

July 12, 2024

Disability Data Interagency Working Group
National Science and Technology Council
Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Ave., NW.,
Washington, DC 20504

Re: Federal Evidence Agenda on Disability Equity RFI

Dear Members of the Subcommittee on Equitable Data,

On behalf of 39 organizations dedicated to improving the wellbeing of lesbian, gay, bisexual, transgender, queer, intersex and other sexual and gender minority (LGBTQI+) people, we write in response to the Office of Science and Technology Policy’s request for information (RFI) to help the Disability Data Interagency Working Group (DDIWG) develop the Federal Evidence Agenda on Disability Equity.¹

Our organizations are committed to ensuring that the work of the DDIWG, the evidence agenda that is developed, and efforts to make data-informed policy decisions that advance equity for people with disabilities are inclusive of LGBTQI+ people with disabilities. Improving data collection about disabilities is critical, as is continuing to advance demographic data collection on sexual orientation, gender identity, and variations in sex characteristics (SOGISC). Together, these efforts will make it possible to better identify and address the disparities that LGBTQI+ people with disabilities face, as well as to assess how the government is progressing in its mission to meaningfully advance disability and LGBTQI+ equity.

Disparities faced by LGBTQI+ people with disabilities could be better understood through Federal statistics and data collection

Existing research reveals that LGBTQI+ people face disparate and inequitable treatment, which adversely affects outcomes across key areas of everyday life, including health status; access to health care and health insurance; economic and housing security; educational attainment; and family and social support.² Importantly, the health of LGBTQI+ communities is severely impacted by discrimination, stigma, prejudice, as well as other social determinants of health.³ Recent studies also reveal that LGBTQI+ people experience substantial economic insecurity. For example, LGBT people experience higher rates of poverty, food insecurity, homelessness and housing

¹ *Federal Register* 89 (46924) (2024); 87 (163) (2022): 46924-46926, available at [Federal Register :: Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity](#).

² National Academies of Sciences, Engineering, and Medicine, “Understanding the Well-Being of LGBTQI+ Populations” (Washington: 2020), available at <https://www.nap.edu/read/25877/chapter/1>.

U.S. Census Bureau, “American Community Survey (ACS),” available at <https://www.census.gov/programs-surveys/acs> (last accessed August 2022).

³ *Ibid.*

instability, and are more likely to use public benefits to help meet basic living standards.⁴ LGBTQI+ people of color,⁵ LGBTQI+ people with disabilities,⁶ LGBTQ youth⁷ and LGBTQI+ older adults all experience higher rates of economic and health disparities.⁸ For example, Black and Latinx LGBT people are more likely than white LGBT people to live in low-income households, experience food insecurity, and be unemployed.⁹

Emerging research highlights the extent to which LGBTQ people are more likely to report having a disability.¹⁰ Analysis of the 2020 Behavioral Risk Factor Surveillance System found that LGBTQ+ adults, and transgender adults in particular, were significantly more likely than non-LGBTQ+ adults to self-report having at least one disability.¹¹ Overall, one in three (36%) LGBTQ+ adults self-reported having a disability, compared with one in four (24%) non-LGBTQ+ (cisgender and heterosexual) adults. In addition, more than a third (35%) of cisgender LGBTQ+ adults, and more than half (52%) of transgender adults (including both LGBTQ+ and straight transgender adults), self-reported a disability.

⁴ Soon Kyu Choi, M.V. Lee Badgett, and Bianca D.M. Wilson, “State Profiles of LGBT Poverty in the United States” (Los Angeles: Williams Institute, 2019), available at <https://williamsinstitute.law.ucla.edu/publications/state-lgbt-poverty-us/>; M.V. Lee Badgett, Soon Kyu Choi, and Bianca D.M. Wilson, “LGBT Poverty in the United States: A Study of Differences Between Sexual Orientation and Gender Identity Groups” (Los Angeles: Williams Institute, 2019), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf>; Christopher S. Carpenter, Samuel T. Eppink, and Gilbert Gonzales, “Transgender Status, Gender Identity, and Socioeconomic Outcomes in the United States,” *Industrial and Labor Relations Review* 73 (3) (2020): 573–599, available at 10.1177/0019793920902776Transgender Sta; National Academies of Sciences, Engineering, and Medicine, “Understanding the Wellbeing of LGBTQI+ Populations” (Washington: 2020), available at <https://nap.nationalacademies.org/read/25877/chapter/1>; Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al. (2020) A national study on the physical and mental health of intersex adults in the U.S. *PLoS ONE* 15(10): e0240088; Caitlin Rooney, Charlie Whittington, and Laura E. Durso, “Protecting Basic Living Standards for LGBTQ People” (Washington: Center for American Progress, 2018), available at <https://www.americanprogress.org/issues/lgbtq-rights/reports/2018/08/13/454592/protecting-basic-living-standards-lgbtq-people/>.

