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DOES FEDERAL STATISTICAL DATA ADEQUATELY SERVE PEOPLE LIVING WITH DISABILITIES?

HEARING

BEFORE THE

SUBCOMMITTEE ON INFORMATION POLICY, CENSUS, AND NATIONAL ARCHIVES

OF THE

COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

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DOES FEDERAL STATISTICAL DATA ADEQUATELY SERVE PEOPLE LIVING WITH DISABILITIES?

WEDNESDAY, JUNE 4, 2008

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON INFORMATION POLICY, CENSUS, AND NATIONAL ARCHIVES,
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:05 p.m., in room 2154, Rayburn House Office Building, Hon. Wm. Lacy Clay (chairman of the subcommittee) presiding.

Present: Representatives Clay and Turner.

Staff present: Darryl Piggee, staff director/counsel; Jean Gosa, clerk; Alissa Bonner and Michelle Mitchell, professional staff members; Charisma Williams, staff assistant; Leneal Scott, information systems manager; John Cuaderes, minority senior investigator and policy advisor; and Benjamin Chance and Chris Espinoza, minority professional staff members.

Mr. CLAY. The Information Policy, Census, and National Archives Subcommittee will now come to order. In today's hearing we will examine whether Federal statistical data adequately serves people living with disabilities.

Without objection, the Chair and ranking minority member will have 5 minutes to make opening statements, followed by opening statements not to exceed 3 minutes by any other Member who seeks recognition. Without objection, Members and witness may have 5 legislative days to submit a written statement or extraneous materials for the record.

And I will begin with an opening statement. Today we will explore the challenges of collecting reliable data that measures the status of individuals living with disabilities.

We will also examine ways in which the Federal Government can better monitor and evaluate effectiveness of laws, policies and programs that serve disabled Americans.

Over 50 million Americans living with disabilities rely on public programs for support. In addition, the Federal Government spends billions of dollars on programs aimed at improving the lives of individuals with disabilities.

Program enrollment and allocation of Federal dollars have grown and will continue to grow. Therefore, it is essential that Congress and other policymakers know if current programs perform according to expectations.

Hopefully this hearing can begin a process to evaluate current policies and determine whether they are effective to assist people living with disabilities and help Congress plan for future needs.

We have some outstanding witnesses who are here to share their expertise about this issue and to make recommendations on how Congress can best move forward. I thank you all for appearing and look forward to your testimony. And I now yield to the distinguished ranking minority member, Mr. Turner of Ohio. Mr. Turner.

Mr. TURNER. Mr. Chairman, thank you for holding this hearing on whether Federal statistical data adequately serves people living with disabilities. Today we will examine an important aspect facing our Federal statistical community, the assembly of data that is both consistent and intelligible to different agencies and organizations in order to accurately reflect the number of people living with disabilities here in the United States. This type of data is of critical importance to policymakers so they can target specific programs to varying needs.

Mr. Chairman, there are many stakeholders interested in our hearing today. Most importantly are those whose livelihoods are affected by our government's ability to make sure that they are accounted for.

As you know, the results of collecting accurate and uniform data is important to decisionmakers across all levels of government and the private sector. It is not enough to just collect data. We must ensure that what we are doing we are doing in a uniform and accurate manner. Unlike many countries, our Federal statistical system is decentralized. The Census Bureau is not the only Federal agency that collects statistical data. There are also other Federal agencies which have offices that collect narrowly tailored data sets that assist them with agency specific programs.

The problem we are addressing today arises when various agencies collect data using different criteria for what is supposed to be a common problem. As the GAO reported, our current system of data collection for those living with disabilities can easily lead to difficulties. If not managed properly, our decentralized system can sometimes produce confusing and often misleading data on what are supposed to be common factors. For these reasons we need a Federal body to take the lead.

Mr. Chairman, I look forward to a productive hearing with the assembled witnesses we have today. I look forward to hearing witnesses' testimony about how we can account for those with disabilities. Again thank you for holding this hearing, and I yield back.

Mr. CLAY. Thank you so much, Mr. Turner.

If there are no additional opening statements, the subcommittee will now receive testimony from the witnesses before us today. And I want to start by introducing our first panel. We will begin with Mr. Steven Tingus, Deputy Assistant Secretary for Planning and Evaluation within the U.S. Department of Health and Human Services. Prior to his service at HHS, Mr. Tingus worked at the California Foundation for Independent Living Centers, Inc., where he provided an information clearinghouse for the State's 6 million people with disabilities.

And our final witness on the first panel is Mr. Daniel Bertoni, GAO's Director of Education, Workforce and Income Security team.

This team assists Congress by examining whether Federal programs are being effectively implemented and assuring that Federal dollars are spent wisely. The work of his team includes oversight of related programs within the Departments of Health and Human Services, Agriculture, Education, Labor and Veterans Affairs. Thank you both for appearing before the subcommittee today.

And as is the policy of this subcommittee I would like to swear you both in today.

[Witnesses sworn.]

Mr. CLAY. Let the record reflect that the witnesses answered in the affirmative.

I ask that each witness now give a brief summary of their testimony and to keep his summary under 5 minutes in duration. Your complete written statement will be included in the hearing record. And Mr. Tingus, you may begin.

STATEMENTS OF STEVEN TINGUS, DEPUTY ASSISTANT SECRETARY FOR PLANNING AND EVALUATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY MR. ENOCH; AND DANIEL BERTONI, DIRECTOR, EDUCATION, WORKFORCE AND INCOME SECURITY ISSUES, GOVERNMENT ACCOUNTABILITY OFFICE

STATEMENT OF STEVEN TINGUS

Mr. TINGUS. Thank you, Mr. Chairman.

Mr. CLAY. Make sure the mic is on and pull it up closer.

Mr. TINGUS. Thank you, sir. Thank you, Chairman Clay and distinguished members of the subcommittee. I am honored to be here to talk about Federal statistical data on people living with disabilities, and the current state of efforts and resources that we should think about for the future.

As you said, my name is Steven Tingus. I'm the Deputy Assistant Secretary For Planing and Evaluation at Health and Human Services. Prior I was a Director of the National Institute on Disability and Rehabilitation Research at the Department of Education.

While these important positions have been remarkable in my tenure in the administration, my—as you can see, I am a person living with a disability in the community and also in the work force. I was born with a rare form of muscular dystrophy and used technology to maintain my independence. I use a ventilator at night, assistive technologies also during the day, personal assistance services, such as my assistant Mr. Laws, and other types of needs so that I can take care of my activities of daily living, both at home and at the workplace. A vast, extensive research, disability research and service programs and technologies has made the difference for me between a life of dependence and perhaps institutionalization compared to the life I lead, fully independent, active in the community, and a hard worker, and a great career.

I came into the world when people like myself attended handicapped schools, regardless of disabilities. That was before the Individuals with Education Act and the Rehabilitation Act in 1973. Disability services were State and local if they existed at all at that time.

My teacher in the handicapped school said I had the potential to succeed, and she worked to get me into public school. Davis, CA, a city in northern California, said that I could try it if I were mobile. If it weren't for the help that the Muscular Dystrophy Association gave me in purchasing a power chair at that time, I would not be before you today. And as a result I was the first mainstream disabled student in northern California basically in 1974.

I grew up along with the rapid development of private and public services. When I finished high school, I was fortunate and became eligible for SSDI and SSI, which gave me access to Medicare and Medicaid benefits. Since I had a preexisting condition, I was the not eligible for health insurance. Because of the public benefits I was able to attend school, undergraduate and graduate school. After I worked for Governor Pete Wilson in charge of health care for long-term care, and ever since then I've been a proud taxpayer.

I am grateful for the progress thanks to both formal and informal services I received. And I'm glad that many others like me are moving forward. To keep our national disability policy agenda moving forward, we must work on establishing credible data systems about people with disabilities and the services that they use.

As you know, 51 million Americans have a disability and are served by over 200 Federal programs. Thus, data is critical and cover a large range of needs. We're fortunate to live in the United States with excellent civil rights laws. It's a great place for a person with a disability. It can be confusing because of the number of programs. Some people with disabilities get services, but they don't know what program they are on. Thanks to the President's commitment to the New Freedom Initiative, a lot of programs are starting to collaborate in ways that better meet the needs of people with disabilities; for instance, disabilityinfo.gov administered by the Department of Labor.

Many of the surveys contained, as provided in my written testimony, provide a question on disability. However, we need to work on combining these surveys with administrative data such as that provided by SSA to show how many people with disabilities are served by Federal programs.

ASPE, my office and others have been working to merge survey data into one source. By having a variety of data sources on disability provides great benefits to you, the policymaker. Each source measures disability in a particular way. Work is currently under way to standardize survey questions.

I commend my colleagues here, GAO and NCD, for their recent reports on this issue and would like to refer to the programs—that I would—sorry, I would like to say that they are making efforts with regard to the issue, especially providing government coordination. Recently there has been a number of recommendations by NCD to incorporate measures that evaluate participation. I think this is a great step forward and will help the Federal Government to improve services for people with disabilities.

I want to be clear it is very important that services and benefits be well designed and coordinated and that each person is evaluated along their life span, because there are different issues at each life span—part of the life span.

I would like to also say that detailed survey and data information on some populations of disabilities, especially those apparent with ethnicity data, is lacking. And we hope that greater efforts are made by the outcome of this community.

In conclusion, over the past 7½ years we have made enormous strides implementing the President's New Freedom Initiative. Doors have opened in education, community living, technology and work force. I am very pleased to have played a small part in this progress.

The President's initiative for people with disabilities, however, has not been fully met. We remain fully committed to continuing to use disability data to pursue innovative strategies for people with disabilities so that they can partake in the American dream.

Thank you, Mr. Chairman, for holding this meeting and I'm happy to answer your questions.

[The prepared statement of Mr. Tingus follows:]

TESTIMONY OF

STEVEN JAMES TINGUS
DEPUTY ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
DISABILITY, AGING AND LONG-TERM CARE POLICY
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

HOUSE COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM
SUBCOMMITTEE ON INFORMATION POLICY, CENSUS, AND
NATIONAL ARCHIVES

ON

JUNE 4, 2008

Good afternoon, Chairman Clay and distinguished Members of the Subcommittee. Thank you for inviting me here today to talk with you about Federal statistical data on people with disabilities – the current state of our efforts and resources and what we need to think about as we move into the future.

My name is Steven James Tingus and I am the Deputy Assistant Secretary for Planning and Evaluation (ASPE), Office of Disability, Aging and Long-Term Care Policy at the Department of Health and Human Services. Before I came to HHS, I was the Director of the National Institute on Disability and Rehabilitation Research in the Department of Education. Perhaps more important than my positions in the Administration, my career experience in rehabilitation research and independent living…as you can see…I have lifelong personal experience living with a disability.

I will use my time to tell you a bit about my personal experience, because it illustrates the need for accurate disability data for use by policymakers and program developers. As you requested, I will comment on the GAO report, "Modernizing Federal Disability Policy," and the National Council on Disability's recent report, "Keeping Track: National Disability Status and Program Performance Indicators." Next, I will talk about the extensive disability data resources we have today, and finally, offer some thoughts about future disability data development.

My Own Story

I was born with a rare form of muscular dystrophy that is associated with limited mobility and difficulty using my arms to reach. I am a heavy user of assistive technology. For example, I sleep using a ventilator each night and rely on a power wheelchair to work and participate in the community. I also rely on personal assistance to enable me to take care of activities of daily living such as food preparation, dressing and personal hygiene at home and in the workplace. Advancements in disability research, disability service programs and assistive technologies have made the difference for me between a life of dependence, and possibly institutionalization and – the life I have – living in the community and pursuing a great career.

I came into the world when parents were advised to send people like me to "schools for the handicapped." This was before the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973. Disability services, especially in the education arena, were State and local services, if they existed at all. Around the time the Rehabilitation Act was passed, I had a teacher who told me and my parents that she believed I could succeed in regular schools. The Davis, California school system said they would be willing to give it a try but I would need to be mobile. Our local Muscular Dystrophy Association paid for my first power wheelchair, enabling me to become the first disabled student mainstreamed into the Northern California schools.

I grew up in parallel to the rapid development of private and public services for people like me. When I finished high school, I was fortunate to be eligible for the SSDI and SSI programs, which gave me access to Medicare and Medicaid benefits. Since I had a pre-existing condition, I was unable to get health insurance to cover my extensive medical expenses on my parents' policy. Access to public benefits meant that I could attend college and graduate school. I was on Medicare and Medicaid from 1981 through 1995. When I finished school, I had the opportunity to work for Governor Pete Wilson, at which point I went off the public programs; I have been a proud taxpayer ever since.

