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FAX TRANSMISSION

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From: Bob Williams

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COMMENTS: Please deliver to individuals listed above.

Thank you

For Chris Jennings, Jeanne Lambrew & Diana Fortuna from Bob Williams. The CASA testimony before it was cut due to time constraints. Background info for meeting w/ NCIL + CCD on Fri. May 15.

INTRODUCTION

We are pleased to be here today to talk about the President's commitment to expanding and promoting consumer-directed home and community-based services so people with disabilities can live their lives to the fullest potential. It is consistent with our views about the basic rights of all Americans to control and direct their own lives. It is consistent with our strong and rigorous support for equal rights for people with disabilities, as articulated in the Americans with Disabilities Act.

Like everyone here today, the Administration feels strongly about empowering people with disabilities -- including children, working age adults, and older people who need help with basic daily activities -- and their families, by increasing their independence and quality of life. One of the best ways to do this is to provide opportunities for individuals to choose to decrease their reliance on nursing homes, by increasing their options to choose self-directed personal assistance in home and community-based settings.

We will use our time today to discuss our multi-faceted approach to achieving these goals, recognizing that while we won't achieve our goals all at once, we can be aggressive about making real progress toward them. We would like to explain the Administration's commitment to this issue and the activities currently taking place with an HHS work group on home and community-based services. And we would like to discuss our broader strategy, which includes legislative, regulatory, research/demonstration, and other activities.

THE ADMINISTRATION'S COMMITMENT

In May of 1995, after a series of meetings with individuals from the disability community, Secretary Shalala issued a set of principles supporting home and community-based care. She reaffirmed her support for emphasizing home and community-based care services and offering consumers the maximum amount of choice, control and flexibility in how these services are organized and delivered. Since that time, HCFA has increased its technical assistance to States to assist them in developing home and community-based waiver programs and other options to foster care in the community. We continue to be guided by these principles.

This past September, the President and Vice President met with a group of disability community representatives and Federal officials, including Bruce Vladeck, then Administrator of HCFA and Bob Williams, Deputy Assistant Secretary for Planning and Evaluation, to discuss how to move forward on the community's highest priorities. The President has a longstanding interest in addressing the challenges facing people with disabilities who need long term care services and this Administration has a continuing commitment to increase the availability of home and community based personal assistance services. At that meeting, the President expressed appreciation that the Community Attendant Services Act (CASA) bill had been introduced by the Speaker, noting that it will help focus attention on the expansion of home and community based care. He was particularly pleased that it would enable us to have a discussion about how to move more toward a system where "the money can follow the person," no matter in what setting he or she chooses to receive the

services needed. Finally, he noted that a lot of the activity and decision-making regarding home and community-based care and personal assistance services (PAS) is happening in the States. He stressed the importance of enlisting the help of those States that are moving in the right direction, to provide leadership in educating and helping others who are not so far along.

HHS WORK GROUP

As a result of the meeting with the President, and in an effort to pull together all our activities in this area, Bob Williams, HHS's Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, and Sally Richardson were asked to co-chair a work group on home and community based services. The goals of that work group, which began meeting in September, are to review all available information and make recommendations about how to reduce the institutional bias in Medicaid long-term care services and spending and promote home and community-based care. Specifically, we are working to:

- Identify and address the "institutional bias" in the Medicaid program -- so fewer people are forced to move into nursing homes because it is the only way they can get long term care services;

- Provide more program opportunities for consumers and their families to choose the setting in which long term care services are received, with increased flexibility for the "money to follow the person," as opposed to the payment determining the setting in which a person receives services; and,

- Promote consumer direction of home and community based/personal assistance services.

Our work group members include HHS and other Administration officials interested in the issue, as well as an expanded group of "constituency partners" -- representatives of consumer groups, providers, and State agencies -- with whom we consult to ensure that the work group's activities and products take a variety of perspectives into account. The work group is moving ahead on a number of fronts.

Overcoming Institutional Bias

We are exploring a range of demonstration strategies, including opportunities we can offer States to modify their Medicaid programs and try some new ways of helping people who want to and are able to live in the community. We are happy to announce that we will soon be asking States to submit proposals to begin to develop a research design to identify individuals who could successfully move out of nursing homes into the community and to develop the services that would be needed to support these individuals in the community. This solicitation is in response to the commitment made by President Clinton to this issue and the Congressional directive in the FY 1998 Labor/HHS Appropriations Bill. We believe that we will be able to fund research in 3 to 5 States.

