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How Will Health System Reform Address the Needs of Working-Age People with Disabilities?

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Discussant: Peter Thomas, Principal, Powers, Pyles, Sutter & Verville
Moderator: David Stapleton, Mathematica

David Stapleton: We're going to go ahead and get started. I know people are still settling down, but we have a lot of people listening on line.

Welcome to the fourth policy research forum for the Center for Studying Disability Policy. Thank you all for joining us. In addition to the people here in the room, we have about 100 people on the phone and on the web via the webinar. For those of you listening in, you will be on mute throughout the whole forum. We can't hear you, but we hope you can hear us. You can, however, submit written questions via the webinar service, and we will take at least some of them at the end of the session. If you want to hide the webinar tools that may appear at the upper-right corner of the screen, just click on the double arrows pointing to the right. If you want to open them again so you can send us a message, just click on the double arrows pointing to the left.

My name is David Stapleton. I am the director of Mathematica's Center for Studying Disability Policy. The topic of today's session, which will end at 1:30, is "How Will the Health System Reform Address the Needs of Working-Age People with Disabilities?"

Let me begin by introducing the other two speakers today. The first is Su Liu; she's an economist and a senior researcher here at Mathematica. Among other things, Su is currently leading Mathematica's work on the Medicaid Buy-In program, which she is going to talk about today.

The other speaker, whom many of you are familiar with, is Peter Thomas, a principal of Powers, Pyles, Sutter, & Verville, where he leads a federal law and legislative practice in the areas of health care, relocation, disability, and employment. Peter is a well-known legislative expert on health policy for people with disabilities, and among other things, he serves as the co-chair of the Health Task Force for the Consortium for Citizens with Disabilities, which is a Washington-based working coalition of 129 national disability-related organizations.

We plan to talk for a total of about 55 minutes, after which there's going to be about half an hour for questions and discussion, so please be ready with your questions and comments.

It's no secret to anybody here that the current health care financing system poses special challenges for working-age people with disabilities and chronic diseases. We appear to be on the brink of a major health care financing system reform. My guess is that many people with disabilities and their advocates are hoping that the reforms will make the country's health care financing system less of a challenge for them than it currently is.

But the issues driving reform are not explicitly the challenges facing people with disabilities. Instead, there are two broad issues driving the reform—one is the growing number of people who have no insurance at all; second is the very rapid growth in the cost of health care on a per-capita basis. There are many ways these broader issues could be addressed. Some would mitigate the challenges that people with disabilities face but won't necessarily do so, and others might make them worse.

Several commentators have said in the past that working-age people with disabilities provide a litmus test for health care reform. If it doesn't work for people with disabilities, it's not going to work for everybody. There are really two reasons for this: one is that many of the problems that people with disabilities face are exaggerated versions of problems that are faced by everybody else; second is that many people who don't have disabilities now will have them at some time in the future, and the health care system will need to work with them then.

So with that in mind, the purpose of this session is to draw the attention of health reformers to the challenges that are faced currently by working-age people with disabilities, with a larger goal of helping to increase the chance that any reforms put into place in the next year or so will mitigate these challenges and ultimately represent an improvement over the current system for everybody.

If you came today expecting that we were going to answer the question in the title of our session, I'm afraid you are going to be disappointed because we don't have all the answers. Our more limited purpose is to draw attention to these issues and to engage in a discussion about the implications of various reform proposals that are out there. So, I am going to start by characterizing the current financing of health care for working-age people with disabilities as a private-public system with three major holes as well as a growing number of patches for those holes. We don't have time to get into the details of all the holes or of all the patches, so instead I will illustrate a couple of the holes based on our own research related to the insurance and health care experience of workers with disabilities when they leave the workforce and enter Social Security Disability Insurance. Then, Su is going to talk about one of the growing patches that is very important—called the Medicaid Buy-In Program, which I previously mentioned. Finally, Peter is going to consider whether and how the health reforms that are currently being debated on the Hill will address these holes and potentially affect the patches. We will then call on you to ask questions and offer your own observations.

This slide shows two pie charts about the numbers and costs of working-age people with and without disabilities. These slides, as well as the next few, are based on analysis of the Medical Expenditure Panel Study from 2005 done by our colleague, Tom Bell.

