

Center for Studying Disability Policy  
Disability Policy Forum #1  
September 12, 2008

The Employment and Work Aspirations of Social Security Disability Beneficiaries  
Speakers: Gina Livermore, Ph.D., Mathematica and David Wittenburg, Ph.D., Mathematica  
Discussant: Henry Claypool, Policy Director, Independence Care System  
Moderator: David Stapleton, Ph.D., Mathematica

**David Stapleton**

We want to welcome everybody. We are pleased that you are all here. We want to thank the people that, at the last minute didn't come, because we were oversubscribed and were afraid we would have to turn some away. This is about the right size, so this is great. We closed registration earlier in the week, so probably lost people because of that. There are a number of Mathematica staff here and listening in downstairs. If you are looking for someone from Mathematica, we can help you find them.

We want to acknowledge the staff that have been instrumental in making this forum possible. First, Debra Wright—she did a lot of the planning and logistical work. The support staff did a lot of logistical work as well. Bonnie O'Day is leading the effort to plan the forums. This is one of many forums we plan to have, every other month. Dave Wittenburg and Gina Livermore, who will both speak today, also helped with the planning of today's forum.

This is the inaugural event of the Center for Studying Disability Policy. Craig Thornton and I hatched the idea of creating the Center over a drink one dark and stormy night in January 2007. By October, Mathematica had hired me and a few of my Cornell colleagues, including Gina and Bonnie, to create the center.

It turned out that the Center had already been created and existed. We just needed to define what it was. MPR had 30+ researchers with masters or Ph.D.s already conducting disability research and collecting disability data. Our job was to organize them. As some of you know, Mathematica is helping to create valuable disability data resources, most recently as part of the Social Security Administration's work; we have built a longitudinal analysis file that includes a record for each of the more than 19 million working-age people who have received a disability benefit from the Social Security Administration for at least one month from 1996 through 2006. Those records have information on 40 to 50 percent of all working-age people who say they have a disability in this country--and a larger percentage of those that have a significant, long-lasting disability. We have linked those records to Medicaid administrative data to produce statistics for the Medicaid Buy-in program and to state vocational rehabilitation agency administrative data to support research on beneficiary use of VR services. We are also conducting the first ever survey of working-age Social Security disability beneficiaries. Debra Wright leads that effort and Gina Livermore will report on some of the findings. In the last five years, Mathematica researchers have produced some 130 reports and journal articles on disability research projects, most of which were completed before we arrived.

The extensive information in these reports often gets buried in the bowels of the research agency or other organization, because it has already met the organization's needs. It's not secret; it's just

not available in a form available to a broader audience, so many don't find it timely if they find it at all. The primary function of the center is to make such information more readily available to a broad audience.

We are doing that in five ways. First, we have increased the number of documents available in accessible formats. Second, we have produced a CD of Mathematica disability research reports from the last five years and links to the documents are on our website. The CD includes shorter documents on the CD itself. There are copies on the table; some of you already picked them up. Third, thanks to Dave Wittenburg and the communication staff, we have launched the center's website--[www.disabilitypolicyresearch.org](http://www.disabilitypolicyresearch.org). Among other things, you can find disability publications through this site, and in fact many of you will find it more convenient for that purpose than the CD. You will also find descriptions of our current projects and information about upcoming forums. We have now scheduled a forum for November 20, same time and place. It will be related to the Cash and Counseling Demonstration which we evaluated a couple of years ago. I'll tell you more about that at the end of the program. Once we have had a forum, we will put up the Power Points and transcripts.

Fourth, we have tried to make research more accessible through policy research briefs. We have started a new brief series. The first brief came out today. It's by Gina Livermore. There are a number of others sponsored by agencies related to disability topics.

The final thing we are doing is the disability policy research forum series. This is the first of a series of bimonthly forums. They are all designed to present information from our projects to a broad audience, and to stimulate policy discussion. At each event, we will highlight findings from one or more of our Mathematica projects and bring in at least one expert from outside Mathematica to discuss policy implications.

The policy research forums wouldn't be possible without agencies and organizations that fund our research. David Wittenburg's presentation is based on a chapter he and Bob Weathers wrote for a forthcoming disability data book that was funded by the National Institute for Disability and Rehabilitation Research in the Department of Education, through a grant to Cornell University. I understand that the project officer, David Keer, is on the phone, and I want to thank him for the role he's played in helping us complete the book's manuscript. On the table outside the door as you leave, you will find a document that has information about the book including an excerpt from an introductory chapter. Feel free to try to take a copy.

Gina Livermore's presentation is based on a project funded by the Social Security Administration. We want to acknowledge their support for the project, and also Paul O'Leary, who has done a terrific job as project officer, and made it a pleasure to work on the project.

