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July 18, 2014

The Honorable Penny S. Pritzker  
Secretary of Commerce  
Herbert Clark Hoover Building  
1401 Constitution Avenue NW  
Washington, D.C. 20230

**RE: Comment on the American Community Survey - Six Disability Status Questions**

Dear Secretary Pritzker:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) and the Partnership to Improve Patient Care (PIPC), recognize the need for accountability of public funds, the individual's right to privacy, and the importance of having tested, reliable sources of population information publicly available for everyone from school-children to U.S. legislators. We appreciate the opportunity to provide comments on how much the disability community and disability advocates value and use the ACS and the six disability questions asked therein.

CCD is a coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. PIPC represents a diverse, broad-based group of health care stakeholders that are dedicated to working together to promote comparative

clinical effectiveness research that protects patient access to innovative treatment options; supports the ability of patients, doctors and other health care professionals to choose the care that best meets the individual needs of the patient; and, fosters continued medical innovation.

We are submitting these comments as a separate document because the online portal at [http://www.census.gov/acs/www/about\\_the\\_survey/content\\_review\\_feedback/](http://www.census.gov/acs/www/about_the_survey/content_review_feedback/) provided by the Census Bureau forces responses for individual questions and limits the respondent to five questions. The six ACS disability questions comprise an integrated unit of questions that together address a wide range of significant disabilities, thereby identifying those who are most at risk with respect to poverty, unemployment, emergency planning, and so forth. Information from all the questions is used collectively to distinguish and follow trends experienced by people with disabilities, formulate federal policy, and allocate funding appropriately in distinct subject areas. It is cumbersome and illogical to submit feedback that arbitrarily “skips” one of the six questions, reiterates the same “how do you use this information” response for the five questions chosen, or attempts to link a single subject area such as housing or transportation to only one of the ACS disability question rather than the full set.

## **Introduction**

The six ACS disability questions together solicit vital information from the American public that is used to plan service levels and distribute funding in areas as diverse as education, employment, transportation, housing, emergency preparation, healthcare, civic engagement, and income support. These services benefit all Americans by supporting people with disabilities of all ages, including particular sub-populations such as veterans and older Americans, to live full and productive lives, engaging economically, socially and culturally in the community and within society. For example, counties and county agencies commonly use ACS disability data to determine the number of senior citizens with disabilities in their jurisdiction who will be eligible for public services. ACS data from the six disability questions enable local fire, law enforcement, and public health agencies to estimate the equipment they need to have

readily available to meet the needs of people with mobility disabilities, people who are blind, people who need assistance with daily activities, and other individuals who may need additional assistance in an emergency situation. Local and state public education authorities use ACS data to plan for the special education needs of children over five. The specificity of the current questions, which differentiate for example between people who have hearing impairments and people have vision impairments, allows extrapolation to the very different kinds of accommodations or aids that these individuals may need in different circumstances, freeing us from guessing those needs from undifferentiated data about "people with disabilities" or unhelpful medical diagnoses statistics.

The current six ACS questions have undergone an extensive period of testing that took into account the complex relation that Americans have with "disability," including issues of stigma, self-identification, and vocabulary. The way that a question is asked has as much influence over the answer as any objective fact. Through the use of simple language that emphasizes functional capacity and common activities, the questions as written solicit accurate and useful self-reporting of disability. Moreover the ACS solicits the most accurate responses because it is intended to be administered to individuals with disabilities, not to heads of a household unit as with a number of other federal surveys such as the Current Population Survey (CPS).

Unlike surveys such as the biennial American Housing Survey (AHS), the ACS is administered annually. For the approximately 7,200 geographic areas with a population of 65,000 or higher, the ACS provides detailed *yearly* updates of socio-economic data, giving policymakers, researchers, and Congress timely data and an unprecedented ability to spot trends as they happen. After a full five year accumulation of annual surveys, the ACS will have attained data representing 5% of the total population, the largest sample size of any federal survey. This allows statistically significant estimates to be made even for smaller states, counties/tracts, and geographic areas with a population ranging from 50-20,000. While national policy- and lawmakers must be able to focus on the "big picture," the appropriate and fair distribution of federal resources to

address local needs requires accurate local data. Over 90% of the nation's incorporated and census-designated areas have a population below 65,000. The ACS's combination of in-depth answers from many individuals across data topics and geographic areas, and over a five year period for smaller geographic areas, ensures that no one individual's privacy is compromised. Rather, a true granular picture of Americans with disabilities over time emerges. The Decennial Census Long Form, which was essentially replaced by the ACS, was sent to one in six households at a single point in time, and was used to provide essentially unmediated data for the nation, states, counties, townships, ZIP codes, census tracts, and specific cities, irrespective of size. The historical ACS validation process, combined with the rigor of the ACS long-form's three-stage administration process (mail-back questionnaire, computer-assisted telephone interview, computer-assisted personal interview of a sample of remainder), and its multi-year sample data composites, makes the ACS an invaluable and uniquely reliable form of population information.

