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Key Issues Facing People With Intersex Traits

New CAP data and analysis offer insights into the experiences of people with intersex traits.

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A young child carries a box of chalk outside their home, September 2018, in Milwaukee. They are one of a growing number of intersex children whose parents are raising them without early genital surgery. (Getty/John J. Kim/Chicago Tribune/Tribune News Service)



This column was produced in collaboration with interACT, an organization dedicated to using innovative strategies to advocate for the human rights of children born with intersex traits.

There are currently limited data and information available on the population health and overall well-being of people with intersex traits. However, recent research has found that health disparities among intersex populations are driven largely by stigmatization, prejudice, and discrimination similar to what LGBTQ+ communities experience, and that people with intersex traits report identifying as noncisgender or nonheterosexual at higher rates than people who are not intersex. For these reasons, the National Institutes of Health and The National Academies of Sciences, Engineering, and Medicine include people with intersex traits as a sexual and gender minority population in their research agendas.

This column presents Center for American Progress survey data that shed new light on the experiences of intersex respondents. It also provides policy recommendations informed by these data to improve the well-being and advance the rights of people with intersex traits.

“Intersex” is an umbrella term used to describe people born with sex traits that do not fit binary medical definitions of male or female sexual or reproductive anatomy. Intersex populations are born with these differences in sex traits or may develop them during childhood. Human sex development is naturally diverse, with many variations possible in genitalia, hormones, internal anatomy, and/or chromosomes. It is estimated that up to 1.7 percent of the population has an intersex trait and that approximately 0.5 percent of people have clinically identifiable sexual or reproductive variations.

Medically unnecessary, nonconsensual interventions are violations of human rights

Mistreatment of intersex individuals begins early in life, with intersex infants and children commonly subjected to nonconsensual, medically unnecessary interventions to alter natural variations in genital appearance or reproductive anatomy with the aim of conforming their bodies to binary sex stereotypes. These procedures on intersex infants and children, such as clitoral reductions and sterilizing gonadectomies, are often justified by discriminatory attitudes about healthy variations in sex characteristics. They have high complication rates and lifelong consequences such as infertility, reduced sexual function, and other physical and mental health impacts. These outcomes contribute to the high physical and mental health disparities that intersex populations experience. In a 2018 study, for example, 43 percent of adult intersex respondents reported



their physical health as “fair” or “poor,” and 53 percent reported the same of their mental health. Similar patterns are also evident in CAP’s nationally representative 2020 survey data of LGBTQI+ adults* that show mental and physical health disparities between LGBTQ+ intersex respondents and LGBTQ+ nonintersex respondents. (see Figure 1)

Figure 1

Nine in 10 LGBTQ+ intersex individuals report some level of poor physical health



Share of LGBTQ+ intersex and nonintersex respondents who reported mental or physical health concerns during January 2020

Poor physical health kept respondent from doing usual activities, such as self-care, work, or recreation

	LGBTQ+ intersex respondents	LGBTQ+ nonintersex respondents
A lot	30%	10%
Some	49%	18%
A little	13%	26%
Not at all	9%	47%

Number of days respondent was so sad nothing could cheer them up

	LGBTQ+ intersex respondents	LGBTQ+ nonintersex respondents
Nearly every day	15%	5%
More than half the days	30%	14%
Several days	33%	34%



The United Nations has found that these forced and coercive intersex surgeries on minors, frequently performed without their full, free, and informed consent, “violate rights to the security of person, right to bodily and mental integrity, freedom from torture and ill-treatment, and freedom from violence.”

Increasingly, medical associations, LGBTQI+ advocates, human rights bodies, and intergovernmental organizations are asking policymakers to prevent medical professionals from engaging in these harmful practices and to postpone procedures on intersex minors until they can provide informed consent.

