Gender Diverse Children, Teens, and Young Adults: Opportunities for Better Care & Better Outcomes

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Continuing Medical Education Disclosure

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- **Disclosure:** Consultant: Merck and PPLM. All hormone therapy for transgender people is off-label.

It is the policy of The National LGBT Health Education Center, Fenway Health that all CME planning committee/faculty/authors/editors/staff disclose relationships with commercial entities upon nomination/invitation of participation. Disclosure documents are reviewed for potential conflicts of interest and, if identified, they are resolved prior to confirmation of participation. Only participants who have no conflict of interest or who agree to an identified resolution process prior to their participation were involved in this CME activity.
Disclosures

- All medications discussed used off label
  - Recommendations based on available evidence, guidelines, & community experience

- Affiliations
  - Board member
    - Physicians for Reproductive Choice and Health
    - Trans Youth Equality Foundation
    - Center for Sexual Pleasure and Health
  - Consultant
    - Merck Nexplanon trainer
    - Planned Parenthood League MA consultant, provider
Caring for Children, Adolescents and Young Adults

Objectives:

1. Understand how paradigms affect care & systems
2. Explain professional guidelines & practices for care of transgender adolescents & transitional age adults.
1-d(isease) Model

Deviation = Disease & Pathology

Disease ➔ Diagnose

Treat or “Fix”

Stigmatize
- Shame, isolation
- Bias, discrimination

Psych testing
- DSM diagnostic criteria
- Meeting guidelines
- Real life experience
- Gatekeeping model to services

How can children know?
What if we make a mistake?
What if they get hurt? Change their mind? Can’t find love?
Why not wait?
2d-Spectrum Model

Biologic Gender

Gender Identity & Expression

Sexual Attraction, Orientation, Behaviors

Cisgender

Transgender
Gender Diverse

XY Male

Intersex

XX Female

Masculine
Androgynous
Feminine

Androphilic

Gynophilic
3-d(developmental)  
Weaving the Gender Web

Weaving over time various interconnect

nature

nurture

culture

Searching, creating, editing fabric of one’s authentic self

= GENDER HEALTH!
Who to Screen?

- All children
  - Developmental stages
- Non-conformning expression
- Concerns/problems with
  - Mood
  - Behavior
  - Social
Professional Responsibility to Ask - But Do We?

- Studies show medical providers do not talk about gender or sex
- 2014 Adolescent health maintenance
  - Time talking about sexuality
    - 35% 0 30% 1-35 seconds 35% >= 36 seconds
- Pediatrics, Family Medicine only ask about sexual orientation 20-30% time
  - Never about gender!

Developmental, Patient-Centered Paradigms Foster TransPositive Approach

Gender & sexual development are natural parts of human development.

Gender & sexual expression can vary according to person.

Gender & sexual diversity is different than risk.

Open, honest communication is critical to healthy decision making, behaviors, support, & access to care.
Ask more... Listen...

Gender Play
- Passing interest or trying out behaviors, activities, clothes & roles
- Shared characteristics but does not want to “be” other gender

Gender Nonconformity
- Persistent, consistent, insistent
- Desire to be other gender
- Dysphoria about body & gender

Health provider role
- Nothing to “fix”... encourage & support
- Parents accepting, allowing child to be, loving child “as is”
- Ongoing relationship(s) for support & intervention
Range of Treatment Approaches

- **Living in Asserted Gender**
  - No treatment until 18 (after full pubertal experience)
  - Allow some experience puberty, to age 15-16 or Tanner 4, then start GnRH analogues or hormones
  - Gender identity stable, criteria met
    - Initiate puberty with hormones congruent with gender identity
  - Gender identity stable, criteria met
    - Start GnRH analogues at Tanner 2
    - Initiate hormones several years later

GCS
Earlier is Better

Goal

Improve quality of life by facilitating congruency with asserted identity

- Early, strong social support & plan
  - Multiple studies demonstrate family & parent support critical to positive health outcomes
- Early medical & mental health resources
  - Experience puberty congruent with gender
  - Avoid psychological stress - anxiety, depression
  - Prevent unwanted 2nd sex characteristics
  - Reduce need for future medical interventions
Early Social Transition

- Assuming cross gender expression to match identity
  - Multiple or all social settings
  - Reversible, cosmetic
  - Well planned & supported
  - Safety!!

