

IMPROVING FEDERAL DISABILITY DATA

Position Paper

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Synopsis

Every 10 years, the U.S. Census Bureau conducts a complete accounting of every resident in the United States. While there is no Congressional mandate requiring an accurate enumeration of Americans with disabilities by the Decennial Census, communities and people with disabilities will be affected if the Decennial Census is inaccurate. Census data are used by educators, policymakers, and community leaders and directly affect funding for many programs critical to individuals with disabilities, including programs for health care, transportation, employment training, and housing. Federal, state, and county governments use Census information to guide the annual distribution of hundreds of billions of dollars in critical services and supports. While there have been some improvements in the use of a few disability questions and interview methodology in the Decennial Censuses for the past 30 years, those improvements have been small and incremental. At a time when cash strapped states are grappling with major unmet human service needs, and increasing numbers of people who require a range of services and supports from federal-state programs, the ability of our nation's public leadership is at an all time high to provide accurate Decennial Census (and related federal survey data) to states and locales. This paper addresses these issues and provides some recommendations for consideration by the Federal Government which include: (a) The U.S. Congress should legislatively require an official and accurate enumeration of Americans with disabilities through the Decennial Census, through related national Census-like efforts (e.g., American Community Survey); (b) The U.S. Census Bureau should immediately revise Census questions for the Year 2010 Census (and the American Community Survey) to reflect the ADA definition; and (c) The Bureau of Labor Statistics should finish its work with all due haste under the Executive Order 13078.

Overview

The Decennial Census of Population has been taken every ten years since 1790. The Decennial Census encompasses the entire U.S. population. It provides data accumulated at the Census tract level on household demographics, income by source, labor force participation, occupation, and type of dwelling. The number and relationships of persons in each household are also compiled. Included among the many tabulations and tape files is a summary statistics file representing a 100 percent count of persons in group quarters. The group quarters category includes persons in institutions and noninstitutions.

The U.S. Constitution requires the use of Census data in determining the number of seats each state has in the House of Representatives. Census data is also used to determine voting district boundaries with states. Government agencies, businesses, social, and non-profit organizations use Census data to determine need and best locations for services.

The Decennial Census has two parts: the short form, which counts the population; and, the long form, which obtains demographic, housing, social, and economic information from a 1-in-6 sample of households. Information from the long form is used for the administration of federal programs and the distribution of billions of federal dollars.

In fact, more than \$185 billion in federal funds are distributed annually to localities based on Census data. By law, the Census Bureau must deliver population counts for each state to the President by December 31st to determine the number of members of the U.S. House of Representatives each of the 50 states is entitled to have. The Census Bureau is required to provide small-area population counts to the legislature and governor of each state by April 1 for use in redrawing Congressional and state legislative district boundaries.

The Census is also an important source of data on the population of people with disabilities. The demand for data on the number and characteristics of persons with disabilities derives from the need to develop and evaluate programs, and from the need to monitor the nation's success in removing barriers to quality employment. The Census is usually the only available source of disability data for the evaluation of conditions at the state and local level. Census data also help to monitor the social and living conditions of persons with disabilities in terms of school attendance, educational attainment, marital status and living arrangements. It should be reiterated, though, that there is no statutory mandate that the Census Bureau ensure an accurate enumeration of all Americans with disabilities through the Decennial Census.

Policy makers have recognized that an accurate Census can provide valuable information to improve the policy process. Today, policy makers at all levels of government, and many other stakeholders, rely on an accurate Census in various ways that range far beyond the basic fact of how many people live in each state. Inaccuracies in the Census count, however, can cause federal funds to be distributed in a way that is not fully consistent with congressional intent. Many state-funded grant programs to localities also rely on Census counts, compounding the misallocation of grant money. For those jurisdictions that are counted relatively poorly by the

Census, this may translate into fewer services for families with service and support needs provided through various federally funded programs.

Uses of Census Data and Information

As mentioned previously, governments, businesses, social and non-profit groups use Census data and, increasingly, they have been asking for more and better Census disability data and information.¹

1. Federal Government. Certain questions provide critical information for monitoring compliance with the Voting Rights Act, the Civil Rights Act, and other anti-discrimination and affirmative action plan requirements. For example, the U.S. Department of Transportation uses Census data on disability for traffic analysis zones to monitor compliance with the Federal Transit Act and the Americans with Disabilities Act.

