

The logo features a stylized circular emblem composed of overlapping blue and cyan arcs. The text is centered within this emblem.

2023
NATIONAL
HIV & HEPATITIS
TECHNICAL ASSISTANCE MEETING

REAFFIRMING MEANINGFUL
COMMUNITY ENGAGEMENT

Don't Get Mad, Get Data! SOGI Data and Viral Hepatitis

Wednesday, October 11
10:45 AM -12:00 PM

Kellan Baker, Executive Director, Whitman-Walker Institute

Thaddeus Pham, Viral Hepatitis Prevention Coordinator, Hawai'i Department of Health



Today's speakers:



Kellan Baker, Executive Director,
Whitman-Walker Institute



Thaddeus Pham, Viral Hepatitis Prevention Coordinator,
Hawai'i Department of Health



The National Academies Recommendations on SOGI Data Collection

Kellan E. Baker, PhD, MPH, MA
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October 11, 2023
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Report Sponsors

- This report was sponsored by the National Institutes of Health (NIH)
- 19 Institutes, Centers, and Offices contributed funding:
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 - National Institute of Allergy & Infectious Diseases
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 - National Institute of Environmental Health Sciences
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Statement of Task

- Review current measures and the methodological issues related to measuring **sex as a nonbinary construct, gender identity, and sexual orientation** in surveys and research studies, in administrative settings, and in clinical settings.
- Produce a consensus report with conclusions and recommendations on guiding principles for collecting data on **sex, gender identity, and sexual orientation** and recommended measures for these constructs in different settings.

Sex

- Sex is a multidimensional construct based on a cluster of anatomical and physiological traits (i.e., sex traits)
- Sex traits include external genitalia, secondary sex characteristics, gonads, chromosomes, and hormones
- Characteristics of sex and sex traits:
 - Usually assigned at birth as female or male based on visual inspection of external genitalia
 - Sex traits are usually assumed to be unambiguous, but may not be
 - Sex traits are usually assumed to all correspond to the same sex, but they may not, as in the experience of people with intersex traits
 - Some sex traits can change or be altered over time

Gender

- A multidimensional construct linking gender identity, gender expression, and social and cultural expectations about status, characteristics, and behavior that are associated with sex traits
 - Gender identity: A core element of a person's individual sense of self
 - Gender expression: How an individual signals their gender to others through behavior and appearance
- Characteristics of gender:
 - Often conceptualized as binary (male/female or man/woman) in Western cultures, but also includes categories outside this binary
 - Often used interchangeably with sex, though it is conceptually distinct
 - Often assumed to be determined based on sex assigned at birth but may differ
 - Gender identity, expression, and social and cultural expectations may not all correspond to the same gender
 - May be temporally and contextually fluid

Sexual Orientation

- Sexuality is a multidimensional construct encompassing emotional, romantic, and sexual attraction, identity, and behavior
 - Identity: A person's core internal sense of their sexuality
 - Attraction: A multidimensional concept that includes the gender(s) to which a person is attracted and the strength of this attraction
 - Behavior: A multidimensional concept that includes the gender(s) of sexual partners, specific sexual activities, and frequency of sexual activity
- Characteristics of sexuality:
 - Often defined based on the gender(s) of a person's desired or actual partners relative to their own gender in Western cultures
 - The three dimensions of sexuality—attraction, identity, and behavior—may not correspond to the same orientation

Scope of the Report

- Measures that can be used in the **general English-speaking adult population**
 - More detailed response options may be necessary for measures used within LGBTQI+ populations
 - **Modifications** to recommendations **may be needed** if they are used **within younger populations**
 - Also **prioritized representation of indigenous sexual and gender minorities**
- Focus on measures of identity that can also be used to identify sexual and gender minority populations
- Three domains: surveys and research, administrative settings, and clinical settings

Data Collection Principles

- **Inclusiveness:** People deserve to count and be counted
- **Precision:** Use precise terminology that reflects the constructs of interest
- **Autonomy:** Respect individual identity and autonomy
- **Parsimony:** Collect only necessary data
- **Privacy:** Use data in a manner that benefits respondents and respects their privacy and confidentiality

Conclusion 1: Conceptual Clarity on Sex and Gender

Gender encompasses identity, expression, and social position. A person's gender is associated with but cannot be reduced to either sex assigned at birth or specific sex traits. Therefore, **data collection efforts should not conflate sex as a biological variable with gender** or otherwise treat the respective concepts as interchangeable. In addition, in many contexts, including human subjects research and medical care, **collection of data on gender is more relevant than collection of data on sex as a biological variable**, particularly for the purposes of assessing inclusion and monitoring discrimination and other forms of disparate treatment.

