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August 07, 2023

Shefy Simon  
Administration for Community Living  
Department of Health & Human Services  
Washington, D.C. 20201, 202-795-7572

SUBMITTED VIA *regulations.gov*

**RE: Comment on Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; SHIP-SMP Survey of One-on-One Assistance, (OMB Control Number 0985-0057)**

Dear Shefy Simon,

Thank you for this opportunity. At the request of the Administration for Community Living (ACL) within the Department of Health and Human Services (HHS), the National LGBTQ Task Force (Task Force) respectfully submits this comment on the “SHIP-SMP Survey of One-on-One Assistance.”

We applaud the ACL for using a two-step question that is inclusive and validating of transgender people. We request that the ACL include an option for indigenous individuals to answer “Two Spirit” when being asked about their sexual orientation and gender identity. We also ask that the options for one’s gender identity be expanded to include “nonbinary” as an answer option for individuals who identify outside of the gender binary. Finally, we request that the ACL include an additional question that directly addresses intersex status. These changes would allow for greater accuracy in the ACL’s data collection and provide a more inclusive representation of the LGBTQ+ community.

## **I. The Task Force History**

The Task Force advances freedom, justice, and equity for LGBTQ people. We are building a future where everyone can be free to be their entire selves in every aspect of their lives. Today, despite all the progress we have made to end discrimination, millions of LGBTQ people face barriers in every aspect of their lives: in education, housing, employment, healthcare, retirement, and basic human rights.

For many years, the Task Force has had a meaningful impact on marginalized communities, and the nation as a whole through, our *Queering the Census* initiative. Through this initiative, the Task Force has partnered with the U.S. Census Bureau to ensure that the LGBTQ community and all historically undercounted individuals are counted. As a result of the Task Force’s leadership on the Census Bureau’s National Advisory Council, coupled with our work with LGBTQ and allied organizations during our movement-building and training phases, we launched our robust *Get Out the Count*

Campaign. We focused our organizing activities on hard-to-count communities that tend to be disengaged from the overall democratic process. Our target communities included people who identify as LGBTQ, people experiencing economic disenfranchisement, and formerly incarcerated people. We seek to ensure all data collections across the federal government are equitable and accurate.

## **II. The Task Force Commends the ACL for Using a Two-Step Question for Gender Identity that is Inclusive and Validating of Transgender People**

The Task Force commends the ACL for using a two-step question when asking about one's gender identity as this allows for the inclusion of transgender individuals and minimizes error by cisgender respondents. In this two-step question, respondents are first asked to report the sex they were assigned at birth (to which they can respond: "male," "female," "don't know," or "prefer not to answer"). Second, respondents are asked to report their current gender identity (to which they can respond: "male," "female," "transgender," "I use a different term," or "prefer not to answer"). The ACL's inclusion of this two-step question aligns with recommendations from the recent National Academies of Science, Engineering, and Medicine (NASEM) report, "Measuring Sex, Gender Identity, and Sexual Orientation."<sup>1</sup>

In its report, NASEM states that this two-part question is preferred to a single question on gender identity because it allows for a "broader measure of gender identity," clearly enumerates transgender individuals, and prevents "false positives from cisgender respondents who do not understand the question."<sup>2</sup>

## **III. The Task Force's Recommendations to Promote Accuracy and Inclusion**

We commend the ACL for collecting data focused on sexual orientation and gender identity (SOGI) and offer our recommendations to ensure that this data collection is as accurate and inclusive as possible. The 2022 NASEM report reflects the Task Force's mission of strengthening the use SOGI data by including answer options that allow for more precise self-identification and encompass a "wide range of gender minority populations, such as those with nonbinary identities and . . . people with intersex traits."<sup>3</sup> Because the ACL has already utilized NASEM data in its proposed changes, we will not repeat the NASEM report here; rather, we will focus on crucial additions to bolster ACL's current proposal.

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<sup>1</sup> National Academies of Sciences, Engineering, and Medicine, "Measuring Sex, Gender Identity, and Sexual Orientation" (Washington: The National Academies Press, 2022), available at <https://www.nap.edu/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>.

<sup>2</sup> National Academies of Sciences, Engineering, and Medicine, "Measuring Gender Identity and Transgender Experience" (Washington: The National Academies Press, 2022), available at [https://nap.nationalacademies.org/resource/26424/Issue\\_Brief\\_Identity&Transgender\\_Experience](https://nap.nationalacademies.org/resource/26424/Issue_Brief_Identity&Transgender_Experience).

<sup>3</sup> *Id.*

### **A. Our Request: Include “Two-Spirit” as an Answer Option for Sexual Orientation and Gender Identity Questions**

We request that, in accordance with NASEM’s recommendations, “Two-Spirit” be included as an answer option for indigenous respondents for both sexual orientation and gender identity questions. NASEM defines “Two-Spirit” as “an intertribal term” that “serves as a placeholder for tribally-specific gender and sexual orientation identities that are centered in tribal worldviews, practices, and knowledge.”<sup>4</sup> The National Congress of American Indians has stated that “the collection of accurate, adequate, meaningful data is critical to the health and welfare of tribal nations.”<sup>5</sup> Additionally, the NASEM report notes that “American Indian and Alaska Native (AIAN) and other Indigenous populations tend to be undercounted in the American Community Survey (ACS) as well as in other national surveys due to inadequate data collection and reporting or being collapsed into ‘other’ categories due to small sample sizes.”<sup>6</sup> Adding “Two Spirit” as an answer option for indigenous individuals would allow for “[i]ndigenous identities, practices, and traditions [to be referenced] in the context of Western data collection practices” and ensure that “[I]ndigenous sexual and gender minorities are represented and counted.”<sup>7</sup>

