ADVANCING EXCELLENCE IN TRANSGENDER HEALTH

Developmental Approaches to Caring for Transgender & Gender Diverse Pediatric & Adolescent Patients

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NATIONAL LGBT HEALTH EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

HARVARD MEDICAL SCHOOL

Massachusetts League of Community Health Centers

Disclosures

- Michelle Forcier
  - PPLM consultant, clinical
  - Up to Date, author

Friday

- 9.15-10.15 Gender-Affirmative Health Care: Terminology, Demographics, and Epidemiology Faculty: Sari Reisner, ScD
- 1.45-2.45 **Family Systems** of Transgender Children Faculty: Sabra Katz-Wise, MD

Saturday

- 9.15-10.15 **Puberty Blockers and Hormone Therapy** for Transgender Youth Faculty: Jeremi Carswell, MD
- 12.30-1.45 Lunch 10.15-11:15 Transgender **Youth Community Panel**
- 2.45-3.45 **Integrating Pediatrics & Mental Health** Care for Gender Diverse Youth Faculty: Jeremi Carswell, MD, and Francie Mandel, LICSW

Sunday

- 1.45-2.45 **Evidence-Informed Behavioral Health** Care for Gender Diverse Children and Adolescents Faculty: Aude Henin, PhD

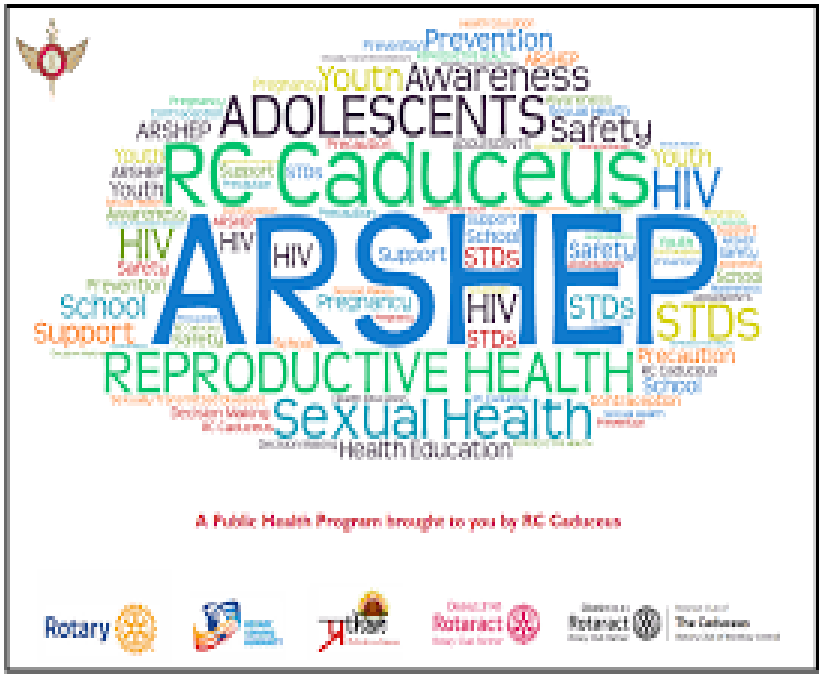
Objectives

- Discuss human development w gender perspective
- Discuss how patient centered, developmental paradigms to gender might reduce bias and stigma that create disparities and lead to risks
- Provide initial strategies for appropriate and competent care
- Understand the role of providers in promoting culture changes that respect diversity

- Cases highlighting literature updates 2018

Child Health & Social Justice

- Gender & social justice
- Gender development
  - Childhood
  - Peri-Pubertal
- Initial screening, intervention
- Risk resiliency



https://prh.org/arshep-ppts/

Why Talk About Gender with Kids?

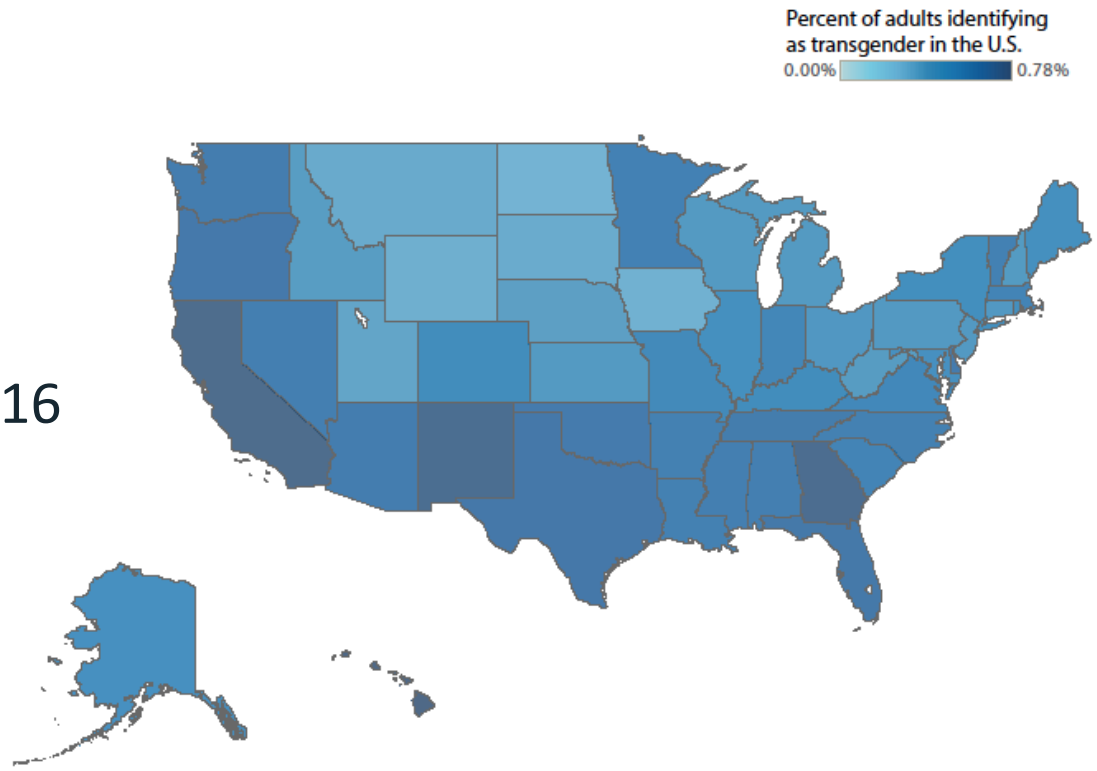
- Professional responsibility
  - AMA, AAMC, AAFP, AAP, SAHM, APA
    - Recommend training on LGBTQIA health
  - Exclusion of coverage illegal in some states
  - Lack of formal medical training no longer “good excuse”
- Gender care is
  - Patient-centered primary care
  - Gender is developmental, universal
  - Anticipatory guidance & prevention
  - Future planning
  - Models & promotes diversity

Reproductive Justice under the Social Justice Umbrella

HOW MANY ADULTS IDENTIFY AS TRANSGENDER IN THE UNITED STATES?

