

“I felt like a second-class citizen:”

“Youth and Caregiver’s Perspectives on Healthcare Barriers for Transgender Youth: the Creation of a Gender Clinic”



David J Breland MD MPH

Pronouns- he/him/his

Associate Professor of Pediatrics

Clinical Director of Adolescent and Young Adult Medicine

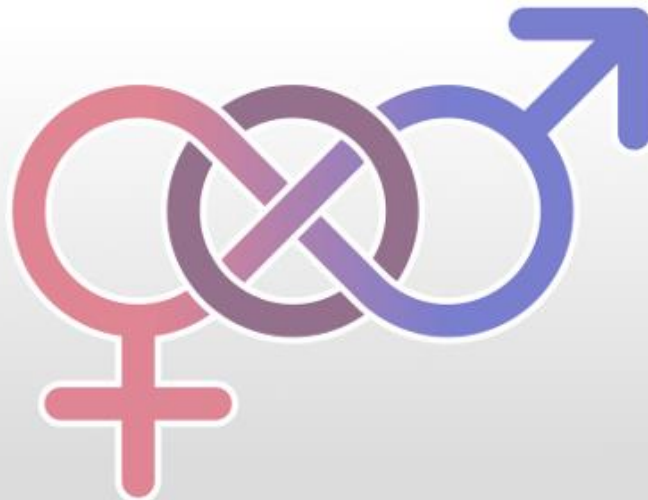
Medical Director Seattle Children’s Gender Clinic

Disclosures

I have no personal or financial conflicts to disclose

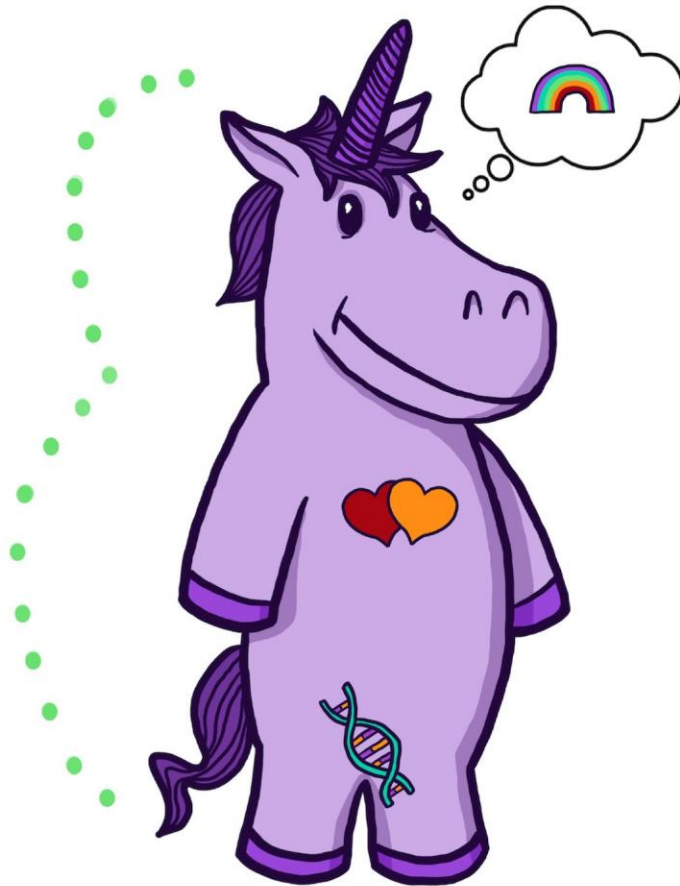
Outline

-
- 1) Background
 - 2) Research project
 - 3) New funding sources and plans
 - 4) Seattle Children's Gender Clinic



The Gender Unicorn

Graphic by:
TSER
Trans Student Educational Resources



Gender Identity

-  Female/Woman/Girl
-  Male/Man/Boy
-  Other Gender(s)

Gender Expression/Presentation

-  Feminine
-  Masculine
-  Other



Sex Assigned at Birth

Female



Male



Other/Intersex



Sexually Attracted To

-  Women
-  Men
-  Other Gender(s)