- Considerations & preparation
  - Trial run – see how it feels, how child responds
  - Specifics- name, pronoun, clothing... restrooms, locker rooms, sleep-overs
  - Disclosure or not ... to who ... how to prepare
  - Family, school, friends, school, church, social groups
Puberty

- Timing
  - Biologic
  - Peer
- Sequence
- Genitalia vs secondary characteristics
- Growth & height

MidParental Height (cm)
(Dad -13cm)+ Mom/2 = cis female
(Mom+13cm)+ Dad/2 = cis male
# Timing Puberty Blocking

<table>
<thead>
<tr>
<th>Tanner stage</th>
<th>Breast</th>
<th>Aerola</th>
<th>Pubic Hair</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Prepubertal</td>
<td>No glandular tissue</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>2</td>
<td>Breast bud, small firm tender glandular tissue</td>
<td>Areaola widens but in contour of breast</td>
<td>Sparse, fine</td>
</tr>
<tr>
<td>3</td>
<td>Elevates extends beyond aerola</td>
<td>Areaola widens but in contour of breast</td>
<td>Increasing coarseness, lateral spread</td>
</tr>
<tr>
<td>4</td>
<td>Increases</td>
<td>Secondary mound, project from contour</td>
<td>Adult quality</td>
</tr>
<tr>
<td>5 Adult</td>
<td>Returns to contour of breast, projecting papilla</td>
<td>Spreads to thighs</td>
<td></td>
</tr>
</tbody>
</table>
## Timing Puberty Blocking

<table>
<thead>
<tr>
<th>Tanner stage</th>
<th>Testicles (volume cc)</th>
<th>Penis (length cm)</th>
<th>Pubic Hair</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 prepubertal</td>
<td>&lt;1.5</td>
<td>&lt;=3</td>
<td>no change</td>
</tr>
<tr>
<td>2</td>
<td>1.6-6 Scrotal skin thins, reddens</td>
<td>No change</td>
<td>Downy sparse</td>
</tr>
<tr>
<td>3</td>
<td>6-12</td>
<td>&lt;6</td>
<td>More coarse, spread laterally</td>
</tr>
<tr>
<td>4</td>
<td>12-20 Scrotum darkens</td>
<td>&lt;10</td>
<td>Adult quality</td>
</tr>
<tr>
<td>5 adult</td>
<td>&gt;20</td>
<td>Average 15</td>
<td>Spreads to thighs</td>
</tr>
</tbody>
</table>
**Timing Puberty Blocking**

- Ideal before or early Tanner 2
  - Maintain prepubertal status
  - Follow exam, LH, estradiol/testosterone
- Can use Tanner 3-5
  - Halt continued puberty changes
  - Prevent continued 2nd gender characteristics
  - Mental health & perimenopausal symptoms
External Gender Characteristic Development

Cis Male

**Testosterone**
- Directly increases size and mass of muscles, bones, vocal cords for heavier/larger skeletal structures, nose, larynx

**DHT in skin**
- Growth of androgen responsive facial, body hair
- Taller stature result of later puberty, slower epiphyseal fusion.

Cis Female

**Estrogen**
- Initiates breast bud, tissue
- Widens pelvis
- Increases body fat in hips, thighs, buttocks, breasts
- Growth of uterus, endometrium, menses
GnRH Agonists

Leuprolelin

Triptorelin

Goserelin

- Monthly $500-1000
- 3-monthly depot $1500-2000

Histrelin implant

12-24 months
- $3500 (Vantas)
- 15,379.16 -$12,560.00 (Supprelin)

Block hypothalamus when given continuously

Stimulate puberty when pulsatile (physiologic)
**Blocking**

**CONS**

- Few long term, lifetime outcome data
- Possible temporary adverse effect on bone density
  - Reversible once hormones initiated
  - BMD normal in teens with prepuberty treatment
- Height reduction
- Cost is high, height for FTMs
- Lack of secondary sex characteristics compared to peers
- Expensive! Insurance sometimes covers

**PROS**

- Delays decision to undergo cross hormone therapy until child is older
- Prevents undesirable irreversible pubertal changes
- Decreases distress, with mental health/self esteem benefits
- Prevents need for costly and invasive surgery as adult
- Cosmetic congruency as adult leading to passing & greater social & financial opportunities

Delemarre-van de Waal, EuropJEndo 2006
Blocker Considerations for...

