

**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 15<sup>th</sup> 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.

# AGENDA

## PANEL 1: Presentation of Research Findings

- **Margaret Campbell**, Moderator: Senior Scientist for Planning and Policy Support at National Institute on Disability and Rehabilitation Research (NIDRR)
- **Johnette Hartnet**, Director of Research and Strategic Partnership Development for the National Disability Institute (NDI)
- **John Kregel**, Rehabilitation and Research and Training Center on Workplace Supports and Job Retention, Virginia Commonwealth University
- **Jon Sanford**, Rehabilitation Engineering Research Center on Workplace Accommodations, Georgia Institute of Technology
- **Richard Balkus**, Acting Associate Commissioner for the Office of Program Development and Research of the Social Security Administration.

## PANEL 1: Presentation of Research Findings

### Introduction:

**Margaret Campbell, Moderator:** Good morning again. My name is Margaret Campbell, and I am the senior research scientist with NIDRR for planning and policy support, and it is my pleasure today to be the moderator for our first panel, which is going to focus on research findings. We are very fortunate today to have four distinguished researchers who will share with us their emerging findings and their insights from investigations of four different pathways to improving the economic security of people with disabilities.

We will start first with Professor John Kregel, Chair of the Department of Special Education and Disability Policy at Virginia Commonwealth University (VCU). He will focus on supported employment research.

Next we will turn to Dr. Johnette Hartnett, Director of Research with the National Disability Institute, and also a co-PI with the NIDRR-funded Asset Accumulation Project, which is in its last few months at the University of Iowa, and will be moving to Syracuse University.

The third presenter will be Jon Sanford, the co-director for the NIDRR-funded Rehabilitation Engineering Research Center on Workplace Accommodations. He will focus on his research on workplace accommodations.

And last, we go to the bigger picture, and we turn to Dr. Richard Balkus, who is the Acting Associate Commissioner for the Office of Program Development and Research, with the Social Security Administration. He will share with us emerging findings and insights from several SSA demonstration studies.

I'm going to lay out a few ground rules. All the presenters have agreed to talk no more than 15 minutes, and that will give us 20 minutes to give the researchers an opportunity to ask each other questions. I think this rarely happens, but I know we have all probably been in that place where you hear your fellow presenter saying something and you're just dying to ask a question.

So, we're going to give them an opportunity to ask each other questions about how they can leverage their findings, what's ready to be translated, what steps they're taking to

translate their research and, what's ready to be translated. If they lack for words, I have a few questions.

Then there will be opportunities in the other two segments of today's meeting for you all to ask questions.

### **Presentation of Research Finding--John Kregel**

**Mr. Kregel:** Thank you for this opportunity. I am delighted to be here representing the Virginia Commonwealth University Rehabilitation Research and Training Center (RRTC) on Workplace Supports. The work that I'm talking about represents the work of over 40 people over the past 25 years. We are finishing our 25th year as a rehabilitation research and training center. I am finishing my 25th year at Virginia Commonwealth University, and the university just gave me this nice nylon commuter bag --

(Laughter.)

in recognition of my 25 years of service. So it's great to be here.

It's also great to be with this panel, one of the rare events I've had in the last few years. We planned, we had a call, we talked about how our presentations would work together, and I am really delighted to be a part of this.

Finally, I'd like to say I'm a proud NASI member, and it's really great to have this invitation to come and participate in this event.

The RRTC on Workplace Support and Employment Retention is in its fifth year. We are compiling results from a variety of studies. Some of the studies have papers that are available on our Web site, [www.worksupport.com](http://www.worksupport.com).

The presentation I am doing today is derived from a paper, "*Organizational Factors That Facilitate Successful Job Retention of Employees with Health Impairments and Disabilities.*" It is also on our Web site.

Our conceptualization of where we've been for the past five years focuses on the notion of employment retention. It's based on a very simple paradigm. There are two sides to the problem of employment and self-sufficiency for individuals with disabilities. Not enough people get jobs, and too many people lose jobs.

A lot of our resources are dedicated to helping people get jobs. Not enough resources are directed towards helping people maintain employment for a protracted period of time.

We are engaged in three specific studies: The first one is the VCU Manpower Six-Site Clinical Trial. This was a supported employment study involving public-private partnerships between community rehabilitation providers, and vocational rehabilitation and the manpower affiliates in six major cities nationwide.

We did a randomized trial. There's a paper about that trial that shows limited results, but an overall effect that's positive in terms of employment. The results vary by site, and in the level of fidelity to the project implementation protocols.

Keep in mind; we are a rehabilitation research and training center with a \$400,000 research budget. We run a lot of different studies, and the difficulties involved in maintaining fidelity across multiple clinical sites and communities is very, very challenging. But, we have learned how to do that and are continuing this line of research in a variety of other activities that we have under way.

We do need additional validation studies for this type of public-private partnership model, and the other public-private partnership models that are coming out. For example, the work that Walgreen's is doing.

There are some parts of various studies that we can look at that are ready to be tested for the possibility of replication across multiple sites. We did organizational case studies with five employers, and I'm going to spend a little bit of time talking about that at the very end.

These were 120 structured interviews over a three-year time period focused on progressive employers with effective disability management and return-to-work programs.

Our conception of demand-side research -- and it's really been led by Jon Sanford and the other folks at Hunter College and the RRTC on employment service systems--is looking at what progressive employers are doing, to address the problem of employment retention and identifying the extent to which the public sector can derive something from these strategies, and convert them to practices that the public sector can use, either to help employees or to modify the programs that we operate.

