



May 5, 2017

Veronica Hogan
Administration for Community Living
Washington, DC 20201

***Public Comment on Document Nos. 2017-03486 and 2017-04169
Centers for Independent Living Program Performance Report***

Submitted via e-mail: cilpprcomments@acl.hhs.gov

Dear Ms. Hogan:

Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”) appreciates the opportunity to provide comments in response to the Notice of Proposed Collection of Information published in the Federal Register on February 23, 2017, at 82 FR 11471-72, as amended on March 6, 2017, at 82 FR 12610-11. Lambda Legal is the oldest and largest national legal organization dedicated to achieving full recognition of the civil rights of lesbian, gay, bisexual, and transgender (“LGBT”) people and everyone living with HIV, through impact litigation, policy advocacy, and public education. Lambda Legal has been a leader in the fight to protect the health care needs of LGBT people and people living with HIV, including through a number of cases in which Lambda Legal has represented elderly and disabled members of the LGBT population.

On behalf of Lambda Legal, please accept the following comments regarding the Department of Health and Human Service’s (“HHS”) 2017 Centers for Independent Living Program Performance Report (“CILPPR”). We are particularly concerned about the removal of data on LGBT persons with disabilities from the CILPPR through the revision of the report issued in March of 2017. We appreciate the opportunity to provide our views.

Lambda Legal strongly supports evidence-based policy making. We believe that the federal data in the CILPPR evaluating the efficacy of programs assisting people with disabilities endeavoring to live independently in their homes and communities must accurately reflect the demographics of the United States. Ensuring such accuracy will better serve the HHS in its research and provision of critical services, and will result in better-informed decisions about how to utilize limited public resources in meeting the

needs of individuals with disabilities across the country who seek to lead productive, active and self-determined lives.

As to demographic data specific to the intersection of disability with sexual orientation and gender identity, it is imperative that the CILPPR paint an accurate picture of diverse communities, including through accurate data about the existence of LGBT people within the independent living population. High quality, accurate data that capture the diversity of our community are essential to ensuring that disabled LGBT people “count,” both in a literal sense and in terms of fundamental protections for a vulnerable population. Data sets that do not include sexual orientation and gender identity information are inadequate and incomplete.

It is well-established that LGBT people generally, and elderly members of the LGBT community especially, face substantial barriers to accessibility services. For example, in 2009, Lambda Legal conducted a survey, with the help of over 100 partner organizations, as part of a national Health Care Fairness Campaign. The results of this survey revealed that LGBT people and people living with HIV, and particularly people of color, experience high levels of discrimination, substandard health care, and barriers to access.¹ A 2016 survey conducted by the National Center for Transgender Equality replicates our findings in various other aspects of life, including housing, employment, education, and public accommodations.² Most pertinently, lesbians, gay men, and bisexuals are more likely to be living with disabilities than heterosexuals in this country,³ particularly in older populations, with nearly half of LGBT elderly adults living with disabilities.⁴

As the federal government has increasingly recognized, LGBT people are in need of protections against hate crime and other forms of discrimination; and laws of the past that criminalized LGBT people and prevented federal and state recognition of same-sex

¹ *When Health Care Isn't Caring: LGBT People of Color and People of Color Living with HIV*, LAMBDA LEGAL, https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-of-color.pdf (last accessed May 5, 2017).

² *The Report of the 2015 U.S. Transgender Survey*, NAT'L CTR FOR TRANSGENDER EQUALITY (2015), <http://www.ustranssurvey.org/report>.

³ Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, and Susan E. Barkan, *Disability Among Lesbian, Gay, and Bisexual Adults: Disparities in Prevalence and Risk*, *American Journal of Public Health* 102 (1) (January 2012): e16–e21. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3490559/>.

⁴ *Disability, Services and Advocacy for GLBT Elders* (SAGE), available at <http://www.sageusa.org/issues/disability.cfm> (last accessed May 5, 2017).

married couples have been struck down as unconstitutional. It is without question that LGBT people, their families, and the dynamic issues impacting their lives should be included in federal data collection efforts, including in the CILPPR.

Indeed, the need to collect accurate data on sexual orientation and gender identity, as well as the feasibility of doing so, is already reflected in other federal surveys that collect these data (as was originally the case in the previous version of the 2017 CILPPR).⁵ The HHS itself acknowledged in its 2017 LGBT Policy Coordinating Committee Report that “there are many questions still left unanswered about LGBT health and human services, which is why improved data collection and coordination of research efforts will continue to be at the forefront of our efforts in this area.”⁶ As the report further stated, the collection of sexual orientation and gender identity data “will prove invaluable in informing the entire process.”⁷

For too many generations, the LGBT community has been largely invisible to government and researchers, exacerbating misunderstanding and discrimination. It is consequently of great concern that the HHS, through the recent revisions to the CILPPR, is now threatening to turn its back on the needs of LGBT people with disabilities, even to the point of denying their existence for purposes of accurate demographic data collection.

Finally, in the federal government’s assessment of programs that help those with disabilities thrive in an independent living context, it can only be a benefit to the government and those it serves for such assessments to be thorough and meaningful in their analysis of the needs of affected demographic groups. The more people are reached through independent living assistance, the more they can contribute to society, and the less they will need more costly and burdensome forms of government assistance.

It is past time to close the knowledge gaps and improve policy accordingly; collection of comprehensive, accurate data is a necessary first step.

⁵ See Baker, K. and Durso, L. E., *Filling in The Map: The Need for LGBT Data Collection*, CTR FOR AM. PROGRESS (September 16, 2015), available at <https://www.americanprogress.org/issues/lgbt/news/2015/09/16/121128/filling-in-the-map-the-need-for-lgbt-data-collection/>.

⁶ *Advancing LGBT Health & Well-Being: 2016 Report*, HHS LGBT POLICY COORDINATING COMM., (2016), available at <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>.

⁷ *Lesbian, Gay, Bisexual, and Transgender Health: Objectives*, OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION, available at <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives>.



For these reason, we urge the Administration for Community Living to reinstate those demographic questions pertaining to LGBT individuals that have been removed through the March 2017 revisions to the CILPPR. We appreciate the opportunity to comment on this important matter.

Sincerely,

A handwritten signature in black ink that reads "Nancy Marcus".

Nancy C. Marcus, Esq.
Senior Law and Policy Advisor