We need to get on with the program. One perk of being the center director is that I got to choose the topic for the inaugural forum. I chose a topic which has been the focus of my own research for a decade and a half--employment. Employment rates for people with disabilities are very low and have been declining for decades. There is a cadre of people with disabilities who are not working but who could work, and probably would work, under disability policies that are different than current policy. It's not possible to identify who they are and how much they could

work if conditions were different, or to determine exactly why they are not working more now.

There is substantial, indirect evidence, however, that the group is large and growing. Dave and Gina will present some of that evidence today. I am convinced, like many people that the existence of this cadre reflects policies that need to be changed. Current policies were designed in an era when it was not possible for people with chronic illnesses or significant impairments to work. Technological and medical advances have changed that. They have also changed the aspirations of people with disabilities. There have been significant efforts to adapt disability policy to the realities of the 21st century, and many of you have been involved with them. The most well known are authorized under the Americans with Disabilities Act and 1999 Ticket to Work and Work Incentives Improvement Act, and there are a number of other important pieces of legislation and related initiatives.

The Social Security administration launched the Ticket to Work program and many states have employment centers working closely with state agencies to help job seekers with disabilities. There are a number of important demonstrations going on, all with the objective of improving employment outcomes. Unfortunately, progress has been painfully slow. It appears that the employment rate for people with disabilities has not yet started to increase and a growing share is relying on public benefits.

Federal expenditures for public disability benefits grew from 6 percent of all federal outlays in 1984 to almost 12 percent in 2002. That's a huge share of the federal budget, and one that will come under increased scrutiny as lawmakers come to grips with mounting deficits, as they eventually must do. My view is that the growing size of the cadre of people with disabilities who could work and be self sufficient is increasing the burden on these programs and will eventually undermine political support for them.

There are good reasons to try to advance policy changes that will increase the employment and self sufficiency of this cadre. I am convinced that we can do more than we have done, but I am not sure how we will do that. I'm not sure anybody is. Fortunately, we have somebody here today who will tell us what to do--Henry Claypool. He will be our third speaker.

Let me introduce the first speaker, and then I'll introduce the other two as we proceed. Dave Wittenburg is a principal investigator for the evaluation of SSA's Youth Transition Demonstrations. He has published several papers on employment for people with disabilities including the book chapter that he will talk about today, co-authored with Bob Weathers. Dave was formerly a senior associate at the Urban Institute and, before that, the Lewin Group, where he first had the opportunity to work with such undistinguished researchers as Gina Livermore and David Stapleton. [LAUGHTER] He has a Ph.D. in economics from Syracuse University, and currently works in Mathematica's Princeton office.

**David Wittenburg:** I think we are talking about a very good kick off presentation for disability forums here at Mathematica. Measuring and evaluating employment is a central point of our work as Dave mentioned. This will be a main topic in our other forums and reports on our website ([disabilitypolicyresearch.org](http://disabilitypolicyresearch.org)).

I'm going to address two key questions today in my presentation. The first is, what do we currently know about the employment of people with disabilities? I'm going to draw findings from a paper that Bob Weathers and I have in a new book on tracking statistics for current working-age adults that should be coming out next year. The second question is, what are the improvements made for people with disabilities? There is bad news and good news in my presentation. The bad news, like my wardrobe, is all black today. People with disabilities consistently fall behind people with employment rates. The news is worse when you look at trends.

The gap in employment has been increasing the last 20 years and calls into question the policies. The good news, represented by my yellow tie here, is that there are a number of federal data issues going on that will improve the way we are tracking the employment outcome of people with disability outcomes. This includes survey data collection, as well as administrative data collection. The new activities should help us understand the dynamics of people with disabilities, and also raise the profile of statistics with people with disabilities.

The first thing that almost always comes up is the challenge in measuring employment rates. These challenges in part reflect why we don't have an official measure of employment for people with disabilities and government document such as the Bureau of Labor Statistics website and the statistics in the United States.

The first challenge is that multiple disabilities exist. A good example of the differences that exist are the differences between the definitions used in the Americans with Disabilities Act and Social Security programs. The Americans with Disabilities Act emphasizes providing coverage for people with limitations of major life activity. The Social Security disability programs cover a more narrow disability population with a much more severe disability definition that focuses on people's ability to perform substantive gainful activity. There is a big difference in what the definition is, and it changes with the context and what you are looking to measure.

A second challenge is that employment attachment varies, depending on whether you are using a weekly measure or annual measure. This exists for all populations, but it is particularly important for people with disabilities because they tend to work part time or part year. You can get a wide variation in those rates.

The final challenge is that the data sources vary. The content and structure of the data sources can be used cross-sectionally or longitudinally.