Within the ACS, the potential for cross-referencing data from the six specific disability questions with other population characteristics such as age, race, ethnicity, gender, and geographic area gives researchers the ability to formulate and answer questions about the health, economic status and activities of specific sub-populations. This is a vital aspect of the ACS for the disability community. The ACS looks at Americans, including Americans with disabilities, *in the total context of their lives*. It is not a survey that examines only health, only unemployment, or only housing. The fact and manner of the six disability questions imbedded within the ACS lends itself to the primary understanding that disability must be understood as an interaction between an individual and the surrounding environment. Just as people with disabilities are not defined by their disabilities, data on the lives of people with disabilities cannot be understood only in the context of their health conditions or any other single aspect of their lives. In an age of global competitiveness, federal and state policies must work together to abolish the barriers in education, employment, housing, transportation, and myriad other areas of life that prevent people with disabilities from contributing to, and fully participating in, American society. We cannot afford to limit the critical thought and

problem-solving capacity of students, researchers, and policymakers by eliminating our primary and best source of data about the lives of Americans with disabilities. The following examples of the statutory and programmatic uses of the six disability questions highlight the ways that the data drawn from the survey further the civil rights, community inclusion and economic independence of people with disabilities.

## **Education**

The correlation between receiving a good education and achieving economic independence and socio-economic opportunities, for people with and without disabilities, cannot be overstated. The ACS disability questions have a significant impact on the funding and operation of special education programs. The Individuals with Disabilities Act (IDEA) is the cornerstone federal law for K-12 students with disabilities, establishing how states and local educational entities are responsible for providing students with a free and appropriate public education. The federal government distributes funds through grants to states to assist compliance with IDEA so that schools can give students with disabilities educational supports, tools, and aids, and learning environments that are as integrated as possible. In order to distribute resources equitably and accurately, the federal government uses the ACS to determine how much and where to give.

In Fiscal Year 2008 alone, ACS data on each state's share of children with disabilities, and children with disabilities living in poverty, was used to allocate well over 10 billion dollars in special education grants to state educational agencies. ACS data also served as the basis for 437 million dollars in grants to families of children with disabilities, and \$371 million dollars in grants to special education preschools.<sup>1</sup> Federal support for education and training of students with disabilities continue with vocational post-graduation programs as students seek specialized skills to enter the workforce. In FY 2013, the Office of Vocational and Adult Education awarded an average of nearly 10

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<sup>1</sup> ["Surveying for Dollars: The Role of the American Community Survey in the Geographic Distribution of Federal Funds,"](http://www.brookings.edu/~media/research/files/reports/2010/3/09%20census%20dollars/0726_acs_reference.pdf) Brookings Institute (2010), and accompanying Reference Document (*at* [http://www.brookings.edu/~media/research/files/reports/2010/3/09%20census%20dollars/0726\\_acs\\_reference.pdf](http://www.brookings.edu/~media/research/files/reports/2010/3/09%20census%20dollars/0726_acs_reference.pdf)).

million dollars to each state with the objective of teaching individuals who had not yet demonstrated “sufficient mastery of educational skills.” In addition, the government earmarked over 1 billion dollars in vocational rehabilitation grants to assist states in running “effective, efficient, and accountable programs.” The allocation for both of these funding streams was based on the ACS and information collected on people with disabilities.<sup>2</sup>

While the fair distribution of federal funds is critical, accurate information is valuable in and of itself when it comes to measuring the administration and effectiveness of educational services. The School District Demographics System, operated under the National Center for Education Statistics as part of the Department of Education, relies on the ACS to stock its database with “information about demographics, social characteristics, and economics” of the children in each school district.<sup>3</sup> In other words, the ACS enables the School District Demographics system to establish a baseline for schools charged with identifying students with disabilities, implementing the IDEA, and monitoring its effectiveness. In addition, the ACS provides demographic information as to how many students with disabilities are attending higher education institutions and their level of educational attainment, thereby allowing states, the federal department of education, and researchers to determine the extent to which IDEA is supporting students to reach institutions of higher education (see excerpted chart below). No other tool allows for such nuanced cross-referenced data in a comparison of educational outcomes between students with and without disabilities

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<sup>2</sup> [2013 Catalog of Federal Assistance](#), General Services Administration, pg. 1486.