I am grateful for the progress I have made, it is a credit to my family and to all the formal and informal services from which I have benefited. I am glad there are many others like me. But there is no question that to keep our Nation's disability research and programs moving forward, so that many more can realize their dreams and potential, policymakers and other stakeholders need credible data about people with disabilities and the services and technologies they use.

Americans with Disabilities and the Programs that Serve Them

Who are people with disabilities? In 2002, 51 million people (18 percent of the population) living in the community had some level of disability, and 33 million (12 percent of the population) had a severe disability. (SIPP data, as reported in "Americans with Disabilities, 2002) Although the prevalence of disability increases with age, disability affects persons of all ages. The majority of people with disabilities (56 percent)

are age 15-64. Among adults aged 15-64, 11.8 million (6 percent) reported the presence of a condition that makes it difficult to remain employed or find a job.

What these numbers do not tell you is that people with disabilities are heterogeneous. The functional abilities and needs of those with physical disabilities like my own are vastly different from those with intellectual disabilities. People with mental illness face an entirely different situation in the services they require in order to live high quality, independent lives. These differences mean that disability data, programs and policies have to cover a wide variety of needs, resources and interests.

As we learned in the GAO report that we will be discussing at this hearing, there are over 200 Federal programs serving people with disabilities; they are operated by over 20 Federal agencies. In addition there are over 50 State Medicaid programs (including D.C. and the territories) and countless other State, local and private sector efforts. These health, income, employment and other programs add up to the patchwork quilt that is our Nation's disability system.

Most of these programs, coupled with our excellent civil rights protections under the Americans with Disabilities Act, add up to the United States being the best country in the world for a person with a disability. It can be confusing, though. I have spoken to many people with disabilities who know they are getting education, health, income support, employment or other disability services, but they have no clue what programs they are on!

Thanks in large part to President Bush's commitment to the New Freedom Initiative, a lot of these programs are teaming up and talking to each other, working together to serve people in ways that better meet their needs. One fine example is DisabilityInfo.Gov, a one stop resource for information on disability programs and related information.

Some might argue that we need one, coordinated disability program, but I think that would be a step backwards, given the different needs of a highly diverse population of people with disabilities. It is this diversity across our Federal, State, local and private programs that makes our service systems so well developed. This same diversity, however, makes it difficult to define and measure disability.

Disability Data Resources

Although many of the surveys conducted by the Federal Government contain at least one question on disability, several collect a considerable amount of information on disability, and are frequently used by policymakers and/or are cited in the media or academic journals.

The National Health Interview Survey (NHIS) helps us monitor the health of the population. Each year data are collected from approximately 87,500 persons of all ages living in 35,000 households. In 1994 and 1995, ASPE and other organizations provided funding to add an extensive set of questions on disability through a supplemental survey

to the NHIS. Detailed data on the conditions associated with the disability, their impact on functioning, living arrangement, caregiver characteristics, accommodations needed, and services used, were collected on all persons in the NHIS.

Several questions on disability were added to the redesigned NHIS in 1997, and have been included each year since then. Since it was first conducted in 1957, the NHIS has proven to be a valuable tool for monitoring the health of Americans. The findings on disability have been mixed. Disability is declining among the elderly, but recent analyses have begun to show increasing disability among working aged adults, some of it associated with increasing weight and obesity. (Health Affairs, January-February 2004, page 168, "Are the Young Becoming More Disabled?", Darius Lakdawalla, et. al.)

The NHIS sample forms the basis for another important HHS data collection effort, the Medical Expenditure Panel Survey (MEPS). Each year MEPS collects detailed information on all of the medical and health services used by a sample of households. Although provider surveys and insurance claims enable us to measure how much spent at the aggregate level in the CMS National Health Accounts, MEPS and similar surveys are critical for understanding who is using these services, and how they and their families pay for them.

The Survey of Income and Program Participation (SIPP) provides another source of disability data on persons of all ages. This panel survey has been conducted since 1984. The 2004 panel consisted of 46,500 households that were interviewed eight times. And

due to a sample cut in 2006, 22,400 households were interviewed twelve times. This household survey contains detailed questions on disabilities and their impact on functioning. SIPP also collects data on the Federal programs that people use. Researchers have used SIPP data to study the characteristics of persons enrolled in SSDI, SSI, and other Federal programs. In addition, SIPP data have been used in simulating the impacts of potential changes in these programs.

A recently implemented survey, the American Community Survey (ACS), collects some of the disability and other data that the other household surveys collect, but the ACS sample is much larger. Although the ACS contains only a few questions on disability, the large sample size enables us to show how disability rates vary across states and local areas. Moreover, since the ACS contains a wealth of household information, it helps us understand the characteristics of persons with disabilities and the families, e.g., their level of education, whether they are foreign born, and how they are currently employed.

Two longitudinal surveys provide valuable information on elderly persons with disabilities. The National Long-term Care Survey (NLTCS) is a sample of people age 65 and over with disabilities. This survey has been used to monitor trends in disability and functioning among the elderly. The Medicare Current Beneficiary Survey (MCBS), while not designed specifically as a disability survey, provides valuable data each year on Medicare beneficiaries and the health services they receive.

The Health and Retirement Survey (HRS) surveys adults age 51 and older every two years. It provides valuable information on the characteristics and financial resources of persons approaching retirement, and then follows them through their retirement years. It enables us to understand disabilities that occur prior to retirement, as well as the impact of disabilities occurring after retirement.

Besides surveys, administrative data also help us understand how many persons with disabilities are served by Federal programs. SSA provides regular updates on the numbers of people who benefit from SSDI and SSI, and the amounts of the checks they receive. But administrative data provide little personal information beyond age and gender. ASPE and other agencies have been working to merge survey data with administrative records. For example, ASPE, NCHS, CMS, and SSA have merged SSDI, and SSI records, and Medicare enrollment and claims records, with the NHIS.

The resulting data set enables us to answer questions that could not be answered with survey or administrative record data alone. For example, many people with disabilities understand that they receive a check from the government, but they often do not know the name of the program that provides the check. By linking the payment records to the survey data, researchers are able to identify the specific program that provides their support. Furthermore, the utility of such linked administrative and survey data sets would be greatly enhanced by facilitating access by other Federal agencies and academic institutions.

Surveys of providers also provide valuable information on persons with disabilities. The National Nursing Home Survey (NNHS) is a sample of nursing homes and their current residents. It provides detailed data on the extent of the disability and the level of functioning. ASPE is working with NCHS and other agencies to conduct a similar survey of residential care facilities (sometimes referred to as assisted living facilities), which have become an important source of care for many elders, often serving as a substitute for nursing home care at the earlier stages of disability.

While having a variety of data sources on disability provides many benefits to policy makers and researchers, each source measures disability in a particular way. Comparing estimates of the numbers of persons with disabilities across surveys, for example, can be challenging when different questions underlie each of the estimates. Work is underway to standardize the questions used in surveys. For example, the disability questions used on the ACS are being added to the Current Population Survey (CPS) and the National Crime Victimization Survey (NCVS), as well as being tested for use in the NHIS. The CPS is the major source of data for computing employment and unemployment rates. Having disability questions on the CPS will enable us to compute rates for persons with disabilities and others each month.

The GAO and NCD Reports

I am pleased that the Comptroller General convened a Forum on Federal Disability Policy and issued a report on the Forum in August of last year. I look forward to hearing

Mr. Bertoni's testimony and I would like to commend GAO on the report entitled "Modernizing Federal Disability Policy."

We at HHS welcome the GAO's line of inquiry: what is working well in our disability programs and what needs improvement? We continually engage in this same conversation, internally and with stakeholders in the consumer, provider and research sectors – for instance, the Centers for Medicare and Medicaid Services regularly holds Open Door Forums, in addition to meeting regularly with consumer and provider groups.

We are pleased to note that the GAO Forum participants recognized the need for more coordination across government programs. This theme is continued in the recent GAO report, "Federal Disability Programs: More Strategic Coordination Could Help Overcome Challenges to Needed Transformation." We agree that partnership and coordination are vital so that individuals with disabilities can make the most of the opportunities out there.

Some participants in the GAO Forum thought it would be a good idea to have one large, national full service disability program. I am glad that the Forum and the subsequent report provided the opportunity for us to discuss how to improve our disability programs. I believe that even if it were possible to combine all the various programs and eligibility groups – it would not serve people with disabilities well.

Speaking for myself, I did not need access to every possible service. My family, for example, provided me with transportation, housing and personal assistance services while

I was in college and graduate school. I am glad I was able to go directly to the services that met my needs. I think that one massive government bureaucracy would detract from the ability of targeted programs to meet targeted and unique needs. It is due precisely to the wide range of programs, I was able to get right to the services and supports I needed when I was a consumer of public benefits.

However, I want to be clear that I think it is very important that services and benefits be well designed and well coordinated. This is exactly why many Federal agencies work together on programs that serve people throughout the lifespan. My Department has invested a lot of resources in single point of entry programs; informally these are known as "no wrong door." This approach recognizes that people with disabilities and their family members may be confused about eligibility and where to go for what services.

One great example is the Aging and Disability Resource Center (ADRC) program, a cooperative effort of HHS's Administration on Aging and the Centers for Medicare and Medicaid Services. The ADRCs were developed to assist States in creating a single coordinated system of information and access for everyone seeking long-term supports, to minimize confusion, enhance individual choice and support informed decision making. Since 2003, 43 States have set up ADRCs. Strategic partnerships across programs are the key to the success of these programs.

A recent report "Keeping Track: National Disability Status and Program Performance Indicators" prepared by the National Council on Disability, provides many suggestions

for improving disability data used in assessing the extent to which Federal programs have improved the lives of persons with disabilities. The report recommends the development of a standard set of disability questions that can be used across all Federal surveys. This is a useful goal to pursue, and considerable effort has been made on this project thus far. If the standardized set of questions is widely adopted, then a number of indicators could be computed from various Federal surveys that would demonstrate how persons with disabilities compare with other people. At the current time only a limited number of comparisons are possible, although we have the core questions in the American Community Survey, which are being incorporated into a growing number of other Federal surveys. These are discussed in more detail in a statement for the record provided by Susan Dudley, Administrator of the Office of Management and Budget, Office of Information and Regulatory Affairs. It is critical, of course, that the multiple administrative and survey data collection efforts are able to continue to identify and gather information needed to meet their unique purposes and users' needs.

The report also suggests a number of measures of the quality of life of persons with disabilities which measure the extent to which they are able to participate in life activities. Many of these measures have not been collected on major federal surveys, and considerable work is needed to develop and test possible questions.

In addition, the report encourages the Federal Government to more fully disseminate data from Federal surveys in a form which compares persons with disabilities to others along several dimensions, including gender and race. Some tables along these lines have been

generated from many surveys, but more can be done, especially as the use of a standard set of disability questions becomes more widespread. We at HHS face this challenge directly as we work, each year, on the National Quality and Disparity Reports to Congress.

Moving Forward: Considerations for Developing our Disability Data

As mentioned earlier, good disability information is critical for determining the effectiveness of current programs, legislation, and initiatives to promote the independence and well-being of persons with disabilities. Specifically, we need good data at the population level in order to monitor aggregate changes, and sometimes even at the State or local level. We also need to ensure that data cover all ages of the population such as children, working age adults, older Americans, and persons with specific types of disabilities, including those from various ethnic groups.

Many of our current survey and data collection efforts adequately meet our needs; however, in many cases the information to help formulate policy or evaluate programs is lacking. For example, national surveys are of limited use to policymakers interested in the use of long-term care services by the working age population. The reason is fairly simple: the number of younger persons needing assistance with activities of daily living is relatively small compared to the overall population. To put this in perspective, less than 2 percent of the working age population (aged 25 – 64) needs personal care according to the 2002 Survey of Income and Program Participation. While this

percentage represents nearly two million persons, the survey's sample size is really too small to be of analytic value to policymakers interested in determining the effectiveness of specific programs. We also know relatively little about the prevalence of some types of disability because we do not have good measures. Cognitive impairment and dementia are two specific examples of disabilities where we have wide variations in prevalence because we are still in the early stages of developing statistically valid and reliable measures of these concepts.

We may need new surveys to meet our data needs in some circumstances, yet more innovative approaches to data collection could be useful. We could, for example, add questions to current surveys and supplement current data collection efforts by linking administrative data. Several years of cross-sectional data could be pooled to increase sample sizes. At a minimum, we need to further develop our current measures of disability and continue to think creatively about how best to collect data and to determine the prevalence of certain disabilities.

