



Health Care & **Research** for the Transgender Community

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Outline

- Brief review of research on health disparities and barriers to healthcare.
- Introduction of Project AFFIRM, current longitudinal, multisite study of transgender identity development, vulnerability and resilience, funded by NICHD (R01-HD79603, Walter Bockting, PI), the MAC AIDS Fund, and the New York Community Trust.
- Preliminary findings on patient-provider relationships.
- Discussion.



Health disparities

- Depression (44%); suicidal ideation (54%) and attempts (31%).
- Smoking (36%).
- Anxiety (33%).
- Substance use (22% at-risk drinking; 24% marijuana; 12% other drugs).
- HIV (12% self report, 28% testing); less likely to be engaged in HIV care due to past negative experiences, giving priority to transition-related care, and concerns about ART and hormone interactions.

(Bockting et al., 2016)



Health disparities cont'd

- Compared to LGB older adults, transgender people aged 50 years and older are at higher risk for poor physical health, disability, depression, and perceived stress (Fredriksen-Goldsen et al., 2013).
- In part due to fear of accessing health services, lack of physical activity, internalized stigma, victimization, and lack of social support.
- Need for population studies with probability samples to more accurately determine the prevalence and predictors of health concerns among transgender and gender nonconforming people (currently underway with a supplement funded by OD to R01-HD078526-03 (Ilan Meyer, PI)).



Barriers to healthcare

- Lack of culturally and clinically competent providers; lack of training.
- Distrust of health providers due to actual or perceived stigma and discrimination.
- Stigma attached to providing care.
- Health system barriers, such as inappropriate electronic medical records, forms, lab references, and clinic facilities.
- Socioeconomic barriers, such as poverty and lack of health insurance, transportation, and housing.
- Mental health.

(Safer et al., 2016)

Findings from Project Shakti in Mumbai, India



- Funded by NIDA (R21-DA033719; Swagata Banik, PI).
- Assessment of stigma and development of an intervention to reduce stigma in health care for hijras.
- Stigma included:
 - Refusal or delay of treatment;
 - Negative attitudes, blame, stereotyping;
 - Judgment based on perceived sexual behavior;
 - Proxemics and excessive precautions.
- More experience in working with hijra resulted in more positive attitudes and empathy. Yet also here, providers are stigmatized.

“The doctor in the [public hospital] scolded me for ‘doing it’ with another man and he went on to see another patient. I had fever and was coughing constantly. The nurse would not come near me. She wrote me a prescription without checking my temperature and told me to go to another hospital. I did not have enough money, so I went and took some herbal decoction. I would never go to that hospital again. . .”

(32 years old hijra)





Research gaps on barriers to care

- Mainly self-report by convenience samples of transgender people.
- Mainly transgender people's perceptions; provider perspectives have been largely overlooked.
- One study of medical students and one of medical residents found less comfort providing hormone therapy to transgender patients compared to hormone therapy to other patients.
- Some formative research on understanding physicians' need for education and training in transgender medicine, but without adequate understanding of physicians' barriers to providing care.
- Focus has been on LGBT rather than transgender-specific barriers.
- No systematic analysis of workforce needs to provide care, the current status of that care, or third-party financial support.
- Lack of research on solutions.

(Safer et al., 2016)



Project AFFIRM: Aims

1. Describe transgender identity development based on lifeline interviews ($N = 90$);
2. Refine a model of identity development, minority stress, risk and resilience;
3. Test this model in a cohort of transgender individuals ($N = 480$), aged 16 and older;
4. Triangulate qualitative and quantitative data to inform interventions and capacity building.



Team of investigators

New York City

NYSPI / Columbia Psychiatry

- Walter Bockting, PhD (PI)
- Anke Ehrhardt, PhD
- Heino Meyer-Bahlburg, Dr. rer. nat.
- Will Mellman, MSW
- Curtis Dolezal, PhD
- Cheng-Shiun Leu, PhD

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- David Frost, PhD

Consultant, Epidemiology

- Larry Nuttbrock, PhD

San Francisco

San Francisco State University, Sociology

- Allen LeBlanc, PhD

Atlanta

University of Georgia, Counseling and Human Development

- Anneliese Singh, PhD

Consultant, Emory University, Medicine

- Vin Tangpricha, MD, PhD



Collaborators

Advisory board members

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SF

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ATL

Sarah Roan Coughtry, Antonio, Holiday Simmons, MSW, B.T., Jamie Roberts, Tori Cooper

