October 3, 2022

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building,
1650 Pennsylvania Ave. NW, Washington, DC 20504

Dear Ms. Maury:

The American Psychological Association\(^1\) (APA) appreciates the opportunity to comment on the Office of Science and Technology Policy (OSTP) Federal Evidence Agenda on LGBTQI+ Equity Request for Information. Our comments address:

1) APA resources
2) Investing in sexual orientation and gender identity (SOGI) data collection
3) Engagement and transparency
4) Intersex/DSD: Dearth of Research; Unique from LGBTQ
5) Recommended priorities

**APA resources**

In February 2016, APA adopted the [Resolution on Data About Sexual Orientation and Gender Identity](#) which highlighted data collection among LGBT populations. The resolution addresses problems with collecting population-based data, such as concerns with anonymity, concerns with stigmatization, and methodological difficulties in collecting data on underserved populations, and also explained the importance of survey data for assessing the need for public policies that address group disparities in mental health, health, and social outcomes, as well as for evaluating the impact of these policies.

In 2020, APA updated demographic questions used in surveys of members. The questions around gender are structures so that there is an opportunity to indicate one’s gender identity, then a separate question asking if the respondent identifies as transgender. There is then a separate question about whether the respondent identifies as someone who has a difference of sex development (DSD), sometimes also known as having an intersex variation (see exhibit 1 – APA Demographic Questions).

**Sustain progress in collecting SOGI Data**

The U.S. government has made great strides in the past decade on SOGI data collection, including health, living conditions, and victimization. In 2011, the Institute of Medicine (IOM) – now the National Academy of Medicine -- recommended that standardized questions about, sexual orientation and gender identity in all federally-funded surveys administered by the Department of

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\(^1\) APA is the leading scientific and professional organization representing psychology in the United States, with more than 133,000 researchers, educators, clinicians, consultants, and students as its members.
Health and Human Service and in other population-based surveys through the federal government.\(^2\) Recommendations led to NIH convening the Sexual and Gender Minority Research Coordinating Committee in 2015 to address research activities affecting sexual and gender minority communities; NIH now has a webpage dedicated to developing methods to accurately capture and understand the health of LGBT populations.\(^3\) In 2016, the NIH National Institute on Minority Health and Health Disparities (NIMHD) designated SGMs a health disparity population, and an Office of Management and Budget report called for more representative and better-quality SOGI data.

As a result of these initiatives, under the Obama administration, 12 federal surveys and studies measured sexual orientation; seven of these also measured gender identity or transgender status. Questions on sexual orientation (SO) and/or gender identity (GI) were included in many public health surveys, such as the Behavioral Risk Factor Surveillance System (SOGI) and Youth Risk Behavior Survey (SO), the National Health Interview Survey (SO), the National Survey on Drug Use and Health (SO), and the Health Center Patient Survey (SOGI). Several other surveys collected SOGI data that examined social determinants of health, such as the National Crime Victimization Survey (SOGI), which collects data on intimate partner violence, and the National Inmate Survey (SOGI), which collects data on sexual assault in prison.\(^4\)

Engagement and Transparency

Further progress on SOGI data collection was threatened during the Trump Administration where we observed federal agency actions that would limit or restrict SOGI data collection. The NSTC Subcommittee on Equitable Data’s consultative process in the development of the federal evidence agenda is a step the right direction towards bolstering future efforts to collect, use, and distribute equitable data about the health and well-being of the LGBTQ+ individuals, families, and communities. For the federal government to truly collect more comprehensive and impactful SOGI data, it must seek to meet these communities where they are. Data collection methods should be created with the input of LGBTQ+ persons and their allies to ensure validity of collection methods. More effort must be made during the development stage to avoid harm. Meaningful engagement of members of LGBTQI+ populations must be a priority of both agencies. Federal agencies should consult with these groups on effective strategies for collecting and disseminating data that all agree are crucially across sectors, e.g., law enforcement, mental and physical health, education, and the economy.

Intersex/DSD: Dearth of Research; Unique from LGBTQ

APA appreciates federal attention to people with intersex variations or differences of sex development (DSD). While agreeing with the importance of gathering good demographic data –


\(^3\) https://dpcpsi.nih.gov/sgmo

and gathering of more data overall – on these populations and subpopulations to better understand their uniqueness and needs, it is also important to do so with sensitivity to the ways in which “LGBTQ” and “I” are distinct. A concern is that the “I” can get lost and perhaps short-changed if reflexively included with the “LGBTQ” and can lead to unexamined assumptions and misunderstandings.

With this opportunity, APA would like to draw particular attention to the fact that even after intersex/DSD was placed under the umbrella of Sexual and Gender Minority Research Office by National Institutes of Health, most of the research focuses on LGBTQ, with few extramural-funded research projects devoted specifically to people with intersex/DSD variations. What is documented is that these populations face significant health disparities and poor access to care, all impacting quality of life and mental health, and these disparities could be better understood with well-grounded Federal statistical and data collection.

