



April 17, 2023

OMB Desk Officer for ACL  
Office of Information and Regulatory Affairs  
Office of Management and Budget  
New Executive Office Bldg.  
725 17th St. NW, Rm. 10235  
Washington, DC 20503  
*Submitted via reginfo.gov*

**RE: Public Comment in Response to Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; of the State Councils on Developmental Disabilities (Councils) State Plan OMB Control Number 0985-0029**

To Whom It May Concern,

On behalf of the Human Rights Campaign's more than three million members and supporters nationwide, we write in response to the above-captioned information collection proposed by the Administration for Community Living (ACL) regarding the 5-year strategic State plans ("State Plans") it requires be filed by State Councils on Developmental Disabilities under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act Councils).<sup>1</sup>

The Human Rights Campaign (HRC) is America's largest civil rights organization working to achieve lesbian, gay, bisexual, transgender, and queer (LGBTQ) equality. By inspiring and engaging all Americans, HRC strives to end discrimination against LGBTQ+ citizens and realize a nation that achieves fundamental fairness and equality for all. As an advocate for LGBTQ+ individuals, HRC believes that all people—including LGBTQ+ people with developmental disabilities and their families—deserve to be counted and have their lived experiences meaningfully considered as part of the federal government's data collection and service delivery efforts. We therefore write in support of this proposal.

DD Act Councils receive funding from ACL to identify and help meet pressing needs for people with development disabilities in their regions, including through the delivery of resources to ensure those individuals and their families receive essential information, training, and other services to build intracommunity capacity to sustain all their residents. DD Act Councils are required to submit State Plans to operationalize their goals and strategies in this regard—including by using demographic information collected from program beneficiaries allowing for the monitoring of needs within and services provided to members belonging to specific

---

<sup>1</sup> Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; of the State Councils on Developmental Disabilities (Councils) State Plan OMB Control Number 0985-0029, 88 Fed. Reg. 16,261 (Mar. 16, 2023).

communities. The current proposal calls for these State Plans to include data on beneficiaries' sexual orientation and gender identity (SOGI), consistent with other recent proposals by ACL.<sup>2</sup>

LGBTQ+ people are a growing population in the United States, living in every state and county and reflecting the breadth of diversity and lived experiences of the communities in which they live. Using data collected through the U.S. Census Bureau's Household Pulse Survey, we recently estimated that at least 20 million adults in the U.S. identify as LGBTQ+.<sup>3</sup> Consistent with others' research, we have also found evidence that younger people are more likely to identify as LGBTQ+.<sup>4</sup> LGBTQ+ people are a demographically diverse population, with the Williams Institute using Gallup Daily Tracking survey data from 2012–2017 to estimate that 58% of LGBT adults identify as female and that 42% identify among communities of color, including 1% of LGBT adults that identify as American Indian and Alaska Native.<sup>5</sup> The Williams Institute also recently reported on evidence that individuals belonging to certain communities of color appear more likely than their White counterparts to identify as transgender.<sup>6</sup> And, data from the Behavioral Risk Factor Surveillance System indicate that LGBTQ+ adults, and transgender adults in particular, are significantly more likely than non-LGBTQ+ adults to self-report having at least one disability.<sup>7</sup>

Federal agencies have long been researching and collecting information on LGBTQ+ people like what is being proposed here.<sup>8</sup> In a recent report on the collection of SOGI information in the survey context, the Office of Management and Budget (OMB) highlighted guiding principles that have emerged out of agencies' decades of work on collecting and analyzing SOGI data to support the ongoing collection of SOGI information, including that collected data should have utility, be in support of an agency's mission, and done with emphasis on protecting respondents' confidentiality.<sup>9</sup> The proposal here aligns with OMB's recommendations, and would serve to

---

<sup>2</sup> Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; of the State Councils on Developmental Disabilities, 88 Fed. Reg. 6742 (Feb. 01, 2023); Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; of the National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service, 88 Fed. Reg. 6744 (Feb. 01, 2023).

<sup>3</sup> HUMAN RIGHTS CAMPAIGN FOUND., WE ARE HERE: UNDERSTANDING THE SIZE OF THE LGBTQ+ COMMUNITY (2021), <https://hrc-prod-requests.s3-us-west-2.amazonaws.com/We-Are-Here-120821.pdf>.