**GNC Boys**
- Breast development early in puberty
- Broaden hips
- Early epiphyseal closure, shorter height
- Early identification before menses
- Low dose T for promoting height

**GNC Girls**
- Tanner 4-5 testes but minimal external gender characteristics
- Bigger heavier skeleton
- Adam’s apple
- Male pattern face, body hair
- Estradiol earlier for earlier puberty & height reduction
Better Question is: How Do I Help My Kid?

Helping Parents with their OWN Transition Process

- Who should we tell? How do we tell?
- Worries about safety

Grieve the child & dreams they lost... not yet realize
The happier child to gain

Parenting from a place of their child
Not from the parent needs
Family Acceptance Project

- 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

RyanC J2010, 2009
Addressing Parental Concerns

- This is just a phase.
- Why can’t we just wait & see?
- Is my child going to be gay?

Prepubertal Trajectories

- Cisgender Heterosexual
- Cisgender Homosexual
- Transgender

Behaviors & expression may non-conform, but children can still feel that they are in right-gendered body
Prepubertal Trajectories

- Early, consistent, persistent insistent presentation
- Prepubertal social transition
- Significant body/gender dysphoria

...Continue into transgender adolescence

Almost 100% continue to gender affirming hormones, surgeries, with NO regret

Why Providers Should Identify Early?

Seminal Amsterdam Work

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


Strong support with ongoing data:


Invisible or Different Leads to Health Disparities

- ReisnerSL 2014
  - IPV, child abuse, discrimination, suicide ideation/attempts
- ReisnerSL 2014
  - 11.5% self id gender minority
  - Bullying assoc alcohol, MJ, drug use
- Clark TC 2014
  - 5% gender diverse
  - 6x depressive sx, 5x suicide attempt, 4.5x bullying,
  - 0.3 OR parental support
Transition is More than Hormones

- Assess readiness for transition
  - Physical (Tanner stage) ... Psychological ... Social
  - Encourage patience for changes, effects
  - Focus on healthy lifestyle & plan
  - Encourage therapy - can provide skills, support to make transition easier, healthy

- Providers, parent(s), patient feel confident

- Comprehensive plan
  - Safety, health, happiness ...
  - Review benefits risks desired outcomes
Puberty

- Timing
  - Biologic
  - Peer
- Sequence
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- Growth & height

MidParental Height (cm)
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(Mom+13cm) + Dad/2 = cis male
# Estradiol Feminization

<table>
<thead>
<tr>
<th></th>
<th>Sublingual</th>
<th>Intramuscular</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Agent</strong></td>
<td>17 b estradiol</td>
<td>Estradiol</td>
</tr>
<tr>
<td></td>
<td>Generic</td>
<td>Cypionate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Valerate</td>
</tr>
<tr>
<td><strong>Pre-orchiectomy</strong></td>
<td>2-6 mg daily</td>
<td>5-20 mg IM q 1-2 weeks</td>
</tr>
<tr>
<td></td>
<td>Sublingual 30 minutes, swish spit</td>
<td>?New data Subcutaneous?</td>
</tr>
<tr>
<td><strong>Maintenance after 2 years</strong></td>
<td>Reduce to level needed to keep serum free testosterone suppressed,</td>
<td>Estradiol</td>
</tr>
</tbody>
</table>
**Feminizing Effects**

**Reversible**
- Decrease acne
- Decrease hair
- Decrease muscle mass
- Softening of skin
- Slowing balding
- Decreased libido
- Suppress testosterone
- Fat redistribution

**Irreversible**
- Breast development
- Nipple enlargement
- Loss of erection, ejaculation
- Testicular atrophy
- ? Sterility
## Testosterone Masculinization

<table>
<thead>
<tr>
<th></th>
<th>Injection</th>
<th>Transdermal gel</th>
<th>Transdermal patch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agent</td>
<td>Testosterone cypionate</td>
<td>Testosterone enanthate</td>
<td>Testosterone crystals dissolved in gel</td>
</tr>
<tr>
<td>Brand name</td>
<td>Depo-Testosterone®</td>
<td>Delatestryl®</td>
<td>AndroGel®</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Androderm®</td>
<td></td>
</tr>
<tr>
<td>Pre-oophorectomy</td>
<td>40-100 mg SQ every week</td>
<td></td>
<td>5-10 g daily</td>
</tr>
<tr>
<td></td>
<td>previously</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>100-200 mg IM every 2 weeks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintenance after 2 years</td>
<td>Reduce to level needed to keep serum free testosterone within lower-middle end male reference interval; Monitor risk of osteoporosis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Masculinizing Effects

