



# Affirming Sex and Gender Diversity in Genetics Practices, Policies, and Laws: A Call to Action

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ELSI Friday Forum  
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# Gender and sexuality are diverse across the globe





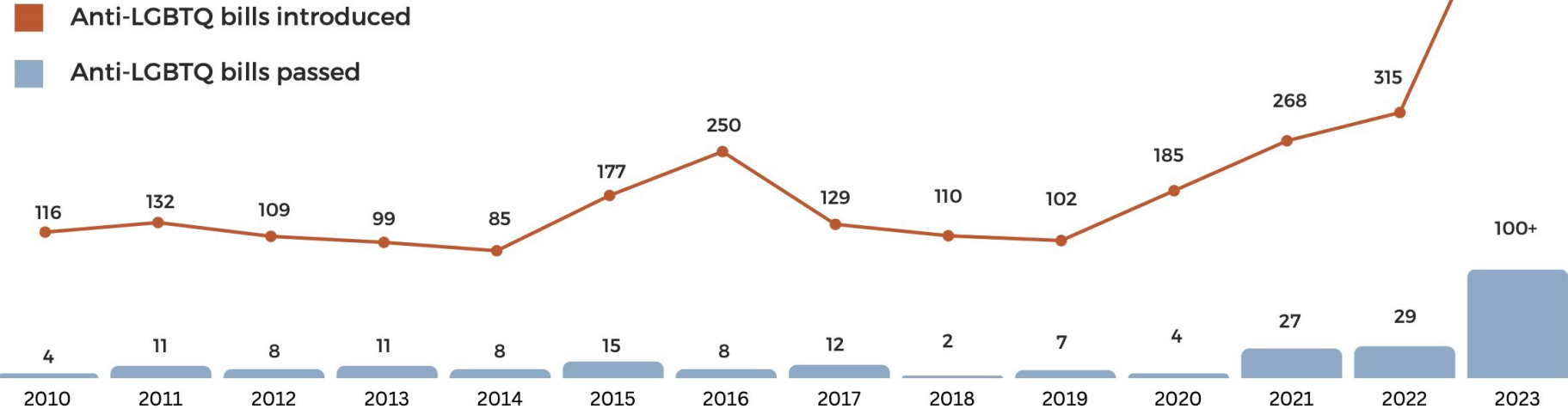
**National State of Emergency for LGBTQ+ Americans**

**Anti-LGBTQ+ law in Uganda that threatens the death penalty sparks international outcry**



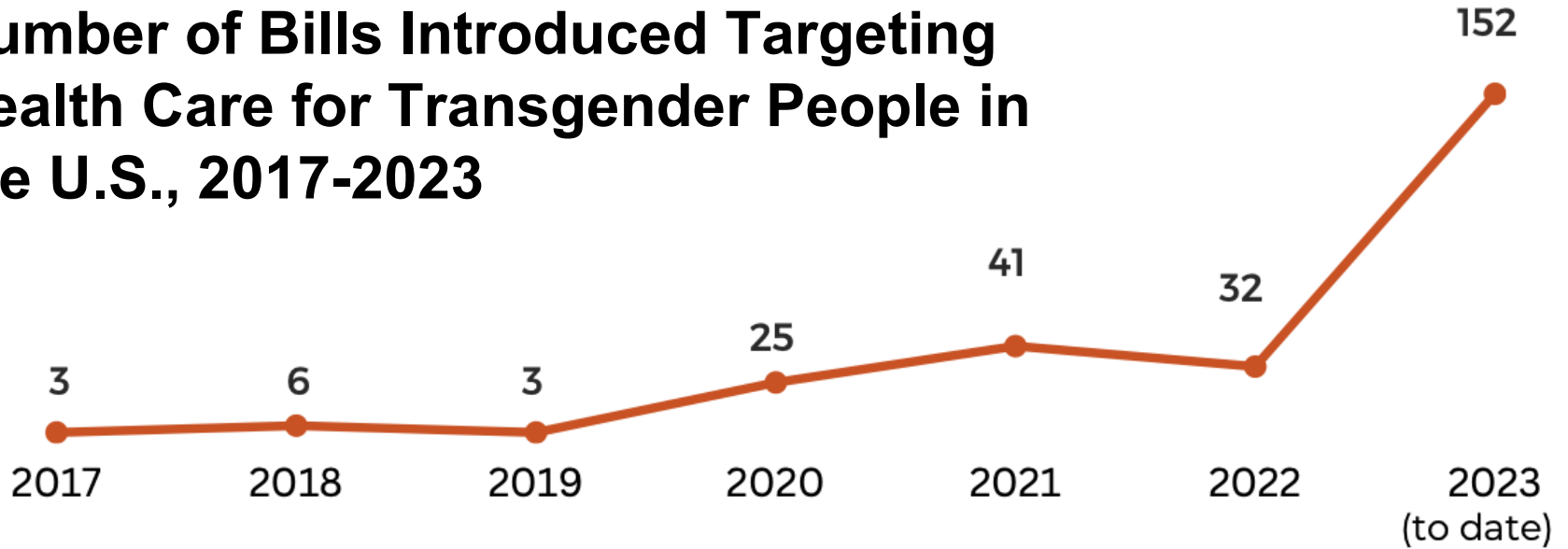
Map of Countries that Criminalise LGBT People

