Creating Gender-affirming Medical Services for Transgender and Gender Non-conforming Youth in Rural and Under-resourced Areas

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We will make mention of off-label use of histrelin and leuprolide for pubertal blockade in youth with gender dysphoria. (Although these medications are not FDA approved for treatment of gender dysphoria, this is widely accepted standard of care)
Objectives

Œ Identify **barriers** to establishing gender-affirming medical services for trans youth in these areas

Œ Identify **concrete steps** that can be taken to establish gender-affirming medical services for trans youth in rural or under-resourced areas

Œ Identify **resources** for establishing gender-affirming medical services for trans youth in rural or under-resourced areas

⚠️ Results may vary!

Outline

Œ Background
Œ Getting basic training in trans care
Œ Assessing needs in your area
Œ Utilizing available resources and building your network
Œ Considerations for getting started
Œ Questions & Discussion
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Where do we practice?

Burlington, Vermont
Where do we practice?

**Burlington, Vermont**
- Population 42,000
- College town
- Most populous city in VT

**Vermont:**
- Population 620,000
- Total escalators: 4
- # of Target Stores: 0

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How much demand is there for gender-affirming medical care for youth?

- Prevalence of gender dysphoria not well established
  - Initial estimates: transfemales 1: 12,000 - 45,000
    - transmales 1: 40,000 - 200,000

  **But, if this were correct...**
  - total Population of Vermont: 620,000
  - < 35 trans people in Vermont

- More recent estimates from population data: **1: 50 - 200** (Winter, et al., 2016 *Lancet*)
How much demand is there for gender-affirming medical care for youth?

► If you build it, they will come…
  ▪ Since beginning in Sept 2016, have seen ~70 youth
  ▪ Initially…hoped to be able to fill 1 half-day session per month
  ▪ Currently… ~3 half-day sessions per month, waiting list

► Growing demand seen elsewhere too
  ▪ Ex: Boston Children’s Hospital (GeMS)

Spack, et al. “Children and Adolescents With Gender Identity Disorder Referred to a Pediatric Medical Center” Pediatrics (2012)

Why is this work necessary?

► High morbidity & mortality in untreated gender dysphoria!
► Trans youth have high rates of…
  ▪ Low self esteem
  ▪ Depression
  ▪ Anxiety
  ▪ Self-injury
  ▪ Substance Use
  ▪ Suicide
  ▪ Homelessness
  ▪ Survival sex
  ▪ Trauma

30-50% of Trans Youth report a past suicide attempt (e.g., MA Dept of Ed, 2006; Dean et al., 2000)

Why is this?
Marginalization
Victimization
Lack of Access to Appropriate Care
Where to Find Gender-Affirming Care for Youth?

- Almost all programs in urban areas
- Many urban areas remain that do not yet have services
- What about rural youth?
  - 15% of US population

https://www.hrc.org/resources/interactive-map-clinical-care-programs-for-gender-nonconforming-childr

Ideals vs. Realities

In an ideal world, every youth with gender dysphoria would have…

- Accepting and supportive family
- Safe and supportive school
- Governmental protection
- PCP who gets it
- Knowledgeable and affirming mental health care
- Access to gender-affirming medical care
- Multidisciplinary, fully comprehensive youth gender clinic
Ideals vs. Realities

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In the real world...
- Many youth with gender dysphoria go without care because
  - Lack of family support
  - Fear for safety
  - PCP’s don’t recognize it or don’t know what to do
  - Insurance/financial barriers
  - Lack of local providers
  - Can’t access comprehensive multidisciplinary gender clinic

Can safe, ethical, and quality care be provided outside of this model??
Yes
What are the general needs of this population?

► Primary Care/Medical Home
► Mental Health Support
► Social Support: Family, Schools, Community, etc
► Puberty blockers, hormone therapy
► Fertility Preservation
► Access to Surgical Services
► Legal Support: Changing name/gender markers, insurance coverage, etc.