Community organizations

Callen-Lorde Community Health Center

- Asa Radix, MD, MP

Lyon-Martin Health Services

- Nick Gorton, MD

Southern Comfort Conference

- Alexis Dinyovszky

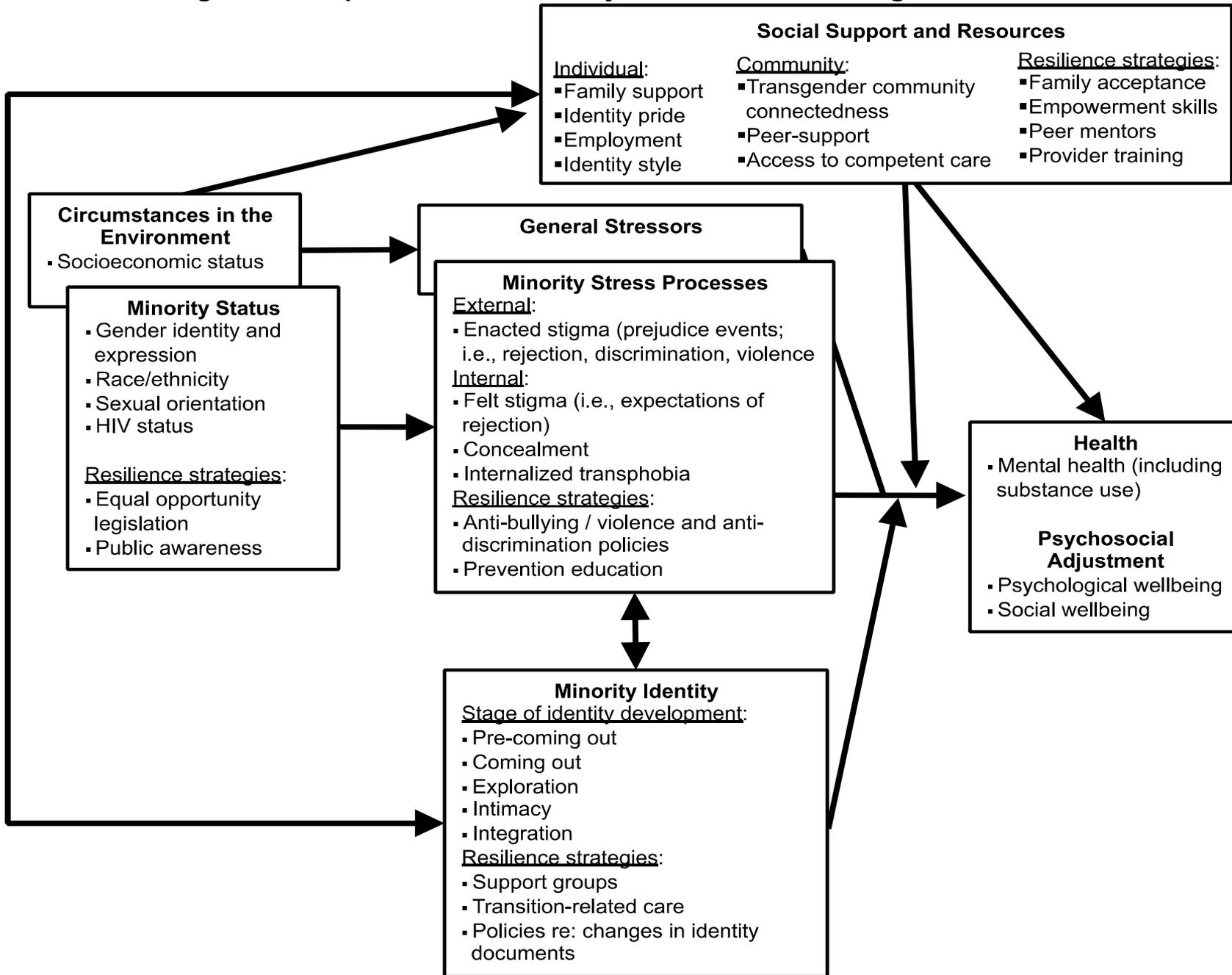




Significance and innovation

- Need to develop a contemporary, empirically-based understanding of transgender identity development, and, within this context, identify periods of vulnerability and opportunities for tailored interventions to foster resilience.
- Beyond the binary and beyond transition.

Figure 1. Adaptation of the minority stress model to transgender health





Resilience

Factors of resilience identified in previous *qualitative* research by our team (Singh et al., 2011) include:

- Identity affirmation;
- Awareness of oppression;
- Hope and future outlook;
- Social activism;
- Being a positive role model for others.

Quantitatively, peer support and transgender community involvement have been shown to moderate the negative effect of stigma on mental health (Bockting et al., 2013; Nuttbrock et al., 2014). For youth, this was family support.



Approach: Design and methods

- Longitudinal, multi-site, mixed-method, prospective cohort design.
- Phase I (formative):
 - Lifeline interviews ($N = 90$; 30 in each city).
- Phase II (longitudinal):
 - Quantitative interviews at baseline, 1-, 2-, and 3-year follow up ($N = 480$; 160 in each city).
 - Qualitative interviews with a subset of participants (randomly selected 10%).



Approach: Recruitment and sampling

Purposive, venue-based sampling

- Six venue categories:
 - Bars and clubs / non-bar establishments / outdoors;
 - Events (e.g., Pride festivals);
 - Groups (e.g., community groups);
 - Online (e.g., Facebook);
 - Transgender-specific care clinical sites;
 - Other, including referral by a friend.

Quota sampling

- Stratified by city, gender, and age.
- Age groups:
 - Adolescence: 16-20
 - Emerging Adulthood: 21-24
 - Early Adulthood: 25-39
 - Mid Adulthood: 40-64
 - Late Adulthood: 65+
- Maximize ethnic/racial diversity.

Phase I sample

Demographics of interview participants (N = 86)

	Variable	Frequency	Percent
Sex at birth	Female	40	46.5
	Male	46	53.4
Age	Adolescence (16-20)	18	20.9
	Emerging Adulthood (21-24)	17	19.7
	Early Adulthood (25-39)	19	22.0
	Middle Adulthood (40-64)	18	20.9
	Late Adulthood (65+)	9	10.4
Race / ethnicity	White	34	39.5
	African American	19	22.0
	Latino	17	19.7
	Other	16	18.6
Genderqueer, nonbinary identity	Genderqueer / nonbinary	25	29.0
	Not genderqueer	61	71.0



Phase I method

- Lifeline interviews.
- Grounded in life course and life events research traditions.
- Semi-structured approach in which participants:
 - Create a lifeline along which they identify and rate key events and periods of time over the course of their life that are critical to their transgender identity development.
 - Discuss events in detail.
 - Use the graphical representation of their life to identify broader stages of development.
- The lifeline is an interactive document; participants add as events emerge through discussion.