Andrew R. Flores, Jody L. Herman, Gary J. Gates, and Taylor N. T. Brown

Figure 1. Percent of Adults Who Identify as Transgender in the United States



CDC Behavioral Risk Factor Surveillance System (BRFSS) 2016

National estimate transgender persons

- 0.6% =1.4 million
- Range 0.3% ND to 0.8% HI
- **Highest 18-24 versus older adults**

This survey does not include < 18 youth

Sexual Orientation and Gender Identity of Middle School Students

- Transgender Gender Identity
- 1.3%

- Non_Hetero Sexual Orientation
- 15.9%

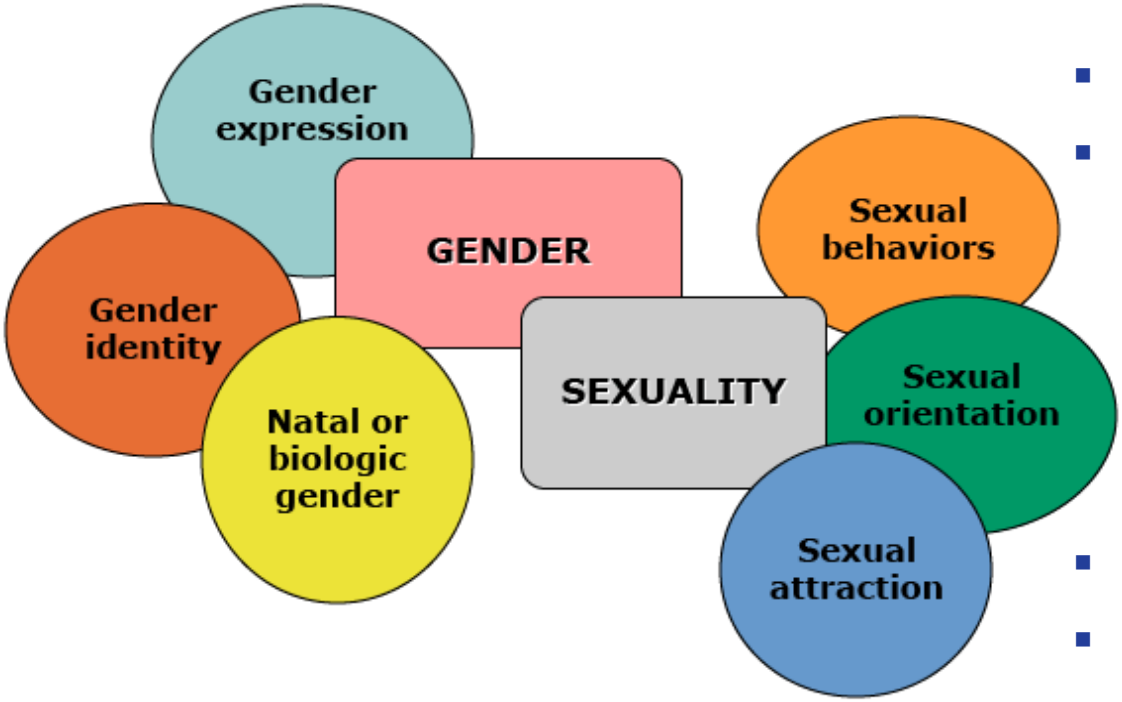
Table 1
Sexual orientation and gender identity of middle school students: population statistics

Sexual orientation/ gender identity	Unweighted count	Population estimate	Standard error	95% Confidence interval	
				Lower	Upper
Sexual orientation					
Heterosexual	2,254	8,721.410	316.362	8,094.191	9,348.628
Gay or lesbian	48	172.724	26.727	119.734	225.713
Bisexual	59	217.362	37.171	143.667	291.057
Not sure	276	1,250.964	131.543	990.167	1511. 761
Total	2,637	10,362.459	374.772	9,619.437	11,105.482
Heterosexual	2,254	84.2%	1.1%	81.9%	86.2%
Gay or lesbian	48	1.7%	0.3%	1.2%	2.3%
Bisexual	59	2.1%	0.3%	1.5%	2.9%
Not sure	276	12.1%	1.1%	10.0%	14.5%
Total	2,637	100.0%	0.0%	100.0%	100.0%
Gender identity					
Female	1,331	5,148.062	224.796	4,702.382	5,593.742
Male	1,337	5,381.086	231.687	4,921.744	5,840.429
Transgender	33	137.053	48.423	41.050	233.057
Total	2,701	10,666.201	398.453	9,876.230	11,456.173
Female	1,331	48.3%	1.2%	46.0%	50.5%
Male	1,337	50.4%	1.1%	48.2%	52.7%
Transgender	33	1.3%	0.4%	0.6%	2.5%
Total	2,701	100.0%	0.0%	100.0%	100.0%

Shields JP, et al. “Estimating population size and demographic characteristic of LGBT youth in middle schools.” J Adol Hlth. 2013:248-50.

Early Childhood and Prepubescent Gender Development

Defining Gender



- **Assigned gender/sex at birth**
- Gender assigned at birth; body parts, hormones,

- **Gender Identity**
- Understanding of one's self (female, male, transgender, gender non-conforming, genderqueer, non-binary, gender fluid, cisgender)

- **Gender Expression**
- Ways in which a person acts, presents self, communicates gender within a given culture

Awareness of Gender Identity

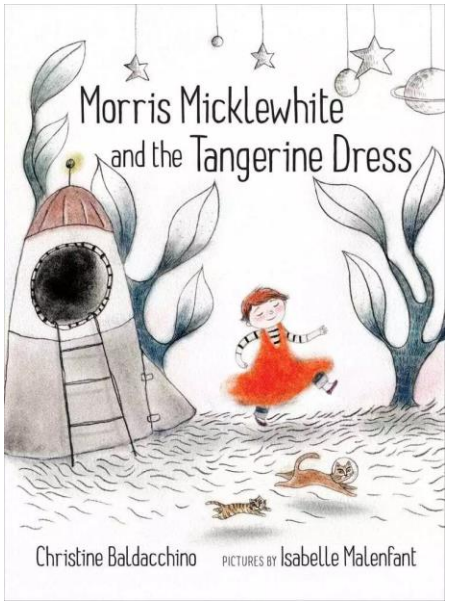
Between ages 1 and 2
Conscious of physical differences between sexes

~ 3 years old
Can label themselves as a girl or boy

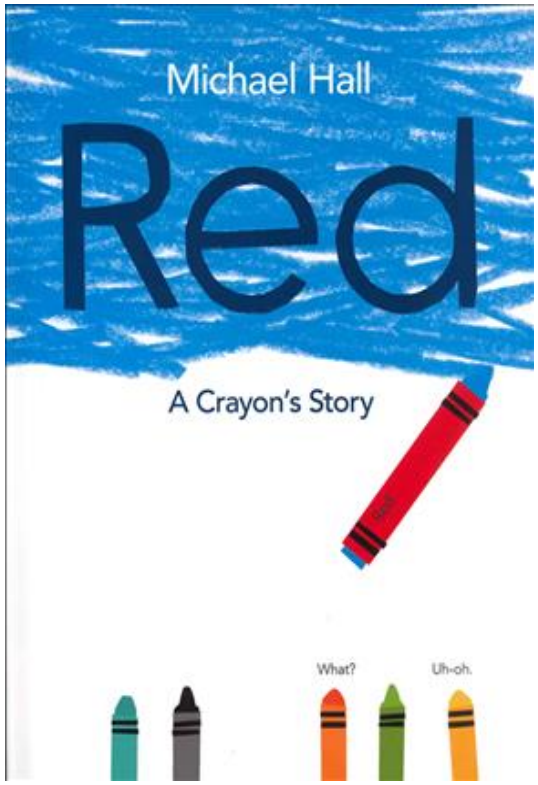
By age 4
Gender identity stable, recognize gender constant

Gender Play

- All pre-pubertal children play with gender expression & roles
  - Passing interest or trying out gender-typical behaviors
  - Interests related to other/opposite sex
  - Few days, weeks, months, years



Gender Diversity



Persistent, consistent, insistent

- Cross gender expression, role playing
- Wanting other gender body/parts
- Not liking one's gender & body (gender dysphoria)

Fluid, nonconforming

- Agender
- Non binary
- Refuses to ascribe to typical masculine or feminine assignments