So, we find out what the progressive employers are doing to solve their health and disability management problems, and their job retention problems. Then we ask how can we learn lessons that can be applied to the employment and employment retention of individuals with disabilities?

A third study was the collaborative survey with the Disability Management Employer Consortium that focused on current general retention practices, disability

management practices, the effect on employment retention, and their current experiences employing individuals with disabilities.

Remember, when we talk about “disability management,” and “integrated disability management wellness programs,” those all have to be justified within the corporations--within the businesses to determine, “Is it cost effective that we spend \$700,000 on this wellness program every year?” How do they go about doing that; what are the benchmarks that they set; and how can we translate some of those benchmarks into things that might be beneficial to our public programs?

The purpose of this presentation is to say where we are in terms of identifying evidence-based practices that can be rigorously tested in the future through other Federal agencies that will promote employment retention or improve employment retention of individuals with disabilities. There are very few evidence-based practices at present, and we'll talk about that in just a minute.

We also want to ask, where are the promising practices that should be tested through rigorous methodologies? Where are there projects, practices, strategies, and programs that we might raise to the level of actually running a clinical trial or test with experimental rigor?

Then, where are there innovations that should be examined as potentially promising practices?

And finally, we want to identify areas where we don't have any promising practices that we can say we should set this up as a large-scale demonstration.

I'm going to use two terms for the next few minutes, and the first one is “front-door factors.” This means the hiring behavior of employer organizations as it relates to people with disabilities, job seekers, and new employees.

We spent a lot of time, a lot of effort, and a lot of resources on how to approach employers, how to talk to employers about making accommodations or customizations that allow people to obtain employment. These are front-door factors; and there are whole sets of structures within business organizations that are involved in this process, from HR to employee benefits, to a variety of other offices that work on what we would call the front door.

There's also the “back door.” That focuses on retention behavior of employers as it relates to protecting the health and productivity of all employees, but especially to the support and accommodations of people who develop work limitations for any cause.

We have people who may have diabetes or people who may develop cancer, or people who may have cardiac problems. There's a whole structure in place to assist these individuals in returning to work. This structure comprises the ergonomics folks, the return-to-work people, the disability management people, the employee assistance programs, and whatever else it might be.

The first thing to understand from the public sector, is that current policy efforts to influence the demand-side aspect of employment for people with disabilities have been focused on the front end to the exclusion of the back end, and learning from what people do to retain their employees because they don't want to train new people. The public sector has to maintain its aging workforce. The public sector doesn't want people slipping out.



They're also hiring and finding people to fill jobs. However, hiring qualified people who can run the machines is a huge problem that business and industry face right now.

We need to be involved in both strategies. In addition to everything we're doing at the front-end to get people initially employed, we need to be involved at the back end.

From the paradigm, we can identify two problems. Not enough people get jobs, and too many people lose their jobs, and when they lose their jobs, they enter the benefits programs, and have difficulties securing employment on a long-term basis.

The other thing that we learned -- and this is just throughout our research in terms of working with manpower, working in qualitative work, and working with the Disability Management Employer Consortium-- is that in business there are two towers: There's the front-end tower and the back-end tower. There are the individuals who might help you with your accommodations as you come in, the HR side, and people who assist you once you are employed -- you are injured or acquire a disability, acquire a health condition. The two sides don't talk to each other. And it's very, very rare to have an integrated system. It's also very, very hard to define that.

So as we think about our audience for demand-side research -- and we're talking about retention as opposed to initial hiring -- we need to talk about different structures, different organizations, different vice presidents, and different officers within the overall business organization that we're involved in.

The high cost of health care, global competition, and the need for highly skilled and productive workers have forced progressive employers to increase the work that they're doing to maintain people in employment. And they're doing very, interesting, very

progressive things. I'm going to give you one example down the road that I think is valuable for us as we move towards lessons that we might learn.

Another key point that I think really affects the design of intervention programs, or the design of policies, or the design of future research is that the provision of accommodations and return-to-work services are not one-time events.

Someone doesn't have an accident, or develop cancer, or have a stroke, and then go through rehabilitation, return to work and then go on as if nothing were different.

We did individual case studies. In each of the five employers we studied we identified five folks, and we interviewed them every year for three years. In all 25 cases, their situation changed every year.

We can't think of return-to-work as a one-time event. We need to think of return-to-work as an ongoing event. An event that affects how public policy and public agencies may interface with employers in terms of developing collaborative programs that keep us engaged and keep individuals engaged for protracted periods of time.

Effective supports and accommodations are rarely provided through external sources, but rather through highly knowledgeable support staff immediately available in the work environment. That's the secret of *Project Search*, one of the programs that I'm going to recommend as a program that could go through rigorous trials. We're doing that in another one of our NIDRR-funded DRRP projects at present.

What we are finding is people working on-site all day, every day, providing support to individuals who need to retain their jobs is really the key element in what needs to be done.

There are a couple of different models to talk about, ones that are rehab-driven, and one sort of employer-driven, that I would like to discuss in just a second.

In terms of where we are, there are few evidence-based practices beyond support in employment and the work that's been done with that population of individuals with psychiatric disabilities.

There are lots of other studies that can and should be done in this area and the area of customized employment, and employer partnerships. There should be studies that can test a supported employment model with various populations, and those should be done in rigorous trials. Some of that is being done through work by other agencies.