Conclusion

Over the past seven and a half years, we have made enormous strides implementing President Bush's New Freedom Initiative. Doors have been opened in education, community living, technology, transportation and work supports, to name only a few. I am pleased to have been able to play a small part in this progress. The President's vision for people with disabilities is not yet fully achieved, however. We remain fully

committed to continuing to develop and use disability data to pursue innovative strategies to ensure that the diverse groups of people who are Americans with disabilities are able to partake in the American Dream.

Mr. CLAY. Thank you so much, Mr. Tingus. Mr. Bertoni, you may proceed.

STATEMENT OF DANIEL BERTONI

Mr. BERTONI. Mr. Chairman, members of the subcommittee, good afternoon. I'm pleased to be here to discuss the importance of comprehensive and reliable data as a tool for evaluating Federal policy in assessing the status of those with disabilities. At present about 50 million individuals in the United States have a disability and are served by more than 20 agencies and almost 200 Federal programs which provide an array of assistance such as employment services, medical care and monetary support.

We have reported that Federal programs generally compile and track data to assess whether they are meeting specific service delivery goals, such as improved case processing times rather than to provide for a more comprehensive assessment of the status and well-being of the disabled population on the national level. Thus, we continue to lack key data on how individuals with disabilities are faring and what role Federal programs play in this regard.

My remarks today focus on the limitations of data currently available to assess the status of those with disabilities and how better coordination could facilitate the collection of data to inform policy decisions.

In summary, disability policy and programs in the United States have been developed on an individual basis over many years with success often measured by narrow, programmatic outcomes rather than a set of unified national indicators essential to determining how we as a Nation are serving this population.

The many programs serving those with disabilities often have different missions, goals, funding streams and eligibility criteria, and they also vary in the populations served due to different definitions of disability. Not surprisingly, the data these programs collect is often unique to their individual caseloads, processing goals and timeframes, and cannot be easily compiled to assess whether the beneficiaries are being provided comprehensive services and supports nationwide.

Some efforts are underway to improve the consistency and quality of data on a national level, more specifically in the area of some Federal surveys where standardized questions and definitions of disability are slated to be used to better assess disability status.

Experts who participated in our 2007 Comptroller General Forum on Disability Policy have noted that standardized language that can be used by related programs could facilitate consistent data collection, as well as any future efforts to assess the status of individuals with disabilities.

We and others have also acknowledged the need to move beyond narrowly focused programmatic measures and to develop a comprehensive set of outcomes to measure the Federal Government's success toward improving the lives of individuals with disabilities. To that end some experts have suggested using multiple indicators, including quality of life and economic indicators, as key data elements. Regardless of the indicators ultimately selected, rigorous data reporting requirements should also be established to ensure comprehensive and reliable information is available.

In regard to this issue, the National Council on Disability's recently issued report is consistent with our view given the complex challenges facing our Nation, including serving those with disabilities. Indicator systems can be useful for measuring progress toward meeting national goals, identifying gaps in service delivery, ensuring accountability and helping the Congress set priorities.

Moreover, GAO has called for a strategic plan for all of government, supported by national outcome-based indicators for key programs. The NCD report and other data sources could inform this effort in the area of disability policy.

In conclusion, taking the critical first steps would be finding agreed upon outcomes for assessing the status of individuals with disabilities, and the metrics that will be used to measure progress will require a coordinated effort. Unfortunately, prior initiatives to coordinate Federal disability programs have not been successful in this regard, most notably the Interagency Disability Coordination Council established by Congress in 1992. Without strong Federal leadership to facilitate governmentwide agreement on outcomes and coordination of cross-cutting programs, it's unlikely that leaders from individual agencies will be able to effectively reach consensus.

In May 2008, we noted that the Congress should consider authorizing a viable coordinating entity consisting of key Federal agencies that serve people with disabilities. As part of its mandate this entity could facilitate discussion, build consensus on national outcomes for Federal disability programs and the data necessary to assess progress. It could also work to bridge the gap between needed and available information and prioritize further data collection efforts.

Mr. Chairman, this concludes my statement. I'm happy to answer any questions that you or other members of subcommittee may have. Thank you.

[The prepared statement of Mr. Bertoni follows:]

United States Government Accountability Office

GAO

Testimony
Before the Subcommittee on Information Policy, Census, and National Archives, Committee on Oversight and Government Reform, House of Representatives

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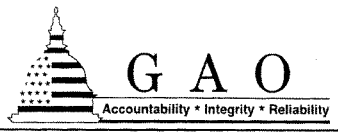
FEDERAL DISABILITY PROGRAMS

Coordination Could Facilitate Better Data Collection to Assess the Status of People with Disabilities

Statement of Daniel Bertoni, Director
Education, Workforce, and Income Security



GAO-08-872T

June 4, 2008

GAO
Accountability·Integrity·Reliability
Highlights

Highlights of GAO-08-872T, a testimony before the House Subcommittee on Information Policy, Census, and National Archives, Committee on Oversight and Government Reform

FEDERAL DISABILITY PROGRAMS

Coordination Could Facilitate Better Data Collection to Assess the Status of People with Disabilities

Why GAO Did This Study

Multiple federal programs provide services and support to the approximately 50 million individuals with disabilities in America. While some health and economic data on people with disabilities are currently available, these data have limited use in providing a comprehensive assessment of how these individuals are faring. Additionally, the lack of more useful data limits the federal government's ability to determine how well federal programs are serving individuals with disabilities.

GAO is providing information on (1) the limitations of data currently available to assess the status of individuals with disabilities and (2) how better coordination could help facilitate the collection of such data to inform policy decisions.

This statement is based on prior GAO reports, including the May 2008 report on modernizing federal disability programs (GAO-08-635), the 2007 Comptroller General's forum on disability (GAO-07-934SP), and multiple reports on national indicators (e.g. GAO-05-1); and studies by other organizations, including the National Council on Disability.

What GAO Found

Disability policy and programs in the United States have been developed on an individual basis over many years, with success being measured by individual program outcomes rather than with a unified set of national goals and indicators to assess how people with disabilities are faring. In 2005, GAO identified over 20 federal agencies and almost 200 federal programs serving individuals with disabilities that provided a wide range of assistance, such as employment-related services, medical care, and monetary support. These programs often have different missions, goals, funding streams, eligibility criteria, and policies that sometimes work at cross-purposes with other federal programs. In addition, these programs collect data to measure specific programmatic goals but not to provide a set of metrics to assess how federal programs are improving the lives of individuals with disabilities. Although other data on individuals with disabilities are collected on a national level, these data do not share consistent definitions of disability. As a result, these data cannot be easily compiled to create a comprehensive picture of the status of individuals with disabilities, which could better inform federal disability policy and help ensure that beneficiaries are given timely and appropriate supports. GAO and others have acknowledged the need for creating a common set of outcomes for disability programs and the appropriate measures for assessing progress toward shared goals.

To facilitate an effort of reaching consensus on desired outcomes for people with disabilities, coordination among the key players in the disability community is required. In May 2008, to better serve people with disabilities, GAO suggested that Congress consider authorizing a coordinating entity consisting of leadership from appropriate agencies that serve this population to develop a cost-effective strategy to integrate services and supports for individuals with disabilities. Consistent with its proposed charter, such an entity should play a critical role in developing agreed-upon, desired outcomes for disability policies and programs and in determining what metrics and data will be used to assess progress toward meeting those outcomes.

To view the full product, including the scope and methodology, click on GAO-08-872T. For more information, contact Daniel Bertoni at (202) 512-7215 or bertonid@gao.gov.

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss the importance of comprehensive and reliable data to evaluate policy and assess the status of people living with disabilities. About 50 million individuals in the United States are reported to have a disability. Although some health and economic data are currently available, these data have limited use in providing insight into the status of people with disabilities. The lack of more useful data also limits the federal government's ability to determine how well individuals with disabilities are faring and what role federal programs play. My remarks today focus on (1) the limitations of data currently available to assess the status of individuals with disabilities and (2) how better coordination could help facilitate the collection of such data to inform policy decisions.

My statement is based on our May 2008 report on modernizing federal disability programs, our 2007 Comptroller General forum on disability, and other prior GAO reports. (See related GAO products at the end of this statement.) We also reviewed studies conducted by other organizations, including the National Council on Disability. We conducted our work in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

In summary, disability policy and programs in the United States have been developed on an individual basis over many years, with success being measured by individual program outcomes rather than with a unified set of national goals and indicators to assess how people with disabilities are faring. In addition, these programs collect data to measure specific programmatic goals but not to provide a set of metrics to assess how federal programs are improving the lives of individuals with disabilities. GAO and others have acknowledged the need for creating a common set of outcomes for disability programs and the appropriate measures for assessing progress toward shared goals. To facilitate this effort, coordination among the key players in the disability community is required. In May 2008, to better serve people with disabilities, we suggested that Congress consider authorizing a coordinating entity consisting of leadership from appropriate agencies that serve this population to develop a cost-effective strategy to integrate services and supports for individuals with disabilities. Consistent with its proposed

charter, such an entity should play a critical role in developing agreed-upon, desired outcomes for disability policies and programs and in determining what metrics and data will be used to assess progress toward meeting those outcomes.

Background

Multiple federal programs provide services and support to individuals with disabilities. To hold federal agencies accountable for their programs, certain data are collected and used to assess program performance. The Government Performance and Results Act of 1993 (GPRA) mandates that federal agencies develop performance information describing the relative effectiveness and efficiency of federal programs and requires federal agencies to publish strategic and annual performance plans describing specific program activities. While these performance data are critical for assessing program effectiveness, it is unique to each program's mission and has a limited focus.

Data that are more comprehensive can help generate a broader perspective on the status or condition of various issues. Indicators, which can produce more comprehensive data, are used as quantitative measures to describe an economic, environmental, social, or cultural condition over time. The unemployment rate, infant mortality rates, and air quality indexes are a few examples of national indicators. There are several types of indicators; some involve specific or related sets of issues, such as health, education, public safety, employment, or transportation, while comprehensive indicator systems pull together only the most essential indicators on a range of economic, environmental, social, and cultural issues. These data can help inform policy areas by clarifying problems and opportunities, identifying gaps in what we know, setting priorities, testing effective solutions, and tracking progress toward achieving goals. The National Council on Disability and other disability experts have advocated for developing better indicators to assess the status of individuals with disabilities.

Current Data Limit the Assessment of the Overall Status of People with Disabilities

Disability policy and programs in the United States have been developed on an individual basis over many years, with success measured by individual program outcomes rather than by a unified set of national goals and indicators that assess how people with disabilities are faring. In 2005, we identified over 20 federal agencies and almost 200 federal programs serving individuals with disabilities that provided a wide range of assistance, such as employment-related services, medical care, and monetary support. These programs often have different missions, goals,

funding streams, eligibility criteria, and policies that sometimes work at cross-purposes with other federal programs. In addition, these programs primarily collect data to assess whether they are meeting specific goals rather than collect data to make a more comprehensive assessment of how the population they are serving is faring. For example, the Social Security Administration's (SSA) performance measure of the average time to process a disability claim provides information on how SSA is meeting its program goals with respect to service delivery, but the measure does not provide direct information on the well-being of the individuals applying for benefits.

While other data on individuals with disabilities are collected on a national level, these data do not share consistent definitions of disability. As a result of this variation, these data cannot be easily compiled to create a comprehensive picture of the status of individuals with disabilities, which could better inform federal disability policy and help ensure that beneficiaries are given timely and appropriate support. Some efforts are being made to improve the quality and usefulness of national data. For example, according to a Department of Labor official, the Bureau of Labor Statistics' national Current Population Survey (CPS) will incorporate new disability questions into its household survey. The CPS questions will be based on existing questions used in the American Community Survey and will use the same definition of disability. These questions could advance federal efforts in assessing the status of people with disabilities. Also, to better define disability terms and concepts, experts have suggested applying a broader approach by creating a conceptual framework within which all disability programs would operate and use standardized disability language. Experts who participated in our 2007 Comptroller General Forum on Modernizing Disability Policy generally agree that a standardized language that can be used by related programs would facilitate consistent data collection, as well as any efforts to assess the status of individuals with disabilities.

We and others have acknowledged that a common set of outcomes to measure the federal government's success toward improving the lives of individuals with disabilities is needed. This includes the need to move beyond narrowly focused programmatic measures that capture specific data, like the average time an agency takes to process a disability claim. Experts have suggested using multiple indicators, including quality of life and economic indicators, to develop a more comprehensive picture of how individuals with disabilities are faring. Regardless of the indicators selected, data-reporting requirements should be established to track outcomes to obtain the data needed to inform disability policy.