Common Parental Reports

Before Puberty

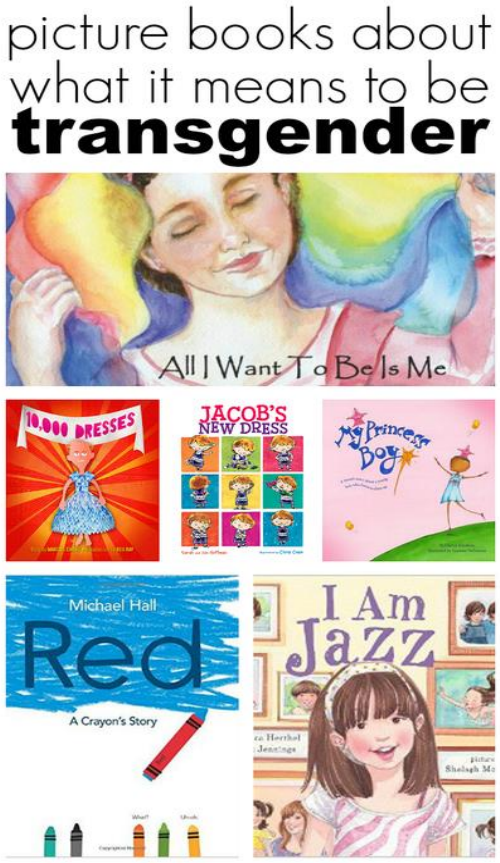
- “She told me in first grade that she was a boy.”
- “He wanted to grow his hair long and wear jewelry.”
- “She adamantly refused to wear a dress to her aunt’s wedding.”
- “He wanted to be in the school play in the role of Cinderella.”

Peri Puberty

- “We did not notice anything different before puberty”
- “She had a miserable time with puberty.”
- “Before puberty we thought maybe he was gay, but then he told us he was trans.”

Who & When to "Screen"?

- All children!
  - Developmental stages
  - Opportunity for improving child/family communication & support
- Nonconforming expression
- Concerns/problems with
  - Mood
  - Behavior
  - Social



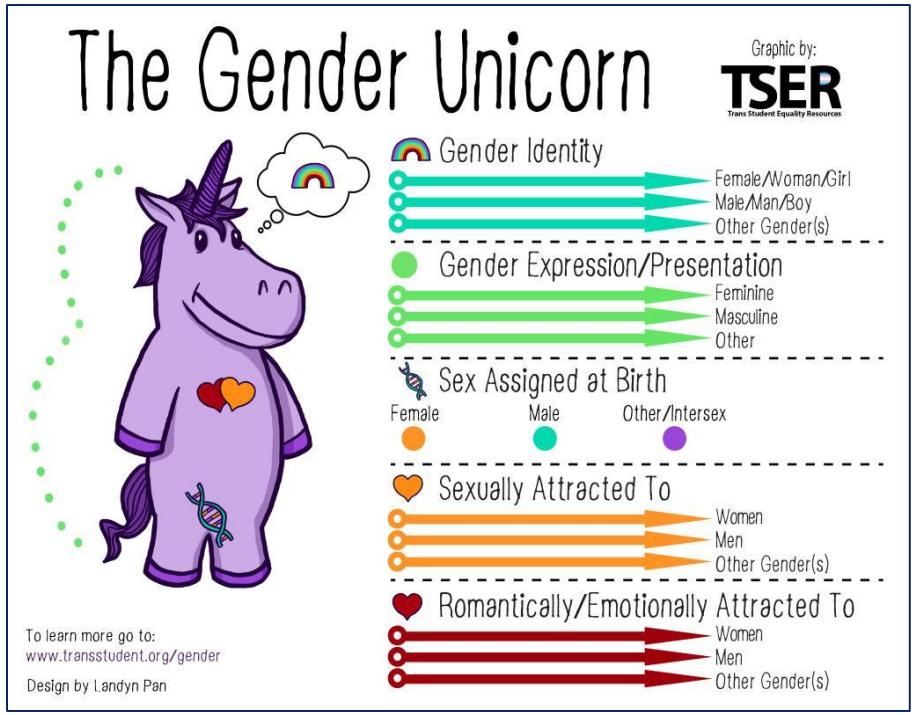
Ask! Parent(s)

- Child play, hair, dress preferences
- Concerns with these
- Concerns with behavior, friends, getting along at school, school failure, bullying, anger, sadness, isolation, other?

Ask! Patient

- Do you feel more like a girl, boy, neither, both?
- How would you like to play, cut your hair, dress?
- What name or pronoun (he for boy, she for girl) fits you?

Gender Screening "Tools"