<sup>3</sup> The School District Demographics System, National Center for Education Statistics, Department of Education (2014).

<sup>4</sup> [“A Guide to Disability Statistics from the American Community Survey,”](#) Robert R. Weathers II, Employment and Disability Institute, Cornell University, pg. 40 (2005).

	No Disability		Participation Restriction		Activity Limitation	Impairment		
	Disability	Disability	Employment	Go-Outside Home	Self-Care	Mental	Physical	Sensory
<b>Education (25-61)</b>								
% Less than High School	11.6	25.0	28.6	31.0	28.4	31.2	25.7	24.5
% High School/GED	28.0	33.6	34.5	33.3	32.5	32.5	33.8	32.9
% Some College	29.4	28.4	26.7	25.1	27.8	25.9	28.9	27.7
% Four Year College Graduate or more	31.0	13.0	10.3	10.7	11.3	10.5	11.6	14.9
Total	100	100	100	100	100	100	100	100

## Employment

ACS data allows the federal government and researchers to develop, conduct, and interpret studies on the current state of employment for people with disabilities. These research findings, in turn, allow for more precise identification of the kinds of targeted interventions and job supports that will achieve a 'level playing field' for people with disabilities seeking employment and economic self-sufficiency in their communities.

The Census specifically reports on:

- [Employment Status by Disability Status](#)
- [Employment to Population Ratios for People 18 to 64 with a Disability by State](#)
- [Employment Status and Median Monthly Earnings by Disability](#)
- [Median Monthly Earnings and Family Income by Disability Status](#)

In addition, the federal Office of Disability Employment Policy and Disability Employment and the Department of Labor's Office of Federal Contract Compliance Programs together sponsor the [Disability Employment Tabulation](#). The tabulation uses three years (2008-10) of ACS data to present 1 billion new estimates highlighting the disability status and diversity of the labor force and population 16 years and older for more than 4,000 unique geographic entities. The information presented crosses the factor of disability with other demographic and socio-economic factors such as employment status, detailed occupation, occupation groups, educational attainment, age, sex, race, citizenship, and earnings. This information is necessary to accurately

understand the employment status of people with disabilities and appropriately target our employment and benefit receipt interventions.

The Institute for Community Inclusion<sup>5</sup> also uses ACS data as their primary source for general population data on employment participation and outcomes, and as a benchmark for data on disability employment from other sources.<sup>6</sup> The inclusion of the six disability questions in the ACS allows the Institute to look at variables like occupation and the relationship between employment, living situation, and disability in a way that cannot be derived from any other source. The Institute's [yearly report](#) on the status of employment and economic self-sufficiency for people with intellectual and developmental disabilities is used by researchers, policymakers, and advocates across the country to shape disability employment policy.

The specificity of the current six ACS disability questions contrasts sharply with the two compound disability question asked in the ACS prior to 2003. One of those earlier questions conflated “conditions” that affected hearing, vision, mobility, and strength. The other question broadly asked about “physical, mental or emotional conditions” that affect activities or daily living on a spectrum of complexity. Putting aside the threshold issue of whether the language and approach used would elicit self-identification with disability, these two questions failed to provide data that would allow researchers to differentiate among the highly heterogeneous population of people with disabilities. For example, a study that seeks to quantify the relationship between age, the increased prevalence of disabilities, and how certain types of disabilities alone and in combination correlate with labor force participation rates and earnings<sup>7</sup> could **only** be soundly based on the six disability questions now asked in the ACS, which uses person level weights in addition to housing unit weights to derive more accurate full population estimates from an already large sample size. Given the aging American population and workforce,

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<sup>5</sup> A project of the Institute for Community Inclusion at UMass Boston, supported in part by the Administration on Intellectual and Developmental Disabilities, U.S. Department of Health and Human Services, with additional funding from the U.S. Department of Education.

<sup>6</sup> See [www.StateData.info](http://www.StateData.info).

<sup>7</sup> C. Roehrig, D. Klayman, & K. Robinson. Aging into disability beyond 50: The impact on labor force participation and earnings. In Barnartt & Altman (Eds.) *Disability and Intersecting Statuses, Research in Social Science and Disability* (2013), Volume 7, 189-204.



there is a clear and timely need for research that will inform the development of national, state and local policies to maintain the health and functional capacity of American workers so that they can remain in the labor force and continue directly contributing to the American economy.