The National Council on Disability's (NCD) recent report *Keeping Track: National Disability Status and Program Performance Indicators* is consistent with our view that given the complex challenges facing our nation—including serving those with disabilities—indicator systems are useful for measuring progress toward national outcomes, assessing conditions and trends, and helping to disentangle complex program and policy issues.[1] Such indicators could also help identify gaps in what we know and help Congress set priorities and track progress toward achieving results. In developing and implementing an indicator system, we have reported that it would be helpful to establish a clear purpose, define target audiences and their needs, and ensure independence and accountability. Finally, we have also called for a strategic plan for all of government, supported by a portfolio of national and outcome-based indicators for key programs. The NCD report and other data sources could help develop such a plan in the area of disability policy regarding metrics needed to assess the well-being of individuals with disabilities.

Coordinated Strategy Needed to Determine Desired Outcomes and Assess the Status of People with Disabilities

To determine the status of people with disabilities and to define agreed-upon outcomes, a coordinated effort is needed. In May 2008, we reported that a comprehensive federal strategy for coordinating federal disability programs was lacking. We suggested that Congress consider authorizing a coordinating entity consisting of leadership from agencies that serve people with disabilities. This entity could be responsible for leading the effort on reaching consensus on desired outcomes for federal disability policies and programs. This entity could also determine what measures are necessary to assess progress made toward meeting a unified set of goals for people with disabilities. A coordinated entity could also work to bridge the gap between needed and available information and prioritize further data collection.

As Congress considers authorizing such an entity, it should pay particular attention to the membership and goals of this coordinating body. In 1992, Congress authorized the Interagency Disability Coordinating Council (IDCC) to coordinate federal activities to promote independence and productivity of individuals with disabilities. However, to our knowledge, the IDCC has never met or reported to Congress, as required by law. In a prior report, we have identified criteria for successful coordination,

[1]National Council on Disability, *Keeping Track: National Disability Status and Program Performance Indicators* (Washington, D.C., 2008).

including defining and articulating common outcomes and establishing mutually reinforcing joint strategies among federal agencies to achieve identified goals that could be instructive for this purpose.[2] Additionally, the coordinated entity could work with the Interagency Commission for Disability Research to identify what data are available and what data should be collected to assess how individuals with disabilities are being served and how they are faring overall.

Mr. Chairman, this concludes my statement. I would be happy to answer any questions you or other members of the subcommittee may have at this time.

GAO contact and Staff Acknowledgments

For further information regarding this testimony, please contact Daniel Bertoni, Director, Education, Workforce, and Income Security at (202) 512-7215, or bertonid@gao.gov. Shelia Drake (Assistant Director), Susannah Compton, Jean Cook, and Anjali Tekchandani also contributed to this statement.

[2]GAO, *Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies*, GAO-06-15 (Washington, D.C.: Oct. 1, 2005)

Related GAO Products

Federal Disability Programs: More Strategic Coordination Could Help Overcome Challenges to Needed Transformation. GAO-08-635. Washington, D.C.: May 20, 2008.

A Call for Stewardship: Enhancing the Federal Government's Ability to Address Key Fiscal and Other 21st Century Challenges. GAO-08-93SP. Washington, D.C.: December 2007.

Highlights of a GAO Forum: Modernizing Federal Disability Policy. GAO-07-934SP. Washington, D.C.: August 3, 2007.

Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies. GAO-06-15. Washington, D.C.: October 21, 2005.

Federal Disability Assistance: Wide Array of Programs Needs to Be Examined in Light of 21st Century Challenges. GAO-05-626. Washington, D.C.: June 2, 2005.

Informing Our Nation: Improving How to Understand and Assess the USA's Position and Progress. GAO-05-1. Washington, D.C.: November 10, 2004.

Forum on Key National Indicators: Assessing the Nation's Position and Progress. GAO-03-672SP. Washington, D.C.: May 2003.

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Mr. CLAY. Thank you, Mr. Bertoni. Thank you both for your testimony. This now—we will now begin the Q and A portion of the hearing. I will start with Mr. Tingus.

NCD made six recommendations on how the Federal Government can improve its collection of data. One of the recommendations was to have the National Institute on Disability and Rehabilitation Research establish and fund a coalition of disability policymakers and advocates to develop a fuller set of indicators that are important to people with disabilities, building on the indicators in the report.

Is this something that can be accomplished by NIDRR? And if so, what would it require, particularly from Federal agencies that currently serve an individual with disabilities?

Mr. TINGUS. Mr. Chairman, as you well know I was the former Director of NIDRR, N-I-D-R-R. I cannot speak on behalf of the Department of Education. However, NIDRR does have an Interagency Committee on Disability Research and you may want to contact officials at the Secretary's Office to talk to the staff about the possibility of them undertaking such a responsibility.

Mr. CLAY. I do understand the sensitivity of the question.

Mr. TINGUS. There's a body there——

Mr. CLAY. OK.

Mr. TINGUS [continuing]. Within NIDRR that could address the need.

Mr. CLAY. The committee staff will followup with that. Thank you for that response.

Mr. TINGUS. Thank you, sir.

Mr. CLAY. Let me—has the Department of Health and Human Services implemented any other recommendations made by GAO or by participants in GAO's forum. If so, which ones?

Mr. TINGUS. Sir, one of the recommendations was the establishment of the Aging and Disability Resource Centers, that the Administration on Aging is heading. And that is our first job in addressing the need of gathering more data on both those aging and those aging with a disability.

Mr. CLAY. OK. Thank you for that response. Does the President's New Freedom Initiative have a provision for collecting comprehensive data on people with disabilities?

Mr. TINGUS. To my knowledge, sir, I would have to look at the current version of the NFI to see what status that those, SSA and other agencies, are doing. But I can get that information to the subcommittee.

[The information referred to follows:]

Question for the Record to Steve Tingus, HHS

House Committee on Oversight and Government Reform
Subcommittee on Information Policy, Census, and National Archives
"Does Federal Statistical Data Adequately Serve People Living with Disabilities?"
June 4, 2008

Question from Chairman Clay: Does the President's New Freedom Initiative address issues related to data collection?

Answer: The 2007 Progress Report on the President's New Freedom Initiative (NFI) includes a chapter entitled "Working to Ensure that Everyone Counts." This chapter outlines the Bureau of the Census's targeted accomplishments and planned next steps. Specifically, they are as follows:

The President believes that one key to ensuring full participation by people with disabilities is ensuring that they are included in the Census Bureau results. This allows more efficient delivery of essential services, more timely evacuation in emergencies, and more equitable use of resources.

Accomplishments:

- The Census Bureau has established a Disability-Data Users Group to provide a forum for bilateral communication to share ideas, comments, research, and analysis on disability data collected at the Census Bureau.

- The Census Bureau has produced a series of reports entitled "Americans with Disabilities," which are developed using data from the Survey of Income and Program Participation (SIPP).

- The Department of Labor's Bureau of Labor Statistics (BLS), in cooperation with the Employment Rate Measurement Methodology Interagency Workgroup, is determining ways to modify the Current Population Survey (CPS) in order better to track employment rates of individuals with disabilities.

Next Steps:

- The Census Bureau is currently re-engineering the Survey of Income and Program Participation (SIPP) to improve the accuracy, timeliness, and quality of data on economic well-being and program dynamics.

- The Census Bureau has evaluated the results of the disability questions that were tested as part of the 2006 American Community Survey (ACS) Content Test. The tested questions will be included in the Census Bureau proposal for the 2008 ACS.

- The Census Bureau will release the results of the Current Population Survey Annual Social and Economic Supplement by October 2008.

- The Census Bureau expects to build upon the accomplishments from the 2000 Census and to duplicate similar partnerships with the disability population in preparation for the next decennial census in 2010.

- The National Council on Disabilities (NCD) is developing a sample national disability performance indicator system that may be considered for use by the Federal Government or any of its various components to assess the quality of life of Americans with disabilities.

In addition, the 2007 Progress Report on the NFI describes an assessment instrument developed by the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, to uniformly collect assistive device and environmental information from adults with disabilities and older persons living in the community during national surveys.

Further, the report notes that the Department of Health and Human Services will continue to support the national database and resource website on home and community-based services at http://www.hcbs.org.

Finally, the report describes progress made by the Department of Justice's Bureau of Justice Statistics (BJS) in tracking crime victimization of individuals with disabilities. To advance the requirements of the Crime Victims with Disabilities Awareness Act, new questions are being tested for possible incorporation into the National Crime Victimization Survey, which is collected for BJS by the Census Bureau of the Department of Commerce.

The Bureau of Justice Statistics, in response to the Crime Victims with Disabilities Awareness Act, notes that it is working to produce estimates of the number of crimes committed against people with disabilities and evaluate the relative risks for these groups.

Mr. CLAY. I'd thank you for that.

You note in your testimony that there are varying disabilities. This is an important point and will also be stated by members of our second panel. You also state that even if it were possible to combine all of the various programs and eligibility groups, it would not serve people with disabilities well.

Is it possible to have one survey for collecting data on all people with disabilities or should there be different surveys that allow data to compared across agencies?

Mr. TINGUS. Sir, I believe that having one bureaucracy handle this issue would not serve individuals, say, with physical disabilities versus mental health issues versus intellectual disabilities. All of our needs are different. And I believe that our current instruments, while in place, could be dramatically improved by the measures and the questions that are included in the surveys. So I as a person with a disability needing that information as a current member of the administration would value that, but I don't think a one-stop place would serve all people with disabilities.

Mr. CLAY. So—go ahead.

Mr. TINGUS. No, go ahead.

Mr. CLAY. So for instance, the VA should be allowed to render their services to the disabled community that they serve then?

Mr. TINGUS. Yes, sir.

Mr. CLAY. I see.

You note that considerable work is needed to develop and test possible questions that would measure the quality of life of persons with disabilities and the extent to which they can participate in life activities.

Mr. TINGUS. Uh-huh.

Mr. CLAY. Could you tell us a little more about the type of work that must be done and give a rough time line of how long it would take to complete this work?

Mr. TINGUS. Sir, I'm not a statistician or a data collector. However, as a person responsible for helping to coordinate the effort, there are many factors in our lives that need to be measured so that we can have a benchmark and look at improvements for people with disabilities such as going to church, going out to dinner with our friends, the ability to go out because of adequate transportation and assistance. Factors other than just saying, "oh, I'm physically disabled" or "I have a mental health disability" isn't enough in today's world. And it doesn't provide you or your members adequate data to make decisions that affect the 50 million Americans with disabilities. So a lot of work has to be done that I think coordination, as NCD and the GAO have reported, is the best step forward.

Mr. CLAY. Thank you for that response. Thank you for your answers.

Mr. Bertoni, the National Council on Disability recommended using qualitative, as well as quantitative measures to assess the quality of life of people living with disabilities. Can qualitative factors, which may in some cases be subjective, be used as effective measures?

Mr. BERTONI. I have seen the literature where the qualitative-quantitative, objective-subjective—there is validity in that whole

range of measures. And I think it's probably more valid when you have some combination thereof in any vehicle that you send out to try to get your sense of what's going on in a particular group.

Certainly when you get into some of the qualitative areas, the quality of life, there's going to be many potential stakeholders that should be involved in that discussion. There will be many opinions as to what the desired outcome that they are shooting for in any particular policy area; disability policy would be no different. Numerous stakeholders, agency advocacy groups experts, etc. Many opinions, priorities and perceptions as to what should be included in that. I think—can it be done? There are vehicles out there now that have mixtures of qualitative-quantitative, subjective-objective to give you a more holistic picture of a population. But I would agree with the gentleman, he just stated that takes time, and there needs to be consensus.

With variation in opinion, I think you're going to have to have an in-depth discussion across groups, and I think a key thing to keep in mind here is—and we've reported on this—that no one sector or group should own the process. This should be inclusive, it should be transparent, and I think there should be acknowledgment that going into this process there are going to be tradeoffs and folks will have to have some give and take in terms of what's ultimately included in a set of indicators to assess the status of the disabled.

So I think it can be done. At the end of the day what we end up with, will folks—will everybody agree on the range of measures or indicators that we selected? Probably not. But I think if you can—if the folks buy into the process, its inclusiveness, its transparency. The fact that all ideas were vetted, all indicators were vetted, and the time that folks put into this effort I think ultimately the community of stakeholders will fall in behind the indicators. We need something and we don't have much now.

Mr. CLAY. Thank you for that response.

