THE NATIONAL INSTITUTE OF DISABILITY AND REHABILITATION RESEARCH

IN PARTNERSHIP WITH

THE NATIONAL ACADEMY OF SOCIAL INSURANCE

PRESENT A WORKSHOP ON

PATHWAYS TO ECONOMIC SECURITY FOR PEOPLE WITH DISABILITIES: SOCIAL INSURANCE, ASSET DEVELOPMENT AND SUPPORTED EMPLOYMENT-- TRANSLATING RESEARCH INTO POLICY AND PRACTICE

Wednesday October 15th 2008

The workshop convened at 9:00 a.m. in the Equality Center at the offices of the Human Rights Campaign, 1640 Rhode Island Avenue, NW, Washington, DC.

11:30-12:20

PANEL 3: Open Discussion and Knowledge Translation

> If we were to adopt the evidence-informed policies presented in Parts 1 and 2, what strategies are needed to put the policy into practice? What are the opportunities and barriers?

- **Marty Ford**, Moderator, Director of Legal Advocacy for The Arc and UCP Disability Policy Collaboration.

- **Susan Daniels**, Consultant at Daniels & Associates.

- **Michael Morris,** Director of the National Disability Institute of the National Cooperative Bank Development Corporation in Washington, D.C

PANEL 3: Open Discussion and Knowledge Translation

Marty Ford, Moderator; **Susan Daniels and Michael Morris, Discussants**

Ms. Ford: The questions that have been put forward for this part of the session are: If we were to adopt the evidence-informed policies presented in the first two parts of this morning, what strategies are needed to put the policies into practice and what are the opportunities and barriers.

I took a whole ton of notes this morning, like everybody else did, and noticed a lot of interesting trends that are going through the comments.

One thing I just wanted to point out before I turn it over to the speakers here is that we talk about the risk of poverty, which I think was a really important point, and the term means-tested has been used a lot this morning, and one thing that I wanted to mention, means testing usually is associated in Social Security, the SSI program, in Title 16, but I think that you have to also look at the role of the substantial gainful activity level in determining ongoing disability for somebody entitled to is, essentially and practically speaking, another means test.

So when we're talking about means testing in this sense, I think you have to look at both the programs. But that's just one of my observations.

We're going to have two people help start us off. Most of this session is designed to be interactive with the entire audience and the people who have already presented.

First we have Susan Daniels, who is a consultant at Daniels and Associates. Many of you know her; from 1998 to 2000 Susan was the Deputy Commissioner for Disability and Income Security Programs at the Social Security Administration. She received a PhD from the University of Maryland. Then following Susan we will have Michael Morris, who is the director of the National Disability Institute and the CEO of the Burton Blatt Institute at Syracuse University.

Ms. Daniels: Well, thanks for asking me. I always have opinions. But I would like to add just a few comments to this, and then talk a little bit about the movement from policy to practice.

First of all, after 30 years in this field, I know I look very good for 82, but I have been 32 years in this field. It's really hard to accept that we have so few evidence-based practices. It's just -- it's incredible.

What are called "best practices" I call good hunches made by dedicated people, and we seem to skate along with those in our field forever without anybody calling attention to it. So I'm kind of chagrined about that, and I think all of us in the field of disability and rehabilitation and social insurance and whatever ought to be kind of concerned about that.

Number two, I'm going to answer David Wittenburg's question about how policy is made. David, you're too young to know. That's my answer.

(Laughter.)

Regarding fragmentation, in the area of disability policy, at least at the Federal level, one of the things that I learned from my friends at NASI is that the fragmentation in policy mirrors the Congressional fragmentation in jurisdiction. So whereas we might want to point the finger at the executive branch for this craziness that we have--a patchwork of uncoordinated policy, I think we can bring along our colleagues on the Hill for at least contributing their part.

And that was true, and we noticed that immensely, in dealing with the Ticket to Work legislation. Oh my god was that difficult. Marty can tell you more about that end of it than I can. But I'll tell you, that was really, really difficult, because everybody and their grandmother had their hand in the piece. That's the reason some of it doesn't make any sense.

So any time you go from an idea to practice and you have to go through the political process, it's never going to turn out the way you think. So, you just hold your nose and swallow and move on and do the best you can.

I want to say two things about that, and this deals with the fragmentation issue, David, and that is disability is not a word that's really going to be helpful here in this discussion. I find it's getting more and more so that we talk about "disability policy" or "disability programs." We don't know anything when we say that. We might as well just blah blah blah and blah blah blah, because it doesn't describe anything.

