thing we need to say over and over is that Medicare is a success. Nobody's saying this is a broken program. We need something different. This is something we want to build on. As Juliette said, people with disabilities on Medicare are largely satisfied.

So we have to say that enough but I'd also say that in thinking about these gaps and the solutions, we shouldn't think

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about it in isolation. It's not like we have gaps in Medicare. We have a broader insurance and health care delivery system that has gaps. This is just one piece of that.

Then lastly, I think that a key takeaway is just what the Affordable Care Act will do. Now here representing the Obama administration, I'm not here to say it's taking care of every single need that you can possibly dream of but I think if you sort of step back from all the noise about what the law will do, I think in some respects, it's really remarkable how it's going to address a lot of the key issues. If you think about it, we had a debate that, to some respects, that was about the middle class, about the average American.

What we're talking about here are people that aren't the average. They're the exception with very extensive needs. It's kind of remarkable how the Affordable Care Act really will address some of their very specific needs.

So I want to just go back and reflect on some things about how people with disabilities fare differently than seniors on Medicare. First it's not always easy to gain eligibility. Seniors, they're in once they turn age 65. If you think about this, there's a long cumbersome process just to be determined to have a disability.

Some of the conditions, I wrote some notes from recent past work of the Kaiser Family Foundation, some of the major

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qualifying conditions, 15-percent of people with disabilities qualify on the basis of mental disorders, 11-percent, back and spinal disc disorders. These are two of the larger categories. Think about those. Those are very subjective conditions.

So it's not immediately clear, if you have an injured back, if it's a qualifying condition or mental disorder. Often we know that people have experiences where they apply and they're denied. It takes years, in some cases for not an illness, for repeated hospitalizations so they have a record of getting disabilities. So it's not as though getting on the program is so easy. Then they get on and they have the SSDI waiting period.

So social security finds them to have a disability that's so severe they're unable to work. So that means they're not working. They're not getting income and then they're supposed to wait five months to prove that it's permanent. Then they get their SSDI. So they're getting income support but then they're told to wait during the waiting period. Medicaid does play a critical role in supplementing coverage for this population but it doesn't cover everybody.

Now as you may know, as my role as the AIDS Director at the White House, I focus on this group a lot. One of the things that's also, we shouldn't get lost is, AIDS just as an example here, when we think about Medicare, we don't often,

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AIDS doesn't jump out at us but it's the single largest source of federal financing for HIV/AIDS care. Did any of you know that?

So when we think about our nation's response to the AIDS epidemic, it is front and center. I think that applies, if you go across the list of disabilities. It's critically important but even if you look here at HIV, there are about 100,000 people with HIV/AIDS receiving Medicare benefits, 45-percent or so are duals. So that means you have roughly half that aren't duals.

Now what's the typical situation? I looked at this a few years ago. So these numbers might not be right but a couple years ago, the average SSDI payment for a disabled worker was about 113-percent of the poverty level. By no stretch of the imagination is that rich but it's often too rich to qualify for Medicaid if the base standard for Medicaid is 74-percent of poverty.

So low-income people, extensive needs, little money but yet to some extent, they're on their own during that waiting period. So that's a very significant challenge. Again, as I mentioned before, more likely to have access barriers both access finding doctors and other things but a lot of the barriers that we're discussing are really about finances and just unable to pay for care.

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Now if we get to some of the ways the Affordable Care Act will address some of these, I think it's just important to note that it makes solid progress. Drug costs, I mentioned, HIV they're a big issue there but they're a big issue from a lot of people.

If you look at MS for example, I looked at this recently and about 62-percent of their average spending, an average spending for a person with MS is about \$30,000 a year, about 62-percent of that is drug costs. So you find people that have Medicare. They have drug coverage but yet they quickly find themselves in the coverage gap. Drugs are expensive. If they have limited income, it's hard to supplement that. So the Affordable Care Act does a number of things.

Immediately this year for people in the coverage gap, they get their \$250 rebate check. Next year, they get a 50-percent discount but the real story is that we're getting rid of this coverage gap because it didn't make sense. It was really a financing challenge but we're getting rid of that.

That'll benefit lots of people with disabilities not just one or two specific examples. There is the issue of the waiting period but it's also some of this is about how does the private insurance system work for people with disabilities and

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how can we improve access? The Affordable Care Act does a lot of things.

Immediately, we have the pre-existing condition plan that sometimes called the high-risk pools, people that have been denied private coverage and have been uninsured for six months can get immediate relief but really there's a lot of reforms that are going to just make the private insurance system work better over the longer term, getting rid of lifetime caps, annual caps.

So again if we think that people with disabilities aren't the average person, they're the exceptional person. They're the ones that could find that now they're denied coverage because they have very high lifetime costs so they could, some policies could have \$1 million or \$5 million limit that they could hit. It happens to very few people. For those that do, it's really problematic. So the Affordable Care Act gets rid of that.

We know we have challenges with young adults. Even if you look across the spectrum of non-elderly people, the youngest people are the ones with the least economic security. The Affordable Care Act allows people to stay on coverage until, under parents' coverage until age 26.

So that, again, it's a piece of it but the other thing I would say is some of the bigger things are about just what it

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does to rationalize our health system and improve quality so that delivery system reforms are going to really important.

I think to some extent, we see Medicare leading the way in adoption and medical homes and improving quality, doing all kinds of things and of course, people with disabilities will be some of the primary beneficiaries. I think we all need to make sure that, as we're focused on doing this for everybody, that we're focused on assuring that disability doesn't get lost as we try to take some of these steps.

Then lastly, I would say some of the biggest gaps for people with disabilities relate to long-term care. People that, it's not about their medical needs but they might need help with activities and daily living. They might need help getting out of bed, getting dressed, manage their home, things like that.

One of the challenges for policy makers is that it just seems like such a big challenge, how do we take it on but the Affordable Care Act does a number of things. In Medicaid, it adopts this new community first option, new option for states to extend community services.