Recommendations:

- The U.S. Department of Health and Human Services’ (HHS) Centers for Medicare and Medicaid Services (CMS) should issue guidance to state health officials for Medicaid and the Children’s Health Insurance Program (CHIP) on prohibiting nonconsensual, medically unnecessary surgeries on intersex youth and deferring all nonemergent interventions until patients can provide free, fully informed consent and drive decision-making. The guidance should also provide information on making the documentation of a patient’s informed consent a prerequisite for health care reimbursement for sterilizing or genital surgeries, absent an imminent risk of physical harm, and urge state health officials and providers to comply with Medicaid quality, comparability, and sterilization requirements; the Affordable Care Act (ACA); and the federal genital mutilation statute, all of which as written currently prohibit many of the procedures performed on intersex infants.
- HHS should also establish an education campaign for health professionals that would increase training, knowledge, and cultural competency on providing affirming, appropriate health care that respects the rights of people with intersex traits.

Intersex people face high rates of discrimination and stigma

According to CAP’s nationally representative 2020 survey data of LGBTQI+ adults, LGBTQ+ intersex individuals, when compared with their LGBTQ+ peers who are not intersex, experience higher rates of stigma and discrimination and



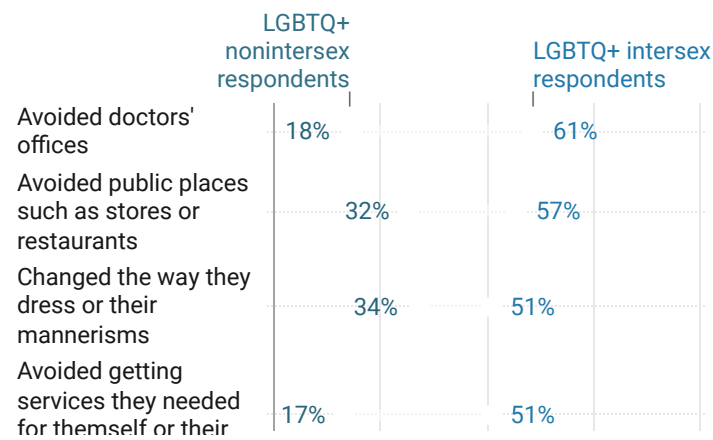
high rates of engaging in behavior to avoid exposure to discriminatory treatment, such as avoiding going to the doctor. (see Figure 2)

Figure 2

Three in 5 LGBTQ+ intersex individuals have avoided doctors' offices to avoid experiencing discrimination



Share of LGBTQ+ intersex and nonintersex individuals who reported engaging in behaviors in order to avoid experiencing discrimination in 2020



Sixty-nine percent of LGBTQ+ intersex respondents reported experiencing some form of discrimination in the year prior, roughly two times the rate of discrimination reported by LGBTQ+ nonintersex respondents (35 percent).

Because people with intersex traits do not conform to binary sex and gender norms, they can encounter significant stigma and discrimination when accessing health care. According to the CAP survey, 88 percent of LGBTQ+ intersex respondents reported experiencing some form of discrimination from a doctor or health care provider in the year prior to CAP's survey—including refusal of care, harsh language, or physical abuse—compared with 19 percent of LGBTQ+ nonintersex respondents. (see Figure 3)

Figure 3



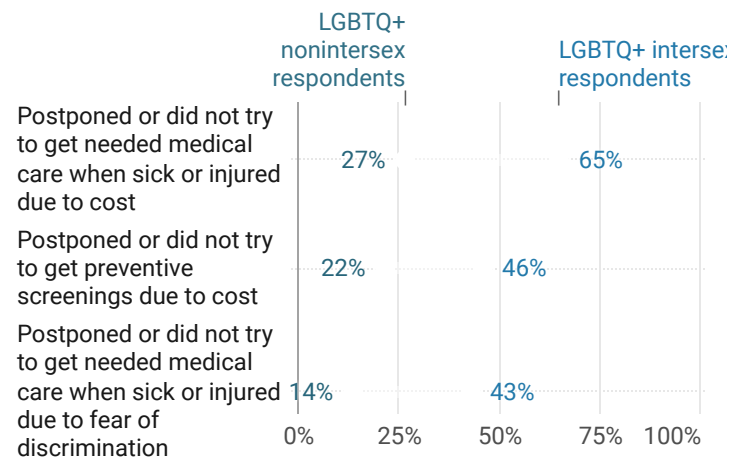
Two in 3 LGBTQ+ intersex respondents postponed or avoided medical care due to cost