Disability is getting everybody all kind of crazy, so I'm going to put again my principle on the table: The word "disability" should refer to the political unity under the

ADA. That is the broadest possible definition of people who are protected in their civil rights under the Americans with Disabilities Act.

After that, we have to say people with disabilities who have certain characteristics: who are poor, or who are working, who are near poor, or who have cognitive deficits, or people who have mental illness-- something. You have to describe what we're talking about because past the notion of equality and political unity on this issue, the word disability for programmatic reasons is absolutely useless. I'm really hoping that we'll start to define the segments that we're talking about.

Because the strategies, I think, for improving the lives of people who have extreme work deficits or who are unemployed and disabled, are not the same as the strategies for people who are employed and disabled. The people are different, so we've got to talk about a lot of different strategies.

Okay, that's the first thing.

The second thing is even though I'm sitting right here next to Marty -- he's going to bop me on the head when I say this -- I'm going to say that I don't know why anybody would want two for one in the DI program. I never understood it when it got in the legislation, I don't understand it now, because we have never ever had a two for one in the SSI program.   Social Security has never administered a two-for-one program anywhere, anytime.

So why everybody likes it so much, I don't know. It boggles the mind. It's never been tried. And yet everybody is so blown out by it and they want it, and this demo that's finally going to give results in year, what, 2013 or something, so wowee, so what if people

like it. It doesn't make any difference. It's not administrable. It's not doable. It's not doable

unless you have monthly accounting--monthly accounting practices that are conducted by

banks, et cetera, are possible--but not a yearly or quarterly accounting system.

But Social Security currently has, if we just take the fog down a little bit and look

at what really happens, what really happens is we have a formula, Social Security has a

formula for figuring overpayments, not a two-for-one offset.

What really happens is that in almost all the work incentives, people get overpaid

and scared. That's what happens. So we don't really have any work incentives to start with.

What we have is a conglomeration of hopeful ideas that people had, and an

implementation that leads to scary situations for people with disabilities. I don't know how

else to put it. I don't know how my friends in the Work Incentive Planning and Assistance

programs (WIPAs) do it--keep a straight face--and my good friend John Kregel over there

training them. But that's the truth. That's what really happens.

And so why we continue to go down this path of pretending that we have work

incentives and that some of them are great and we want to even expand them kind of -- I'm

not there. Somebody is going to have to really take me out in the hall and give me a good

talking-to in order to convince me otherwise. Because I think all of us would say we know

things have happened.

Maybe it's because those kinds of transactions that occur in work incentives aren't

something this kind of agency can do. Maybe it's not; I don't know. Maybe if there were

billions and billions of dollars and more people to administer the program, it could be done.

But I don't think under the current circumstances it's in our lifetime.

So I would like us to start talking about "so now what." So that's true, now what? What do we do now?

And now I'm going to get bopped in the head because my time is up. Thank you.

Ms. Ford: No, just a very simple answer. People are looking for a way to not have that cliff, to allow their benefits to go down when their income goes up, and to go back up when their income goes down. That's the simple answer. But I don't want to take any more time. I'm turning it over.

Mr. Morris: Susan, this is not an intent to answer any of your questions --

Ms. Daniels: How about the one for David? Is he old enough to know about our policies?

Mr. Morris: We'll leave that to others to figure out. I guess what I wanted to do was first take an optimistic view of the context in which we find ourselves in terms of moving from policy into practice.

I would echo what Susan said, we have far too few evidence-based practices that have found their way into policy, so I will tend to avoid that for the purposes of my remarks and really focus on this new framework which I am very optimistic about.

I'm optimistic because of about seven different points:

Number one is that we finally are moving from a discussion around employment to a discussion around the focused topic of this morning, which is pathways to economic security. So the outcome for people with disabilities that we woefully haven't achieved, which is work, stops far short of where we really need to look in terms of outcomes, which

is about economic stability, it's about economic security in terms of really looking at advancing self-sufficiency.

Number two is moving beyond disability service delivery, as has been discussed this morning, to a different focus on breaking down the silos across public agencies, but even more exciting is the public-private partnerships that are now occurring.

Number three is moving beyond disability-specific policy to generic policy. And the context we all find ourselves in today, everything is about economics, whether we understand what a credit-backed derivative is or short selling or what's going on in the financial markets today is what we have now is a new contest that must engage policymakers, must engage regulators in terms of where do people with disabilities fit in. And that's a new context that actually can be used in a positive way.

