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Realigning Disability Benefits to Support Greater Employment and Economic Self-Sufficiency for People with Disabilities

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Panel

David Stapleton:

We know that historically employment rates for people with disabilities have been low and they have been declining. Now, measurement is problematic and controversial. In fact, we have disagreements about this a lot, but I would assert that in fact the employment rate for people with disabilities has been declining for quite some time and the causes for that are not clear.

There were some other economists who thought that the reason was the ADA itself because it discouraged employers from hiring people with disabilities because of the cost of job accommodation, lawsuits, et cetera. There is some new evidence that probably most of you haven't seen that really pretty firmly rejects that hypothesis and indicates the decline in the employment rate for people with disabilities began well in advance of the ADA. But we still don't really understand all the causes that well.

I would argue that the evidence indicates that it has to do with changes and incentives, decreasing incentives to work or increasing incentives not to work, but it's still a very complicated issue from a research perspective. One thing we do know though is that people with disabilities as a group did not benefit from the 1990's economic expansion. Most of these people in this room probably felt their income went up quite a bit during the 1990's, but if you in fact look at people with disabilities, you will find that their household income did not grow and that in fact the percentage remaining in poverty stayed pretty stable and went up quite a lot relative to people without disabilities. The support system is also out of step and I'm now talking about the cash benefit systems and the non-cash benefit systems, are out of step with some important legislation passed over the past 20 years, the Americans with Disabilities Act, the Rehabilitation Act, and the IDEA, Individuals with Disabilities Education Act. I knew it had something to do with disability. So, I always think about it as IDEA. I never try to spell that one out. But anyway, the -- you know, all of these acts have strong self-sufficiency statements in them, encouraging, promoting and trying to develop policies that encourage self-sufficiency and greater inclusion of people with disabilities in our society. And I think that it's easy to argue that our current support systems, the income support system is well as non-- as well as a non-cash support system in a substantial way are out of sync with those objectives. The support systems are also out of sync with what disability is.

We historically thought of disability as a medical issue, a physiological issue, a mental issue, but we now know much better. I think that it's really a combination that has to do with a combination of a person's physical and mental conditions and the environment that they happen to be in. People can do a lot of things with unusual, let's say mental or physical conditions if the environment is right for them to do what they want to do. So we have that understanding better. But in fact if

you look at the programs, they still have a very strong medical orientation. It's the individual's problem, not the society's problem or the environment's problem.

We have also had incredible advances in medicine and technology. In one way it means that some medical conditions are not nearly as disabling as they once were. But also those that were disabling can be accommodated through technological limitations in a variety of different ways depending upon the disability. And it really seems incredible that given those advances that we are not making progress in terms of employment, let alone the income and status of people with disabilities.

Public disability expenditures that support people with disabilities are high and they are growing and growing faster than the growth rate of the economy, GDP and also federal outlays. We spent 226 billion dollars at the federal level to support working age people with disabilities in 2002 -- this is just working age. That's 11.3% of all federal outlays, including both on budget and off budget and also that's equal to 2.2% of the GDP. Most of that support, 97%, of it goes to income support and health care, 75% is for income support and health care for the SSDI benefits in working age in 2002, about \$22,000 for beneficial. There's another \$52 billion spent by State for the Medicaid program to also help support people with disabilities.

Since 1986, federal disability expenditures have grown much more rapidly than total federal outlays or GDP. Grown from 6.1% outlays to 1.3% over a span of, what's that, 16 years and that's 1.4% to 2.2% of GDP. Those are rates of growth that the taxpayers aren't going to be willing to sustain. There's every reason to believe that the situation is going to get worse in the future. The economic security system for people with disabilities that we currently have is really on a collision course with what I call the deficit bus. The factors driving large deficits are only going to get worse as the Baby Boom Generation retires. Disability expenditures are growing much faster than total outlays as I said before and that's going continue to be true because us Baby Boomers are getting to be the age where disability is most likely to occur.

Already there have been significant discussions about cuts and programs that people with disabilities use, with the Medicaid program and the SSI program for sure. I think you may have seen it in the last few days, there's an issue concerning the SSDI program and SSI program and having to do with vocational factors used in disability termination processes which in fact reduces eligibility or SSI or SSDI. Cuts like this are going to be painful, but really they are the only options that Congress currently has to deal with the deficit bus. And as this bus comes rolling towards them and they need to roll back on expenditures, that's all they know how to do, tighten eligibility and reduce benefits and as time goes on, we are going to see more and more pressure to do exactly that. So that's the bad news.

The good news is that I think there is potential for a win-win policy change. I think

that the research supports this potential and the real question is whether we can figure out how to do it and get it done in a timely way. The premise here is that there is some change in program design that would do the following things: make people with disabilities who can work better off, it would increase their economic security, not reduce it, and it would reduce the growth rate of government spending and, I think this is really important, it would reduce the threat of benefit cuts for those who could not be expected to contribute to their own support because it would reduce the pressure to support people who can in effect provide more support for themselves. The resources in such a change would draw results that are twofold.

You know, this sounds like a too good to be true scenario. Where are we going to get the resources to do that? Number one is the under utilized disabilities of people in this population. People could be contributing to their own support but are not working. The second is the incredible waste I think which is apparent in the current system because of its complexity and its design. So what I am suggesting is that there is a new work benefit that could provide economic security for people with disabilities by making more pay and also by fixing the support system for participants.

There are lots of challenges to making a change of this nature and I'm just going to mention two of them. You can read our paper and you'll see many others. One is if we were to apply changes, to a new system indiscriminately to everybody with disabilities, it would harm many people, mainly those that we would not expect to contribute substantially to their own support. So we need to do something to move forward that's not going to have that harmful consequence, and that's going to be very hard to do. The second is the history and the competing interest of many agencies. Others suggest that the multiple federal and state agencies provide the relevant programs will have a difficult time cooperating to do this. That's probably the understatement of the year.

[Laughter].