There are promising practices all focusing on the availability of ongoing site-based supports, and there is an urgent need for demonstrations focusing on specific populations. For example, when we're talking about kids with Asperger's syndrome in postsecondary education and what happens to them and how we work with them--there are no promising practices that we can really identify. There are some populations that-- that we haven't started on, I guess is what I would say.

So, on to new research activities. There should be an efficacy study of the *Project Search* model, where individuals are immersed in 700 hours of work experience within a business such as a hospital, or a financial institution, and then are potentially hired into the business or receive services through vocational rehabilitation.

There are 60 *Project Search* sites. We run our sites around the clinical trials in the area of *Project Search* for adolescents with autism that we're just starting through our autism and vocational rehabilitation DRRP.

There are also manpower collaborative partnerships, other public-private partnerships that in my mind are ready for large-scale testing. There are some fidelity instruments that accurately and adequately measure the independent variable, the intervention that we can move on from.

There are demonstration projects that focus on public-private partnerships and other collaborative relationships, but I want to talk here about one particular type of model that we've seen in a couple of different places.

One model is Cascade Engineering in Michigan. Through their VR partnership, they have what I would call a retention specialist. This person's job is to keep all people retained in employment--this could be identifying an individual with a disability that they can do things for in terms of ongoing support, or it could be identifying people who might need accommodations, or might need specific rehabilitation services, or have other needs whatever they might be. Additionally, Cascade Engineering is concerned with everybody else who has retention problems.

There's another model that's being funded right now by the Vermont Medicaid Infrastructure Grant that is -- they're funding it with seed money for a year, and then employers are going to come in later and provide support. This is another employer-funded, after seed money from the public agency, *retention specialist*.

Why do people lose their jobs? People lose their jobs because they can't get their car fixed, they can't get a loan, and so they can't get to work, and so they lose their jobs. If they're out of a job, then things may happen to them, and they may show up in one of the public employment systems as a result.

Why do people lose their jobs? They need money for childcare or daycare or health care. They go to a payday loan; they borrow \$600 that's withdrawn out of their salary. They've got \$800 that they have spent. Their balance, their principal balance remains \$600.

The *retention specialist* can go into these kinds of situations, work through a credit union, and get help for the individual if he or she needs to find childcare or eldercare, or get a part for the car or whatever else needs to be done to enable individuals to remain in employment.

This approach is ultimately going to reduce the number of folks who contact our systems through one program or another--through the workforce system, through the rehab system, or through the Social Security program. And, it looks at new ways to make a difference in what individuals are able to do.

As we look at redesigning how we go about focusing on retention, one of the demonstration ideas that I feel very strongly about is on-site supports for individuals who have a variety of issues that affect their ability to do their job, from a health condition to a manifested disability, to family problems, to substance abuse problems. If they can be kept in employment then they do not enter our benefit systems and the other programs that are very, very expensive.

Another success of *Project Search* is the Walgreen's demonstrations. What we have seen to this point is the importance of people on-site. The secret, as we have gone through the project and done our collaborative work in the area of work experience for kids exiting schools, is the individuals who are always there, all day, every day. They are in the

hospital, in the large financial corporation, in the Chesterfield County government complex down in Richmond, so that you can't go to the elevator, you can't go to the parking lot, you can't go to lunch, you can't go to a staff meeting, you can't walk the hallways without seeing the supervisor of someone who is employed there, one of the individuals with a disability who is working there, or someone who may be a potential lead for another replacement.

On-site interventions for individuals with disabilities to maintain them in employment I think is an understudied area in terms of demonstrations.

Finally, we need to look at transitions from postsecondary education to employment, transition from secondary education to employment, and veterans exiting the Armed Forces and attempting to access public employment and benefits.

And I would also say attempting to access postsecondary education as well. We are seeing folks in our community college systems and at VCU who are being discharged with TBI or PTSD, and it has really been a challenge for them and for our disability student support services.

So, I've thrown out some ideas. I look forward to discussing these with the panel.

Thank you very much for your time this morning.

(Applause.)

### **Presentation of Research Findings--Johnette Hartnett**

**Ms. Hartnett:** Good morning. It's really a pleasure to be here. It's somewhat of an honor to represent this body of work that started five years ago. I first want to thank NASI for the invitation, and I want to thank NIDRR for the vision of introducing the priority

five years ago that was the first ever research to begin to look at asset development, asset accumulation and tax policy for people with disabilities.

It has been an incredible ride. I also want to thank Michael Morris, who is co-PI on this NIDRR funded grant and his vision over five years ago when he started the National Disability Institute, and we began a brown-bag lunch here in Washington looking at the issues of asset development. We knew that the welfare legislation of 1996 Congress introduced the Asset for Independence Act that provided states with resources to increase savings through an innovative match plan for its low income population. This program allowed people to save up to \$1000 a year for a home, continued education or self-employment. Although there was a national demonstration little was known about how and if people with disability participated in the Individual Development Accounts (IDAs).

From the welfare research we knew that 40 percent of the remaining caseloads on welfare were people with disabilities. We knew that much of the poverty policy work that began or expanded in the 1990s such as the IDAs, financial education and free tax preparation did not include outreach to customers with disabilities.

I think for many, and for those of you that are not familiar with the asset development field this is a new agenda and new thinking, and it's not just about disability. What's happening with this work is we're beginning to understand that this is about poverty; this is about our poverty population that we have really not looked at closely. Through our work over the past four years with the IRS and our outreach to free tax coalitions we have learned that over 25 percent of people accessing free tax assistance in many sites across the country report a disability or a member in their family with a disability. Historically,

disability has not been part of the mainstream economy or participated in investments, savings, and homeownership. For people on public benefits we know that their families are worried if they file a tax return (event if no obligation exists) they might lose their benefits.