Another component of this work involves using HCFA data to improve our understanding of the numbers and characteristics of nursing home residents who may be good candidates for moving back to the community and what they would need in the way of supports. We will then be better able to help the States design strategies that succeed when these individuals attempt to move into the community.

We are also developing strategies to address the President's charge that States should learn from each other how to support and promote home and community based services under 1915(c) Medicaid waivers. Some States are much further along than others in developing innovative and cost-effective service delivery models for home and community-based services. Staff have been talking to a wide range of experts in the aging, disability, and long-term care fields in order to hear what they have learned. We have gotten positive feedback from a growing number of States about the value of developing a "State to State" technical assistance strategy.

We learned from our constituency partners that some States are not fully aware of the flexibility available to them under current regulations. Therefore, we want to clarify some of the things that States can do right now to reduce the institutional bias. We are planning to produce a primer on Medicaid that explains to State officials and consumers what is already available under Medicaid's personal care option, home and community-based waivers, as well as other Medicaid services. This primer will be clearly Stated, so readers can understand what is allowable within the existing framework of Medicaid. The primer will also include some examples of States that have used the flexibility of Medicaid to do some excellent work in reducing nursing home use and increasing community supports.

Finally, last year's CASA bill required a study of the "institutional bias" in the Medicaid program. HHS commissioned an independent contractor -- the University of California at San Francisco -- to conduct such a study. A few weeks ago we received the contractor's draft report. Let me note that this report has already been reviewed by a Blue Ribbon Panel on Personal Assistance Services that includes many consumers with disabilities and other Medicaid and personal assistance services experts.

The report reviews the Medicaid statute and regulations, as well as policy guidance from HCFA, and offers a series of policy options to address the "institutional bias" in Medicaid. The majority of the recommendations would involve statutory changes and many of these changes would involve significant new costs. We are now developing a list of potential regulatory and policy changes on which we can take some more immediate action, while we continue to review long-term legislative options.

ADVISORY COMMISSION'S CONSUMER BILL OF RIGHTS

We understand that a high priority for individuals with disabilities is to ensure that consumer protections are in place that assure access to specialists, continuity of care, and internal and external appeal rights when health plans make decisions that are disputed by its enrollees.

As you know, the President endorsed the Consumer Bill of Rights and Responsibilities, recommended by his Advisory Commission on Consumer Protection and Quality in the Health Care Industry, and challenged Congress to make these important rights apply to consumers of all health plans. The Bill of Rights included important protections such as access to specialists for individuals with chronic care needs, for example: (1) traditional care for consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the second or third trimester of pregnancy) at the time they involuntarily change health plans or at a time when a provider is terminated by a plan, and (2) a fair and efficient internal and external appeals process for resolving differences with their health plans and health care providers.

On February 20th, the President directed HHS, as well as other Executive Branch agencies, to bring their programs into compliance with the Consumer Bill of Rights. This Department reviewed the Medicare and Medicaid programs for compliance with the Consumer Bill of Rights. Based on our review, the President praised the Department for how far along these two programs were in complying with the Consumer Bill of Rights and he directed us to bring the two programs into virtual compliance as quickly as possible. The President is extremely committed to making the Consumer Bill of Rights real for all Americans.

EXPANDED SETTINGS & ELIGIBILITY FOR RECEIVING SERVICES (LEGISLATION)

On the legislative front, we were pleased that Congress included in the BBA our proposal for a new State option to allow certain workers with disabilities the ability to purchase Medicaid. Losing health coverage can devaState anyone. Losing health care and personal assistance services is even more devastating for some people with disabilities -- to the point where they are afraid to even try to work, because if they lose SSI or SSDI eligibility, and thus health care, they lose their life line. The new BBA provision should enable many individuals to make a real transition to work. Two days ago, we mailed to State Medicaid Directors a letter that revised the definition of income for the purpose of calculating the eligibility standard under this provision. Under our revised definition, States will determine eligibility based on income net of income disregards.