The Workforce Innovation and Opportunity Act (H.R. 803) (WIOA) has just passed Congress earlier in July 2014 with substantial bi-partisan support. Section 102(b)(1)(B) of the WIOA *requires* states to provide “an analysis of the current workforce, employment and unemployment data, labor market trends, and the educational and skill levels of the workforce, including individuals with barriers to employment (including individuals with disabilities), in the State” when applying for WIOA grants. Eliminating the current six questions will leave states unable to comply with the law, and individuals who need WIOA services will be unable to benefit from them. States also rely heavily on ACS data when compiling information for state-level policy formulation on particularly vulnerable subpopulations. For example, the New York Makes Work Pay project (NYMWP) seeks to improve the employment outcomes and financial independence of New Yorkers with disabilities. NYMWP’s 2011 Disability and Employment Status Report especially focused on employment for transition-aged youth with disabilities and veterans with service-connected disabilities.<sup>8</sup> It would be difficult or impossible to zero in on such specific subpopulations within a state, and consequently develop appropriate tailored supports, without data derived from the ACS disability questions.

## **Housing**

While education and employment are critical components of independence for people with disabilities, the community mandate of the Americans with Disabilities Act of 1990 (ADA) and the Supreme Court’s 1999 *Olmstead* decision<sup>9</sup> prohibiting the unjustified segregation of people with disabilities cannot be achieved without accessible affordable housing. The U.S. Department of Housing and Urban Development (HUD) heavily

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<sup>8</sup> S. von Schrader, W. Erickson, Z. Nazarov, T.P. Golden, & L. Vilhuber. New York State Disability and Employment Status Report - 2011. Ithaca, NY: Cornell University, Employment and Disability Institute on behalf of New York Makes Work Pay Comprehensive Employment System Medicaid Infrastructure Grant. February, 2012.

<sup>9</sup> *Olmstead v. L.C.*, 527 U.S. 581 (1999).

relies on ACS data to allocate billions of dollars of HUD funding each year to states and localities to facilitate housing for priority populations through the HOME program, the Community Development Block Grants program, Emergency Solutions Grants, and the Housing Opportunities for Persons with AIDS program.

HUD also funds approximately 4.4 million rental subsidies for the lowest income households below 50 percent of Median Income HUD's 2011 Worst Case Housing Needs Report published in 2013 indicates that approximately 960,000 households that include people with disabilities are being assisted through these programs. Among these assisted households, approximately 60,000 non-elderly households with disabilities are being assisted with Non-Elderly Disabled (NED) Housing Choice Vouchers appropriated by Congress specifically for this purpose. ACS data related to area median income for eligibility, and area Fair Market Rents, are critical to the success of these programs.

HUD's periodic reports to Congress on the extent of worst case housing needs<sup>10</sup> are required by law. The federal agency can and does use the American Housing Survey (AHS), but in its 2009 Worst Case Supplement Report on the housing needs of people with disabilities explicitly stated that "ACS is needed to validate reporting on the Worst Case housing needs of people with disabilities." The ACS presents higher disability rates among very low income non-elderly renters without children and with children. The ACS disability rate was 29 percent and 24 percent respectively, while the household reported AHS rate was only 22 percent and 15 percent respectively. The ACS also achieves a better correlation between a positive response to one of the six disability questions and disability sources of income (i.e. SSI, SSD, etc.), thereby presenting a more accurate picture of low income people with disabilities.

HUD not only uses ACS data directly for its own allocation and reporting purposes, it distributes specific ACS demographic and income-related data sets to more than 400

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<sup>10</sup> Defined as very low income renter households who are paying more than 50 percent of their income for housing costs, living in seriously substandard housing, or who have both of these conditions.

state and local participating jurisdictions and entitlement communities. Local government entities then incorporate this ACS data in housing needs assessments and resource planning/allocation decisions required as part of the federally mandated Comprehensive Housing Affordability Strategy (e.g. Consolidated Plan). Accurate and high quality ACS demographic and income data by household is essential to ensure the effective use of HUD programs for highest priority low income, very low, and extremely low income households.

HUD's interest in holding housing authorities and grantees accountable for their use of federal resources also leads back to the ACS. In 2011 guidance to the Fair Housing and Equal Opportunity Regional and Field Office staff, HUD recommends that Public Housing Agency (PHA) compliance reviews utilize ACS data for the geographic area to assess the need for accessible units.<sup>11</sup> Based on the ACS data, HUD can require under some circumstances that a PHA provide a higher percentage of accessible units in their public housing buildings. In addition, a Proposed HUD Affirmatively Furthering Fair Housing Rule will require grantees to use a new online mapping tool to properly assess a community's obligation to affirmatively further fair housing opportunity on behalf of people with disabilities, as well as other protected classes. Data under the ACS will be a key part of that mapping tool.<sup>12</sup>

The Supreme Court's affirmation in *Olmstead* of the ADA's community integration mandate has spurred advocacy, Department of Justice investigations, and private and federal litigation in states that continue to fund segregated group quarters settings in lieu of integrated community-based housing. Unfortunately, a large proportion of people with disabilities are still presented with little or no alternative to living in group quarters settings. AHS surveys exclude all group quarter residents with disabilities. The ACS is the only federal survey that provides data on the distribution of working age people with and without disabilities living in institutional and non-institutional group quarters, including nursing homes, groups homes, board and care facilities, state facilities for

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<sup>11</sup> See <http://portal.hud.gov/hudportal/documents/huddoc?id=disabilitiestransitioning.PDF>.

