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**Social Security: A Disability System
for the 21st Century - Information and
Discussion on the Report**

Speakers:

Dorcas Hardy

Social Security Advisory Board

Connie Garner

Senate HELP Committee

Kim Hildred

Social Security Subcommittee, House Ways and Means Committee

Alaine Perry

United Spinal Association

Moderator:

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Welcome

Susanne Bruyère:

Good morning. If you have a seat -- would you please take your respected seats? We want to make sure we have enough chairs for everyone. Thank you.

We'll be starting in just a moment. We're trying to get our handouts passed around. We'd like to make sure that people have the materials so that we don't have to hand them out during the event and distract you.

Annette Goodman from Cornell University is helping us get these materials out to you as are others. So if you don't have a 5 or 6-set of materials and/or the Social Security paper we'll be discussing today, would you please raise your hand so that my colleague can get those to you. Several people have requested a disk copy. I have three name-designated disk copies. If you raise your hand, I'll come around to you. CD copies. I'm sorry, CD copies. And if we don't connect now, please see me after the event and I'll make sure those get to you. We do have large print, a few copies for the individuals who have requested them and an extra set. And if you need large print, please also let us know and we'll get them to you. Thank you.

I noticed also that some of you have signed in and others did not see the sign-in in the back. Not your fault. We just couldn't catch everybody because there were so many folks coming in at the same time. So we will, during the course of the presentation, pass that around from front to back. Please, if you have not signed it do so, so that we have a record of who has attended and if there are follow-up materials, we are able to find you and get those to you. Thank you.

Okay. Are we ready to start?

Good. Ready to go. All right. Thank you for your attention and thanks for being here and joining us today. We have a banner turnout and we're really pleased about that. My name is Susanne Bruyère and I'm here from Cornell University and specifically I'm representing the Employment and Disability Institute and the project that is sponsoring this, the Rehabilitation Research and Training Center on Employment Policy for People with Disabilities. Several of my colleagues who are working on that project are with us today. David Stapleton, who is our Research Director. Dave, you want to designate yourself?

And Annette Goodman and Bonnie O'Day. Bonnie, you'll hear from later and Annette is helping us to put out materials. Who am I missing?

Is Jeannie here? And Allison, raise your hand, are you here? Not yet.

Also here is Edna Johnson, our sponsor from the National Institution on Disability

and Rehabilitation Research. This is one of a series of policy forums that are being sponsored under our Rehabilitation Research and Training Center funded by NIDRR. Edna, did you want to let people know who you are and say anything?

Edna Johnson:

Well, just basically to say that NIDRR's very much committed to employment policy and its impact on the employment outcomes for individuals with disabilities and we're very, very excited about these forums that we're noticing that the record turnout is phenomenal, so we're very excited.

Susanne Bruyère:

Good. Thank you very much, Edna.

The title of our forum today is Social Security: A Disability System for the 21st Century, and we'll specifically be discussing a report that we have now handed out and Dorcas will be giving you an overview of that. I also want to call to attention that in one of your materials is a listing of upcoming policy forums which will occur about every other month on average in the coming year and we hope we will be using this location at least for the upcoming couple so please do keep us in mind and get us into your calendar. And with that I'm going to turn this over to Bonnie O'Day who is going to give you some information and introduce our stellar list of speakers for today. Thank you, Bonnie.

Introduction

Bonnie O'Day:

Thank you very much. My name is Bonnie O'Day and I work with Cornell University Institute for Policy Research here in Washington, D.C., and as Susanne mentioned, this is one of a series of forums to explore policy alternatives to promote employment of individuals with disabilities sponsored by the RRTC on Employment for People with Disabilities at Cornell University. This forum we'll discuss the report of a Social Security Advisory Board, a disability system for the 21st century which outlines the board's vision of a disability system that is aligned with the goals of the Americans with Disabilities Act, quote, to assure quality of opportunity, full participation and economic self-sufficiency for such individuals.

Upcoming forums will explore private disability insurance innovative approaches to promote employment, which is March 9th, and one that I'm working on which is reform in the UK. They have a really interesting and innovative new program called Pathways to Employment. We're tentatively trying for May 11th, but it may take place a little bit later. And then we'll do a higher education policy for young adults with disabilities on July 13th. We did a policy forum for young adults last year on the 26th of July that was very popular and very fun and interesting. In the Fall we'll be reviewing designs and maybe even preliminary results from some of SSA's national demonstration projects.

So we're very interested in your feedback so we're going to keep the speakers relatively short and we want you to think about what questions you might have for the speakers as we're moving along.

We also have evaluation forms that I think have been distributed to you and so please fill them out and give us your feedback to make these forums even better. If you need assistance filling them out just make your needs known and someone will come and assist you.

So now on to the forum. I'll provide a few background comments and introduce the speakers.

Working age Americans with disabilities are much more likely to live in poverty than other Americans as a group because they did not share in the economic prosperity of the late 1990's. At the same time, public expenditures to support working age Americans with disabilities are growing at a rate that will be particularly difficult to sustain in the future.

Could better policies reduce poverty and improve the lives of many people with disabilities? Could a Social Security system that is more closely aligned with the goals of the Americans with Disabilities Act and other civil rights legislation enable more people to enter and remain in the workforce?

Can we find ways to enable and support those who are able to pursue work, while allowing those who cannot work to make a smooth transitions to benefits that would provide a reasonable quality of life for them?

And can we accomplish these goals while slowing the growth or maybe even reducing expenditures on disability programs? Expenditures for all disability programs have grown to about 226 billion or about 11.3% of total federal outlays in 2002. SSA has established several demonstration programs to evaluate the extent to which some of these goals can be accomplished and we'll be hearing about these in a future policy forum probably in the Fall.

The Social Security Advisory Board has also been considering these issues and has drafted a report that we'll be hearing about today, A Disability System for the 21st Century, which begins to outline a vision for a new 21st century Social Security disability system.

So we will hear from four speakers today, but as I said, we have reserved time for questions, so get your questions ready so we can call on you when the speakers are completed.

First, we'll hear from Dorcas Hardy. She was appointed by then Speaker Dennis Hastard to the Social Security Advisory Board, which is a board appointed by

Congress and the president to offer advice to the administration and Congress on Social Security matters. She was cochair along with David Podoff who was a former disability work group member that was formed to help the board think through the issues that ultimately came out in the report that we're discussing today. Before that, she served as Commissioner for Social Security from 1986 to 1989 and was recently appointed by President Bush to chair the policy committee for the 2005 White House Conference on Aging. Ms. Hardy has launched and hosted, and I didn't know this until I read her bio, Ms. Hardy has launched and hosted her own prime time weekly television program, Financing Your Future, on Financial News Network and UPI broadcasting and the Senior American, a net political program for older Americans.

We had invited to be with us today Connie Garner, who is the Policy Director for Disability and Special Populations for Senator Edward Kennedy. Connie has been waylaid with a New York Times interview with Senator Kennedy that's to take place at 10 o'clock this morning, and so we will hear Connie's comments when she arrives. I will save my introduction for then.

Our next speaker will be Kim Hildred who is the Chief Social Security Advisor for the Committee on Ways and Means, Republicans. She has worked for the committee since December of 1994. Kim served on the subcommittee on Social Security as staff director from 1997 until 2006. The subcommittee has primary jurisdiction over legislation affecting Social Security retirement and disability programs and is responsible for Congressional oversight of the Social Security Administration and of course the Ticket to Work program. Kim's background includes addiction counseling, state disability claims adjudication and various disability policy and program management positions in the Social Security Administration.

And our final speaker will be Alaine Perry who is with the United Spinal Association, which is a national organization that represents individuals with spinal cord injuries and disorders, such as spina bifida. Alaine also cochairs the Consortium for Disabilities Social Security Task Force. She spent six years with the Social Security Administration where she worked on implementation of the Ticket to Work and other policy initiatives. She was detailed to the Senate Finance Committee where she worked on Social Security, SSI, Medicaid and tax issues, and before joining the federal government, Alaine was a policy analyst for the World Disability on issues where she cochaired the NCI and played a critical role in the Ticket to Work Act and I happen to know that in her spare time, Alaine really loves horses and she and I go to a horse show every year in Virginia which is wonderful.