Romantically/Emotionally Attracted To

-  Women
-  Men
-  Other Gender(s)

To learn more, go to:
www.transstudent.org/gender

Design by Landyn Pan

Prevalence of gender dysphoria

MTF 1/12,000; FTM 1/30,000 (Netherlands)

Perhaps as high as 1/1,000-2,000

Ratio MTF:FTM 3:1 in adults, 1:1 in teens, 3-6:1 in prepubertal

- **Wallien et al, 2008**- 77 children with GD then at follow up ~10 yrs.
 - Mean age 8.4 yrs., 59 boys and 18 girls
 - 30% did not respond; 27% (12 boys, 9 girls) still GD; 43% desisted (28 boys, 5 girls)



Prevalence of transgender youth

The Williams Institute (UCLA School of Law)

Estimated 0.6% of US adults identify as transgender
New study finds that 0.7% of youth ages 13-17
identify as transgender



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What happens when one's gender identity is incongruent with one's biological sex?



Slide used by
permission from Dr.
Laura Edwards-
Leeper



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Psychological Profile of Children and Adolescents with Gender Dysphoria

Symptoms of depression and anxiety

Social isolation and rejection

Low self-esteem/self-worth

Self-harming behaviors

Suicidality

Perception of being completely misunderstood and alone

Autism Spectrum Disorders?



Clinical care programs for transgender youth

- Children's Hospital Los Angeles (Center for TransYouth Health)
- Children's Hospital of Philadelphia (Gender & Sexuality Development Clinic)
- Children's Hospital of Chicago (Gender Development Services)
- Boston Children's (GeMS – Gender Management Service)
- Madison (Pediatric Adolescent Transgender Health Clinic)
- Cincinnati Children's Hospital Medical Center
- UCSF Center for Excellence for Transgender Health
- BC Children's Hospital
- And more...



Seattle Children's Hospital: History with gender affirming care

Department of Endocrinology

- A few clinicians used the Endocrine Society recommendation
- 2012-2013 moratorium placed

Adolescent Medicine

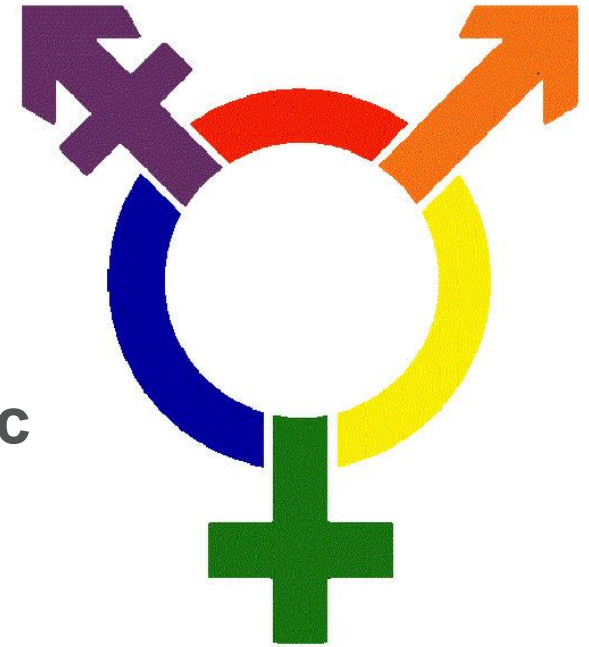
- Began seeing patients in 2011
- 15 years and older
- No prepubertal and young adolescent patients

Disorders of Sexual Development Clinic

- Ambiguous genitalia
- Abnormal chromosomal disorders

Community providers

- Patients within panel
- Not specifically child/adolescent



Steep learning curve for affirming trans care

- **Permission from Division Chief**
- **Division staff and faculty**
- **Saw first few patients**
 - Endocrine dept. → Endocrine Society guidelines 2009
 - World Professional Association of Transgender Health (WPATH) → Standards of care v. 7
 - Psychiatry and Behavioral Health at Seattle Children's
 - Dr. Laura Edwards-Leeper
 - Community providers → British Columbia Children's, others
 - Local organizations → Ingersoll Gender Center
- **# of patients tripled**



Barriers to care from my perspective

Lack of provider knowledge

Few mental health providers with knowledge

Insurance issues or concerns

Patients/families circuitous routes to me

Large Academic Children's hospital bureaucracy

How can I help?