⁵ Lindsay Mahowald, “LGBTQ People of Color Encounter Heightened Discrimination” (Washington: Center for American Progress, 2021), available at <https://www.americanprogress.org/article/lgbtq-people-color-encounter-heightened-discrimination/>

⁶ Caroline Medina, Lindsay Mahowald, Thee Santos, and Mia Ives-Rublee, “The United States Must Advance Economic Security for Disabled LGBTQI+ Workers” (Washington: Center for American Progress, 2021), available at <https://www.americanprogress.org/article/united-states-must-advance-economic-security-disabled-lgbtqi-workers/>

⁷ Centers for Disease Control and Prevention “Health Disparities Among LGBTQ Youth” available at <https://www.cdc.gov/healthyouth/disparities/health-disparities-among-lgbtq-youth.htm> (last accessed September 2022)

⁸ National LGBTQIA+ Health Education Center, “Housing, Health, and LGBTQIA+ Older Adults 2021”, available at <https://www.lgbtqihealtheducation.org/wp-content/uploads/2021/09/Housing-Health-and-LGBTQIA-Older-Adults-2021.pdf>

⁹ Williams Institute, “Race and Wellbeing among LGBT Adults” available at <https://williamsinstitute.law.ucla.edu/visualization/lgbt-races/> (last accessed September 2022)

¹⁰ Movement Advancement Project, “LGBT People With Disabilities” (Boulder, CO: 2019), available at <https://www.lgbtmap.org/lgbt-people-disabilities>

¹¹ [Understanding Disability in the LGBTQ+ Community - Human Rights Campaign \(hrc.org\)](https://www.hrc.org/campaigns/understanding-disability-in-the-lgbtq-community)

Far less is known about the experiences of LGBTQ+ youth with disabilities, however. In the HRC Foundation 2018 LGBTQ+ Youth Report, which surveyed over 12,000 LGBTQ+ youth age 13-17 from across the United States, one in seven (15%) LGBTQ+ youth said they had a disability.¹² More recently, a 2020 Trevor Project survey found that 5% of LGBTQ+ reported having deafness or a hearing disability,¹³ whereas a 2021 Trevor Project survey found that 5% of LGBTQ+ youth were diagnosed with autism.¹⁴

Although knowledge of the disparities that LGBTQI+ people with disabilities face has increased in recent years, significant gaps – driven by lack of reliable data – remain. There remains a dearth of consistent, large-scale sexual orientation and gender identity data collection by federal and state governments, as well as very little data collection about people with variations in sex characteristics. And when surveys may include such questions, especially in private or community-based surveys, they may not also include questions about disability. Additionally, even when questions on disability are included, they may not fully capture a comprehensive range of disabilities. Many functional disability questions fail to capture mental illness or chronic illness,¹⁵ both of which are key areas of known disparities for LGBTQI+ people. These gaps together pose a barrier to obtain adequate data about the diversity of LGBTQI+ people with disability's experiences and policymakers, advocates, and researchers ability to to better comprehend and address disparities.

Our organizations are unified in our strong support for the administration's efforts to engage in comprehensive LGBTQI+ data collection paired with effective, research-based data collection about disability in order to meaningfully advance its Federal Evidence Agenda on Disability Equity and the Federal Evidence Agenda on LGBTQI+ Equity. It is critical that LGBTQI+ people with disabilities are visible, their needs, strengths, and voices are integrated into policymaking, and that they are seen as critical stakeholders in efforts to advance equity for all.

Thank you for your consideration. Please do not hesitate to contact Naomi Goldberg, naomi@mapresearch.org, if you need any additional information.

Sincerely,

Advocates For Trans Equality
American Psychological Association Services
American Speech-Language-Hearing Association
CA LGBTQ Health and Human Services Network
CenterLink: The Community of LGBTQ Centers
COLAGE
Disability and Wellness Research Collaborative
Equality California
Family Equality
The Fenway Institute
FORGE, Inc.

¹² <https://www.hrc.org/resources/2018-lgbtq-youth-report>

¹³ https://www.thetrevorproject.org/wp-content/uploads/2022/03/Deaf-LGBTQ-Youth-Research-Brief_March-2022.pdf

¹⁴ <https://www.thetrevorproject.org/research-briefs/mental-health-among-autistic-lgbtq-youth-apr-2022/>

¹⁵ <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00395>

GLMA: Health Professionals Advancing LGBTQ+ Equality
GLSEN
Human Rights Campaign
interACT: Advocates for Intersex Youth
Jackson State University
LGBTQI+ Rights Clinic, Northwestern University Pritzker School of Law
Los Angeles LGBT Center
Mazzoni Center
MomsRising
Movement Advancement Project
National Health Law Program
National LGBTQ Task Force Action Fund
National LGBTQ+ Bar Association
National LGBTQI+ Cancer Network
National Partnership for Women & Families
National Women's Law Center
Oasis Legal Services
PFLAG Tulsa
Planned Parenthood Federation of America
Pulmonary Hypertension Association
Reproductive Freedom for All (formerly NARAL Pro-Choice America)
The Rural Institute for Inclusive Communities
SAGE (Advocacy and Services for LGBTQ+ Elders)
Transgender Law Center
The Trevor Project
University of Kansas Institute for Health and Disability Policy Studies
US Professional Association for Transgender Health
Whitman-Walker Institute
Elizabeth Wood, assistant professor