

*Testimony
Of
Hon. Tony Coelho
Information Policy, Census, and National Archives Subcommittee
Oversight and Government Reform Committee
Wednesday, June 4, 2008
2154 Rayburn HOB
2:00 p.m.*

Thank you, Chairman Clay and Members of the Subcommittee for holding this hearing on an issue that is critically important to millions and millions of Americans with disabilities – and to me personally. 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. I hope together we can finally change that.

This is a big deal, and why I commend you Mr. Chairman for your leadership. Just last year you responded to my plea and helped lead the fight in Congress to oppose the Administration's plan to eliminate the Survey of Income and Program Participation (SIPP). You helped extend the life of the SIPP and ensured that it is now more robust and ensured it will tell us so much more about the lifestyles of people with disabilities. I thank you for your foresight and your success

It is tempting to view statistics as dry and technical sets of numbers. We must remind ourselves there are real people behind these numbers. The data produced by the federal government's statistical system drive our policy debates, and dramatically impact millions of individual lives.

For example, every month the Bureau of Labor Statistics (BLS) tells us how many people are unemployed. Lawmakers respond when unemployment rises by enacting extended unemployment insurance benefits or targeted job creation strategies. Also each year, the Census Bureau tells us how many Americans are living in poverty. When poverty rises, states and the federal government can adjust their Medicaid budgets and modify their welfare-to-work strategies, or respond in other ways they consider appropriate.

The data do not determine the policies. But the data allow policymakers to know what problems they must solve and what issues Americans must address in their daily lives. And the data allow us to know whether our government's policies are working, or whether they need to be revisited with new strategies and new ideas. Very simply, our government acts only on what it can measure. Government cannot seek to address problems it does not see. We have to know where we are before we can know where we are going.

To matter in our government's policy debates, people with disabilities must be counted by the federal government's statistical agencies. Until very recently people with

disabilities have not been counted. We have largely been left out of the day-to-day data collection work of the federal government's statistical agencies. The unemployment statistics I mentioned earlier are a product of the Current Population Survey, or the "CPS." While the CPS can tell us how many African-American teenagers are unemployed each month it cannot today tell us how many people with disabilities are unemployed from month to month. So 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.

Mr. Chairman, in order for people with disabilities to be considered at all levels of policy-making we must be counted by the federal government's statistical agencies. Every time a statistical agency asks survey respondents about their race, their age, their gender or other demographic characteristics, they must also ask about disability. Disability is an ordinary part of the human experience and we are all just one accident or health tragedy from being among the uncounted.

I recognize that counting people with disabilities as we count others is not a simple task. Disability is a multidimensional and dynamic concept that involves both individual and environmental factors. When I helped to write the Americans with Disabilities Act in the late 1980s, 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". This included working, recreating, and interacting with one's family and neighbors. Of course, the barriers that are found in an individual's environment --- the workplace, the home, the community --- largely determine the impairment's effects on the individual's activities. A person in a wheelchair is just as productive as every other American worker until she encounters a flight of stairs. People with epilepsy, like me, function exactly like everyone else until a seizure hits and we are forced to overcome the fears and stereotypes that pervade our culture. This is the modern model of "disability". It is a complicated concept, I grant you.

As you know, I have devoted much of my career to addressing the extremely low employment rate of people with disabilities. I have tried to highlight these issues and bring people together to respond. 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. The lack of data was such an impediment to good-quality policymaking that it became a critical focus of the work of the Presidential Task Force on Employment of Adults with Disabilities.

Executive Order No. 13078, which created the Presidential Task Force, directed the Bureau of Labor Statistics and the Census Bureau, working with the National Council on Disability, the President's Committee on Employment of People with Disabilities, and other agencies to "design and implement a statistically reliable and accurate methods 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." Executive Order No. 13078 was signed in 1998. The Task Force effectively expired in 2001. And still no reliable measure of the unemployment rate among people with disabilities had been created. Now, ten years

after the Executive Order was signed, a set of six disability questions will finally be included in the Census Bureau's Current Population Survey (CPS), for the first time in June 2008. We have made slow progress, but much more needs to be done.

The six question framework currently being used by the Census Bureau's American Community Survey (ACS), [which is now going to be included in the CPS], provides a model for standardizing the way we collect data on disability in "general purpose" government surveys. I understand that these questions may soon be included in Department of Justice Surveys and the National Health Interview Survey. If the same questions were used in other large national surveys, we would begin to gather clearer picture of the lives of individuals with disabilities.

The experts have tested and refined these six questions over the course of ten years, and perhaps longer. They will be included in some of our most important surveys. Yes, defining "disability" may be difficult. Yes, it may be a complicated concept. But the experts in our statistical agencies have found an effective way to get started.