Seattle Children's Center for Diversity and Health Equity

Grants for Equity 2014-2015:

The Center for Diversity and Health Equity Supported projects to identify, understand or ameliorate potential disparities in experience, care or outcomes for racially or ethnically diverse patients, LGBTQ patients or families, and/or publicly insured patients served at Seattle Children's Hospital.

- **Access to care for transgender youth and their families**
- Disparities in functional outcomes after inpatient rehab for traumatic brain injury in Hispanic children
- Experience of parents/children of East African communities who received diabetes education at Seattle Children's Hospital
- Monitoring Mental Health Outcomes of Diverse Children and Adolescents
- Pediatric Refugee Nutrition and Food Security
- Understanding patterns of interpreter use in the pediatric emergency department



Our Study



Background

- Increased risk of substance abuse, depression, anxiety, homelessness, and suicide
- Importance of support from family, schools, & providers
- Increasing number of multidisciplinary gender clinics



Olson J et al. 2011. Arch Pediatr Adolesc Med.

Olson KR et al. 2016. Pediatrics.

Spack NP et al. 2012. Pediatrics.



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Types of care

Social and
emotional
support



Pubertal blockers

Cross-sex hormones

Surgeries



Knowledge of barriers

- A few published papers have talked about the providers' perspectives on this.
 - They describe provider discomfort, or providers not receiving reimbursement.

Barriers to healthcare for transgender individuals.

Safer JD, Coleman E, Feldman J, Garofalo R, Hembree W, Radix A, Sevelius J.
Curr Opin Endocrinol Diabetes Obes. 2016 Apr;23(2):168-71.

Improving transgender health by building safe clinical environments that promote existing resilience: Results from a qualitative analysis of providers.

Torres CG, Renfrew M, Kenst K, Tan-McGrory A, Betancourt JR, López L.
BMC Pediatr. 2015 Nov 18;15:187.

Health care providers' comfort with and barriers to care of transgender youth.

Vance SR Jr, Halpern-Felsher BL, Rosenthal SM.
J Adolesc Health. 2015 Feb;56(2):251-3.

- But perspectives of transgender youth and their families are largely missing from the medical literature on this topic

