



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

September 1, 2016

Submitted electronically via www.regulations.gov

Karen Humes, Chief, Population Division
U.S. Census Bureau
Room 6H174
Washington DC 20033
Email: POP.2020.Residence.Rule@census.gov

**RE: Proposed 2020 Census Residence Criteria and Residence Situations,
Docket No. 160526465-6465-01**

Dear Ms. Humes:

As Co-Chairs of the Consortium for Citizens with Disabilities Housing and Rights Task Forces (CCD Housing Task Force) we are pleased to provide comments on behalf of the Task Forces to the Notice of Proposed Rule Making, “2020 Census Residence Rule and Residence Situations” (81 Fed. Reg. 42577; Docket No. 160526465-6465-01).

The Consortium for Citizens with Disabilities (CCD) is a working coalition of 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.

The CCD Housing and Rights Task Forces understand that the fundamental reason for conducting the decennial census is to apportion the seats in the U.S. House of Representatives. Decennial census data are also the basis for other critically important national policies, including required periodic assessments of affordable housing needs conducted by the U.S. Department of Housing and Urban Development (HUD) and submitted to Congress in the form of Worst Case Housing Needs reports (Worst Case Reports). Data from the Census are also utilized in various statutory formulae related to the distribution of appropriations that fund certain HUD affordable rental housing programs.

Numerous studies document that the lowest income people with disabilities – particularly the approximately 5 million non-elderly adults with the most significant and long term disabilities who receive income from the federal Supplemental Security Income (SSI) program – have the most critical housing needs of any population group.

Every two years, the CCD Housing Task Force and the Technical Assistance Collaborative (TAC) conduct a national study of the relationship between SSI-level income and modest rental housing costs. The latest study – *Priced Out in 2014* – documents that the average annual income of a single adult household with a disability receiving income from the SSI program was \$8,995 – equal to only 20.1 percent of the national one person household median income. In 2014, the average one-bedroom rent – reflected as HUD’s one-bedroom Fair Market Rent – was \$780 per month.

Using federal housing affordability guidelines – which provide that low income households should pay no more than 30 percent of income for housing costs – a person with a disability receiving SSI-level income of \$8,995 annually would need to pay 104 percent of this income to access a one bedroom unit priced at this HUD Fair Market Rent. Simply stated, people with disabilities who must rely on federal SSI payments are completely priced out of the nation’s rental housing market. This fact is highly relevant to the decennial census because when people receiving SSI are unable to find housing they can afford in the community, they basically have two choices: they can become homeless (as many do) or they are forced to choose a “bed” within one of the nation’s Institutional or Non-Institutional Group Quarters settings.

For many years, virtually no attention was paid to the plight of people with disabilities forced to live in Institutional or Non-Institutional Group Quarters settings. Fortunately, that changed in 1999, when the U.S. Supreme Court issued its *Olmstead vs. L.C.* decision which affirmed the rights of people with disabilities to live in the most integrated setting, in accordance with the Americans with Disabilities Act (ADA). Since 1999, states across the country have entered into Settlement Agreements with the U.S. Department of Justice and private plaintiffs to resolve alleged violations of the ADA and the *Olmstead* decision based on their reliance on and funding of Group Quarters settings. Thus, an accurate counting of the number of people with disabilities residing in Group Quarters settings, which has been long sought by the CCD Housing Task Force and other disability advocacy groups – is also a critical policy priority for the Obama Administration.

To obtain as much Census data as possible on the number of people with disabilities living in Group Quarters, TAC and the CCD Housing Task Force requested and received a Special Tabulation of state-level census data on individuals with disabilities living in specific types of Group Quarters settings. We were pleased to work collaboratively with Census Bureau staff on this Special Tabulation, which has provided us with a greater level of detail regarding certain characteristics of people with disabilities living in Group Quarters. Through the Special Tabulation request process, we also developed a much better understanding of how this data is collected and managed by the Census Bureau.

With this knowledge in hand, we are pleased to offer the following comments on the proposed *2020 Census Residence Rule and Residence Situations*:

Recommendation: The concept of Usual Residence and Group Quarters Settings Primarily Occupied by People with Disabilities – 11b and 16a

Many Group Quarters settings – particularly Nursing Homes (11d) and Group Homes (16a) – are intended to be occupied solely by people with disabilities and have been created or licensed by state or local government exclusively for that purpose. Under policies governing these settings developed many years ago, people residing in these settings are treated as permanent residents, even if they would prefer to live in integrated housing in the community, as is their right under the ADA.