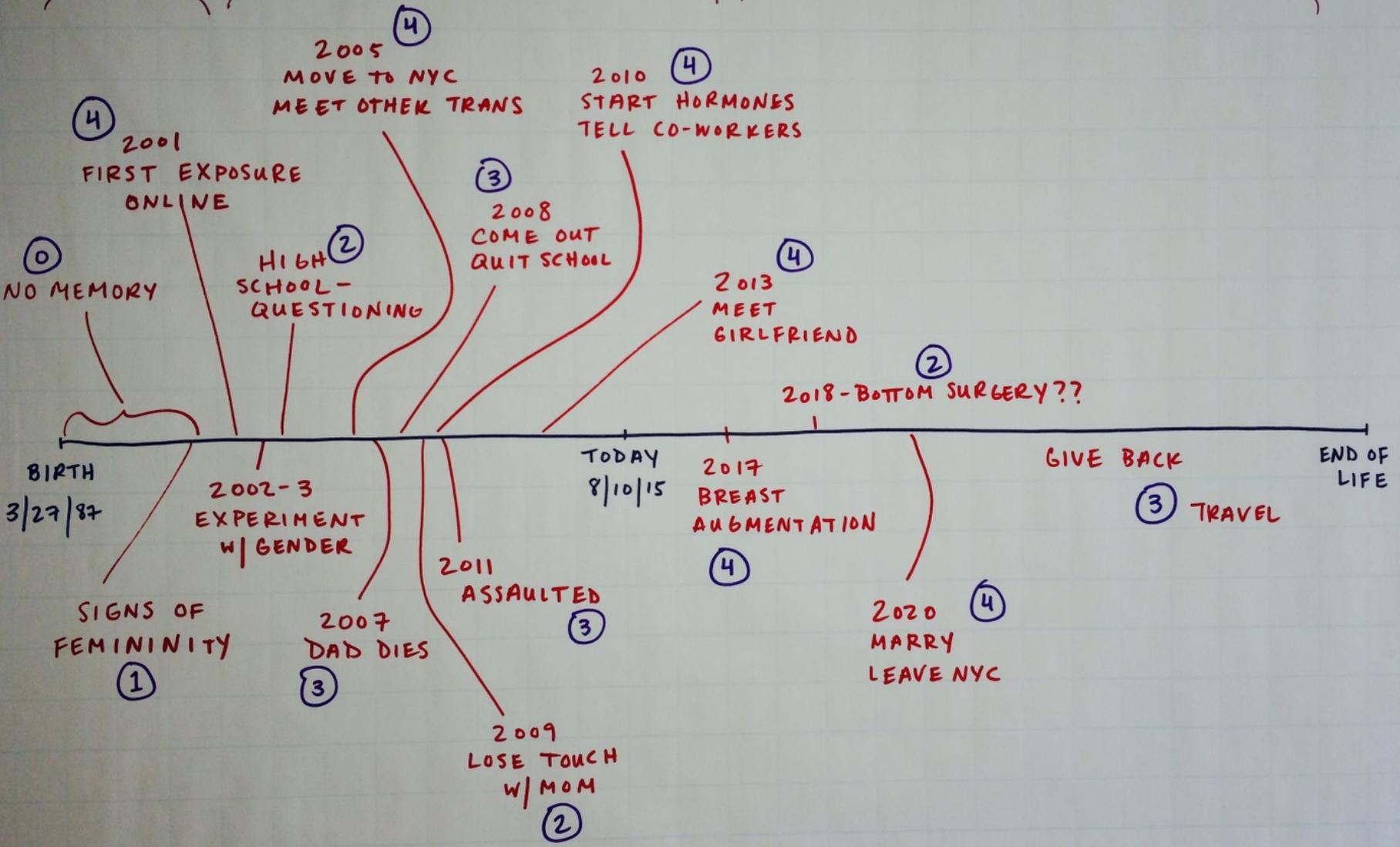
GOING THROUGH THE MOTIONS

QUESTIONING CONFUSION

DARK TIMES

NEW BEGINNINGS

FREEDOM LIVING



0 NO MEMORY

4 2001 FIRST EXPOSURE ONLINE

2 HIGH SCHOOL - QUESTIONING

4 2005 MOVE TO NYC MEET OTHER TRANS

3 2008 COME OUT QUIT SCHOOL

4 2010 START HORMONES TELL CO-WORKERS

4 2013 MEET GIRLFRIEND

2 2018 - BOTTOM SURGERY??

TODAY 8/10/15

4 2017 BREAST AUGMENTATION

3 GIVE BACK TRAVEL

END OF LIFE

1 SIGNIS OF FEMININITY

3 2007 DAD DIES

3 2011 ASSAULTED

2 2009 LOSE TOUCH W/ MOM

4 2020 MARRY LEAVE NYC



Phase I preliminary findings: Developmental stages

Thus far, five developmental stages have been identified:

1. “Confusion and chaos”—Conflict with identity, for some in an unstable environment;
2. “Beginning of life”—Finding myself by finding others, e.g., online, on the street;
3. “Out and about”—Liberation and validation, for some facilitated by a geographical move;
4. “Feeling accepted and loved”—Significant relationships;
5. “Giving back”—Reflection and meaning making.



Phase I findings: Vulnerability and resilience

Factors that appear to moderate identity development:

- Experiences with the healthcare system.
- Intersectionality with other dimensions of identity and related community support (e.g., HIV status; ethnic/racial background).
- Personal drive to survive and flourish.
- Relationships with intimate partners, family members, friends and/or community members.



Phase II in progress

- Quantitative and qualitative, longitudinal data collection.
- Implementation of sub-studies:
 - Non-suicidal self-injury;
 - Dating and relationships;
 - Patient-provider relationships.
- Capacity Building: Increase individual and community capacity to improve access to general and transgender-specific health care, and foster resilience in coping with stigma.



Patient-provider relationships

- In stark contrast to previous reports of overwhelmingly negative interactions with the health care system, our findings indicate that transgender people’s relationships with key health care providers are perceived as “life saving,” and that key health care settings are described as “my home” and “my family.”
- However, little is known about what characterizes the development of a therapeutic alliance between transgender patients and their health providers; what factors foster trust and mutual respect; and what the accompanying challenges and rewards are.



Barriers to care according to providers and stake holders ($N = 11$)

- Health System
 - Lack of understanding of the transgender community;
 - Lack of coordination of care.
- Community
 - Gender-related stigma in care community;
 - HIV stigma in transgender community.

“Because even at [Clinic A] people were saying they feel...what [the clinic] is known for, there is some hesitation to come because it’s known for people who are positive even though it’s not only, there’s still that. . . girls know that that’s what that is going to be perceived as if they just say [Clinic A], you know?”

(Hayley et al., 2016)



Family rejection

Participant: “A couple of girls I saw that went back home to families and one was really close to me. It broke my heart because she was, like, in her room and they cut off her hair. She had to wear masculine clothes. She was sick. They had the Bible and chapels and candles and all kinds of stuff around her trying to exorcise the demon of AIDS and. . .it just. . . it can break a person down, you know? If you don’t have positive reinforcement around you when you are going through this difficult time, you know? It’s like I think it just sucks the life out of an individual.”

Interviewer: “Mm-hmm.”

Participant: “I saw how literally the life just, like, literally drained from her body and, you know, she was such a vibrant person. Within, what, it was like six or seven months, she just fell apart.”

Interviewer: “And then what happened?”

Participant: “She died. When she died, they buried her in a suit like they do with most transgender people and they block your friends from coming to see you. Closed casket funerals, closed funerals.”



Individual barriers

- **Concerns about interaction between PrEP / ART and gender-affirming hormones, and body image.**

“I mean, honestly, a lot of trans women have. . . women in general have body image issues. Um, I’ve been in and out of all kinds of groups for the last God knows how many years. They have body issues, body image issues. Trans women have body image issues. Uh, and if the ARV are going to mess with my body image which is already messed up, you know, I’m starting out with a bad body image and if this is going to f*** it up a little bit, well. . .”

- **Competing priorities (gender-affirming care; housing; love).**

“Our clients, um, in some cases they’ll come with a very low CD4 count and the physician will say, ‘Let’s get you healthy before I let you start hormones.’ And that’s not what anybody wants to hear, you know, if you’re 18 and want it now. . . . It’s the only important thing in their life.”

“She’s, uh, living in an apartment with some guy who just wants to use her sexually . . . she’s not stable enough to seek the medical care or to have someplace to have her medicines and all that. She’s not even thinking. . . that’s, like, steps removed from where she is. She basically just doesn’t even have a place on a daily basis to live . . .”

- **Lack of health literacy.**



Potential facilitators to care

- Provider engagement in ongoing cultural and clinical competence training;
- Improving access to safe, discreet, accessible places for care delivery;
- Strong communication and care coordination among providers;
- Integrating primary care and HIV prevention / care with gender-affirming care;
- Promoting self-efficacy and resilience (e.g., through mentorship, role models, self-advocacy and knowledge of rights and law; education);
- Ideal model of care: Transgender-competent patient-centered medical homes.

(Hayley et al., 2016)



Potential facilitators to care: Examples

Communication

- “[A particular doctor], when you go in to him, it’s more of a personal conversation. . . . Where you feel engaged. So, ‘What did you do this week?’ You know? Not just, ‘Put your arm out, let me take your blood.’ . . . And then explain to these girls what the medications are that they’re taking and explain to them. . . really, really, like, listen. It’s not like you just hand the girl a prescription.”

Safety / accessibility

- “I think it should be someplace that is accessible to them, easy to get to and not scary to get to, and, um, I think it should just be another thing that they do. Like, if they have, uh, mental health issues, HIV or transition, just all that care would be taken care of in a place that’s kind of. . . I don’t want to say obscure but, like, you wouldn’t be able to know all of that’s going on.”