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Share of LGBTQ+ intersex and nonintersex individuals who avoided medical care or preventive screenings in the year prior, 2020



Thirty-four percent of LGBTQ+ intersex respondents to the CAP survey reported a household income of less than \$25,000 annually, compared with 27 percent of LGBTQ+ nonintersex respondents. The high rates of economic insecurity and poverty experienced by intersex adults limit access to health care and contribute to higher rates of using social safety net programs, as shown in Figure 4.

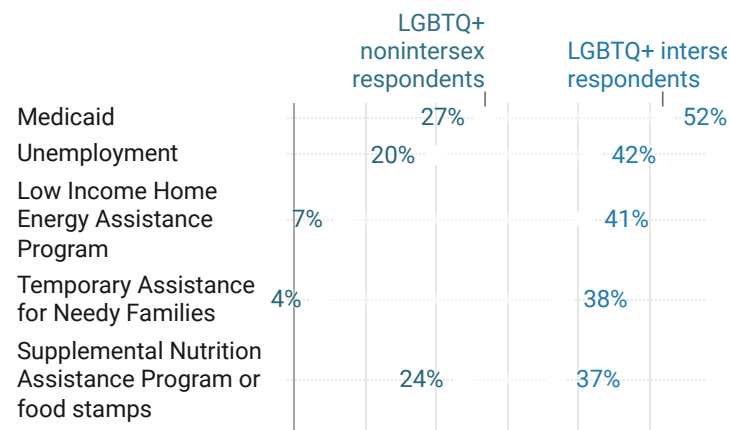
Figure 4



Intersex LGBTQ+ individuals are more than twice as likely as nonintersex LGBTQ+ individuals to receive assistance from unemployment



Share of LGBTQ+ intersex and nonintersex individuals who reported that they, their partner, or their child had gotten help from various public benefits programs in the year prior, 2020



When it becomes known that someone has intersex traits or they are perceived as not conforming with gender norms, intersex individuals are often subjected to discrimination and harassment in other key areas of life, such as education, employment, sports, and beyond. Forty-seven percent of LGBTQ+ intersex respondents reported that they have “made specific decisions about where to work” in order to avoid experiencing discrimination, compared with 34 percent of LGBTQ+ nonintersex respondents.

Figure 5



More than 4 in 5 LGBTQ+ intersex respondents experiencing discrimination report that it has affected their financial well-being



Share of LGBTQ+ intersex and nonintersex individuals who reported various effects of employment discrimination in the year prior, 2020

Not at all Slightly Moderately To a significant degree

Discrimination has negatively affected financial well-being

LGBTQ+ intersex respondents	21%	15%	41%		24%
LGBTQ+ nonintersex respondents	53%			21%	16% 11%

Discrimination has negatively affected salary or ability to be promoted

LGBTQ+ intersex respondents	26%	38%		14%	22%
LGBTQ+ nonintersex respondents	48%		22%	17%	13%

Discrimination has negatively affected ability to be hired

LGBTQ+ intersex respondents	16%	20%	24%	40%	
LGBTQ+ nonintersex respondents	45%		24%	16%	15%

Recommendations:

- The U.S. Supreme Court's decision in *Bostock v. Clayton County, Georgia*, should be enforced in a manner that is inclusive of its prohibition of discrimination based on sex characteristics, including intersex traits, in areas including but not limited to health care, employment, and educational settings. Discrimination based on sex characteristics, including



intersex traits, should also be explicitly prohibited in future rulemaking on the ACA's Section 1557, its central nondiscrimination provision, as well as CMS regulations for marketplace, Medicaid, and Medicare coverage.