<sup>12</sup> Prototype available at: [http://www.huduser.org/portal/affht\\_pt.html#dataTool-tab](http://www.huduser.org/portal/affht_pt.html#dataTool-tab).

people with mental illness and people with IDD, short-term treatment facilities, emergency shelters, college dorms, correctional facilities, and military barracks. ACS institutional and non-institutional group quarters data is essential to accurately assessing the housing needs of people with disabilities overall. Consequently, both ACS and AHS data must be utilized for the federal government to produce estimates of the total number of very low income people with disabilities who have the greatest need for housing assistance.

Finally, states, disability advocates, and other disability stakeholders must have access to ACS data, and particularly group quarters information, to appropriately monitor and evaluate state efforts to comply with the ADA's community integration mandate. Some elements of group quarters data (i.e. the number of people with disabilities living in group homes, board and care facilities, etc.) are not made publicly available and can only be obtained through a request for a special tabulation, the cost of which is borne by the entity making the request. This data is critical to efforts to ensure that people with disabilities can return to, and remain in, their communities as required under federal law. The Census Bureau should make all group quarters data available to other federal agencies that request such data, and to the public, upon request. The loss, in whole or in part, of any of the six ACS disability questions would make it extremely difficult to evaluate how states are meeting their *Olmstead* obligations over time or to compare *Olmstead* practices in a state's urban and rural communities, for example.

## **Transportation**

Accessible transportation services are critical supports needed for people with disabilities to live and work as independently as possible in their communities. Disability data collected by the ACS

assists states and local areas in planning transportation projects and services to meet the needs of people with disabilities. Disability data are used to allocate funds for mass transit systems to provide transit to people with disabilities. Local transit authorities are required by the ADA to provide accessible public transit, and use data on the number of individuals with functional limitations within their service area to ensure that they receive

public transportation services that are comparable to those provided to individuals without disabilities.

One concrete example of ACS use in transportation is found in Section 5310 of the Enhanced Mobility for Seniors and Individuals with Disabilities Act,<sup>13</sup> which allocates funding to applicant states and designated transportation agencies based in part on disability data gathered by the ACS. In FY 2014, \$258 million was allocated to recipients for new public transportation services and public transportation alternatives *beyond* those required by the ADA. These new services assist individuals with disabilities with transportation, including transportation to and from jobs and employment support services. The Act consolidates what used to be known as the New Freedom Program and the Elderly and Disabled Program, and adopts the very specific allocation requirements of the New Freedom Program. That is, 60% of the funding must be allocated according to the state's relative share of seniors and individuals with disabilities in urbanized areas with a population over 200,000; 20% to the state's relative share of seniors and individuals with disabilities for services in small urbanized areas; and 20% to the state's relative share of seniors and individuals with disabilities for services in rural areas. This is information that can only be derived through the ACS.

### **Healthcare Services and Benefits**

Healthcare services and benefits are not always understood as a disability civil rights issue, but many people with disabilities and chronic conditions cannot lead healthy independent lives in the community without access to fully accessible, equally effective, healthcare services. People with disabilities do not all use public healthcare programs such as Medicare or Medicaid, but those who do need those services and supports to be adequately funded and fairly provided. The loss or interruption of quality healthcare, and especially long-term services and supports, can lead to diminished functional capacity, poor health, and eventual institutionalization or death. Medicaid is the only

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<sup>13</sup> 49 U.S.C. Section 5310 / MAP-21 Section 20009.

publicly funded source of long-term services and supports. Federal and state governments need timely, accurate information about on personal income levels, area median incomes, and where Medicaid and Medicare recipients with disabilities are located.