I don't have the solution. I know you're all waiting for me to roll out the perfect program and I don't have that. There's just way too much work to be done and we are trying promote that work, trying to provide information that will help policy makers develop better programs and we hope that we can contribute in a positive way to that. But, I do have a strategy and I'll share it with you now. When I finished the early part of my talk, I said, this is hopeless, we can't possibly do this. So I have to say there is at least a ray of hope here, so let me do that.

I think that we could launch in the next couple of years, note this is my 10-year strategy and I'm talking about the first two years, a demonstration or maybe multiple demonstrations with a target selected population of people with disabilities to show that significant numbers of them in the target populations will work if work pays and better supports are provided and it also shows some

configuration of such a system would in fact be less expensive for these people than in our current system. I think we can do that. I think we are in a position to launch a demonstration like this or multiple demonstrations like this. We would start with a particular row, a fairly easy to target population and the participation by those in the target population would be voluntary to guarantee that they are better off. After all, this new system is supposed to make people better off, so why coerce them into the situation if we were going to design something that will make them better off?

Part of the demonstration is to show them we can do that. There are multiple opportunities out there to do that. I think the best ones at federal level are SSA demonstrations that are currently being designed, the benefit offset demonstration which has now been combined in the early intervention demonstration, another one called Youth Transition Demonstration, and another one called Mental Health Treatment Demonstration. These are all target populations. But it seems to me that these demonstrations are all focused on the same thing -- helping these target populations earn more money, but also reducing the benefit cost and making them better off.

There are also some state demonstrations that are going on in the development stages and I won't get into these, but I think the one that is the most promising appears to be in Florida and Wisconsin and Vermont.

So what happens after we have launched these demonstrations? Well, we really shouldn't be moving ahead until we have had a chance to see if they are working. So we need time to evaluate, get the kinks worked out and see if people are using the systems and being successful and over that period we probably improve the implementation, improve the programs and start to build confidence and support so strategies like this could actually work.

In years 6 to 8, when we have presumably done some evaluation and have some results, we start expanding these programs to serve broader populations. Once we have the programs in place, we then have to figure out how to get people into them.

We expand gateways, as I say the entry into these programs, improve them, adapt them to populations that we have services for. We continue to try to build confidence and support. Then in the years 9 and 10 we can start talking about legislation that would embody the programs that we have developed through this series of demonstrations. I think that's doable, but I also think it's a stretch to do it. But I almost think that we have to do it or at the end of 10 years, or even sooner potentially. Congress is really going to have no options other than to cut benefits very significantly and in non-cash supports to people with disabilities and I think it's going to be devastating for most people affected.

So just to wrap up, the new program as I envision it could become a gateway for

entry into what we have as the traditional programs. I'm not saying that we are going to get rid of those programs entirely. We still need to continue a substantial share of those people that we serve now. The new program would be a gateway. People wouldn't be able to get in -- many people, not everybody, many people wouldn't be able to get into the programs until they passed through this gateway. I also think the traditional programs could be greatly simplified once we got this work support program in place because we could get rid of all of the little things we packed on the program, work incentive, et cetera. But we have tried, not very successfully, to increase employment in this program.

Finally as I said earlier, at the end of the 10 years, Congress would have a better cost saving option and that option would not simply be adopting the system but also to encourage people to use that system, having that as a fallback when they have expenditures for the existing system. Thank you.

[Applause].

Andy Imparato:

Thank you, David. I neglected to mention that we have copies of the paper that Dave referred to in the back of the room. We also have them on disk if anybody needs them in a different format and I think we have large print versions as well.

Our next speaker is going to be Dorcas Hardy. She is the president of Dorcas R. Hardy and Associates and served as Commissioner of Social Security from 1986 to 1989. In 2003 to 2004, she chaired the Department of Veterans Affairs Task Force Vocational Rehabilitation and Employment, charged to improve provisions of services for service connected disabled veterans returning from Afghanistan and Iraq. Recently, she was appointed by President Bush to chair the policy committee of the 2005 White House Conference on Aging and in '02, she was appointed Vice Speaker to the Social Security Advisory Board. Please join me in welcoming Dorcas Hardy.

[Applause].

Dorcas Hardy:

Thank you, Andy. It's a pleasure to be here. David has given us a charge of 10 years here. I'm going to go through some thoughts that I have according to Andy's and David's conversation over the past couple of months, probably years, as to maybe some new thoughts as to how we can look at some of this.

First, I should introduce two folks who are here, Joe Humphries and the Executive Director of the Social Security Advisory Board. In their spare time and their day jobs, they sometimes get around to thinking about disability, so it's nice to have them here and I'll tell you more about how it SSA is really doing some interesting things in this area.

First I kind of like to add a little bit more to David's comments about who we are talking about, who is our population. I did focus most of my remarks on SSDI, not to ignore SSI, but this would make it a little easier. These things are difficult to tackle.

A SSDI recipient is most likely to be a male about 50 plus years old. The women are just a few years younger and are coming on to benefit in their late 40's. Note these groups are all averages. Mental disorders are still the very high diagnosis for about a third of the beneficiaries and the muscular skeleton disorders are about 20%. About one out of 76 disabled works receives SSI and the benefits for SSDI make up about 45% of that beneficiary's family income.

GAO has been in this space for many years and has done some outstanding work I think. And they rightfully stated that SSA and VA need to update their criteria to reflect medical and technological advances and changes in the labor market that affect needed skills and workplace performance. Also I think and they have stated they need to be addressed as part of any disability decision making process -- the SSA population.

We know that the community of persons with disabilities is very diverse, has lots of needs and an array of services and David's pointed out many of them. But Andy asked me to look a little bit at the VA population and I'll just make a comment here that we may not want to discuss that in detail today, but it needs to be integrated. Even though it is a different population, we talked about the silos in federal government and VA is certainly an equally large silo as well as Social Security is and that's maybe silo in terms of administrative pieces but they provide incredible support to people who need it. So should they be looked at better, et cetera?

