

Data Move Us Closer to Full Equality by Speaking for Those Who Cannot: Advocating for LGBT Older Adults

The Older Americans Act, first signed into law in 1965, codified the recognition that government has an obligation to respond to the needs of older adults and to create programs that maintain basic living standards and prevent older adults from suffering in isolation and without support. The law enables significant investments in states and tribal nations across the country, values flexibility in developing approaches to service provisions that reflect local needs, and funds a nationwide network to coordinate and strengthen program implementation. The programs and services funded under the act—from meal programs to in-home services to caregiver support—combine to ensure the health of older adults. At the same time, data from the accompanying National Survey of Older Americans Act Participants make visible the unique needs of this population and enable program refinement and effective targeting of resources.

ERASING SEXUAL AND GENDER MINORITY OLDER ADULTS

In March 2017, quietly and without explanation, the Administration for Community Living, a component of the US Department of Health and Human Services, proposed eliminating from the survey a question on sexual orientation that had been in use since 2014.¹ Modeled after a question successfully

used in the National Health Interview Survey, the item allowed for the identification of lesbian, gay, bisexual, and transgender (LGBT) program participants. The proposal to remove this question is troubling in light of the evidence of disparities in health and social supports experienced by LGBT older adults relative to their peers,² and it is particularly troubling given the Administration on Aging's own recognition of the negative impact that interpersonal and institutional stigmas have on this population (bit.ly/2rmd3lv).

Data from the National Survey of Older Americans Act Participants provide information on which recipients have access to home-delivered meals, transportation, case management, and other services and are critical to evaluating program reach and effectiveness. Although analyses of the characteristics of program participants have been conducted on the basis of demographic characteristics such as age, gender, race, and ethnicity,³ no data on LGBT older adults have been released. If the proposal to eliminate this question is approved, researchers both inside and outside the government will be unable to assess the degree to which LGBT older adults are benefiting from these programs and whether additional policies are needed to eliminate barriers to access. In short, despite clear evidence for the need for these data to support LGBT communities, the Administration for Community

Living is instead proposing to keep this population invisible. In doing so, the agency is undercutting its own ability to meet the charge of protecting all older adults.

ADVANCING HEALTH AND RIGHTS

Advocates for LGBT rights are not unaccustomed to operating in the dark. From calling for funding to fight the AIDS epidemic in the face of lawmakers' silence to arguments in favor of marriage for same-sex couples, public policy to improve the lives of LGBT people has moved forward most effectively when researchers have presented concrete evidence that has shattered stereotypes and challenged misinformation campaigns. A statistic as simple as the raw count of the number of children being raised by same-sex couples in California may have decided the fate of the state's ban on marriage for same-sex couples, Proposition 8. As legal equality for LGBT people moves further forward, the advancement of health policy reforms that address the needs of underserved and historically marginalized populations demands high-quality data. Data on the

incidence of HIV among gay and bisexual men and transgender women and glaring statistics on the estimated number of LGBT young people experiencing homelessness have yielded new federal funding for services and programs to reduce and eliminate these disparities.^{4,5} Decades of work showing the breadth of negative health outcomes reported by the community supported the recent designation of LGBT people as a health disparities population by the National Institutes of Health.⁶

EVIDENCE-BASED POLICYMAKING WITHOUT EVIDENCE

To further merge research and practice, both the executive and the legislative branches of the federal government have taken up the mantle of evidence-based policymaking, including bipartisan passage of the appropriately named Evidence-Based Policymaking Commission Act of 2016. The Department of Health and Human Services' own LGBT Policy Coordinating Committee stated in its 2016 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

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forefront of our efforts in this area (bit.ly/2qliW0E).

Yet in 2017, the new administration is signaling that we may be heading backward. In addition to the proposed elimination of a question on the National Survey of Older Americans Act Participants, other negative actions include the Administration for Community Living halting the planned addition of a question to identify LGBT people with disabilities on the Centers for Independent Living Program Performance Report; the US Department of Housing and Urban Development indicating that it may no longer evaluate the effectiveness of programs developed to reduce homelessness among LGBT youths in three US cities (apne.ws/2rc2ZHH); and the Census Bureau continuing to claim a lack of federal need to include sexual orientation and gender identity questions in the American Community Survey (bit.ly/2nhKWO2). Congressional leaders have called on these agencies to reinstate deleted questions (bit.ly/2qKstQf) or move forward with expanding data collection efforts to include sexual orientation and gender identity (bit.ly/2pOtClQ), but without

further action, progress in this area may be stalled for years to come.

Contemporary debates on enacting comprehensive non-discrimination protections in employment, housing, and education; protecting the right of transgender and gender-nonconforming people to fully participate in public life; and developing and evaluating treatments to end health disparities are all hampered by the lack of data to identify LGBT people. In particular, the persistent lack of data from government surveys with large sample sizes hinders the ability to understand the relationships among sexual orientation, gender identity and expression, race and ethnicity, age, socioeconomic status, disability, and other key characteristics that help paint a complete picture of health and wellness. The academy has made significant contributions to understanding these complex interactions and, in doing so, has a central role to play in conducting research that directly affects public policy. These contributions, however, cannot be a replacement for the value and power that government data bring to the advancement of LGBT rights.

Those who report knowing an LGBT person hold more

positive attitudes about the population, and disclosure of sexual orientation and gender identity paired with acceptance promotes better health. Visibility can be a tool to improve both the social climate and civil rights, but that visibility is not without cost. In a nationally representative survey conducted by the Center for American Progress, more than half of LGBT people who had experienced discrimination in the past year avoided speaking about topics related to LGBT issues in social situations.⁷ As LGBT people continue to experience discrimination unchecked by explicit and comprehensive civil rights protections, data can move us closer to full equality by speaking for those who cannot. **AJPH**

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LGBT Data Collection Amid Social and Demographic Shifts of the US LGBT Community

A strong call for better data resources constitutes a key recommendation in the 2011 Institute of Medicine's landmark assessment of how to improve our understanding of lesbian, gay, bisexual, and transgender (LGBT) health needs.¹ Since

then, publicly funded and accessible data resources in the United States that measure sexual orientation and gender identity have improved. Two high-profile examples of this improvement include the Department of Health and

Human Services' (HHS) National Health Interview

Survey, which added sexual orientation measurement in 2013, and the Department of Justice's National Crime and Victimization Survey, which now includes both sexual orientation and gender identity measurement (bit.ly/2pDiXKs).

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