Integrated care

- “I believe that if hormone therapy was directly linked with mental care, once you start hormones, you must start mental care, I think that will set up for the individual to become more comfortable with their practitioner, for the individual to understand what they’re going through and what the terms are that they’re using, explain to them the. . . pros and cons of the transition.”



Discussion

FFI, please visit www.projectaffirm.org or email Dr. Bockting at wb2273@cumc.columbia.edu

HIV & Clinical Trials for the Transgender Community

Increasing access – a deeper look into the DC/MD/VA area

Marco Zurita

PACT Program Outreach Liaison

(301) 518–2995

June 2016



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Objectives

- Educate
- Advocate
- Create awareness of outreach effort
- Promote transgender community inclusion

NIH Building 10

“Mi casa es su casa!”

“My house is your house!”



National Institutes
of Health

Clinical Center



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Partnership Access to Clinical Trials (PACT)

20+ year project of NIAID

Created to expand access to clinical studies at NIH Clinical Center in Bethesda for:

- Women
- Individuals of color
- Other populations currently underrepresented in clinical studies



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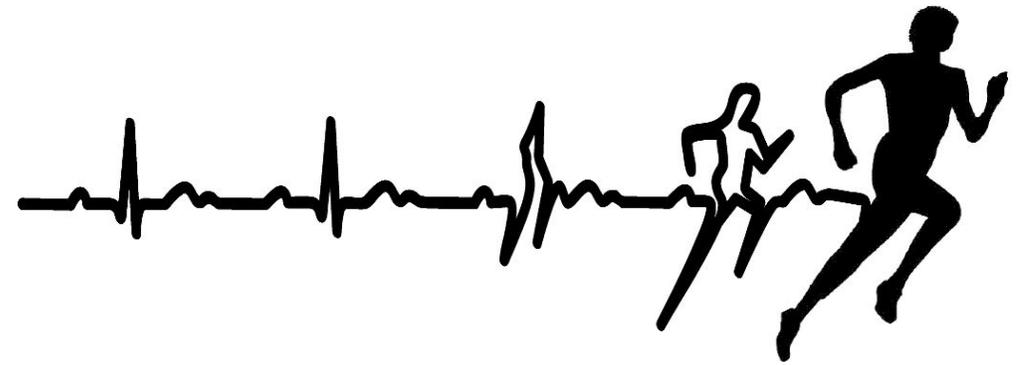


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Universal Diversity

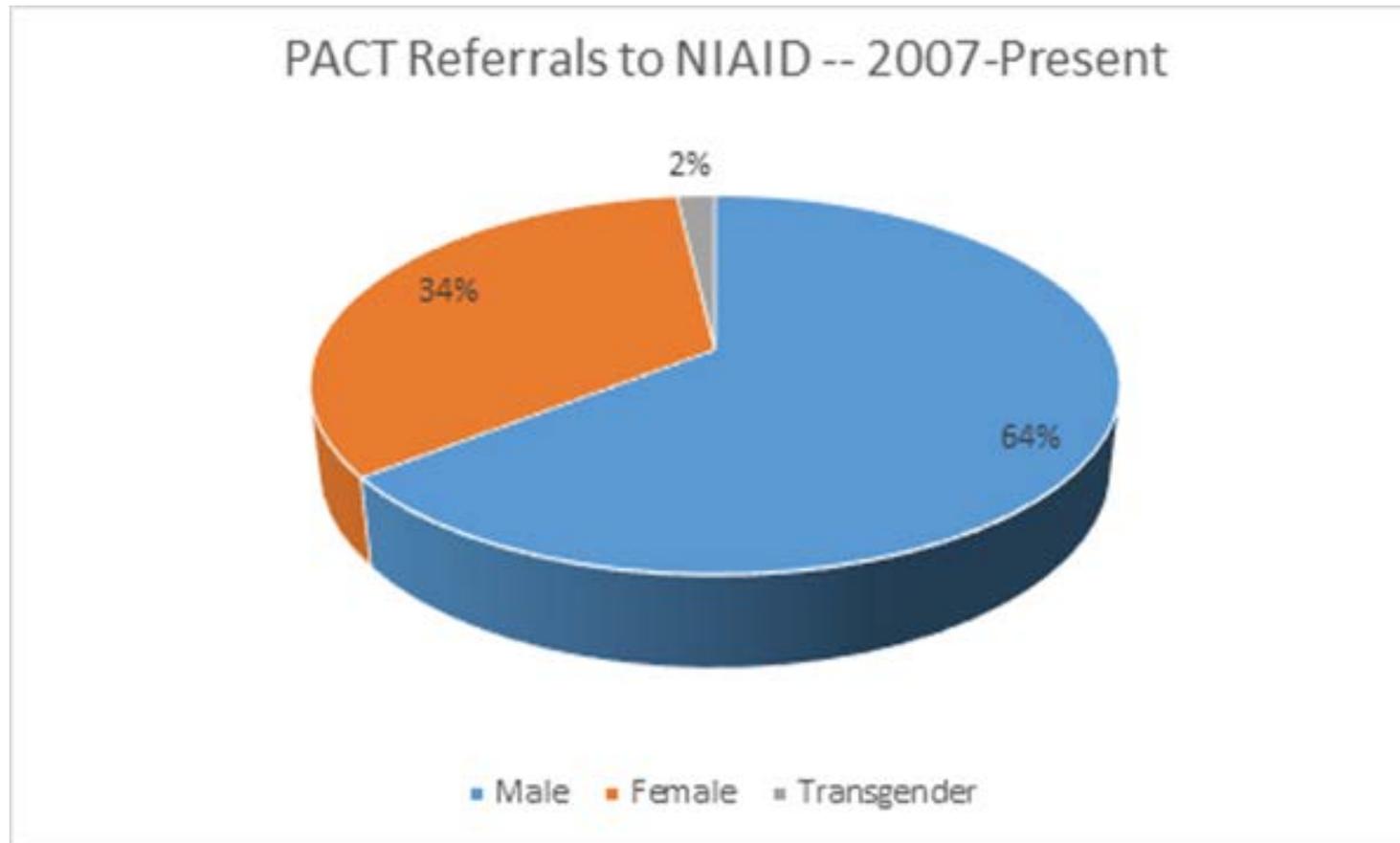


Being HIV+, What Does That Mean?