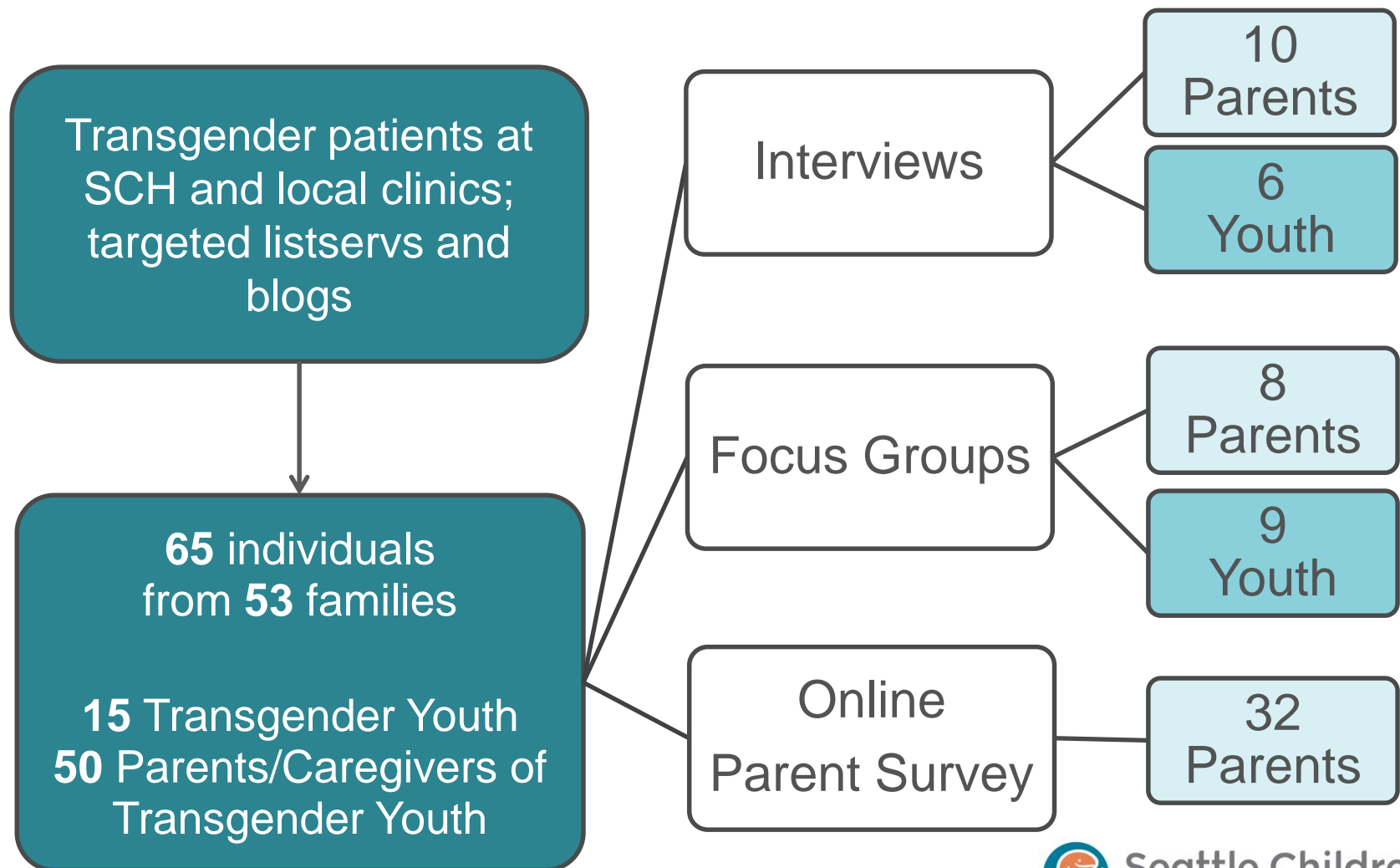


Research question

What barriers do transgender youth and their parents or caregivers face when trying to access supportive, gender-affirming care?



Recruitment and data collection



Participant demographics

	Parents/caregivers (n=50)	Youth (n=15)
Average age (range)	47 years (29-71)	18 years (14-22)
Gender identity	Female: 83% Male: 15% FtM: 2%	Transgender female (MtF): 20% Transgender male (FtM): 47% Other/non-binary: 33%
Race	White: 78% More than one race: 8% Native American: 4% Other race: 10%	White: 67% More than one race: 20% Native American: 7% Other race: 0%
Education	Bachelor's degree or higher: 68%	High school diploma, GED, or higher: 60%



Qualitative Analysis

- Theoretical thematic analysis
- Main themes regarding barriers to care
 1. Lack of providers
 2. Preferred name and pronouns not used
 3. Lack of consistently applied protocols
 4. Uncoordinated care
 5. Delayed access to blockers or hormones
 6. Insurance difficulties
- Participant recommendations for overcoming barriers



1) Lack of providers

- 90% of participants
- Not accessible
- Not pediatric
- Not experienced with or open to transgender healthcare



“...it was hard enough to find [providers] who were accepting new patients and worked with adolescents and took my insurance... on top of it, **finding somebody who was trans-friendly made it all but impossible.**”

- Youth, 19



1) Lack of providers; continued

“I don’t know why we have to go to California to get estrogen, when Seattle Children’s is sitting here. There’s a Gender Clinic in San Francisco. There’s one in Los Angeles. There’s one in Boston... I just think since Seattle Children’s has a reputation for being the leader in so many things, I don’t understand why it hasn’t chosen to take, if not the lead, at least be on par with what healthcare facilities that are similar... are doing.”