I think that's one of the things we need to talk about. There are many of the same issues in both places, though many of the benefit determinations at VA are mostly physical based, but we know that there's very little at VA about any employment conversation and any employment determination. We also know that employment is a major concern on the part of the VA and they are currently looking at who these people are, what their issues are, et cetera and these are issues that they are struggling with as well as the issue of how that benefit platform is based, where you have an increase in disabilities, and how their system is or is not in sync with ADA, or how to increase applications therefore, and how should they intervene regarding rehab and return to work.

So clearly on both of these programs, which are large like I said, if we don't count the VA piece on the work side -- very large and in many cases not very modern. So the picture for both beneficiaries of those two programs is further complicated I think between the low-income issues and poor health status. So we look back at a report that the Irvine Institute did on health problems in low populations. I think without a study we can all say that low-income adults are more likely than other

adults to report a health condition that results in a work limitation. We are trying to put all of this together and what do we do about it?

David mentioned the cost of disability. We didn't get into all the dollars except for the significant increases in benefits, work benefit dollars, and the programs. But we have costs that are not only government costs if you will, benefits costs, but we also have medical costs, lost wages issues, a psychological well being of an individual, which is extremely poor, and you have got to remember that these will dramatically affect the Baby Boomers that are coming. They are here, and I will add with my White House Conference on Aging, that beginning January 1, 2006, a Boomer turning 60 will occur every 7.7 seconds and it will go a long way. I mean, it's years and years and years.

So we have a whole other population coming in and that obviously will impact federal and government programs. It incredibly impacts the workforce and employers from what the private disability side should be doing and what the employers should be doing. How do they get ready for this? What kind of accommodation should they be doing and how do you put all of this together?

I think one of the things that we should assume, I assume, is that the American population wants to participate in the workforce by and large. I'm sure there is an exception of somebody down the street and over the hill, but by and large we are willing to work and we would like to work. And so how do we accommodate all of this? And the Boomers come along and get into the disability age and how do we integrate that with the anxiety we are starting to have here? We need to have safety net programs, but how do we make them better, make them more modern, and how do we integrate them into the 21st century? I think we can all agree despite the fact that change is tough, these were built in another day and I simply think we can do better.

David did point out the problem with the one size fits all to public policy and I would like to consider that really at the top of our list. This is not a one-thing-fits everybody issue and we have got to do better with our public policy in this arena or we're never going to achieve our goal. So I would like to give you an update to what the Social Security Advisory Board is trying to do. Since the board's inception, which is quite a few years ago, 8, 9, 10, the disability program and the public policy around that have been part of the board's conversation and been quite a major focus. You may have seen some of our reports. We had one in '98 and we had a more recent one that basically says that finding jobs is only part of the job and we need to develop programs that have that array and that continuum of services that are rehab services and that facilitate retaining the job.

Restructuring rehab services; some say that Ticket to Work has done that and I think we can have a conversation about that and how do we include things like functional capacity assessment or evaluation as to who is the right person at the right time? And who should be the lead with all of these return to work issues?

Should the lead be at the private sector level when you have disability insurance and you are in generally a medium to large size employment situation, you get into go to a short term to a return to work, short-term of a disability, a return to work, hopefully not.

But sometimes there is a long-term disability and then no return to work and then Social Security. Is that the right continuum? That's pretty much what we have now. How do we fix that, and do we fix that? We have historically said we have got to fix the Social Security piece. Well, maybe there's some other things along the way as we start through the continuum that we should be working in a partnership trying to figure out where that is. And I'm like David -- we have all been around here, but I don't have all the answers. But I'm trying to raise some of the things that the board will be talking about.

Another issue is kind of related to what I said about early intervention. Do we know enough medically, technology-wise to be able to project that someone's going to have a program? Can we do some early intervention, some of the Social Security demos that are starting now are looking at those issues. Do we do some kind of early intervention and then have a different benefit base? How do we try and figure this all out? SSA has started to act on some of these demos. Some of them have been going on for a little bit longer, some of them are brand new.

I get concerned when David says that 10 years is when something might happen. That's far too long though it's very logical. But it doesn't send a sense of let's fix it now through me anyway.

The board had a January 2001 study also called Charting the Future of SSA's programs and it raised questions as to whether the programs were really well aligned with the ADA. We then had another study a couple of years ago that led to a forum and the study was the definition of disabilities so I think you can see where the board is trying to go. We concluded that we needed to face up to the contradictions in the existing program, many of which David has pointed out already. We had a forum a little over a year ago, April '04. We had some outstanding participants, but was the discussion really what are we looking at? What are the features of a consistent national disability benefits and support system? And although I think the participants agreed that we are not there yet, there was not one thing that everybody agreed on. It's America. We are getting there.

But one thing that we did agree on was that the process for determining eligibility for the disability benefits needs to be altered and so that we don't have these kinds of disincentives to seek either rehab or retraining, and we don't overwhelm the system. Many of those disincentives do overwhelm, the incentives to engage in a competitive way. So where is the role of SSA in all of that? How do the standard stovepipes within government play that role? How do we get there? I don't think we have figured that out yet, but we are looking at the demonstration projects

that SSA is beginning on time-limited benefits. There's been a lot of conversation about that over town in the last couple of years. Medical coverage for treatment and medication and maybe some kind of accelerated access to benefits and private health insurance. The whole conversation about cash versus support, not just personal support, but support in terms of insurance or meds or whatever. How do we get that built into this?

Our project for this year, which I expect will take at least a year, is that we are trying to look at reconciling national disability policies and programs and we'll be starting a public hearing on Monday in Dallas and we'll be talking to a variety of folks, mostly on the academic side, to see what people are thinking, whether they are satisfied. I can't imagine that -- but satisfied with the current disability federal situation. And try and figure out if there's something we can come to, a conclusion and consensus about the definition and what needs to be in that eligibility and disability benefits and services. And if we could ideally come up with some kind of model of a system that looks like what we would want to create, I personally believe we should figure out what you really want regardless of constraints and then try to figure out how you're going to get there. That, for example, we are really starting with a blank slate and what really could work and then we figure out the dollars, the ability to make it work, the roles of different parts of government, the roles of the private sector, and the roles of individuals. This could be hopefully a program or an idea that's built on the assumption that the most impaired individuals would retain some capacity for productive self-support.