All of these things create important challenges when you try to Google employment rates for people with disabilities. You find a huge variation. I did a Google search yesterday and found that rates varied from 35 percent from the Cornell website to 55 percent from the Census website.

The approach we use to developing employment statistics is outlined in the upcoming book that Dave mentioned in people with disabilities. The first step is to define disability. We define disability using a model that can be applied to data so we can measure disability, and we use multiple measures because we know there is not a single definition that everybody can agree on.

We also know that statistics have to be used in different context. For example, the way it's used in Social Security administration is different from the Americans with Disabilities Act.

The second step is to define employment rates. The employment rates I use in this presentation are the general employment rate, which is the employment of the general population, and second, the relative employment rate, which is the employment rate of people with disabilities divided by the employment rate of people without disabilities. What does the relative mean? If you have 100 percent relative rate, that would indicate there is no difference between those with or without disabilities and anything under that is the gap. We selected four representative data sources. They have their advantages. They are the American Community Survey, National Health Interview Survey, Current Population, and Survey of Income and Program Participation.

The first chart I'll show is employment rates for people with disabilities across disability subgroups. I draw on data from the Survey of Income and Program Participation. The relative advantage of these data are that they have a large number of disability definitions in their modules and can be used to examine several subgroups of people with disabilities.

The first subgroup that we examined is impairment. The impairment is shown in red. It essentially measures a loss of a limb or a major bodily function. We break up impairment restrictions into three subgroups. The first is sensory, such as having difficulty seeing. The second is physical, such as having difficulty with standing or sitting. The third is mental, such as having a diagnosis of mental retardation. The employment rates for people with sensory impairments are 64 percent, 59 percent for physical impairments, and 46 percent for people with mental impairments.

The second disability definition that we use is something we refer to as participation restrictions. There are two types of participation restrictions that we use. The first is work limitation, which includes respondents that have an impairment that restricts work. The second includes people that have a limitation in an Instrumental Activity of Daily Living, such as going outside or writing checks or doing daily activities. We find that the employment rates are lower than the impairment groups. It's 41 percent for people with work limitations and the other is 34 percent for people with IADLs.

The third definition we use is one of activity limitation. These are things like activities of daily living such as bathing, eating, and dressing. These types of definitions are used in studies of older populations. Again, the employment rates for this group are lower than the impairment definitions.

Finally, we develop employment rates for any disability, which includes all of the previous categories. We find an employment rate similar to the Impairment group, in large part because the Impairment group is the largest portion of this population.

Finally, we show that 91 percent of people without disabilities are employed at some point during the current year.

The key findings are that employment rates vary substantially within the population; broader

definitions, such as impairment or any disability definition, have higher employment rates. Second, regardless of the definition you use, there is a major gap between those with disabilities and those without.

The second chart contrast employment trends with program trends, which was a key focus of Dave Stapleton's opening remarks.

On the left-hand side we will track employment trends of people with disabilities, and on the right hand side we will track Disability Insurance program trends. To track employment rates for people with disabilities, we use the Current Population Survey, which has the advantage of lots of long-term trend data over 20 years, but has only one definition, which is the work limit measure.

In 1985, the relative employment rate of people with work limitations was 49 percent. That means the employment rate was half of those without disabilities. The problem is, the relative employment rate declined each year from 1985 through 2005, and this represents a 20-year increase in the gap in employment rate. By 2005, the relative employment rate was 32 percent. At the same time, the disability insurance program grew substantially. In 1985, 1.9 percent of working age adults participated in the insurance program, and by 2005 that number nearly doubled to 3.7 percent. Over this same period, the size of the actual case loads more than doubled

There are many reasons for D.I. growth: baby boom population, female labor supply, and changes in the economy. But there are also several program changes over this period of time, including expansion of disability criteria and changes in state programs that serve people with disabilities, which affect employment decisions of people with disabilities. The inverse relationship between employment and program participation is striking because it questions whether we are promoting people with disabilities.

The third chart shows the relative employment rate across states. I have changed the data set to the ACS. The ACS has the advantage of a large sample that you can use to calculate state samples. The first major point of the slide is that there are major differences from the high and low relative employment rate states. In West Virginia, it's 35 percent. In Utah, it's 66 percent. The other thing worth noting about the slide is that the regional variation in relative employment rates is depicted by the colors of the map. White represents relative employment rates of 50 percent or more, and the gray and black represent states where the employment rates are lower than 50 percent. There are three states lower than 40 percent--Mississippi, Louisiana, and Kentucky. Washington, Oregon, Idaho, Montana, Wyoming, Utah, and Nevada--the states in the West--have higher relative employment rates.

There is a lot of discussion over the trends and how robust they are. The general employment trend findings hold for groups such as people with impairment. Rich Burkhauser, Andrew Houtenville, and others have found these downward trends even after adjusting for demographic characteristics within the population.