Also included in the BBA was our proposal to allow States to include prevocational, supported employment, and educational services for all home and community-based services waiver recipients with developmental disabilities. Before this provision was enacted, only those who were formerly institutionalized could receive these services through a home and community-based services waiver.

Finally, the BBA establishes a new type of service provider called Program of All-Inclusive Care For the Elderly (PACE). States may elect to provide PACE program services to individuals who are

Medicare and Medicaid eligible and are enrolled in a PACE program agreement. PACE provides for a coordinated set of services to frail elderly individuals living in the community.

EXPANDING SETTINGS & ELIGIBILITY FOR RECEIVING SERVICES (REGULATION & POLICY)

On the regulatory and policy fronts, this Administration has been very supportive of expansions in home and community based services under the Medicaid 1915(c) waivers. All States are now operating at least one and sometimes several home and community based waivers. Many provide additional supports with other Medicaid services as well. Thirteen States provide attendant care under their home and community-based waiver programs, while thirty-nine States provide personal care under their home and community-based waiver programs. The waiver program has flourished and grown under President Clinton's leadership, and currently there are 226 approved home and community-based waiver programs. We expect the program to continue to expand at an even greater pace as we work with States to find new ways to promote the use of existing services in States that have not provided them yet. In July of 1997, the State Medicaid Directors a letter that promoted the use of Medicaid home and community-based waivers.

We also recently issued revised regulations to increase the responsiveness of the Medicaid personal care option to better meet the needs of people with disabilities. There are currently 31 States providing personal services under their State plans. Individuals are now permitted to receive services both in the home, and outside the home. The new regulation eliminates the requirement that a registered nurse must supervise personal care services, thus reducing cost and making the service more consumer responsive and less "medicalized."

Consumer-Directed Purchasing

Our home and community based care and PAS research agenda is a key part of efforts to help ourselves, and help States and consumers, to find out what works, for whom, how well, and at what cost.

We are promoting our home and community based services agenda by working with States to develop and implement Medicaid demonstrations under the 1115 authority of the Social Security Act. Some focus on the integration of acute and long term care, such as the projects underway in Minnesota and the District of Columbia. Others, such as the newly-approved Colorado home health demonstration address different aspects. Colorado's demonstration will permit home health services to be provided in settings other than the home, such as schools, work sites, or day treatment centers. Wisconsin and Rhode Island have applied for 1115 waivers to serve beneficiaries under age 65 with physical disabilities and adults with developmental disabilities respectively. Four States working with the Robert Wood Johnson Foundation have applied for 1115 waivers to offer consumers cash allowances and counseling to purchase their own attendant services. We are currently reviewing

these waivers and expect to complete our review shortly. We are very interested in finding new ways of doing business in Medicaid and encourage States to bring us their ideas and proposals.

CONCLUSION

We believe it is critically important to continue to develop models both at the State and Federal level that support and encourage the move from reliance on institutional care to a broader array of consumer-directed home and community-based services.

We embrace these goals and will continue to work toward them. The challenge, of course, is to balance our goal of providing more flexibility and choice for people with disabilities, with the need to ensure that any legislation is affordable. Preliminary cost estimates raise the very real questions about whether the balance has yet been achieved. However, we remain committed to working together with you and other interested parties to craft an affordable, consumer-responsive system, that takes advantage of and promotes flexibility in our current programs, to help people obtain and keep the help they need to live as independently as possible.

In conclusion, we would like for all of us to remember that people with disabilities are a very diverse group of individuals. They are children, working-age adults, and the elderly. They have developmental disabilities, emotional or cognitive disabilities, and physical disabilities. This is not a group of people for which a "one solution fits all" answer is appropriate. These individuals need more opportunities, more choices on where and how they are to receive services. Nursing homes, intermediate care facilities for the mentally retarded should be available, but home and community based services must also be available. We cannot afford to have any bias in service delivery.

DRAFT 4/21 -- For 4/22 Task Force Meeting on Returning Individuals to Work

DRAFT Outline for the Administrator's Talking Points

INTRODUCTION

- As Secretary Shalala said, access to health care and long term care can be crucial to job access for persons with disabilities. At HCFA we are mindful of the critical role that our programs, Medicare and Medicaid, can play in providing this essential link for persons with disabilities.