# Number of Anti-LGBTQ Bills Introduced and Passed in the U.S., 2020-2023

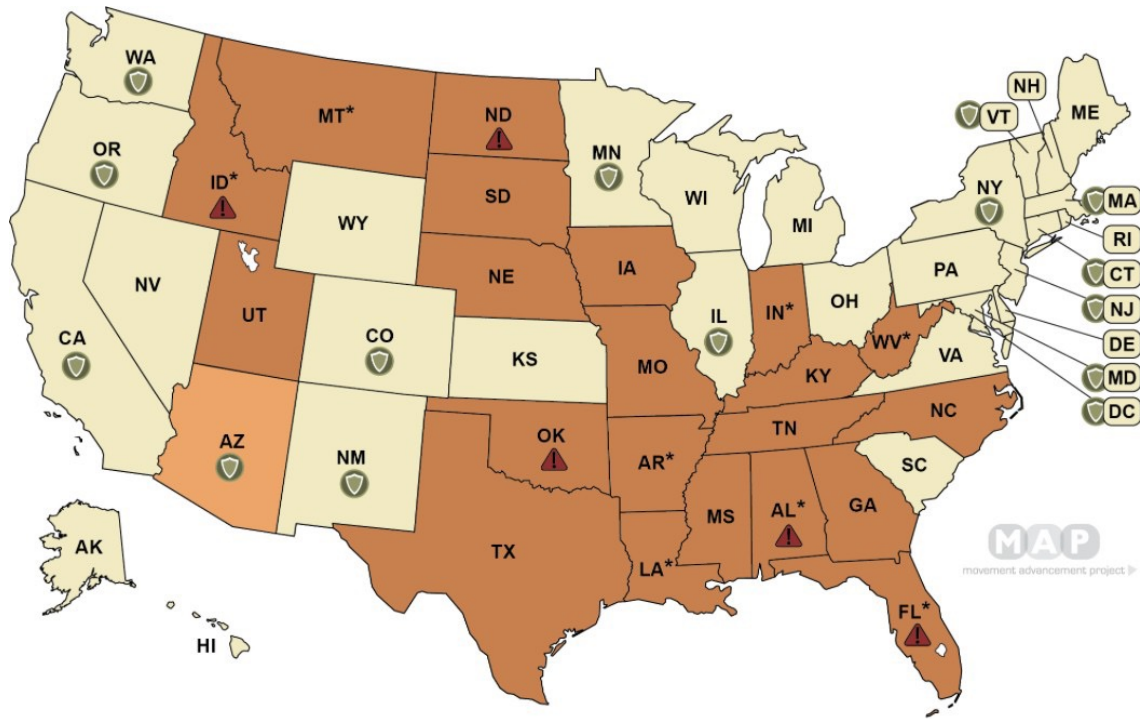








Source: data adapted from Human Rights Campaign and the Equality Federation's [State Equality Index](#) (2022), and updated with 2023 tracking by MAP. As of August 28, 2023.