There's the money follows the person program. This was started a few years ago. It's underway, 30 states. The law extends it but also creates new opportunities for the other

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states that haven't come in to come into the program. That's something to build on but also we have the Class Act.

This is a new voluntary program outside of Medicaid and Medicare that will provide a cash benefit for people that develop disabilities. It's voluntary. You pay into it when you're working but one of the challenges in the past, as we've said, "Medicaid's strapped. The costs are huge. How can we bring in a new revenue service?" This is a very attractive option that again will be an important part of the puzzle because it adds to our tools for responding to the long-term services' needs of people with disabilities.

So just in closing, I'd just leave you with what I started with at the beginning. We have a diverse population. Medicare covers eight million people with disabilities. So it's a really critical program. There are some challenges but as we go forward with the Affordable Care Act provides a platform for addressing a lot of these challenges that we have.

JUDY WOODRUFF: Alright. Thank you very much [Applause]. Now we're going to hear from Joe Baker, the Medicare Rights Center.

JOE BAKER: Thank you Judy. Thank you for inviting me to be here today. Thank you to the Kaiser Family Foundation once again for putting out this report. I think it's an important, as Jeff was saying, piece of data or pieces of data

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that I think can be used ongoing to look at some of these problems. I think there's further research that will jump off of this report as we've talked about a little bit.

I'm taking this from the perspective of the Medicare Rights Center and the 15,000 clients we help every year across the country, 6,000 professionals that help their clients as well helping them help people with Medicare and really what I'm seeing and, as Jeff is saying a lot of this information is anecdotal, but what's interesting is the anecdotal matches some of the data that the foundation has found. For example, over the last three months, 80-percent of our callers that are under 65 and disabled are asking about low-income programs because they can't afford the cost of their care, which definitely dovetails with what we're seeing here.

Many of them are particularly unable to afford or have problems affording pharmaceutical care, so prescription drugs. That's whether they are in a Part D plan, Medicare Part D plan or not, there is problems getting access to their drugs either because of the cost or because of other utilization management rules that I'll go into in a moment but before we get to costs and some of the access issues there, we talked about the waiting period quite a bit. As the report notes, there's a third of folks in the waiting period that are uninsured. They are really up the creek.

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Over the past few years, Medicare Rights Center's worked in coalition with a lot of groups and maybe many of you here to get rid of the two-year waiting period. That goal was not met as part of health care reform but what we did get and Jeff talked about were two important expansions of coverage opportunities for people with disabilities in the waiting period. One, of course, is an expansion of Medicaid up to 133-percent of federal poverty. That is key particularly in states that were well below 100-percent of federal poverty for single adults and people with disabilities.

The other piece is the individual coverage that will be available in the exchanges, much of which will be subsidized for people with lower incomes. Of course, we'll need to watch what that coverage is and make sure that it covers the kinds of care that people with disabilities need but the fact that that will be available without health underwriting guaranteed issue is a major accomplishment for people with disabilities and will open up a whole world of coverage to them that most folks don't have today.

Before I move on, we talked about the satisfaction rates with Medicare and I think part of it is not dissimilar to people when they turn age 65, folks breathe a sigh of relief to get into the Medicare program because it is so stable and because it's not dependent upon employment or it's not

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dependent upon your individual status and maybe you've heard about rescission or you've heard about these other shenanigans in the individual market, premiums going up, etc. even for those that have insurance.

Getting into the Medicare program is the Promised Land in many instances because of its stability and the trust that folks have in the program. Of course that doesn't mean Medicare's perfect. As Jeff was saying and was alluded to in the report, the Affordable Care Act does a lot to alleviate some of these costs over a period of time. I wanted to give, and I know many of you are familiar with this and I have my cheat sheet here as well but what these costs are, so what are we talking about when we're talking about these out-of-pocket costs?

We know that Part B has a premium up to \$110 this year if you're new to the program, a month, I should say \$110 a month. There's \$155 deductible. We've got a \$1,100 Part A deductible. You've got, with regard to Part D plans, premiums of on average like in the \$35-40 range. If you're in a Medicare Advantage plan, you've got maybe \$45-50 range premiums. When you're in the drug plan, you've got co-payment amounts. So those can range from \$76 for a non-preferred drug to \$42 for a preferred drug to \$7.

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When I'm giving out these numbers, numbers are all over the place because plans are all over the place but just to give you a marker. Of course, the big kahuna in costs for people with disabilities in prescription drugs is the donut hole. Basically what we're talking there is \$4,500 out-of-pocket expense to get to catastrophic coverage and a period of time that you go bare.

You pay 100-percent of your drug cost. That's where we have the folks calling us that used to call us before the passage of Part D, both seniors and people with disabilities, but a lot of people with disabilities saying I'm splitting my pills. I'm not going, I'm not taking my drug regimen anymore. I'm not doing what I should do to maintain my health. So that's a kind of snapshot.

The other thing I think bears mentioning is in Medicare Advantage plans, a lot of people think oh okay, there's less cost sharing. In some instances, that's true but you also do have co-payments every time you access service. Those co-payments can mount up.

They can also particularly be higher for specialty care, which this population needs more than others and even though there are out-of-pocket maximums in many of the plans, something that Medicare lacks and would be great to have in the Medicare program and it's good that many plans do have these

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out-of-pocket maximums, some things are excluded from these out-of-pocket maximums like specialty visits or like skilled nursing facility care. So there's plenty of cost sharing and it's a particular stress with this population given their relatively low income.

I also wanted to spend a little bit of time talking about some of the other issues that folks come up against in the Medicare program and particularly looking at those through the prism of Part D but there are issues with regard to DME particularly.

And we could go on about different pieces of coverage like skilled nursing facility and home care are also difficult to access and many folks end up paying out of their own pocket but with regard to pharmaceuticals, I think it's interesting particularly because the report does say and I think this needs further research and that is, is the problem that we're seeing with access and cost one caused because of the drugs that people with disabilities need, the kind of pharmaceutical care they require, or is it because of the plan design, the benefit design for Part D?