Recommendation 1: Gender by Default

The standard for **the National Institutes of Health should be to collect data on gender and report it by default.** Collection of data on sex as a biological variable should be limited to circumstances where information about sex traits is relevant, as in the provision of clinical preventive screenings or for research investigating specific genetic, anatomical, or physiological processes and their connections to patterns of health and disease. In human populations, collection of data on sex as a biological variable should be accompanied by collection of data on gender.

Recommendation 2: Sexual Orientation Identity

Which of the following best represents how you think of yourself? [Select ONE]:

- Lesbian or gay
- Straight, that is, not gay or lesbian
- Bisexual
- [If respondent is AIAN:] Two-Spirit
- I use a different term [free-text]

(Don't know)

(Prefer not to answer)

Sexual Orientation: Topics for Future Research

RECOMMENDATION 3: To further improve the quality and inclusivity of current measures of sexual orientation identity, the National Institutes of Health should fund and conduct research on the following topics:

- Alternate wording for the “straight” response option
- The ordering of response categories
- The addition of response options such as: “queer,” “questioning,” and “same gender loving”
- Guidelines for measuring sexual orientation attraction and behavior
- Best practices for collecting sexual orientation information within adolescent populations
- Proxy reporting of sexual orientation identity

Recommendation 4: Gender Identity

Q1: What sex were you assigned at birth, on your original birth certificate?

Female

Male

(Don't know)

(Prefer not to answer)

**Q2: What is your current gender?
[Mark only one]**

Female

Male

Transgender

[If respondent is AIAN:] Two-Spirit

I use a different term: [free text]

(Don't know)

(Prefer not to answer)

Cross Tabulation of Two-Step Measure

- Cisgender women (female/female)
- Cisgender men (male/male)
- Transgender women (male/female)
- Transgender men (female/male)
- People who can be classified as transgender (trans men, trans women, people who identify using the term “transgender”)
- People with nonbinary gender identities (Two-spirit, write-ins)

Gender Identity: Topics for Future Research

RECOMMENDATION 5: To improve the quality and inclusivity of the recommended two-step gender measure—sex assigned at birth and current gender—the National Institutes of Health should fund and conduct research on the following topics:

- Gender-based response options (man/woman) and optimal response ordering
- Performance of a “select all that apply” approach for current gender
- Replacing or augmenting the gender response option “transgender” with “nonbinary”
- Categorization of nonbinary people vis-à-vis transgender status or identity
- The need for a “nonbinary” response option for sex assigned at birth
- Stability of responses over time
- Alternative two-step measures that can be used in circumstances in which asking about sex assigned at birth is inappropriate
- Best practices for collecting two-step sex and gender information from youth, people with limited English proficiency, and with proxy reporting

Intersex/DSD Status and Sex Assignment at Birth

- Most intersex people in the U.S. are assigned either male or female at birth
- Variations can occur on any sex trait, not always visible or easily identified
- Many do not find out that they have an intersex variation until later in life—
if at all
- Historically, concealment was prioritized, and surgical intervention was standard treatment for the small proportion of people with intersex traits who are born with ambiguous genital characteristics

Recommendation 6: Intersex Status Measurement

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.

Intersex/DSD Status Measures with the Strongest Evidentiary Support

- Very little evidence on the quality of intersex/DSD status measures is available.
- Three question stems have been tested in population-based surveys:
 - *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?*
 - *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.)*
 - *Have you ever been diagnosed by a medical doctor with an intersex condition or a difference of sex development’?*

Conclusion 3: Potential Measure

Based on the best available evidence, community guidance, and expert opinion, intersex status can be measured using the following question:

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?

Yes

No

(Don't know)

(Prefer not to answer)

Intersex/DSD Status: Topics for Future Research

RECOMMENDATION 7: To improve the quality and inclusivity of current measures of intersex status, the National Institutes of Health should fund and conduct research on the following topics:

- The use of a single-item intersex/DSD status question
- The relative quality of the three measures of intersex/DSD status identified by the panel
- The effects of using terminology such as “intersex” or “DSD” or definitions of these terms in question stems or supplemental text
- The prevalence of “intersex” as a gender identity term among people with intersex traits
- Proxy reporting of intersex/DSD status, particularly by parents