Number four is, as has been mentioned, moving beyond social insurance and income maintenance to a new calculation which has to look at how to make work pay, and it's an alignment of public policy that we have yet to achieve, and it goes beyond disability-specific policy into other areas in terms of where is the interface between tax and social policy.

Number five, it's moving beyond research timetables to real time opportunities. If the opportunity for change in tax policy is here today, we can't wait for seven years to find out what will be the results of longitudinal research that is way in the future. By then we will have changed tax and social policy six times. So we have to get into a very different context.

Number six is moving beyond, as was mentioned, specific accommodations in terms of Jon Sanford's presentation and also in John Kregel's presentation to looking at universal design. But we have then a new set of issues which has to focus on where does that fit in terms of the ADA and reasonable accommodation, what do we do in terms of changing tax policy that actually incentivizes universal design rather than looks at people in frustration around reasonable accommodation.

And number seven is really understanding this context we find ourselves in today with CMS moving forward with self-directed budgets and individuals picking their own providers to the world of work incentives and Ticket to Work Program and the new types of partnerships outside the traditional corridors of the vocational rehabilitation program. How do we really sustain this notion and operationalize this notion of choice and flexibility that goes outside our traditional context of where people with disabilities go for assistance, and what they look to in terms of their aspirations to advance their economic self-sufficiency.

I see that as a new context and a new framework that has to impact our research, has to impact our ability to change policy, and has to move us in terms of policy to practice.

Where are opportunities? Well, they're obviously about 21 days away, I think--the opportunity of a new administration. Whether one thinks about mavericks or change agents, whether one thinks about lipstick or language, whether one thinks about donkeys or elephants, we can all ride the horse of change, and the change that we have here is change that will focus, like this country has never looked at before, in terms of priorities in spending money, in terms of the way our tax code creates barriers and facilitates people in terms of asset ownership and asset accumulation.

It is an opportunity, as some candidates say, it's the most important one we will face in our lifetime. And it is certainly that in terms of people with disabilities.

Second, we have to examine and reexamine, take this opportunity of a new administration to reexamine performance measures and measurement.

Our individual systems, whether they are the traditional disability systems or we look more generically at the workforce development system, Medicaid, Social Security, we have to have a different set of measures and measurement that focuses on this notion of advancing economic security, economic strength for all Americans, for all people in this country, not leaving behind people with disabilities.

Third, I think, as has been mentioned several times, there's the opportunity of the new populations. More than ever before we will be dealing for years to come with disabled veterans and their families, and this is an opportunity to refocus, "what does it mean," as Susan said, "to have a disability in this country, whether newly acquired or a disability since birth."

And perhaps finally we will get a context that understands that disability is a natural part of the human experience. But what does it mean in terms of our policies that we don't leave behind other classes and other parts of the disability population.

And then my last two points would be in terms of the point of discovery and moving policy to practice is we are here in Washington, we tend to focus at a Federal level, but the real innovation in movement of policy to practice most frequently takes place on the ground, at a state level, in state capitals, and even more so on the ground in local

communities. We can't forget that context in terms of where we truly will see innovation and where we support policy moving to practice.

And then finally, knowledge translation. My pet peeve, wherever I go and have a Federal audience, is if we're really serious about knowledge translation, then we've got to change the rating criteria for all of us who live and breathe on Federal grants. Knowledge translation, knowledge dissemination, technical assistance, whatever you want to call it, is increasingly a smaller percentage of the points out of a hundred.

Is it any wonder that as a result when we get into gatherings like this, people are talking about, "I don't really know how to do knowledge translation."

Well, if you believe in it, then you back it up in terms of the review criteria. And as important as the research is, one should have to be giving greater weight and value to activities proposed in terms of knowledge translation.

And last, related to knowledge translation, again, a point that I think we can't dismiss, we live in a world where knowledge transfer and knowledge translation is all around us. We live in a world of the Internet. We live in a world where social networks are formed and reformed every day. People are communicating via podcast and text messages. They're finding new ways to actually build alliances, build new affinities, and change thinking and behavior. We're not doing that either in a consistent way or in a very powerful way to really translate policy to practice to benefit people with disabilities.

Thank you.

Ms. Ford: Thank you to both Susan and to Michael. They were very good challenging comments.