Because of *Olmstead*, many states are now beginning to modify their policies regarding the permanency of Nursing Home and Group Home settings and eliminate the once-common presumption that people will continue to reside in these settings on a permanent basis. States have increasingly taken advantage of federal programs designed to promote the transition of individuals with disabilities into their own homes and communities. These programs, such as Money Follows the Person and Medicaid home and community-based services waivers and options, provide federal support and incentives for people who desire to live in a more integrated community setting to do so. We believe that the current language in the proposed rule is not sufficient to capture information that is relevant to people with disabilities residing in these settings who are in the process of transitioning to community living. In other words, the current language creates a strong presumption that the individual with a disability will continue to reside in the Group Quarters setting.

We understand that persons may be counted only once on Census Day, and that the lack of a usual home elsewhere (where they live and sleep most of the time around Census Day) requires that the person be counted at the Group Quarters setting. To do otherwise, would, by definition, mean they would not be counted at all.

However, we urge the Census Bureau to add language to the Group Quarters categories of Nursing Facilities/Skilled-Nursing Facilities and Group Homes for Adults that would permit persons to be counted at a residence which they are actively preparing to transition to, which could be defined by one or more of the following criteria: (1) a discharge date has been set for the person for a specific address; (2) community-based services Long Term Care Services and Supports (LTSS) have been arranged in a community setting to be delivered at a specific address that the person is in the process of transitioning to; (3) the person has a signed lease or rental agreement for a housing unit in the community; the person owns a residence in the community and is in the process of transitioning back to that residence or another residence with a specific address.

Recommendation: People In Health Care Facilities 11(b) mental (psychiatric hospitals) and psychiatric units in other hospitals

The Census Bureau's proposal to count people in mental (psychiatric) hospitals and psychiatric units in other hospitals as residing at the facility misunderstands the functioning of state or private psychiatric hospitals which today provide primarily acute and short term treatment (e.g. less than two weeks in most cases) to people with mental

illness. A relatively small number of people in psychiatric facilities do reside there for longer terms, typically under civil or forensic commitments. However, in both instances, these people are likely to have a permanent residence elsewhere. It is critically important for the Census Bureau to make these distinctions when determining the Usual Residence of people in psychiatric facilities.

The CCD Housing Task Force recommends that people living in psychiatric hospitals on Census Day be counted at the residence where they sleep most of the time and not counted at the facility unless they do not have a usual home elsewhere.

Recommendation: Provide More Public Access to Census Data On Other Noninstitutional Facilities within the Group Quarters Category

Currently, the Census Bureau does not provide public access to national or state level data that is specific to one or more of the five sub-categories of facilities within the Noninstitutional Facilities category of Group Quarters. These subcategories include:

1. Emergency and Transitional Shelters (with Sleeping Facilities) for People Experiencing Homelessness
2. Group Homes Intended for Adults
3. Residential Treatment Centers for Adults
4. Religious Group Quarters
5. Workers Group Living Quarters and Job Corps Centers

Three of these five subcategories – specifically #1, #2, and #3 above – are highly relevant to the enforcement of *Olmstead* and the need to accurately account for the housing needs of people with disabilities living in these settings in HUD's Worst Case Housing Needs reports to Congress. Because of major deviations in data collection within states and localities that license these facilities, as well as across the states, the Census Bureau is – without question – the most reliable source for this information.

As the CCD Housing Task Force and TAC have suggested in prior written and verbal communications, we urge the Census Bureau to agree to provide Special Tabulations of data on these three subcategories, preferable within each subcategory but if not feasible, then in the aggregate across the three categories. These data are critically important to both housing advocates struggling to accurately assess the full scope of the housing needs of people with disabilities as well as to legal advocates for people with disabilities who are working to enforce the community integration mandates of the ADA.

In closing, thank you for the opportunity to share recommendations by the CCD Housing and Rights Task Forces.

Sincerely,

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Co-Chair, CCD Rights Task Force

Samantha Crane, Autistic Self Advocacy Network
Co-Chair, CCD Rights Task Force

Sandy Finucane, Epilepsy Foundation
Co-Chair, CCD Rights Task Force

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