In the past the business sector and financial institutions have not been given a business case for why customers with disabilities make good sense. Many think disability is a wheelchair, or is a physical disability. Most don't know the history of disability – how we had institutions well into the twenty century, no civil rights law, or that our children could not attend school.

We passed legislation in the '70s that allowed our youth to go into the mainstream classroom. There are still issues about what students are learning in the classroom, and what happens to them when they transition into the adult world. Unemployment for people with disabilities is almost double what it is for a person without a disability – and our highest high school drop out rates are young boys with disabilities.

The new asset agenda that is being led for low-income Americans is helping us in disability understand the potential of this work. Historically disability has focused on income maintenance now it is employment maybe with some income assistance as well. Part of this work is generating new conversation. Yes, people with disabilities can work; people on SSI can work; people receiving a number of benefits can work.

Disability policy is looking at individual plans to self-directed accounts for individuals who qualify for specific waivers. These are customized accounts that forward autonomy and self-determination. Other accounts such as the 529s, which are savings accounts for families with kids headed to college don't provide for families with kids not



headed to college but instead use resources for a computer or that first apartment. Currently, there are four bills in Congress on tax advantaged savings for families with members with disabilities – the first time in history Congress is considering these issues.

Parents that have children born today with lifelong disabilities want their kids to be full citizens. They are not going to face the same issues that the generations before them faced that fought for the civil and human rights of people with disabilities. They want their kids to go to school, be educated, get good jobs and be active members of their communities. And unlike the generations before them, they will expect an environment that is fully accessible.

We're finding through some of the research that there are trans generational wealth transfers that really do indicate as people grow up how they are going to be financially as adults. New research just released demonstrates that a young boy today has a 40 percent chance of having the same salary as his dad when he grows up and more likely to be in the same class.

Oliver and Shapiro's research on trans-generational wealth in the African-American community demonstrated that individuals and families that received land from the Homestead Act in the 1800s are today better off than those who did not. We know from the history of disability that, from the early 1600s on, if you lived in communities and you were a person with a disability and you received an inheritance, you were not allowed to keep it.

We have never really studied trans-generational wealth and disability but we know from the research of Shapiro and Oliver the results are pretty devastating.

The slide in front of you “who are people with disabilities” is here because many people do not understand that we are people with disabilities. Well, they're us. And if I asked every one of you in this room, you probably know somebody or you have somebody in your family. I was raised by two parents with disabilities. My dad had cerebral palsy, my mother had polio. My father was a professor for 50 years. So disability has been a part of my life.

We know from the demographics that the population with disabilities is rising. Many people don't understand, and when I go out into the funding world, the nondisability funding world, people don't understand that 22 million of our American families have a member with a disability; that of 22 million working-age people with disabilities, about 7.6 million are taxpayers and about 1.3 to 1.5 million are not filing taxes and could be missing out on over a billion dollars of the Earned Income Tax Credit.

Through our national tax work we are implementing an innovative pilot for the 2009 filing season to help Deaf participate more fully in free tax preparation. The REI Tour Deaftax will be piloted in five cities and use new video phone technology that will assist in providing real time tax preparation remotely using tax preparers in two locations who are Deaf to assist individuals calling through the video phone.

The technology we are using is the Snap!VRS phone that has a real-time interpreter on the screen when you dial. This pilot will have a Deaf tax preparer working with a Deaf client. The video technology provides tremendous opportunities for serving rural America and populations that are homebound.

We know that there have been reports to Congress. *Taxpayer Advocate* did a report two years ago on the needs of accessibility to Web sites for people with disabilities--people who are blind. They cited the IRS.gov website as not fully accessible for people who are blind and deaf. The importance of this report to Congress is that all of our Web sites whether at a federal agency or private company need to be totally accessible, and as we know, they are not.

The asset work is happening because of the non-traditional disability partners who have come to the table. For example *the National Federation of Community Development Credit Unions* - there are 230 of these faith-based credit unions who work with the poor have developed a curriculum and outreach strategies for reaching customers with disabilities. The World Institute on Disability in Oakland, California has an online newsletter – Equity – that is a clearing house for asset development articles and information; Southern New Hampshire University, Center for Economic Development and Disability have conducted the first research on the financial and tax needs of taxpayers with significant disabilities; and the Burton Blatt Institute at Syracuse University who is a research partner will host the next generation of asset research over the next three years; and, of course, the National Disability Institute that is leading the work in asset development nationally for its signature project the Real Economic Impact Tour (REI).

The focus of research we have conducted is the various opportunities for tax reform, and profiles and characteristics of taxpayers with disabilities. This is the first time ever that we actually looked at who our taxpayers with disabilities are and what they need. IRS's Stakeholder Partnerships Education and Communication, Wage and Investment

Research Division, collaborated with us at the National Disability Institute to do the first focus groups nationally that produced qualitative research on the profile and characteristics of taxpayers with disabilities. As a follow-up to this research IRS SPEC W&I Research did a national survey of taxpayers with disabilities to provide quantitative data on their preferences, habits and use of tax services and products.

IRS SPEC and NDI began outreach to taxpayers with disabilities and their families to better understand and utilize the various provisions available in 2004. The Real Economic Impact Tour (REI Tour) began in 11 cities and in 2008 was in 62 cities and in four years assisted over 151,000 taxpayers with disabilities with tax refunds of \$135. We started with 11 cities. That is our real on-the-ground work.