- HCFA has been pursuing a number of activities aimed generally at increasing consumer choice, independence and quality of life for all persons with disability. I will focus my discussion today on those that we see as being of most benefit to disabled individuals who want to work.

- Our work has encompassed legislative, regulatory, research/demonstration, and other activities.

LEGISLATIVE - BBA

- On the legislative front, HCFA has been working with the States to implement the new provision in the Balanced Budget Act that gives States new authority to allow working individuals with disabilities with incomes up to 250% of the federal poverty level to buy into Medicaid.

- We've interpreted the income threshold based on net family income. This means that an individual with an income of $40,000 can qualify to buy into the full array of Medicaid services.

- We believe the new BBA working disabled provision will provide an even greater opportunity for workers with disabilities to maintain health coverage by expanding and simplifying States' abilities to allow individuals with disabilities to return to work and maintain their Medicaid coverage.

- As the Secretary has promiseded, HCFA and the Department of Health and Human Services will do everything they can to encourage States to adopt this optional provision because it is so important to achieving our goal of helping people who want work and can work, to work, by providing that critical link to affordable health care.

- We will immediately engage the States about this matter by meeting with State Medicaid Directors and by writing to the Governors. We will facilitate the sharing of best practices

in this area among States.

REGULATORY -

- We know that the availability of Personal Care Services is also a critical element in enabling a person to work. Personal Care Services are an optional service under Medicaid. At last count, 31 States do offer this optional service.

- This past September the Department published a regulation on personal care services under Medicaid to provide more flexibility to States to encourage the expansion of this option.

- This final rule gives States the option to expand the availability of personal care services by allowing services to be provided outside the home. In addition, the regulation removed the requirement that registered nurses supervise the provision of personal care services.

- Other States provide personal care services through Home and Community Based Services Waivers -- which I'll discuss in a minute.

- As a result, almost all States provide personal care services under their Medicaid programs and these services can now go outside the home – including into employment settings.

RESEARCH/DEMONSTRATIONS

- One of the crucial tasks currently before HCFA and the Department is to determine why the existing tools we have to encourage individuals to go back to work are not being used.

- We need much better information on what motivates individuals to return to work, as well as what services these individuals need in order to stay working.

- Our research and demonstration agenda in this area will provide us with more data and information to help us better understand the health care needs of and obstacles faced by working individuals with disabilities.

- Specifically, let me mention 4 demonstrations whose results and evaluations will help us plan future activities:

1. **cash & counseling**
   + this demonstration will test the concept of providing cash to individuals and allowing them to choose and purchase the personal assistance services they need.
   + information and counseling will be provided to assist consumers to make

informed choices
+ FL, NY, NJ, AK are the States that will be testing this concept

2. **"date certain"**
+ HCFA is sponsoring a grants program to assist States to develop mechanisms to work with individuals and their families prior to admission to an institution to consider community-based alternatives and/or mechanisms to transition individuals currently in institutions to the community if that is their choice.
+ the objective of this program is to identify and remedy barriers to community-based care.
+ community based alternatives can include services which will assist individuals to return to work (e.g., prevocational and supported employment services)
+ we expect to issue the grant solicitation before summer and to award grants to 3-5 States in September

3. **Consumer-Directed DME Purchasing -- Medicare**
+ In Medicare, we will be releasing a Program Announcement for a demonstration of consumer-directed choice and purchase of durable medical equipment, such as wheelchairs.
+ Having the right equipment can facilitate a person's ability to perform activities of daily living, including work.
+ Centers for Independent Living (CIL) will be partners in the demonstration.
+ We expect to award developmental funds to four CILs this fall.

4. **Dual Eligibles Demonstrations**

+ This past month, HCFA awarded 4 grants to 3 States to help improve care for low income Medicare beneficiaries who are also eligible for Medicaid.
+ Projects are being funded in Florida, Wisconsin and Maryland to address the needs of these "dually eligible" beneficiaries.
+ These grants will help us learn how to better coordinate care between Medicare and Medicaid, help disabled beneficiaries move from nursing homes into the community, and target needs of people likely to become dually eligible as they use up their own assets on medical care.