So we are trying to figure out does that mean a work with support? What does that all mean? How do we get there? And how is it going to be different? We have been thinking about trying to look at how do you facilitate the strengthening and the maintenance of that individual's ability to be self-sufficient?

On the other hand, that's kind of a, what should we say, a social goal. Is that the role of a cash paying agency or of the government -- some government somewhere? So, how do you integrate the issues and the desires to make a better program and where should that be done?

How do you come up with these lack of disincentives and more incentives for individuals and is it really a question of do we need incentives or do we fix the program for everybody? It wouldn't be that we're talking about incentives and disincentives for so long. If we could build up a system that is consistent with the ADA, obviously, and ask ourselves a lot of questions and hope that you all will participate as the years goes by.

What's the feasibility of establishing something that's all or nothing? How do we differentiate between those who would automatically be found eligible for income supports and the other applicants? What kind of criteria should we consider in terms of entry into the system? Should we change the criteria that we have now? What are the core services that people really want/need? Income supports?

Incentive issues? Et cetera, and I feel strongly also about some kind of evaluation of what you can do in the workforce as opposed to just the observation and the kind of people telling you can't do something.

So how do we use functional capacity testing, functional capacity assessment? What are the needs in our new workforce in the future? We cannot have the same kind of workforce and how do we put that together and utilize the incredible capacities of all of our population?

So I leave you with those questions and I'm sure Andy will be able to figure them all out. Thank you.

[Applause].

Andy Imparato:

Thank you, Dorcas. I want to thank you and Dave both for putting a lot of provocative ideas and questions on the table and we're going to have plenty of time for Q&A. We have got a lot of thoughtful people in the audience who I'm sure are going to have some thoughts in terms of how to approach answering those questions.

Our next speaker is Marty Ford who is the Director of Legal Advocacy for the ARC and UCP Disability Collaboration. Marty has over 20 years of experience in federal public policy affecting people with disabilities. She's currently the Vice Chair of the Consortium of Citizens with Disabilities and serves as a cochair of CCD's task force on Social Security and Long-Term Services and Supports. So please join me in welcoming Marty Ford.

[Applause].

Marty Ford:

Thank you. I'm going to touch on a number of issues that have been touched on before and just add maybe a slightly different perspective in some cases. But I want to start with a definition of disability. And this is the definition in the Social Security Act and it applies to both SSI and to the Title II programs that impact people with disabilities.

The first part of it is the requirement that the person has the inability to engage in any substantial activity and the second part is by a reasonable medical and physical and mental impairment of substantial duration and that's defined as being expected to result in death or be expected to last for a period of less than 12 months.

I just put it out there because everything else stems from that, but it's the source and it seems to be the magnet for a lot of complaints and I'm not sure that the definition itself is necessarily the problem. For instance, the substantial gainful

activity issue -- if SGA were defined differently in the regulations, we might think about the whole definition of disability very differently.

Right now for people with disabilities it's \$830 a month. Let's suppose it was \$2,000 a month. Does that change the nature of how you think about the definition of disability? So I'm not sure if the definition is the problem. The definition is looking to see that there's a legitimate impairment that is the cause of the issue. But it may be that it's how we look at the definition and how it's been not implemented that needs to be really discussed and that's where most of my comments will go.

While the definition of disability has not changed in Social Security, the rules around it have changed. I have heard a lot of criticism that it's an old definition; it's caught up with the real world. Well, in fact the changes that have occurred have been in the programs that flow from that definition.

So the definition hasn't changed, but the programs in the system have changed. Congress has been back to this issue over and over and over again. I'm not saying that I think that the programs are perfect by any means, because we are up there all the time recommending changes, but I don't think it's fair to say that the definition hasn't taken account of what's going on in the world. I think in fact the programs have attempted to do that -- some to a better extent than others perhaps.

Yes, there are people who are in Social Security and SSI who are working. As you know, the folks in the Social Security system have limited opportunities to work because of the role that SGA plays in that program, versus those who are in the SSI program. The cash cliff is entitled to a very serious problem. The disability community has for a long time felt that in the SSI program we have seen some better policy choices in terms of making work pay. David refers to the SSI 1-for-2 dollar asset as a tax and I think it's an interesting way to look at it. But the way I have also looked at it, and many people that I know do, is that you are always better off working in SSI than not working. You will always have a higher monthly income if you are working than not working. And so it's just a different way of looking at the program.

Another aspect of this is looking at it for people who work despite a severe disability that is potentially lifelong. For many people that I'm thinking about, we are talking about lifelong impairments and the people who work are working despite a severe lifelong impairment. So the concepts of support systems around them that both David and Dorcas have talked about I think is very important.

In December 2004, there were over 320,000 SSI beneficiaries who were working and that works out to be 5.6% of the caseload. Alan Jensen, who is here in the audience, caught me before we started and indicated that if you take out the people who are over 56 and the children, that you are talking more like 7% of the

population and perhaps, 8% Alan tells me, and perhaps he's got some additional information about that, which would be very interesting I think during Q&A.

The ages of people in the Social Security 1619 Program span the entire age range of people who are in the adult disability program and it's interesting that the majority of working SSI beneficiaries have a mental impairment -- they are diagnosed with a mental impairment. And that's true for those who use Section 1619a and b also. Two thirds of 1619a participants and 3/5 of the 1619b disability have either mental retardation or another mental impairment.

There are other support programs that have been built around the SSI program. The Medicaid Buy-In is an important one that is used for people who are working but who are not eligible for Section 1619b. I think these are often people with low earnings who are in the Title II program who need the supports of Medicaid, and these kinds of programs exist in about half of the states.