What are the policy implications? I'm going to reiterate many of the points Dave Stapleton

mentioned in his overview. First, the declining trends in poor employment rates represent a major policy problem. The key question is, is it time for new intervention and policy tests? The answer depends on whether or not you believe the employment rates can be moved. If you don't believe they can be moved, then it isn't time.

If you do believe they can be moved, it may be time to try to reverse the current employment decline. There are some tests already in the field. We have the Youth Transition Demonstration project that some in the room, such as Jamie Kendall, have been involved in, providing specialized support for youth. We have the Benefit Offset Demonstration of work incentives for insurance beneficiaries, providing earlier access to health insurance.

We have an early set of findings from the benefit implementation, if you are interested in those findings. However, a key question is whether more could be done in the future, including interventions outside of SSA programs.

The findings from state trends from the ACS suggest that there is a potential for state policies and programs for promoting employment. For example, why is there such variation across states and what differentiates the employment rates in the Northwest from other states?

Finally, I'm going to end on the spirit of the political campaign, a message of change and hope. There are a lot of planned changes going on in future data collection that will better help us understand the employment rate. The first change is a consistency in data collection. Through efforts from several government agencies, including the Bureau of Labor Statistics and Census, several measures are being added to the 2008 CPS that are going to be consistent with the 2008 ACS.

It gives us hope that the disability statistics on the Labor Bureau website and other places should increase the debate. The Council of Disability wrote a report that recommends further changes in coordinating similar measures across services that don't have the measures. They urge federal agencies to continue to publish the data, because they are currently underpublished and not well understood.

The second message of change is the improved access to administration data. The Ticket research file is a major administrative file including information on earnings. It is being linked to survey data and plans for the ACF, and more information can be found on the linkages in a paper Craig Thornton and I wrote in the upcoming book Dave mentioned in the overview.

The key message of hope here is that the data will help us better understand the overlap between program participation and employment.

The final message of change is that we are adding more surveys of people with disabilities. All the demonstration projects have surveys, so people with disabilities are participants. The Ticket to Work evaluation, which you are about to hear from Gina Livermore, has a beneficiary survey. I'll turn it over to Gina who will guide us through more employment data.

**David Stapleton:** Thank you, Dave. Okay, let me introduce Gina Livermore. Gina is a senior

researcher in the DC office. Her work has focused for years on employment of people with disabilities. One of the things she is currently working on is the Ticket for evaluation. Among other things, she designed the instrument for the National Beneficiary Survey and is leading the analysis of the data. She has a Ph.D. from the University of Wisconsin, and a master's from Tulane. We have been working on disability research together for longer than I can remember, and I suspect longer than she would like to remember. It's my pleasure to introduce Mathematica's own pit bull in lipstick. [LAUGHTER]

**Gina Livermore:** [LAUGHTER] Thanks, Dave--I guess. [LAUGHTER] I'm going to jump right in because I think the two Daves in front of me were longwinded. I want to talk briefly about the work employment expectations and barriers of Supplemental Security Income and Social Security Disability Insurance beneficiaries. In particular, how many are working and what are their characteristics. How many want to work, or say that they do, and what are some of their barriers to employment?

Why is this interesting? The Social Security Administration and other state and federal agencies, as you heard earlier are investing substantial resources to promote employment among people with disabilities. These efforts are in response to the things Dave was speaking about--decline in labor force participation and growth in the disability programs, changing demographic patterns, advances in technology that allow people to live longer and better with disabilities, and changing societal views of disabilities. At the same time, as was discussed earlier, the basic structure of the disability program is at odds with work. Applicants must prove they are unable to work before they can gain access to the support the programs SSA offers to promote employment. The DI program in particular is designed as a program of last resort, initially created as an extension of the Social Security retirement program. Few DI beneficiaries ever leave the rolls due to work. If you access these resources, you have to first prove that you can't work. Given that, can the recent efforts to promote employment among beneficiaries be successful?

I'm going to present some information that may help address that question. The findings are based on work that Mathematica is conducting for the Social Security Administration to evaluate the Ticket to Work program. I don't have time explain what the Ticket to Work program is, but for people that don't know, it is a way for SSI and DI beneficiaries to get employment and vocational rehabilitation services. The findings are based on a 2004 survey conducted for the Ticket to Work evaluation, with a sample of about 7,600 working-age SSI and SSDI beneficiaries.

What I'm going to present is a small tip of the iceberg. There is a lot more information from the survey available in two evaluation reports available on Mathematica's website ([www.mathematica-mpr.com](http://www.mathematica-mpr.com)). There is a lot of information in the survey that has never before been available because the survey was focused on employment and work activity and had such a large sample of SSI and SSDI beneficiaries.