The REI Tour is working with all of you in this room. I have the CMS, SSA, VR, DOL OneStops, FDIC, IRS, VA, and many more public and private partners at the table. We are working with a number of veterans' organizations to help our cities providing free tax preparation to understand the needs of taxpayers who are veterans with disabilities.

Steve Mendelsohn, who is our lead tax attorney, and is blind, lives in New York City, and is a lead researcher on the NIDDR grant. Steve's work found that the tax system does not help low-income individuals with the initial formation of capital and although there are a few opportunities to accumulate assets for the Earned Income Tax Credit for someone on a public benefit the majority of tax incentives do not benefit low-income people with disabilities.

We know from our research, NDI and IRS that 51 percent of our taxpayers with disabilities make under \$20,000, compared to 33.5 percent for nondisabled taxpayers. We

know that 21 percent of taxpayers with disabilities make over \$40,000. So, we have about 80 percent of our population making under \$35,000.

Steve Mendelsohn's research also recognizes that there are certain gateway costs that people with disabilities accrue just because of their disability and an environment that is not accessible. The cost for someone with a disability to go work is higher than it is for someone without a disability.

The perennial topic we research is the removal of barriers to self-sufficiency posed by the means-tested provisions. There is little doubt that we need to develop a new model for social insurance, employment, and asset development programs to work together.

We have learned that the Earned Income Tax Credit (EITC) is important for persons with disabilities. Just to give IRS a little plug, because they've been such a wonderful partner for disability. They are the ones who said initially when we asked what they were planning to do with their publications on disability tax provisions and credit that "we don't do anything with these other than post them because nobody likes us." We said "We do" and the rest is history. We began in 11 cities four years ago, with no money, and we started going to the free tax coalitions in each city and saying, "Oh, by the way, would you expand your outreach to people with disabilities?" And of course the cities did. For 2009 we will be in 84 cities with mini-grants to 54 of those cities.

The EITC started in the Nixon Administration, and it was really designed to be a supplement to low income, minimum wage workers. And as you can see, TANF is about a \$17 billion program, food stamps about \$17 or \$18 billion, and the EITC is about a \$43

billion program. It helped over 22 million families this past year although it is estimated that about 20 percent of the EITC goes unclaimed.

I think it's really interesting -- the IRS says it's the most effective anti-poverty tool because it lifted over 5 million individuals out of poverty each year, including 2.6 million children.

In 2006, the Ford Foundation supported research to study the needs of taxpayers with disabilities in four cities. *Educating Democracy* is the name of the study. Please visit [www.reitour.org](http://www.reitour.org) for this and other reports. We surveyed about 3,100 filers walking into free tax preparation sites in New York City, Wichita, West Palm Beach, and Boston, and we also surveyed individuals who were associated with disability organizations. What we found pretty much matches the profile of the low-income population without disability, but only 30 percent of those surveyed reported having a checking account. And, the new research that's just come out from Washington University is that 20 percent of Americans do not have a transaction account -- 20 percent. The Ford Research found that 12 percent of people with disabilities had savings accounts, 24 percent had both checking and savings. Twenty-five percent reported receiving the EITC, and 57 percent said they needed special accommodations at the tax sites. None had participated in an IDA and 12 percent received SSI and nine percent were on SSDI. The average age of the taxpayer with a disability was 42, compared to 32 for a taxpayer accessing the same service without a disability. The No. 1 fear people with disabilities expressed about why they are afraid to file is the possibility that they would lose their health care benefit.

So, there's lots of innovation going on in the area of asset development and disability. The next wave is to translate the innovation into sustainable infrastructure within communities that are serving low-income populations.

Our research demonstrates that people absolutely desire to get off public benefits. Not one person interviewed in our focus group research with IRS reported they wanted to stay on benefits.

In addition, our research found an alarming lack of basic financial and tax knowledge and association with institutions or organizations that provide this information. People could not tell us the benefits that they were on and or what the eligibility rules were. They could not tell us any of the tax provisions that were available to them.

And, of course, we heard that many of the financial institutions are just not accessible, especially for people with sensory disabilities or mobility issues. The lack of materials and alternative formats--I'm not going to even go there because it's another big issue that needs its own seminar and discussion.

I attend many national conference put on by financial institutions and think tanks that talk about serving the underserved market. It turns out they're looking at people whose average median incomes (AMIs), are \$45,000 to \$48,000. So, if you even go 10 percent or 15 percent below that AMI, you're talking about people with incomes \$38,000, or \$40,000. To capture the EITC population, a family of four would have an income of only \$40,000. We know from our research that many of the 3 million taxpayers using the volunteer income tax assistance have incomes well below \$35,000 a year.

So much of the work that's going on, the innovative poverty work and even some of the asset building work is looking at populations that have income over the EITC limit, over \$40,000. And this really excludes probably about 80 percent of our taxpayers with disabilities, because their incomes, as we have seen, are well below \$40,000.

Fifty-nine percent of people with disabilities said they use a computer at home, and that's compared to 76 percent of persons with no disability. Thirty-one percent prepare their own tax returns, compared to 42 percent with no disability. I could go through this in more depth but my time is up. I guess I'm just going to stop here.

(Applause.)