Many of you know this inside and out, but the programs are very problematic when you are a person who has dual eligibility for both SSI and Title II. It's very confusing to receive both benefits and have different program rules for what happens when you work. It would be much simpler to look at one set of rules. In fact the disability community and advocacy have been working for many years trying to get a 1-for-2 offset for Title II that would reflect the SSI approach so that people would have a consistent approach to their work if they are on both programs. It is a real problem. The cost estimates have always sort of stopped this and I think that the demonstrations that SSA is conducting and have already started conducting will go a long ways towards helping give us good information for the future on this.

Another health related issue for the Title II population is the Medicare waiting period. That is a very difficult time period for people who have to wait 29 months before they are eligible for Medicare. A recent study found that most participants suffer irrevocable deterioration before the waiting period, while many want to return to work, but they are unable to do so after that point. The vast majority of participants see Medicare's two-year waiting period as a barrier to work. And that's certainly something that we would like to see eliminated. There is a bill on Capitol Hill, Senators Bingaman and Dewine, that would eliminate the disability waiting period and phase it out over 20 years and also give the secretary an opportunity to waive the waiting period to people with life-threatening illnesses.

One huge disincentive for people in SSI and in Title II is what happens when they report their earnings and they receive overpayment notices and are put into a payment recovery process. This is a huge disincentive to work. It doesn't matter how good the support programs are. If somebody finally does get back to work and has a good job and enjoys their work and finds out months later, they come home and there is a letter waiting for them from the Social Security Administration and tells them they owe thousands of dollar, that's a serious barrier

to their continuing to work or to ever attempt it in the future if they lose that job.

And the word spreads quickly in the community. People who know others who have tried to work and have been hit with a major overpayment recognize it as a problem that they don't want to encounter and so it's a disincentive not just for the individual that it happens to, but also those who knew of the situation. SSA has known about this problem for a while. It's been identified by advocates and people with disabilities for a couple of decades now. We have had it in testimony over and over again. And SSA is in fact trying to resolve this problem. We believe it would eliminate a major disincentive.

So what do we do with all of this? How do we make the systems work better? And I think that there's likely more than one answer. We have heard some ideas here. I believe that we need some more information. A lot of it we already have.

People with disabilities have been speaking out for quite a long time of the things that are keeping them from being able to work. Sometimes the barrier is the cost estimates in Congress. But we need to learn a lot more about some of these things. Definitely fixing the overpayment issue is a must. If we can't, no matter how good the programs are -- if we can't address that overpayment issue, I'm not sure that people will continue to be able to try working.

The results of SSA's demonstration projects is also going to be very important. David has spoken of these in his discussion. There was 1-for-2 benefit offset administration that was mandated in the Social Security Protection Act and it could help to make SSI and Title II work rules more parallel particularly to those people who are more dually eligible or those people who start out in the SSI program in one set of rules and move into the program with a completely different set of rules. There is one proposal in that would suggest that we ought to try a choice option within that demonstration that would allow people to choose that offset beginning at a lower level than the SGA level. In a way that might result in the short term in slightly slower benefits for the individual, but over the long term could mean a longer attachment to security in the attachment to the program and to health benefits.

They are also testing accelerating health benefits for people -- this is clearly an issue for people when they lose their jobs and then on Title II and they are in their 29th month waiting period and many are not able to pay their coverage and therefore lose their health coverage and it's difficult to stabilize your health if you don't have health care.

That particular demo is focused on people who are H.I.V. positive and people with mood disorders and SSA will be testing that with a new health insurance product also to meet the needs of the people in the target population. There are some youth transition demonstrations that are going on that are focused on current beneficiaries as well as those who are at risk of becoming beneficiaries when they

turn 18, either because their parent's income won't be deemed to them anymore or when they become eligible as disabled adult children.

The Ticket program was mentioned. We know that that's gotten off to a bit of a rocky start in some ways but there is new proposed legislation that is out there that has the potential for improving some of the problems that have been identified and the Ticket program. And there's a lot of enthusiasm behind it and a lot of value in trying to continue to make that work. From our perspective, what is not the answer? And I'm responding to things that have been raised in sort of the public debate, and things like imposing the work requirements in the SSI program we do not believe will work.

Studies have made clear that this doesn't work for families where the child has a disability. These families are more likely to need support. We need to have the flexibility to serve them and get the credit for that and so we do not want to see that type of approach in terms of speaking about responsibility of the person with the disability or the parent in this case of the child with the disability, we have to be careful that we are not getting the unintended consequence of just kicking someone off the program without their having the continuation of support that they need.

And I return to the definition of disability. I think it's unwise to move quickly in making any changes to the definition of disability and in SSI there are lots of things to be done in the program and the implementation of the definition. We think it's really important to look at what has come up in the definition of disability debate -- how you incorporate advances of medicine and the availability of assistive technology into the definition of whether or not somebody is disabled. We have expressed serious concerns about approaching the definition this way because we are worried that it misses people who are without work and no longer have health insurance and do not have access to medical benefits or assistive technology. So if we create a definition that includes an assumption of things as they are to them, we will be causing harm and so we come at looking at these issues from a set of principles. The first thing those of you who worked on the Ticket to Work program will recognize rule number 1 is to do no harm.

Let's be very careful, move carefully and make sure that we are not, as David said, doing harm to people that we don't mean to harm. There are some people who will not be able to take advantage of work opportunities and we need to protect them in the system. We need to look carefully at every proposal as to who will be helped and to who potentially could be hurt. How do we design proposals that assist people to go to work and provide the right supports for them without harming those who won't be able to work?

We need to look at the lessons that we learned from the demonstration projects and I think there will be plenty coming out of that. And I think I have covered my main points.

Questions from the Audience

Andy Imparato:

Thank you very much, Marty. So we have got plenty of time for the Q&A part. I think what I would like to do is keep one microphone on the table and keep two microphones over here. Raise your hand if you would like to make a comment. If you could say your name and where you're from, that would be great.