I think we're going to need to drill down into some of the claims data for this population and benefit packages and see what, on a systemic basis, what we're dealing with but just anecdotally what I can tell you and this connects to something

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else in the study, I would say the most frequent pharmaceutical or prescription drug issue we have is pain medication. That's for two reasons, well three.

One can be the cost of that care because frequently it is either all formulary or brand name medication that folks are paying top dollar co-payments for. The second is utilization management of that care, of that particular prescription drug care by the plans. When I say utilization management, it can be different thresholds where you start to look at care but particularly prior authorization required. That can be very onerous and prevent access to the coverage.

Finally there are issues about off-label. So a lot of people with disabilities are prescribed drugs for off-label uses and those are typically denied by the plan at first and appeals process ensues. While we're very lucky to have the due process protections we have in the Medicare program in both Part D and other parts of the Medicare program, this is a population that's particularly challenged, lots going on in their life.

Mental illness as we talked about is an issue and of course depression doesn't always lead to a robust defense of your rights in the context of the appeals process. So that's another thing I think we need to look at in making those

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processes and systems more accessible to people with disabilities. Thank you.

JUDY WOODRUFF: Joe Baker, thank you very much [Applause]. We're hearing such depressing information and yet we're applauding you [Laughter].

JOE BAKER: There's hope.

JUDY WOODRUFF: With hope, yes. Elizabeth Priaulx, you're next.

ELIZABETH PRIAULX: Thank you. Hi, I'm Elizabeth Priaulx. As was said earlier, I work as an attorney at the National Disability Rights Network and in such capacity, I come upon many people in the situation of the report discussed here. So when I was asked to do this actually, my first thought was oh I can find better folks for you, folks who can tell horror stories that so few people have to face but when you have to face, it's tragic.

Then I started realizing, this is about problems that people with disabilities have accessing health care and even nobody wants to think they have, everybody with a disability has worked around their disabilities and believes that they are functioning quite well. I'm probably in that category and realize that I have many barriers to health care. So I think that it's valuable for someone like me to be up here saying that yes, you don't have to be poor and have terrible troubles

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with transportation although that does expound the problem tremendously.

You don't have to be unemployed although, as was said earlier, so many people with disabilities are unemployed. You could be employed as an attorney like me, married with a very supportive husband, and raising a nine-year-old child and have problems with access to medical care that you never bring up to others because you just deal with it.

So it is so valuable for Kaiser to have done this report, to be able to tell the stories that individually we don't tell because that's not the style to do so and to compile this so that some of it can come out so that people like Jeff Crowley who I respect so highly, really pleased to be on the same panel with you, can do things like this through the White House division but a lot of what I'm speaking about will be pre- the Affordable Care Act and I'm not going to try to mention how the Affordable Care Act will change some of these problems. Maybe we can do that later.

What I want to talk about is that what is so valuable to me as a person with cerebral palsy and now pretty extensive arthritis that has developed as a result of cerebral palsy, also a seizure disorder and a lifetime of depression, which is controlled with medication, these are the kinds of multiple problems that have been mentioned that people with disabilities

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often have that can make it more difficult to find a provider and you know what? I actually find that I scare some providers. It sounds funny but you can see it on their faces. They think oh my gosh, cerebral palsy, what did I learn about cerebral palsy in school?

They're not saying it out loud and they're thinking oh my gosh, should I ask her to go up on to that table and then when I go up on to the table, you know they have these tiny little steps and you can't really pivot on it, so I'll pivot and maybe fall over and grab and the provider wants to be in the other room.

So a lot of what I'll talk about would be just finding a provider that has an attitude of disability is natural part of life. People with disabilities are experienced or maybe if they've just developed their disability are learning to get up on to a table if they can or if they cannot, figure out how to ask what they want but at the same time, you want to find a provider that has your, well actually I should say I grew up in the era of the Individuals with Disabilities Act, which says you can be included in schools, should be provided free appropriate public education, which really only came about in 1973 not that long ago and the Americans with Disabilities Act, which fights discrimination against people with disabilities

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such as accessible medical centers. I'll mention in a few minutes that they're still difficult to find.

I grew up with a world, which said, as a person with disability, I should be able to access all areas of society. When I look at what Medicare covers that is my expectation as well.

I've found it falls a little short in the areas of long-term care, as I'll mention later but I also want to find a provider who has that feeling that when I go in to my neurologist to get a note that says I can scuba dive, which I shouldn't have to get in the first place but which I'm required to get, they won't start asking me all these questions, are you sure you can scuba dive? So to me and to so many people with disabilities, choice of providers is vital and it's one of my biggest barriers and barriers to other people with disabilities that I talk to.

One of the things I find is that as I get older and other people with intellectual disabilities, a whole range of disabilities, all of the providers that specialize in disability are pediatric. I'm not quite sure why. This is just my opinion. I'm just here to talk about myself not to be the expert but I think that you can make the most change as far as disability with early intervention, pediatric, physical therapy.

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It also could be a result of our health programs where if you are under 21, you're more likely to get coverage for health care than you are older when it's just what is is, forget it but you probably have determined that with your private insurance as well as Medicaid and other insurance if you access that.

As a result, you have more doctors who are familiar with younger ages. I find that as I'm getting older, I'm over 40, that there are all sorts of secondary conditions and it did come up in Juliette's report. Those are the types of things where if you go to your provider, your general practitioner, they're already accustomed to the fact you have cerebral palsy and then you say gosh I'm developing arthritis in my lower back, in my toes, and here, here.

Well their first response is well do you have a neurologist? The neurologist, you don't go and see a neurologist regularly if you have cerebral palsy but that right away tells you okay, this doctor is a little nervous and automatically assumes if you have this, so you go to the neurologist and the neurologist says well, I'll cover your seizure issues but you need to go here. It's the same problems that everybody has with disability, with medical care.