(Applause.)

So now it's time to open this up to everybody -- people who have already had a chance to speak, folks in the audience who want to ask questions or comment or challenge any of the folks here.

Ms. Kornblau: My name is Barbara Kornblau, I am with Special Olympics. And I have a concern when we speak about universal design and we're talking about sensory, that it not be limited to auditory and visual people, meaning people who can see. Because people with intellectual disabilities and people with head trauma, post-traumatic stress disorder, and especially people on the autism spectrum, also experience sensory issues. It might be the fact that the air conditioning just came on just now and that might throw them off on their work, or a light buzzing, or they need to be in a quiet environment.

I think that in looking forward and having to serve these new populations that really haven't been served, that we need to consider that. I also want to express my concern that individuals with intellectual disabilities are really underserved by VR, and that's a concern because many of them are able to work in competitive employment, they just need the same kind of supports that everybody else in the disability community has.

Mr. Sanford: Can I just respond to that? I'd just like to say that the concept of universal design is for -- is about everybody. So when you talk about not excluding a disability or a functional limitation, it takes it back to disability. Universal design shouldn't be about disability. It shouldn't be about don't forget about, you know, little Johnny, who has such-and-such functional limitation, because it's about everybody. It's about people who

have no function, people who have full function, in all of the range of skills and abilities that we have.

Ms. Kornblau: Well, I agree. Just when you put up sensory, you have auditory and visual.

Mr. Sanford: I understand. And the last slide I had, it had people with cognitive. It was the sample that we had.

Ms. Korblau: The definition of sensory is what I-

Mr. Sanford: And what I'm saying is that particular slide did not include that sample in that study. But we did include them, and that study actually wasn't about universal design, it was about workplace accommodations and assisted technology.

What we were trying to do was learn about assisted technology and accommodations to be able to inform universal design. But when we talk universal design, we talk everybody. We don't exclude. Although because we're funded by the National Institute on Disability and Rehabilitation Research, we have to focus universal design and talk about it in terms of disability, even though it applies to everyone.

Ms. Ford: Thank you. I actually have a little bit of a follow-up on the universal design. Does the notion of universal design leave room for making the individual accommodations above and beyond that for people who need it?

I believe that universal design can bring everybody up to a certain level, but there are some people who are going to need a bit extra in a different way that wouldn't be shared by other people in that particular context. So that's one of the questions that came up to me when I was hearing the discussion.

Mr.Sanford: Yes.

Ms. Ford: The answer was yes.

(Laughter.)

Ms. Ford: Who else? Other questions, comments?

Mr. Jensen: I am Allen Jensen from George Washington University, but it turns out that I'm also running something called Medicaid Infrastructure Grant here in the District of Columbia, which is a new task. I started local in 1966 and now I'm local in DC in 2008.

What I was struck by here was the argument, in effect, between Susan and Michael-- both friends. You did not agree on a lot of things in your comments, and I guess I agree more with Susan that disability is not a helpful term because you can't deal with mental illness the same way as with someone in a wheelchair, as we talked about here. And the one-to-two issue, it's very difficult to administer, and they're planning that in the pilot project we have going on in the states right now. Trying to administer it in the states is a big issue.

Now I think it is being done in the SSI programs with the help of friends, shall we say, to make it work. But I understand it -- leads to scary stuff, shall we say.

And so I think the moving to generic, one of the things that the customized employment, you know, tried to get that one-stop to deal with the disability population, I don't know you say that actually worked or not. I tried to evaluate one of those, and they just couldn't get that one-stop to do it, and I'm not sure that's even realistic when you go that way.

So here again, I think we have to deal with the individual as compared to generic. I just don't see the idea of trying to make the generic system serve this very diverse population of people with disabilities. And once we decide that's really not the way we need to go and beat our head against that wall, I think -- and that's both on the disability but also on the specific disability that Susan talked about.

There's a lot of different -- I'm involved right now in evaluating; now five years into it, the Medicaid Buy-In Program in Indiana, and the thing which I tell the data people, who are pulling the stuff out, do not mix disabilities, don't even mix years, because there are policy changes, as you talked about during those times. They changed the way Part B Medicare came in. It all changed things.

So, anyway, that's not a coherent thing, but I think that there is real differences between what Susan said and Michael said on the two things.