And so with that, I will introduce Dorcas Hardy.

Panel

Dorcas Hardy:

Thank you, Bonnie. Good morning to all of you. It's good to be back here again. This is the second time we have been talking about the report and now we have something that has been absolutely published. It's on paper here.

I would just like to say thanks to Cornell and thanks to AAPD for putting this all together. And also would like to introduce two folks, one of who is up here, Kate Horn, Deputy Director of the Social Security Advisory Board and Joe Humphries, who everyone knows, who is Executive Director of the Social Security Advisory Network. So it's good to have you all with us as well.

This is a pretty dense report. We appreciate on the board -- I'm going to talk about how we got where we are and then some of the additional comments that we might want to add to the report.

As Bonnie started talking, I thought it was useful to go back to where we started in terms of October 2003 with the Social Security Definition of Disability Report. And in that report we said that the original Social Security disability programs were designed to serve those who had no realistic expectation of a return to the workforce because of a combination of severity of disability and obtaining of near retirement. We're talking about the original report in '03 by the Board which raised the question for us of whether or not the Social Security definition of disability facilitates an appropriate approach to supporting and enabling persons with disabilities.

So after three years of what was pretty intensive conversation and study of that particular question, the board has issued the report that either you will have seen or it's in the back of the room and will see. And as Bonnie said, it outlines really a vision of a disability system for the 21st century that's in alignment with the ADA, which as I will remind you as she said, that the nation's proper goals regarding individuals with disabilities are to assure equality of opportunity -- equality of opportunity, full participation, independent living and economic self-sufficiency for such persons.

So let's look at where we are and where we came from and how we got here. In '94, the Social Security Advisory Board was established as an independent by an, and as was mentioned earlier, bipartisan board. There had been long years of study way before I got there in terms of the disability program. And as we all know, this is a difficult issue. But basically we have been trying to focus on the task of how to modernize the program, and we believe that the disability system is disjointed and uncoordinated with too many, what I call stovepipes, that are also in other programs throughout our governments, federal, state and local.

So we also came up with the issue that the current national system does not really foster economic self-sufficiency, independence, and therefore we believe it is at

odds with the ADA and that dependency on SSDI and SSI should be hopefully to the best of one's ability, an option of last resort and not the only option. Let's look at where we are in terms of the trends and what we saw...In '02, we have 2.7, almost 3% of GDP, just from the federal state program cost with regard to disability.

In the last 15 years, we have seen our working age population increase dramatically. Our SSI beneficiaries increase -- SSDI increased exponentially and our SSI recipients are also increasing significantly and our long-range SSDI cost as we look at this whole big picture is also expected to increase significantly. And these trends, as we all know, are clear and their related costs will continue to shift as the Baby Boomers enter the disability-prone years and the disability incidence rates continue to climb.

So when we look at today and '05, here is what we have got in terms of individuals who are, quote, disabled. We have the next future trends, which are only 20 years out -- if I could do my math correctly -- and I think all of us in this room can remember where we were 20 years ago. So this is not a long time away. So how do we deal with these issues? How do we figure out where we're going to go?

So we came up with this thought about future public policy, that the strength of our workforce is obviously based on one's ability to participate, not your inability to participate. So that public disability policy clearly needs to be better focused on assisting the workers that remain in the workforce or that enter the workforce.

So the -- how we looked at all this we thought was extremely important. We need to develop some new mechanisms that allow workers with limitations to remain in the workforce and how do we figure out how to get there?

So today we have SSDI and SSI programs that have, as we all in this room know, kind of an all-or-nothing definition, unable to engage in SGA due to impairment so the benefits has less than 12 months. So they are generally to have a bleak employment outlook. Efforts like Ticket focus on returning to work and are being tried, but are not necessarily as successful as we would want them to be. So the paradox it seems to me is the definition of disability, and many of you in this room have said to us, "No, it is not the definition." We could still have a conversation with that. Or is it that Social Security is targeting persons with disabilities at the wrong time?

So the board looked at all this, thought we really needed to -- the more work that we did and the more that we talked to people throughout the country, we thought that it is the timing of the return to work intervention that needs to be addressed. So in our disability system for the 21st century we thought we should be better informed by an expert panel. We put together these outstanding folks. I saw Marty here today. I saw Andy here today. Ken Mitchell from Unum. We had

some input from the private sectors as to how they deal with these issues. Dr. Alan Hineman from Chicago Rehab Institute and the good Dr. Burkhauser from Cornell. We met throughout the country. We had forums in Dallas, Kansas City and many of you participated in the Washington, D.C. forum.

We developed a vision that we think supports individuals and maximizes employment outcomes, facilitates a culture of ability to work, addressed the dynamic nature and understands and recognizes the dynamic nature of disability and its impact on work, and tries to coordinate and integrate services. And using this vision, if you will, those high priorities, we tried to create two models for the 21st century. One for adults and one for children.

Our conceptual model for adults was based on these assumptions: we do not want to make this a barrier to permanent disability benefits; timely intervention is extremely critical; and triage assessment and work scripts need to be available before applying for these federal safety net programs. So how do we do that?

We suggested that there be a front end, if you will, or as some people call it, an additional door that coordinates and integrates the return to work assessment that is needed. And there it becomes a single point of entry. We also talked of how we look at case management and how do we coordinate the services, the stovepipes, that are out there to assist the worker?

And key to this process, we think, is the availability of a multi dimensional evaluation that can be carried out through a network of public and private, medical and vocational providers.

The process that we -- that is outlined is, as I said, to develop a tailored work prescription or script that includes income maintenance, medical treatment, rehab, counseling and training. And the group and I felt particularly strongly that the administration of all this should be outside of the Social Security Administration, whose core mission is to determine eligibility for programs and to maintain benefit roles.

So here is how we outlined, in very basic form, this whole conceptual model of a triage step, a brief assessment that helps individuals decide which way to go.

They can elect to continue on the traditional, SSI, SSDI determination process or they can move to some kind of a transition program. If they choose the traditional, then the current work incentive and reinstatement rules apply. And those that enter the transition program have access to multi- dimensional assessment, the work script and case management. So if you choose the transition program you maintain your program attachment and you can reenter, you can go back and forth. You can reenter the transition program or apply for federal benefits without any kind of penalty. The rules for program reentry and exit will be flexible and will reflect the cyclical nature of many disabilities and the impact of a disability on the ability to work.

Now, on the youth side, as a second model, where we are now, and many of you are well aware of this, is less than half of the SSI youth graduate from secondary school. Over half of the youth, the older youth, 19 to 23, are not working. The post age 18 redetermination that is now in place, shows that 50% are not working in school or in a training program. And people are on and off SSI and incomes are just above the poverty levels.

So even if they're on or they're off of SSI, they still are hovering around those poverty lines, poverty levels. With that, we again looked at how do we integrate these models? How do we come up with a better system? These are broad outlines and our assessment was that we need a comprehensive assessment. We expect as a community, as a society, as individuals, that to the best of one's ability they should be expecting to be independent, self-supporting and to be included in the community. Clearly again, continued access and guidance to services and supports, and so that services and support pieces, I see Jeff here, are clearly what the National Council on Disability has also been talking about lately.

The integrated model for SSI youth would have some kind of a life progression plan and one of our concerns there was that we didn't want to repeat the whole story of what the educational system is doing with the IAP's. So we haven't come up with a way -- an exact process, but that was our thinking. -- so that there's some kind of multi-dimensional assessments that might include IAP, but it is not a copy of that.

So we have an educational support program trying to come out of that. Participation is voluntary; not linked to Special Ed and continues to receive SSI and Medicaid, and then come up with some kinds of incentives for participation. So, again, we would also suggest that administration would be external to Social Security Administration. Some of the incentives, just in terms of the program rules, would be to postpone CDR's and have expedited services for some things that are needed. So those ideas have been talked about and are included in the report.

What this does with these two possible approaches to beginning to think about a new system is we tried to incorporate policy thinking and policy challenges. We don't have all the answers, but we thought it was important to try and at least list a few. One is that we wanted to make work pay, and I think this translates to changing, if you will, policies that have provided barriers to people working, such as the benefit offset demonstration that's being done by Social Security. If that comes out well, you can clearly see there that you can include supports and services as they go up and you get back into the workforce to some extent, you have exclusions or decreases in your cash benefits. So there is a trade-off there, which is gradual and avoids the -- what do we call it? Cash cliff situation.