Accurate Census data are required to determine and forecast the number of persons eligible for benefits based on age, such as Social Security and Medicare and to forecast the number of persons eligible for Social Security disability benefits. Accurate Census data are necessary to develop baselines for reducing employment barriers faced by persons with disabilities and to allocate funds for vocational education and rehabilitation programs for workers with disabilities. Accurate Census data are required to determine where to build veterans hospitals, to establish baselines for veteran population projections, and to report to Congress on the needs of selected groups of veterans.

The accuracy of Census data affects the allocation of funding for numerous Federal education programs such as vocational and adult education.

2. State and Local Government. Decisions on redistricting and the determination of state and local voting district boundaries require accurate Census data. Accurate Census data are necessary for appropriate state planning and implementation of a variety of Federal programs. Accurate Census data are critical for programs that aim to identify areas eligible for housing assistance and rehabilitation loans; housing subsidies; job training and employment services; energy cost assistance; and community economic development. Accurate Census data also are critical to allocating funds for supplemental food programs and other social services for women and children. Accurate Census data also help city and community officials pinpoint areas that need special programs such as meals-on-wheels and social service agencies identify special needs such as telephone access in case of medical emergency.

Accurate Census information helps local governments predict transportation needs in emergency preparedness and disaster recovery and contingency planning initiatives. The data help governments and relief agencies in assessing the amount of the shelter and recovery needs of populations affected by: natural disasters such as floods, hurricanes, tornadoes, and earthquakes; and, by unnatural disasters such as domestic or foreign terrorism .

3. Business and Industry. Accurate Census data on where people of different ages live helps, architects, contractors, and real estate firms that need accurate information on the size and composition of households and their housing as they design, build, and sell (accessible) houses and apartments.

Accurate Census data help businesses set up and monitor affirmative action and anti-discrimination plans. And they help companies comply with anti-discrimination legislation such as the Equal Employment Opportunities Act.

4. Community Groups. In many cases, private social service agencies and community groups have the same needs for accurate Census data as state and local government agencies that provide social services. Private groups benefit from accurate Census data to set up and administer assistance programs for children, teens, and older persons; to provide services that reflect cultural differences; to teach English, and conduct voter registration drives.

5. Academic Research. Accurate Census data are vital to researchers in a wide variety of endeavors. Some of the most important needs include: (a) Any research requiring comprehensive information at the neighborhood level must rely on the Census, with its tract level information; (b) Research on disability, ethnicity or other research requiring reasonable numbers of observations of relatively small population groups must rely on the Census; and (c) The Decennial Census is the only consistent source of data for researchers examining trends over periods of decades.

6. Uses by Other Surveys and Data Collections. The Decennial Census serves as an important base for other surveys - for example through the development of population sampling units (PSUs). Data from the Decennial Census form crucial input into the sample designs of other national surveys such as the Current Population Survey (the source of the nation's unemployment statistics), the Survey of Income and Program Participation, the National Crime Victimization Survey, the Survey of Recent College Graduates, the Consumer Expenditure Survey (the source for expenditure weights used in calculating the Consumer Price Index), and statistics compiled by the National Center for Educational Statistics (NCES) and the National Center for Health Statistics (NCHS). For example, NCHS uses its own survey data combined with Census data to calculate numerous vital statistics and rates for health service utilization. Similarly, the Bureau of Justice Statistics uses Census data to calculate imprisonment and victimization rates. Census data are used to adjust surveys to be nationally representative. For example, the NCES uses Census data to make its survey results on education indicators reflect the total United States population.

Issues Around Disability Data for Censuses During the 1970s to 1990s

Questions about "disability status" were asked in the Censuses of 1970, 1980, and 1990. The 1970 Census was the first Decennial Census in many decades to contain a disability item, and the content of that item indicated a concern with the size and growth of programs that provided benefits to individuals who were "unable to work." The 1970 Census contained three questions

about work disability: (a) whether the person had a condition that limited the kind or amount of work that could be done; (b) whether the condition kept the person from holding any job at all; and (c) the length of time the person had been limited in the ability to work.

The 1980 Census disability item was adopted only after an extensive testing effort that attempted to develop a disability item that would cover several major life activities, including: doing school work, driving a car, using public transportation, taking care of personal needs, and doing housework. Screener question used in National Content Tests, checking for the reliability with which persons reported limitations in specific activities, conducted prior to the 1980 and 1990 Censuses showed that persons generally did not provide reliable responses. Based on concerns about reliability, and facing unusual space constraints on the Census questionnaire, the 1990 disability items were limited to two questions: one question about work disability; one question about health and related difficulty going outside alone and/or about taking care of personal needs.