How many beneficiaries are working? Focusing on the first column, overall, when we interviewed the beneficiaries, 9 percent said they were employed, 6 percent were looking for work, and 13 percent indicated they had worked one month or longer during the previous year. Overall, 18percent had done any of those three activities. If we look at work activity by program

status, we see that concurrent beneficiaries are more likely to be engaged in the three recent work activities relative to other beneficiaries--23 percent said they were working at interview or looking for work, compared to day the previous year of 17 percent.

What are the characteristics of the 9percent who were working when we talked to them? They were more likely to be younger (under age 40) and to have experienced onset of disability during childhood. They were more likely to have low levels of Social Security benefits. They were in better physical and mental health as reported by health measures in the survey and more likely to have education beyond high school. They were less likely to need assistance in activities of daily living.

To illustrate how beneficiaries who are working are different from all beneficiaries, I will put a few statistics up here--41percent of working beneficiaries were under age 40 compared with 22 percent overall; working beneficiaries were about three times as likely to report that they are in excellent or good health, and twice as likely to report that the onset of disability occurred during childhood. Working beneficiaries are quite different from beneficiaries in general.

What are some of the characteristics of jobs that they held? On average, they were working 22 hours per week. One-fifth said they were working full-time (35 or more hours per week), and earning an average of \$7 an hour. One-fifth had earnings above the level of substantial gainful activity (SGA). The SGA level is significant because it's the earnings level at which SSA determines that you are able to work. The job median duration was about two years (26 months).

There were some differences in job characteristics depending on the program. Relative to other beneficiaries, SSI beneficiaries were more likely to be working full-time, had higher average monthly earnings and were more likely to work above the SGA level. These differences probably reflect two things: differences between the programs and differences in the characteristics of the populations. SSI recipients are younger on average and report being in better health. Also, SSI benefits reduce gradually as earning rise compared with SSDI benefits which are all or nothing -- If SSDI beneficiaries have earnings above SGA for a certain amount of time, they lose everything. This combination may be why, among the SSI beneficiaries who are working, we see them working, on average, at higher levels.

Although only 9 percent of all beneficiaries were working when we talked to them, more said that they were interested in work: 40 percent saw themselves working in the next five years or had goals that included work or career advancement. Fewer thought they could earn enough in the next five years to get off disability rolls--only 12 percent saw themselves working without benefits in the next five years. SSDI beneficiaries were less likely than other to report having work goals. That probably reflects differences in the characteristics of beneficiaries and structures of the two programs.

The 81 percent of beneficiaries who were not working gave a number of reasons for not being employed. Not surprisingly, their health was the first and most important reason, reported by 96 percent of beneficiaries as a reason why they were not working. Non-health-related reasons were also frequently reported--60 percent gave a reason other than their health for not working. The top three were: being discouraged by previous work attempts, inaccessible workplaces, and the

ability to find a job that they were qualified to do. Some other reasons include a lack of reliable transportation (reported by 18 percent of beneficiaries), and 11percent were worried about losing their benefits if they went to work.

I put up a column focused on the small share of people that were Ticket to Work participants to illustrate differences in the reasons why beneficiaries are not working among the general population of beneficiaries and a select subgroup who are out there trying to go to work as evidenced by their Ticket to Work participation. First, Ticket to Work participants are less likely to say their health is the reason they are not working. Still, a large share reports this reason, however. They are also two to three times more likely to report all other non-health reasons for not working. For example, 54 percent reported they were unable to find a job they were qualified to do (compared with 28percent of all beneficiaries), and 19percent say they don't want to lose their benefits (compared with 11percent of all beneficiaries).

Some other circumstances that might post challenges to employment are that large shares of beneficiaries don't have a high school level of education (42 percent). Half lived in households with incomes below the federal poverty level which suggests that they rely on other programs for support which may be jeopardized if they go to work and that may also jeopardize the income of their entire family. Half have been on disability rolls for ten or more years, meaning they have probably lost any attachment to the labor force they had in the past.

Despite the significant challenges, the data suggests that there is hope that the efforts to promote employment among beneficiaries won't be in vain. We found that 40 percent of the beneficiaries say they want to work. Close to 20 percent were engaged in recent work activity or actively seeking employment. Even if the 40 percent is optimistic and unrealistically high, somewhere between 20 and 40percent is probably the true target population for efforts to promote employment. That's a lot of people--somewhere between 2 and 4 million people. There seems to be a huge potential to do something that could improve their employment prospects. What we have been doing so far seems to be of limited success, and if you want some evidence of that, read Mathematica's Ticket to Work evaluation reports. But going along the way we have been going may be more costly--as was mentioned, 12 percent of federal outlays are on supports for working-age people with disabilities, most of which is income support and public health insurance. It may be much more costly in the long run to do nothing.