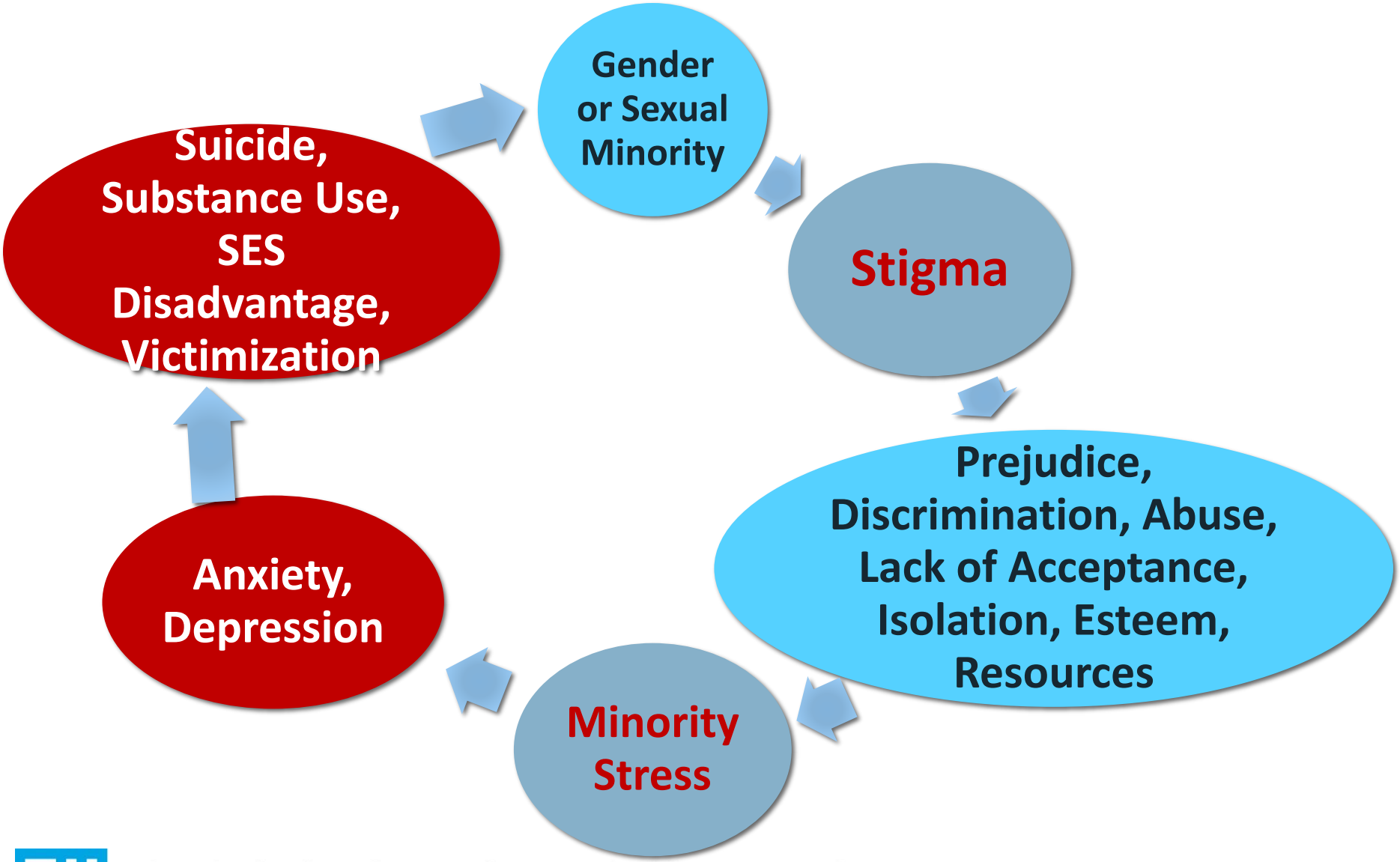
DIAGNOSIS of GENDER DYSPHORIA

F64 DSM 10 Coding

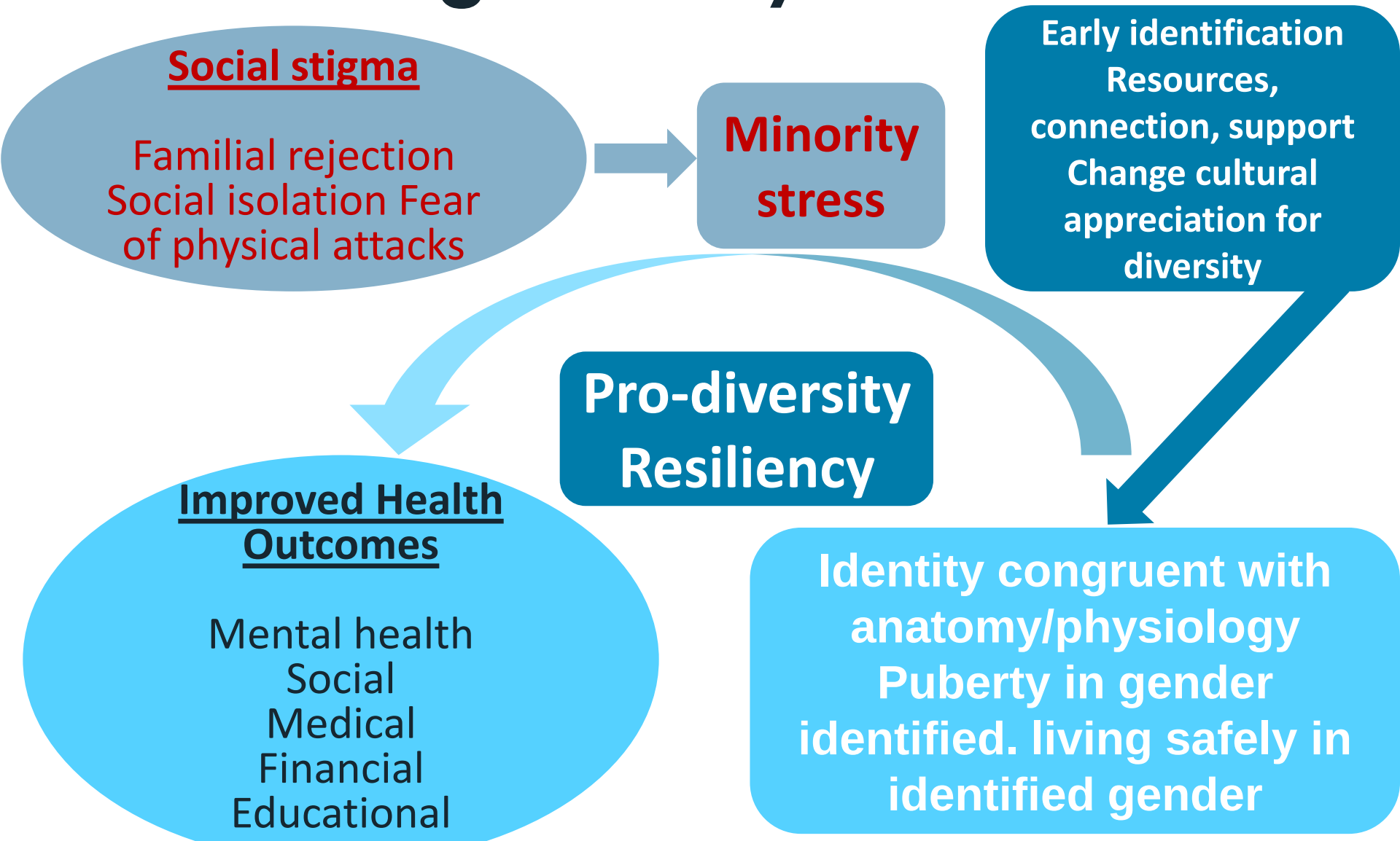
Pathology Based

- Marked difference between expressed/experienced gender and gender others would assign
- Must continue for at least six months
- Causes clinically significant distress or impairment in social, occupational, or other important areas of function
- In children, the desire to be of the other gender must be present and verbalized

Minority Stress Theory



Countering Minority Stress



Patient-centered developmental care—
Allows flexibility and clinical judgment

Developmental Perspective

GENDER DIVERSITY

E34.9 ICD 10

- Gender is universal, normal
- Variance is expected aspect of biology & human development
- Diversity not = deviance
- Improve care
- Impact minority stress
- Advocate another form reproductive justice
- Advocate, empower vulnerable populations
- And sub bullets

Increasing Evidence

- Known benefits >> potential risks
  - Early completely reversible social transition
  - Early tanner 2 initiation to stop puberty, for single puberty in the identified gender
  - Gender affirming hormones & surgeries to address severe dysphoria
- Parent & family acceptance offer critical protective factors
  - Short & long term healthier outcomes
- Child health professionals can improve early support & improve resource

Seminal Puberty Blocker Work

Early Intervention

- Early blocking of puberty followed by cross gender hormone replacement At follow-up, all 54 patients were satisfied with their pubertal development
  - No patients decided to stop GnRH agonist therapy
  - All patients eligible decided to take cross gender hormones
  - There were no adverse events from GnRH agonists
- **No suicides**
- **No street hormones**

Reconfirmed over time….

OlsonKR 2016, deVries AL 2014, Steensma TD 2013, deVries AL 2012, Spack NP 2012, deVries AL 2011, Steensma TD 2011, Steensma TD 2013, Malpas J 2011, Teurk CM 2012, Bussey K 2011, DeVries 2010, Wallien MS 2008, Drummon 2008, Zucker 2005, Green 1987, Davenport 1986

TransYouth Project

Large-scale (>150 children) longitudinal study of transgender children in 25 states

(2016) 73 children, age 3-12

- **NIH Patient Reported Outcome Measurement Information System**
- **Symptoms of depression or anxiety during past week**
- **Rates depression (50.1) and anxiety (54.2) no higher than 2 control groups -- their own siblings & cis age- and gender-matched children**
- **Significantly lower than those of gender-nonconforming children in previous studies**

Olson KR, Durwood L, DeMeules M, et al. Mental Health of Transgender Children Who Are Supported in Their Identities. Pediatrics. 2016;137(3):e20153223

(2017) 116 trans, 122 controls, 72 sibs age 6-14

- **NIH Patient Reported Outcome Measurement Information System**
- **Symptoms of depression and self worth same**
- **Slightly higher anxiety**
- **Significantly lower than those of gender-nonconforming children in previous studies**

Dunwood L, McLaughlin KA, Oslon KR. Mental Health and Self-Worth in Socially Transitioned Transgender Youth. J Am Acad Child Adolesc Psych. 2017 Feb;56(2):116-123.