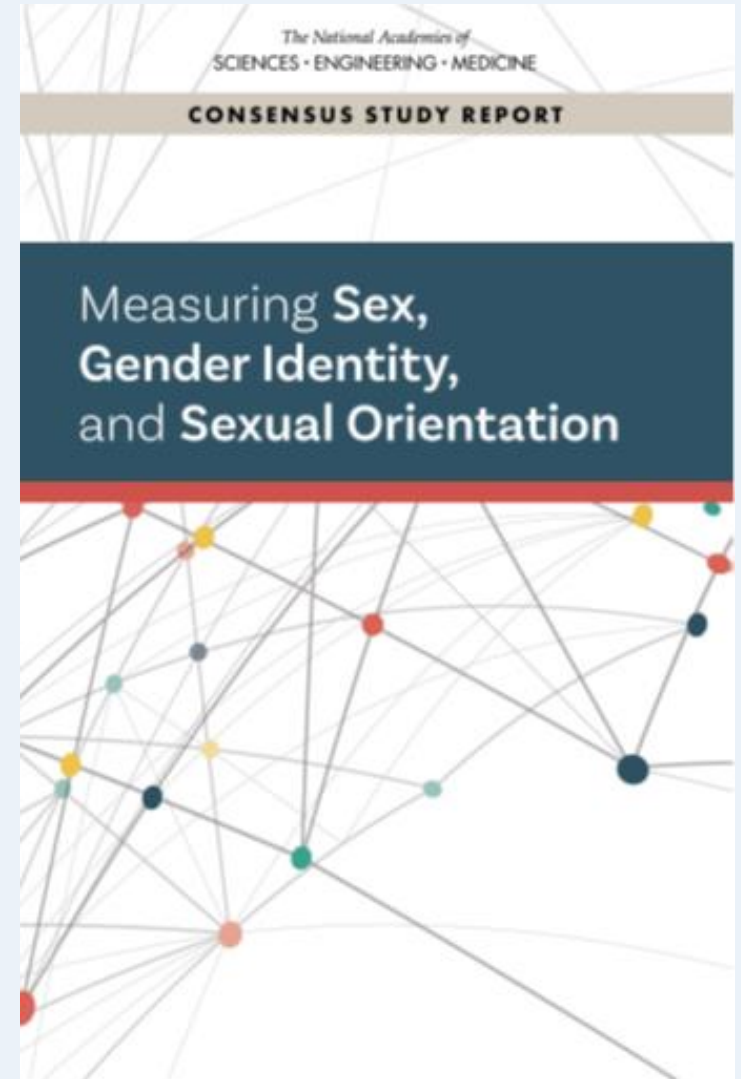
Thank you!

Access the report:

<https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>

Contact:

Kellan Baker, kbaker@whitman-walker.org



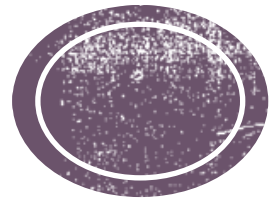
Time and People: *Sexual and Gender Minority (SGM) Data in Hawai'i*



Adapted from slides by Ranjani Starr

Thaddeus Pham (he/him), Hawai'i Sexual and Gender Minority Workgroup

October, 2023 for NASTAD TA Meeting



How it started...



Back in 2015...

**No Hawai'i
data reports
on SGM
disparities**



HI Youth Risk Behavior Survey

2005: sexual orientation question added

2011: sample size increased

2015: opt-out consent process



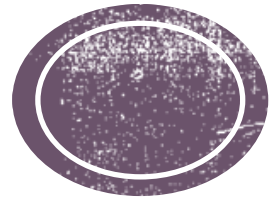
Policy Background

Section 226-20, Hawaii Revised Statutes, was amended in 2016 (Act 155 (14)):

- “Objectives and policies for socio-cultural advancement...(3) Elimination of health disparities by identifying and addressing social determinants of health.”