Lots of variation in which of these services people may want/need

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► Questions & Discussion
How to obtain basic training in trans health

- Medical Knowledge
  - Fairly easy

- Understanding Psychosocial Context
  - Harder

Optimal Care

How to obtain basic training in trans health

Medical Knowledge
- Puberty Blockers
- Cross Sex Hormones
- Menstrual Suppression
- Knowledge about surgical interventions
- Fertility Preservation

Understanding Psychosocial Context
- Comfort with preferred names & pronouns
- Understanding lingo
- Legal needs
- Adversity
- Supporting Families
- Sensitivity with History-Taking & Exams
- Anticipating Issues
- Counseling/anticipatory guidance with respect & affirmation

Optimal Care
How to obtain basic training in trans health: Building Medical Knowledge

Guidelines
- Endocrine Society Guidelines
- WPATH Standards of Care

Online Resources
- UCSF Center of Excellence for Transgender Health http://transhealth.ucsf.edu/protocols

Workshops & Conferences
- Gender Odyssey http://www.genderodyssey.org
- Gender Conference East https://2017gceprofessional.sched.com/overview/type/Medical
- GEMS Conference: http://www.gemsconference.org/
- WPATH http://www.wpath.org
- Philadelphia Trans Wellness Conference https://www.mazzonicenter.org/trans-wellness

Mentorship
- Other providers willing to mentor (in your region or remotely)

How to obtain basic training in trans health: Understanding the Psychosocial Context

Connect with Trans Community
- Local LGBTQ center
- Trans-Identified Professionals

Workshops/Conferences
- Most we mentioned have a component for the general public
- Numerous regional conferences

Reading
- Trans Bodies, Trans Selves Laura Erickson-Schroth, Oxford Univ Press (2014)

Online Resources
- Gender Spectrum https://www.genderspectrum.org/resources/
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Local Needs Assessment

► LGBTQ Community Center
► LGBTQ Youth Center
  ▪ Met with staff
  ▪ Invited to lead Q&A sessions on LGBTQ health for youth
    ▪ Youth shared what they saw as unmet needs and most pressing issues
► Providers caring for trans adults
► Regional Transgender Conference
► Primary care providers

Your needs assessment doesn’t have to be fancy. Just listen to people!
Local Needs Assessment

► Youth
► Parents
► LGBTQ Organizations
► Primary Care Providers
► Providers Who Offer Gender-Affirming Care for Adults

Main Areas of Need
- Gender affirming care for youth
- Knowledgeable and supportive mental health providers
- Pooling of knowledge and resources
- Education for primary care providers
- Outreach & education for schools

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Engaging Resources within Your Community

Trans Health Group

Trans Youth Program
Patient/Family Advisory Council

► By word of mouth created a list of providers who:
  ▪ Offer gender-affirming care of any type, and/or
  ▪ Expressed interest in learning to provide gender-affirming care, and/or
  ▪ Had several trans patients

► Included…
  ▪ PCP’s (pedi, FM, IM), pedi endo, adolescent med, adult endo, OB/GYN, urologist, mental health providers, plastic surgeon

► Later additions…
  ▪ Hospital admin, nurses, social worker, lawyer, parent of trans youth, trans-identified hospital staff, enthusiastic med students, representatives from community organizations (ex. Planned Parenthood)
Trans Health Group

- Met quarterly
- Created a list-serv
- **Purpose:**
  - Create connections
  - Build a referral network
  - Share information
  - Problem-Solving

Engaging Resources within Your Community

- Trans Health Group
- Trans Youth Program
- Patient/Family Advisory Council
Trans Youth Program
Patient/Family Advisory Council

- Ensure the community we serve has a seat at the table
- Members of trans community and parents of trans youth
- Share perspectives and experiences
- Offer feedback and advice
- Sounding board
- Ex:
  - Letter writing campaign for EMR changes
  - Bathroom signage
  - Helping train front office staff

Establishing a Mental Health Network

- Investigate resources in the community
- Vet mental health providers before referral:
  - Cold calling/emailing providers
- Create referral list
  - Keep updated
  - Includes insurance, ages of clients, areas of expertise
- Consider establishing lead referral clinician if possible
  - Help with triage and match-making
Establishing Additional Referrals