Access to affordable health care...We recognize this is a critical piece. We're seeing

some demonstrations in states that could possibly be models to be used by the feds. Refocusing the age 18 redetermination or the assessment criteria to include an evaluation of life skills, as well as the medical and the vocational criteria. We have also looked at the system or thought about the system-wide buy-in programs that maintain connections, again, to supports at a reasonable cost.

So a little more detail about a few of these...The making work pay is to create more effective work incentives and I talked about a few of them. But on the tax or income side, we also discussed the earned income tax credit for persons with disabilities; tax sheltered-savings instead of deductions for personal attendance and tax- sheltered savings that could be used to finance work efforts. Tax credits that could be developed for employers who invest in their employees through strong return-to-work programs. So those are some of the pieces that are outlined in more detail in the report.

The access to health care. We recognize that system change needs to address the whole issue of health insurance coverage and expand access based on some kind of cost sharing like the Medicaid Buy-In program. That's a possible, variable, if you will, or a viable alternative. And to perhaps include to encourage more state programs and programs that can be compared or that are more similar as opposed to everything being, 'A' in one state and 'B' and 'C' in two other states. Establish a lifetime certification for health coverage for beneficiaries with life-long conditions, and we also think that there has got to be some public/private partnerships to provide health coverage. The administration, SSA, is doing some things with regard to specific health insurance supports for individuals. So as these roll out I think we'll have some more data to look at that will help us with making decisions in that area.

And lastly, there was in-depth conversation about state short-term disability programs and how we could use that as an opportunity. We looked at this as perhaps pretesting some kind of concept. I'm not one who thinks that we need 20 years of demos, but there are some pieces here that we think we could partner with a select number of the five -- of the six states -- I keep getting my numbers wrong here -- six states that have short-term disability programs. How could we fit into that process and use that kind of basic design if it could work, so that you're on a short-term, state-financed or personal, employer or employee-financed program? How do you move from there, an assessment, maybe return-to-work issues before somebody is making an application for SSDI?

And that doesn't necessarily cover the whole world, but it does cover a portion that obviously has come out of the workforce for whatever reason. State would still pay their benefits and there would be some kind of wrap-around program about return to work and assessments to see if there's any better cost effectiveness, cost benefit in terms of an integrated system in that direction.

So we think that the board should continue to explore that and expect that we can come up with maybe an outline and maybe even more than that for some kind of demo that could be done in some of these states.

So lastly, just to sum this all up, we see that -- and we made this very clear -- we hope, in our report, that Social Security disability programs are vital supports that need to continue. Seems to us that there's got to be a way to revisit a definition of disability that emphasizes -- does not emphasize inability, but that emphasizes abilities of individuals.

We clearly understand, despite the absolute brilliance of everybody who participated in all of this around the country that there is no magic answer, but we also believe that we're in a new century -- a new time to fulfill the goals of the ADA and to encourage people to participate in the workforce more than we have in the past. We believe it's now time to explore alternatives, to explore just different thinking about how we address disability in the United States. So with that, I know we'll have some more questions and Bonnie hasn't raised her hand, so I think I got through in less than 19 minutes and I look forward to having a conversation with you all about it. Thank you.

[Applause].

Kim Hildred:

Good morning, everyone. I thank you for the opportunity to be here. I have to start off with a standard disclaimer that my comments are my own and do not reflect the vision of the members of the Ways and Means, so please keep that in mind as I share my views. I also want to thank the Social Security Board and staff in their remarkable efforts over the last year regarding the challenges and opportunities facing Social Security disability programs and that thanks also goes to Cornell and any of you who are out there doing educational seminars about these issues and challenges that are facing disability programs because we all know that we're not going to have movement in terms of actually changing the law unless more people are informed, understand the challenges and understand potential solutions.

Let me first -- let me also say that members of Congress are, in my experience, are extremely committed to ensuring that individuals with disabilities receive the services and essential benefits provided through Social Security. Everyone recognizes the importance of this essential safety net, particularly for those with disabilities, and I think their commitment is illustrated in the work achieved by Ways and Means and the subcommittee for the past dozen years or so.

Two important bills have been signed into law, both originating in our subcommittee. The Social Security Protection Act, which you may know, improves payee oversight, requiring the issue of a receipt for reported work activity,

improves the attorney fee process, and adds tools to fight program fraud. And perhaps more well known is the Ticket to Work and Work Incentives Improvement Act, which I know you're all very familiar with.

In addition, the subcommittee has held many hearings covering service delivery provided by the Social Security Administration and related budget issues, needed improvements in the disability determination process which ultimately resulted in the commission's improvement initiative now being implemented in the Boston region and implementation of Ticket to Work. In addition, the subcommittee has also examined some of the bigger picture questions that the Advisory Board has tackled, but certainly not in detail as they have.

These public examinations of Social Security, as I mentioned, are very important, particularly as we all know, changes must be made. I guess as I think about the disability system for the 20th century, I tend to focus on four issues, none of which will surprise you: financing, eligibility, stewardship and work incentives. For financing, I guess I'm very concerned, as are members of Congress, about the financial Status 69 of the Social Security disability program. Social Security actuaries have told us every year that this faces insolvency. That means that without change, full benefits cannot be paid in the future. Expenditures exceed revenues on a cash flow basis beginning in 2005. And in 2025, the disability trust fund balance is projected to reach zero. Then tax income is projected to cover about 82% of scheduled benefits.

The actuaries and others have talked to us about kind of the key cost drivers. Certainly there's been increases in average benefits earnings and the monthly averages, and increases in the number of beneficiaries, of course largely attributed to the progression of the Baby Boom generation, ages 50 through normal retirement age. And also of course the termination rates or exit rates for the program are low due to the younger age of beneficiaries ending the rolls and improvement mortality.

In terms of eligibility, which as I know is the question that we're getting at today, I think it's also really important for us to remember the magnitude of the Social Security Administration's case processing and responsibilities. As of May 2006, over 8.4 million disabled works and their families received over \$6 billion in monthly benefits. According to the actuaries, the DI rolls are expected to increase to 3.4 million by 2015. Over 5.2 million blind disabled individuals under age 65 received almost 3 billion in monthly SSI payments. The disability insurance and SSI application sent by the SSA to the federally funded determination services for a decision had increased 22% over the past five years, from 2.1 million in fiscal year 2000 to 2.5 million in fiscal year 2005. And of course while the disability and SSI programs accounted only for about 22% of benefit payments in 2006, these programs have consumed over 57% of the agency's administration resources due to the complexity of making a determination of disability.

The fact of the matter is no matter how you define disability, determining the criteria who meets that definition is really hard. That could be why there are 67 different statutory provisions defining disability for various disability programs in the federal government.

The concept of disability has both medical and functional components and in most cases is very much subject to the judgment of the decision maker. And because Social Security is a national program, we have to be mindful of whether any change to the definition can be administered effectively and that consistency is achieved between decision makers, assuring the public that similar cases will be handled similarly across the country.

So those are the eligibility pieces I think about. In terms of stewardship, we have to be sure that the public will have confidence in the program. Part of gaining that confidence is ensuring that confidence can be delivered effectively and clearly. The Social Security Administration is trying to get their arms around that through their new disability initiative. Part of that is also having a real process in place so that decision makers may receive feedback about the accuracy of their decisions and training, policy clarifications or needed procedural change. All of that should be identified early in the process, again, to make sure that we have got a consistent policy and process in place that our public can feel confident about. Part of that is also ensuring that opportunities for overpayments, fraud, waste, and abuse are minimized. And also part of that is ensuring that there's an adequate research agenda to constantly test ideas for program improvement, and Dorcas has mentioned that, and the Social Security Administration has really stepped up to the plate in terms of issues in terms of research lately.

Lastly, in terms of work incentives and in terms of the Advisory Board's recommendations, clearly, we all know we need to do a lot more in terms of work incentives and we need to do more at the front end. I think there's no doubt about that, as this report and many others have said. But we're also approaching 10 million and growing on the rolls today so we need to find the formula, and this report shares a number of ideas for that formula so that more people feel comfortable choosing work. And to me that's got to mean simplification, choice, education and an agency that can administer these provisions effectively. These are some real challenges.