Policy efforts at state and national to support SGM people in HI





Strategies for First Report



Strategies for First Report

- Create a small cross-sector workgroup

Epidemiologists

Psychologist

Public Health
Program
Managers

Community
Members

Policy
Advocates



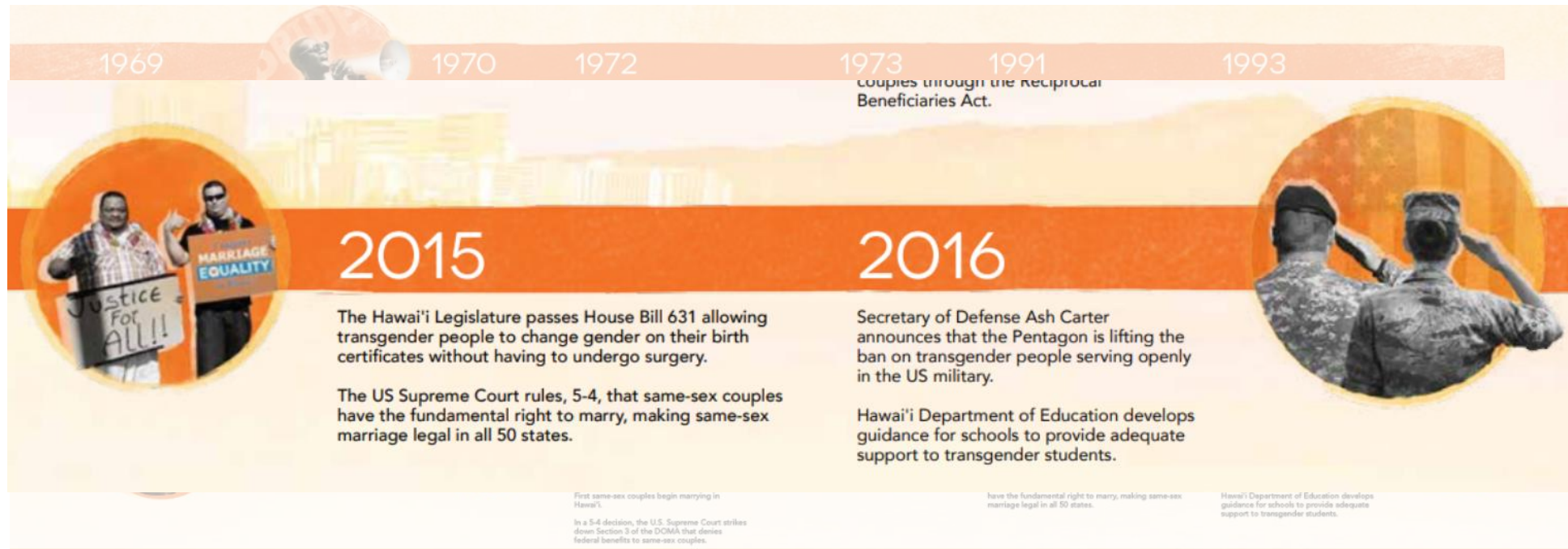
Strategies for First Report

- Create a small cross-sector workgroup
- Provide Hawaii-specific historic context (e.g. pictures, policy)



Historical Timeline of Sexual and Gender Minority Policy in Hawaii

- Included significant events both nationally and locally.
- Included Hawaii or national pictures as relevant.



Strategies for First Report

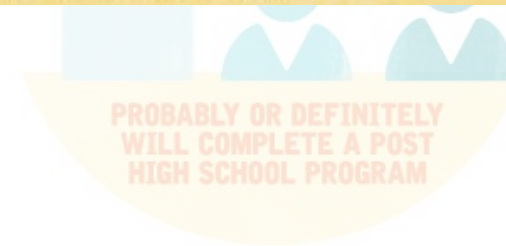
- Create a small cross-sector workgroup
- Provide Hawaii-specific historic context (e.g. pictures, policy)
- Provide context for YRBS indicators (few indicators of a larger problem)
- Explain the source of the problem (i.e. to avoid misplaced blame and further marginalization) with the evidence-base
- Provide solutions/examples of successful initiatives to address the “What do we do now?” questions





Numerous studies have documented the close relationship between health and academic achievement.⁷³ Inequities in education may negatively impact an individual's earning potential and quality of life. School health programs have the potential to contribute to academic success.⁷⁴ Attaining higher levels of education is associated with greater income, lower rates of obesity and chronic diseases, and longer life expectancy.^{75,76} While schools must strive to provide a safe atmosphere for learning to all students, many SM & TG/GNC students experience a hostile climate at school and may choose to miss school to avoid unpleasant and negative experiences that threaten their safety and well-being. Studies show that experiencing negative school climates and victimization are related to lower academic performance and self-esteem among SM & TG/GNC youth.⁵⁷ School-located resources, such as GSA clubs, that address these issues have a positive impact on school climate for SM & TG/GNC students.⁷² Sexual minority youth who attend schools with GSAs are less likely to hear homophobic remarks or report feeling unsafe at school, less likely to experience dating violence or feel threatened or injured at school, less likely to miss school days

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Strategies for First Report

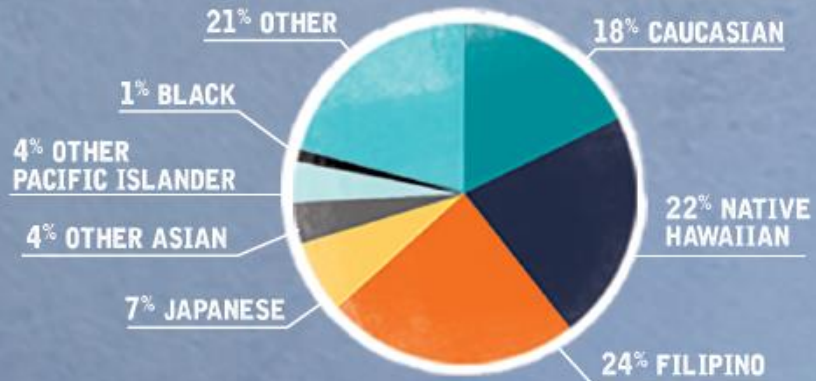
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- Represent health holistically, rather than focus on issues historically attributed to be LGBT-specific (e.g. race-specific, sexual health, substance use) – an “everyone” problem