Mr. Turner.

Mr. TURNER. Well, I want to thank you both for participating in this hearing. And Mr. Tingus, I want to thank you for your description of your personal history, because not only is it very inspirational, but it's a great timeline of how resources, and interests, and adaptability has shifted. Your sharing that story with us certainly, certainly helps us and I appreciate it.

My first question to both of you relates to the census itself and accurate counting. Mr. Tingus, when you began your description, you spoke of the assistance of technology that allows you to have the great career that you have today.

Mr. TINGUS. Right.

Mr. TURNER. And some of the accomplishments that you've had. And one of the concerns that we have is that as the surveys are being undertaken as part of the census, you know, that they be accessible to those with disabilities. And we're obviously concerned that possible implementations and changes to data collection must take into account the different mediums that are required to collect data from all parties.

And I wonder if either of you had an opinion or information you could share with us about our success or lack of success in provid-

ing accommodation for the various technologies for disabled individuals to participate?

Mr. TINGUS. Sir, I think I will begin in answering that question. A lot has been accomplished through section 508 with regard to accessible IT. But I believe there needs to be a lot more work to be done, especially with the evolution of the Web and now talk about a Web 2.

Making information available to persons with disabilities has always been one of the forefront efforts I believe in my department, but the Department of Education as well. And I believe that will continue. To the degree it depends upon Congress, as you well know, there is limited funding. I believe there needs to be more public-private partnership with regards to making all sources of information accessible, not only that coming from the Federal Government. So I think—I think we are all doing our effort, but obviously that need will change as technology changes, both for the person and as a communication tool.

I hope I answered—I think——

Mr. TURNER. Yes, you did. And I appreciate it very much. Mr. Bertoni, do you have any comments on this issue?

Mr. BERTONI. I can't speak to what is, because I don't have that information. I can speak to perhaps what should be. Clearly with technology that we have today, if you are trying to tap into a specific community or subpopulations within the disabled community, you have to have a way to get there. And I do believe that we have technology available to us now that I—I don't see that as insurmountable. We—you just have to want to do it. I think it would require public-private partnerships to get there. I don't know how much is being done now. If it isn't, I think it will require public-private partnerships.

One issue I—or concern that just came to mind is what's going on at the State and local level, whether they have legacy systems, their ability to fund, and be able to tap into the state-of-the-art technology environment. I would see that as something that could be a barrier.

Mr. TURNER. Excellent, thank you. Very good comments. Mr. Tingus, your comments with the Web are certainly very important.

My second question goes to the issue of the various agencies collecting data. Obviously we would hope in the best cases that these agencies would coordinate among themselves with sharing agreements and the ability to access each other's data, but also go to the level of sharing strategic approaches of what data are they collecting and why does it need to be slightly modified in order to be usable by another agency. Also what analysis the data goes through.

I wonder if you guys could speak for a moment on the issue of the data sharing between Federal agencies, the challenges associated with trying to merge the data, and the desire to tailor it to the uses of the various agencies. How well are we doing in cooperation, Mr. Tingus?

Mr. TINGUS. We are—my office is doing a lot of collaboration with the National Center on Health Statistics and AHRQ. Specifically ASPE 94 and 95 was very active, actually contributed to the development of disability questions in the National Health Interview Survey on Disabilities.

So my office where I am now has been very active in working on data collection needs. In fact, I see in the gallery some leaders in that effort as well. So I'm not again a data collector. I'm just a person within the administration trying to make coordination as productive, as outcome oriented as possible, but we are continuing to be a facilitator and a broker of that effort. We do collaborate a lot.

I can't speak for the other departments. When I was at the Department of Education, we also worked with HHS on the National Health Interview Survey.

Mr. TURNER. Thank you.

Mr. CLAY. Thank you, Mr. Turner.

Mr. Tingus, just to I guess restate the question that I asked Mr. Bertoni, can qualitative factors which may in some cases be subjective be used as effective measures?

Mr. TINGUS. I believe so. I believe it depends on the questions that are developed. I would hope either now or in the future in my next phase of my life will be a part of that effort in developing the questions that will be of use in getting solid data for both the agency and for Members of Congress. But I see it—I've been here almost 8 years and I have seen dramatic change within the timeframe that I've been here. But as Mr. Bertoni has said, a lot of work still needs to be done.

Mr. CLAY. Just out of curiosity, what is the next phase? Where do you see yourself?

Mr. TINGUS. Well, as NCD reported in their performance indicators, they really—I was very proud of their work—emphasized quality of life measures that typically have not taken the forefront in the talk that we have been involved with. So I think that effort that they are doing and the work and the guidance that GAO is providing will come together and make quite a difference. Again as you all know, it is dependent upon the funding that we receive. And these surveys do cost a lot of money, and I hope that it improves in the future.

Mr. CLAY. I thank you.

Mr. BERTONI. Mr. Chairman, I could offer one insight in that area. I have another job looking at what's going on in the area of VA's disability process and, to comment a little bit on the Dole-Shalala proposal, they have a provision in there to revise the benefit payment process or scheme for the VA program that is going to—that would like to incorporate a quality—some quality of life payments. And their model would use a model that looked at activities of daily living. If you had lost two or three of these activities of daily living, that would equate to some payment in terms of a deterioration in quality of life. Bathing, being able to dress yourself, drive a car, feed yourself, etc. So packaging two or three of these together would equate to some percentage disability rating. So that's an example of trying to use that as a model to come to a payment for loss of quality of life.

Mr. CLAY. And of course that's not lobbying for increased payment by GAO?

Mr. BERTONI. Excuse me.

Mr. CLAY. That's not lobbying for an increased payment?

Mr. BERTONI. I'm just telling you what's out there.

Mr. CLAY. Subjectively.

Mr. BERTONI. I'm looking at it very closely.

Mr. CLAY. Well, thank you for that. Thank you both for your testimony, and that concludes the testimony of the first panel.

Mr. TINGUS. Thank you.

Mr. CLAY. Without objection, we will submit into the record a report from OMB on the related topic. Thank you, and the second panel my come forward.

[The information referred to follows:]

Statement for the Record by Susan E. Dudley
Administrator,
Office of Information and Regulatory Affairs
U.S. Office of Management and Budget

For the Hearing before the Information Policy, Census, and National Archives Subcommittee
Oversight and Government Reform Committee
U.S. House of Representatives

"Does Federal Statistical Data Adequately Serve People Living with Disabilities?"
June 4, 2008

Chairman William Lacy Clay, Ranking Member Michael Turner, and Members of the Subcommittee, as Administrator of OMB's Office of Information and Regulatory Affairs (OIRA), I am pleased to provide this statement for the record for your hearing on "Does Federal Statistical Data Adequately Serve People Living with Disabilities." Under the Paperwork Reduction Act of 1995 and predecessor legislation, OIRA is responsible for a number of statistical policy and coordination functions. Among other things, within my office the Chief Statistician of the United States is charged with promoting the quality, integrity, objectivity, and utility of Federal government statistics and with issuing various classifications and definitions to standardize the collection and analysis of data gathered by the agencies of our decentralized statistical system.

My statement focuses on the April 8, 2008, report of the National Council on Disability (NCD), "Keeping Track: National Disability Status and Program Performance Indicators." In particular, I would like to apprise you of some recent developments within the Federal statistical system with respect to the collection and dissemination of status indicators of the condition and progress of the disabled population in the United States. Within that context, we are pleased to report that while challenges indeed remain, considerable progress has been made.

In its recent report, the NCD suggests that current federally sponsored surveys do not include adequate measures of disability. Further, the NCD maintains that in cases where measures are included, they vary across surveys with respect to consistency in definition and administration, and thus preclude comprehensive comparisons across data sources. The report suggests the promotion of a standard set of disability questions and recommends that the definition should identify people who, because of their functional limitations, are at risk for the loss or restriction of opportunities to take part in the normal life of the community on an equal measure with others. It further proposes that the questions used to operationalize this definition should meet several criteria, including, among others, minimizing the number of questions necessary to capture needed concepts and ensuring their reliability and validity for self-reporting. A second recommendation calls on Federal agencies to provide comparisons of people with and without disabilities in their aggregate reports and to provide comparisons of people with disabilities by demographic and socioeconomic status characteristics (where sufficient data exist). Third, with respect to indicators of the condition and progress of the disabled population, the NCD recommends a set of "statistical social indicators" to be used to measure annually the status of working-age (ages 21-64) people with disabilities and recommends the expansion of federally sponsored disability data collections. The report proposes a set of 18 indicators (considered key quality of life indicators) to track the status over time of people with disabilities. While the NCD does not suggest that all 18 indicators be collected in each Federal survey, the report specifically calls for each survey to collect indicators of disability.

I am pleased to report that the agencies of the Federal statistical system have a variety of activities currently under way that respond to these recommendations.

- First, in conjunction with ongoing work on the American Community Survey (ACS), the Census Bureau, in collaboration with other statistical agencies, has completed the development of a common set of disability measures that use the NCD's suggested definition of disability and meet the criteria outlined by the NCD. As the members of

this subcommittee know well, the ACS has replaced the Decennial Census long form and will provide data annually, rather than only once a decade.

- The ACS disability questions are similar to and based on the same theoretical reasoning as those that have been developed for use in the international community. As the NCD has recommended, the ACS disability measures focus on difficulties people have in undertaking basic activities, such as concentrating or remembering, walking or climbing stairs, and dressing or bathing, as well as in hearing and seeing.
- The new disability questions were first included in the ACS beginning in January 2008, and will continue to be used on an ongoing basis, thereby providing data annually.
- Thus, as the ACS data are disseminated in the future, it will be possible to distinguish outcomes for the disabled population on an array of social and economic characteristics ranging from educational attainment to earnings and poverty status to employment status and means of commuting to work.

- Second, I am pleased to report that the same series of questions currently on the ACS will be implemented in other Federal data collection activities.
  - Beginning this month, the Bureau of Labor Statistics will use these questions in the Current Population Survey (CPS), which provides a comprehensive body of data on the labor force, employment, unemployment, and individuals not in the labor force, with the intention of publishing information on a monthly basis beginning early next year. Data from the CPS, which follows respondents over a period of time and provides greater detail on certain variables, will provide information on the disabled population with respect to a number of the indicators called for in the NCD report, including those related to education, employment, and marital status.
  - Furthermore, beginning with the collection of the Annual Social and Economic Supplement to the CPS in 2009, it will become possible to analyze the basic CPS data in conjunction with the supplement data to gain additional understanding of the income and poverty status of the disabled population.

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I came into the world when parents were advised to send people like me to "schools for the handicapped." This was before the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973. Disability services, especially in the education arena, were State and local services, if they existed at all. Around the time the Rehabilitation Act was passed, I had a teacher who told me and my parents that she believed I could succeed in regular schools. The Davis, California school system said they would be willing to give it a try but I would need to be mobile. Our local Muscular Dystrophy Association paid for my first power wheelchair, enabling me to become the first disabled student mainstreamed into the Northern California schools.

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Mr. CLAY. We will now hear from the witnesses on our second panel. And our first witness will be the Honorable Anthony Coelho. Congressman Coelho was first elected to the U.S. House of Representatives in 1978 from California's Central Valley. I would like to also note that Congressman Coelho happened to serve with my father and I've known him for a number of years. While in the House, Mr. Coelho authored the Americans with Disabilities Act, widely recognized as the most important piece of civil rights legislation in the last 30 years.

Congressman Coelho retired from the House after six terms but continued to devote much of his time to public service. He served as chairman on the President's Committee on Employment of People With Disabilities from 1994 to 2001. In addition, President Clinton appointed him as Vice Chair to the National Task Force on Employment of Adults with Disabilities and as cochair to the U.S. Census Monitoring Board in 1998.

Welcome to the committee, Mr. Coelho.

Mr. COELHO. Thank you, Mr. Chairman.

Mr. CLAY. Our second witness will be Ms. Pat Pound, vice chairperson on the National Council on Disability. NCD is an independent Federal agency which makes recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

In addition, Ms. Pound has served as executive director of the Texas Governor's Committee on People with Disabilities since 1997, where she makes policy recommendations to the Governor and legislature regarding Texas' disability policy. And thank you for coming today, Ms. Pound.

Our next witness will be professor emeritus, Dr. Eddie Glenn Bryant with the South Carolina Governor's Committee on Employment of People with Disabilities. Dr. Glenn Bryant earned tenure at Illinois State University in the Department of Special Education. She received her doctorate in counselor education and a graduate degree in gerontology from the University of South Carolina. That makes you a Gamecock and a Cardinal.