- Parent (* title)



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2) Chosen name and pronouns not used

- 55% of participants
- Usually repeated, but perceived as unintentional
- Sometimes perceived as intentional or malicious
- Evoked anger, shame, self-consciousness

“...the doctor said, ‘her, her, her’ and [my son], who’s 10, said, ‘him, him, him!’ and **the doctor got mad and started being dismissive and irritated, and kept saying ‘Her!’...**”

- Parent



3) Lack of consistently applied protocols

- 45% of participants
- Families uncertain about prerequisites or next steps
- Different management strategies at different clinics
- No protocol for patients presenting under age 16
- (roadmap)

“[Doctors need] a protocol... I felt that with [my child’s doctor] it was always like, ‘Well, I’m not supposed to be doing this,’ and, **‘We’re not really supposed to be using this medication for this process,’** and, ‘I don’t feel comfortable treating somebody who is under 16.’”

- Parent



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4) Uncoordinated care

- 48% of participants
- Mental health providers perceived as gatekeepers
- Conflicting messages from medical and mental health providers regarding eligibility for cross-sex hormones

“We were told that ‘This is our team,’ but they hadn’t actually all talked together; ...not organized, thought out, and planned, so **no one really knows who and what everybody else is doing.**”

- Parent

“**Living on two separate worlds**”

-Youth, 17



5) Delayed access to blockers or hormones

- 46% of participants
- Physician discomfort or lack of training; lack of parental approval; minimum age requirements
- Onset of natal puberty provokes anxiety, self-harm

“I had been trying to find any way I could get on [testosterone], even if it wasn’t legal, which really sucks, because you can seriously get hurt by doing that... **I was feeling really, really desperate.**”

- Youth, 19

“Why would you not do blockers immediately? To me that is insane... **This is an emergency. Look at the suicide rates on these kids.**”

- Parent

6) Insurance difficulties

- 39% of participants
- Arduous appeals process
- Exclusions
- Difficulty deciphering insurance policy language



“[Our insurance is] paying for all the medical visits... up until that point where he needs the surgery, and it’s like really? Now you say he doesn’t need the medical assistance, because it’s not a medical issue anymore?”

- Parent

Study strengths and limitations

- Limitations

- Reliance on participants' ability to recall past events
- Possible overrepresentation of families with negative experiences
- Limited generalizability beyond supportive families in Washington

- Strengths

- Triangulation of data
- Adequate sample size, reached thematic saturation



Overcoming Barriers:

Participant recommendations

1. Education for pediatric staff and providers
2. Recording of preferred name & pronoun in EMR
3. Development of care protocols & a roadmap for families
4. Creation of multidisciplinary gender clinics
5. Providing pubertal blockers & cross-sex hormones at an age that permits peer-congruent development
6. Dedicated staff person to assist with insurance navigation



“It’s really cool to be able to go somewhere that I wasn’t immediately uncomfortable as soon as I got there.”

- Youth, 19



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Future directions

- 1) Working to implement these recommendations at Seattle Children's Hospital
- 2) Understand barriers for youth without supportive families
- 3) Study long-term physical and mental health outcomes of transgender youth who receive care



Research funding and team

<u>Funding from Seattle Children's:</u>	<u>Research Team:</u>
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Center for Diversity and Health Equity

Center for Clinical and Translational
Research



Research Team:

David Breland, MD MPH, PI

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Jake Woodward

Aidan Key



So what happened to the data?



ELSEVIER

JOURNAL OF
ADOLESCENT
HEALTH

www.jahonline.org

Original article

Youth and Caregiver Perspectives on Barriers to Gender-Affirming Health Care for Transgender Youth



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Paving the way for a future gender clinic

- Grand Rounds- focus on trans health
 - Meet with important stakeholders
- Ongoing meetings with clinic administration
- Connect with community organization
- Help with patient/parent advocacy efforts
- Connections with multidisciplinary teams
- Evidence-based care
- Primary or additional funding to support



Additional Funding



Additional Funding

- Local health equity funder
- Major grant: July 2016 through June 2017
- Funding for Seattle Children's Gender Clinic:
 - Community Outreach
 - Training of faculty, staff and community
 - Year 1 Program Evaluation
 - Advisory board