In FY 2008, approximately 260 billion, or almost 63% of ACS-guided funding, was allocated through Federal Medical Assistance Percentages (FMAP).<sup>14</sup> FMAP distribution is based on state per capita income levels, which the Department of Commerce's Bureau of Economic Analysis derives from the use of several data sources, including the ACS. The FMAP formula is used in many of the U.S. Department of Health and Human Services' (HHS) federal assistance formula grants and project grants. In only a few examples from FY 2012, FMAP (or the enhanced FMAP rate used in the Children's Health Insurance Program (CHIP)) determined the allocation of \$4,500,000,000 to states in Foster Care – Title IV-E formula and project grants, \$9,781,000,000 in CHIP formula grants, and \$265,572,900,000 in Medicaid formula grants.<sup>15</sup>

The role of the ACS in the determination of state per capita income and the FMAP percentages has helped policymakers to develop and determine funding for innovative projects to address long-standing issues faced by the disability community. The Demonstration to Maintain Independence and Employment (DMIE) took place from 2007-2009, seeking solutions to the impossible choice that workers and people with disabilities all too often face between gainful employment and needed comprehensive healthcare benefits and supports. Under the DMIE, federal funding was allocated to the applicant states of Hawaii, Kansas, Minnesota, and Texas on the basis of the FMAP percentage. These states provided participating workers who had chronic conditions with employment supports and additional financially subsidized health benefits that were

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<sup>14</sup> [“Surveying for Dollars: The Role of the American Community Survey in the Geographic Distribution of Federal Funds,”](#) Brookings Institute (2010), and accompanying Reference Document (*at*: [http://www.brookings.edu/~media/research/files/reports/2010/3/09%20census%20dollars/0726\\_acs\\_reference.pdf](http://www.brookings.edu/~media/research/files/reports/2010/3/09%20census%20dollars/0726_acs_reference.pdf))

<sup>15</sup> Federal Uses of Bureau of Economic Analysis Regional Statistics, *available at*: <http://search.bea.gov/search?query=fmap&commit=Go&utf8=%E2%9C%93&affiliate=u.s.bureauofeconomicanalysis/>

equivalent to those available under Medicaid, for which they were otherwise ineligible. to determine if the workers' loss of employment and independence due to disability could be postponed or prevented. In FY2008 alone, over \$4 billion was allocated in DMIE project grants. Concluding analysis of the project found a positive impact on functional capacity and health, and a decline in the receipt of Social Security Administration benefits, among participating workers in at least some states.<sup>16</sup>

In addition to determining the allocation of federal funding among states, the capacity of ACS data to provide local information allows it to be used for funding allocation within states. For example, the Older Americans Act Area funds Area Agencies on Aging (AAAs) in every local community to provide Americans 60 and over with a range of service options for living safely and independently in the community. AAAs already use the ACS to determine the numbers of older Americans by county, income/poverty, and race/ethnicity, but the increasing prevalence of disability with age means that AAAs look to the ACS for determine the number of older Americans with disabilities in their jurisdictions. In particular, AAAs seek reliable statistics concerning older Americans with mobility activities and those who are experiencing have limitations in activities of daily living. All of this information will help each state to refine its Intrastate Funding Formula for AAAs. Other state agencies also rely on ACS disability data. For example, the Nevada Aging and Disability Services Division used ACS disability data "to identify trends in populations with disabilities" when developing its 2012-2016 State Plan.<sup>17</sup>

### **Long Term Supports and Services**

The ADA and the *Olmstead* decision requires states to provide long term supports and services "in the most integrated setting appropriate to the needs of qualified individuals

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<sup>16</sup> D. Whalen, G. Gimm, H. Ireys, B. Gilman, S. Croake. Mathematica Policy Research, Inc *Demonstration to Maintain Independence and Employment (DMIE) Final Report*. February 13, 2012. Available at: <http://www.mathematica-mpr.com/our-publications-and-findings/publications/demonstration-to-maintain-independence-and-employment-dmie>.

<sup>17</sup> National Association of States United on Aging and Disabilities. State Responses on their use of American Community Survey (ACS) and Aging Integrated Database (AGID). June 11, 2012. Available at: <http://www.nasuad.org/documentation/Surveys/State%20use%20of%20ACS%20and%20AGID%20Data.pdf>.

with disabilities.”<sup>18</sup> Most people with disabilities want to live in their own home rather than be forced to live in an institutionalized setting to receive the supports and services they need. However, many people with disabilities have little or no alternative to living in a nursing homes to receive health care and personal assistance services. It is essential for states to determine where people who require long term supports and services are living so that home- and community-based systems can be put in place to support them. People with disabilities, their families and disability advocates urgently need population-based data to accurately assess the need for long term support and services, identify mid- and long-term policy solutions, and evaluate potential costs and sustainability.<sup>19</sup>

ACS data is used to determine the prevalence rate of people with disabilities needing long term support and services. There are ten to eleven million people with disabilities living in the community that fall into the category of needing long term support and services. Further, policy makers can use ACS data to distinguish between the number of people with disabilities needing long term support and services who live in the community and who live in institutionalized settings. This data allows policy makers to better allocate funds for the Money Follow the Person Grant, a program that helps states to rebalance their Medicaid long term support and service systems away from a foundational bias toward institutional services and toward community-based services. Over 31,000 people with chronic conditions and disabilities have transitioned from institutions back into the community through Money Follows the Person programs as of December 2012.<sup>20</sup> State and federal officials must be able to appropriately distribute Money Follows the Person Grant funds locally, using validated ACS data, so that people who need long term support and services can receive them in their own homes instead of in segregated institutions.