In terms of my reactions to the report itself, I think it's a great work product. I think it gives us lots and lots of things to think about, which is wonderful in this debate. We have had hearings that have talked about kind of the role of case management on the front end, and clearly in any research or any experience that I have seen with case management, there's no question I think of the benefits of case management and really working with people individually to help them and assess their needs. Of course we also know that case management is extremely expensive. So I think generally speaking in our discussions on the Hill, members of

Congress are certainly potentially open to spending more money on the front end, but they're also going to be mindful of the overall cost and I was so pleased for Bonnie to talk about some of those fiscal impacts or in terms of slowing the growth of these programs or making sure that what's going to happen is going to be cost neutral. Because, as we are looking at this particular piece of entitlements, any of you had the chance to hear David Walker from GAO talk about the long-term fiscal challenges facing our nation, they are severe. By 2030, entitlement spending could well consume all revenues. So there are clearly changes which have to be made that we're all going to be taking a look at, we all need to take a look at the fact that we're looking at disability under this bigger umbrella of our long-term challenges, which creates some unique challenges and I think also some amazing opportunities as you have heard here.

I think in terms of some of the other things just to be mindful that one of the areas where I think Congress is ineffective -- well, I think many would argue that there are a lot of areas that Congress is ineffective, maybe one of them that I would like to share with you in my experience working there -- [laughter] -- is this whole issue of jurisdiction. The statute is divided up amongst a number of committee jurisdictions and it is very hard to get committees of jurisdiction to work together to pass comprehensive legislation. The fact that within Ways and Means that Republicans and Democrats can get to a bipartisan solution on anything is hugely a miracle. And beyond that, to do that in other committees and then have everybody work together to advance a major piece of legislation and having worked directly on the ticket, getting a bill signed into the law is nothing short of a miracle, I just have to tell you that. So particularly when I see some of the challenges facing the disability program, so much of what needs to happen there involves multiple committees of jurisdiction. So kind of the constant education of the committee staffs and the members of these issues is so extremely important, and remember that those staffs sometimes can be kind of young, sometimes turn over very rapidly, so that ongoing education is just, you know, just so terrifically important. So kind of coordinating jurisdictions I think are clearly some challenges to move forward. Not insurmountable, but nevertheless challenges. And then also even getting Congress to act in advance of a crisis.

Other issues of the day can completely consume the Congress. The Iraqi war is clearly consuming the Congress, and so it's very difficult for them to focus on other huge issues and many would argue that addressing challenges in the disability program is a major issue. That's tough to do when there are other big issues that are on the forefront. So those are some of the challenges that I think that we face. There are some great opportunities and I never underestimate the ability of an individual member of Congress to really make change, but those are some of the things that we're going to have to be thinking about as we think about all of these great suggestions and ideas.

In terms of moving forward in my view clearly, we need to and the sooner the

better.

As I highlighted briefly, any solution or any proposal that is ultimately agreed to has to be bipartisan. This cannot become a political issue. It just can't. If it does, it will never happen. I talked about the importance of the fiscal issues, solutions have got to be cost neutral. At the end of the day, that's going to be something that everybody is going to be very mindful of. Dare I say it would be lovely if the disability community could agree on some of these solutions -- [laughter] -- I know. I'm just throwing it out there.

But there is no question that, you know, no matter what the issue is, if we have got half for and half against, members of Congress, especially on something as sensitive as this and politically sensitive as this, they are going to look at me and go, "You got to be crazy." There's no way we're going to be able to ever get this done. So to the degree that the community can continue, I think this is a great opportunity to continue the dialogue, talk to each other, identify those issues where there is consensus. All so important in terms of your influencing the members of Congress and if you really want change, change is going to mean changes to the law. So if you really want to see that happen, I can't emphasize that piece enough.

And lastly, you know, let's recognize that Congress tends not to act in advance of a crisis.

So there are some challenges that we have got out there to bring this to their attention. It can be done. It's extremely important. And I think it's certainly reaching its time due to all of the great work that all of you in this room and others are doing on these critical issues that are facing people with disabilities.

So thank you.

[Applause].

Alaine Perry:

Thank you. I would like to also thank AAPD for inviting me today and particularly the board for developing this report. It's a very important issue and I appreciate all the attention the board has paid to this over the past several years. We have seen issues that are against people in the National Spinal Association and it's also something I care about personally. Bonnie mentioned that I love horses and something that she didn't mention was that I was a disability beneficiary who returned to work and that's how I got interested in this field through the process of returning to work and I probably used almost all of the SSDI work incentives, most of them at least, and got to see a lot of the problems and got intrigued in trying to improve the work programs and ended up making a career change. I initially was going to go into health care management and made a switch into disability policy and Social Security policy. Probably cost myself a lot of money over

the course of a lifetime by making that change, but it's been very satisfying.

One of the points I wanted to make today was to talk about the vast diversity in the disability rolls, so I certainly don't declare that my experience is relative of all beneficiaries. But at the same time I think there are some commonalities in particular. I was on the rolls for a chronic illness and I think some of my experiences are shared in some ways by other people with chronic illnesses. What I want to do today is start by talking about some general premises and then talk about a concept that gets mentioned a lot, which is the concept of do no harm, and then I want to look specifically at the adult model that's outlined in the SSA report and talk about some of the things that needed clarification and some of the things that we were concerned about.

A couple of disclaimers. First Bonnie mentioned that I cochaired the CCD task force and I just want to clarify that I'm speaking today solely on behalf of the United Spinal, not the entire CCD. However, they have spent an incredible amount of time looking at this report and we have submitted written input to the board on a couple of different occasions and I will be referring to those documents. Also, due to time constraints I'm going to limit this discussion to individuals who fit the Social Security definition of disability, whether they are on the rolls or not on the rolls, or at least fit it except for the fact that they are working. So if I mention people with disabilities, this is the group that I'm talking about.

Okay. General concepts... We very much support the goal of promoting employment for people with disabilities and one of the things that we really like about the report is the concept of providing additional alternatives and supports outside of the Social Security programs for people who do not need those supports and would take advantage of other advantages if they had them. At the same time, we think it's very critical to protect the existing disability programs.

The programs provide, you know, obviously I think we all agree, very important support for people who can't work or have minimal ability to work. And there's been a lot of discussion about the question of how many people are currently on the rolls or who qualifies for the rolls but can actually work and I think no one knows the answer to this question. I have heard estimates ranging from almost all to almost none. So we don't have a lot of data on this, but I think it's clear that there are a lot of people on the rolls who really do need those income supports. There is a large number of people who get on the rolls who are terminally ill who die soon after getting on the rolls and some who die after age 50.

One other thing that I hear is the distinction between disability and illness. And it's certainly not a black-and-white issue, I think it's more of a spectrum. But I think it's a useful concept in approaching this debate because there are a lot of people on the disability rolls who are just really very sick, you know, terminal cancer is an example. And I think some of the disability rights model comes more from a

disability paradigm by looking at people who might be, you know, might have an impairment that affects functioning. But they are healthy. They are not a really sick person. One person that comes to mind for me is an individual that I work with who has a spinal cord injury who is a Para Olympic athlete. This is someone who is bursting with energy but has a disability and needs to work. And someone like that is in a very different situation versus someone who really feels bad a lot of the time due to pain or fatigue and that can be an individual with MS or cancer or another physical ailment. So I think that's something important to keep in mind when we discuss this.

Another issue is whether this is in line with the ADA. This is one area where I have to disagree with the board. Our organization was very involved in the development of the ADA. It went back to when we were Eastern Paralyzed Veterans which was before my time. But the ADA is something that's very close to our hearts and we really disagree that the Social Security definition is not consistent with the principles of the ADA. And I just want to quote a letter that was received and signed by a number of disability organizations. And the letter stated the goal of the employment provisions of the ADA is to ensure that people who are able to work will have fair opportunities to work by discrimination on the basis of disability. The Social Security programs were created to provide basic income and access to health care for those who cannot work or who has worked in the past and it's very limited. The Social Security disability programs make it possible for the people with the most severe programs to make a self-directed independent life with economic security. Their circumstances would be far worse without these vital programs.