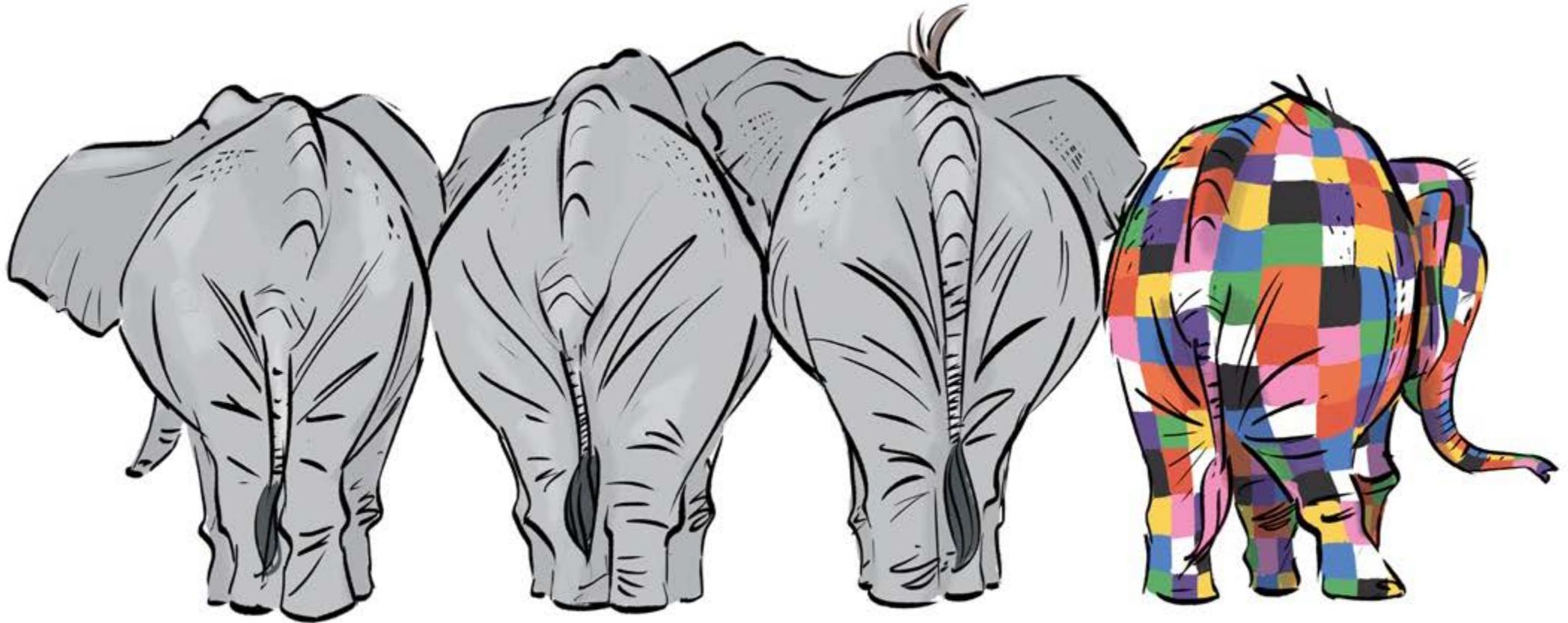


... HIV/AIDS is not a “death sentence” anymore. There are resources available to all!

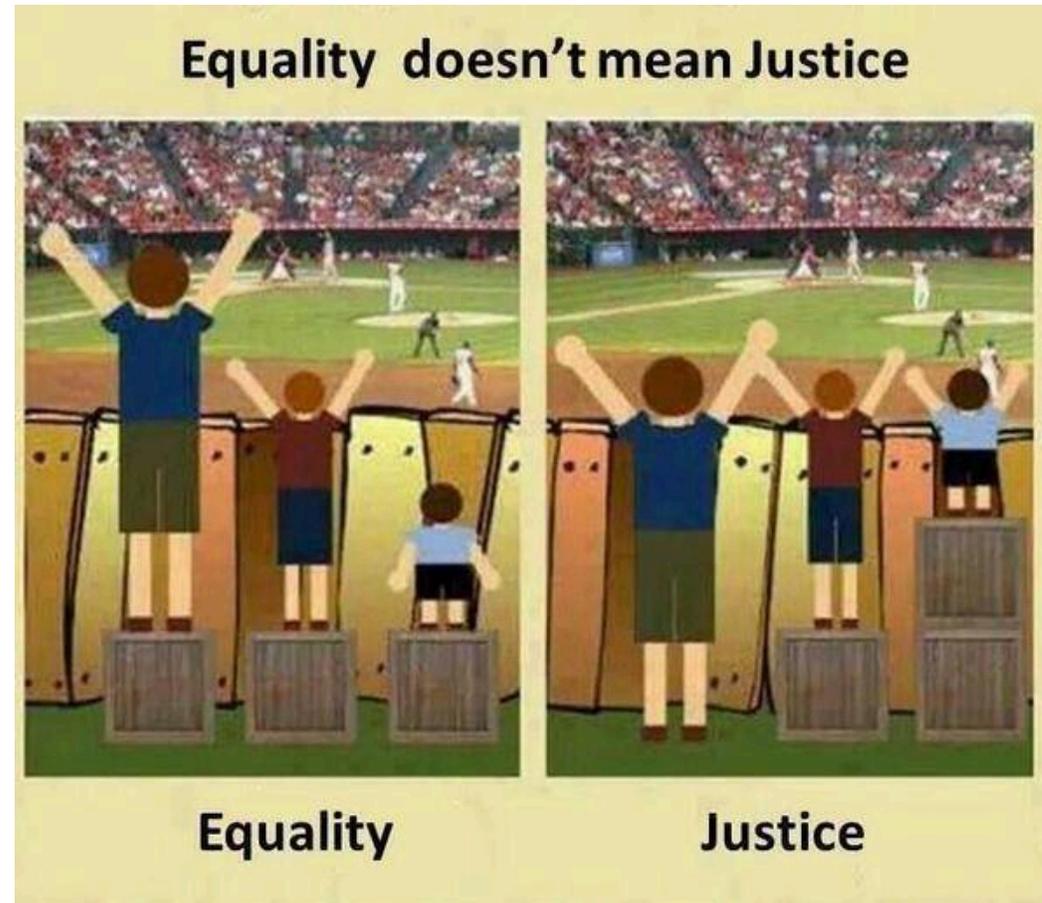
PACT Statistics



It is normal to be different!



Is NIH prepared/educated to include transgender individuals in research?



Barriers to Patient Participation

NIH Staff



Transgender Patients



Brainstorm

Minds are like parachutes.
They only function when open.