### **b. Our Request: Include “Nonbinary” as an Answer Option for Gender Identity Questions**

When requesting information about a person’s current gender identity, the ACL should include “nonbinary” as an answer option to allow for individuals to self-identify outside of the gender binary. While the NASEM report includes “nonbinary” as an area for future research, the Federal Evidence on LGBTQ Equity makes it clear that the need for future research “should not delay the Federal Government’s progress on including SOGI data collection on surveys and forms.”<sup>8</sup> The Williams’s institute at UCLA estimates 11% of LGBTQ adults—approximately 1.2 million people—identify as “nonbinary.”<sup>9</sup> Through its survey, the ACL is compiling data to determine the quality of its care to patients; thus, collecting accurate information on the nonbinary community is crucial to the achievement of the ACL’s research goals, especially because “nonbinary LGBTQ adults [have]

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<sup>4</sup> National Academies of Sciences, Engineering, and Medicine, “Gender Identity and Sexual Orientation in Indigenous Context” (Washington: The National Academies Press, 2022), available at [https://nap.nationalacademies.org/resource/26424/Issue\\_Brief\\_Indigenous\\_Context.pdf](https://nap.nationalacademies.org/resource/26424/Issue_Brief_Indigenous_Context.pdf).

<sup>5</sup> *Id.*

<sup>6</sup> *Id.*

<sup>7</sup> *Id.*

<sup>8</sup> Subcommittee on Sexual Orientation, Gender Identity, and Variation in Sex Characteristics (SOGI) data, Federal Evidence Agenda on LGBTQI+ Equity, 13 (2023).

<sup>9</sup> Bianca D.M. Wilson & Ilan Meyer, “NONBINARY LGBTQ ADULTS in the United States” (Los Angeles: Williams Institute, 2021), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Nonbinary-LGBTQ-Adults-Jun-2021.pdf>.

reported relatively high rates of mental health concerns.”<sup>10</sup> In fact, “41% [of nonbinary adults] said their health was poor or fair, 51% . . . had symptoms consistent with serious mental illness, and 39% . . . attempted suicide” in the past.<sup>11</sup> By collecting this information about nonbinary individuals, the ACL would have the data to determine whether respondents’ Medicare and Medicaid benefits are sufficiently strong to serve the needs of the nonbinary community.

### **c. Our Request: Include a Question Asking About Intersex Status**

Intersex individuals are those who “are born with, or naturally develop over time, sex traits that do not correspond to a single sex.”<sup>12</sup> NASEM notes in its report that, “[i]ntersex is a measure of sex, which means that it is an important demographic characteristic.”<sup>13</sup> Additionally, 1.7% of people are born with variations in their genitals; however, because these variations are often difficult to recognize early on, a person’s intersex status may remain undiscovered until later in life. Due to this delay, many individuals with intersex characteristics do not have this status reflected on their birth certificate. Thus, the current survey proposal fails to include almost 2% of Americans in the U.S.

The NASEM report suggests asking respondents the following question: “Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?”<sup>14</sup> We endorse the language of this question and suggest that the available answer responses to this question be: “yes,” “no,” “don’t know,” and “prefer not to answer.” Including a question that explicitly addresses one’s intersex status allows for more accurate data collecting, validates the existence of intersex individuals, and allows for these individuals to obtain greater medical autonomy.

## **IV. Summary of Our Request**

First, the Task Force commends the ACL for using a two-step question when asking about one’s gender identity as this allows for the inclusion of transgender individuals and minimizes error by cisgender respondents. Second, we request that the ACL expand its question-and-answer options to advance its stated objectives of “promoting increased choice and greater independence among older adults and

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

<sup>11</sup> *Id.*

<sup>12</sup> National Academies of Sciences, Engineering, and Medicine, “Measuring Intersex Status or Differences in Sex Development” (Washington: The National Academies Press, 2022), available at [https://nap.nationalacademies.org/resource/26424/Issue\\_Brief\\_Intersex\\_Status.pdf](https://nap.nationalacademies.org/resource/26424/Issue_Brief_Intersex_Status.pdf)

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

individuals with disabilities.”<sup>15</sup> Specifically, we ask that, when requesting a respondent’s sexual orientation and gender identity, the ACL include “Two Spirit” as an answer option to recognize people of indigenous heritage. Additionally, we ask that the ACL include “nonbinary” as an answer option for gender identity questions to acknowledge those who identify outside of the gender binary. Finally, we ask that the ACL include a question that directly addresses intersex status to validate the existence of intersex individuals. In sum, including these additional options would allow for greater accuracy and inclusion in the ACL’s data collection and promote increased medical autonomy and independence for respondents.

In addition to more robust survey questioning, the ACL must make the data collected from this report available to the public twice a year. By providing the data semi-annually, both the ACL and other interest groups will be able to more easily track the ways this data changes through the year ensuring the best possible services to members of the LGBTQ+ community.

We appreciate the opportunity to submit our recommendations. Thank you for the opportunity to comment and your consideration of our request. For more information, please contact Clermon Acklin, Federal Regulatory Counsel, at [ceacklin@thetaskforce.org](mailto:ceacklin@thetaskforce.org) or 202-604-9830.

Sincerely,



Kierra Johnson  
Executive Director

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<sup>15</sup> Administration for Community Living, HHS., “Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; SHIP-SMP Survey of One-on-One Assistance, (OMB Control Number 0985-0057),” Federal Register 88 (43357) (2023): 2023-14336, available at <https://www.federalregister.gov/documents/2023/07/07/2023-14336/agency-information-collection-activities-submission-for-omb-review-public-comment-request-ship-smp>.