It's just compounded. It can lead to issues like depression and also as was said earlier, Judy said that her son

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is her hero and very much probably is her hero in her family but what buys into that is that you want, that's the expectation of society. You're not going to be saying bummer that I have to now have this chronic pain.

I'm certainly not going to talk about it to my husband or my child but it is there and it is limiting what I'm able to do. I do feel it compounding in the future. These are things that you don't talk about and where a choice of providers, which Medicare actually offers becomes so vital and yet one of the worries now is with Medicare Advantage plans and other ways in which managed care is becoming pushed, what that does is limit your choice of providers.

So I think I've gotten off track here but some of the ways also, which it's more obvious that choice of providers is necessary is for example, if you have an intellectual disability with a lot of spasticity, when you go to a dentist, you need to have anesthesia. A lot of dentists won't do that now. That limits your abilities.

If I go to an OB/GYN, I want to find someone who's not going to have me put my feet in the stirrups because my feet don't go out like that or in a few years, I might not be able to climb on to the table. The Department of Justice has just put out guidelines for how medical offices have to become more accessible and I'm thrilled about that because it leads to

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problems with preventative care, which is what Juliette mentioned.

If you are getting your annual exam from a wheelchair, they might decide oh I'm not going to take a urine sample because the bathroom, which I can attest to, the bathroom in my child's pediatrician's office is not accessible. What if he had a wheelchair? He could not take a urine sample. Well we'll just skip that. We'll just do it from the chair.

So let's not take height and weight because the height and weight machine, I'm too scared to ask him or her if she has a way of figuring out how to do that. These kind of things can really lead to less preventative services.

If you're in a wheelchair and you might not see the lump that could be an early detection of cancer. These are things that we're excited that Jeff Crowley and Kaiser Family Foundation will be bringing up so that when these DOJ orders do get to small providers, they'll understand how important it is.

So another area I really wanted to bring up was that provider issues could have usually unconscious subconscious medical misperceptions about disability and they could make assumptions based on these, you could say old fashioned ideas or just ideas we grow up with because we don't understand all disabilities. I wanted to mention just a few in my own arena but you can imagine them further if it was a person, blind,

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deaf, paralysis, whatever it might be but I see many of doctors make decisions based on assumptions without consulting.

One time, there were some very dramatic examples that we get in my office, for example just not even telling somebody about a drug care routine because let's say the AIDS drug care routine is, well at least in the past, we've heard about AIDS drugs being multiple steps and hard to keep track of, well if you were a person with intellectual disability, maybe your doctor might decide not even to mention that option based on an assumption not out of animus but an assumption that the person can't follow that complicated drug routine.

I'll give you an example of my life, which is when I, at the age of 37, all of a sudden I became a person with seizures. The first thing that the doctor asked me is, is this related to your cerebral palsy and I thought it was kind of funny because I wanted to ask them that but they asked me [Laughter]. So that occurred.

JUDY WOODRUFF: Were you able to answer the question [Laughter]?

ELIZABETH PRIAULX: I said I don't know but I since did my own research and determined no, it was not. I never heard back from that particular doctor [Laughter]. So in this instance, the doctor, one of the problems again with managed care and with doctor care in general is if you have multiple

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conditions, you could take longer to tell all the well I'm on this drug, I'm on this drug and I'm also feeling this.

Also if people don't want to open up about all their medical problems, it could take even longer psychologically and with managed care, you want people to take 15-20 minutes per patient or you could make them have to wait longer so they're waiting three months because oh this is the person with the communication disability. I'm going to have to wait for this individual to use his aug comm device. I'm going to need 45 minutes. So let's put him off. Luckily with me, I talk very fast as you can see.

One of the things that happened was when I had the seizures, the neurologist in the emergency room came in, never left the doorway, standing right in the doorway like that and said okay, you're about to be discharged, put you on a drug. Just want to let you know there are multiple seizure drugs. I put you on this one because a lot of the others interfere with balance and I see you have cerebral palsy.

I said okay. Sounds good. He walked out of the room. I didn't expect anything else from the doctor. That's my expectation. I went home and I have taken antidepressants for 20 years. I'm very stable on them and started to feel suicidal and knew all of the characteristics of it, arranged for my

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husband to stay home from work. I had my child near me, all the things that should not make a person feel suicidal.

I call up this neurologist, leave a message that I'm feeling this way. He gets back to me 24 hours later and says just wait it out. So I'm like oh this person does not understand. I've told him very clearly I know all the signs. So then I call my regular doctor.

She says oh I'll give you a better neurologist. A better neurologist, long story short, tells me that many seizure drugs are actually prescribed for people with depression.

What I wanted to make the point of doctors making sort of assumptions without consulting is that he didn't talk to me about the fact that this drug that was good because it didn't interfere with balance was known to cause depression, which I later find out were that these other options. These are the things that can happen if you have multiple chronic disabilities.

JUDY WOODRUFF: Elizabeth, not to cut you off but I want to try to work in some of what you're saying as we hear from the other panelists as we get to the audience questions.

ELIZABETH PRIAULX: Right, right. I just have two more that I really want to mention, which is a lot of people are not offered transplants because their life is less valued. Oh if

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you have this intellectual disability, we're not going to offer you this transplant. I think it's very important for people to hear how there are some major medical decisions that are made based on assumptions about disability and I believe that was my very last important thing to say yes [Applause].

JUDY WOODRUFF: Great. Thank you. We have another 30 minutes if you think of another point you want to bring up. I do want to, I mean given what we've heard from Elizabeth, from Joe, and from Jeff, I want to come back to Juliette. We started out thinking okay, one of the big problems is the waiting period. Do you still believe that that is the principle barrier confronting individuals with disabilities?