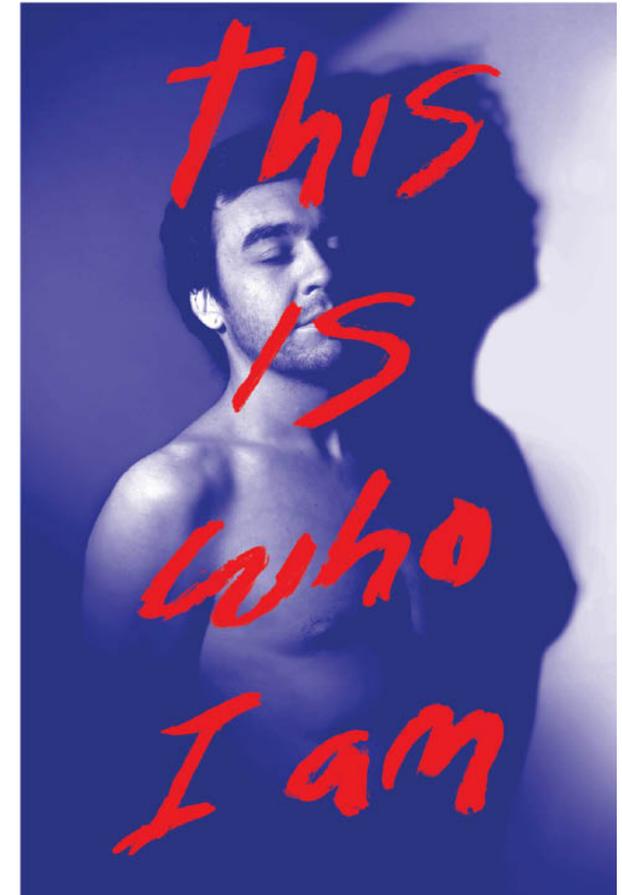
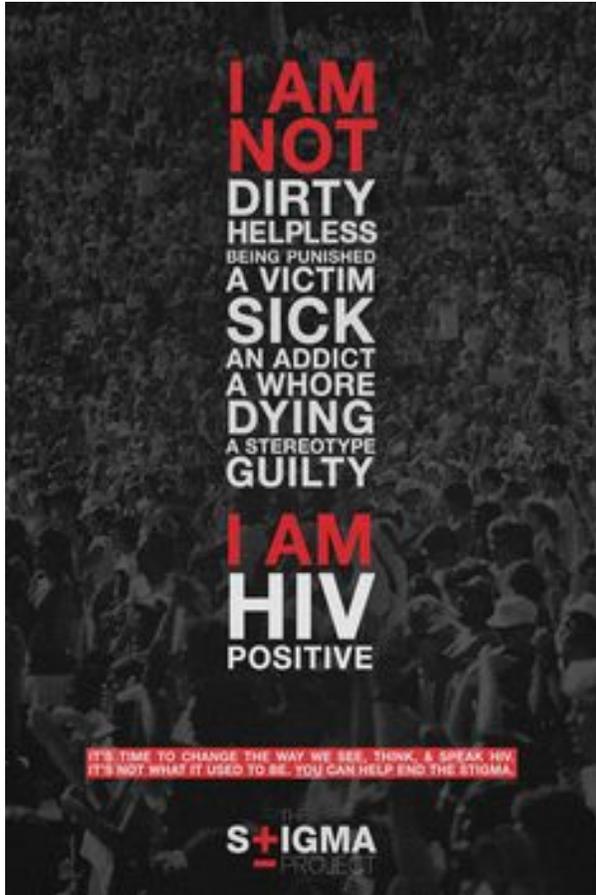
(Sir Thomas Dewar)





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General Stigmas





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Stereotyping



Elchicotriste 2011



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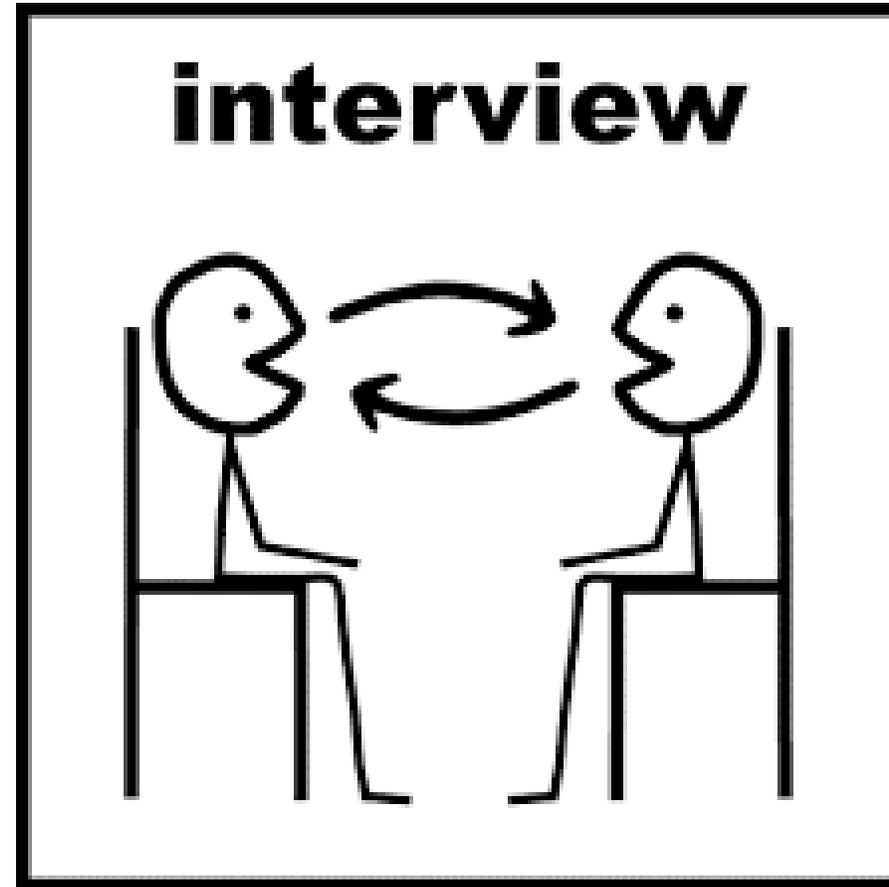
The Admission Process



Patients' Needs at the Clinic



Personal Experiences





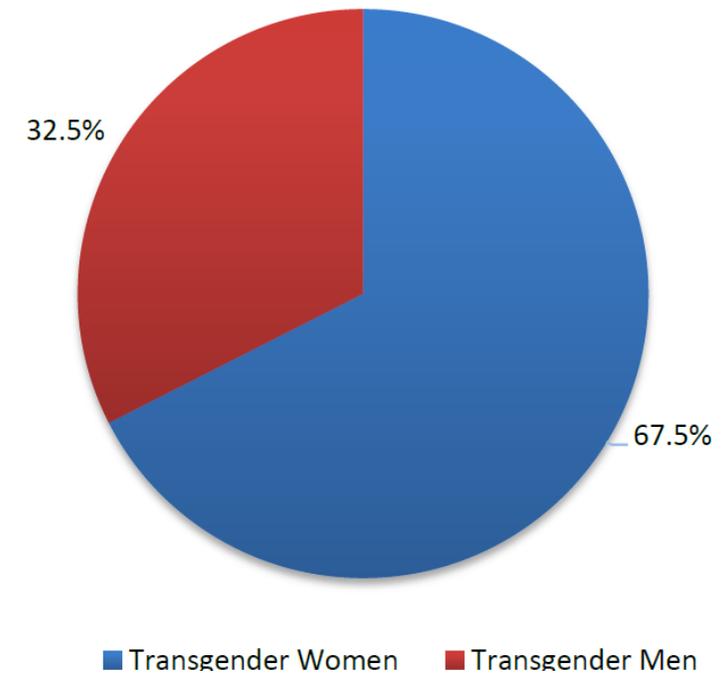
Background Information & Quick Facts

- Higher HIV prevalence in transgender women in the US
- African-American transgender women are more likely than any other race/ethnicity to contract HIV
- Social, structural and economical factors challenges to prevent HIV among transgender people
- Among the 3.3 million HIV testing events, percentage of newly diagnosed highest among the transgender persons

Statistics in D.C.