Audience Member:

My question sort of comes out of the fact that if we are talking about self-sufficiency, one's capacity, one's motivation. It seems like the element that's tied to that is the basic element of the individual's decision making -- the ability to make a decision -- and that decision making is tied into their relationship with the government agency, state agency, private agency. That decision making element is what I want to ask about. How do we, one, define the scope and ability to make a decision? How do we measure that? And how do we know whether or not the government's actions or decisions are affected? Do they diminish decision making? And maybe that's a little philosophical, but I think we should lean it towards a measurement as to how do we affect an individual's capacity to make a decision and work on those decisions to be determining. And if you give me an answer, please tell me who has the teeth to make that happen.

Panelist:

I'll try to hit on a piece of that. How do we get around to finding out anyone's access to health care? The fact that if you don't have health care under Title II, doesn't mean the disability programs in Title II -- that you don't have access to health care for 29 months. You can contest that governmental decision. What that means to people is by taking away the lack of access and in fact providing health care and then see what that does in terms of whether people are able to get back into the work world sooner than those who -- well, actually very few are on Title II program now. I mean, that's part of what SSA is testing.

For me in looking at the population of the people that I represent, decision making is an issue for some people as a part of their very impairment. What capacity do they have for decision making? For making good choices that are beneficial to them over the course of a lifetime in terms of work and the kinds of supports that they need? Sometimes they may not even realize yet what they are going to need. So I think that's a huge issue. And I don't think in any way can we look at the group in one way. There are so many people, so many variables, and so many levels of capacity for decision making and for work. It gets back what Dorcas was talking about in terms of the functional capacity that has to be looked at for each individual.

Audience Member:

Someone had raised the point earlier about looking at needed skills and workplace performances, and this is something that I'm very curious about in terms of the

data that we have about what is happening in the workplace and what affect that may have on anything that we are trying to do now in public policy and in fact what we may be trying in the future.

Panelist:

What comes to my mind first is some studies that have been done very recently. I'm sure there are some academic studies, but there's also MetLife and they have been looking at the workforce and its future and its disability -- disabilities and how people are going through the workforce with disabilities and what is the impact of their work itself upon aging with disabilities and that could be an entirely different population than exactly what we have.

That's the only thing I have seen and I don't have the numbers off the top of my head. But it was based on large employers, small employers, expectations of disabilities, the kinds of disabilities and what it might lead to in terms of different impairments.

Panelist:

I have a different take on that. I have studied some -- a very difficult study in part because the work requirements are changing all the time in particular ways and just about the time that we figure them out they have changed. To my mind, the biggest issue is the fact that the work environment is changing a lot and maybe more rapidly today than it was 20 years ago or 30, 40 years ago, and the key isn't sort of figuring out keeping updated on the requirements all the time, but rather helping people with work and disabilities to adapt to new environment, so as the environment changes, that's problematic for everybody, but is often problematic for other people. So it seems to me we really need to be focusing on changing policies in a way that makes it easier for people with disabilities to adapt.

Andy Imparato:

Doris Gray has her hand up and then Alan Jensen.

Doris Gray:

Thank you. I work at a Center for Independent Living in the Virginia suburbs of Washington D.C. and at the grassroots level with regard to the issue of a 2-for-1 drop-off for SSDI, most people with disabilities, and I also have personal experience, who have been on a DI think it's important to have the trial work period. That's a very important period and the provision that allows you to continue to receive a full benefit check and work is extremely important for a variety of reasons. And so as I think policy makers consider a 2-for-1 drop off just so that it would benefit us said dual eligibles. I think it's a double-edge sword, and I don't think it should be done without continuing a trial work period. I think it's a financial issue.

The second thing I wanted to bring up is that small nonprofits in on our area, especially peer-based ones have wanted to attempt to participate in the Ticket to

Work program. But they don't have the resources to -- financial resources to do and I think that that's a grave flaw in the program. And I wonder what's going to be done about that. If you covered that earlier, I'm sorry, I was late.

Marty Ford:

This is Marty. I'll take a stab at the two parts of that. In terms of the 1-for-2 offset, that's why some of us are looking at the potential for having a voluntary program that you choose to participate in Title II. So for those people for whom it makes sense, particularly those who would be dually eligible and for whom it would make sense to have a long-term link to the Title II program, they might choose to go into the part of it that would have the 1-for-2 offset. I think if you did that though, I don't think the trial period works because it complicates it and leaves a cash cliff sitting there in the middle of the whole thing.

So -- but I think a lot of that becomes no longer a program if this is a voluntary choice that an individual makes and I happen to think that in the population of people who are members of the ARC, I think there will be a lot of people who consider that long-term link to the two a promise of being valuable enough so that's something that we would like to see tested and we won't know the answer until we see it tested. On the Ticket to Work, I understand that a lot of organizations don't think they can get enough out of it and being an employment network and the proposed rules would increase the percentage of the amount of money that an employment network would be paid overall from 40% that was written in the statute. I think the proposed rules would take it up to 67%. I'm getting a lot of nods so you get it, and that will make it more possible for organization to become employment networks. That's the goal.

Panelist:

I have one additional comment on the Ticket. I do think the rules would make it much more attractive for an organization like this. I think one change is that this period of waiting is going to be shorter, so you would be getting a higher percentage over a three year period instead of a lower period over five years.

The other thing is if they implement proposed rules, like they were supposed to do, is that a person would be able to get services from VR -- potentially have VR done by SSA and then assign it to another provider. So IRC or another small organization could potentially provide ongoing services after the initial services to get into the workforce where they provide ongoing and continued support and I think that would be attractive to quite a few organizations.

One other thing about the benefit offset demonstration -- I think SSA's intent, but you never know -- is continue with the benefits and I do know there has been some discussion about replacing or changing the trial work period in a way that would be better for the beneficiary than the trial work period currently is, which as probably most of you know has basically continued the benefits for nine months, but if you think about different ways you can use the same amount of money

to ease somebody's transition labor course, there are ways you can do that. So potentially it would be not eliminated but rather replaced with something better.

Andy Imparato:

I think Alan Jensen had his hand up.

Alan Jensen:

Just a couple of comments -- just a kind of update on the 1-for-2 benefits. There are a couple of states that are on that and I happen to be on the advisory council by phone to see where they are at and they are currently enrolling people and sending out notices to people, just to get them enrolled and they'll be divided into those who get it.