As represented in the left-hand pie chart of this slide, over 12 percent of the working-age population, or some 22 million people in 2005, had a long-lasting functional limitation, [had] a health-related work limitation, [had a] severe sensory impairment, [were] limited in activities of daily living, and/or [were] a participant in a major federal disability program. Although people with disabilities are often characterized as people who cannot work, many do. In fact, according to this slide, almost 10 million, or about five percent of the working-age population, are people with disabilities who do work.

Expenditures on health care for people with disabilities are disproportionately high as you can tell by comparing the right-hand chart, which is for expenditures, to the left-hand chart, which is for people. In 2005, working-age people with disabilities accounted for one-third or over 37 percent of all health care expenditures for the working-age population. On a per capita basis, their expenditures are more than three times as high as expenditures for those without disabilities.

There are two obvious takeaway points from this slide. The first one is that working age people with disabilities have a very special interest in health reform. A lot of health care expenditures are for their needs. The second one is that health care reformers ought to have a special interest in working-age people with disabilities if for no other reason than they account for such a large share of health care expenditures for the working-age population. There are a lot of other reasons that they ought to be interested.

Now, I lied a minute ago saying that all of these charts were based on the Medical Expenditure Panel Survey. This one I just made up—its fictitious data. It represents what I think people who are not familiar with disability often think about how the health system works for people with disabilities. Over on the left we have a bar for people with disabilities, the working population. It's all red, representing everybody in the working-age population who has a disability covered by some type of public health insurance: Medicare, Medicaid, or veteran's health plan.

On the right we have another bar for working-age people without disabilities and it shows that most of them are covered by private health insurance, mostly through an employer or spouse's employer, with a few, mainly low income parents receiving benefits from public programs such as Medicaid, and a certain percentage who are uninsured—a significant percentage who are uninsured. This is a stylized picture that I think many people unfamiliar with disability and health care think is the case for current coverage.

But in fact, most of you know that the real world is more complicated. This next slide represents real data, again from the MEPS. The right-hand bar again is for people without disability and that looks quite similar to the bars on the previous slide with about 73 percent of people having private coverage only and just 6.7 percent having public coverage only. Then there is 2.6 percent in the middle that is for those who, at least for part of the year, had public coverage and part of the year had private coverage. Then almost 18 percent with no insurance. This is from 2005.

The left-hand side is the bar for people with disabilities, again from the MEPS, and it shows that the largest group of coverage is those with just private coverage, 41.6 percent. Only 35.3 percent have only public coverage, and almost 10 percent have both at some time during the year, one or the other, which may vary during the year. About 13 percent are uninsured. So people with disabilities rely quite heavily on private coverage; it's not simply the public coverage, and many of them do not have insurance.

Now, part of the reason people with disabilities rely on public coverage is that many of them do, in fact, work, as I pointed out earlier. This bar, which is now four bars, has two bars from the previous chart along with two intermediate bars. So the left hand intermediate bar is just for

working-age people with disabilities who are not, in fact, working. What you see here is that most of these individuals do have public coverage—51 percent have only public coverage, another 13 percent or so have public coverage and some private coverage (perhaps through a spouse), and just 24 percent rely solely on private coverage. We still have almost 13 percent who are uninsured.

The remaining bar, which is the third bar from the left, or second from the right, is for working-age people with disabilities who are in fact working. What you see there is that their coverage is much more like the coverage of other working-age people without disabilities. That is, they are relying mostly on private coverage—not quite as much as others without disabilities, but almost—and their public coverage is relatively low, although it is higher than it is for others without disabilities. But we also have the 14 percent of them who are without insurance at any point in 2005. So it's a very significant share. The third bar is the 65 percent private [insurance] only. Another 6 percent have both public and private, and 15 percent have no insurance.

So the main point of these slides, to me, is that the financing of health care for working-age people with disabilities cannot be easily separated from the financing of health care for everybody else in the working-age population. This fact reflects a broader reality. People with disabilities cannot be readily separated from those without disabilities and if you don't believe me, just ask the Social Security Administration, which has been trying to do that for over 50 years without a lot of success.