These same questions should be included in every appropriate general-purpose government survey. Mr. Chairman, this Subcommittee can play a vital role in assuring that people with disabilities get counted. 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 already asks about respondents' race, sex, age, or ethnicity

More In-Depth Surveys

Even if we achieve this, these six questions do not provide a perfect answer to the question of who in America has a disability. Internal perceptions of disability, stigma, and other factors effect how people respond to the survey questions. Individuals with episodic conditions may not self identify as having 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. But we have made a good start and we should immediately expand on our success throughout the federal government.

This first step is important, but I believe we can do more. We must be cognizant that using such a small group of questions to gather disability data raises concerns about undercounting certain disabilities or failing to address particular problems within the disability community. Individual surveys should also include additional supplements, questions of specific interest to the purpose of that particular survey while also giving us a common view of the population in question, whether addressing health, work, housing, transportation, crime or other issues.

Thus, a second goal should be gathering more comprehensive, substantial data focused upon people with disabilities. Several strategies will likely be needed in order to fully explore the complexity of disability and the impact on peoples' lives. Supplements to

existing surveys with a specific focus, such as the CPS or the Survey on Income and Program Participation (SIPP) are likely needed to study disability more deeply and to help inform the larger policy questions.

Similarly we have not had a large-sample study devoted to disability since the 1994 National Health Interview Survey Disability Supplement (NHIS), nor have there been supplements to the NHIS to provide needed follow up information. We should regularly schedule another comprehensive survey and special supplements on problem areas. For example, learning more about insurance or access to care during the intervals would be invaluable in addressing policy questions and monitoring progress.

We also need “longitudinal” surveys to follow persons of all ages with disabilities over a period of years to measure how disability evolves, changes, and impacts individuals’ lives and the lives of their families. This is a critical difference between “disability” and other human characteristics like race and gender. Race and, in most cases, gender do not change over time. Disability can change over time. As you might expect, more people over the age of 65 report having a “disability,” (even if they will not call it by that name), than people under the age of 21. Also, some young people with disabilities adapt over time to their conditions and may be better able to perform major life activities in their 40s and 50s than in their 20s and 30s. Perhaps most important, some impairments are episodic, so they may be “disabilities” in one month or year, but not in a different month or year. The disability community is diverse, but it is also changing. We need statistical tools that will measure those changes.

The SIPP is an example of a longitudinal survey. It provides far more information about various disabilities and much more opportunity to delve deeper into people’s experiences. However, we understand that the questions have changed just enough over the years that it does not provide a true longitudinal view. As SIPP is being redesigned, I would hope that it will better address the needs of individuals with disabilities.

Another longitudinal survey, the National Long Term Care Survey (NTLCS), could also be better designed to meet the needs of people with disabilities. This survey follows a sample over a period of years, is narrowly focused on persons 65 and over and narrowly defines disability among that population, based on the ability to accomplish tasks associated with living independently, such as bathing and dressing oneself or the ability to walk inside and outside the home. Such a restriction in sampling and definition does not allow us to study the larger population with disabilities, or to monitor how they adapt and their disability evolves over a period of years.

Recommendations

As I suggested earlier, the Subcommittee can help move the OMB to require all appropriate government surveys include the basic set of question on disability tested and employed in the ACS and the CPS. It is important that you require OMB to reach out to the national disability community as they assess which additional surveys are most appropriate.

I also urge you to consider two additional steps the sub-committee might take to continue the progress we have already made.

I recommend that the sub-committee -- perhaps working with the National Council on Disabilities, the National Institute on Disability 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. The policy makers who use the data, the researchers who gather it, and the people with disabilities who are affected by the information all have important contributions to make. We need to build upon that to create a comprehensive plan for moving forward and I believe this sub-committee can play a leadership role in assembling the player who can craft that plan.

Finally, it is absolutely critical that with the leadership of this sub-committee work with the leadership of the Appropriations Committee and its sub-committees to assure that the research agencies are adequately funded and, in particular, that funding is set aside to continue and expand our data collection activities. The Census Bureau, the Bureau of Labor Statistics, the National Center for Health Statistics, the National Institute for Disability and Rehabilitation Research and the other federal agencies responsible for gathering data need to be fully funded to meet their mission. Expansion in the federal government data collection efforts will require additional funding. The disability community will work with you to build support for these agencies' funding requests if they demonstrate a commitment to counting people with disabilities in every appropriate survey. 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.

Mr. Chairman, thank you for inviting me to testify. I look forward to the sub-committee's questions and to working with you in the future.