# Number of Bills Introduced Targeting Health Care for Transgender People in the U.S., 2017-2023



Source: MAP original analysis. Data as of August 28, 2023.



-  State has "shield" law protecting access to transgender health care (see this map for more information) (14 states + D.C.)
-  State bans best practice medication and surgical care for transgender youth, though ban may not be in effect (see note) (21 states)
-  State bans best practice surgical care for transgender youth (1 state)
-  State does not ban best practice medical care for transgender youth (28 states, 5 territories + D.C.)
-  State ban makes it a felony crime to provide best practice medical care for transgender youth (5 states)
-  State has taken steps to ban or restrict best practice medical care for transgender youth, but state law does not ban this care (see note) (0 states)

U.S. Territories

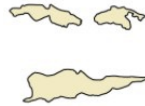
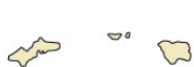
American Samoa

Commonwealth of the Northern Mariana Islands

Guam

Puerto Rico

U.S. Virgin Islands



# Bans on Transgender Medical Care

# Genetic bioessentialism underlies transphobia



## ***Alabama SB184 (2023)***

*“The sex of a person is the biological state of being female or male, based on sex organs, chromosomes, and endogenous hormone profiles, and is **genetically encoded** into a person at the moment of conception, and it cannot be changed.”*

# Genetic bioessentialism targets intersex people



## ***Kentucky SB150 (2023)***

*”[These prohibitions] shall not limit or restrict the provision of services to...a minor diagnosed with a disorder of sexual development, if a health care provider has determined, through **genetic** or biochemical testing, that the minor does not have a sex chromosome structure, sex steroid hormone production, or sex steroid hormone action, that is normal for a biological male or biological female”*



# Genetic bioessentialism underlies transphobia



## ***Department of Health and Human Services Draft Memo (2018)***

*“Sex means a person’s status as male or female based on immutable biological traits identifiable by or before birth...The sex listed on a person’s birth certificate, as originally issued, shall constitute definitive proof of a person’s sex unless rebutted by reliable **genetic evidence.**”*

# Genetic bioessentialism underlies transphobia



## ***Fairness in Women's Sports Act (Idaho 2020)***

*“If disputed, a student may establish sex by presenting a signed physician’s statement that shall indicate the student’s sex based solely on:*

- (a) The student’s internal and external reproductive anatomy*
- (b) The student’s normal endogenously produced levels of testosterone; and*
- (c) An analysis of the student’s **genetic makeup.**”*

Healthcare professionals “have the potential to provide care that is ***oppressive, transformative,*** or ***does nothing*** to address disparities.” (Woolsey & Narruhn, 2018)

# Systemic Inequity

**Systems—NOT individual identities or actions—are the root cause for health disparities**

- LGBTQIA+ identities cited as biological reason for health disparities as opposed to *cisnormativity, homophobia, transphobia*
- Parallels how race has been inappropriately medicalized as opposed to *racism, white supremacy*
- There are no quick fixes and this work is urgent



## **Medical System**

Made up of institutions that interface with other institutions (governmental, research, academic)

Pathologizes differences (sexual orientation, sex characteristics, etc.)