But we wouldn't want them separated from everybody else. Separation is sometimes a convenient fiction for policy makers because if we can have certain people in a certain pot and certain people in another pot, we can treat them differently. But the reality is much more complicated than that. I think this is a really central point that makes policy reform in the health care area very difficult to do and puts, I think, people with disabilities at risk.

The next three slides describe the holes that we have decided to define as our way of capturing what we think are the major problems for working-age people with disabilities in the current health care financing system. I'm just going to go quickly through these holes, enumerating what they are. I think most of you are familiar with at least some of them. There is a lot of research on almost all of them and we can talk about them later on, but I just don't have time to get into them all.

The first hole is for those who do have public coverage. There are significant limitations of public coverage itself. The first of these is that coverage for many services depends on people's incomes and assets. In order to be eligible for Medicaid, which has the broadest coverage, you have to have low income and it has a spend down. The payment policies for public payers often restrict provider availability; that's especially true for Medicaid. Access to care is often problematic, long waiting times perhaps, care coordination is often poor, and the financing has historically favored institutional care over home and community-based care for people who need long-term care, as I suspect many of you know.

The second hole has to do with incentives. The current system has incentives that, in fact, discourage people with disabilities from working and encourage them to become dependent on public programs. A lot of this is because most public coverage is conditioned on an individual

with disabilities not working, at least for some period of time. In order to get on Medicare, you need to go through SSDI [Social Security Disability Insurance], which means some time out of the labor force; same for Medicaid with SSI [Supplemental Security Income]. There is a private coverage market but it is usually too expensive or unavailable for people with disabilities because of pre-existing conditions. So, they [people with disabilities] only have employer coverage or public coverage to turn to. More and more employers are not offering coverage at all, so that just leaves public programs, and the only way to get those is if you are not working or have reduced your amount of work. Another point that I think people are less aware of is that employers have a disincentive to hire or retain workers who have high health care costs because they are paying for part of those costs. We don't see very much about this because it's a difficult thing to measure, but clearly the incentive is there. Also, increasingly, employer-sponsored plans are limiting coverage for special services and equipment that people with disabilities often need. In fact, many of the restrictions that we see in public coverage are more severe for private coverage.

The final hole, which is the one I'm going to spend a little bit more time on, is what happens to people's coverage when certain life events occur. The first life event is the transition from youth to adulthood. Our focus here is on the working-age population, but before you get to be working age you've got to be a youth and those that have disabilities face the problem of changes in health care coverage as they become adults. People with disabilities face the problem of job change—changing a job or changing your insurance coverage, may lead to a gap in coverage and may even discourage job changes.

The problem of mobility across states is particularly true for the Medicaid population—you move across states, you change your Medicaid coverage. This can also be true for people covered by employer insurance. And finally, there's the transition from employment to SSDI. As I said, we don't have time to look into the detail of all the holes in the current system for people with disabilities, so I'm going to take a look at some recent research findings that illustrate two of the holes—especially this third hole.

First, I'd like to thank the Commonwealth Fund that sponsored this research. The research was led by my colleague Gina Livermore, and Henry Claypool, who did his best to keep Gina on the straight and narrow, but any remaining errors are hers.

We examined the health care utilization and the insurance coverage of entrance into the Social Security disability program for three years immediately before SSDI entry and three years immediately after entry. In order to conduct this study we used data from the National Health Interview Surveys from 1994 to 1996. These data are somewhat dated. They have been linked to Social Security disability records and also Medicare records by the National Center for Health Statistics.

I suspect if we had more recent data—Bob Weathers had some more recent data and he will maybe comment on it later—we would see that the situation is worse today than it was back then.

The key findings are at current levels. There are about 800,000 entrants to SSDI in every year. Most entrants move from working—not surprisingly three years, two years or even one year before they enter SSDI—to not working, so they have lost income. Health care use greatly

increases during this period. We found that the average entrant spends about 65 days in bed during their first year on SSDI including seven days in the hospital. That is the average. They visit a doctor during that year an average of 22 times. Almost all of them during this year have limitations in activities of daily living or instrumental activities of daily living. Many report health access problems during this period—10 percent did not receive care because of cost or lack of insurance and another 21 percent reported that they delayed care because of cost.