Irreversible

- Uterine atrophy
- Hair loss/baldness
- New & increased facial & body hair
- Deepen voice
- Clitoral enlargement
- ? Sterility
Androgynous Agender Patient
New Frontiers in Gender Care

Parents

- If only my kid was trans...
- I don’t understand this as well as I would understand them wanting to be fully a ...
- Risk of inaction vs action
- Not much data

Youth

- Specific dysphorias
- Specific goals
- Tailoring meds & surgeries to the patient
- Listening to the patient & consent based care
Gender Diversity Expands

- **? Hormones**
  - None needed
  - Low dose titrated
  - Need some gender hormone?

- **? Surgery**
  - Women love their penis
  - Men don’t want a penis
  - Hysterectomy/oophorectomy preventive benefits for cancer risk?
  - Orchiectomy benefits as patients age?

- Why so much discomfort on part of providers?
Fertility Conundrum

For youth: Two messages both true!

- Not effective birth control
- Unpredictable future fertility
- Consider
- MTF-sperm banking
- FTM-ovarian tissue, oocytes banking
- Couples-embryo banking

Concern for parents

- Wanting all options for future
- “How can a 14 yro know?...”
- Projection cis mindset
- Perceived loss of grandchildren
Fertility Conundrum

Need to listen to patients...

For many trans/GNC

IDENTITY PRECEDES FERTILITY

- Trans males—pregnancy NOT male paradigm
- Trans females—many mourn inability to become pregnant
- Adoption, surrogate, partner’s pregnancy
- Many ways to create a family!
Data on Fertility Efforts for Trans Pops

Sperm banking
- Effective
- Cost
  - Initial
  - Ongoing storage
- Not an option for Tanner 1 to feminizing hormones

Oocyte retrieval
- Ovarian tissue banking
- Less effective
- Very costly
- Men on T can get pregnant in future if off T

In many instances, fertility services covered for cancer patients... why not trans persons??
Fertility services ARE covered by Fenway!
From Tanner 1 to Hormones to Surgery

- How will lack of scrotal and penile development affect vulvovaginoplasty?
- With greater access & insurance coverage, new surgical techniques & improvements to penoplasty?
- Continued innovation in fertility care
  - Sperm & oocyte extraction prepubertally
  - Oocyte & ovarian tissue efficacy
  - Uterine transplant
Are We Doing Harm??

Cost NOT intervening >>>> Risk of harm

- Self harm
- Suicide
- Depression
- Anxiety
- Substance use
- Homelessness
- Sex work
- HIV

One reason people resist change is that they focus on what they have to GIVE UP, rather than what they have to GAIN!

~Rick Godwin
TransYouth Project

- Large-scale (>150 children) longitudinal study of transgender children in 25 states
- 2015 → childhood trans gender identities as deeply rooted as cis peer
- 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

“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.”

Identity congruent with anatomy/physiology

Puberty in gender identified

Early RX
Change cultural appreciation for diversity

Social stigma
Familial rejection
Social isolation
Emotional, physical distress

Health Outcomes
Mental health
Social
Medical
Trans Supportive Culture
Expectations of Safe Space

Staff trained, engaged, advocates

Network
Community, Youth resources, Parental Support

GLBTQ affirming youth affirming space

Explicit consent
• Patient centered focus on gender goals
• Parent (provider) goals
• Safety, healthy, happy, place in world

Explicit discussion, understanding re privacy & confidentiality

ADVANCING EXCELLENCE IN TRANSGENDER HEALTH
Recommendations for Education, Health & Human Services Professionals

- Gender-sexuality pervasive & important
- Deserves developmental anticipatory guidance
  - Start young, continue conversations across lifespan
    - Childhood ➞ pre-pubertal ➞ puberty ➞ adulthood ....
- Consistent, persistent, insistent
- Mood, behavior, social concerns
- Early interventions is better!

Just Ask ... Listen ... Plan ... Support... Refer
- Early identification
- Timely intervention
- Opportunity to educate, advocate diversity
For Parents

- Gender & sexuality
  - Normal, lifespan
- Look & listen
  - Let kids pick clothes, hair, activities
  - Talk about & support interests
- Unconditional
  - Love
  - Acceptance
  - Support
- Support for parents themselves
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