- HHS should also create an awareness campaign focused on the need for affirming care and informed consent for intersex youth. The campaign should be designed with input from intersex communities and should target community stakeholders, families of people with intersex traits, and the public to increase awareness, visibility, and representation.

Intersex people must have access to accurate identification

Accurate forms of identification are crucial for accessing employment, essential services, transportation and more. In many states, burdensome requirements or lack of inclusive identification options prevent people with intersex traits and transgender people from obtaining accurate identification, increasing the risk of harassment, discrimination, and violence. Data from CAP's 2020 survey find that 77 percent of LGBTQ+ intersex respondents who reported discrimination in the year prior said that it affected their "ability to obtain accurate ID documents" to some degree, compared with 23 percent of LGBTQ+ nonintersex respondents who reported discrimination.** Recently, the State Department has made progress on removing the medical requirement for gender marker selection and adopting "X" as a third gender marker for people who identify as nonbinary, intersex, and/or gender nonconforming.

Recommendation:

- The White House should expand its efforts by directing all federal agencies to review their policies regarding the display of gender markers on federal identification documents with a focus on both ensuring that all individuals can self-select an M, F, or X designation and considering a phaseout of the display of personal gender information on certain documents that do not require that information.

There is a lack of data on people with intersex traits

The lack of available data on people with intersex traits and their experiences is a significant concern. Estimates of the size of the intersex population vary based



on the definition researchers use, and ensuring a representative sample size outside clinical contexts is difficult. Stigma around intersex traits also makes many intersex individuals unwilling to disclose their intersex status. Unfortunately, no intersex status questions currently exist on any federally funded general population surveys, and population-level data on people with intersex traits are unavailable. Additionally, there are no nationwide data on the prevalence of surgeries performed on intersex individuals, as most hospitals opt not to disclose this information.

Recommendations:

- HHS should expand research on intersex populations by testing, validating, and implementing measures for intersex status on large-scale federally funded surveys.
- It should also increase the inclusion of people with intersex traits in qualitative and quantitative health research, including cognitive interviews; promote best practices for intersex community-based participatory research; and invest in supporting the advancement of these research agendas.

Conclusion

Like other sexual and gender diverse populations, people with intersex traits experience significant discrimination, stigma, and prejudice that detrimentally affect their health and well-being. Policymakers have a responsibility to implement robust nondiscrimination protections, human rights safeguards, and research agendas that will deepen the understanding of intersex populations and generate data-driven policy solutions to improve their welfare. Additionally, Congress should pass the Equality Act, which would update federal civil rights laws to protect people from discrimination based on sexual orientation, gender identity, and sex characteristics (including intersex traits) in employment, housing, credit, jury service, and federally funded programs—such as those for health and education—as well as public accommodations.

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** This survey includes a sample of 1,528 LGBTQI+-identifying adults and was jointly conducted by the Center for American Progress and NORC at the University of Chicago. The sample has been weighted to account for both U.S. population*



characteristics and survey nonresponse. The study's full results and methodology are on file with the authors. All in-text comparisons between LGBTQ+ intersex respondents ($n = 75$) and LGBTQ+ nonintersex respondents ($n = 1,439$) are significant at the 0.05 level.

*** Select survey questions were asked only of respondents who reported experiencing discrimination in the year prior. This sample includes 46 intersex respondents and 467 nonintersex respondents.*

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CAP Survey Data on LGBTQI+ Experiences

The Center for American Progress has worked with NORC at the University of Chicago to design a comprehensive, nationally representative survey that collects data on the lives, attitudes, and experiences of LGBTQI+ Americans. The survey results reveal LGBTQI+ communities' experiences in a wide range of situations in both the public and private spheres—including discrimination, physical and mental well-being, medical care, the workforce, education, and government services. It also breaks down participants' responses along demographic lines such as race and ethnicity, gender identity, age, disability status, and educational attainment. Survey results play a critical role in better understanding these groups' realities and informing policy responses to disparities as well as paths forward for potential future research.

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