Currently Dr. Glenn Bryant serves as an adviser and consultant to the South Carolina Commission for the Blind. For 8 years she served as a representative on the Commission on Rehabilitation Education, which is the accrediting body for graduate rehabilitation counseling programs. In addition, she is the cofounder of Sarcoidosis of the Midlands of South Carolina. And thank you for being here Mrs.—Dr. Bryant.

And our final witness on this panel will be Dr. Holly Hollingsworth. Dr. Hollingsworth is a statistician and associate research professor of occupational therapy at the Washington University School of Medicine in St. Louis. Dr. Hollingsworth received his doctorate in applied statistics from University of Illinois Champaign Urbana. And Dr. Hollingsworth has previously served on the faculties of the University of Illinois, the University of Pennsylvania, St. Louis University and Maryville University. Dr. Hollingsworth joined the Cognitive Rehabilitation Research Group at Washington University in 2003 where he provides data analysis for investigations aimed at improving everyday life of people who have experi-

enced a stroke. Thank you for being here, too, Doctor. And thank you all for appearing before the subcommittee today.

It is the policy of the committee to swear in our witnesses before they testify, and I would like to ask all witnesses to please stand and raise your right hands.

[Witnesses sworn.]

Mr. CLAY. Thank you very much. You may be seated. Let the record reflect that the witnesses answered in the affirmative. I ask that each witness now give a brief summary of the testimony. Keep your summary under 5 minutes in duration. Your complete written statement will be included in the hearing record. And Congressman Coelho, we will begin with you.

STATEMENTS OF HON. ANTHONY COELHO, FORMER MEMBER OF CONGRESS, AUTHOR OF THE AMERICANS WITH DISABILITIES ACT; PAT POUND, VICE CHAIRPERSON, NATIONAL COUNCIL ON DISABILITY; DR. EDDIE GLENN BRYANT, GOVERNOR'S COMMITTEE ON EMPLOYMENT OF PEOPLE WITH DISABILITIES; AND DR. HOLLY HOLLINGSWORTH, ASSOCIATE RESEARCH PROFESSOR, OCCUPATIONAL THERAPY, WASHINGTON UNIVERSITY SCHOOL OF MEDICINE

STATEMENT OF HON. ANTHONY COELHO

Mr. COELHO. Thank you, Chairman Clay. I appreciate it very much that you are holding this hearing on an issue that is critically important to millions and millions of Americans with disabilities and to me personally.

I have submitted a written statement and with your permission I will summarize the major points. Unfortunately, after working on this issue nearly all my adult life, I cannot today tell you precisely how many millions of Americans with disabilities may benefit from this hearing. As you have already heard, one of our witnesses said there were 51 million Americans, another witness said there were approximately 50 million Americans, and there are others who say there are 54 million Americans. So that's why this hearing is so important because nobody really knows.

This is why this hearing is a big deal and why I commend you, Mr. Chairman, for your leadership. Just last year you responded to my plea to help lead the fight in Congress to oppose the administration's plan to eliminate the Survey of Income and Program Participation [SIPP]. You helped expand the life of the SIPP and ensure that is now more robust and ensured that it will tell us so much more about the lifestyle of people with disabilities. I thank you for your foresight and for your success. Thank you, sir.

It is tempting to view statistics as a dry and technical set of numbers. We must remind ourselves that there are real people behind these numbers. Every month the Bureau of Labor Statistics tells us how many people are unemployed. The data allows policymakers to know what problems they must solve and what issues Americans must address in their daily lives. Very simply, our government acts only on what it can measure. Government cannot seek to address problems it does not see.

Until very recently people with disabilities have not been counted. The unemployment statistics I mentioned earlier are a product

of the Current Population Survey [CPS]. While the CPS can tell us how many African Americans or Hispanic American teenagers are unemployed each month, it cannot tell us how many people with disabilities are unemployed from month to month. So the government does not even know that it should respond to rising or persistent unemployment among people with disabilities, because it does not even know whether unemployment is rising or persisting. Yet disability is an ordinary part of the human experience. We are all just one accident or health tragedy away from being among the uncounted.

I recognize that counting people with disabilities as we count others is not a simple task. When I helped write Americans with Disabilities Act in the late 1980's, we defined disability not merely as an individual's physical or mental impairment, but also how that impairment affects the individual's major life activities. People with epilepsy like me function exactly like everyone else until a seizure hits us, and we are forced to overcome the fears and stereotypes that pervade our culture.

I worked in this area for more than 20 years. However, these efforts have been frustrated in part by the lack of data needed to answer basic questions about employment and people with disabilities. This became a critical focus of the work of the Presidential Task Force on Employment of Adults With Disabilities. That Executive order directed the Bureau of Labor Statistics and the Census Bureau to design and implement a statistically reliable and accurate method to measure the employment rate of adults with disabilities as soon as possible, but no later than the date of termination of the task force.

Now 10 years after that Executive order was signed, finally a set of six disability questions will finally be included in the CPS for the first time this June 2008, 10 years later. We have made slow progress, but much more needs to be done. The six-question framework provides a model for standardizing the way we collect data on disability in general purpose government surveys.

The experts have tested and refined these six questions over the course of these 10 years and perhaps longer. These same questions should be included in every appropriate general purpose government survey.

Mr. Chairman, I encourage you to ask the Director of the Office of Management and Budget on behalf of the Congress, urging him to require that these same six questions be included in every Federal Government survey that asks about respondents' race, sex, age or ethnicity. Even if we achieve these, these six questions do not provide a perfect answer to the question of who in America has a disability.

As we continue to gather data using these six questions we need to evaluate whether people with certain disabilities such as serious mental illness, cognitive impairments or episodic conditions are represented in the survey data. Thus, the second goal should be gathering more comprehensive, substantial data focused upon people with disabilities.

Supplements to existing surveys with a specific focus are likely needed to study disability more deeply and to help inform the larger policy questions. We also need longitudinal surveys to follow per-

sons of all ages with disabilities over a period of years to measure how a disability evolves, changes or impacts individuals' lives and lives of their families. This is a critical difference between disability and other human characteristics like race and gender. Disability can change over time. As you might expect, more people over the age of 65 report having a disability than people under the age of 21. Perhaps more important, some impairments are episodic as they may be disabilities in 1 month or year, but not in a different month or year. We need statistical tools that will measure those changes.

As I suggested earlier, the subcommittee can help move the OMB to require all appropriate government surveys include the basic set of questions on disability tested and employed in the ACS and CPS. I also urge you to consider two additional steps the subcommittee might take to continue the process we have already made.

I recommend that the subcommittee, perhaps working with the National Council on Disabilities, the National Institute on Disabilities and Rehabilitation Research, and the leaders of national disability organizations bring together experts and advocates to recommend changes to existing surveys and new avenues for the in-depth and longitudinal studies I just discussed. We need to buildupon that to create a comprehensive plan for moving forward.

Finally, it is absolutely critical that with the leadership of this subcommittee that you work with the leadership of the Appropriations Committee and its subcommittees to ensure—to assure that the research agencies are adequately funded and in particular that funding is set aside to continue to expand our data collection activities. Expansion in the Federal Government data collection efforts will require additional funding. The pennies we invest in these agencies for good data help us save millions in spending on Federal programs that are better, more efficient and more effective.

Thank you for inviting me to testify today, Mr. Chairman.

[The prepared statement of Hon. Anthony Coelho follows:]

My Own Story

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Mr. CLAY. Thank you so much, Mr. Coelho.

Ms. Pound, you may proceed.

STATEMENT OF PAT POUND

Ms. POUND. Good afternoon. My name is Pat Pound, and on behalf of the National Council on Disabilities I want to thank you for allowing us to provide testimony to this very distinguished subcommittee. Entities and independent Federal agencies comprised of 15 members appointed by the President and confirmed by the Senate, NCD's purpose is to promote policies and practices that guarantee equal opportunities for people with disabilities regardless of the severity or nature of the disabilities, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living and integration into all aspects of society.

Please note that in my written testimony I provided a historical overview of national disability policy that I won't cover verbally today.

NCD research and perspective. NCD is proud that during the last 50 years advocates, policymakers and a wide variety of public and private organizations have undertaken significant efforts to pass or improve upon the law—legislation that improves the lives of people with disabilities. For example, the Americans with Disabilities Act, various sections of the Rehabilitation Act, Individuals with Disabilities Education Act, Ticket to Work and Workforce Improvement Act, to name but a few.

Notwithstanding these various pieces of legislation and policies, NCD has also noted that insufficient effort and progress have been made to measure and reflect upon the overall performance and effectiveness and impact of these laws and policies related to people with disabilities. This conclusion is based on various NCD policy evaluations over the last 6 years, and here's some examples.

In 2002, NCD published a report, and that noted the problems that continued to be associated with widely used disability employment data from the CPS and the summary disability ability from the 2000 census. NCD also indicated its concern with the collection of valid and reliable employment and other data about Americans with disabilities arising from a series of Supreme Court decisions over the last 3 years which could likely raise the potential of a dramatic narrowing of the legal standards for who is a person with a disability and confound Federal data collection discussions further.

In a 2005 report, NCD found that Federal agencies have given low priority to collecting and analyzing section 504 program data and there were major differences in the data collection across agencies. None of the agencies have developed information systems that comprehensively collect, aggregate or summarize detailed information about compliance or complaint reviews and their outcomes.

Again in a 2004 report, NCD expressed its interest and support for improving two Federal data collection efforts that are directly related to the Decennial Census, the U.S. Census Bureau, ACS, and the Bureau of Labor Statistics CPS. And in the written materials there are Internet references for each these reports.

In the 2005 report NCD indicated grave concerns over a lack of data that presents a comprehensive and accurate picture of the cost

of long-term supports and services for families that have children and adults with disabilities.

In the 2006 report NCD noted a need to modify current performance measures being used by OMB to assess individual and program strengths and weaknesses, to focus on cross department and agency collaboration to enhance livable community outcomes.

In the 2007 report, NCD described a surprising absence of ongoing systematic data collection about the ADA and reported the significant mileage gaps that result from this situation. Several critical assessments from the GAO have been made that support many of these findings. You have heard about them earlier, on the first panel.

As a result of the analysis and the findings just described, NCD concluded that more needs to be done on a national level to address the need for a relevant disability information system.

Now to our latest work. In 2008 NCD released a report entitled "Keeping Track National Disability Status and Program Performance Indicators." This NCD report identifies and describes three major objectives for the U.S. Government to improve the lives of millions of people with disabilities. First it lays out a road map for the Federal Government to improve the status of its information, policies and programs, performance accountability systems.

Second, keeping track includes a set of statistical social indicators that have been mentioned already that NCD believes are currently able to measure the progress of people with disabilities in important areas of their lives over time. The report includes 18 such indicators. And they are developed by stakeholders, and they measure quality of life using both objective and subjective measures. The indicators span a wide variety of vast domains, including employment, education, health status and health care, financial status and security, leisure and recreation, personal relationships and crime and safety. Collectively, they can create a holistic relevant picture of the lives of people with disabilities.

Third, this report also provides or serves as a mechanism for installing the set of indicators mentioned above into the key national indicator system which is currently being considered by the Federal Government. This national indicator system is known today as the state of the USA, previously known as the key national indicator initiative.

Conclusion. The landscape of American government is rich with disability policy and programs designed to address identifiable national issues, at least over the last 50 years. Some of these policies and programs have worked well, some have not achieved results intended. It is important that Congress work to design a national disability information system that is effective.

Do we need to stop?

Mr. CLAY. Just for a minute, ma'am. OK, you may proceed, ma'am.

Ms. POUND. OK, thank you. Congress should work to design a national disability information system that is effective. Based on NCD's scrutiny of these policies and programs, we make six recommendations.

First, that the Federal Government establish and fund a coalition of disability policymakers and advocates to first develop a

fuller set of indicators that are building on the NCD indicators in this report. And second, to ensure the disability that's included is a subgroup characteristic as the state of the USA is developed. The state of the USA offers an important opportunity to integrate disability into a larger national indicator system. When completed, the SUSA will offer individuals who are looking for disability data reliable, easy-use access to this data. It will also highlight the importance of including disability as a subgroup in analyzing the relative status and progress of the population and highlight gaps in disability data.

Second, promote a standard set of disability questions; you have heard that already. Some important Federal surveys have known disability measures while others are inconsistent and vary, often resulting in inconclusive and confusing results. A common core of disability questions on all Federal surveys would improve comparability and improve national discourse about disability data.

Mr. CLAY. Excuse me. Ms. Pound, we're going to have to ask you to conclude your testimony. Would you care to wrap up?

