

# Measuring Sex, Gender Identity, and Sexual Orientation

## Measuring Intersex Status or Differences in Sex Development

This issue brief is based on the report *Measuring Sex, Gender Identity, and Sexual Orientation*, which recommends that the National Institutes of Health adopt new practices for collecting data on sex, gender, and sexual orientation. The report recommends standardized language to be used in survey questions that ask about a respondent's sex, gender identity, and sexual orientation. This issue brief outlines the committee's recommendations for the measurement of intersex status or differences in sex development in the U.S. adult population.

### DEFINITION

Sex is a multidimensional construct based on a cluster of anatomical and physiological traits that include external genitalia, secondary sex characteristics, gonads, chromosomes, and hormones. People with intersex traits, also known as people with differences in sex development (DSD), are people who are born with, or naturally develop over time, sex traits that do not correspond to a single sex. An estimated 1.7 percent of people have an intersex trait. Biologically, intersex variations are highly heterogeneous, can involve any sex trait, and may not be apparent from an external examination. Those that result in obvious external anatomic diversity, sometimes called "ambiguous genitalia," are relatively uncommon, accounting for about 1 in 2,000 (0.05%) births. Most people with

intersex traits are born with genitals that appear to be male or female; consequently, the majority of people with intersex traits are not identified as having an intersex variation until later in life, often in adolescence or adulthood—if at all. Some people with intersex traits may go undiagnosed entirely, and most children born with any intersex trait are assigned a binary sex at birth.

### INTERSEX STATUS: A HISTORY OF CONCEALMENT AND STIGMA

In the early 20th century, intersex variations that were not associated with genital difference were not readily identified by clinicians. Standard medical practice prioritized concealment and surgical intervention for those born with ambiguous genitalia under the assumption that any perceived uncertainty about sex could introduce gender uncertainty and expose a child to social stigma. This model was also applied to intersex children without genital difference. By the 1990s, however, intersex advocacy organizations had begun to underscore the internalized stigma that this systematic concealment caused in intersex/DSD persons. As a result, in 2006, the standard of care shifted toward recommending increased engagement of children in decision making and routine disclosure of medical information to children.

Most people with intersex variations born before the early 2000s are likely to have learned about their intersex status as adults, and may have incomplete knowledge of their anatomy, medical treatment, and surgical history. Some adults may be aware of their intersex status but have never received a formal medical diagnosis. The history of silence and erasure of intersex status means that many intersex adults may be reluctant to disclose their intersex status because they were taught that it is confidential or because they fear stigma or discrimination. This history has also contributed to disagreement on preferred terminology for this population. However, in one study based on a convenience sample of those who self-identified as intersex or had a DSD diagnosis, all of the participants endorsed the inclusion of a measure of intersex status in survey research.

#### **IDENTIFYING PEOPLE WITH INTERSEX TRAITS OR DIFFERENCES IN SEX DEVELOPMENT**

Intersex status is a measure of sex, which means that it is an important demographic characteristic. At the same time, it is private medical information, which means it should be protected. It is also an aspect of identity; in a sample of people with intersex traits more than half identified “intersex” as a component of their gender identity. Because of historical, legal, and medical factors, almost no person in the United States is assigned intersex at birth. Therefore, when asking respondents to disclose their intersex status, it is inappropriate to assess intersex status primarily with an “intersex” response option for sex assigned at birth. However, when sex assigned at birth is asked, it may be appropriate to include “prefer not to answer” or “do not know” options.

**RECOMMENDATION: When the National Institutes of Health seeks to identify people with intersex traits or differences of sex development in clinical, survey, research, and administrative settings, they should do so by using a standalone measure that asks respondents to report their intersex status. They should not do so by adding “intersex” as a third response category to a binary measure of sex.**

There is little evidence evaluating the performance of standalone measures of intersex/DSD status. However, based on the available research, historical context, expert opinion, and community recommendations, there are three questions that appear to have the strongest grounding in evidence. These are as follows:

#### **Option 1:**

**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?**

#### **Option 2:**

**Were you born with a variation in your physical sex characteristics? (This is sometimes called being intersex or having a difference in sex development, or DSD.)**

#### **Option 3:**

**Have you ever been diagnosed by a medical doctor with an intersex condition or a difference of sex development?**

Of these three options, the only measure that has been tested among intersex populations is Option 1. For this reason, the committee concludes that based on the best available evidence, community guidance, and expert opinion, intersex status can be measured using Option 1. However, further research assessing and comparing the performance of the three measures is needed. Because intersex status is a demographic measure of sex, this measure is best included with other demographic measures, such as race, ethnicity, and age.

**COMMITTEE ON MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION** **Nancy Bates** (*Co-Chair*), Retired, U.S. Census Bureau; **Marshall Chin** (*Co-Chair*), Department of Medicine, University of Chicago; **Kellan E. Baker**, Whitman-Walker Institute, Whitman-Walker Health; **José A. Bauermeister**, Department of Family and Community Health, University of Pennsylvania; **D’Lane Compton**, Department of Sociology, University of New Orleans; **Katharine Dalke**, Department of Psychiatry and Behavioral Health, The Pennsylvania State University College of Medicine; **Aliya Saperstein**, Department of Sociology, Stanford University; **Karina Walters**, School of Social Work, University of Washington; **Bianca D. M. Wilson**, Williams Institute, University of California, Los Angeles, School of Law

**STUDY STAFF** **Tara Becker**, Study Director; **Katrina Baum Stone**, Senior Program Officer; **Eric Grimes**, Senior Program Assistant

#### **FOR MORE INFORMATION**

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