There are a couple of challenges policymakers have to address. In particular, how do you change the programs from being the graveyard for the labor market to a means for people to become independent? They need to restructure the financial incentives in the programs to make work pay and offer supports that address the wide range of employment barriers faced by this population.

Second, to make a dent in the long-term trend, there needs to be a way to intervene earlier. The current system has little to offer an individual who becomes disabled after they leave school but before they become so severely disabled that they qualify for the SSI or SSDI program. We have to find ways to offer support before individuals get on the disability rolls to turn around the trends in program growth. Thank you.

**David Stapleton:** Thank you, Gina. Before I turn the mic over to Henry, I wanted to mention

that there is some emerging evidence from other countries that policy changes can change the trends we have looked at. Rich Burkhauser at Cornell has worked with a professor at the University of Mannheim to compare employment rate trends for people with disabilities in the U.S., Germany, Australia, and UK. Their statistics are striking. In the other countries, employment rates are higher in the U.S., and also improving, not declining. Germany has a long history of policies to encourage and support work by people with disabilities, and the UK is moving in that direction now. Canada has also moved in that direction in recent years, and there is new evidence from Canada suggesting that their employment rates for people with disabilities are increasing. There is hope. We have to figure out how to do it ourselves, which is why we have Henry here.

Henry is the policy director at Independence Care System, a managed long term care provider in New York City, and also works as an independent consultant. He has nearly 25 years of experience in federal, state, and local disability policy—and in navigating the nation’s complex health and long-term services system as a person with a disability. During the Clinton Administration, he served as the Senior Advisor for Disability Policy to the Administrator of the Centers on Medicare and Medicaid Services in HHS. While at HHS, Henry played a key role in marshalling implementation efforts in response to the Olmstead decision. He also was instrumental in developing policies that expanded Medicare's coverage policy regarding certain assistive technologies. More recently, he was a senior advisor to the Office of the Deputy Commissioner for Disability and Income Support Programs at the Social Security Administration.

As many of you know, there is a very small, elite group of people who have exited the SSDI or SSI rolls because of work. I’ve been told that two of them are attending remotely. The other one is Henry! [LAUGHTER]

**Henry Claypool:** Well, thank you, Dave, for having me here today. I would like to start off my remarks with some flattery for the researchers since I tend to discount all that time that people take to do research to turn out products that often need to be studied further and don't allow us to move forward. In fact, I think that we in the adequacy and policymaking arenas often find ourselves caught in an echo chamber. We end up with things like, well, people in these rolls are too disabled to work. People are stuck on the rolls because they fear losing benefits. They don't help inform policy.

I think it's important to note that I believe. That was my personal experience, and I believe it happens that sweeping generalizations creep into a process and it's not helpful in terms of moving an agenda forward. We do need to sometimes take a break and look at what the research is telling us, and then move forward again. I’m glad to be here, though it's sometimes frustrating to work with our counterparts in the research community.

We need to really continue to better understand what is in the research. I think Gina's and David's presentations were particularly helpful. I’m going to focus in my remarks more on what Gina had to say. Digging into that is really enticing and yet, I don't think it occurs enough. I’m going to pick one of these issues and look at that issue of reported health of these beneficiaries, and talk more about that, and meld that with the desire to work. It did seem like those were in

conflict.

If 96 percent of the overall folks are telling us that their health is the primary barrier to them seeking employment, yet 40 percent of them believe that at some point they'll look or go to work, what is going on there? I think that's pretty rich, and if we can spend time with it, I think we will learn a lot more. Clearly, when you see the Ticket to Work group broken up, that changed that a bit, but you saw the health as being a primary reason, the primary barrier to going to work.

So, what's behind that? I think we should look deeper into it and learn more about what is going on. Reported health status is how that shows up. It's fair or poor, but what does that really mean, and why are people reporting that way? There are a variety of reasons I would pose to you that people are experiencing very poor health. Certainly, in the DI program, a great deal of the individuals are there because their health has deteriorated to the point that they are not seeking work.

Their bodies, basically, excuse me, have failed them in some way and have caused them to degenerate to a state where they are trying to stay alive. I don't want to minimize that because I think the program is extremely important. Going back to Dave's comments in the beginning, if we look at the population, we will find a group in there that will look more toward work. Focusing back on that population, what are the reasons?

Are people reporting they have poor health because their healthcare coverage is inadequate? Is it certain benefits that they need to maintain their health better so they can pursue work? Are there supports that prevent them from going to work? Are the hassles of just coordinating their healthcare so consuming that it discourages them from spending the bit of time that they have left to do something like employment?