- Also, as the Secretary mentioned, we are providing technical assistance to States, like Wisconsin, that are interested in exploring options and developing concepts around the goal of employing persons with disabilities. We are seeing a growing interest in this area.

OTHER ACTIVITIES

Home and Community-Based Waivers

- The Medicaid program has evolved to better meet the needs of the disabled population, particularly with respect to the provision of home and community based services.

- States are taking advantage of the home and community based waivers under Medicaid -- 1915(c) waivers -- to explore innovative approaches to delivering long term care in community or home settings.

- Some time ago, we made it easier for States to obtain these waivers by eliminating the long-standing "cold bed" rule. This had been a test of whether the state maintained sufficient bed capacity in its institutions to serve those who would be on the waiver in case the waiver failed.

- In 1995, Secretary Shalala issued a set of principles supporting home and community-based care. She reaffirmed her support for emphasizing home and community-based care services and offering consumers the maximum amount of choice, control and flexibility in how these services are organized and delivered.

- Since that time HCFA has actively promoted these waivers, increased its technical assistance to States and developed streamlined waiver applications to facilitate States' efforts to provide more home and community-based care in lieu of institutionalization.

- We have seen a substantial growth in the number of waivers requested and approved. We now have 226 approved and many States have multiple waivers. Thirteen states provide attendant care in their waiver; 39 states provide personal care services in their waiver; and 21 states provide pprevocational and supported employment services to enable persons to enter the workforce.

- Keeping people out of institutions is certainly a step along the route to better serving those individuals who want to be employed. These waivers are an important tool in our arsenal.

Home and Community Based Services Workgroup

- Before closing, I'd like to mention one other activity that is underway and will help inform the future debate about what activities we need to undertake to move us further down this road. I'm referring to the Home and Community-Based Services Workgroup.

- This past Fall, the President met with Representatives from ADAPT to discuss increasing access to home and community based services, including personal care services under Medicaid.

- Secretary Shalala established a workgroup in response to the President's meeting with

ADAPT to address specific issues regarding home and community based services.

- This workgroup is chaired by Bob Williams from ASPE and Sally Richardson, Director of HCFA's Center for Medicaid and State Operations. I'd like to ask Sally to stand so that all of you can see her. I must tell you that it is she, not I, that is owed the credit for much of the activity that has taken place, and is taking place, in HCFA with regard to the subject we're discussing today. Thank you Sally.

- The purpose of the Department workgroup is to consider all available information and make recommendations about how to reduce the institutional bias and promote home and community-based services under the Medicaid program.

- In addition to HHS offices and agencies, other Federal agencies and our constituency partners, including advocacy organizations, are involved in providing input on various issues addressed by the workgroup.

- The Department contracted with the University of California at San Francisco to study "institutional bias" in the Medicaid program. A final report is due by May 1 following review by an Advisory Group comprised of persons with disabilities, as well as, other disability experts. As we review the recommendations of the contractor, I'm sure we will be able to incorporate many of them into our future planning efforts.

- As I mentioned, we will soon release a solicitation seeking State proposals to test the "date certain" concept of moving persons from institutions to the community. The work on that proposal has emanated from this workgroup.

- We also are currently planning to contract for development of a "primer" on Medicaid for individuals with disabilities, detailing what States can do under current law and provide examples to help States better use the options they currently have available to them.

- In summary, I would say that we have been and will continue trying to facilitate States' leadership in expanding home and community-based supports and consumer-directed personal assistance services.

- In closing, I think you can see that we have a multi-faceted approach to achieving our goals. While we recognize that we won't achieve our goals all at once, we can be aggressive about making real progress toward them.

Draft Talking Points for Peggy Hamburg's April 22 Presentation to the Presidential Task Force on Employment of Adults with Disabilities

- I am Margaret Hamburg, Assistant Secretary for Planning and Evaluation in HHS.

  - I am honored to appear here today, as you undertake the important challenge of increasing work opportunities for people with disabilities.

  - My office provides analysis and advice to Secretary Shalala on the policy challenges facing the Department of Health and Human Services. Bob Williams, my Deputy Assistant Secretary for Disability, Aging, and Long-Term Care has helped me keep our disability research and policy work moving steadily forward, and focused on the important issues of the day.