Ms. Reno: I would just like to inject before passing the mic on. From Nancy's perspective, I do want to remind you to be thinking about filling out your evaluations, but in particular -- in particular -- it asks on the back what topics would you like to pick up on for future seminars. And that's been going through my head as I listened to this conversation. You know, where should we go next with this? That would be very helpful to us.

Ms. Button: Thank you. I want to respond to Allen's comment and elaborate a little bit.

Having spent most of my professional life out in the real world and not, as a friend of mine says, in the belly of the beast, where I currently reside, the customized initiative was

never intended that the one-stop should solely in and of itself serve people with disabilities. That was not the intent. So if you're not finding that, it doesn't surprise me.

The intent was that the one-stop would have a door that is open to everyone, and through partnerships, through new partnerships with generic and disability-specific systems, we would be able to bring to the table resources, funding possibilities, things to leverage that were never before there. So that it's not just the responsibility of the VR or just the responsibility of any one system to provide the supports and the services that a particular individual needs.

We had, as at the beginning of any demo, dismal failures, and we had a handful of absolutely spectacular successes with a one-stop as a hub leveraging the community and the state and the Federal resources.

I want to comment on something that Michael said about not being able to wait how many years for the next round of research to come forward before we could make some of the policy changes that we need.

I would ask us to reflect back on the supported employment policy. Nobody questions how successful supported employment has been.

I was on the Hill with former Senator Weicker when it passed, the amendments to the 1986 Rehab Act, and before that, added as a line item, when there were a handful of state demos around the country that RFA funded, a handful of state demos, added as a line item with no corresponding line in the actual authorizing statute, and it kind of snuck by and nobody saw it.

So sometimes you don't wait. And there was a lot of opposition to the '86 amendments by the VR community, look what's happened over the years. And it was because, to use Susan's words, some people had some good hunches based on a handful of evidence, as opposed to the big body of evidence.

I don't know where the line is that you draw, but I know that it's hard to think about waiting another 10 years before something else comes down the pike.

Thanks.

Ms. Ford: I'm going to take an opportunity to add a little bit to the thread that Allen and Chris started, and raise a question about evidence-based practices to start with.

Because I come out of the field dealing with people with intellectual disabilities, severe cognitive impairment, I know that there are so many people who have very significant or profound multiple disabilities, including cognitive limitations, for whom their family, their circumstances, their individual strengths, their individual limits and fears and capacities, make it, I think, very difficult to imagine evidence-based, research that goes across the board able to focus in on what is really necessary for that individual. I'd be happy to be proved otherwise, but I suspect that sort of like in medicine with the word "most," most people react this way to this medication, why are you reacting differently?

The "most" does not mean all, and we have to be careful not to reach a point where if it's not evidence based, it won't be paid for. So much of what happens for the population that I'm concerned about really is very individualized and tailored. I want to throw that onto the table in this whole discussion.

Michael had a comment, and I saw one over there, and I think there's another one over there.

Mr. Morris: I guess in reaction to Allen, first, Susan and I agree on more things than you could quite imagine, in fact, probably about 99 percent of things.

I think one needs to be careful about oversimplifying a conceptual framework that incorporates generic as well as disability-specific policy as well as practices.

If we ignore the generic systems, it's like basically you're ignoring 90 percent of the way the Federal government allocates resources. If you ignore the generic system, you're basically allowing people to live by fear and frustration and disappointment, whether it's the workforce development system, whether it's a postsecondary institution of higher education, whether it's the structure of any one of our systems that ought to serve all people, all job seekers, or all people in lifelong learning.

Our real challenge -- and perhaps what is most unbelievable is for every step forward we've come in terms of a better understanding of the importance of people with disabilities being included in generic systems and whatever their supports or services are, we are still miles away from where it should be.

But to abandon that approach is to basically say that people with disabilities are more different, are more in need of their own programs, and it's the opposite of what we've learned in the Real Economic Impact Tour and working with the IRS and financial institutions, public and private agencies.

We actually have shown that people are willing to come together, people are willing to realize that attitudinal change can take place, behavioral change can take place,

and we need to do more, as I think John Kregel started us this morning, in understanding from a research perspective more about how you form public-private partnerships, how you break through the silos of different public agencies, at all levels of government, Federal, state, and local.

But one quick other thing is I think -- and really maybe the challenge to NASI -- the most fundamental change is taking place in our government today in redefining the lines in terms of responsibility and role, in terms of our economic system. It really challenges us to also think about the social contract that government has historically had that in fact for you to receive public assistance; you fundamentally have to stay poor.