1 IN 10 PUBLIC HIGH SCHOOL STUDENTS IDENTIFY AS LGB OR QUESTIONING.

RACE/ETHNICITY OF LGB AND QUESTIONING HIGH SCHOOL YOUTH



HEALTHCARE ACCESS



GENERAL HEALTH



BEHAVIORAL RISK FACTORS



INJURY & VIOLENCE



ACADEMIC ACHIEVEMENT



PROTECTIVE FACTORS



MENTAL HEALTH



HEALTHCARE ACCESS



Strategies for First Report

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- Address youth and adult issues.
- Write a report that the public can understand (i.e. use infographics) - *Budget for design/infographics + initial printing: \$15,000*



Centerfold Infographic focused on Lesbian & Bisexual Women Health Disparities (compared to Heterosexual Women)



Strategies for First Report

- Create a small cross-sector workgroup
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- Address youth and adult issues.
- Write a report that the public can understand (i.e. use infographics) - *Budget for design/infographics + initial printing: \$15,000*
- Obtain feedback from a small group of prominent community stakeholders.



Acknowledgements

The Hawai'i Sexual and Gender Minority Work Group is comprised of many individuals and community-based organizations that contributed to the report by providing content, feedback, reviews, and expertise on a variety of topics within the report.

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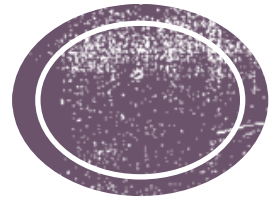
Hep Free Hawaii

Life Foundation

Kua'ana Project

The CHOW Project





First Report Published May 2017

2017

LGB Youth
LGB Adults

**HAWAI'I SEXUAL &
GENDER MINORITY
HEALTH REPORT**



Mixed Reviews...

"We're 20 years behind the times, but finally glad that it's happening."

"The transgender community was mentioned in the beginning, but there was no data provided for them."

"I would like to see that any further study be not only inclusive of the 'T' in LGBT, but also something comprehensive"

"Hopefully this is not a one up and done.. that they do a follow up to help what legislation comes forward to protect our transgender community."



“They forgot about us...”





“We, the undersigned, respectfully request that the Hawaii State Department of Health build upon this ground-breaking report by:

... committing to developing and releasing annual updates

....assuring that as data becomes available, these reports will also highlight the health of Hawaii’s transgender and gender non-conforming communities

....supporting integration of the findings of the report...to address the needs of sexual and gender minority communities in Hawaii”

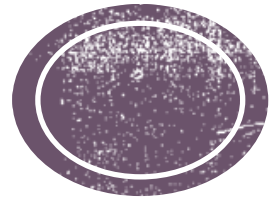


Sexual and Gender Minority Health Work Group

- Add* and commit to retaining gender identity questions into population health surveys
- Commit to publishing a transgender health report as soon as feasible
- Incorporate feedback from a broader coalition of partners

*Already added in 2017





Strategies for Second Report



New Strategies for Second Report

- (9 key strategies previously used minus adult data) +
- Incorporate historical elements of concern to the transgender and gender non-conforming community in Hawaii



1963

Disorderly conduct legislation in Hawai'i is amended to include persons wearing clothing of the opposite sex with "intent to deceive" others by failing to reveal one's sex.⁴⁴ Trans and māhū persons are required to wear "I am a Boy" buttons to avoid fines.⁴⁵

1969

The historic Stonewall Revolution—riots that ensued following a New York City police raid on the Stonewall Inn, a gay club—marking the start of the LGBT civil rights movement.⁴⁶

1960

1970



1970

The first Gay Pride marches take place in Los Angeles, Chicago, and New York.⁴⁷

1972

Hawai'i decriminalizes consensual same-sex acts occurring in privacy between consenting adults.⁴⁸

Hawai'i's disorderly conduct law revised, deleting the "intent to deceive" clause.⁴⁸ Trans and māhū persons no longer required to wear "I am a Boy" buttons.⁴⁵

1973

The American Psychiatric Association removes homosexuality from its official list of mental disorders.⁴⁹

1963: "Disorderly conduct legislation in Hawaii is amended to include persons wearing clothing of the opposite sex with "intent to deceive" others by failing to reveal one's sex. Trans and māhū persons are required to wear "I am a Boy" buttons to avoid fines"

1972: Hawaii's disorderly conduct law revised, deleting the "intent to deceive" clause. Trans and māhū persons no longer requires to wear "I am a Boy" buttons.