Uses strict categorization

Looks toward past for evidence



## **LGBTQIA+ Community**

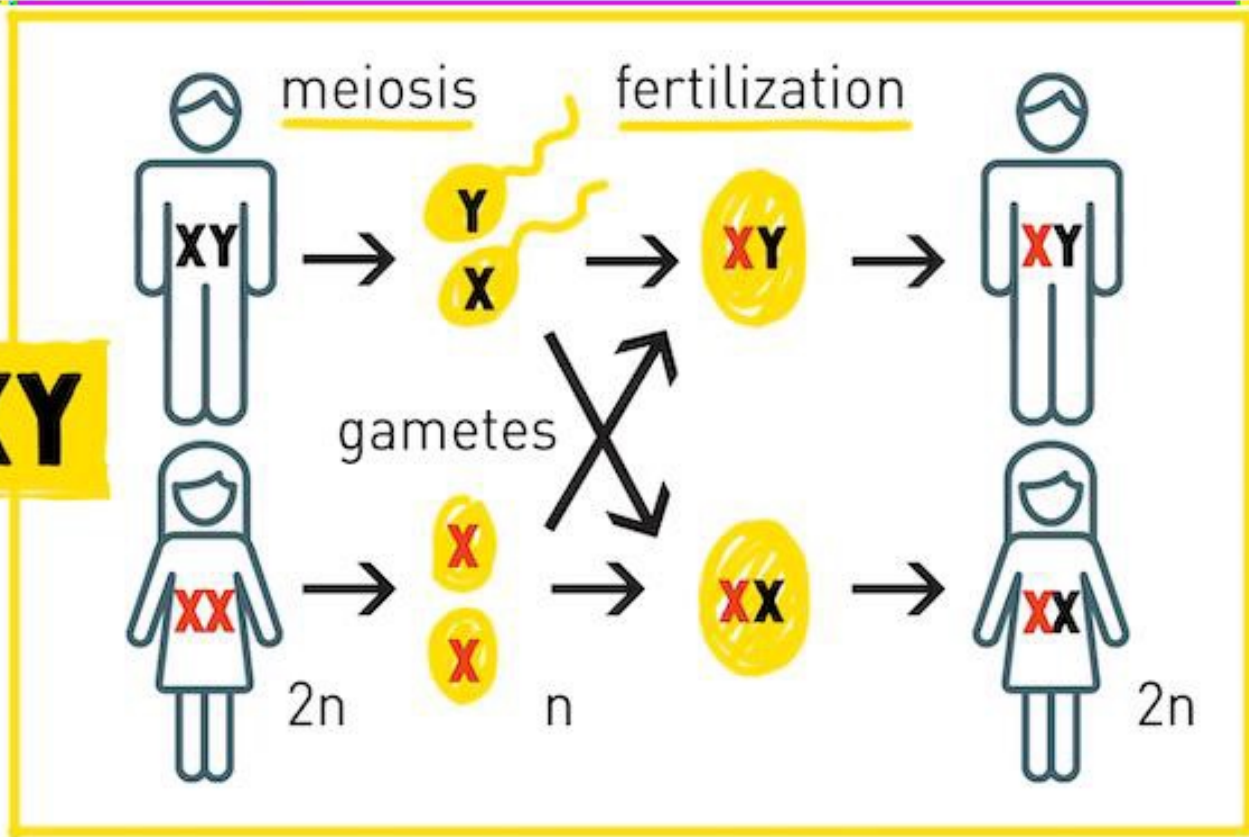
History of institutionalized discrimination, medical system has not earned trust