On the other question that was raised earlier as far as what decision making by people -- I didn't think I was ever going to learn information about disability after working on this for 30 years -- quite frankly I have and Marty eluded -- alluded to some information that there's incredible information on the SSI side and I think it's instructive to what's to be done on the SSDI side. Of the percentage of people on SSI that have got earnings -- the national 17.8%. But highest state percentage-wise is North Dakota, but Minnesota is more, and there you have 22.8 instead of 7.8. And in Minnesota almost 44% are mental retardation in a particular month earnings. But then you go to the state of Florida. It's 11%.

So you control for disabling condition and you have four times as many people in Minnesota with mental retardation and working on SSI than you do in another state. And I even tried to deal with it as far as well, they are older, the lower income situation but it didn't in any way deal with this. But I also know that Minnesota has, long before the benefits planning, had an extensive approach as far as the benefits plan. But also they have had an extensive approach as far as services. Now, I think that's being threatened. There's something going on as far as to cut off the rehab of Medicaid.

But I think that if we look at what is possible and ask parents for the averages as far as making people understand what their options are, giving them services both on the SSI side and on the SSDI side. And we do have a lot of people, as you said -- people want to work. And you're going to have other kinds of variables which are intangibles that deal with their informal support groups and all those kinds of things that are going to make a difference. But I think if you look at what is possible and what is shown, there are people who can work.

Andy Imparato:

Thank you, Alan. Other questions or comments from the audience? Susan?

Audience Member:

I would like to ask Dorcas Hardy to explain a little or elaborate a little on the -- you brought up the issue of time limited benefits. Is that what Marty was -- the same

thing Marty was referring to as a style program?

Dorcas Hardy:

I suppose you could put that as part of a definition, but you could also have other -- I think it's looking at the comments that have been made over the last couple of years by all of us. Should we look at this? Should we look at that, so there's not a definition of it -- it's I think more of a phrase.

Andy Imparato:

Other questions or comments? Curtis Richards?

Curtis Richards:

David and Marty. David, in your presentation you talk about the demonstration project, Social Security demonstration projects, three of which are very different and the three waivers that you thought held all promise. Can you identify? And Marty, I would appreciate your comments on this too -- the employment related elements of those demos and of the waivers that we should be paying attention to?

David Stapleton:

I have to be careful because I'm involved in working on some of this and should not expose information -- disclose information that shouldn't be disclosed. In early intervention demonstration I think is the first one that I listed and I am involved in work on that. Alan was speaking of what's going on right now which is the pilots and those are going on in four different states. The main demonstration -- which will test a better offset and probably a straight 1-for-2 from SGA that's required by the legislation, but also perhaps other accommodation where people who have volunteered to take an offset are more generous in the sense that it's 1-for-4 or 1-for-3.

But in addition by coupling the early intervention demonstration too, basically what SSA can do potentially and whether they do it or not remains to be seen -- is for people who are applying for Social Security, basically in the application process, again, voluntarily and instead put them into a new program that's oriented toward securities who work. In other words, trying to get them back into the labor force and reducing their benefits so that in the end it won't cost the program as much. Not saying it will cost the program \$0, but it's an idea that I think is entirely to address the whole concern about induced demand and 1-for-2 wasn't enacted on the legislation, but simply Congress thought it would open up the flood gates of people with disabilities for the 1-for-2. And so this is one way to stop that from happening and that's very important. -- The Mental Health Treatment Study I know lessened them, not involved it.

Some people in the audience probably know more, but it has to do with providing employment supports for beneficiaries -- I think it's DI beneficiaries with mental illness, and what's the other one I mentioned? The -- oh, the youth transgression

demonstration. These are actually demonstrations that were put forth by the states and I think there are nine of them going on now. SSA's planning to support four more. And those have not been designed yet.

I think some of the existing demonstrations aren't terribly hard in saying what the project needs to say but perhaps a few of them are. Some of the ones that SSA would like to see would definitely be in that order. I am involved with the state of Wisconsin which is designing what they call a Make Work Pay demonstration. That's kind of interesting. The basic idea there is to take people -- beneficiaries who are already working, and to let them choose to be in this program. It has to be a premium. They call it a cost share and the cost share is 15% of the earnings above some minimal disregard. And in exchange for that, they are ensured that they will keep their Social Security benefits in place and their Medicare benefits in place and housing and a number of other things. So they pay something to get this insurance, but once they pay that, they can work as much as they want basically paying 15% tax on their earnings. So you can think of it as a 1-for-6.5 offset or something.

There is a Florida -- I think it's called the Florida Freedom Initiative that involves some -- maybe somebody else can talk about this because I don't know much about it but I understand it involves some special savings account built in, which I think is a good idea and I know much less about the Vermont than you.

Andy Imparato:

Okay. Marty, did you want to respond to Curtis?

Marty Ford:

Just a second, I can't add anything to David's descriptions of those demos, but I would say that Eileen Sweeney in The Center of Budget Policy has written a paper on sort of keeping track of what these demos are doing -- a good description of each one. So if you are interested in that, you can find that on The Center on Budget and Policy's website which is cbpp.org.

Panelist:

I wanted to just throw out a question, picking up on Marty's comment about maybe the problem is not the definition and the statute, but the way people understand that definition, and I'm just wondering for door -- Marty is saying Los Angeles... -- that would not involve changing the statute that would make it clear and they are not, say Prince George's mechanic -- and the people that are applying think what they are saying is their disability prevents them from working and I'm just wondering if you all have reactions in terms of Marty's focus on the statutory language?

David Stapleton:

I mean, I agree with Marty that -- well, the statute hasn't changed for some time. In 1960 I think was the last change. There have been technical changes or

regulatory changes in the definition, but I see part of the fundamental flaw is on commissions. Part of it is -- it's a line in the sand and if you are on this side of the line, you can work. If you're not on that side of the line, you can't work. If you're on this side of the line, you're not going to get any benefits. If you're on that side -- and I think Social Security's disability termination process has been difficult to reform, based on a fundamental problem of drawing this line in the sand that doesn't exist. In fact, if it did exist, you could describe it as being wide and moving around all the time and changes with the economy, et cetera. So I think that's a fundamental problem that won't go away until we do something different legislatively.