So now I want to talk a little bit now about the concept of do no harm. I think we all agree that we don't want to do any harm. That's not something that's really in debate. But at CCD we decided to take a closer look at that and look at exactly what does it mean to do no harm with regard to the Social Security disability programs? And we came up with four principles that are not a CCD-wide position, but it was something that the Social Security Task Force submitted in a letter to the board which was signed by a number of disability OS. The four principles. The first is there should be no changes to the Social Security statutory definition of disability. I think the definition of disability is appropriate for a program that provides income replacement. It provides income for people that are unable to work. Participation -- second principle, participation in work or activities to prepare for the work should be voluntary. And this is very important.

You know, we know that there are people who are currently on the rolls who have some work capacity. But one principle that I think is really important is that the individual themselves needs to be the person who determines when they're ready for that and the extent to which they are able to do that. There is no assessor who can tell, for example, how much pain someone has, how much fatigue someone has, how much participating in a particular work activity takes

out of this person. And so I worked very much with Brian McDonald, some of you know, when we were working on the Ticket to Work bill and one thing that Brian used to say over and over is the beneficiary has to determine when they are work ready and I think that's an important concept. Some people take a long time to go back to work. I myself took almost 10 years and to try to rush that process in any way or to put people into work activities that they are not ready for can be very counterproductive, damaging to someone's health and damaging to them to get back to work in the future. And going along with that, eligibility for cash benefits should not be subject to time limits for the same reason. The person needs to do things in their own time when they are going to go back to work. And finally any new programs to promote employment should not be coupled with cutbacks for existing Title 2 and programs, i.e. eligibility programs should not be narrowed.

So I want to talk now a little bit about the adult model on the board, and the adult model on the board report and how it fits for these concepts of do no harm. One of the things we liked a lot was, as I mentioned, the idea of making additional supports available outside of the DI and SSI programs and in particular a couple of supports that are particularly important are access to health care, the need to go on cash benefit and broader access to short-term disability benefits which are now only available in only a few states.

We tried to reproduce this as well as we could. This is the board's chart up there. I apologize for any small areas on that. And what the chart shows is that the individual would go into a triage assessment and then would go into either a transition program, a work support program or go into the traditional SSDI and SSI program. One of the things we found unclear in this report was to what extent this assessment and triage and the decision to go into the work support programs or the traditional programs would be a completely voluntary decision. I heard when Dorcas was talking earlier, she was referring to the individual making a choice into which program to go into. We think that's extremely important in this process and did not feel that was made clear in the report, so that might be something to look at.

Also one question that arose is if this is completely voluntary and if indeed the SSDI and SSI programs are unchanged and so the person still has the opportunity to go into the traditional SSDI and SSI programs that they choose to do that, why is there a need for a change in the definition of disability? So this is the confusion we had and go to the next slide. So I took the liberty of revamping the model a little bit. And what I were to do if it were my model is take off the triage assessment. Next slide, please. Rework it something like this. The top box under the revised model would be informed consumer choice and what we would want to see is to have a two-model system where there was an opportunity to go into the traditional SSDI program, SSDI or SSI program for those who need that or there's an opportunity to go into an alternative work support program for people who feel like they can get back to work sooner if they have the right supports, if they maybe just need health

care, short-term cash benefits, some type of rehab benefit.

And then under this model both programs would provide information about the other programs and also one of the things I added under the SSDI model is that the traditional program model, in other words, that information would be provided about this alternative work support program and information would also be provided about existing work incentives in SSDI and SSI. This is something that I know the Social Security Administration has been working on, but it's still far from adequate and I can say from my own experience, I was on benefits probably for about four years before I knew about 1619A and B and I think I was probably one of the more educated, informed, you know, people on the rolls. But, you know, it never trickled down to me and that was the early '90's, so hopefully things have improved then. But there is still the need to get information out there. So informed consumer choice, why is this important?

Again, it's important that people not be pressured into participating in a work program that's not good for them. We hear a lot about early intervention. I think early intervention is great, fabulous, if it means getting information to people early about alternative supports. If it means any type of pressure of getting them into work, then it can be a problem.

And, again, this harkens back to disability, that there are people for who early intervention maybe inappropriate. Other people maybe need some time -- you know, I talked last night to an individual who has MS who was able to return to work after being on DI and he talked about the fact that for the first year or so after he got on benefits, he was just really sick and it took him about a year to get his medical treatments together to figure out what type of medication worked well for him, to get himself stabilized, to get some rest. After then, he was able to go back, get some retraining and go back to work and it took him maybe two years. But had there been pressure on him to try to work, that could have been a set back for him. And one of the things he said to me was the bottom line is once I knew that I had financial security, that I wasn't going to be on the streets, that I wasn't going to be sleeping in my car, then I could start to focus on the next step. So I think that's really critically important.

Some of the other concerns I have about some kind of assessment triage process that isn't directly consumer directed is we already know how difficult it is to do disability determination. If there is some kind of triage or an assessor is trying to judge who is in the worse condition, whether they have to go on full benefits, who is in a condition that he can go into a work support program or who doesn't need anything or isn't eligible for any of these supports, what I fear would happen is that the people who have disabilities that are more difficult to determine are going to be the ones who end up being put into that work support program and I don't know if there's any data or any studies that have been done that can give us any information about the correlation between how actually work-impaired a

person is and how easy it is to determine an impairment, but I would suspect that the correlation is not that great and there are people who are quite impaired who don't have impairments that are very objectively determinable. And again, people who have a lot of fatigue, people who have a lot of pain, these are symptoms that can be extremely work disabling but are not easy to determine a disability, determine a process. So if you have some type of triage for putting people into categories, are you people today who are going into J level or today going to step 4 and 5 in the disability process going to be people who get put into a work program?

So I think that's a real concern. So a couple of things that we would recommend, we liked a lot of the recommendations as I mentioned. -- First I want to say I'm not going to go through an exhaustive list of recommendations for changes to the disability programs or initiatives to promote employment. That would just take too long. But I'll give some of the highlights. In terms of changes within the disability programs, the first is to improve administration of existing work incentive programs and policies. SSA has made some progress in this area, but there is still a lot more needed. I referred earlier to the need for better information and supports. This is something that when we worked on the Ticket to Work legislation, we were very concerned about getting information to beneficiaries, getting accurate information to beneficiaries. Getting accurate information to beneficiaries and getting beneficiaries to feel a sense of trust in the information they are getting in that they are not going to end up in a got-you situation where they thought they were doing the right thing and are now getting in trouble. The Ticket to Work situation included a number of provisions to address outreach and support. The BPAO's which are now the WIPA program. The ESR's which turned into the Awics which are information -- people within the SSA agency whose job it is to help give information to beneficiaries about the work incentives, but I think partly due to administrative funding problems, I think that the programs have not been funded nearly as well as they need to be, so a lot more needs to be in there.

And I just want to make a little side, that one of the things that I have heard in the context of not so much the board report, but the whole broader discussion about this issue is that our return to work policies have failed and therefore we need to go off into a more radical direction -- a few minutes?

Okay. And I have some concerns about this statement for a few reasons. One, I don't think any of us know if we had ideal policies how many people would be going back to work from the disability rolls so it's kind of hard to say that our policies have failed when we don't even know what success would be. We don't even have a measure for that. But second many of the recommendations that we have had for work incentive changes have never been enacted. Some of the important ones are: elimination of the Medicare two-year waiting period, the one-for-two offset and other things have been enacted primarily to expense, so they haven't been given a chance to succeed, so we can't say they have failed. And

third, the work incentives do need a lot of improvements. And the Ticket to Work was just passed seven years ago which is still new and in Social Security years it's still a short time. So I think it's too new to say it's been a failure and the legislation even acknowledged, and Kim is very aware of this, that the Ticket program itself is going to need some trial and error and it was written into the legislative language that this commissioner should tinker with it and make some adjustments as it goes along. So that's a little aside.