- There were 16,423 residents of the District of Columbia living with HIV as of December 31, 2013. Of these cases 246 (1.5%) were transgender. The majority of transgender cases were transgender women (67.5%).
- About 84% of transgender people with HIV in DC are African-American
- 29% of transgender people with HIV were diagnosed between the ages of 20-29 years old, 33% were diagnosed between 30-39 years old.
- 97% of transgender persons were linked to care for HIV, about 70% received care in 2014 (69.9%) and about 62% achieved viral suppression
- One-third of transgender persons were initially diagnosed with Stage 3 HIV disease, previously known as an AIDS diagnosis.

Transgender Persons Living with HIV by Gender Identity, 2013



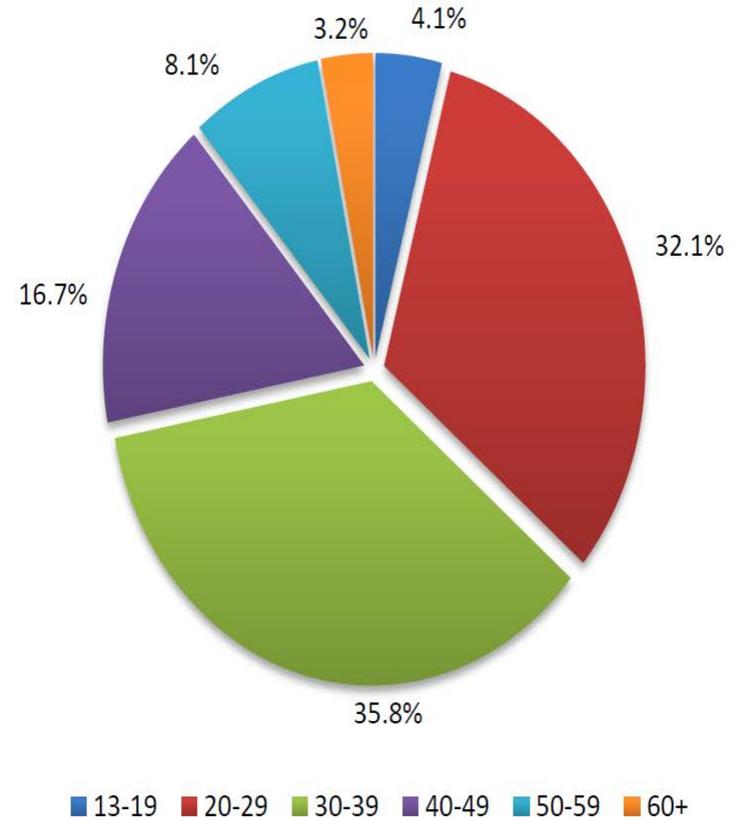


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Transgender Persons Living with HIV by Race/Ethnicity, 2013