JULIETTE CUBANSKI: Well I don't believe it's the principle but I do believe that people who are particularly challenged have many health needs, many health problems, and as our research shown and as other research shows, people with disabilities tend to have lower incomes, less connection to the employment market and therefore are less likely to have coverage when they're faced with two years of no health insurance coverage that's really essential to all of us not just people with disabilities but people who don't have disabilities that they don't have health insurance during this really critical time is a real problem. If they make it

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through the waiting period and they make it on to Medicare, they may be less likely to have connections to doctors.

They may be more likely to have certain challenges that have worsened over time as a result of having to go through the waiting period without health insurance coverage. So they're coming on to Medicare sicker than they might otherwise have been. So clearly the waiting period is a problem. It's definitely something that we know that the Affordable Care Act will help with in terms of broadening coverage, expanding access to Medicaid, expanding access to private coverage.

JUDY WOODRUFF: In real political terms, I want to bring Jeff and Joe in on this question, what are the prospects of reducing, we know the Affordable Care Act is going to address it in part but what are the real prospects of getting that waiting period down?

JOE BAKER: I think the political calculation right now is not one that is favorable to getting rid of the, sounds very bureaucratic but I don't think we're going to see a lot of movement on the two-year waiting period in this fiscal context we're in because I think CBO scored it about \$110 billion over 10 years. I think we have very viable, well I mean the good news is we have very viable options in the Affordable Care Act. Now of course, they don't come into play until 2014.

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So we've got that waiting period. That is of concern but I think we've taken a step in the right direction. There is some interest in Congress about looking at the waiting period again. So there may be something that we can do there. We're still working on the issue but I think that we have to kind of look at it in the context now of what the Affordable Care Act has done and maybe there's some grand compromise that has yet to be thought of as we kind of think it through over the next few years.

JUDY WOODRUFF: Well in that period when we're waiting for that to kick in, are there any other measures that can be taken that you really raised the question I have, is there anything?

JOE BAKER: Well the high-risk pool. I think Jeff talked about both nationally and in the states, the high-risk pool will be an important resource for people with disabilities. It has its limits as well but it is there. I think is going to be accessed in places like New York even where we have a fairly robust, well not robust, but an available individual market even in New York we're going to see the high-risk pool. So I think it's critical that we roll it out. It is being rolled out. So I think it will be a resource for people with disabilities in this interim period.

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JEFF CROWLEY: Yes, I mean I think we need to think about the solution has multiple parts. It is making the private insurance system work better, it is the pre-existing condition pool. It's also Medicaid. We recently fought and we enacted another extension of the supplemental FMAP. That'll be important to ensure that states don't further cut into Medicaid's critical role for this population as well.

JUDY WOODRUFF: What's another practical step that can be taken in the short-term given the fiscal environment that we know our country, our government's operating under that can be taken to address some of the main problems that come out in your report?

ELIZABETH PRIAULX: Jeff, I know something that would help but I don't have the knowledge to know whether it's already addressed in the Affordable Care Act but one thing that was mentioned is that Medicare is not really designed to provide long-term care or at least it's out of sync with Medicaid's recent efforts to make long-term care more accessible.

One example could be, and I think was brought up, that if you are employed and you are still engaged in the world and you want to avoid going into a nursing home and your needs are non-medical, which sometimes we call personal assistance services, like help getting out of bed, with cooking, those

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kinds of things maybe just for a couple of hours each day, that's not what Medicare is designed to provide. That would be a very important change, also durable medical equipment.

Right now if, a couple of years, I know I'm going to go to a wheelchair, if I was a Medicaid recipient, it would only cover a manual chair and yet I would be using it for long distances and probably need an electric chair. That's just not what, the types of durable medical equipment that Medicare provides is designed to keep you in your home.

JUDY WOODRUFF: What's on the horizon to address those?

JEFF CROWLEY: Well I think we've enacted probably the most comprehensive multi-faceted reform we could imagine. There's lots of things going on. We are both trying to expand coverage, which we've just been talking about but we're also trying to introduce more evidence into how we do things and improve quality by making sure that providers know the best latest standards and there's lots of quality improvements.

There's a lot of talk about medical homes. I know again from an HIV perspective, that's been a very big success in the Ryan White program. So we're trying to adopt those in Medicare but I think it's all of these things together that will have an effect in improving quality.

So even, I can't say that some of these policies directly will change how a plan covers durable medical

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equipment but as we integrate care and as we make it easier for, you see, the payers as well as the patients see the benefits sometimes in making these upfront investments that improve their quality of life but also could forestall more expensive needs later. I think it's these sort of incremental steps that collectively will improve the quality of care.

JOE BAKER: I think that's right and I think with Jeff, you mentioned money follows the person. There's been more money put into that. Hopefully more states will take it up. In a state like New York, where we took off very early on, we've added housing supplement money to that and of course, in this fiscal climate, not able to add more but that's something, I think it's a federal investment that the states can use and then jump off from hopefully in better fiscal times as well.

I think as well, I think you have a lot of the delivery system reforms that we are going to see in the Medicare program really are, and this is for folks in Medicare of course, are trying to really realize the promise of some managed care plans and that was to coordinate care amongst people with disabilities and those that are over 65 as well and those that are dual eligibles.

I mean right now you've got, there are a lot of advantages, as the report shows, of being both Medicaid and Medicare eligible. You seemingly have this best of both worlds

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and all the coverage you'd ever want and yet the right hand doesn't talk to the left hand and people actually can fall in a crack that's deeper than just being in one program.

So there's a lot in this bill and actually structure at the Center for Medicare and Medicaid Services now because of the Affordable Care Act that is really dedicated to finding integration and coordination there. I think that bodes very well for people with disabilities and for anybody that has a number of chronic illnesses because that's really where the juice is right now.