Other recommendations such as process improvement and such as reduction of overpayments, Kim mentioned this and underlying this is the importance of adequate administrative funding for the Social Security Administration, something we have been pushing for at the United Spinal. Another thing is reduce fear. The need for continued attachment or easy reentry into the program. The need for health care and including very importantly PAS after return to work. Protections for beneficiaries fears around continuing disability reviews. And all of these provisions were addressed to some extent in the Ticket to Work legislation but I think there's still more that needs to be done. And then, again, access to accurate information, which also helps alleviate fears.

One more slide. And then just a couple of external changes, and I could mention many. I'm just going to mention two that came to mind. One is as the board has recommended improved access to health care without needing to access cash benefits and then another that I think is very important and particularly for some of our means, which is people with MS, making the workplace more disability friendly by things like having a more flexible employment policy and the Cornell and AAPD did an excellent forum a few months ago on the issue of flexibility employment and the importance of that for many groups of people. So that's all I have. I'll be happy to answer any questions you have. Thank you.

[Applause].

Questions from the Audience

Bonnie O'Day:

Well, these were very fine, thought-provoking and thank you very much, panel concise presentations. So we still have almost 45 minutes for questions and discussion and I know that there will be a lot of questions this topic has generated for you, and a lot of interest among folks. So do we have a roving mic?

Susanne Bruyère:

Yes, we do and is somebody ready to pass the mic around?

Bonnie O'Day:

All right. Well, do we have any questions from the audience?

Female Audience Member:

I just have a logistical one. Can we have copies of just the talks today?

Susanne Bruyère:

You certainly can. If you would like them, I'm happy to e-mail them to you. Are you speaking specifically of the power point presentations?

Female Audience Member:

Yes. No, just the power point presentations.

Susanne Bruyère:

The transcription will be on our website. So what we can do is when it's up there, we can send all of you, if you put your e-mail on this list, we can certainly send you the link to the transcript if that would be helpful.

Female Audience Member:

Thank you.

Bonnie O'Day:

All right. Are there other questions? Okay. Thank you.

Jim Markathy:

Good morning. I'm Jim Markathy with The National Federation of the Blind and before I came here, I did a lot of benefits planning-type stuff prior to and I'm somewhat following the ticket and I still have some Social Security access for blind people under the confederation and they call me for national support and I guess one of the things that worried me and I think a few people have talked about it, is I agree with Alaine's comment with the triage issue. But in the report it mentions a little bit that we recognized our instruction problems but we're not really going to talk about that now. It goes on to talk about this proposal, which is an interesting, courageous proposal. I don't think the disability programs can work unless the structural problems are ultimately really fundamentally addressed. And I guess I appreciated Ms. Hildred's comments, you know, to the extent they have been outlined for them, but about the work incentive programs, but, you know, we make things -- every time we tinker with this, we make them more complex instead of less. Now we have expedited reinstatement, great condition. But now how are we going to counsel people, or should you reapply or seek expedited reinstatement. It just gets that much more complex and, you know, I figure the same thing is going to happen to the two-for-one offset. My experience with beneficiaries is I don't think that they necessarily like the SSI model. They like the fact that they don't fall off a cliff. But they don't like the fact that they have an \$18 underpayment this year, a \$23 overpayment this year and who knows the next few months down the line. How can we maintain this but decrease the complexity? I think that's the bottom line.

Bonnie O'Day:

Thank you very much. We are trying to address the feedback problem. And I don't think it's coming from a microphone. It sounds like it's coming from someplace over there. I don't know what that is. Dorcas, would you like to go first?

Dorcas Hardy:

I'm open to answers that you guys have. I do not have a perfect wish list of -- I am certainly open to ideas. The board is open to ideas that you all might have.

(Feedback noise, very loud)

I guess my concern is that we need to come up with and we need to talk about structure. I don't do the claims very well. I have never done that and I'm not sure I can ever get through it. I always said to Social Security staff that I could never be a claims representative. But the issues that you address seems to me that the board needs ideas from you all, whether they decide to agree or disagree or go forward with that. Structural details, I think, are dependent upon whether or not they are administrative or whether they're statutory. So ideas are welcomed, but I think we have got to have a positive focus on change...(Noise gone)...And I want you all to be thinking about changes. Alaine and I may not decide that we both have the same list of changes, but at least we're all looking at those kinds of changes. You cannot be afraid of change. And I appreciate the do no harm and that's certainly where the board is coming from. But we need to have, I think, some bigger picture of this program as we move forward. So that's not a direct answer to your question. I don't have all the structural details in my head about the ticket or anything else. But I think we have got to come up with some bigger ideas.

Kim Hildred:

I guess I would like to say a couple of things. One is I think there's been some really good progress in the agency. I know we're never going to be happy. But, I mean, the fact that Joann Barnhard has devoted much of her commissionership to the disability program I think is an amazing achievement. What's been done with the disability service improvement I think is good. I think there have been some real solid, positive steps on the Ticket to Work implementation. I know Sue Switter is here. She and her staff worked very, very hard day in and day out to make that program work better. We know we're waiting for a regulation that I think is going to have some good steps as well. So we clearly need to keep the pressure on and continue to push the agency to do even more.

But I think there's good news. I think the disability program like I said is really being paid attention to. And I think that's all good. It's not perfect. It never will be. But I think it's good. It's much better. From a statutory perspective, again, some changes have occurred. The ticket was clearly one. It's not perfect either. You'll have to help me in terms of what you might mean in terms of structural kinds of changes and I do disagree with Dorcas, if we're talking about regulatory

interagency procedures, those of you who paid attention to the hearings, we paid a lot of attention to disability programs and I think that's why we like to unfortunately create fires and get people to pay attention and run and fix things. But sometimes that works so we are very interested to hear your idea for change that the agency can make on its own. I think that's terrific.

In terms of statutory, we addressed the whole two-for-one issue. We spent hours and hours and days and weeks on the two-for-one issue and that's why you have got a demo that's looking at that. You have to look at Congress -- you can't look at it in a vacuum. When there are going to be cost changes and the cost fears for two-for-one for Title 2 were huge at the time. Everyone disagreed with the estimators, but nevertheless they were huge. So we felt that if we didn't demo, maybe the costs aren't going to be so huge and that could be an issue that we could take on eventually. You know, that Medicare eligibility piece, members every year introduce legislation to repeal the two-year waiting period, to repeal the reduce for Medicare, repeal or reduce the waiting period for benefits. Members are very mindful of those kinds of things. You know, they don't make sense to you. They don't make sense to the members and then I say, well, sir, ma'am, there happens to be this little billion plus whatever cost, ooh, gee, then, you know, that's -- that creates some other challenges. So, I mean, I think we continue to look at it and we need your suggestions and advice. The simplification point that you made, sir, I cannot agree with you more than anybody in the universe. I mean, I don't even know how people with disabilities navigate this stuff. I can't even explain it to members half the time. So clearly more needs to be, absolutely more needs to be done and we continue to push the agency in that regard too to make some of this stuff simpler and easier for folks to get their arms around.

Susanne Bruyère:

Thank you. Alaine, would you like to speak to that?

Alaine Perry:

Yes, particularly speak to the issue about this. When we talked about the Ticket to Work legislation, Pat Beaty here being one of them and Bonnie, one of our principles was to simplify the work incentives and that one ended up getting dropped fairly quickly as we moved into the process because we realized that we really couldn't and one of the things that I have learned working on drafting legislation and drafting regulations is you have three choices. You can make things simple and liberal or you can make them extremely simple or strict and affordable or you can try to find some way in making them beneficial and affordable and keeping the cost down and doing them by making things complicated. What we ended up doing while working on the ticket bill was decide we're going to give up simplicity and try to address that by getting as many informational supports in place for beneficiaries as we could throughout outside programs which are not the Wipas and the insight advisors who are now the Awics.

Bonnie O'Day:

Thank you. Other questions from the audience?

Dorcas Hardy:

Bonnie, let me just add...We are hearing very good things about the Boston regional rollout and the quick decision making seems to be going very well. The other pieces that the commissioner committed to are trying to get -- if you all saw the brown paper that went around the room, about what now, four, five years ago, about the time that it took to get through disability adjudication, I suspect that all of her vision will be successful and it looks like it's working quite well. There are some initiatives and whatever, but things are really doing very well and the DDS's are really doing a good job as well.

Bonnie O'Day:

Thank you. Other audience questions?