  - We know this Task Force will address health and long-term care supports for people with disabilities who want to work. Without access to this coverage, many people with disabilities would be unable to live in the community at all, much less participate in the work force. We hope our presentations on this panel can help inform this effort.

  - In fact, as Secretary Shalala told us earlier, the fear of losing health coverage is a great concern to many people with disabilities who want to work. As most of you here know all too well, giving up SSI and SSDI benefits to go to work can also mean losing health coverage.

- The work of this task force is important to HHS.

  - We know that people with disabilities want to work -- they tell us so in survey after survey;

- Yet, over 70% of people with disabilities are not even in the work force at all, and this is simply unacceptable;

- I know that few people with disabilities use the work incentives now available, and even fewer are actually able to leave the rolls and go to work each year -- my colleagues at SSA tell me that fewer than 8500 of the over 4.4 million people on SSDI and only about 300 of the 3.3 million on SSI leave the rolls each year; and

- Also, I understand that there is concern that too many young people with severe disabilities leave school and go directly onto the SSI rolls because they think there is no way they will ever be able to do real work.

♦ I will use the analytical and policy strength of my office to shed light on these problems and help craft solutions.

♦ This morning I will briefly summarize a few key issues about people with disabilities that I think are particularly relevant to your deliberations.

♦ Let's start by taking a look at what current research tells us about working age adults with disabilities -- by functional status, employment rates, and some health issues like insurance coverage and health care utilization.

Disability Characteristics

♦ **[Show slide #1]** First, I want to show you the prevalence of disability in the population. As you can see, one in five working age adults, 30 million Americans between the ages of 18 and 65, have a disability.

- A relatively small proportion of the working age population, 4 percent, or 6 million, are disabled enough to meet the disability

eligibility requirements of the SSA income support programs SSI and SSDI. It is this group that experiences the highest rate of unemployment, and it is these individuals who face some of the most significant challenges as they seek the health and long-term care coverage they need while they engage in meaningful work.

- **[Show slide #2]** This next slide shows functional characteristics of working age people with disabilities. The great majority of such individuals -- 77% or over 23 million people -- have disabilities such as mental retardation, mental illness or musculo-skeletal problems, but are still able to carry out basic activities.

  - About 23% or 4.5 million people have moderate limitations -- and need assistance with one or two routine activities of daily life like bathing, dressing -- or shopping or preparing meals.

  - About 2.3 million need help with at least three of these activities. People in this group are most likely to need long-term supports, such as personal assistance services.

Employment Status

- **[Slide #3]** The next slide examines the employment rates of people with and without disabilities. Clearly, the more disabled a person is, the less chance he or she is working. Almost 80% of Americans without disabilities are employed. As you can see, the employment rate decreases, as the severity of the disability goes up. Only 18% of those with significant disabilities are in the work force.

Education

- The last slide showed that employment rates go down as the level of disability goes up. What explains this? The next slide examines the role that education might play. After all this is a significant predictor

for the non-disabled population.

- **[Slide #4]** I think this slide shows an important point– even when people with disabilities have comparable levels of education to people without disabilities, they are markedly less likely to be employed. This is so at every educational level. What is very troubling is that less than half of people with significant disabilities who have a college education are employed.

- **[Slide #5]** In the next slide, we see that people with disabilities who work tend to earn substantially less than their non-disabled counterparts. People with significant disabilities are the lowest earners of all.

Health Care

- Next I would like to share with you some statistics on health care and people with disabilities and how they compare to people without disabilities.

- **[Slide #6]** In this slide we see that people with disabilities have more hospital stays than the non-disabled. Fewer than 4% of working age adults had one or more hospital stay in 1994. For those with functional disabilities, a quarter of them had at least one hospital stay.

- **[Slide #7]** In the next slide, we also see that people with disabilities visit the doctor three times more, on average, than those without disabilities. People with significant disabilities had 85% more doctor visits than those without disabilities.

- **[Slide #8]** Not unexpectedly, people with disabilities have higher health care expenditures than the non-disabled.

Health Insurance

- **[Slide #9]** In the last slide, we see another important fact that bears upon your deliberations.
  - People with disabilities who are employed rely primarily on private insurance. For people who are not employed, Medicaid and Medicare provide the safety net, that for many can mean the difference between life and death.