### **Presentation of Research Findings--Jon Sanford**

**Mr. Sanford:** Good morning again. I'm Jon Sanford and I'm from the RERC on Workplace Accommodations at Georgia Tech.

Just for those of you who aren't familiar with the differences between an RERC and John was talking earlier about the RRTC, the RERC focuses on rehab engineering intervention. So we focus on -- in general RERCs do -- on workplace accommodations which would fall under one of the kinds of supports that John would have been referring to earlier this morning, and as a rehab engineering center we focus on those interventions that are related to technology and environment.

In particular, we focus on those related to universal design, and so I wanted to talk specifically about the research that we are doing and have done that is related to universal design as an accommodation.



Because I think this has very large implications for our practice and for policy.

Whereas most of what we do as an RERC is to develop new technologies, and new designs that could be implemented as accommodations, some of the work that we are doing and the research that we're doing related to universal design is much more focused or has greater implications for policy.

How many of you are familiar with universal design at all?

(Show of hands.)

Okay. A lot. Good. Just to bring everybody up to speed, universal design was coined by an architect, Ron Mace, who had polio when he was a child, and went through school and was instrumental in the accessibility movement. Along about the late '80s and early 1990s, he came up with this idea of universal design, and that is the design of products and environments to be usable by all people to the greatest extent possible, without the need for adaptation or specialized design.

So, in essence, the idea of universal design was to try and design the world in such a way that we had limited needs for system technologies and specialized products--that these were things that everybody could use in the same way.

Six years after Ron came up with this term, a number of us who were working at NC State at the time, came up principles of universal design, which are listed on my slide as: equitable use, flexibility use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and use.

I don't want to have to go into all of these, but suffice it to say that this is how we think of design and universal design. It's not just about being easy to use; it's a lot of different things all wrapped up into the design itself.

So when we first got funded as an RERC six years ago, workplace accommodations hadn't been funded as an RERC for a number of years. And when it had been funded as an RERC, it was focused mostly on "one-of" designs and coming up with new products and technologies for particular individuals. There were few published studies that described the type of accommodations or examined their effectiveness.

The degree to which a common set of accommodations that could be used to address similar problems across individuals was dependent on the expertise and the experience of individuals in the field. In other words, the field was driven by practice-based evidence rather than the other way around, and this is similar to what John was talking about this morning. We have little evidence-based practice in the field of workplace accommodations. As a result, this led to a lot of unnecessary reinventing of wheels and one-of-a-kind accommodations that might not meet the needs of all of the users.

What I'm going to talk about is a couple of projects that we started in the first five-year cycle of our funding that fed into the research that we're now continuing on in the second cycle. (We just finished our sixth year.)

There are two studies that I want to focus on. One study described the types of accommodations made and for whom (remembering that we have no history of research in this field, and we were starting from scratch). So we really wanted to know, what was out there; what people had, and try and understand how they fit and for what kinds of limitations

people were being accommodated. We also wanted to understand the use of these accommodations and their effectiveness.

The first study was a national study. We ended up with 510 employees with disabilities. The chart is really just there to let you know that what we did was we looked at people with motor limitations, cognitive limitations, and sensory limitations. The majority ranged in age from 18 to over 65. I think actually we had people who went up into their early 80s in the sample.

So I'm not going to go through all the results, but what I want to do is show you a couple of slides that illustrate the kinds of accommodations in several of our disability categories or our functional limitation categories.

For example, people with mobility issues, their accommodations mostly focused on basic access, the kinds of things that you might find in the ADA, like modifications to restrooms, accessible parking, and ramps.

Basic accommodations to the building were the most common-- remember, however, that the ADA doesn't cover this. The ADA covers these kinds of accommodations for the public, not for employees. So for employees, while there may be a ramp into the building, that ramp -- and that ramp might meet ADA guidelines--doesn't necessarily mean it's a reasonable accommodation. A 1-in-12 may not be a reasonable accommodation, given the type of functional limitation that that an individual has.

So, basic access fits under the principles--the universal design principles of equitable use, low physical effort, and size and space for approach.

Also, there are a number of different kinds of accommodations for people who have difficulty positioning themselves, and these accommodations mostly fit into accommodations for the work stations. They are modified work stations, ergonomic chairs, steps or lifts at the work station to raise somebody up. And these fit into the principles of flexibility in use, low physical effort, and again size and space.

Now, for people who need vision accommodations, visual technology. Note: we have gone from basic access to work station, and now we're getting into technology kinds of accommodations. Accessible documents, reading guides, Braille displays, pretty much these fit into the universal design principle under perceptible information.

And then, there were people who got no accommodations at all--we had fairly large percentages of individuals who got no accommodations at all, yet had functional limitations. This is really important because it tells us that people are working at some level and not being accommodated for all of the functional limitations that they have.

The implications for universal design out of this particular project were that mobility, (and that is sort of lumping all of the mobility issues together such as moving, positioning, coordinating movement) basic access issues to common areas and work stations, fit into the universal design principles of equitable use, low effort, low physical effort, and size and space for approaching. People who had dexterity problems -- that is manipulating objects -- generally had adaptive work stations and computer hardware that fit into the flexibility and use tolerance for error and low physical effort.

People with sensory issues had adapted computer hardware, but for perceptible information and tolerance for error.

And finally, people with cognitive problems, those with perception attention and memory deficits, used primarily memory aids and those were fit under the categories of simple and intuitive use and tolerance for error.

The second survey we did was with clients of Georgia Voc Rehab. These were individuals for whom the Center that I work for had made workplace accommodation recommendations over a 10-year period prior to the RERC starting. We went back to those clients to look at what kind of accommodations had been made, how effective they were, and how long they used them.