New Strategies for Second Report

- (9 key strategies previously used minus adult data) +
- Incorporate historical elements of concern to the transgender and gender non-conforming community in Hawaii
- Include personal narratives to provide context and lived experiences



Stories of Resiliency



New Strategies for Second Report

- (9 key strategies previously used minus adult data) +
- Incorporate historical elements of concern to the transgender and gender non-conforming community in Hawaii
- Include personal narratives to provide context and lived experiences
- Explain the intersection between gender and culture – explain the local context for the gender identity spectrum



Discussion of Third or Middle Gender in Non-Western Cultures

GENDER AND CULTURE

Gender identity is also culturally informed. There are identities central to cultures outside of the U.S. norm that are additional, third, or middle genders. These genders include, but are not limited to, the māhū wahine and māhū kāne of Hawai'i (page 7),³ fa'afafine of Samoa,⁴ fakaleiti of Tonga,⁴ two-spirit people in some Native American cultures,⁵ and hijra in India,⁶ among many others. These identities are not to be confused with transgender identity. Individuals with any of the mentioned identities may or may not identify as transgender. The abundance of gender identities found across cultures highlights the problematic nature of the gender binary, as there are significantly more genders than male and female.

- Māhū wahine and māhū kāne of Hawaii
- Fa'afafine of Samoa
- Fakaleiti of Tonga
- Two-spirit people in some Native American cultures
- Hijra in India



New Strategies for Second Report

- (9 key strategies previously used minus adult data) +
- Incorporate historical elements of concern to the transgender and gender non-conforming community in Hawaii
- Include personal narratives to provide context and lived experiences
- Explain the intersection between gender and culture – explain the local context for the gender identity spectrum
- Be more explicit about what isn't there!





Where is **ADULT TRANSGENDER** and **OTHER IMPORTANT DATA?**

ADULT GENDER IDENTITY DATA

In 2014, the Hawai'i State Department of Health (DOH) added a question on gender identity to the Hawai'i Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is the world's largest ongoing annual telephone survey of adults aged 18 years or older and collects data on health risk and health behaviors related to the leading causes of disability and death. The data is collected to be representative of all adults in the State of Hawai'i; however, only a small proportion of adults identify as TG. At the time of writing this report, despite several years of data collection, the sample size of TG adults, including those who identify as TG men, TG women, and gender non-conforming, was insufficient to report out. Data will be published as it becomes feasible.

The data presented in this report is not comprehensive. Notably, while factors such as incarceration; sex work; access to other health services such as mental health, vision, and substance use treatment; number of family members who identify as a gender minority; employment; effects of black market silicone, international surgery, and early hormone replacement therapy; unsheltered homeless locations; types of sexual practices; graduation rates; and types of adult supports available

therapy; unsheltered homeless locations; types of sexual practices; graduation rates; and types of adult supports available to youth are interesting and essential to a comprehensive understanding of public health issues faced by Hawai'i's gender minority communities, questions about these risk factors have either not been included in the YRBS, or the current question wording limits the amount of information collected. Other data sources containing information on the health of SM & TG/ GNC people in Hawai'i may exist. More effort and collaboration are needed to identify and evaluate the representativeness of those data sources.



New Strategies for Second Report

- (9 key strategies previously used minus adult data) +
- Incorporate historical elements of concern to the transgender and gender non-conforming community in Hawaii
- Include personal narratives to provide context and lived experiences
- Explain the intersection between gender and culture – explain the local context for the gender identity spectrum
- Be more explicit about what isn't there!
- Seek feedback from the community!



Acknowledgements

The Hawai'i Sexual and Gender Minority Work Group is comprised of many individuals and community-based organizations that contributed to the report by providing content, feedback, reviews, and expertise on a variety of topics within the report.

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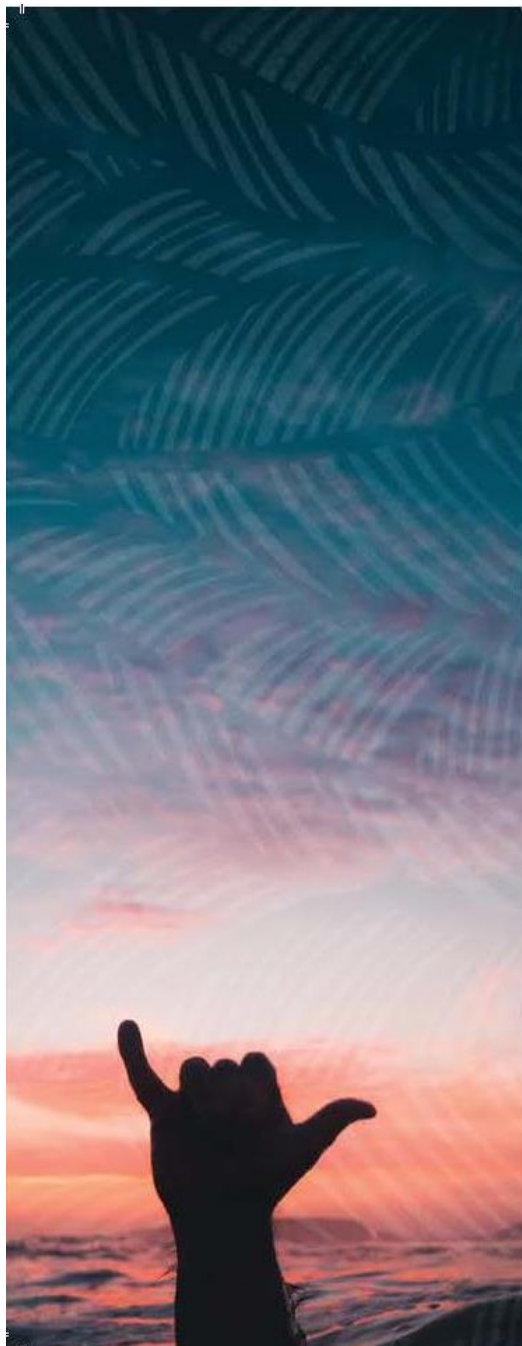
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New Strategies for Second Report