The question today becomes: What is the role of government in terms of helping not just the rich get more wealthy, hold on to assets and grow assets, but what is the role of government in helping reach to the bottom of the economic ladder and really provide that hand support, that flexible support that enables an individual with or without disabilities at the lower end of the economic spectrum to be able to come up out of poverty.

There has never been a more fundamental change going on in government in my life than what's going on right now, and this kind of question has to also be taken on in terms of people at the lower end. It's not being asked on the campaign trail, it's not being asked by the questioners, and yet this is a fundamental a time to take on this challenge.

Mr. Balkus: I just wanted to follow up on a point or two, and this is one time where I think I agree with Marty Ford more than I do with Susan Daniels.

(Laughter.)

First, I think Marty's observation in terms of Substantial Gainful Activity is very appropriate. It is a means test, and for a lot of individuals, that's what they'll work to.

I recently came back from visiting one of our mental health treatment sites during one of their fidelity reviews that we do to make sure that they are following the protocols. Part of the day I was able to sit down with a number of our enrollees, and the only rule that they knew was, "I can't work over $940 a month or I'm going to lose my benefit."

These are DI workers. I'm not talking about the SSI population. I'm talking about people who have more.

Getting back to the four-state pilot, yes, we do have a four-state pilot with a benefit offset action, where we're testing the one-for-two offset. That pilot was designed for us to learn -- learn what we needed for a national demonstration, and we have learned a lot. That's why we're proceeding with automation to the fullest extent possible here, to make sure that we pay people correctly, and no, we're not doing monthly accounting for the benefit offset demonstration. We are doing an annualized earnings test for the benefit offset national demonstrations. So we get out of the business of having to do any type of dollar-for-dollar accounting per month.

We're doing it in a way that we want it to work. We want it to make a difference in terms of providing a real work incentive for people to take advantage of, to go above that $940 a month, and to get them out of poverty or near poverty.

Ms. Beedon: Do you mind introducing yourself?

Mr. Halliday: Oh, I'm John Halliday with the Institute of Community Inclusion in Boston. A couple or two points. One is about how we do things, which I think is a bit of

this debate here. Recently I received the interesting book I'll call "Nudge" a couple of guys from Yale wrote. One thing we don't do well in government is looking at the way we implement policies. It's a decision basically how you implement policy. For example, a 401(k), it's the simple study of you can opt in if you wish--a low percentage opt in. In contrast, you are automatically in but you can opt out-- and in a higher percentage are in— they don't opt out. Same way what we're talking about here in terms of how we track earnings, how we do anything else.

We tend to do it more in a protective control, in a debate of policy of limiting risk, to this side of the table, the government side, and not making it easier to participate. I guess that would be one.

The second, it boggles my mind why we don't have a policy at the national level that basically says if we're all in work incentives -- and I can't think of a Federal program that doesn't talk about incentivizing someone to work, whether it's Medicaid, whether it's HUD, whether it's Social Security, and so forth -- why there isn't a larger operating policy that says "and when we find out that your policy doesn't do that, you can change it." Because it's about work, rather than having to, you know, try and over regulate.

I mean I think classic state agency problem is with regulation -- that we over regulate. We should really be minimalists in terms of - in intent rather than in the other piece.

One other thing that I would say in our research that I find interesting when we talk about going to work and returning to work and helping people out is we learn very much at the individual level on what works, and a lot of this is talking about the individual, yet on

the institutional level we've been, particularly in the last 15 to 20 years, driving ourselves in the opposite direction, and I'll give you two -- three classic examples.

TANF and SSI. The TANF Program is set up, the data were there in Social Security -- in fact, I worked in a state where legal aid societies appealed the turndowns, to get everybody I can off TANF onto SSI, and then I stop, because under welfare reform I don't have to talk to them about going to work.

Now there's some benefit to the recipient to doing that, I agree. But here's a classic example of a policy that's driving in the other direction.

The Medicaid funding of community-based services, particularly in the intellectual disability in the DB system is doing the same thing. The research that I see, I've done, and others have shown that the amount of Federal funding has gone up within the last 15 years, and correspondingly what has gone up? It's not work services. It's nonwork services. That's what's gone up.

So we have systems that we know at the Federal level. I agree with Michael, you decentralize everything to state control in most programs now. The best the Federal government can do is set sort of a tone and assist in a larger context and give those states some sense of direction. Because, in reality, that's what's going on.