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<sup>18</sup> U.S. Department of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* [http://www.ada.gov/olmstead/q&a\\_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm) Retrieved on 7/7/2014

<sup>19</sup> Kaye, S., Harrington, C., LaPlante, M. (2010). Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much? Health Affairs, vol. 29, 1, pp. 11-21.

<sup>20</sup> Medicaid.gov, Money Follow the Person. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Money-Follows-the-Person.html> Retrieved on 7/3/2014.



The disability questions on the ACS include questions regarding self-care and difficulty in performing activities of daily living, such as bathing, dressing, transferring from bed or chair, eating, using the toilet, and getting around inside the home. This data helps policymakers to determine the need for long term support and services on the state and local level. In addition, ACS data allows policy makers to make more informed decisions on the allocation of Medicaid funds based on the individual needs of consumers. Medicaid is the only public source of funding for long term supports and services, and allows consumers with disabilities and chronic conditions to receive home- and community-based long term support and services based on their levels of need.

### **Emergency Preparedness**

The importance of emergency planning for persons with disabilities while overlooked or completely disregarded for years was brought to center stage after the hurricane disasters in 2005. Evidence that persons with disabilities faced vastly different experiences in evacuation, shelter, and recovery than people without disabilities during Hurricane Katrina finally brought this problem to the attention of state and national government. People with disabilities were often unable to evacuate because transportation was inaccessible while people with visual and hearing disabilities were unable to obtain necessary information pertinent to their safety because communications did not comply with federal law. Further, emergency managers and government officials also failed to recognize that in the sheltering process, basic needs for persons with chronic conditions and functional limitations had to include meeting medication, equipment and service needs.

Almost immediately after Hurricane Katrina devastated the Gulf Coast, the National Council on Disability (NCD) estimated that there were roughly 155,000 people with disabilities over the age of 5 – or about 25 percent of the cities' populations – living in the three cities hardest hit by the hurricane: Biloxi, Mississippi; Mobile, Alabama; and

New Orleans, Louisiana.<sup>21</sup> Another statistic from the American Association of Retired Persons (AARP) provides further insight into the extent of the problem: “73 percent of Hurricane Katrina-related deaths in New Orleans area were among persons age 60 and over, although they comprised only 15 percent of the population in New Orleans.”<sup>22</sup>

The challenges faced by persons with disabilities (physical, sensory, cognitive, psychiatric, etc.), seniors, and residents of low-income households (among which considerable overlap exists) in all disaster-threat situations have been made even more clear through events such as September 11, Hurricane Sandy, and the latest wildfires in Southern California. Problems with warning transmission and receipt, transportation, evacuation, shelter, and long-term recovery have been documented through both research studies and government investigations, as noted in several GAO reports, inquiries by the U.S. Congress and the White House, the National Council on Disability (NCD), and other organizations, such as the National Organization on Disability.

Fortunately, this trend seems to be at a critical turning point, with greater recognition of disability and disaster issues, as well as increased determination to address those concerns and enhanced efforts to produce both empirical and practical materials. An essential basic element of building appropriate levels of capacity, specific planning, and response success is to be able to identify the size and nature of the population needing such planning at the smallest geographic levels possible. **The six ACS disability questions provide the only source of this information currently possible.** The set of six disability questions used in the ACS is currently used by several areas or sectors of CDC to support preparedness, response, recovery and mitigation (factors identified by the National Council on Disability as essential to emergency preparedness). In particular, the Office of Public Health Preparedness and Response uses the ACS

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<sup>21</sup> National Council on Disability, (2006) **THE IMPACT OF HURRICANES KATRINA AND RITA ON PEOPLE WITH DISABILITIES: A LOOK BACK AND REMAINING CHALLENGES**  
<http://www.ncd.gov/NCD/publications/2006/Aug072006>.

<sup>22</sup> AARP, *We Can Do Better: Lessons Learned for Protecting Older Persons in Disasters* (2006),  
<http://assets.aarp.org/rgcenter/il/better.pdf>.

disability questions to accurately describe the size and nature of populations in small geographic areas to supplement their planning activities. In addition the National Center on Birth Defects and Developmental Disabilities also funds 18 states in the priority area of improving access to, and the effectiveness of, emergency preparedness, including risk communication, evacuation, sheltering and continuity of services.