Socially transitioned transgender children who are supported in their gender identity have developmentally normative levels of depression and only minimal elevations in anxiety, suggesting that psychopathology is not inevitable within this group. Especially striking is the comparison with reports of children with GID; socially transitioned transgender children have notably lower rates of internalizing psychopathology than previously reported among children with GID living as their natal sex.

FAMILY ACCEPTANCE PROJECT

... building healthy futures for youth

Lifetime Suicide Attempts for Highly Rejected LGBT Young People

(One or more times)

N=245 LGBT Retrospective assess family accepting behaviors in response to gender & sexual minority status

Predicts improved

- Self esteem
- Social support
- General health status

Protects against

- Depression
- Substance use
- Suicidality

I love you.
I accept you, even if
I don't understand.

Protective…Resilience

Family acceptance, love, support is critical.

All children are at risk for crisis when their true sense of identity is discouraged and/or punished

Behaviors and expression may be nonconforming, but children can still feel that they are in the right-gendered body

Adolescents and Gender

Setting Up the Initial Assessment

To do

- Establish privacy
  - Ask parent to step out of room
  - Explain what can (and can't) be kept confidential
- Establish trust and rapport
  - Ask name and pronoun
  - Ask goals of visit
- Getting to know the person
  - General adolescent health assessment HEADDSSS
  - Leading into more detailed & sensitive history

Gender Experience

- Review history of gender experience
  - Open-ended encouragement, “Tell me your story in your own words”
  - Ask about specific feelings, thoughts, behaviors, preferences
  - Parent may offer excellent insight into early childhood
- Document prior efforts to adopt desired gender
  - Clothing, makeup, play
  - Hormone use, if any
- Review patient goals

- Engage parent(s) to support their child
  - Explore parent’s concerns and priorities
  - Assess parental support and knowledge
  - Facilitate discussion and negotiations
- Establish expectations for all stakeholders
  - Incorporate patient goals, with parental expectations, and management options

Remind Youth and Parents

Gender and sexual development are natural parts of human development

Gender and sexual expression vary

…What is Healthy?

Gender and sexual diversity are different than risk

Open, honest communication is critical to healthy decision-making, behaviors, support, and access to care

Identities and Transition

Identities include but are not limited to

Asserted female

transgender woman

(assigned male at birth)

Gender Queer, Non-binary

Trans feminine, Trans masculine, Agender

Asserted male

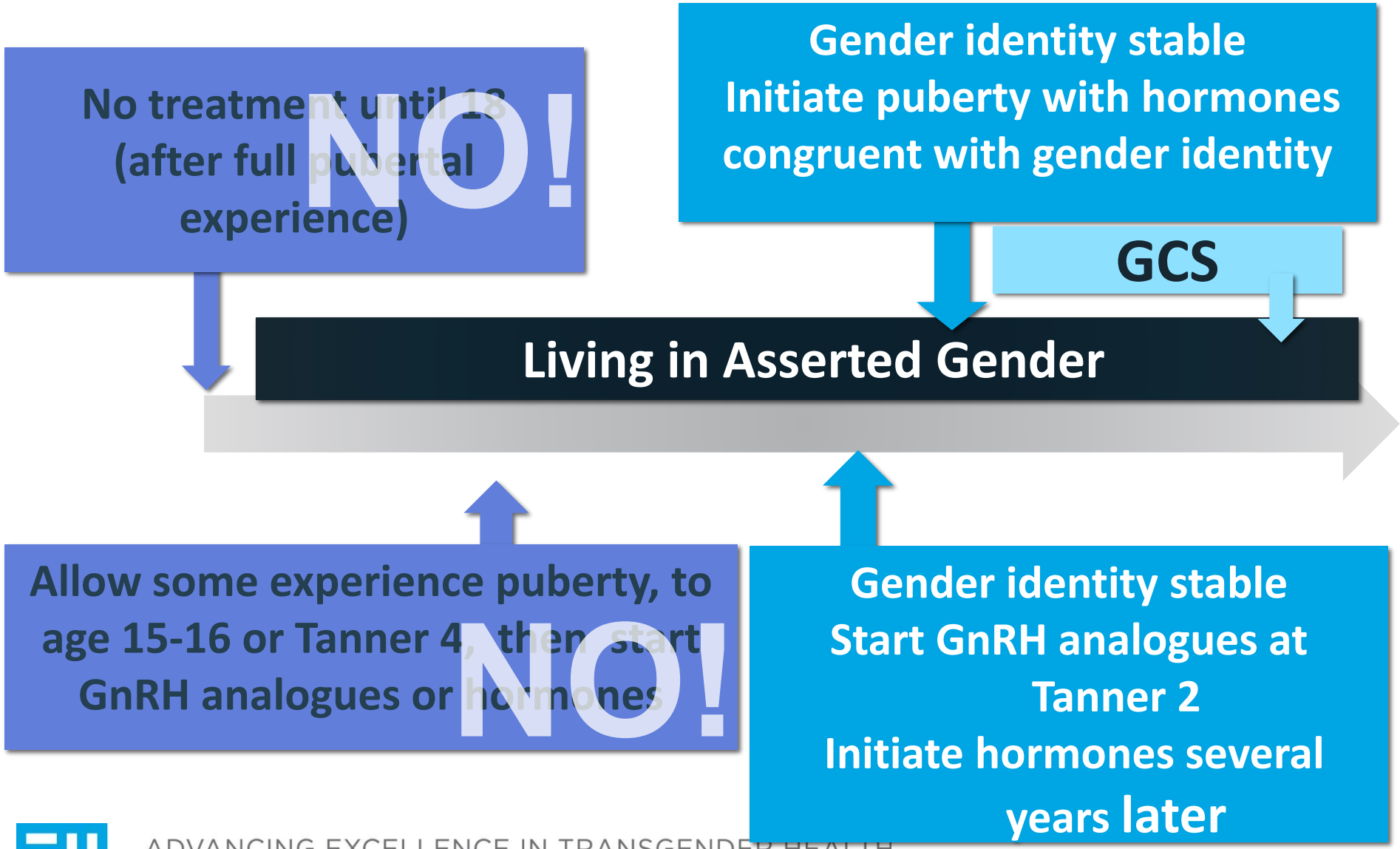
transgender man

(assigned female at birth)

Phenotypic Gender Transition → **Gender Affirmation**

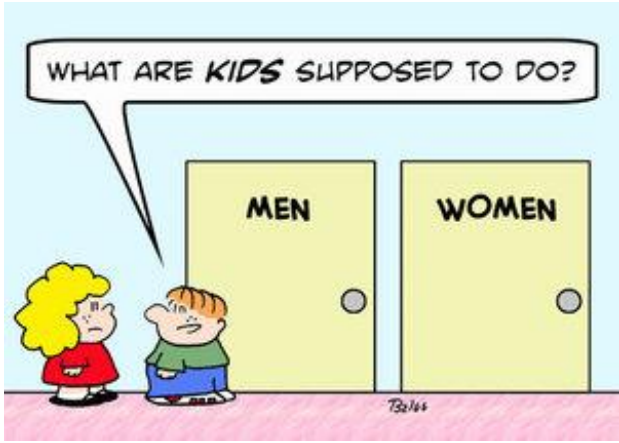
Process & time when person goes from living as one gender to living as another gender