The other comment I have about the disability termination process is that while we have made some changes, it's clear that a lot of people are allowed because they have conditions that meet the listings -- I think most of you probably know what the listings are -- equal listings that automatically qualify them, provided that they are not in fact working above SGA. If you are deaf and you're not working above SGA, then you automatically meet the medical eligible criteria.

One of my colleagues who is back here, Bob, who is doing a project with the Rochester Institute for the Deaf, matched data of their deaf graduates to Social Security data so they can see what happens to them after they graduate in terms of their earnings. Each one of the graduates who has earnings and none of them get on SSDI except for one group -- female, after being on -- working for a while, they end up being on SSDI. In some cases, not all cases, but the clear thought here is because they left the labor force and have children for a while. And it's not saying that that's a bad policy, but let's think about it. We all know deaf people who can work. Deafness itself is not something that prevents people from working if they have reasonable support, they have a college education, that's college support as an example. But in fact that's in the listings. And there are other examples that we can talk about.

But -- and I think we all know people who meet the listings but who are in fact working, and I think the alternative to doing a program that is supportive of work is to cut back on those listings. Let's no longer have deafness qualify somebody for a listing. But we know a lot of deaf people who do that -- so we don't want to do that. So unless we have some initiative that's in place to help people who have a significant disability but in fact can work at some level, you know, we're kind of stuck with what we have.

Panelist:

I think David said it all. Again, I'm trying to put this all together. How do you frame all these responsibilities to look at whether or not a new definition? (low audio) This is going to be a labor of lots of ideas -- but because there's so many other implications of that aside from the dollars.

And it just seems to me, and I am not as articulate on this as David is, but they

were just not in the right pew when they were looking at making judgments as to whether or not you need to be a beneficiary and maybe part of that or a good piece of that is functional assessment. How do we use that in all of our serious functional assessments which would be less cognitive but would certainly give us a baseline. It's one of the things that in talking to the VA that was recommended to -- before you get into a VR situation, what are your capacities? Capabilities before you get into a training situation and work hard to get to that place in the employment market. So...

Andy Imparato:

Offer Doris, did -- Doris, did you have another question or comment?

Doris Gray:

One of the things that we have been working with is that when folks apply for Social Security, what happens is that step 1 of the application determination process is whether you're working at SGA and that in itself presents a big barrier because there are people who may earn slightly over and who have significant disability expenses, like somebody with MS and they are taking Betaseron or something, and although they may get help from the pharmaceutical company, there are caps on that.

So it's not -- even though they have those significant expenses where they may not be working really in a job that is in a compet -- it's in a competitive environment, but maybe it's not really competitive because of all of the complications of their disability. When you take them through the process, the very thing they see is about SGA and you can forget it even if you take them through -- that's it. I mean, if we don't get over that barrier, then we don't even get to the definitions.

Andy Imparato:

Susan, I think Susan Daniels has a comment but I want people to react to what Doris said. Do any of the speakers want to say anything in response to Doris' comment?

Doris Gray:

What I guess I was trying to say is therein lies its first step in the perception that you can't be working and apply for disability, you know, and you can't be working and have SSDI.

Panelist:

That comment is right of course and I think it is a substantial problem. I guess -- I try to think well, how would we want to change that? And just coming back to this idea of having an option for Social Security, economic security and you could imagine a program that says this person's earnings are above SGA, but she's clearly struggling because of her medical costs and maybe some other things going on. What we would really like to do is get her income up to some target which would provide her with a reasonable standard of living and then how can we do that?

Can we give her some kind of subsidy to her earnings that actually encourages to earn more? Do we help her employment so there may be other approaches that can be taken? If you took those other approaches, which are helping somebody increase their standard of living as opposed to helping them get benefits as long as they don't work, then you can get over this problem.

David Stapleton:

I think that falls under this time limited benefit, and I was asking Marty, but I'm trying to think about the Vermont project, the Vermont demo, that has something do with health benefits up front, early intervention with regard to health, so you split the cash benefit and the support.

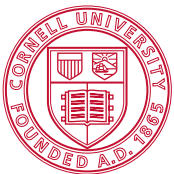
Audience Member:

Actually I would like to speak to Doris's comment and I think one of the questions -- I have two comments really. One of the questions is whether or not we think in this country we ought to have an income replacement program for people with significant vocational limitations. That means that there are a lot of people with ADA-type disabilities that would not meet that criteria and I think that's just fine. I mean, the criteria are tough under Social Security. It's not easy to get Social Security. Half of the people who come through the door are turned away every year.

Note, two million people walk through the doors and somebody's got to decide it if they get it or not. And most people, at least half of them, get told no, they don't meet the criteria. So that to me is a significant weakness to everything that happens -- and all of those programs save Social Security and SSI state admin, not federally administered so you have this overlay of what I consider a problem. You have Social Security picking up the failure of the upstream programs at a state level. So I think that has to be addressed and the other thing I want to say is that Social Security, and especially SSI, are terribly meager benefits, terribly meager. These people aren't going to Disney World with their grandchildren, I promise you that. You don't see SSI people on cruises.

So as attractive as they are to some people, they are terribly meager and the only way I can think of getting around this definitional problem and the meagerness is to have a program in the United States where people who have ADL or some significant limitations simply get compensated on the basis of that for their functional needs, so that it's not related to work at all. But I'll tell you if you are talking about a program that's expensive, we are talking serious expense then.

I think we have got the cheapest that you can get for what's going on in the world today and although it looks like a lot of money when you aggregate it, anything related to Social Security just kills you over with zeroes that follow it. But we are talking to people who are living on \$555 a month. Think about it ladies and gentlemen, this program is poverty level. It's not even food everyday.



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