As America began to prepare for the 2000 Census, major forces shaped the Federal Government's thinking about disability questions to be included in the questionnaire. First, with the enactment of the Americans with Disabilities Act (ADA) in 1990, a new paradigm of thinking about disability was firmly established in law and policy. Moving away from the medical model that usually formed the foundation of disability policy, this new paradigm offered a civil rights orientation that focuses on societal barriers to full participation rather than the functional impairments of the individual. The disability community embraced ADA as its declaration of independence, one that articulated a vision of an accessible and equitable society.

However, the vast majority of data collection activities of the Federal Government retained the medical bias and had not yet adopted the new paradigm. Examples of medical bias were to be found in questions about work in population-based surveys such as the Decennial Census. Questions in the Census survey focused on the individual's impairment and functional level but failed to identify barriers in society and the environment—such as discrimination and lack of accommodations in the workplace—that were potential obstacles to employment, assuming instead that the obstacles to employment resided solely with the individual as a result of the impairment itself.²

Second, the size of major government-funded programs—such as Social Security disability, Supplemental Security Income disability, and Medicare disability—that provide benefits to persons with disabilities that kept them from working was very large and continued to grow.

Third, the work disability questions that had been asked in the 1970, 1980, and 1990 Censuses and that continued to be asked in the Survey of Income and Program Participation and in the March Current Population Survey had been criticized as unreliable by many experts.³

And fourth, one of the disability questions asked in the 1990 Census provided results that were deemed unsatisfactory. Based on data from the 1990 Content Reinterview Survey (CRS), the question about whether a person had difficulty taking care of personal needs produced responses

that were unreliable and biased upwards. The CRS results suggested that the 1990 Census rate of “difficulty with self-care needs” was about twice the true level.

In light of these criticisms, and in recognition that there had been minor improvements in the disability questions in previous Censuses, interagency discussions and research activities held in preparation for the 2000 Census were intense.⁴ The interagency group:

“... reviewed questions initially proposed by the Census Bureau, developed an alternative proposal, tested both versions in the Census Bureau’s cognitive questionnaire lab, and on the basis of testing, derived a consensus version for Census 2000.” (p. 21)

Issues Around Disability Data and Information for Census 2000

Census questions about disability are designed to provide information that helps to define disability as a limitation in the ability to perform one or more major life activities. The two disability items included in Census 2000 aimed to obtain information about health conditions that limit an individual in activities such as working at a job, going outside the home alone, and taking care of personal needs such as bathing, dressing or getting around inside the home. The individual activities were themselves of interest, and Census officials believe that the ability to identify persons with a limitation in one or more activities helps determine a valid overall measure of disability status. The two disability questions contained in Census 2000 were newly designed to address acknowledged shortcomings in the two disability questions contained in Census 1990.

Early “reports” about the quality and integrity of Census 2000 data and information, particularly as it relates to or affects people with disabilities in America, are now available. One report involves an analysis by the U.S. Census Monitoring Board that estimated that Census 2000 undercounted the actual U.S. population by a net of over three million individuals, representing an undercount rate of 1.18 percent⁵.

This type of inaccuracy certainly has major implications for Americans with disabilities who rely on state and local government run programs that rely, in part, on adequate levels of federal service and supports funding. For example, according to the U.S. Census’ Monitoring Board Final Report to Congress from 2001, the estimated undercounts of Census 2000 will result in funding losses to eight federal grant programs which affect millions of Americans with disabilities. More specifically, according to the *Final Report to Congress*, 31 states will be affected by funding losses for Fiscal Years 2002–2012 with projected funding losses in the millions of dollars as follows: Medicaid at 3,735; Foster Care at 82; Rehabilitation Services at 72; Child Care and Development Block Grants at 48; Substance Abuse Block Grants at 44; Vocational Education at 33; Adoption Assistance at 32; and, Social Services Block Grants at 27. At a time when most of the states are in dire fiscal straits, these funding losses will have devastating effects at the program, community, and individual levels.

A second assessment or analysis looked at the impact that survey methodology had in Census 2000 and the Census 2000 Supplementary Survey (C2SS).⁶ Among the conclusions made based on this analysis include:

“..two surveys—C2SS and Census 2000—administered in the same year found divergent disability rates in the same population.” (p. 29)

and

“The Census 2000 enumerators found a questionable number of people with an employment disability, especially since both the C2SS and Census 2000 mail respondents reported this type of disability at the same rate.” (p. 30)

A third report provides an additional view and some new information by the Census Bureau.⁷ While praising most Census 2000 figures as “the best data ever collected,” Census officials also described the group quarter data as “weak” and urged people to “use some caution” in relying on them for analysis. This official caveat is based on the evaluations that found problems with the count of people living in “group quarters” including such institutions as mental hospitals and group homes, as well as prisons.