Range of Treatment Approaches



Benefits of Early Treatment

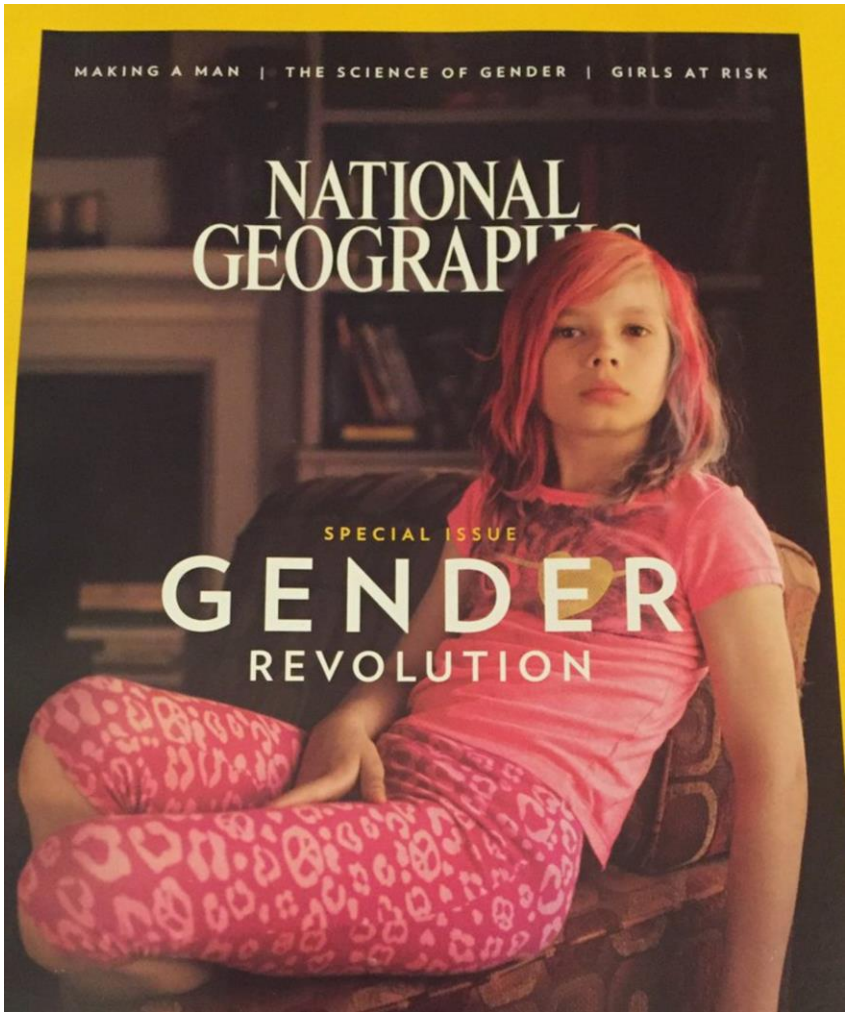
- Children with gender diversity or questions
  - See when concerns identified, ideally BEFORE puberty
  - Gives providers time to engage with family and patient, build rapport and trust
  - Offer relief to patient worried about upcoming puberty



- Consider "blocking" puberty
  - Effects fully reversible
  - "Buys time" and avoid reactive depression
  - Psychotherapy facilitated when distress eased
  - Prevent unwanted secondary sex characteristics
  - Reduces needs for future medical interventions

Providing Gender Care

- Medical and mental providers assist with identifying
  - Gender identity and gender needs
  - Gender dysphoria, other psychosocial stressors
  - Options, planning for safe social transition
  - Benefit from delaying puberty
  - Benefit of gender affirming hormones
  - Benefit of surgical referrals
  - Documentation and support for name, gender marker, and other options for transition



Treatment Goals

Improve quality of life by

- Facilitating transition to physical state that more closely represents the individual's sense of self
- Experiencing puberty congruent with gender
- Preventing unwanted secondary gender/sex characteristics
  - Reduce need for future medical, surgical interventions
- Avoiding depression, risk-taking
- Establishing early, strong social support

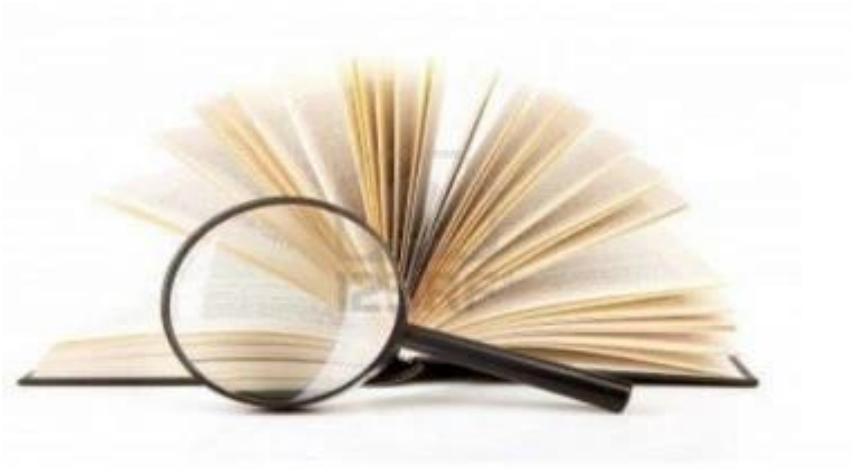
Starting Gender Hormones

Timing

1. Is the youth ready?
2. Is the parent(s) ready?
3. Is age congruent w peers?
4. What is current, predicted, desired adult height?

- Assess needs & goals around phenotypic transition
  - Physical (Tanner stage)
  - Psychological
  - Social
- Patient-centered consent process
  - Review benefits, risks, common & uncommon side effects
  - Differentiate reversible & irreversible physical changes
  - Determine if realistic sense of what can and can't be impacted by hormones
  - Review follow up, monitoring

What we continue to learn from our patients, from increasing research …



Literature Review

Patient Stories

Patient : Sammy

- 12 yro assigned female struggling in school at annual WCC
- 6 months later follow up visit post psychiatric in patient admission for self harm & suicidality with plan
- Presents to clinic withdrawn, androgenous in clothing/hair, with evidence of cutting on left forearm

- What next?

- Becerra-Culqui TA, Liu Y, Nash R, Cromwell L, Flanders WD, Getahun D,Giammattei SV, Hunkeler EM, Lash TL, Millman A, Quinn VP, Robinson B, Roblin D,Sandberg DE, Silverberg MJ, Tangpricha V, Goodman M. Mental Health of Transgender and Gender Nonconforming Youth Compared With Their Peers. Pediatrics. 2018 Apr16.

Mental Health Compared to Match Cis Peers

- 2164 cohort 3 -17 years identified in EMR
- 1333 subjects matched with 13,151 reference males and 13,149 reference females.
  - 588 (44%) transfeminine , 745 (56%) transmasculine

Prepbubertal 3-9 years

Prevalence ratios (PR 95%CI)

- 2.8-13 Attention deficit disorders (15% transfeminine; 16% transmasculine)
- 4.4-23 Anxiety disorders (12% transfeminine; 16% transmasculine)

- Relative to reference
  - Transfeminine highest PR = 83 Conduct and/or disruptive disorders
  - Transmasculine highest PR = 43 Depressive disorders

Adolescents 10–17 years

- Common “ever” prevalence
  - Attention 25% transfeminine , 16% transmasculine
  - Anxiety 40% both

- Highest prevalence = depressive disorders
  - 49% transfeminine, 62% transmasculine
- Compared with reference PR (prevalence ratios)
    - Suicidal ideation = 54 transfeminine, 45 transmasculine
    - Self-inflicted injuries = 70 transfeminine, 144 transmasculine

Russell ST, Pollitt AM, Li G, Grossman AH. Chosen Name Use Is Linked to Reduced Depressive Symptoms, Suicidal Ideation, and Suicidal Behavior Among Transgender Youth. J Adolesc Health. 2018 Mar 30.

Use of Chosen Name Protective!