My last comment would be before coming here, I was talking with states, talking about what's going on at the grassroots level, about a director who was talking about 38 percent of his counseling positions being vacant and that they have been vacant and will continue to be vacant. Ninety percent of his support staff positions are vacant.

This is going on across the country. So to have a discussion about a system responding has to be put in that context – any state agency at this point is probably in discussions not looking for evidence-based research, their discussion is looking at survival in that context.

Ms. Hartnett: I just want to make two comments, and the first one is on the evidence-based practice, and I think that, you know, from the work that we're doing right now in the asset development, certainly there haven't been the resources to even think about developing real long-term evidence-based practices. I can't even get resources to give to my city.

So it's sort of what comes first, but more importantly is that there are on the Federal level -- HSS, and I don't know if John is still there, the gentleman whose work involved the poor finance series, but that is the work that Michael Sherraden has just published in a number of papers, and they looked a few years ago at 18 data sets, and then they narrowed it down to three data sets that are very specific. One is from University of Michigan, the Survey of Consumer Finances, which is from the Federal Reserve, and then the SIPP data, two of those don't even ask the SSI question. They don't ask anything on disability.

So, you know, even if we don't have a lot of resources, we can at least join some of these big data sets to help us understand our population, which is what everybody does.

But we don't have that advantage because we don't have the IDA, and I know a couple of years ago Michael and I did some research for NCD on long-term services and supports for the under-65 population, and OMB is actually giving us—saying-- this is what we need to do, and they have no data on people with disabilities under 65 and what the real

issues are for them in terms of services and support. So how can you do policy if we're not even funding and designing the data set so that it's there?

And I think just a second remark. It's sort of the philosophers always said that we notice differences more than we do likes. There's just something about disability that is just so very true.

But I know from our work right now, when I go to Detroit, Michigan and I hear that they have 1800 calls and they couldn't answer 500 on the free tax line because they have so many people with developmental disabilities and intellectual disabilities coming to the free tax site and bringing their case managers. You know what? That's huge. That's like -- that's the beginning of what we want to see.

And so what are they doing? They're calling us and saying we don't know how to do this, we need help, and that's why we're all working together. That's the future, because we can't afford to have our own tax sites just for disability. It's got to begin there.

Ms. Picerno: My name is Sue Picerno. I'm from the Office of Disability Employment Policy, and I was very intrigued by John Kregel's comments about the worth of having a retention person on site at businesses to help people remain at work or return to work.

One question I had, though, was Project Search was held in a major business in a huge hospital, and I'm wondering if you have a model for a small employer? Is there a way it can translate to that?

Thank you.

Mr. Kregel: One of the programs that I would refer you to is the Vermont Medicaid infrastructure grant that is working in a community, so you do have a community-wide base. It had this retention specialist, with the three largest employers in a particular community. That may be county government, it may be the hospital, and it may be one manufacturing plant, but there are ways of doing this.

We're working with Chesterfield County right now in the southern suburbs of Richmond in what they call the government complex. It's not one physical location; it's a research park area, where folks are implementing the Project Search model that way.

What struck me was one of the questions was, "what did I learn today from the other presenters." And that really changed the way that I perceived things. And there were a couple things that were said that were really intriguing to me because I believe talking about what we can do to promote retention and using generic strategies, and one of the things that John said was to talk about this difference between performing duties, performing tasks, and participating in the workplace, being integrated into the workplace.

In my mind, integration into the workplace is the same as a predictor of retention in the workplace, what I might call engagement or we just use a different paradigm, but we're really talking about the same thing.

Then when Richard talked about the mental health treatment study, it was very, very interesting to me. He said he's using the evidence-based practice. He is using the Dartmouth supportive employment model, but the interesting thing to me was these folks needed hand-holding, and that's one of the things that they talk about constantly in their model.

John and I could talk about hand-holding as a support. Is it an accommodation, or is it a customization of someone's particular job. There are different models that have a lot of commonality, but we talk about from different paradigms.

The notion of what can we do as we try wraparound services, we can also do in the area of how you support people at the beginning of employment or throughout the duration of their employment. There was a commonality of responses here, and I thought it was very interesting to bring together these multiple perspectives like this.

Mr. Wittenburg: I want to talk about good hunches and policy, because even though I'm young --

(Laughter.)