These statistics represent only those who actually survived to respond to the National Health Interview Survey; many of them died. During this period, 13 percent of the entrants died before they reached the 24-month after entry into SSDI.

This bar graph depicts what happens to insurance coverage for those who enter SSDI from the third year prior to entry until the third year after entry. I used the same color scheme as the earlier graphs, blue representing private coverage and red representing public and yellow uninsured, but the statistics aren't strictly comparable. I wasn't able to separate the private and public group so I have a private only group in blue and the red is people who have public [insurance] but many of them also have some kind of private coverage.

What you see here is that 22 percent of beneficiaries didn't have insurance in the three years before they entered the rolls. That stays pretty constant until the second year after they enter. Now, that represents at today's levels, about 200,000 people every year entering the rolls without any health insurance. Most of them had private coverage on the order of 70 percent, prior to entering SSDI and about 10 percent were already in some kind of a public program before they even entered SSDI.

Once they entered—in the first year and the second year after entry—what you see is that employer coverage declined, employer-only coverage declined and public coverage expands. By the second year after entry, 32 percent reported that they had some sort of public coverage whereas only 51 percent had only employer coverage, and the number of uninsured also went down by the second year to 17 percent. So what happens during this period is that quite a few of those beneficiaries give up their own employer coverage, some continue to have it, but more continue to have coverage through a family member and larger and larger numbers become eligible for Medicaid because of income and resource restrictions.

As you may know, beneficiaries are entitled to Medicare coverage in their third year after entry. In fact, we found that not everybody that responded said that they had public coverage—10 percent said they didn't even though they were in their third year. One reason for that is that they simply may not have known that they have Medicare. Another reason is that some people don't get their benefit awards until they have already completed the Medicare waiting period. There's a long backlog on decisions in the Social Security Administration so if you don't get your award until over two years after you are eligible, you may be eligible for Medicare but you won't know it until later on. In this period that we looked at, this happens about 11 percent of the time. They got into their third year and they still didn't have an award from SSA.

One other point about the 24-month waiting period, while I'm on it. As I indicated earlier, 13 percent of people die before they finish their 24-month period of SSDI, so they never get Medicare even though they have paid into the system all their working life.

To sum up, every year about 800,000 workers exit the labor force and enter SSDI. For many this is a traumatic period medically, financially, and personally, and health care financing problems just add to their problems. The current financing system fails to ensure that such workers have access to care when they need it the most, care that for some might allow them to continue work and not become dependent on public benefits—13 percent die before getting the Medicare benefits they have been paying for since they started to work and another 11 percent must wait longer than the 24-month waiting period because of delays in disability determination. Further, significant numbers of uninsured workers (on the order of 200,000 per year) find that labor force exit and entry into SSDI is the surest, if long, path to the care they need—i.e., if you have a disability and you need coverage, your best option might be to stop attempting to work and apply for SSDI.

So this is just one of the holes. I've tried to give you a sense of its magnitude but some of the other holes are just as big and just as difficult. We've tried to patch this particular hole in a couple different ways. One is through COBRA coverage. I'm not going to try to remember what that stands for, but as most of you probably know if you have employer coverage and you leave your job, you can continue to get your employer coverage for some period and it's extended if you are applying for disability benefits. But, you have to pay the full premium. Premiums are high and after all you have had a major loss of income.

The second patch, which is of growing importance, I think, is the Medicaid Buy-In Program. At this point I'm going to turn the microphone over to Su Liu and sit down and eat my lunch and let her tell you about that.

Su Liu: Thanks, Dave.

Before I move through the next few slides I just want to mention that the findings you'll see in the next few slides are actually drawn from the now eight-year-old project that we have had the fortune to have from the Centers for Medicare and Medicaid [CMS] services. A large group of people here have worked on the project. Some of them, like Bob Weathers, I saw his face here, and Henry Ireys, I saw in the room, and Gilbert Gimm, Jody Schimmel and Bonnie O'Day and many others are probably on the call, so I want to acknowledge that all of their hard work went into the slides, and of course, the views presented here are those of our teams and not necessarily those of the CMS staff or any state agency.