Finally, a visual review of the Census 2000 Tables DP-2, Profile of Selected Social Characteristics indicates that no national data was collected for people representing the disability status of the civilian noninstitutionalized population who were 0 to 5 years of age. This will likely have negative implications for a range of interested stakeholder groups, particularly at the program and community levels. For example, the Census Bureau estimates that a total of 649,000 children under age 6 years had some type of disability in 1999 according to the Survey of Income and Program Participation (SIPP).⁸ According to this report, the Census Bureau estimates:

“Children under age 6 were twice as likely to have a developmental disability (2 percent) as they were to have difficulty with movement (1 percent).” (p. 19-3)

Accurate data about such young children with disabilities is important to educators, as well as to healthcare and childcare providers. For example, educators rely on Decennial Census data to prepare short-term and long-term projections for possible changes regarding: school facilities development and improvement; curricula development and modifications; personnel hiring; and, professional development. Given federal policy makers’ current concern and efforts to vastly improve the nation’s early childhood education and intervention programs (e.g., Head Start), the lack of Decennial Census data on children with disabilities under 6 years of age may serve as a barrier to long-term planning and improvements in this arena.

Current Efforts

There are two federal disability-related data collection efforts that are directly related to the Decennial Census: the U.S. Census Bureau's American Community Survey (ACS), and the Bureau of Labor Statistics' Current Population Survey (CPS).

The ACS is a nationwide survey designed to provide communities a fresh look at how they are changing. It is a critical element in the Census Bureau's reengineered 2010 Census. Because the richness of Census data are available only once every 10 years, long-form information becomes out of date. Planners and other data users are reluctant to rely on it for decisions that are expensive and affect the quality of life of thousands of people. The ACS is a way to provide the data communities need every year instead of once in ten years. It is an on-going survey that the Census Bureau plans will replace the long form in the 2010 Census, and may likely be used to collect and report nationally representative disability data before the next Decennial Census is due.

The ACS is conducted under the authority of Title 13, United States Code, Sections 141 and 193. Full implementation of the ACS is planned in every county of the United States, pending Congressional funding. The survey would include three million households. Data are collected by mail and Census Bureau staff follow up with those who do not respond. The American Community Survey will provide estimates of demographic, housing, social, and economic characteristics every year for all states, as well as for all cities, counties, metropolitan areas, and population groups of 65,000 people or more.

Since September 2002, the ACS Disability Subcommittee has met on a regular basis. A number of federal entities are members of the Subcommittee (Social Security Administration, Federal Communications Commission, Bureau of Labor Statistics, Department of Education, Agency for Healthcare Research and Quality, National Institute of Mental Health, Department of Housing and Urban Development, National Center for Health Statistics, Department of Veterans Affairs, Census Bureau, Office of Management and Budget, and National Council on Disability). The Subcommittee's work includes drafting both new and modified questions on disability that approximate the space constraints of the Census 2000 questions on disability, and which may be cognitively tested over the next 18 months. This Subcommittee is awaiting results of the questions being developed by the Bureau of Labor Statistics (BLS) to identify people with disabilities in response to Executive Order 13078 through its redesign of disability employment questions for the BLS Current Population Survey (CPS). NCD has previously addressed the issues involving the CPS and the need for its redesign of disability items and infusion into the Decennial Census.⁹

Presumably, then, if the redesigned CPS questions—based on E.O. 13078—prove to be valid and usable, the Census Bureau will then incorporate those questions into the ACS. If the redesigned CPS questions are not determined to be valid and usable, BLS may then turn to the ACS Disability Subcommittee to see if their drafted questions yield valid and usable items as a result of cognitive testing and field tests. It remains to be seen which, if any effort, will succeed.

Conclusions and Recommendations

Over a period of 30 years, the nation has made some small progress in the quality and reliability of disability questions, and survey methodology used for the Decennial Census. Other national surveys (e.g., CPS) have shown little or no improvement in the reliability and quality reliability of their disability data and information collection. Efforts to improve some of these surveys, particularly as they affect and relate to the Census, have been underway for a number of years and may soon bear fruit.

The early returns and analyses of Census 2000 (disability) data and information highlight a number of areas in need of significant improvement. In the absence of Congressional authorization and sufficient funding for an accurate and complete enumeration of Americans with disabilities through the Decennial Census, as well as its proposed successor the American Community Survey, we may only be able to see small and incremental progress in the quantity and quality of federal Census information representing tens of millions of Americans with disabilities. Americans expect more from their government and their leaders than small, incremental progress in this critical data and information area.