Freedom of self-determination

Celebration of liminality, or existing outside categories

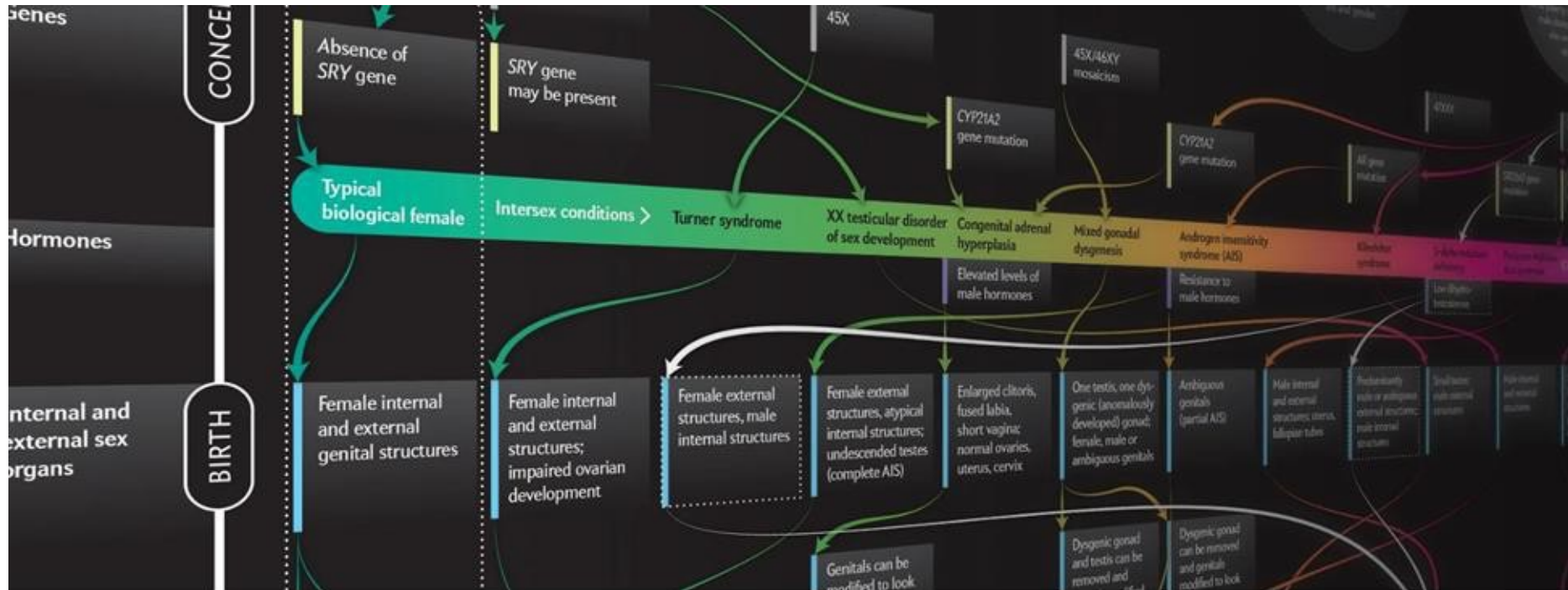
LGBTQIA+ identities largely erased from recorded history

**XY**



Source: HudsonAlpha





Credit: Pitch Interactive and Amanda Montañez; Source: Research by Amanda Hobbs; Expert review by Amy Wisniewski University of Oklahoma Health Sciences Center

## Beyond XX and XY: The Extraordinary Complexity of Sex Determination



September 1, 2007

<https://www.scientificamerican.com/article/beyond-xx-and-xy-the-extraordinary-complexity-of-sex-determination/>



SCIENTIFIC  
REPORTS

natureresearch

## The Use of Whole Exome Sequencing in a Cohort of Transgender Individuals to Identify Rare Genetic Variants

J. Graham Theisen<sup>1\*</sup>, Viji Sundaram<sup>2</sup>, Mary S. Filchak<sup>1</sup>, Lynn P. Chorich<sup>1</sup>, Megan E. Sullivan<sup>1</sup>, James Knight<sup>3,4</sup>, Hyung-Goo Kim<sup>1,5</sup> & Lawrence C. Layman<sup>1\*</sup>

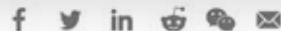
“A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation” (1993), by Dean H. Hamer and Charles A. Thomas.

10. 15. 19 / BY DAN ROBITESKI

**THIS STARTUP SAYS IT CAN ANALYZE YOUR DNA TO DETECT IF YOU'RE GAY**

EXPERTS TOLD US THE APP IS AN ETHICAL DISASTER THAT'S BASED ON FLAWED, TOTALLY INACCURATE SCIENCE.

RESEARCH ARTICLE



## Large-scale GWAS reveals insights into the genetic architecture of same-sex sexual behavior

ANDREA GANNA , KARIN J. H. VERWEIJ , MICHEL G. NIVARD, ROBERT MAIJER , ROBBEF WEDOW , ALEXANDER S. BUSCH , ABDEL ABDELLAOUI, SHENGRU GUO,

J. FAH SATHIRAPONGSASUTI , [...] BRENDAN P. ZIETSCH 

+12 authors

[Authors Info & Affiliations](#)

# Personalization & Autonomy

**If the universal goal of genetics is precision medicine, then we're failing LGBTQIA+ patients.**

- Informed consent for procedures and examinations
- Transparency from providers
- Personalized risk assessment
- Access to gender-affirming care

# Depathologization & Inclusive Language

- Moving away from pathologizing language
- Support policy changes for just care
- Educating on spectrum of sex and gender to public



“There is no neutral body from which our bodies deviate”  
- Aurora Levins Morales