Ms. POUND. Certainly. There are six recommendations here. I will let you review them in your written testimony. Many of them are similar to things that you've heard already. And we appreciate you very much listening to us and giving us this opportunity and holding the hearing.

[The prepared statement of Ms. Pound follows:]

My Own Story

I was born with a rare form of muscular dystrophy that is associated with limited mobility and difficulty using my arms to reach. I am a heavy user of assistive technology. For example, I sleep using a ventilator each night and rely on a power wheelchair to work and participate in the community. I also rely on personal assistance to enable me to take care of activities of daily living such as food preparation, dressing and personal hygiene at home and in the workplace. Advancements in disability research, disability service programs and assistive technologies have made the difference for me between a life of dependence, and possibly institutionalization and – the life I have – living in the community and pursuing a great career.

I came into the world when parents were advised to send people like me to "schools for the handicapped." This was before the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973. Disability services, especially in the education arena, were State and local services, if they existed at all. Around the time the Rehabilitation Act was passed, I had a teacher who told me and my parents that she believed I could succeed in regular schools. The Davis, California school system said they would be willing to give it a try but I would need to be mobile. Our local Muscular Dystrophy Association paid for my first power wheelchair, enabling me to become the first disabled student mainstreamed into the Northern California schools.

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I grew up in parallel to the rapid development of private and public services for people like me. When I finished high school, I was fortunate to be eligible for the SSDI and SSI programs, which gave me access to Medicare and Medicaid benefits. Since I had a pre-existing condition, I was unable to get health insurance to cover my extensive medical expenses on my parents' policy. Access to public benefits meant that I could attend college and graduate school. I was on Medicare and Medicaid from 1981 through 1995. When I finished school, I had the opportunity to work for Governor Pete Wilson, at which point I went off the public programs; I have been a proud taxpayer ever since.

I am grateful for the progress I have made, it is a credit to my family and to all the formal and informal services from which I have benefited. I am glad there are many others like me. But there is no question that to keep our Nation's disability research and programs moving forward, so that many more can realize their dreams and potential, policymakers and other stakeholders need credible data about people with disabilities and the services and technologies they use.

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Who are people with disabilities? In 2002, 51 million people (18 percent of the population) living in the community had some level of disability, and 33 million (12 percent of the population) had a severe disability. (SIPP data, as reported in "Americans with Disabilities, 2002) Although the prevalence of disability increases with age, disability affects persons of all ages. The majority of people with disabilities (56 percent)

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Mr. CLAY. Thank you very much, Ms. Pound, and we will get back to you with questions.

Ms. Bryant, you may proceed for 5 minutes.

STATEMENT OF EDDIE GLENN BRYANT

Ms. BRYANT. Good afternoon. Thank you so much Congressman Clay, your staff, and the other congressional people who are present, for holding this hearing and allowing me to be a part of it. As a person who has been severely visually impaired, coupled with two major chronic disease disorders for approximately 30 years, worked in a variety of professions and settings, lived in several States in different regions of the country, served on board committees, task forces, researched published referee articles and founded several organizations that focus on persons with chronic illnesses and disabilities, I bring a unique or varied opinion and approach to this all-important question. I serve as an academician, a person with a disability, and an advocate for persons with disabilities.

Quality of life has been a big issue for me for a very long time, and as a result I have done an intense study on women, especially women of color, with disabilities and their quality of life. And also focusing on the impact that psychosocial issues have on the quality of life of a person with a disability. After thorough review of the National Council on Disability Report entitled, "Keeping Track National Disability Status and Program Performance Indicators," April 21, 2008, I support the conclusions and the recommendations. However, there are some challenges.

Mr. CLAY. Disband for a minute, please. OK, you may proceed, I'm sorry.

Ms. BRYANT. However, there are some challenges and gaps. Today there is a group of individuals living with disabilities that are not on any Federal, State or local rolls that would collect information necessary to identify these indicators which we need in order to determine the quality of life. Some of these subpopulations include individuals that are underrepresentative of disabilities, women of color with disabilities, persons with disabilities in rural areas, persons who desire not to be counted because of not being enrolled in some type of program because they don't know about the programs and services, or they are suspicious of the programs and services.

Strategic exploration is needed in order to look at this review process. Options for collecting data are vital. We must maintain some of the traditional methods of collecting data by strengthening them and expanding them, as well as expanding and increasing some of the more modern methods of securing information through technology. We must continue to do the face-to-face, we must continue to do the door-to-door, we must continue to meet with individuals in their cultural environment, we must go to roundtables, town halls, conferences, seminars, so on and so forth. We must find these individuals, sit down with them, use standardized questionnaires to collect this data.

It is vital that a coalition be created, which was suggested in the end in the report. However, this coalition must do more than develop fuller indicators for the instruments or the assessment tools.

This coalition must set guidelines and policies so that there may be consistent questions included on all Federal, State and local questionnaires and surveys that are used if they are receiving Federal funds or will be applying for Federal funds in the future. Multicultural and cultural issues must be addressed when we are looking at the underserved populations or the hard-to-count population with disabilities, as well as when we are developing this coalition to design and develop these instruments.

This coalition must do more than identify and develop a fuller set of indicators that are important to people living with disabilities to ensure that disabilities are included as a subgroup characteristic. There must be some type of mandate that these agencies or entities must subscribe to, and there must be some penalty if they fail to comply. These individuals that receive Federal funding must submit a report at the end of the year showing the instruments, or including a copy of the instruments that they used to collect the data. There should be someone in the coalition or a department within the coalition to oversee and to assist individuals developing instruments so as to make sure that there is consistency, continuity and standardization.

In order to develop an instrument that will assess accurate and adequate information about the quality of life for individuals with disabilities, these individuals living with disabilities must be assessed in numerous ways and we must include multiple indicators.

The functional description of the term "disability" is a cornerstone of adequately measuring the quality of life for people with disabilities. As a professor and a person living with a disability, the definition has always troubled and frustrated me. It never seemed to capture the essence of what a disability really is. This term is so encompassing and complex that, to define it as it has been in general terms, reduces it to a very narrow and somewhat skewed concept with a confusing and limited denotation.

Therefore, this problematic definition negatively influences policies relevant to disability issues and concerns, developments of instruments, collection of data, interpretation of data, dissemination, and application of information which may be inadequate and incorrect. In order to answer the broad question regarding adequate data collection that can be qualified and then expressed in quality-of-life terms, the word "disability" must become a description which can be translated into a meaningful functional application regardless of who or which agency or institution uses it.

This description also has to include aspects that are sensitive to cultural issues in a diverse society which is present and ever-growing in the United States. When the concept of disability was written as a description with expanded and inclusive information and criteria, then it becomes a functional definition that can be used across agencies on Federal, State and local levels to be inserted in all instruments that are designed to measure issues relevant to people with disabilities. This concept cannot be limited and narrowly focused with the final indicator measuring being a job, consistent work or gainfully employed.

The concept must move along with spectrum or indicators with varying dimensional aspects addressed and included. If we are truly serious about this functional description for the term "disabil-

ity," the Coalition will need to examine every definition and description it can find and determine if it belongs, and if it does where should it be located along the continuum on the spectrum of the description.

In conclusion, quality of life can be more adequately determined when the above-mentioned items are developed, integrated, and implemented with policy guidelines designed to assist the process of collection, interpretation, and application that have flexibility with uniformity. Thank you.

Mr. CLAY. Thank you so much, Dr. Bryant.

[The prepared statement of Ms. Bryant follows:]

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Mr. CLAY. And, Dr. Hollingsworth, you may proceed.

STATEMENT OF HOLLY HOLLINGSWORTH

Mr. HOLLINGSWORTH. Thank you Mr. Chairman. It's my honor to stand in for Dr. David Gray as a witness at this hearing. By most measures, Dr. Gray would have values comparable to a very successful person. He's a recognized researcher at the highest-ranked occupational therapy program in the country. Before joining the faculty of Washington University he was a Presidential appointee and Director of the National Institute of Disability Rehabilitation Research. He's a family man with three grown children and two grandchildren. It is because of a several-time-delayed visit to his grandchildren that he is not here today. For many of the objective measures of quality of life, Dr. Gray would exceed national averages on income and education, housing, transportation. By many objective measures of society. Dr. Gray is far below national standards. Because of an accident, Dr. Gray is a quadriplegic, a person who is permanently unable to move his arms or legs. He does have some arm movement, and with the aid of assistive devices he's able to feed himself, drive an adaptive vehicle and use a computer. A medical model measure, such as the functional independence measure, Dr. Gray would score poorly. Medical modern measures assess the ability to perform a function. These measures are what people can do in clinical settings.

For example, Dr. Gray would score a 1, performs less than 25 percent of the task on the FIM item of dressing lower body. The logical extension of this assessment of Dr. Gray is that he could not leave his house or go to work unless he had assistance to get dressed. Clearly, work is important to Dr. Gray and others with disabilities. The gab in our understanding of why some people with disabilities work while others do not require that we move beyond the can do measures to a holistic social model of disability.

Using a social model of disability assessment can focus on what people with disabilities do and the factors that help them do activities. These measures assess what people with disabilities do and what their quality of participation in activities, not their health-related quality of life. The construct of participation includes the evaluation of engagement in activities that are felt important; the degree of choice—when, where, how and the satisfaction derived from that participation in an activity. The social model also postulates that the environmental context can create barriers of facilitators of participation by people with disabilities. Using this approach, service programs could determine what facilitators are useful to improve participation of specific activities.

For example, I work with Paraquad, a federally funded independent living center in St. Louis has shown that outcome measures are needed that focus on the specific and general goals of the services offered.

The Olmsted Supreme Court decision that supported the right of people with disabilities to choose where they live resulted in many State Medicaid programs funding consumer-directed personal assistance services. To examine the effects of this program. We asked consumers to answer questions on the quality of the services pro-

vided; for example, the times the attendant was late or the choice and satisfaction with the attendant.

To assess the influence of the personal assistant services on the consumers' quality of participation, we asked those receiving the services if they participated in community activities more often and how they evaluated that participation. The "take-home" lesson from our experience in the use of outcome measures is that there is a need to include questions on the specific program services, as well as the effects of the consumers' community participation. Such measures require establishing baselines and then frequent subsequent assessments to examine program effectiveness.

Most of the Federal statistical data is demographic and normative. Federal agencies report the number of people with disabilities that are eligible or enrolled in the services. However, Federal disability data is inadequate to identify the dynamics of disability. Federal disability statistics are largely derived from household surveys and individual level of administrative records. As a result, a vast majority of research and policy discussions derived from these data treat disability as a one-dimensional personal phenomena, while ignoring the environmental components of a disability.

The existing data cannot show a relationship between service provided and the beneficial changes in the lives of people with disabilities. To assess change, criterion-based assessments are needed, rather than status relative to general population. To report that unemployment rate of a person with disabilities has remained stable while the same rate for the general population has risen might be a misleading indicator of beneficial change based on normative criteria. Another consideration is that many consider disability to be a one-dimensional construct.

As an example, the level of disability of a person is whether a person can or cannot do an activity, such as dressing or bathing. According to the World Health Organization's International Classification of Functioning, Disability and Help, or the ICF, disability is an umbrella term for impairments, activity limitations and participation restrictions. The ICF defines activity as the execution of a task by an individual. Activity limitations are difficulties an individual may have in executing activities. The ICF further defines participation as involvement in life situation. And participation restrictions are problems that an individual may experience in that involvement. The aggregate of activities defines a life situation. Employment is a life situation defined by its job duties. Participation restrictions in employment can be the lack of transportation, accessible environment or education. The key to understanding disability requires the examination of interventions that enhance an individual's capacity to do activities and the implementation of environmental facilitators that result in the full participation of people with disabilities.

In summary, we would like to offer three suggestions to improve the adequacy of data that serve people with disabilities. One of the most often used national surveys is the National Health Interview Survey. We recommend that this survey be modified and reissued, having the diagnostic categories who allow this function-based survey to be linked to the ICF. Also adding questions on participation and environmental context will also link the survey to the ICF.

Second, data used for program evaluation should be quite criterion-referenced, based on the goals of the program. The evaluation of progress should be referenced to valid and reliable baseline measures. After implementation of program services, subsequent assessments can establish program effectiveness.

And third, data used to assess people with disabilities should be multi-dimensional, using scales that span the barriers of facilitators to full participation, a tenet of the American with Disabilities Act. Compliance with this tenet mandates the measurement of a variety of dimensions of disability, including capacity, participation and the environment. Thank you.