As we saw, the numbers are modest. People are not engaging in full time work. Perhaps they shouldn't have to. If they want to start with a modest number of hours, perhaps that's a good place to start. Are the issues they have with their health preventing them from pursuing what they would like to pursue? I don't know what the research is that goes on there. I would hope in the future people would dig deeper into what is behind the poor health or health being a barrier to work.

Looking a little further upstream to that, I think we have an excellent opportunity. We have quite a few people with significant disabilities that are working. What are they doing that is allowing them to remain in the workforce? These are the folks we need to understand better. They are living the dream, so to speak. It's -- I think, quite a challenge for those folks. If we can understand what is going on in their lives better, we will have a much better chance of helping those folks on the disability rolls find a way to make more than modest contributions in the labor force.

I do think that we probably can't do these things in a sequential fashion. We have to do them both. I would urge people to immediately look at the employed individuals and find out what is going on there and why these folks are actually working. Is it just that their boot strap mentality has them going to work each day? Do they drive such a benefit that they continue to do it? Is

their health status altered by going to work?

I'm sure there are a number of factors going on, but underneath it, what allows them to maintain their health so they can continue to go to work? Do they have modified work schedules? Are they involved in telecommuting or policy modifications that employers could make? That population, I think, is in great need of examination. I think--more scrutiny should be given to the types of health insurance that those individuals are receiving. Particularly, are they receiving employer based coverage, Medicare, wrapping something around it? Are they in a Medicaid buy-in?

By comparing these, I think we can learn a lot about the type of medical services and related supports that these individuals need to maintain employment, and I hope it doesn't take too long to have one of the federal agencies give some group some money to take a look at these questions. I think--further, you would want to look at some of the coverage gaps. Clearly, people are relying on the Medicare program.

We know there are certain gaps in coverage there that people report to be barriers to work. It's interesting when you compare the Medicare benefit to employer based coverage, how they match up. It's hit and miss, obviously. It's difficult to generalize about what you would receive under employer based coverage, and what that would mean. You also introduce differences in co-pays, deductibles, and co-insurance.

Pretty soon, it makes, I'm sure, for a difficult analysis. Just in general, going back to these types of services, looking for gaps in coverage, and trying to find out what services are essential in order to ensure people maintain their health to make these types of contributions. I think a number of presenters acknowledged that we are entering an important time of year. There will be a new administration in Washington.

What will they bring to us in the way of a, perhaps initiative or policy framework, that they would like to push forward? I believe Senator Barack Obama talked about creating a commission for people with disabilities and Social Security. I would hope and imagine that Senator McCain would do something since this seems to be a universal theme that people with disabilities are important, and that's an area in which we need to focus, but at the same time, I'm concerned going back to the echo chamber that often times these policies get written off, and as was said earlier, can our systems hold with the policies we have now, and can we move away from the public rolls and make it less difficult to continue to work in any way?

What will the new administration bring for us? I would hope that--I just made two quick pleas in my little preparation, that I think the Medicaid buy in is something that was thought to be almost a panacea, and the way it ended up rolling out, and the nature of the Medicaid program, almost makes it a trap in some way. It's not a program that is consistent across the states. Many states or some states don't have them.

Even if you do have them, you can build your Medicaid buy-in in such a way that it's targeted to a certain population with income and asset limits that don't encourage some folks to pursue some type of employment. I would hope this would be bumped up to a priority and see a Medicaid

buy-in would be on the order of a SCHIP program which will say the federal government will match, like they do in the children's program, as a way to offer it with a certain structure so we move away from "we will we offer it up to 250 percent of poverty."

I know that's where most of the earnings are showing up, but I believe we have some people bumping their heads up against this, so what can we do about that? We can offer benefits that they know they can receive through the Medicaid program to help them go to work. Medicaid provides personal assistance and support which is not found in any other health or medical assistance program. Really, Medicaid for people with personal assistance needs and other types of disabilities is the type of program that's going to work best. Certainly, states can deal with the cost issues about--basically establishing, if your earnings are high, you would pay a greater premium to participate.

The plea is for a national priority. My preference would be a national buy-in program. I know how that works in the Medicaid program. The other thing I think is critically important and should occur on day one of the new administration is that the administrator of the center for Medicare and Medicaid services should establish a group in their office that is responsible for coordinating with the Social Security administration around work incentives.

Thrown in there would be things around part d, and significant interactions that CMA and CMF need to have, but not to diminish my point, I think that's crucial to have someone in the administrator's office that is responsible on a daily basis to work with a counterpart that would be in the commissioner's office, that would be working on, focused on moving a work agenda forward and try to steer the bureaucracies in a way that I don't think has been tried before.

Experiencing life, that's what you need. You need leadership to say, this is a priority. We are going to do this. The bureaucracy is going to accommodate this. Once that is set, it's remarkable how the bureaucracy tries to accommodate these priorities. I am confident that if this was to occur, we would see demonstrations not bouncing around, hanging out to dry, waiting for certain types of funding. You would have someone reporting on a daily basis, saying, excuse me, what is going on, and we would make greater progress. With that-- I don't know if we have time for questions, but I'll end it there.