I think the question is, is it a managed care context? Is it medical home? Is it accountable care organizations? There's a variety of things that could be used. I think we need to be creative but we also need to be vigilant. We also need to make sure that there's the right supervision and monitoring and accountability but I think these are all things that are coming down the pike and hopefully they're coming down very quickly. There's a lot of movement right now.

JUDY WOODRUFF: Juliette did you have a comment?

JULIETTE CUBANSKI: Thank you. That was exactly what I was going to make a point about in terms of the Affordable Care Act offering promise not in 2014 but much sooner than that for people with disabilities who are currently enrolled in Medicare who are also enrolled in Medicaid who will have the greater

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coordination of care that the Centers for Medicare and Medicaid Services is now getting underway and greater opportunities to innovate in terms of how care is delivered not just of people with disabilities but other beneficiaries in the Medicare program.

JUDY WOODRUFF: Alright, I want to leave plenty of time for questions from all of you. So please raise your hand and I'll try to recognize, a hand already in the back there, if you could just stand up, tell us your name, if you represent an organization.

LESLEY FRIED: Hi. I'm Lesley Fried. I direct the Medicare Advocacy Project for the Alzheimer's Association and the ABA Commission on Law and Aging. I found this very interesting. I guess my question is for Juliette but then you can all jump in.

It had to do with access to care because you have the slide where you're asking questions about problems with access to dentists and doctors and a problem we have found certainly there are more people now being diagnosed with Alzheimer's and related dementias under 65.

The issue I often get calls about is access to rehab therapies, physical therapies, occupational therapies, speech language therapists especially with regard to the improvement standard because folks aren't going to improve to their former

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function, yet some people get physical and occupational therapy and speech therapy in order to slow deterioration or maintain their current function. We're finding that more and more people are getting denied care on that, access to that care, which is really important for under 65 chronic conditions.

JUDY WOODRUFF: When you say more and more, you mean since when or compared to what?

LESLEY FRIED: Well you could say that there's more local coverage policies that are using an improvement standard in Medicare. I would say over the last 10 years, there is more denial of access and this is really important for people with chronic conditions, conditions of deterioration and many people under 65 with disabilities. So I'm wondering if you asked any questions in your survey about that or whether you're hearing anything on that.

JULIETTE CUBANSKI: We didn't really probe, as I said, sort of why these access and cost-related problems are occurring at a greater rate among non-elderly people with disabilities. The survey was pretty long as it was. You have a copy of the top line document in your folders so you can see all of the questions that we asked and unfortunately, we weren't able to probe for a lot of the scratching beneath the surface, what's really going on here. I don't know Joe if you

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have any sort of anecdotal evidence to support some of what
Lesley's-

JOE BAKER: Yes, I think that is true. You've seen it
both on the original Medicare side, the traditional Medicare
side as well as in the Medicare Advantage plans. You also see
it in home health where there's more of either local coverage
kind of determinations that improvement is the standard as
opposed to maintenance, which has traditionally been the
standard.

There are actually regs out right now from CMS on home
health that we're going to comment on and Center for Medicare
Advocacy has been leading the charge on. So I mean I do think
this is one of those areas where folks with physical
disabilities and other disabilities are kind of the canaries in
the coal mine. Because they need access to these services so
much, they're the first ones that kind of note the problem as
it were.

So I think we need to make CMS aware of kind of some of
these local determinations or regional policies if you will and
also kind of work on the national coverage guidelines as well
because I do think maintenance is important particularly and
slowing any kind of deterioration is just as important as the
maintenance side. I think those are the right standards and we
need to make sure they get ratified in the Medicare program.

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That's why this is a multi-front battle and never ending but one where I think we have a very responsive Center for Medicare and Medicaid Services at the moment so hopeful.

JUDY WOODRUFF: Alright, great. We have a question, the gentleman back in the back.

HENRY CLAYPOOL: Sure, Henry Claypool. I'm from the Office of Disability at the Department of Health and Human Services. This is kind of directed to Jeff. When Elizabeth mentioned the fact that many of the coverage gaps that people find might be augmented by help from the Medicaid program for people living in the community, I thought you might want to talk a little bit about the home and community-based services state plan option that is available now.

JUDY WOODRUFF: I like it when HHS can direct a question to the White House in public.

JEFF CROWLEY: Well that was something that the disability community pushed in health reform and something that was enacted but years ago or the DRA, the Deficit Reduction Act enacted this new 1959 option that was intended to really give states new options for expanding access to community services but as it was enacted, it didn't really work very well because the idea was that we had the home and community-based services waiver program and so states said let's implement this without

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a waiver but that program could go up to 300-percent of SSI and then the waiver could only go up to 150-percent.

There are all these different policy things that really just made it really challenging for any state to take it up. So this community first option, which is really designed to address some of these issues by saying how can we make it easier for states to take it up? So now a state could take up this option and again cover people up to 300-percent of SSI.

JUDY WOODRUFF: What would it offer in brief?

JEFF CROWLEY: Well it allows them to offer the full range of HCBS services, so from the waiver program, this whole range of non-medical services they can offer, so personal attendance, respite services, different things like that that in the past, it was really challenging to offer outside of, you had the personal care option in Medicaid but most states often provide this through the waiver.

They sort of said we want to provide this range of services without having to get a waiver. So again, it's another way that facilitates for states to offer these services to people with disabilities.

JUDY WOODRUFF: So you're saying it takes up some of the gap of what we've been talking about?

JEFF CROWLEY: Yes and it's another tool for states that if they choose to do more.

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JUDY WOODRUFF: Great. Let's see, I thought I saw a hand, right here in the front row. Yes sir and we'll get you a microphone.

STEWART JONES: Stewart Jones, Can Do TBI, which is a group through the United Church of Christ. I sustained a traumatic brain injury 28 years ago. So I've got both Medicare and Medicaid and Medicare right now but personally, I don't feel that I should rely on the American people to foot the bill for me. You said that there were the high-risk pools. I've already been checking into those and the price that they are quoting me is anywhere from \$150 to \$200 a month and I'm on social security. How can I get coverage if they are going to do that if I've got to pay that kind of price?