Because of the critical need for comprehensive Census-based data regarding individuals with disabilities, and the need to adequately allocate federal funding including the group quarters circumstances of people with disabilities, NCD acknowledges that the total number of persons with disabilities in the United States is comprised of both a subset of the civilian institutionalized population (involving people with disabilities) plus the civil non-institutionalized population of people with disabilities.

Because of the critical and urgent need for reliable and comprehensive national level data regarding individuals with disabilities, NCD makes the following recommendations:

1. The U.S. Congress should legislatively and timely require an official and accurate enumeration of Americans with disabilities through the Decennial Census, through related national Census-like efforts (e.g., American Community Survey), as well as through related national level data collection efforts (e.g., Current Population Survey). A legislative mandate is that is appropriately funded is the only way that the Federal Government will be able to move from the piecemeal approaches to improving Census disability data collection it has maintained over the past 30 years to a more comprehensive and authorized reform.
2. The U.S. Census Bureau should immediately revise Census questions for the Year 2010 Census (and the American Community Survey) to reflect the ADA definition. Numerous federal agencies have been working to revise the 2000 Census questions on disability for use in the Census' successor, the ACS. Such efforts should proceed and the ACS Disability Subcommittee should ensure that the questions that are developed reflect the paradigm of thinking about disability embodied in ADA. Questions that do not should not be recommended to the Census Bureau for consideration for use in the ACS.

3. The Bureau of Labor Statistics should finish its work with all due haste under the Executive Order 13078. It should report the results of its cognitive and field test as soon as practicable. If the results of its work under E.O. 13078 do not yield valid and usable questions for incorporation into the Census 2010 or the American Community Survey and the Current Population Survey, perhaps the work of the ACS Disability Subcommittee will yield useful and valid survey items.

The National Council on Disability wishes to acknowledge Martin Gould for his work in the preparation of this document.

¹ National Academies Press (1995). *Modernizing the U.S. Census* (pp. 264, 274-276, 304), Barry Edmonston and Charles Schultze (Eds.), Author: Washington, D.C.

² National Council on Disability (1998). *Reorienting Disability Research*. Author: Washington, D.C. Available at <http://www.ncd.gov/newsroom/publications/reorienting.html>.

³ See, for example, the three reports issued by the Presidential Task Force on Employment of Adults with Disabilities (PTFEAD): *Recharting the Course, 1998 Report to the President*; *Recharting the Course: If Not Now, When? 1999 Report to the President*; *Recharting the Course: Turning Points, Third Report to the President, 1999*.

See also, John McNeil (June 29-July 3, 2000). Employment, earnings, and disability (pp. 16-17). Paper presented at the 75th Annual Conference of the Western Economic Association International, Vancouver, B.C.

See also, Linda Levine (August 15, 2000), Congressional Research Service issue brief, "The Employment of People with Disabilities in the 1990s," RL30653.

See also, Tom Hale (2001). The lack of a disability measure in today's Current Population Survey, *Monthly Labor Review Online*, v. 124, n. 6, at <http://www.bls.gov/opub/mlr/2001/06/ressum1.htm>.

See also, National Council on Disability (June 21, 2001), *National Disability Policy: A Progress Report*, at <http://www.ncd.gov/newsroom/publications/progressreport2000.html>.

⁴ Michele C. Adler, Robert F. Clark, Theresa DeMaio, Louisa F. Miller, and Arlene F. Saluter (1999), *Social Security Bulletin*, v. 62, n. 4, pp. 21-30.

⁵ For example, the U.S. Census Monitoring Board (September 1, 2001), *Final Report to Congress*, p. 119, Figure A, Estimated Effect of Census 2000 Undercount on Eight Federal Grant Programs.

⁶ Sharon M. Stern (July 25, 2003). Counting people with disabilities: How survey methodology influences estimates in Census 2000 and the Census 2000 Supplemental Survey. Prepared for the Annual Conference of the American Statistical Association, San Francisco, CA. U.S. Census Bureau: Washington, D.C.

⁷ D'Vera Cohn (November 25, 2003), Census Bureau Praises Data: 2000 Figures Weakest for Hispanics, Mixed Race People. *Washington Post*, A 27.

⁸ U.S. Census Bureau (2000). *Population Profile of the United States: 2000*. (Internet Release). Available at <http://www.census.gov/population/pop-profile/2000/chap19.pdf>.

⁹ See, for example, National Council on Disability (June 4, 2001). *National Disability Policy: A Progress Report*, available at <http://www.ncd.gov/newsroom/publications/progressreport2000.html>