► Primary care providers
  ▪ Pediatrics, Family Medicine
  ▪ Adult providers to transition pediatric patients
► Mental health providers
► Fertility preservation services: Gynecology, REI
► Plastic Surgery
► Urology
► Therapists, psychiatrists
► Supportive Community Based Organizations
► Legal assistance

Even if you can’t be a Multidisciplinary Clinic, you can still create a Multidisciplinary Network

Borrow/adapt materials

► Don’t reinvent the wheel
► Borrow & adapt materials
  ▪ Consent forms
  ▪ Insurance appeal letter templates
  ▪ Letters of medical necessity
  ▪ Letters for schools
  ▪ Handouts on injecting T
Insurance Issues

► Drastic variation between states and insurance policies
► Paperwork & calls can be time consuming
► Borrow templates for appeal letters
► Reach out to local legal aid groups
► Friends in high places (ex: supportive legislators)

Educating office staff/colleagues

► Essential to good patient experience
► Changes often benefit the cis-gender kids too
  ▪ Ex: using preferred name
► Another opportunity to involve patient/family advisors and community members
► Don’t underestimate your colleagues’ capacity for support and acceptance
  ▪ They might surprise you!
Outreach for Primary Care Providers

Primary Care Providers:
► Many lack training or experience caring for trans youth
► Front-line for recognizing and referring
► Field questions from kids and parents
► Potential ally in care delivery

Grand Rounds
(Attended live or via video-stream by majority of VT pediatricians)
► Covered the basics
  ▪ Sex ≠ gender
  ▪ Gender identity ≠ sexual orientation
  ▪ Terminology
  ▪ Importance of social and family support
  ▪ Risks of untreated gender dysphoria
  ▪ Range of treatment options, including blockers and hormones
► Services we have to offer
► Handouts with community resources

To learn more, go to
www.transparent.org/gender
Design by Jordan Fien and Annik Boone
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► Services we have to offer
► Handouts with community resources
► Advance promotion of session to maximize turnout
  ▪ Emailed peds/FP practices around the region
  ▪ Emailed mental health providers around the region
  ▪ Invited DCF/CYS
    (Best grand rounds attendance in departmental history!)

Immediate ↑↑ in referrals following grand rounds

Outreach for Primary Care Providers

Lunchtime Visits with Primary Care Offices
► Informal discussion about gender dysphoria, services we offer, community resources, Q&A
► Providers brought some cases to discuss
Outreach for Primary Care Providers

School nurses
► Even more front-line than PCP’s
► Presented at state-wide school nurse conference

Interpreters in Small Towns
► In-person interpreters may know your patient/family
  ▪ Confidentiality can be difficult to ensure
► Consider offering a remote interpreter service if available
► Prep the interpreter in advance!!
  ▪ What is their understanding of any key words you plan use?
  ▪ How will they translate words like “transgender”?
Utilizing media and public relations

► Not surprisingly… Word spreads quickly in a small community
► Approached by our hospital’s PR department
  ▪ Suggestions about naming of our program
  ▪ Website
  ▪ Pamphlets and handouts
  ▪ Internal news stories
  ▪ Fielding requests from media, offered coaching
► Local Media
  ▪ Local newspaper
  ▪ Local news
  ▪ Radio
► Requests for talks/panels

Overcoming Anxiety

► The first step is the hardest
► Important to be thoughtful and plan ahead, but…
► You can’t anticipate every issue
► Consider starting with just a couple of patients, embedded into your usual practice setting
Suggested Steps for Getting Started

► Needs assessment (informal is fine)
► Build your local/regional network
► Find mental health provider(s) to collaborate with
► Find a clinical mentor (remote is fine)
► Seek guidance from the trans community
► Borrow and adapt materials
► Begin by embedding gender-affirming care into your current practice model
► Educate PCP’s, then enable them to assist with care delivery

If we could do this, so can you.
Acknowledgments

Many thanks to....
► Martina Drawdy
► Candy Bedard
► Theresa Emery
► Nicholas Bonenfant
► Christopher Janeway
► Emiry Potter
► Marlene Maron
► Lewis First
► Children’s Miracle Network
► Outright Vermont

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