JUDY WOODRUFF: Excellent question.

JEFF CROWLEY: That's a good question. I would say a couple things. One, there were high-risk pools before the Affordable Care Act in some states. The Affordable Care Act ensured that that would be available in all states. They're really a temporary solution until we have the broader reforms in a few years and price is a barrier for some people. For some people, they find that it's worth, they'll find a way to get the \$200 but I can't say to you that it's a solution for everybody.

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I think what's more important is longer term that we're trying to take steps to make private insurance more affordable to everybody through the exchange where you can go in and buy coverage. I think that's for the longer term a better solution for the future. Now in the short-term, this plan is a partial solution for some people but I think we can acknowledge it doesn't work for everybody.

JOE BAKER: I would add that I think that's where and while the premiums are more than we might want them to be, if you look at private coverage in most states and I'm just familiar with New York, sorry to harp on New York but we're looking at individual premiums in the \$800 to \$900 a month for open enrolled guaranteed issue policy, so compared to that this is the best deal going.

I think the other solution with regard to folks that are on Medicare and Medicaid and we haven't really touched upon this but it is there as a number one making it easier for people with disabilities to work and not only keep their benefits but of course then maybe transition to other benefits that they might feel are more responsive to their needs or also could replace Medicare and Medicaid.

I don't think we're there yet but I think certainly the market that we're creating with the Affordable Care Act will create a lot of opportunities and the question there is what

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are the next level of opportunities not only for people with disabilities but others that are uninsured or need affordable care.

JUDY WOODRUFF: So you do see a path for addressing it?

JOE BAKER: I think it's a possible path. I mean there's been a lot of work done and Henry has worked on that and others about easing and Jeff, of easing the ability of people with disabilities to work and to keep benefits in trial periods and transition periods, the take it to work program, etc. that are all trying to get folks into their own comfort zone and not put them out there without any safety net. So the question will be they can keep Medicare and Medicaid for over a very long period of time while they're working at certain levels in certain ways.

Then the question will be well then after that now that we have this affordable Care marketplace, the exchange or other insurance options, will we be able to say okay, you then go out into that market? Right now we can't do that because there really isn't a viable, small group market in many states or certainly not an individual market. So I think these are the kinds of things that 10 years out we're going to be talking about if, as we hope, this market that we're creating with the Affordable Care Act is robust as we hope it will be.

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JUDY WOODRUFF: Thank you. Trying to decide if the glass is half full or half empty. My answer changes with every question.

JULIETTE CUBANSKI: I just wanted to add, it may've been mentioned already but for people with low incomes, in addition to new sources of coverage through Medicaid if you're a low-income adult without a child or you're not a pregnant woman, you can sign up for Medicaid in 2014 if your income is low enough and that hasn't been the case today.

There are premium subsidies as well that will be available to other low-income people through the exchange. That's not available today if you're a low-income individual in the individual insurance market. So that will, unfortunately, not until 2014 but it will be helpful to low-income people at that time.

JUDY WOODRUFF: Question right here. Yes?

MARY ANDERSON HARTLEY: Hi. My name is Mary Anderson Hartley. I'm from Achieva, the disability health care initiative and I'm also the mother of a child with a disability. I just had a question about the exhibit five, the larger share of non-elderly beneficiary access problems. Dental care is a huge piece here. Now correct me if I'm wrong, Medicare does not cover dental care in and of itself.

JULIETTE CUBANSKI: That's correct.

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MARY ANDERSON HARTLEY: So in doing this survey, did you just survey Medicare recipients? Mostly these were dual eligibles correct?

JULIETTE CUBANSKI: The survey was a survey of Medicare beneficiaries only, so no people without Medicare were surveyed.

MARY ANDERSON HARTLEY: So likely these were people who were only looking for a dentist? My issue is that in most states, the majority of states, there was very limited access to dental care through Medicaid period, less than half the states provide it. Most of it's emergency care. So if someone's going to have cancer treatment for instance, they can likely get their gums fixed.

This is a serious issue in the disability community mostly because a lot of people have a difficult time even accessing their own teeth. They take medications that may cause harm to their teeth. We have a he issue with dental care in this country in general and we know that it relates to other health care concerns.

My question is could Medicare, as a program that really provides a standard of care, ever provide dental care?

JULIETTE CUBANSKI: Well I certainly think it could. The dental benefit and vision care are not standard Medicare benefits. Some Medicare beneficiaries who are enrolled in

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Medicare Advantage plans can get access to some dental and vision services but it is certainly a big gap and we had a couple of open-ended questions in our survey.

There were several people who commented on the inability to get dental care. They were losing their teeth and that affected both their self esteem as well as their ability to maintain their physical health because they couldn't eat. They couldn't make their way in the world because they didn't have teeth and they felt very self-conscious.

It definitely hit home with me that we all know Medicare doesn't have a dental benefit but what does that really mean for people who have disabilities and other challenges? It is a serious problem. There's, unfortunately, it seems little appetite for expanding Medicare coverage at this point in time.

We've done some pretty big things in terms of filling the donut hole over the next 10 years and all the other changes to Medicare that are a part of the Affordable Care Act. I don't know if CBO has done any cost estimating of how much it would cost to add a dental benefit to Medicare but it certainly is a gap in the Medicare package.

JUDY WOODRUFF: Juliette, I've always been curious about why dental and, I guess, vision, are not covered. Is it purely a matter of money?

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JULIETTE CUBANSKI: I don't know if it's purely a matter of money.

JUDY WOODRUFF: Because they clearly are connected to health.

JULIETTE CUBANKSI: Right, no. Absolutely you're right. I don't know if Joe or if anybody has—

JOE BAKER: Well when Medicare was originally formed in 1965, most employers didn't offer dental benefits or vision benefits either. I mean it was seen as kind of a standalone and something you paid out-of-pocket for even if you worked at IBM for example. So I think definitely the number one question we get on our hotlines, on our Medicareinteractive.org site, the biggest page view is dental services. People are looking for that care whether they be older than 65 or under 65.