-- or at least I hope I am; my kids don't say that I am. But it feels like our disability policy has been made on good hunches, and particularly if you look at the VR system. We have numerous approaches there that people fervently believe in, and they believe in it because they provide them, they have their own incentives for providing them. So I want to be careful -- I think we should be very careful when we say we've got a good hunch and we should make that a policy.

I'll use another case study here. Susan, you talked about the quagmire of the Ticket to Work legislation, and the question that I would have for the group is the Ticket to Work legislation was a really interesting idea. As a matter of fact, it came out of a NASI document that I think Virginia held up earlier today.

But it changed, and it was really rushed into the field. I mean even though it changed so much, we wanted to make it a national demonstration or a national program.

And the question that I have is would we have done some things differently if we started small and then went bigger? And would we have saved money, and would we have done things more efficiently?

I fully agree that we need to make fundamental changes to the system, but we need to be smart in how those changes come about. Look at examples of how systems have changed, it's not a perfect example, but look at the welfare reform experience. Also, a lot of state demonstration projects, lots of things at the local level. Deb and I were talking about some of the things that the Centers for Independent Living were doing prior to this session, and I think having those sorts of demonstrations, those small-scale projects, getting evidence base, really starts to build the framework for much better policy.

The second part of my comment is I'm going to sort of agree and disagree with you on BOND, Susan. I think it's because I like the name.

Mr. Balkus: We're going to change it, by the way.

Mr. Wittenburg: The one part that I think we should be careful of is when we look at some of these demonstrations, I think we say is it a policy? Is this a policy that we can implement? I think we have to be careful to holding all the demonstrations exactly to the letter of the law. Is it a policy that we can implement?

I know GAO does this, and I know they rank SSA demos for this, but I think there are a number of interesting ideas that we could test. I'm not going to name the person, but somebody said this at an APPAM conference and here today, about the ultimate incentive, where we just say, you know what? Let's wipe out all the SSA work disincentives, use it as a treatment test.

Okay, what is the effect of having no work disincentives on the behavior of SSI and SSDI recipients? What is the behavior of having the ultimate incentive plus employment supports, customized employment supports for employment, types of things -- many of the things we're testing in the current demos. And what is the effect of those policies?

I bring that up because that's not a generalizable policy, but it's a policy that tells us something about what the work capacity is of current beneficiaries, and it tells us something about the direction that we should go in for the program. And again, this wasn't an idea that I first brought up.

Ms. Daniels: Can I have the last word?

Well, yes, I was there for that presentation, and I think that is a brilliant idea, and one that should be adopted, and let me find out the answer to that question.

In the demo, you choose a segment or group of people on Social Security disability insurance and/or SSI and you say no matter what you do, you'll continue to receive your benefits for your lifetime, whatever work earnings, whatever you do, and then see what happens to them.

I think that's great. First of all, it's simple, and second of all, we would learn something about the elasticity of this population.

Anyway, that will hardly ever happen, but that's okay. So that's one thing.

The other thing is that there was a lot preceding Ticket to Work. In fact, the entire set of SPI projects, state partnership initiatives, and some of the ideas about the venture planning came out of those SPIs. So I think there were items preceding the actual Ticket to

Work legislation. Demonstrations in the field, letting people try out new ideas, to see which ones had merit. And I like that kind of field research, letting, you know, those people with good hunches and real commitment figure out what they can do, and then see if it can be replicated.

And then on the last thing, I'm dying to hear Richard explain this yearly thing. So, Richard, when this is over, would you explain to me this yearly thing?

(Laughter.)

Ms.Reno: Okay. Well, I would just like to conclude by first of all thanking everyone for being here, and please join me in thanking each other for being here.

(Applause.)

Just a few wrap-up things. First, again, a reminder about the evaluation, and please do suggest where you think this conversation should go next, because NASI really does benefit from that.

In addition, we have some publications here that various people have brought, and you are welcome to take them away, one from Johnette about the National Disability Institute Real Economic Impact Tour, Health Benefits for the Uninsured, a few remaining copies of a NASI report on Social Security, a Mathematica report from David, and a few of our workers compensation reports. So they are here for the taking. It means we don't have to carry them away.

We look forward to seeing you at what we hope will be our next National Academy Social Insurance Forum on Disability Policy, where we hope to again collaborate

with Federal agencies and facilitate the interaction of Federal agencies. I think this has been very energizing, for me and for many of us here.

So thank you.

(Applause.)

Whereupon, the meeting was concluded.

12:20-12:30

Wrap Up and Adjourn