- Community cohort sample LGBTQ youth
  - Recruited 1 yr 2011-2012 I
  - 3 US cities (Northeast, Southwest, West Coast)
- 129 transgender and gender nonconforming youth (ages 15–21)
  - 74 reported a chosen name different

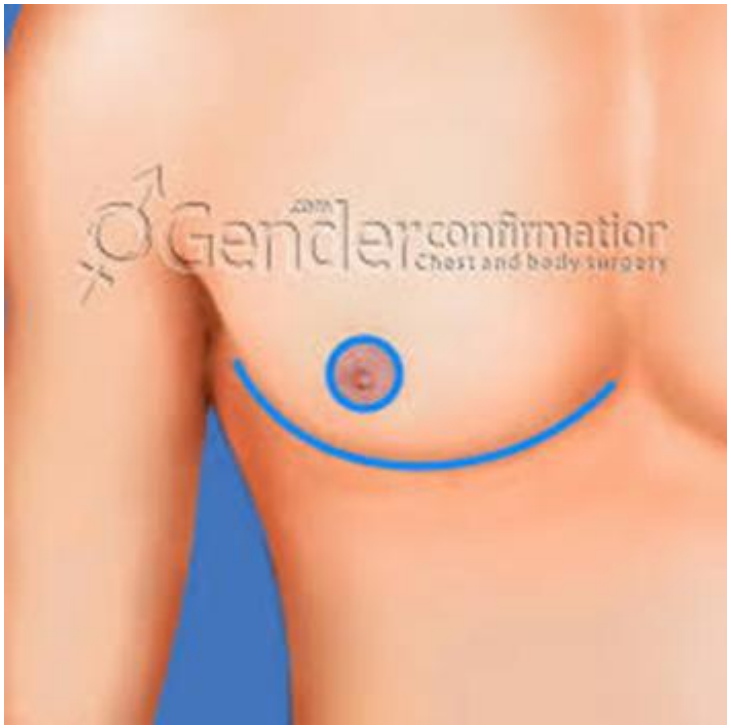
- No difference in depressive symptoms or suicidal behavior by personal characteristics including gender identity, race/ethnicity, sexual identity, age, access to free lunch, or study site

Use of Chosen Name Protective!

- Adjusting for personal characteristics, total social support, chosen name use in more contexts predicted fewer depressive symptoms and less suicidal ideation and suicidal behavior
- Use chosen name in1 context predicted
  - 5.37-unit decrease in depressive symptoms
  - 29% decrease in suicidal ideation
  - 56% decrease in suicidal behavior

  - Except that chosen name use with friends did not significantly predict mental health after adjusting for demographics and close friend support
  - Depressive symptoms, suicidal ideation, and suicidal behavior were at the lowest levels when chosen names could be used in all four contexts.

Olson-Kennedy J, Warus J, Okonta V, Belzer M, Calark LF. Chest Reconstruction and Chest Dysphoria in Transmasculine Minors and Young Adults: Comparisons of Nonsurgical and Postsurgical Cohorts. JAMAPediatr. 2018 May1;172(5):431-436.



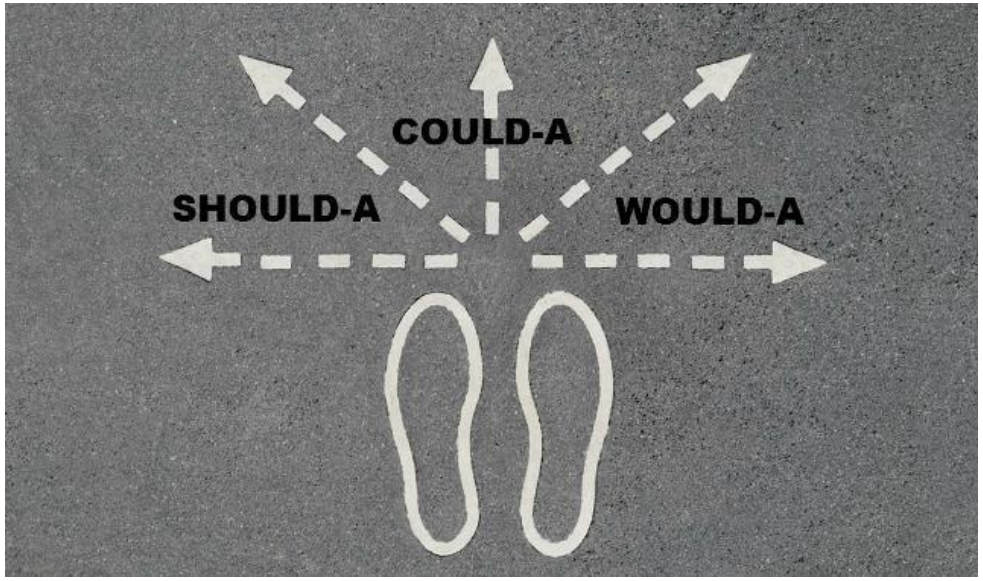
Surgery for Minors?

- Cohort study at a large, urban, hospital-affiliated gender clinic
  - Ages 13 - 25
  - Identified gender as something other than female.
  - June - December 2016
- 136 completed surveys
  - 68 (50.0%) postsurgical, mean age 19 yrs
  - 68 (50.0%) non-surgical, mean age 17 yrs
- Outcomes
  - Chest dysphoria composite score (range 0-51, with higher scores indicating greater distress)
  - Regret about surgery
  - Complications of surgery in patients who were postsurgical

Surgery for Minors?

- Chest dysphoria composite score
  - 29.6 non surgical vs 3.3 surgical $p<0.001$
  - Nonsurgical cohort
    - 64 (94%) perceived chest surgery as very important
    - Dysphoria increased by 0.33 points each month that passed between a youth initiating testosterone therapy and undergoing surgery
  - Surgical cohort
    - Most common complication = loss of nipple sensation, temporary 59%, permanent 41%
    - Serious complications were rare
      - Hematoma 10%
      - Anesthesia 7%
  - Self-reported regret was near 0

Wiepjes CM, Nota NM, de Blok CJM, Klaver M, de Vries ALC, Wensing-Kruger SA, de Jongh RT, Bouman MB, Steensma TD, Cohen-Kettenis P, Gooren LJG, Kreukels BPC, den Heijer M. The Amsterdam Cohort of Gender Dysphoria Study (1972-2015): Trends in Prevalence, Treatment, and Regrets. J Sex Med. 2018 Apr;15(4):582-590.