We do think that there is some work and once again, working with the Center for Medicare Advocacy, taking a look at the statute, we do think there's some room for advocacy there around the traditional view that Medicare is not allowed to or doesn't have the legal authority to do to cover dental services but whether we'll be successful or not, I don't know.

Money's a big issue at this point and certainly I think looking at Medicaid plans and what we can do for dual eligibles particularly will be important over the next few years in this

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coordination and integration of care models that we're talking about.

JUDY WOODRUFF: Okay. We have time for one more question. I see a hand right back there. Yes, the microphone.

BOB: Jeff, first how should these findings inform the design of both coverage under the exchanges and the Medicaid expansion branch of our coverage?

JEFF CROWLEY: Bob, that's a good question but I don't know that I have the answer for you. I mean clearly as people are working to implement the law, they should be reading this report and taking a look at that but I don't know that I have more thoughtful comments than that on what that tells us we need to do but one thing I've said all along about the Affordable Care Act is just even if you look at what we've done so far, the proposed rules we've put out, there's just so many things going on so fast that it's not for malice or bad intent but people are just thinking okay what's the next deadline?

I think people need to be consciously raising this saying hey there's both an opportunity here but a concern if you don't focus on this population that we could be doing something bad. So I do think we need to make sure we raise this to the attention of the people at HHS and elsewhere that are working on implementing the exchange.

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JUDY WOODRUFF: Just a couple of sum-up questions. How worried are you, Jeff, about the efforts we hear about across the country to repeal all or part of health care?

JEFF CROWLEY: I don't have a good answer for you. It's hard in a political environment to sort of separate just the noise that you're going to have all the time from what's real but I think this country's needed comprehensive health reform for so long and I think that despite all the bluster, I think not that what Congress enacted and what we're working implemented is perfect but we put so many of the best ideas out there that we think are needed to really improve our health system in a good way.

I think people are going to start seeing immediate benefits but also the promise is real of what we're going to see in 2014. It's not like when we talk about even improving our delivery system that we're just imagining some world.

We're thinking about specific examples that we know now work in specific cases and we're saying how can we scale up the successes? So I think there's enough there that we can sustain it but I'm also not under any illusions. We're going to have to work to sustain it.

It's going to require us as the administration to keep defending it and showing we're working hard but it's also

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requiring people on the outside that fought really hard to get this law, they're going to have to fight to keep it as well.

JUDY WOODRUFF: I asked because the polls show the public support for health care reform is declining rather than increasing, which is I would think is of concern of the administration. I have a very quick last question about younger adults with these issues. Is there anything particular you would add, Juliette, about the challenges facing those 30 and under young adults with disabilities?

JULIETTE CUBANSKI: Well I think I mean we think of the Medicare program as a program for old people but it's really as our research shows, it's really a very important program for people who are younger who have disabilities who are entitled to get the coverage through Medicare that the law grants them.

I think it's important for us to keep a focus on that population because Medicare really can offer them very vital support but our research definitely points out ways in which Medicare can be improved for that population.

JUDY WOODRUFF: A final sentence the three of you want to leave your audience with as we depart this morning?
Elizabeth?

ELIZABETH APRIAULX: Boy I don't want to blow that chance [Laughter]. I do think the Affordable Care Act is so important to address some of the issues of just on a personal

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level. I can feel more comfortable to change employment and not have to worry about pre-existing conditions.

I mean there's so many concrete things and I would hope that polls are not what's going to drive whether health care reform continues because one of the polls I heard, for example, about the high-risk pool was will I have to go out and prove that I've been turned down from insurance in the past six months and I have a chronic disability.

So why would I have to continue to show that? There are going to be things that are hard, loopholes that people have to jump through in order to prove that it's financially solvent. I hope that the American people can, that Jeff can continue to get the word out.

JUDY WOODRUFF: Big job on your shoulders there Jeff. Joe?

JOE BAKER: I think that that is a challenge. Certainly we saw last year a lot of misinformation out about the bill at that point and certainly that has continued to be in people's minds.

I think one of the things that we were and Jeff acknowledged is that nothing's perfect. When we enact something that's perfect, we will truly be in Xanadu at that point but we would just and particularly for this forum, it's particularly instructive and that is that when Medicare was

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formed in 1965, it did not include coverage for people with disabilities. That was added in 1972.

We've continued to improve the program. We've been talking a lot about the gaps but once again, people generally breathe a big sigh of relief when they get into Medicare and they're highly satisfied with the program. So this is something that we're going to need to chip away at. It can always be criticized but it's the right endeavor.

As Jeff said, there are things being done now that many in this room have fighting 20 years of their whole lives to accomplish even before 2014 and then of course 2014 is the big bang but I think we need to keep our eye on the prize and make sure that we're giving out accurate information about what's there and being honest with folks about what's not there so that we can continue to work on improving it.

JUDY WOODRUFF: Jeff you made an important point. Do you want to add anything?

JEFF CROWLEY: No. Just that Medicare plays an important role today in the lives of millions of people with disabilities and with the Affordable Care Act, it's only going to have a more important role going forward.

JUDY WOODRUFF: And Juliette?

JULIETTE CUBANSKI: I would just echo what Jeff said. I mean I think it was sobering in a way for us to do this

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research but it also shows us the way forward in terms of improvements that can be made for people with disabilities on Medicare.

JUDY WOODRUFF: Well I want to thank the Kaiser Family Foundation for sponsoring this discussion, important, timely, and one that I know that all of us will continue to monitor and I want to thank all of you for coming. I especially want to thank our panelists, Elizabeth, Joe, Jeff, Juliette and Tricia Neuman. Thank you very much. Thank you all [Applause].

[END RECORDING]

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