Medicaid Buy-In was initially authorized by the Balanced Budget Act of 1997 and then reauthorized by the Ticket to Work and Work Incentive Improvement Act of 1999. The Ticket Act added a few more generous provisions. It's an optional state program under Medicaid and as of December 2008, it is offered by 41 states and about a third of them use the legislation of BBA for authorization. Another two-thirds are implementing it under the authority of Ticket. More than 215,000 individuals with disabilities have enrolled since the first program was implemented in 1997, so you can get a sense of how big the program is.

So how does the Medicaid Buy-In work? As Dave mentioned, there are all these holes in the current system that people with disabilities are facing. One of them is employment disincentives. Medicaid Buy-In is not only a health care program, it also is seen as a work incentive program.

Basically, it encourages employment by allowing individuals with disabilities to work while having higher earnings and assets, allowing them to stay on Medicaid with their higher earnings and assets. In exchange, they buy into the program usually in the form of paying premiums on a sliding scale basis, sometimes with co-pays. So the hope here is trying to have people continue to work and earn more while not having to face the risk of losing their Medicaid coverage.

It's considered a patch for SSDI beneficiaries in the waiting period to get Medicare. So right after they get entitled to SSDI, they have to wait 24 months. In this period, a lot of them probably are getting COBRA and some of them probably have nothing so Medicaid Buy-In provides a good option for that if they are still continuing to work somehow.

Before Buy-In, many state agencies have set up what's called Medically Needy Program under their Medicaid. Basically, people can incur medical expenses, spend down their income, and therefore qualify to get Medicaid. With Buy-In, people can pay a premium, usually a much smaller amount than the spend-down amount. So that way they can keep their income and still get Medicaid.

There are also SSI beneficiaries who can take advantage of 1619a and 1619b, earning more while still keeping some of the cash benefits as well as Medicaid coverage. But once you exceed 1619b limit, what are you going to do? Buy-In, a lot of times, does have a higher income and asset limit, higher than 1619b limits, so again it's a patch for these SSI beneficiaries who may want to take another step forward.

Finally, I think what I consider as a bright spot, especially for the Buy-In, is for people who are not on SSDI or SSI rolls. They fit SSA disability definition in terms of their medical condition but they are still in the labor force. Many of them still have substantial gainful activity and have higher assets so Buy-In actually gets them coverage through Medicaid, keeping them in the labor force and in some way probably prevents them getting on SSDI and SSI.

The next slide—if you can see the right-hand side of the bars, you can actually see 28 percent of people on the Medicaid Buy-In program have neither SSDI nor SSI before their enrollment. So you can see it's actually not a trivial proportion of the enrollment in the program, but of course, again, it's an important patch for people transitioning from work to SSDI represented by that 68 percent of participants who were SSDI beneficiaries before their enrollment.

This slide also gives you some sense of the people currently in the Buy-In program. A lot of them are middle-aged, 30 percent are ages 41 to 50 years old, another 28 percent are 51 to 60 years old. Certainly it has a lot of people with severe mental illness; about a quarter of them had severe mental illness, and another 8 percent with other mental disorders.

Of course, because it's considered as a work incentive program, a question we often ask ourselves is “Are Buy-In participants actually employed and how much are they earning?” You can see here, we found that 70 percent of Buy-In participants reported earnings from the IRS through their tax report. They have some reported earnings and among those with reported earnings, the average earnings were about \$8,582 in 2007. Even though work is a requirement for somebody to get on the Buy-In, every state defines it differently and has different

requirements for showing evidence of working. So some of these 30 percent who we didn't see any reported earnings may have attended sheltered workshops. Their earnings probably are not reported. Some of them probably have some level of cash earnings from baby-sitting or dog walking or things like that. But, as I will mention later, I think the program itself has much potential. The \$8,000 is much lower than average of 250 percent of FTL many states have as the income limit for this program, so it has greater potential beyond what is currently now utilized.

This is also another interesting finding. Forty percent of first-time Buy-In participants actually saw their earnings increase in the year after enrollment in the Buy-In as compared to the year before their enrollment. Again, other evidence to show that a lot of people are taking advantage of this program—working while still maintaining their health coverage. This is probably the reason why they are able to work and continue to earn. And among these people who saw earnings increase, the median increase is about 50 percent over a two-year period, so I think that's an interesting finding right there. And from a tax revenue and state spending perspective, in total in the year of 2007, Buy-In participants earned \$631 million in reported earnings and they were charged \$27 million in premiums. Remember, you have to buy into the program to get coverage.