Additional funding

File Edit View History Bookmarks Tools Help

Mozilla Firefox Start Page x http://www...3dDG-800-82 x youth transgender barrier... x Center for Diversity and Health Equity

www.seattlechildrens.org/clinics-programs/diversity-health-equity/ Search

4800 Sand Point Way NE Seattle WA 98105 206-987-2000, 866-987-2000 (toll-free) Donate Now

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Center for Diversity and Health Equity

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Welcome بك أهلاً
Soo dhawoow Bienvenido
欢迎 Chào mừng

Created in 2006, Seattle Children's Center for Diversity and Health Equity (CDHE) strives to empower children and families at risk for [health inequities](#) and improve health outcomes for all children.

We work both inside and outside Seattle Children's and in partnership with the community to ensure our patients and all families in our region get the highest-quality care – no matter their race, ethnicity, language, literacy, age, gender, gender identity, sexual orientation, religion, disability or finances. Our work focuses on these areas:

+ Equitable care

Also in This Section...

- Overview
- Meet Your Team
- Contact Us and Locations
- Patient and Family Resources
- Talk to Us
- Hable con nosotros

Related Clinics and Programs

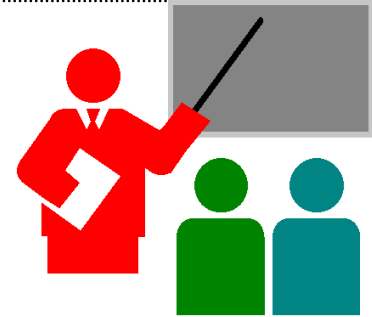
- Patient Navigation Program
- Interpreter Services
- Spiritual Care
- Center for Children with Special Needs
- Family Resource Center
- Centro de Recursos para Familias



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Working to implement participant recommendations at Seattle Children's Hospital

1. Education for pediatric staff and providers
2. Recording of chosen name & pronoun in EMR






- **The PHPDA grant is a big help**
 - Gender Clinic providers-sent to USPATH in Los Angeles
 - Providers and staff at Seattle Children's putting on a series of trainings (Trans 101) during the grant year that can continue to be presented in future years.
 - For some of these sessions, we'll bring in outside trainers to co-present
- **Epic scheduling software updated last summer**



Screenshot from Epic

Patient Demographics

Name:  SSN:

 **Name Edit** 

Title:

First name:

Middle name:

Last name:

Suffix:

Academic:

Confidential name:

Preferred name: Preferred type:

Screenshot from Epic

Krider, Test C	5111269
Pref Name: Harvey	Language: Minangkabau
Prefers HE/HIM *	Cmt.: These are the language comments. They d...
	Need Interp: No

Screenshot from Cerner/CIS

P BIRD, BIG - 5111214 Opened by Robinet, Dan

Task Edit View Patient Chart Links Notifications Navigation Help

Schedule Viewer Message Center Patient List Ambulatory Worklist Provider Home Patient Access List Staff Assignment Multi-Patient Task List

Tear Off Suspend Exit Calculator AdHoc Medication Administration Depart Communicate + Add Explorer Menu Charge Viewer

CHILD Patient Education Toolkits LabMan Policies and Procedures

ICD Data Medication Formulary CHILD Immunization Registry DynaMed Referring Provider Directory CIS Online Help Micromedex Formula an

BIRD, BIG x

BIRD, BIG "ROGER"

MRN:5111214 DOB:12/19/2015 Sex:Male

Account Number:30144544 Age:6 months Loc:ED; ED A x78822

Emergency [6/28/2016 13:14]

Menu Patient Summary

CIS Patient Contacts tab

?

Patient/Family

Language for Care: Minangkabau

Language Comment: These are the language comments. They do not have line breaks but they can be very long. The user can just type tired of it.

Patient Contact info from Epic:

KRIDER, TEST C

Pref Name: Harvey

Prefers HE/HIM

Home Phone: 360-121-1212

Work Phone: 230-456-4545

Mobile: 425-121-5454

Comments: These are the patient phone comments.
They have embedded line breaks that can be entered by the user.
This is line 3.
There is no practical limit to the number of lines.