Dave Stapleton:

Thank you, Bonnie. This is Dave Stapleton. I was very impressed by the board's report and I like this idea for a triage unit or for an informed choice unit up front. There we go. Sorry.

So I like this idea of this unit up front helping people make choices about the best for them and getting that to work. The biggest issue I see in getting this done is needing agency cooperation and talking about rolls that are currently served by SSA, helping the Veterans Administration, maybe others, and I don't see how to get from there to where we are now. Do we need to have a cabinet-level agency, a new cabinet-level agency to do this and supervise as Dorcas said, 11% of the current federal outlays for what we spend if we're looking at people with disabilities?

Dorcas Hardy:

I'm the optimist, Dr. Stapleton, and I think that we should be able to do this in a coordinated fashion and that's why we started I guess to shy away from all the other federal agencies and have gone with the idea that if we could develop some kind of federal, state, private partnership on these -- in these six states or a few of them and see how that works, it seems to me that would provide some leverage because you would be pushing people at the state level and therefore the local levels to work together. And often things bubble up better than they come from the feds telling the states how to do their programs.

So that seemed to us to be the way that we could come out with the quickest, I guess, answer to some of these questions. I mean, we may come out with a bad idea and we may come out with a good idea. So as for my personal opinion, I think we probably got too many cabinet departments already.

[Laughter]

And to get the VA to work with the rehabilitation employment group over at the Veterans Administration, the VBA will need to talk to the health side, so for them it's almost unheard of. I just think that will take us more time and more grief and more active persons pushing the rock up...

Bonnie O'Day:

I have a question for Alaine Perry and my question is this: I liked a lot of things about your model and coming from independent living and am familiar with and endorse the concept of consumer choice. However, our society is full of misconceptions and negatives and it's my experience that when a person first experiences disability, they feel that their life is over and the research shows that oftentimes a person who is in the workforce who begins to experience disability makes several tries at work before they eventually go on benefits. And so my concern is that equipped with these negative experiences as well as the negative attitudes of friends, family and others in the general public that the person who newly experiences disability will think that benefits is their only option. And even if presented with the option to go to work, may still think that that's impossible. Oftentimes for people to go to work, it really takes a lot of work, a lot of seeing other people with disabilities who function at work with their similar disability, training, counseling, assistive technology and all that sort of thing before they can even adequately make the decision. And so I'm wondering if you can speak to that issue in your model.

Alaine Perry:

I agree with what you said. For one thing, I think there's such -- again, this issue of diversity. This is going to look different depending on the type of disability the person has, depending on the age of onset and how that experience plays out for them. So it's a little bit hard to generalize across disabilities. But I think, you know, the alternative to informed choice is what?

You know, if the individual is not making the choice, then someone else is making the choice for them. And again, I'm talking about a subset of people who fit the definition of a disability. So we are assuming a significant impairment.

Bonnie O'Day:

I guess my question is in your model, how would you -- and I did notice that it did say informed choice, so how would you inform that choice before the assessment happens, the assessment of ability to work happens?

Alaine Perry:

I think the assessment could be part of the process of informing the person, but first of all, I think the assessment should be voluntary to undergo that. And second that the results of the assessment should be information that the individual can

then take to make their own decisions. So it shouldn't be a determination that places them into one path or not. But that it's informational for them.

Bonnie O'Day:

Thank you. And I understand that Connie Garner is on her way up. So we'll break from the questions and hear from her as soon as she gets here.

Karen Lee:

Hi. My name is Karen Lee and I'm actually a practitioner who supports people with disabilities in employment and helps folks to get off of SSI and SSDI using the benefits. I'm also here today representing NASH and I have to say that in my experience that I know a number of people who have had assessments that have developed disabilities and I have never once seen an assessment that says they can work. And so I really fear your model for people who have significant needs and cognitive disabilities and developmental disabilities because I never saw anybody who could work. So I would hate to have the opportunity to work or the presumption of being able to work mitigated by an assessor who in the past has not thought that folks could work. So I'm concerned about the assessment step and the triage step. I'm also concerned about who it is that does assessment and triage.

Bonnie O'Day:

Thank you. Dorcas, if you would like to respond briefly. I understand that Connie Garner is here. So we would like to hear from her too.

Dorcas Hardy:

Let me just say that this is a work in progress. So I may have some thoughts about that personally. But the board or the advisory group that we put together did not address that specifically in terms of the who. There are various places where that could occur. It could be in the physician sector. It could be OC-med. But we have -- the important piece was not just information to the person, but an assessment that would be much broader and would be comprehensive and how we get to that point is a question in our minds as well.

Alaine Perry:

If I could just make a quick comment. I think your concern is very similar to the concerns that I was raising and I was focused more on the danger of the assessor saying that a person could work when they felt that they couldn't but the flip side of that is certainly a concern as well.

Bonnie O'Day:

Okay. Thank you. Now, I would like to introduce Connie Garner. Connie Garner is Policy Director for Disability and Special Populations for Senator Edward Kennedy on the Committee on Health, Education, Labor and Pensions, which is called the HELP committee. Currently, she develops interagency help policy for the HELP

committee and she consults for the Senate caucus on disability, mental health, and domestic H.I.V. issues. She was one of the lead democratic people for the Chip Legislation in 1997, the lead democratic staff person for the Ticket to Work act of 1999, the idea reauthorization and the New Family Opportunity Act of 2006, which is a bill to allow states to offer a Medicaid Buy-In to middle income families for their significantly disabled child. Prior to joining Senator Kennedy in 1996, she was a Senior Policy Analyst in the Office of the Assistant Secretary for Special Education and rehabilitation at the United States Department of Education. Connie?

Panel

Connie Garner:

Thank you for having us here today. I'm sorry I'm a little late. And I am going to try to talk the best I can. I just finished a relatively long interview with one of the major newspapers. One of the major pieces that I would like to highlight today in terms of needs for people with disabilities and also the aging community who have functional challenges as a part of living -- I did take the time, however, to read as much as I could get through of the report that came out, let me be honest with that. And it brought to mind, at least for me, and I have been with Senator Kennedy now for 13 years and as you heard, prior to that, a little bit with Bush 1 administration and a lot with the Clinton administration. So I have kind of had a lot experience with that. But the most important thing is my nursing career, which I'm still keeping up with, the neonatal practice, so my malpractice insurance doesn't go up too high. And my seven kids, one of whom does have a disability and is now really at the crossroad, which is a great frame of reference learning-wise now.

But she's at the crossroad now of a living idea for the rest of her life. And so she is now sitting with five eligibility/entitlements that we are arguing about on a weekly basis at the school in terms of getting people to agree to put whatever the aggregate of all these eligibilities and entitlements are on the middle of the table, at which case I will throw the ticket in at that point, and seeing if we can develop some kind of a model that is really based on her strengths and where she would probably do best as opposed to what vendors we have contracts with. And that has become a very interesting scenario and it's been a lot of fun for us because we have focused a lot in the last year with Senator Enzi's staff in the Senate on this whole issue of employment with people with disabilities and that's really where it starts. I would argue that it starts really a lot before that. But that's really where it starts.

So this has been fun to quite frankly watch people who don't even know each other much the less the programs in their state and then people who have variations on the theme. And what it raised for me, that experience is continuing to raise for me as well as some of the questions as raised in your report about how we think about disability as a whole and the word disability, I'm beginning

to think its, its own problem because the word disability smacks somebody out of the ordinary who doesn't have abilities beyond work. It's not just work. But disability may have the definition of meaning I don't have the ability to be on that soccer team, I don't have the ability to be on this classroom and I don't have the ability to have housing to take care of myself. So I'm beginning that this whole word that we have really smacks us of not having capability and that maybe is where things are beginning to break down from a societal point of view. And I heard someone say the other day and I think they were right to say, is why that we in this country have to re create everything based on an issue like disability that really should be considered a variation of a part of living. Everybody's going to age and get functional limitations, no matter who they are. Everybody is a subject and has 24-hour open enrollment to the disability community. So really if people I guess would think about this as part of living, then it really argues for the issue of universal design in whatever we do. Instead of pulling it out, re creating the system, putting it back in.