One of the important things we found was that in terms of longevity, 38 percent never used the accommodations or discontinued their use within a year. And 66 percent discontinued using within five years. We found that although 80 percent reported being satisfied with their accommodations, 67 percent discontinued use over five years.

Well, why? The most common reasons for disuse were that they had obsolete technology, failure or incompatibility of accommodations, and a lack of training or they left their job.

We found that over half of those who left their jobs took only part of their accommodations with them. Their accommodations didn't fit with what they needed for their new jobs. So they were then not used either by them or anybody else--they were totally obsolete.

What does this tell us about universal design as an accommodation? Well, universal design can reduce the need for and the cost of individualized accommodations. All those accommodations that people are getting, over and over again, the same

accommodation, if the workplace itself, if the work stations, if the computers, if the technologies were universally designed in the first place, it would reduce the need for all of these specialized designs, especially those that aren't going to be used and those that are becoming obsolete because people are moving to new jobs.

Universal design can reduce the amount of time to start or return to work because you don't have to wait for your accommodations. You can use what's already there. There's less need to go with an individual across jobs, so that they don't have to take things with them. The accommodations are already there when they go to a new job.

Universal design can facilitate work and social inclusion, which is also linked to positive work impacts. And finally, universal design has benefits to multiple workers with or without disabilities. In other words, everybody can use it, not just the individual with the disability.

This sounds great, but what are the key barriers? The first deals with the multiple disabilities and multiple employees. A design may not qualify as an accommodation if it has benefits to everybody in the workplace. It has to be shown to have benefit just to the employee with the disability to qualify as an accommodation. The problem also is this can increase the initial cost even though it reduces the life cycle cost because you don't have to keep replacing things over time.

The second issue is that we consider work as an activity, not work as a social behavior. As long as we consider work as an activity, accommodations are based on an individual employee performing essential functions of the job; that is, essential job activities as determined by the employer.

However, social inclusion in the workplace, that is, being able to participate as an employee, is not an essential job task. We don't consider it that. Again, universal design helps to accommodate inclusion in the workplace, yet it's not considered an accommodation.

So, what are the key policy issues? For me the key policy issue is defining the paradigm and the metrics that define positive employment outcomes. And what we need to do is we need to re-evaluate and redefine what we are currently doing, which is driven by ADA assumptions about performance of work activities.

The ADA presumes that inclusion follows function. If people can perform work tasks, oh, they're going to be included. They're going to be able to participate in the workplace. That really doesn't quite happen.

The other way of looking at this is through the World Health Organization understanding of the international classification of functioning disability and health. Their idea is that both activity and participation -- that is inclusion -- are equally important constructs and they are independent of each other. They are interrelated, but one doesn't follow the other. You need to address both of them, and if you don't address both of them, and you only address the activity (which is what we're doing) then we can accommodate people and they can work, but will they be happy, will they participate, will they be included, and will they have positive outcomes beyond the physical ability to produce at the workplace. That is another issue.

Thank you.  
(Applause.)

## **Presentation of Research Findings--Richard Balkus**

**Mr. Balkus:** I am very happy to be here, and I thank NASI and NIDRR for the opportunity to speak to you this morning about some of the research activities that we have ongoing in the Social Security Administration. I think it's important that we try to improve the communication that we have between each other as far as our research. We all share a common goal, and that is to facilitate job retention and return to work for people with disabilities.

I am also very pleased to be here as a somewhat new NASI member.

First, being a part of the Social Security Administration, I think I need to point out that we have a new strategic plan and disability plays a very important part in that strategic plan. Two of the major goals are devoted to disability issues.

The first one is to work on the backlog that we have pending at the hearings level and to prevent the recurrence. I think the second part of that objective is important.

Second is to improve the speed and quality of the disability process.

We have several research activities that are relevant to both of these objectives.

One thing in our toolbox now is an electronic disability claims folder and that helps us expand upon our ability to do research--look at some of the issues that are out there regarding differences in adjudication and program outcomes at the initial determination level among states. State Agencies referred to as Disability Determination Services (DDS), issue the initial determination, The electronic disability claims folder also facilitate looking at differences in adjudication between the initial determination and the decision that is made by the Administrative Law Judge (ALJ).



Part of the research agenda includes analyzing options for simplifying work incentives. The office that I am in, the Office of Program Development and Research, is also responsible for the work incentive policy for the agency except for the Ticket to Work Program, and that's Sue Suter's responsibility.

But a big part of our research agenda is the conduct of demonstration projects. I'm going to talk to you very briefly this morning about four demonstration projects. And I can tell you, every time I do a briefing on a demonstration project for a senior manager within the Social Security Administration, the issue of translation research comes up.

How is this going to translate into policy? How is this going to facilitate our administration of the program?

I can make some connections here, and some of those connections are completely within the control of the Social Security Administration, or may require working with our partners on the Hill, to effectuate. But many connections here in terms of some of the interventions that we are testing and hoping will be evidence-based practices--that are best practices-- require the cooperation and collaboration among other agencies within the Federal government to make it work.

I'm going to go through four studies. Three of them – including the mental health treatment study -- are already out there. They're being conducted.

Okay, the mental health treatment study. This involves our disability insurance beneficiaries, who have either schizophrenia or an affective disorder. The study has an experimental design. It's a very rigorous evaluation that we're going through. We have 2,000 people in the study, 1,000 in the treatment group, and 1,000 in the control group.