[The prepared statement of Dr. Hollingsworth follows:]

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What these numbers do not tell you is that people with disabilities are heterogeneous. The functional abilities and needs of those with physical disabilities like my own are vastly different from those with intellectual disabilities. People with mental illness face an entirely different situation in the services they require in order to live high quality, independent lives. These differences mean that disability data, programs and policies have to cover a wide variety of needs, resources and interests.

As we learned in the GAO report that we will be discussing at this hearing, there are over 200 Federal programs serving people with disabilities; they are operated by over 20 Federal agencies. In addition there are over 50 State Medicaid programs (including D.C. and the territories) and countless other State, local and private sector efforts. These health, income, employment and other programs add up to the patchwork quilt that is our Nation's disability system.

Most of these programs, coupled with our excellent civil rights protections under the Americans with Disabilities Act, add up to the United States being the best country in the world for a person with a disability. It can be confusing, though. I have spoken to many people with disabilities who know they are getting education, health, income support, employment or other disability services, but they have no clue what programs they are on!

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Mr. CLAY. Thank you, Dr. Hollingsworth. And let me thank the entire panel for their testimony. We will now proceed with the Q and A period. Excuse me. OK, we've been notified that the Capitol Police, because of the storm, are now evacuating all hearing rooms and asking everyone to proceed to the hallways. So we will take a recess and hopefully bring you back for questioning. Thank you.

[Recess.]

Mr. CLAY. The subcommittee will come to order. I would like to start the questioning off with Congressman Coelho. Congressman, this subcommittee has jurisdiction over information policy in the Federal Government. What are some of your suggestions for how Congress might proceed with establishing the coordinating entity? What are some of the facts and issues that need to be considered?

Mr. COELHO. Well, I think the first thing, Mr. Chairman, is that we finally have, after 10 years, an agreement as to the six questions. And I think if we can get that implemented governmentwide at least, we will have a foundation to get started on.

Nothing is perfect. I know people would like better definitions and they would like lots of different things, but we've got to get started. Nobody has an idea of how many people there are who have disabilities. We have rough estimates, but we don't have any good numbers. And I think we just got to get these six questions asked across the board. It's going to take some effort. I think this committee, this subcommittee, would be able to play a big role in making sure that OMB does that. And then as we move along then to improve the process, just like they did with this instance, with everything else. But we need to get started.

We have been trying to do this for several decades and we've never been able to get it done. Finally we're making some progress. And that's my strong, strong position. I mean, you can take, for example, the EEOC requires of all employers that have 100 employees or more that they collect and report the make-up of their work force. That doesn't include people with disabilities. Why not? There's a lot of things like that would be helpful for us to gather information to better serve people with disabilities, but also to monitor what is being spent, how it's being spent and so on. And I think that there's a lot of times GAO is, of course, saying, you've got to do X, Y and Z. I don't disagree with what GAO is saying. But the Congress is the one who legislates what each of these programs are supposed to do. And each of these programs have to comply with what Congress wants, not what some survey says. And so I think getting data is the critical thing, just absolutely critical, and you got to start step by step.

Mr. CLAY. Would you recommend using the six questions on the American Community Survey as the foundation for governmentwide questions on people with disabilities?

Mr. COELHO. Absolutely. And I would do it on every survey that asked the basic questions about sex and race and so forth. Every survey that does that, I would have OMB insist that the six questions be included.

Mr. CLAY. Can you tell the subcommittee what insight these questions might provide on the quality of life of people living with disabilities?

Mr. COELHO. I think first off, Mr. Chairman, that we would get a better idea of the numbers that do exist out there. And then as you well know, as being in charge of the census and are overseeing the census—and I had the pleasure of doing that for a period of time in the monitoring board, the data that is collected, and you can get it from different regions of the country and so forth, is tremendous as long as you start collecting it. And I think one of the problems is that data is collected but it isn't effectively used. And so there's two parts to this whole thing, is collecting it and using it. And so that if it is effectively used we can get all kinds of information of where people are living, what their different types of disabilities are, what we need to be doing in different parts of the country to be of help and to be of assistance. It's just basic information that we don't have today. We assume we know but we don't know.

Mr. CLAY. And for the record, OMB has submitted written testimony and this committee will followup with questions of them, and we will include your recommendations in those questions.

Mr. COELHO. Thank you Mr. Chairman.

Mr. CLAY. You're very welcome. You also note that despite the difficulty in defining disabilities, statistical agencies have been able to get started on survey questions. Have they applied any practices that might be of use to Federal agencies?

Mr. COELHO. Well, I think that if you start with that basic, those basic questions, and you start with that basic data, it will be used to all Federal agencies. And so I'm a big advocate that you got to start somewhere and you got to start with a basic platform. And if you don't then nothing else matters. But you've got to start with a platform. And once you start getting that then you can build on it. And I don't think the six questions are absolute or the six questions are something that you're going keep forever, but I think you've got to start somewhere. And those six questions have been debated and tossed around and every little word was dissected for 10 years.

Let's get started on it, let's move it across the board. And then let's get moving. But now that those six questions have been established, let's get it across all the surveys and then let's have the governmental agencies start using them.

Mr. CLAY. Thank you so much for your responses.

Dr. Bryant, let me go to you. Some of the challenges that Federal agencies face in collecting data run across agencies and across demographic groups. One of the problems is getting people to respond to surveys. Can you speak to the nonresponse rate as it relates to the disabled community and steps agencies can take to improve response?

Ms. BRYANT. Mr. Chairman, I don't have an accurate number, but it is less than 50 percent. And just giving you an example, because of some of the projects I've been involved in—for example, getting information back from the visually impaired and blind, putting it in the formats that it needs to be in, but for whatever reason we never get more than 23 percent to 30 percent back of the surveys. If we send them out in the necessary format, if we call them on the telephone it may be apprehension in dealing with the interview. Putting it in the proper format and then being able to

read braille on what level, 1, 2 or 3. So there are problems in collecting information or collecting data because of the suspicion sometimes of these individuals who are not on rolls and do not participate in receiving services. There are those who are suspicious of services in general. And then there are those who do not have the surveys and questionnaires in an accessible format whereby they can respond privately. Because sometimes when a third party or a second party is involved in responding, to helping someone respond to a survey, they don't answer or don't answer as honestly.

Mr. CLAY. You know, you recommended that a diverse coalition be assembled to further explore conclusions and recommendations on data collection. And that included in the coalition must be national organizations that focus on multicultural disabilities and diverse disabilities. It is important to have those views represented on any committee that considers recommendations.

Can you tell the committee in your professional opinion the void that is created when these groups are not represented and the benefits of having them at the table when decisions are being made——

Ms. BRYANT. The void is we have mentioned, or someone mentioned earlier, that there are common similarities but there are cultural differences. And just starting from—basic individuals from various cultures see disabilities differently. First of all, they define them differently. And so when you're working from that premise you're going to get information from different perspectives. And so you need to understand, first of all, that global cultural perspective, and then how the individual within that culture with the disability sees the world or sees him or herself.

Now, the benefits would be if we are trying to find out what indicators enhance quality of life, you have to understand that person within his or her culture context with the disability. So that's why it's important that we include individuals from, quote, minority, racial ethnic groups with disabilities.

Mr. CLAY. OK. Thank you for that response.

Dr. Pound, NCD recommended that NIDRR develop a fuller set of indicators that are important to people with disabilities. An emphasis was placed on moving beyond using ability to work as the determining factor in setting policy.

What other indicators should be used to assess the quality of life of people living with disabilities?

Ms. POUND. Well, the NCD report actually noted 18 indicators and regrouped them by the domains I mentioned, like education, employment, health, etc. Some of those might be things like employment rate, employment rate by attainment of education, median annual earnings for full-time for your employees, meeting annual earnings by education status, skip down to some, maybe health might be obesity, smoking; others in the area of financial status would be things like median household income or poverty status; leisure recreation may be participation in leisure physical activities, personal relationships might be social emotional support available, marital status; crime and safety may be the crime rates per 1,000, like property crime and violent crime. And actually what would determine in those is that there's data currently available to

gather this information and present it annually to figure out how we're doing to compare year to year.

Also I might mention our stakeholders in those focus groups didn't mention a number of other things that others have mentioned here today that are more subjective but are very important such as choice, spontaneity, aspirations, empowerment, things of that nature that relate more directly to quality of life.

Mr. CLAY. What are some of the challenges agencies might face in implementing NCDs and recommendations?

Ms. POUND. Well, I think traditionally a lot of what has been said, most agencies are not going to go do this on their own, they're going to need some directive to do it, and/or some funding to do it. And ideally, there would need to be a coordinating body, hopefully something at the level of the Interagency Coordinating Council; revive that to get the people at that level to buy in and have some structured supervision of how it was to be done. I don't think this effort is going to go further without some kind of a mandate in funding to push it forward.

Mr. CLAY. What role could OMB play in facilitating the collection of data across programs? Any thoughts on that or anyone on the panel? Ms. Pound, no thoughts on that?

Ms. POUND. I'm thinking. I would rather see the testimony before I provide that.

Mr. CLAY. All right. Let me give you another one, then. What would prohibit the collection of data that would allow data users to assess how well individuals with disabilities are faring? What would prohibit the collection of data that would allow data users to assess how well individuals with disabilities are faring? Are there any obstacles now?

Ms. POUND. Yeah. I think it's pretty obvious that there are. Most agencies aren't going to do that on their own. If they do it, then they do it differently, one to another. That's what we found. Like they do something that they believe is useful for their needs, but it doesn't necessarily work across agencies and for disability populations as a whole.

Mr. CLAY. Thank you for your responses.

Ms. Hollingsworth, you talk about the great work that Paraquad in St. Louis is doing to establish outcome measures. Could you tell us a little more about any instruments you are working on that could be used in models for collecting Federal data?

Mr. HOLLINGSWORTH. It would be difficult to take, as it is now, what we're doing at Paraquad to the national level without a lot of work on establishing the reliability or validity of items. I think one of our problems is now we're collecting basically 01 kind of data; a person is blind or is not blind. We're not getting the data on how this disability influences our participation in activities of daily living.

To answer questions like that requires more than just a 01 kind of a response. So it's the same kind of questions that we see in the political poll; strongly agree, strongly disagree, agree. We all answer that agreement question differently. And to come up with a reliable response set to these kinds of questions is the task.

Mr. CLAY. How could we measure the effectiveness of Federal programs in improving the status of people with disabilities?

Mr. HOLLINGSWORTH. I suggest that we establish some valid, reliable, baseline measures before services are implemented; or, at a particular time, if the services are already in place, so that we can measure change. And that's fraught with difficulties of reliability and validity. Changed scores are difficult. Knowing just the number of people is important. It's an important question. But how people view the participation in major life activities is important. And what facilities those activities—can we use the information on a successful employee to help train people coming back from Iraq with disabilities?

Mr. CLAY. You recommended that the national health interviews survey be modified and reissued. What modifications would you suggest?

Mr. HOLLINGSWORTH. One of the recommendations of the National Council of Disability was to include disability, and I would suggest even subgroups of disability, so that a person with a spinal chord injury might be a paraplegic, a quadriplegic or a complete incomplete. These are all subgroupings. And that information gives us a little bit better detail. But I also think we need to get in those questions. It will probably have to be a supplemental to end this, but functioning in major life activities.

Mr. CLAY. Thank you. Thank you for your response. Let me thank this panel. Congressman.

Mr. COELHO. Mr. Chairman, there's one thing that I would like to just say, because I think there's been a huge change going on in the disability community. For so many years Congress and others have treated the disability community paternalistically; let's give you X and then you go away. And what's happening in the disability community is that we want our quality of life, we want to participate, we want to be treated like everybody else, we want to be involved. And so what you're hearing a lot of is that we want to be part of everything that is going on. And that's why we want the statistics to show what is happening to us. We just don't want a handout. We want to participate. We want to be involved. And so that's why these statistics become critically important, is so that we can be engaged and be involved. And that's why it's important for the Congress to treat us as equals, to let us participate, let us be engaged, let us be involved. And that's why I think it's so important that you're holding these hearings, that you're leading this fight, and we appreciate it very much.

Mr. CLAY. Thank you so much. And thank the entire panel. You have certainly made the case for the disabled community for us to be inclusive. And I found this hearing to be insightful for me personally.

I want to thank you all and panel I for their participation in this hearing. I look forward to working with this community as we go down the road. Thank you, and that concludes this hearing. Hearing adjourned.

[Whereupon, at 3:55 p.m., the subcommittee was adjourned.]

[Additional information submitted for the hearing record follows:]

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