### **Civic and Social Participation**

Fundamental civil rights such as the right to vote, as well as opportunities to fully participate in mainstream American life, are integral components of living in the community. Yet they remain aspects of life that are out of reach for many people with disabilities because of access barriers and discrimination. Federal lawmakers recognize this fact through funding grants to the Voting Access for Individuals with Disabilities program. States applied for and received 9.5 billion in FY 2008 to make polling places physically accessible; provide people with a range of disabilities an equal opportunity to vote privately and independently; train election officials, poll workers and volunteers; and inform people with disabilities on the accessibility on polling places. In addition to those grants, 5.3 billion was allocated in the same year to state Protection and Advocacy Systems to monitor and enforce the rights of people with disabilities to full participation in the electoral process. Federal funding also supports the provision of independent living services to promote the leadership, independence, productivity, and full inclusion of people with disabilities. In FY2008, 4.5 billion was allocated to state agencies through Independent Living State Grants on the basis of population estimates.

### **Health Disparities and Public Health**

The academic world and public policy have only relatively recently come to recognize disability as a factor leading to avoidable health disparities, rather than purely a consequence of health disparities that are raised by other demographic characteristics such as race, ethnicity, or socio-economic status.<sup>23</sup> The Centers for Disease Control

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<sup>23</sup> U.S. Department of Health & Human Services, *Healthy people 2000*. Washington, DC: 1990; U.S. Department of Health and Human Services, *Healthy people 2010. 2nd ed.* Washington, DC: 2000; U.S. Department of Health and Human Services, *About healthy people: Healthy people 2020*, updated 2014. Available at: <http://www.healthypeople.gov/2020/about/default.aspx>; Institute of Medicine, *The future of*

and Prevention (CDC) was among the first to initiate research on disability and health through the funding of state disability and health programs in the late 1980s.<sup>24</sup> At this point, CDC's Office of Minority Health and Health Equity (OMHHE) itself uses, and recommends the use of, a variety of ACS variables including income, race, ethnicity, sex, disability, educational level, employment status, and disability status to assess health equity issues. The ACS is one of the few sources of national data from a large sample that both identifies disability status through the validated six disability questions, and captures other social determinants of poor health. It is hard to imagine the science of social determinants of health progressing without sources of national data such as ACS. Altering or removing the six ACS disability questions would be a great set back at this critical juncture when there is a growing body of actionable research into the relationship between disability status and health disparities.

The Affordable Care Act (ACA) strongly recognizes disability as a health disparity factor. Section 4302 of the ACA on health disparities and data collection mandates federally conducted or supported health care and public health programs, activities or surveys, explicitly including the ACS, to collect and report data on "disability status for applicants, recipients, or participants." The data is to be available "at the smallest geographic level such as State, local, or institutional levels if such data can be aggregated," and there must be "sufficient data to generate statistically reliable estimates." The characteristics of how the ACS is administered allows statistically reliable estimates to be made for smaller local geographic areas. As a happy consequence, the six ACS disability questions substantially fulfill the ACA's statutory mandate, as well as the further requirement in Section 4302 that collection standards must include self-reported data by the applicant, recipient, or participant. The six ACS disability questions therefore

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*disability in America*. Washington, DC: The National Academies Press; 2007; U.S. Department of Health and Human Services, *The Surgeon General's call to action to improve the health and wellness of persons with disabilities*. Washington, DC: Office of the Surgeon General, US Department of Health and Human Services; 2005; G.L. Krahn, G. Fujiura, C.E. Drum, B.J. Cardinal, M.A. Nosek MA, The dilemma of measuring perceived health status in the context of disability. *Disability and Health Journal*. 2009;2(2):49-56; National Council on Disability, *The current state of health care for people with disabilities*. Washington, DC: National Council on Disability; 2009.

<sup>24</sup> M.A. Turk, S. McDermott, From the editors. *Disability and Health Journal*. 2008;1(1):3-4.

provide an excellent disability data collection model for all other federal surveys, programs and activities.

Thank you once again for the opportunity to comment on six ACS disability questions and their vital importance to the disability community. We would be happy to speak with you on any of the issues that we have raised. If you have any questions about the above, please feel free to contact Silvia Yee, senior staff attorney at DREDF.

Yours Truly,

American Association on Health and Disability (AAHD)

American Association of People with Disabilities (AAPD)

Association of University Centers on Disabilities (AUCD)

Disability Rights Education and Defense Fund (DREDF)

Partnership to Improve Patient Care (PIPC)

The Arc of the United States...