- (9 key strategies previously used minus adult data) +
- Incorporate historical elements of concern to the transgender and gender non-conforming community in Hawaii
- Include personal narratives to provide context and lived experiences
- Explain the intersection between gender and culture – explain the local context for the gender identity spectrum
- Be more explicit about what isn't there!
- Seek feedback from the community!
- Validate the experience of the transgender community as being the *most* marginalized within and among the LGBTQ+ community



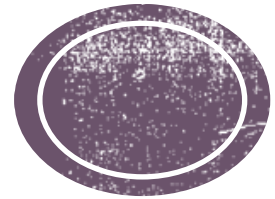
Using Magnitudes of Disparity

- Direct comparisons of LGB and transgender students are inappropriate



- Therefore, we compared the magnitude of disparities using 2017 data for both comparisons (LGB/heterosexual and Transgender/Cisgender) – *centerfold infographic*





First Report Published September 2018



2018

Transgender Youth

HAWAI'I SEXUAL AND GENDER MINORITY HEALTH REPORT 2018

A FOCUS ON TRANSGENDER YOUTH



Second Report: Community Feedback






Hawaii

‘Tragic’ Findings For Hawaii’s Transgender Youth In New State Report

Transgender kids in public high schools are in “survival mode” but more resources and role models are emerging, according to the first-of-its-kind study.



By Nathan Eagle    / September 24, 2018

 Reading time: 8 minutes.



“[I]t puts the entire state, all youth service providers in every agency, on notice”

"This systemic discrimination is a recent thing in Hawaii. ...It was created and we can uncreate it."

“This survey opens a door to many other conversations that need to happen. But we have to press the state to make sure that happens.”

“There has to be hope...”



Data Dissemination



2 in 5
currently use
(in past 30 days)