Putting it All Together

- In summary the data tell an important story:
  - The employment rate for working age adults with disabilities is extremely low. Those who work earn much less than non-disabled people.
  - Health care use and costs for people with disabilities are much higher than for those without disabilities.
  - People with significant disabilities are the least likely to work and the most likely to have high health care costs.
  - People with disabilities who are employed rely heavily on private health insurance.
  - People with disabilities who are not in the labor force rely heavily on public insurance.
- Further, we know that:
  - People with disabilities say they are afraid to leave the SSA rolls and risk losing health benefits.

- Despite the fact that there are work incentives that specifically permit people on SSI or SSDI to go to work but still keep Medicaid or Medicare within certain limits; but participation in these programs is very low.

More Research is Needed

- Our information raises a number of important questions that need to be addressed:

  - Why are some people with disabilities able to go to work without ever entering the Social Security disability system? Is it something about the individuals, the service systems, or both?

  - Why is participation in our work incentive programs so woefully low? Is it a function of lack of outreach? What are the characteristics of people who use them successfully and those who do not?

  - What role does access to a secure source of health care play in the decision to work?

  - Who among the population with disabilities need PAS and what role do these services play in the decision to work?

  - What more can be done to link service systems that address the education, training, employment and health care systems, with the ultimate aim of getting more people into good jobs earning a living wage?

Current ASPE Research to Address these Questions

- I'm pleased to report that my office has a solid research agenda underway to address some of these questions.

- First, our **employment studies**. We started a few years ago with a study to review the evidence that supports the proposition that people do not seek work because they fear losing health coverage. While there are few empirical studies to date, they do suggest that health care access is an important factor in the decision to seek work.

  - In a follow up study last year, we looked at participants in the SSI 1619 work incentive program -- which allows people to keep Medicaid when they go to work, if they earn below about $20,000 per year.

  - You won't be surprised by the preliminary findings: there is a group of 1619 participants who deliberately restrain their earnings so they can keep Medicaid.

  - The same researchers at the Lewin Group are looking at labor force participation and earnings levels of people with disabilities before and after substantial Medicaid expansions in the "natural laboratories" of Tennessee and Oregon.

- Also, we must understand the impact of welfare reform on the nearly 40% of former AFDC recipients reporting a disability. We want states to be able to help many of these "hard to serve" people get into and stay in the work force.

  - Bob Williams co-chairs an Interdepartmental Work Group on Welfare Reform and Disability. That group is pulling together the research -- past, present, and future -- to help understand the characteristics and needs of this special population.

  - ASPE is also supporting two important studies in this area. First, we are surveying states to see how they treat people with disabilities under TANF. We are particularly concerned about

the extent to which states are enabling people with disabilities to enter the work force with appropriate supports. We will have a report by the end of the year.

- We are also adding a disability component to a major study of the impact of welfare reform on poor families with children. Through a comprehensive family survey, as well as intensive longitudinal case studies, we will examine how people with disabilities and their families are doing as a result of welfare reform.

Planned Research

- I believe we have a good research program underway to get some answers, but we still have a long way to go.

- As the Secretary said, we are beginning new studies that will move us much closer to the critical answers we need.

  - First, we are planning to study why some people with severe disabilities are able to work while others are not. What are the characteristics of those who work and the systems that serve them, versus those who do not?

  - Second, the Disability Survey is a rich source of information on work. The latest data will be ready for analysis in the next few months and we will use it to better understand earnings, barriers, accommodations and health care spending and utilization.

    - I know that the Executive Order clearly states that we need good data to address the challenges we face. We are eager to work with you to achieve that goal. The Disability Survey, the first ever comprehensive survey of Americans with disabilities, is a good start. I'm proud of the role my

office has played in developing it.

- And finally, we must get a better understanding of why so few people use the available work incentive programs to leave the rolls and go to work. We will study state and local success stories and identify key factors responsible for their success, and we will talk to consumers who use the programs.

Conclusion

- Thank you for this opportunity to share our findings and activities. I welcome your feedback on our ambitious research agenda. I look forward to combining efforts with you in the coming months and years, as we seek ways to offer people with disabilities the same opportunities afforded those without disabilities to be independent, productive Americans.