Family Contact info from Epic:

Krider,Mom (Mother)

Lives With

Legal Guardian

(Legal documentation received)

Comments: free text comments go here

12101 Mountain View Place

AGATE, CO 80101

Home: 360-121-1212

Mobile: 206-121-1212

Work: 425-654-3210

Working to implement participant recommendations at Seattle Children's Hospital

1. Education for pediatric staff and providers
2. Recording of chosen name & pronoun in EMR
3. **Development of care protocols & a roadmap for families**
4. **Creation of multidisciplinary gender clinic**
5. **Providing pubertal blockers & cross-sex hormones at an age that permits peer-congruent development**
6. **Dedicated staff person to assist with insurance navigation**





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Seattle Children's Gender Clinic

Seattle Children's Gender Clinic (SCGC)

Adolescent and Young Adult Medicine

- Care Navigator
- Adolescent Medicine/Medical Director
- Endocrinologist
- SCH Psychiatry and Behavioral Health
- Community mental health
- RN
- Medical Assistants



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One day a week

Opened 10/4/2016

Patients 8-21 years old

Care coordination

Care Navigator

Initial phone intake

Case conferences weekly

Educational opportunities

Medical students, residents and Fellows

Community Advisory Board

Research



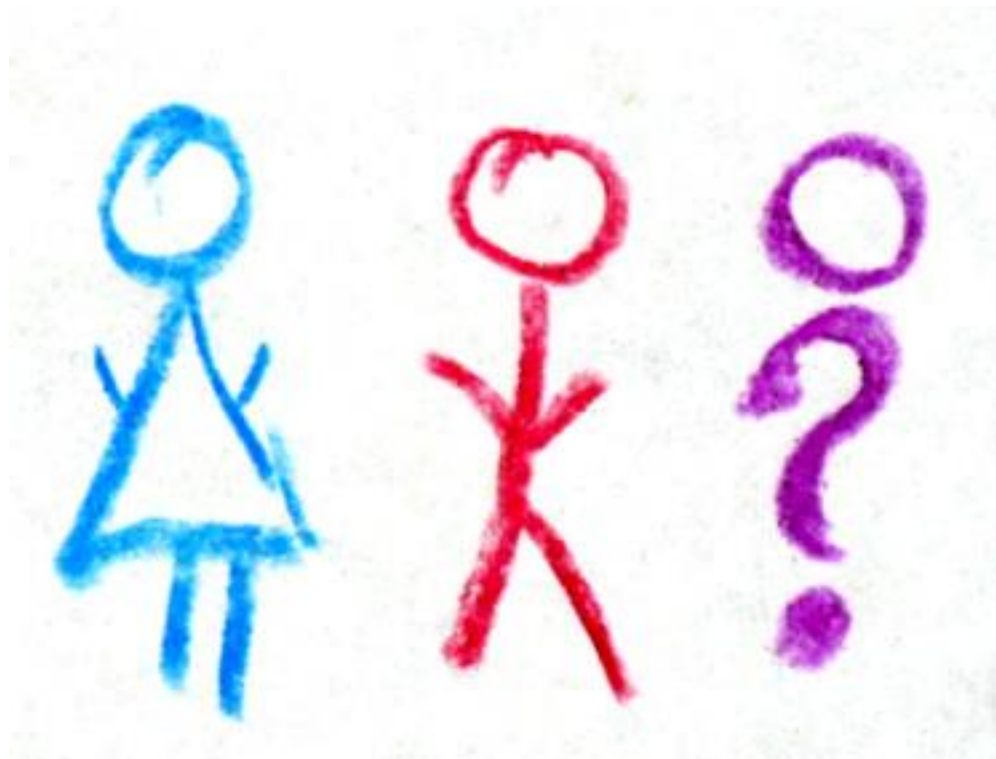
Systems for success



Adapted from Dr. Linda Hawkins (USPATH 2017)

Questions

Thank you for listening!!



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for
All Families



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Hope. Care. Cure.[™]