marijuana



1 in 4
ever injected

illicit drugs



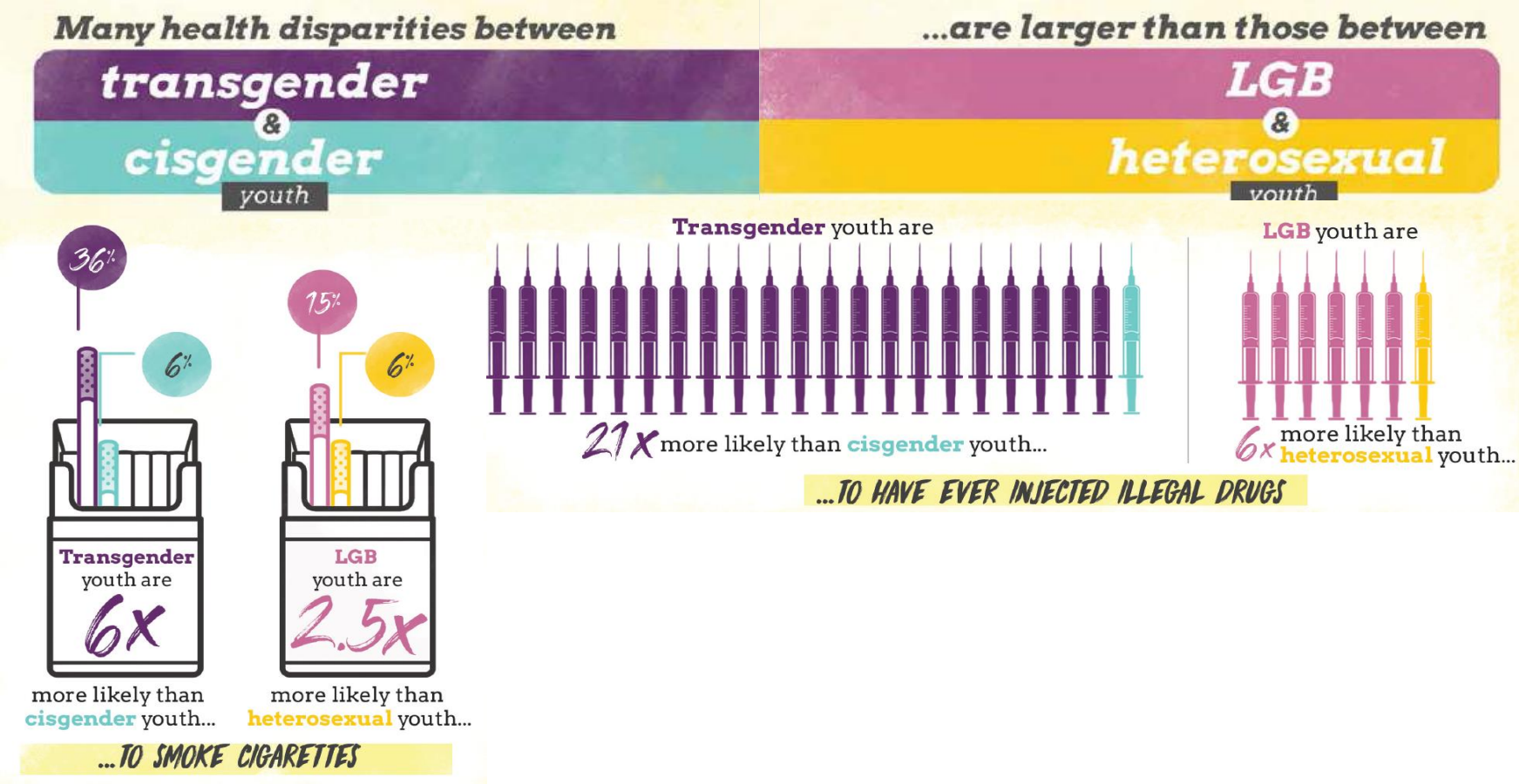
1 in 2
ever used
(without a prescription)

prescription drugs

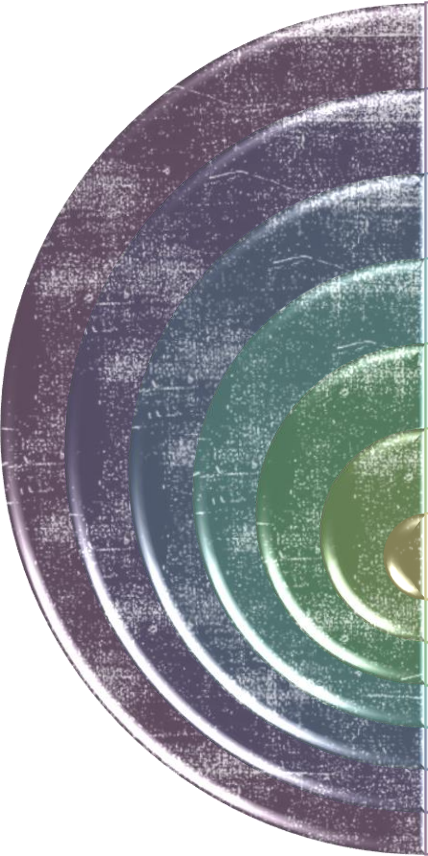
TRANSGENDER YOUTH



Data Dissemination



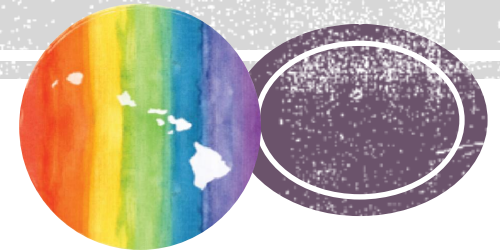
Lessons Learned



Include context – explain why the disparities exist
Ask the community for feedback
Involve the community in the content
Invest in good infographics
Acknowledge what isn't included
Build hope and resiliency into the report
Find a way to keep up the momentum for the work



Questions?



Roundtable Questions to Consider

1. How can SOGI data be used for policy change?
2. What policies need to be changed for better SOGI data collection?
3. What existing data sources (eg, YRBS) might be available in your jurisdiction?
4. What strategies are used to ensure resulting data will be used *and* shared back with the community?



Upcoming Sessions:

12:00-2:00pm Lunch on Your Own

2:00-3:15 PM Engaging people of Trans Experience in Hepatitis Elimination Planning and Outbreak Response

Room: Congressional A/B

3:35 PM THRASH Plenary: Centering People with Transgender Experience in Program Leadership

Room: Regency Ballroom