<sup>4</sup> SHOSHANA K. GOLDBERG ET AL., HUMAN RIGHTS CAMPAIGN & BOWLING GREEN STATE UNIV., EQUALITY ELECTORATE: THE PROJECTED GROWTH OF THE LGBTQ+ VOTING BLOC IN COMING YEARS (2022), <https://hrc-prod-requests.s3-us-west-2.amazonaws.com/LGBTQ-VEP-Oct-2022.pdf>. The Williams Institute has previously estimated that at least 2 million youth ages 13–17 identify as LGBT in the U.S., including approximately 300,000 youth who are transgender. JODY L. HERMAN ET AL., WILLIAMS INST., HOW MANY ADULTS AND YOUTH IDENTIFY AS TRANSGENDER IN THE UNITED STATES? (2022), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Pop-Update-Jun-2022.pdf>; KERITH J. CONRON, WILLIAMS INST., LGBT YOUTH POPULATION IN THE UNITED STATES (2020), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Youth-US-Pop-Sep-2020.pdf>.

<sup>5</sup> *LGBT Demographic Data Interactive*, WILLIAMS INST. (Jan. 2019), <https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic>.

<sup>6</sup> HERMAN ET AL., *supra* note 4, at 6.

<sup>7</sup> Human Rights Campaign Found., *Understanding Disability in the LGBTQ+ Community*, HUMAN RIGHTS CAMPAIGN (Aug. 12, 2022), <https://www.hrc.org/resources/understanding-disabled-lgbtq-people>.

<sup>8</sup> See generally NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION (2022), <https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>.

<sup>9</sup> OMB, RECOMMENDATIONS ON THE BEST PRACTICES FOR THE COLLECTION OF SEXUAL ORIENTATION AND GENDER IDENTITY DATA ON FEDERAL STATISTICAL SURVEYS 3 (2023), <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>.

advance equity for LGBTQ+ people by ensuring necessary evidence can be collected to allow for their full inclusion in programs like those supported by DD Act Councils.<sup>10</sup> Additionally, we note that the proposal here appears consistent with recommendations issued by a panel formed by the National Academies of Sciences, Engineering, and Medicine on SOGI measurement in federal surveys and other instruments (the “NASEM Panel”).<sup>11</sup>

It is our opinion that the benefits of this proposed collection would therefore outweigh any potential increased burden on respondents and other relevant entities, given our knowledge on LGBTQ+ people and their experiences with disabilities generally. While it is not the case that only certain populations are impacted by developmental disabilities, data on whether and how individuals belonging to specific communities—including on the intersectional experiences of groups like LGBTQ+ people of color and others historically experiencing the brunt of marginalization and exclusion from government programs—are being accounted for and receiving assistance under the DD Act Councils’ State Plans would be necessary to ensure they fulfill their purposes. We would encourage ACL to continue exploring improvements to its mandated collection of SOGI data in the future, given the NASEM Panel and others’ recommendations on needed research on SOGI measures and response options that would allow even more individuals to be counted in collected data exactly as they identify.<sup>12</sup>

Finally, we wish to note our support for ACL’s proposal to establish a “workgroup with DD network grantees . . . to establish guidance on how to effectively capture” SOGI information, which was raised in response to two past commenters who expressed their opinion that SOGI items are “highly personal demographic questions [that] often elicit very low response rates.”<sup>13</sup> We disagree with those two commenters, as for decades, government and other researchers have studied SOGI and found that it is more than possible to measure these concepts and obtain quality data; and likewise that respondents largely do not find this information to be so sensitive that they would not provide it.<sup>14</sup> As the NASEM Panel describes in its recent report, “sex assigned at birth, gender identity, and sexual orientation are not the only types of potentially sensitive information that need to be collected respectfully and confidentially and used appropriately in administrative settings.”<sup>15</sup> Indeed, in many ways, SOGI information is not different from other forms of sensitive information already collected and operationalized by ACL and the DD Act Councils through their existing State Plans, such as information about individuals’ race, ethnicity, and disability. We therefore recommend that ACL move forward both with implementing SOGI items as part of the State Plans as proposed here and with establishing that workgroup for future guidance in this specific context, rather than delaying the implementation of SOGI items until that workgroup has completed its work given what we already understand on the feasibility of collecting these data.

---

<sup>10</sup> See NAT’L SCIENCE & TECHNOLOGY COUNCIL, FEDERAL EVIDENCE AGENDA ON LGBTQI+ EQUITY 3 (2023), <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>.

<sup>11</sup> NAT’L ACADEMIES OF SCIENCES, ENGINEERING, & MED., *supra* note 8.

<sup>12</sup> See, e.g., *id.* at 132–33 (recommending assessment of nonbinary response options and other possible improvements to gender identity measures), 145 (recommending research on measures of intersex status).

<sup>13</sup> 88 Fed. Reg. at 16,262.

<sup>14</sup> NAT’L ACADEMIES OF SCIENCES, ENGINEERING, & MED., *supra* note 8. at 52–55, 67.

<sup>15</sup> *Id.* at 10.

Thank you for the opportunity to submit comments in favor of this critical step toward ensuring LGBTQ+ people are consistently and safely included in the government's data collection efforts.