APA does not currently have official policies regarding people born with an intersex or difference of sex development variation. The association has, however, formed a multidisciplinary task force to prepare a report that can inform clinicians, researchers, policymakers, and advocates. The report will: 1) review the extant research psychological literature and APA policies in this area to identify (a) gaps in knowledge, (b) ongoing controversies, and (c) ethical issues for psychologists; and 2) recommend appropriate collaboration with other professional organizations concerning these issues. Task force members have raised concerns that the “I” being tagged on to the “LGBTQ” may not always be carefully thought out or appropriate. Among the concerns are as follows:

- There is a great deal of research on LGBTQ populations relative to research on people with intersex or DSD variation. For example, the Presidential Executive Order 14075 of June 15, Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals, opens with the following statement:
  - LGBTQI+ individuals and families still face systemic discrimination and barriers to full participation in our Nation’s economic and civic life. One task force member notes that while there have been numerous studies substantiating this (and related negative experiences) for LGBTQ+ people, they cannot think of a single study of intersex people that supports this. Additionally, research across lifespan with people with an intersex/DSD variation is especially lacking, with most of it focused on children and adolescents.

- APA’s Task Force on Gender Identity, Gender Variance, and Intersex Conditions (authorized by APA’s Council of Representatives in 2005; report published in 2009) changed its name to the Task Force on Gender Identity and Gender Variance to remove “Intersex Conditions.” The task force found the two populations to be too distinct from one another to address their unique issues and needs in a single report, and the task force members considered their expertise on intersex conditions to be too limited for them to handle the topic well.

- Quoting from the Institute of Medicine’s 2011 report, The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding:
“Although intersexuality constitutes an additional type of “otherness” that is stigmatized and overlaps in some respects with LGBT identities and health issues, the committee decided it would not be appropriate to include intersexuality in the study scope. Most individuals affected by disorders of sex development do not face challenges related to sexual orientation and gender identity, although homosexuality, gender role nonconformity, and gender dysphoria (defined as discomfort with the gender assigned to one at birth [see Chapter 2]) are somewhat more prevalent among this population compared with the general population (Cohen-Kettenis and Pfafflin, 2003). The committee acknowledges that while very little research exists on the subject of intersexuality, it is a separate research topic encompassing critical issues, most of which are not related to LGBT issues, and hence is beyond the scope of this report.” (p.16-17)”

In addition to these concerns, the APA task force members have also identified the following areas where research is lacking:

- That either substantiates or contradicts the inclusion of “I” within LGBTQ (noting that LGBTQ are identity markers and intersex/DSD variations are physiologically based).
- That documents the pathways of health care received by patients with intersex/DSD variations in the US: there is negligible research on the current standards of care and their relationships to patient outcomes.
- That is directed toward development of interventions that mitigate the well-documented neurocognitive, psychosocial, and psychosexual risk faced by this diverse population.

Based on the above, NSCT subcommittee should consider that there is no necessary connection between “SOGI” (sexual orientation and gender identity) and DSD/intersex traits. Implying so by the grouping of I within LGBTQ+ would be tantamount to imposing an identity on someone who views DSD as a medical condition but not as their identity. (APA has not formal position on this point at this time.)

**Recommended priorities**

1. Resolve any methodological challenges to adding sexual orientation, gender identity and sex at birth questions.
2. Differentiate between sexual orientation and gender identity in data analysis.
3. Incentivize state and local jurisdictions to add sexual orientation and gender identity questions to their federally funded surveys and surveillance systems.
4. Include sexual orientation, gender identity and sex at birth in the 2030 Census.
5. Integrate of behavioral health indicators and analysis across data collection efforts dictated by research and science.
6. Address gaps in data about transgender women, particularly transgender women, in the areas of violence, contact with law enforcement and health disparities.
7. Develop best practices for collection dating in behavioral surveillance, research and clinical settings.
8. Assess and report the need for and status of SOGI data collection across all federal agencies.

9. Identify best practices for all agencies engaging in SOGI and intersex data collection to follow to safeguard privacy, security, and civil rights, including appropriate and robust practices of consent for the collection of this data and restrictions on its use or transfer.

10. Convene a consultation or a set of consultations with multidisciplinary behavioral and medical health experts, intersex/DSD community members and parents of people with these variations, along with agency statistical officials, chief science officers, data officers, and evaluation officers to develop a well-grounded research agenda.

Thank you again for this opportunity to provide input. If APA can be of any further assistance, please contact Leo Rennie, Senior Director of Congressional and Federal Relations, at lrennie@apa.org.

Sincerely,

Katherine B. McGuire
Chief Advocacy Officer