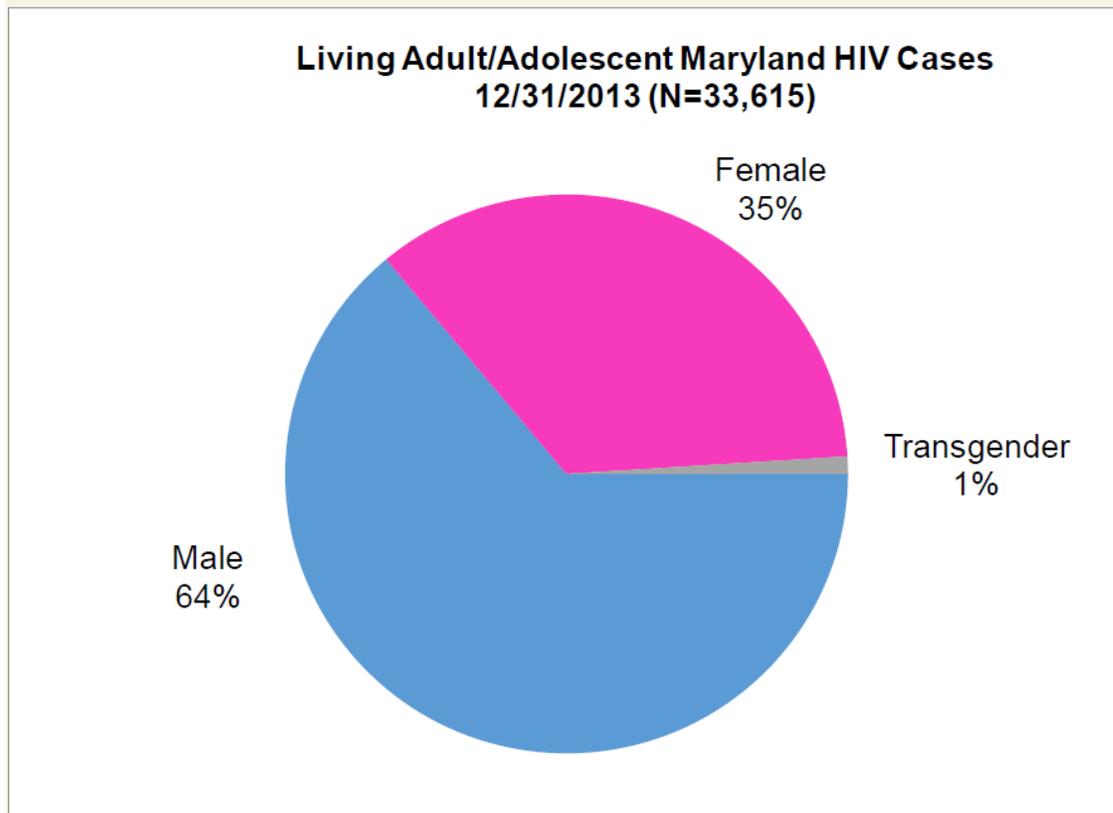


HIV among Transgender Persons in the District of Columbia



Source: Department of Health, DC 2016

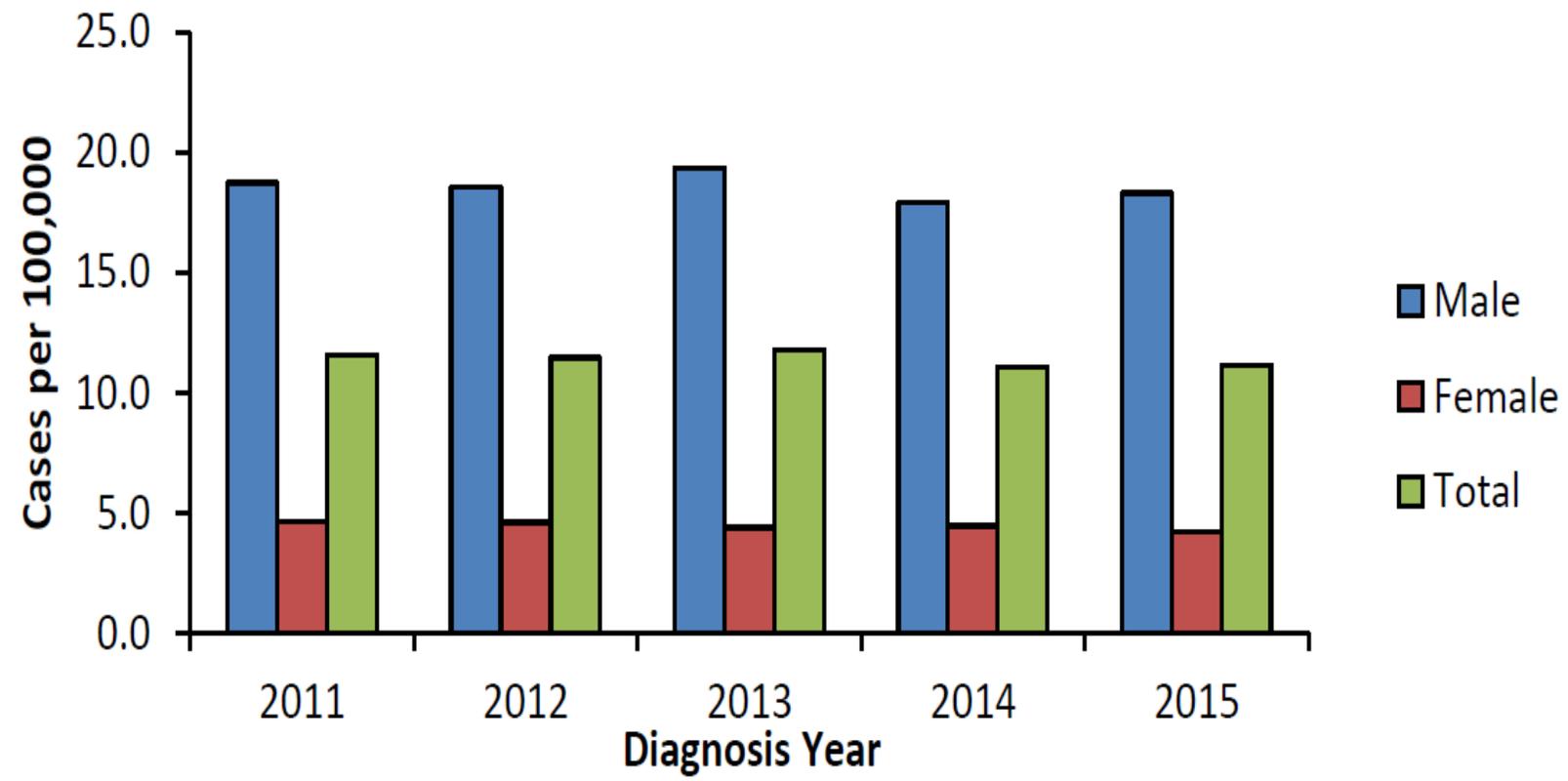
Statistics in Maryland



- Twice as many males with HIV than females... 64% to 35%
- Transgender people account for about one percent of all HIV cases
- A 2004- 2005 survey of 84 transgender persons in Baltimore measured HIV rates of 40%, which is 17 times higher than the 2% rate for all adults/adolescents in Baltimore City.



Statistics in Virginia



Why is the prevalence of HIV high among the transgender community?

- Sex trafficking and prostitution
- Unprotected sexual activity
- Drug and alcohol use
- Self or “black market” injections of hormones and other supplements
- Overlapping social, cultural, legal and economical factors
- Lack of economical and educational opportunities



HIV Diagnosis

HIV is most commonly diagnosed by testing your blood or saliva for antibodies to the virus which can usually be detected up to 12 weeks after the initial infection. There is a newer type of test that checks for HIV antigen, a protein produced by the virus immediately after infection, can quickly confirm a diagnosis soon after infection.

**FIGHT STIGMA.
GET TESTED.
KNOW YOUR
STATUS.**



- Home test, which are a FDA approved
- Tailor treatment tests (CD4 count, viral load and drug resistance)
- Complication testing (Tuberculosis, hepatitis, toxoplasmosis, STI, liver or kidney damage, UTI)



There are resources readily available!

- Clinical Care (clinical trials and clinics)
- Private Care (primary care physicians)
- Community Support Groups
- Harm Reduction & Syringe Exchange



HIV clinical trials are research studies in which people help doctors find ways to **prevent, detect, or treat HIV.**



Let's focus on.... Clinical Trials

HIV clinical trials are research studies done to find new ways to prevent, detect, or treat HIV. Clinical trials are the **safest and fastest** way to determine if new medical approaches to HIV prevention or treatment are safe and effective for people.



Current Recruiting Studies with PACT



The National Institutes of Health (NIH) in Bethesda, Maryland, is seeking participants **who are not currently taking HIV medications** for a clinical study. The aim is to better understand how the immune system fights HIV, and to use this information to create additional options for treatment.

You may be eligible to participate if you are at least 18 years old and:

- Are HIV positive
- Have never taken HIV medications OR have not taken HIV medications for at least 6 months
- Do not have difficulty having blood drawn

Study participants who qualify for the study will visit the Clinical Center at NIH and undergo a procedure to collect white blood cells. If you decide to start HIV medications during the study, those medications will need to be obtained from your physician.

All volunteers will be compensated.

For more information, call:
301-594-9905
(Reference the 02-I-0202 Study)



APHRODITE

COPE

DOTCOM

ECHO

ECSTATIN

GUTCHEK

LIFE-HIV

LTNP

PANDORA

RPHI

TESLA

TRANSAM

DEPARTMENT OF HEALTH AND HUMAN SERVICES and NATIONAL INSTITUTES OF HEALTH (NIH)

HIV controlled

Inflammation



HIV infection can cause inflammation even after the HIV virus is suppressed with antiretroviral medications. Inflammation can be harmful to the body and even cause long-term problems of the heart or the blood vessels.

The purpose of the APHRODITE study is to learn if an investigational medication designed to prevent and treat inflammation is safe for people with HIV who are taking HIV medications.

You may be eligible to participate if you are at least 18 years old and:

- Are HIV-positive, with undetectable viral load
- Have taken HIV medications continuously for the past year
- Do not have hepatitis B or C

Study participants who qualify for the study will visit the Clinical Center at the National Institutes of Health in Bethesda, Maryland, up to 7 times for study-related tests and procedures. Participation in the study will last about 6 months.

All volunteers will be compensated.

For more information, call:
1-800-411-1222

TTY: 1-866-411-1010) Se habla español
(Reference 16-I-0044)



Conclusion



... Where do we go from here?

... Are we on the right track?

... How can we educate others far and near?



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Acknowledgement

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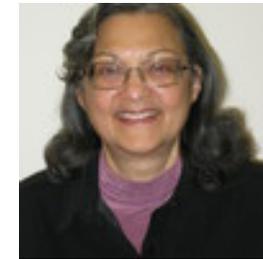
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