**Debra Wright:** We have one question. This is for Gina. Are there data available on age?

**Gina Livermore:** The answer is yes. I can't remember which report, but we have--I believe it was the 2006 on Mathematica's website, Appendix C with all the tables on it. One of the columns is working beneficiaries. The other is called program. There is a detailed distribution there as well as every other characteristic you can think of.

**David Stapleton:** Questions in the audience here? Comments? Yes?

**Audience member #1:** Sue from the office of disability employment policy. I was intrigued by Gina's research in particular because I had heard a conference three years ago that featured Martin Gerry. He was saying he thought Social Security should focus less on people with congenital disabilities and attempting to return them to work and spend most of the money on

people with acquired disabilities and their own research survey showed that people who were born disabled are more likely to work. That was astonishing to me. Just in general, we shouldn't be making different disability groups work off each other trying to get a job. We are supposed to be in it together and should act that way.

**David Stapleton:** I'm not going to try to repeat all of that. We do have microphones down the table. I think it will get picked up fairly well. I don't think that was a question, but did you want to comment on that, Gina?

**Gina Livermore:** No. I don't want to comment on that.

**Audience member #2:** This has been an excellent program. The work you all are doing is quite impressive. I am wondering, are there other organizations doing similar research?

**David Stapleton:** I don't think anybody is doing as much of it as we are, but we are collaborating with a couple of organizations on two important studies. We are working with MDRC on the Youth Transition Demonstration and the Accelerated Benefits Demonstration, and we are working with Abt Associates on the Benefit Offset Demonstration.

**Audience member #3:** [Laurel Beedon, National Academy of Social Insurance] We are going to be doing a seminar on Wednesday, October 15, featuring some of the lighter return-to-work stuff, so keep looking at the National Academy website. It will be up shortly, invitations and dates will be out next week. Thank you.

**Audience member #4:** I'm Bob from Senator Sander's office. There is no attention on the demand side, what employers can do. It's been an excellent analysis from the supply side and from the interaction with government, but don't you think, particularly to Henry, that it comes to mind that with facilitate access on the rolls, employers could do it?

**Henry Claypool:** I would have to go back to the individuals employed. I think we will find the answer there: how is it that the individuals have managed to navigate the system? Are they all working for the federal government that is a model employer, or are they working in smaller organizations scattered in small towns? I think there are plenty of people with disabilities out there. We don't know yet why those employers have brought those people onboard. That would be my quick way out of answering the question.

Is there a sense that the people that are working, looking for work, whether they come from impairments that are equal to disability listings, or people that had to go to higher levels in the decision process to get allowed?

**Gina Livermore:** I can't really say what levels they got allowed and that sort of thing. I do know from levels I was looking at recently. The highest unemployment rates are among those with retardation. I'm trying to think how it trickles down. Muscular skeletal tends to be lower, average or slightly under the average employment rate overall. Those tend to be more of the squishier ones.

Mental, psychiatric employment rates of those with psychiatric disabilities somewhat lower. I think we are looking at fact categories. I'm not sure I'm answering your question. People with mental retardation are definitely--29 percent employment rate. That's huge.

We have that data. We can take a look at it.

**David Stapleton:** We have the information that the more difficult it was for someone to get on to benefits, the less likely they are to be working. Right?

**Gina Livermore:** I'm not sure. I would think it would be less likely that they would be participating. That may translate.

**David Stapleton:** One more question, and then we will call it quits.

**Audience member #4:** Has there been research on the disabled student services throughout the colleges and universities in the country that are so phenomenal and what they have done to employ people with disabilities?

**David Stapleton:** Not that I am familiar with.

**Audience member #4:** I highly recommend it.

**David Stapleton:** All right, I want to mention a couple of things. We'd love to have your feedback. If you want to send us an email and tell us what we can do better, please do. One issue is whether we need to move to a place where we can accommodate more people. I also want to encourage you to sign up for the next forum. Remember to look at the flyer when you leave. It's about Cash and Counseling, as I said earlier. Randy Brown, a vice president at Mathematica and the principal investigator for the evaluation will talk, along with two guest speakers. The results are somewhat dated. The purpose of the forum is to help push the ball forward in this policy area-- o review how Cash and Counseling has expanded since the demonstration and to consider how the concept can be applied in other areas. Kevin Mahoney, the Director of the Cash and Counseling Center at Boston College, will speak, along with Pam Doty and Vidhya Alakeson from the Office of the Assistant Secretary for Planning and Evaluation in HHS. I hope to see you there, if not, sooner. Thank you.