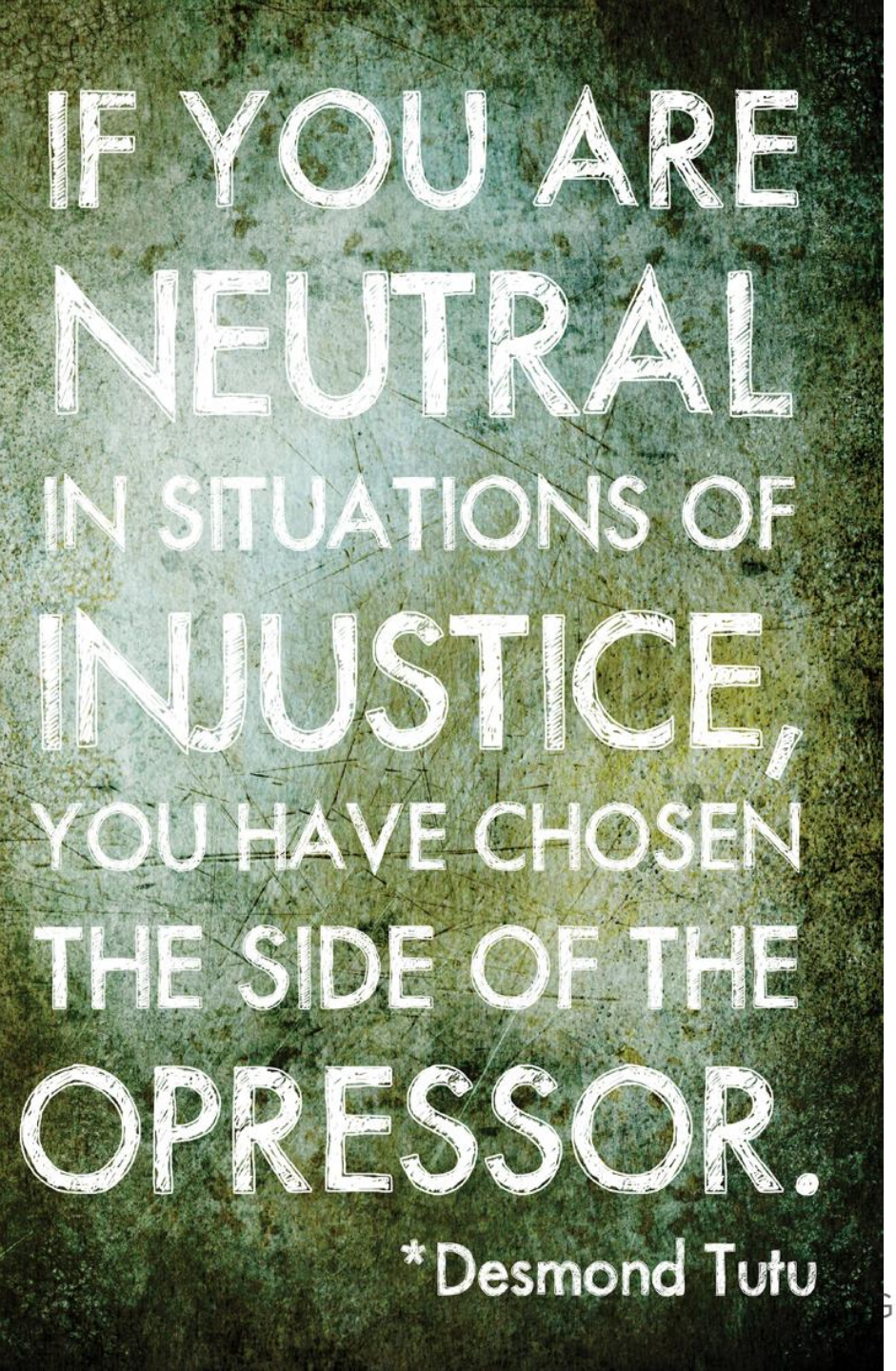


Regret over time?

- Amsterdam gender identity clinic 1972-2015 retrospective
- 6,793 people (4,432 birth-assigned male, 2,361 birth-assigned female)
  - Number of people assessed per year increased 20-fold from 34 in 1980 to 686 in 2015
  - Estimated prevalence in the Netherlands in 2015
    - 1:3,800 transwomen
    - 1:5,200 transmen

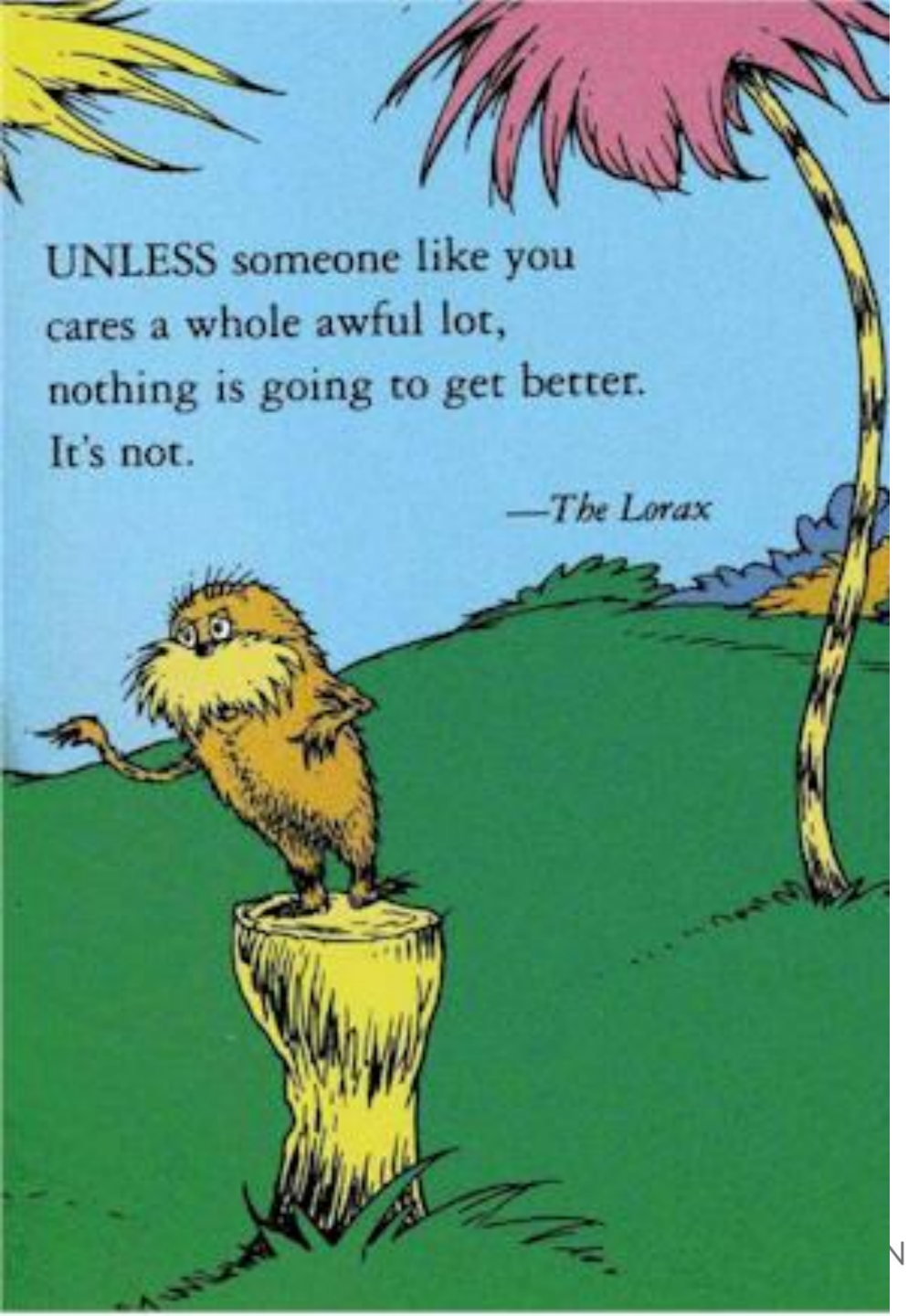
% people within 5 yrs first visit

  - Started GAH decreased over time, 90% in 1980 to 65% in 2010
  - Gonadectomy after GAH stable over time
    - 74.7% transwomen, 83.8% transmen
- 0.6% transwomen, 0.3% transmen who underwent gonadectomy identified experiencing regret



Take Home Points

- Screening for gender issues, like sexual health concerns, important through life span
- Earlier parental support, along w early medical engagement, can be lifesaving, decrease risks, improve outcomes
- Mental health & social support is important
- General strength focused, harm reduction strategies continue, incorporating knowledge of minority stress impact


UNLESS someone like you
cares a whole awful lot,
nothing is going to get better.
It's not.
—The Lorax

Questions