I was saying to some folks that I was talking to the other day, I guarantee we're going to see this happen when No Child Left Behind comes up for reauthorization the next time. I am certain that if it comes up the next time and if we leave the idea out here for alignment, not integrated into that process, those kids -- that system would be a third rail to the education system from this point forward because even now when I hear this conversation about it and I say anything even to my staff in our office as well as others, I say, well, you know, we have got this thing coming up now, we have got one schoolhouse, one schoolhouse roof and you in this audience need to care about this because these are the people that need to get employment and jobs or sit and watch TV over the long haul, so it's not about whether it's 21 or up. And they say to me, you know, why are we talking about that, they have got this thing over here called IDEO, so IDEA, which over the years has provided a way for kids to get the support they need to benefit from that 6-hour day in school and be part of a system that they were not even part of, they were in the basement, is now almost in some senses going to work against itself from an integration point of view because we have this thing over here.

So you don't really need to be talked about in the larger system. So it reminded me of all these when I heard a gentleman on NPR on another issue talk about how we go along creating separateness when we don't need to. Argue for universal design systems instead of accommodation for what may be an issue for everybody, or certainly a risk for everyone if they are not there now. So in thinking about that and thinking about what your concerns are that you have identified here across a life continuum, what we need in order for people to be part of their community, successful and be gainfully employed and get the right kind of education, own a house and even be able to die by their own wishes, you know, there are different systems that need to be able to be looked at. As far as our agenda over in the help committee and in the Senate, because I work with the help committee, but I also consult in the Democratic Caucus on Disability Issues as a whole and we're having a

big kind of briefing in the next couple of days on disability, on both what the issues for the disability community are, but disability as a whole and then also what the community itself is like because it is a very unique community in terms of having things. But where we are with our agenda is to kind of look at three different areas, two in particular that are very important. One is this issue of rights. Rights of people who are not treated fairly in the country and there are several different places in the area of disability, programming and laws, where we have seen the issue of rights eroded over the past few years. Senator Harkin feels very strongly about restoring the ADA and so does Senator Kennedy to where it was intended to be in a very bipartisan circumstance, under George Bush 1 back in 1990. And we have seen that change over the course of the time since 1990. So the question is why are we letting that happen, number one?

Next. And number two, and there may be real questions as to why and what needs to be looked at. And number two, how do we get it back so that it really meets the intent of what the legislators on both sides of the aisle say was important to protecting the rights of people who have to fight for their rights all the time? The second thing is when we did Special Education a couple of years ago we were very fortunate that it wasn't a blood bath, which it usually is and it took three years to get that legislation done. But there was never a blood bath and nobody ever left that negotiation, whether it was a parent or whether it was a teacher or whether it was a child feeling like they had to defend who they were or argue for their validity and that's not what happened in 1997. And so in that sense, I think we came to the middle ground, you know, assuming everyone has similar perspectives. But over the interpretation of that law, there are some places in the procedural safeguard section that really have tied the hands of parents in particular of being able to get what they need in order to fairly argue for their children. And so there is a package of two or three pieces there that need to be better clarified in terms of the intent of the Congress and the intent of the Congress was always there. And that for the sake of children and families who have the right to an arguable platform as I see it. That's what this is about. This isn't giving somebody a right. Those pieces are the rights piece that we are going to be talking about.

So there is a whole issue of, you know, restoring and clarifying what the rights are of people to an arguable platform and that's really what we are asking for, to be brought to be as equal as everyone else. We're not asking for anything higher.

The second area that we will be spending a lot of time in is this area of long-term services and supports. What does it take, with the policy being as objective being as it is, what does it take to allow people to be accountable for who they are and to plan for their future of where they are going to be without having to get poor and without having to get significantly disabled or functionally impaired in order to get what they need, and this goes back to the original premise that I'm sure Kim may have talked about that we may have thought about with Ticket to Work. You know, that was a very large bill and she's very right, went through lots of

committees. No one expected that to be perfect and to work perfect coming out of the gate and now is the time to retrospectively say, "Where do we go?" We felt like health care, that three-cornered piece of legislation, was very important and people need to know and until the insurance industry says, okay, we are going to take the risk and insure people, that means that their usage is up.

I can tell you as a nurse practitioner that there are people who have systemic asthma that follows them all the way through their whole life that costs a whole lot more money than someone who comes along with Down Syndrome. Plenty of people show up in the doctor's office a whole lot less than kids who have asthma but there is this rating that goes on and if you have got the rating, you must be, without looking at what the usage data is and that's what we are trying to find out to impact health care issues from a universal design point of view. So that bill took a lot of work and needs some revamping, but one of the underlying principles of it was in this country we have a reverse incentive that says you always have to be poor and have always got to be significant before you get what you need. So people gravitate that way. Whether it's using up all their grandmother's money which has to be paid for in the nursing home or whether it's for my child and whether I legitimately saved for her. So what am I going to do, put it under a mattress? These six kids are entitled to a life, and because she has a disability, you know, as a result of viral encephalitis, nobody is going to insure her. So you're caught between being a responsible individual in this country and doing what they taught you in Civics 101 and trying to take care of your family.

That is the hugest whole that I see right now in disability policy, not allowing families and people who have other people with this to be able to save for the long-haul. We say you need to be accountable, but we're not going to give you an inch three steps away to be able to play out that accountability and that's a very big issue that we are going to look at again in this Congress and we're going full steam ahead to try to do that without allowing people to be gaming the system. We have tied the hands, I can tell you for families, of 6.5 million families coming out of the gate. They have no way to do anything for their kids when they get older other than say my god, fill out that Social Security form and hope you get that check and that health care and the rest we're going to hide under the mattress and that's kind of a paradigm, no matter what your philosophical roots are, that is a bizarre paradigm to have in this country so we're going to work bipartisan to see how we can address that in a way that works for everybody but people at the end of the day will have some vehicle to be more effective parents, more effective for the other members that have disabilities in their family.

On the issue of community services and supports...We have a bill and we are going to be -- it is one of Senator Kennedy's top three priorities along with minimum wage, Iraq, all the other things you hear him mention. This has been identified as one of his priorities and the issue in this bill is to have some endorsement, more than anything, of a national model so that you have the largest risk pool

out there to be able to help people with an air, food and water benefit when they have a functional kind of an impairment, whether it's a person under 65 with a disability, whether it's a person older than 65 without having to ring them all the time and say we're going to help you, but only again if you have only got assets and resources so that all you can do is go to the giant. And so that's really the framework that we are trying to form here on this piece of legislation. We introduced it last year. It's called Class Act. We have a 150 groups supporting it right now. We have elderly groups, unions, provider groups, disability groups and we do work with the insurance groups as well. But it's really the theme that we are trying to get out here. This bill will never look like when it started out. But it's like the ticket. The theme. How do you get the federal government to work so that the two can provide a system that can work for everyone. Not that the poor are the sick people and my people are the wealthy people that have money for health care.

When you stand back, we have an awful lot of employment programs for people with disabilities. We have RSA, Voc Rehab, we have the Ticket, we have PAS. At some point, people are going to stand back and say, how many programs do you need for people with disabilities, particularly with the outcomes that we see?

So we are now taking a look, not at one, but across the entire continuum of programs to see what it is that's caused us to need so many, and secondly what do we need to do to make it so that they work? One thing we're going to have is a hearing in our committee. But that panel should be all employers. I want to hear the employers say Why don't you hire them? Why? and to tell the truth about what the reason is and they are going to say things that we don't want to hear. They are going to say I need a 1.1 productive guy in my group or I can't pay my overhead. We can train out here all the you want, but if somebody's not going to hire you, you haven't done the other half it and so we're going to think about how you get more input program, is it an apprenticeship program, what does it take?

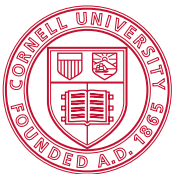
So those are the issues that we are looking at now in the next Congress and to hopefully move the disability community forward in what their needs are and what their thoughts are overtime. And thank you, and sorry I was late.

[Applause].

Questions from the Audience

Bonnie O'Day:

All right. We have about five minutes left by my watch and so we'll find out if there are any additional questions for the audience and if you want to address questions to Connie, that would be great since she hasn't been able to respond to any questions so far. And if not, you can address questions to the rest of the panel.



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