We have 23 treatment sites across the country, and most of these sites are mental health providers. It involves a two-year intervention based on the individualized placement and support model that originates with our partners at Dartmouth College and one of our principal investigators, Dr. Robert Drake.

It's important to say here, we're talking about competitive employment for these individuals; we're not talking about supported employment.

We are about halfway through the field portion of the study, and already we are seeing some encouraging results. Thirty-four percent of enrollees in the treatment group were recently employed in competitive jobs as opposed to 21 percent of the control group.

I must point out for this particular study, the participants are volunteers. These people expressed an interest in going back to work; but still we are seeing, I think, a good difference here, and we're hoping that this will continue and translate into a finding.

This program requires a lot of hand holding for these beneficiaries--a lot of support, even once they get back to work.

One thing that we are looking from the perspective of translation research is encouraging our mental health treatment sites is to move into the employment network world upon completion of this study, and focus on customized support for this population in assisting their return to work.

The Accelerated Benefits demonstration project is designed to provide health care to individuals during the 24-month waiting period for Medicare. For the disability insurance program, we not only have a five-month waiting period before you are entitled to benefits, but once you are entitled to benefits, you then have a 24-month waiting period for Medicare.

So, in this demonstration we are providing health care coverage for individuals who are uninsured during this 24-month waiting period.

One of the first things that came out of this study from the enrollment period, is a slightly lower uninsured rate during the 24 month waiting period than what we expected and it's running about 20 percent of beneficiaries that are in the waiting period for Medicare do not have health coverage. Most (we found about 80%) of them who do have health coverage, have private coverage through their spouses or through their former employers. Some have COBRA coverage; others get workers comp, Medicaid, or coverage as a veteran. So far we're finding out -- and this is somewhat consistent with other research that we have ongoing here -- only about 20 percent of disability insurance beneficiaries during that 24-month waiting period are actually uninsured.

Again, what we're hoping to do here is by providing health coverage, for that 20 percent - we're stabilizing their conditions, we're getting them to a better state physically and mentally to go back to work.

The Benefit Offset National Demonstration is a project we haven't started yet. I know some people around the room remember that this goes way back to the Ticket to Work legislation passed in 1999. My main reason in being here today is to convince you we are really going to do this project.

(Laughter.)

And, we are moving ahead. We accepted in September the final design from our contractor. I've been in this office, in this position, for about a year, and during this year we've been going back and forth trying to finalize the design that we think we can actually

put out there, operationalize, and get good results. For this particular intervention, what we are doing is eliminating what is often referred to as the cash cliff. I think many are aware that once beneficiaries complete their trial work period and their grace period, they go into the extended period of eligibility, which is a 36-month period from the end of the trial work period. If they're working above substantial gainful activity –SGA -, they get no benefit; if they're working below SGA, they get their full benefit. What this demonstration means is, for those individuals during that extended period of eligibility who are working about substantial gainful activity, (for most people \$940 per month in 2008) their benefits will only be offset \$1 for every \$2 earned.

That's stage one.

In stage two, we're also including some additional support as far as benefit counseling--what we're calling enhanced benefit counseling. This is basically actively contacting the beneficiary and advising him or her of the work incentive, helping them get back to work, and providing some ongoing support.

This gives you what this whole experimental design is about. It's national, it's massive, and it's going to be a challenge to operationalize.

I might add that we just completed the business process for this, working with our partners in Operations within the Social Security Administration. And we are working on the development of the system requirements at this particular point. I think it's an accomplishment, at least within this last year that we have figured out how to move forward and have gotten our partners to agree on final design.

These are the 10 areas that the project will be conducted in. These are Social Security areas, so as you can see, they encompass like Boston, or actually several states there, but for other areas it includes many metropolitan areas.

This next year we will continue with designing the business process. The big thing this next year is actually building the automated system that is required to make this demonstration project work.

The last demonstration I wanted to talk to you about is the Youth Transition Demonstration Project. This is mainly our SSI child population. As many of you know, we have over 1 million children under age 18 who are receiving SSI benefits. For many of these children, it becomes a life sentence in terms of dependency on the SSI benefits. The SSI benefit, by definition, means that the individual is going to be living in poverty or near poverty for a very long period of time and for many of these children for the rest of their lives. So for this particular demonstration project we're testing ways to break this dependency by working with SSI youth in transitioning to adulthood. It's an experimental design. We have six random assignment sites involved in the project. The types of interventions for each of these sites vary, but they have to have an individualized work-based experience as the main intervention. There are interventions for youth empowerment and family supports. We engage that child in their last year in high school in terms of making decisions, in terms of what they want to do, and try to help them make that dream occur.

Also for these individual sites, we have many linkages. Our other partners, other Federal and state programs are providing support services, and a big item is benefit

counseling, because there are a number of waivers for this program. We grant waivers to these participants, and these waivers increase their ability to keep more of their income, but also their ability in terms of asset development, either through a plan for achieving self-support (PASS) or an individual development plan.

This gives you some of the timeline of the history of the project. We did start out with cooperative agreements in a number of sites. It wasn't a random experiment at that particular point, but around 2006, we did move to an experimental design and we now have six sites.

Three of them have been added recently, and you can see we are still doing enrollment for one of the prior sites, but benefit enrollment will continue into 2010.

One of the preliminary findings -- and this is very preliminary -- is that we are seeing -- when you look at our overall population of SSI children for this particular age range, we are seeing some success here in terms of the treatment group and getting them into competitive employment.

(Applause.)