So in providing service to this group of people, the state is actually getting something back in the form of a premium. So how much is the state spending on these people? It's actually interesting to see in terms of per member, per month Medicaid expenditures. Buy-In participants are not more expensive to cover than other Medicaid recipients with disabilities. You can see here, even though it's based on relatively old data (year of 2000), it shows \$984 per member, per month Medicaid expenditures among Buy-In participants, which is about 40 percent lower compared to other disabled Medicaid recipients. I think this is showing possibly, as Dave showed earlier in that pie chart, people with disabilities who are working are probably healthier and may have incurred lower expenses. But I should also point out it may have also reflected some level of systematic difference between Buy-In participants and other disabled Medicaid recipients. Just to give you an example, among the Buy-In population, the dual eligible population, it's about 80 percent higher than usual—around 50 percent among the other disabled Medicaid recipients—basically meaning that Medicare is picking up a chunk of what these people are spending. So that may lead also to a lower per member, per month Medicaid expenditures for these people.

I think what we are trying to show here, hopefully by using Buy-In as an illustrative example of the patch, is to really think about all these patches that are existing and how have they worked and what are some of the lessons we can learn from these patches moving forward in hopefully doing a comprehensive health care reform.

A few thoughts here. Certainly Buy-In has filled some coverage and service gaps in terms of people transitioning and life event changes, especially for those people transitioning from work to SSDI. And I want to point out again those people who may not have transitioned. This may have prevented them from incurring such life-changing events. It also incentivizes employment and encourages earning increases, at least for some people. I should point out that some of the research done did shows that younger people have more potential increasing their earnings, comparing their earnings after Buy-In participation to earnings before. So I do think this population that can be more effectively targeted.

So far there is no evidence of higher per member cost for Medicaid, which is another interesting finding for Buy-In. Like I said, states have the flexibility to set up the program very differently and they do. They have different income asset limits. Some of them actually have no income limits and really have a greater potential to be utilized there. So I think part of why the program has worked today is because states can really tailor the program to their individual environment and also while the Buy-In was implemented during the decade period from 1997 onward, a lot of other things were going on at the same time. SSA rolled out the Ticket to Work program, there's the Benefit Offset Demo pilot program, and work incentive planning and assistance grants are out there as well. And I should point out that many of the states were able to implement the Medicaid Buy-In program using what is called Medicaid infrastructure grants, also managed by CMS. So really it's targeting the infrastructure level, the system level type of changes. So Buy-In is only a component of that system change and I think that hopefully, with all the SSA's efforts, it really creates some synergy to better support people with disabilities.

So what work is still ahead? This is kind of funny because we saw Buy-In providing a patch for many of the holes that Dave mentioned earlier, but really, there is still a lot of ground to be covered here. So what I call this is making a bigger and better patch and maybe just reinventing the whole system again. But some lessons learned. As Dave mentioned, this is not unique to Buy-In but more to Medicaid in general. There is no portability across state lines. Actually a quarter of the states don't even have Buy-In so if you move from a state that does to a state that doesn't have one, then you don't have any choice there. It does not address the limitations, in general, of public coverage, the access to care, the care coordination issues that Dave mentioned, and also it's part of a very complicated system. People with disabilities can, you know, use different means to get their patch benefits to actually get health coverage. SSI people have 1690a/b and even Buy-In as incentive. There are other disincentives out there like SSDI cash plans. A lot of people do not want to earn more because even though they can still maintain Medicaid coverage, they may lose altogether their SSDI cash benefits once they earn above that level. So, again, just to say that there is potential here to better utilize Buy-In. There's huge room there but I don't think it can be fully met if there are other disincentives that counter what Buy-In is trying to do.

Hopefully Dave and I gave you some flavor of what are the holes and what are the patches and we showed patches do exist, but they are imperfect. With that, I will turn to Peter who will talk about whether leading health reform proposals actually affect these patches.

Remarks of Peter Thomas and Q&A will be posted after final review.