PLUS Legacy Report: Improving Health Outcomes for Gender Non-conforming Children Ilana Sherer, MD July 2011

Problem

Gender Variant children are at high risk for violence, bullying, suicide, and other issues starting at very young ages. Hormone treatments and psychological therapies exist that reduce these risks while allowing the child to express their affirmed gender. However, gender variance is poorly recognized and understood by pediatricians, and most pediatricians lack the skills to appropriately diagnose, counsel families, and provide or refer for appropriate care.

Key words

gender variant, gender spectrum, transgender, lesbian, gay, bisexual, mental health, gender transition, gender development,

Personal Learning Objectives

- 1. Educate self about current medical and psychological treatments for this population, review body of literature.
- 2. Learn about organizations currently providing services to this population in the geographical area, identify gaps in services, create asset map to Bay Area.
- 3. Identify and address challenges for clinicians when dealing with gender variant children.
- 4. Identify and address challenges for families when accessing care.
- 5. Develop a vision and project plan to address gaps in services that is clear to stakeholders and invites interest and further communication.
- 6. Develop strategies to navigate and network within a special interest community and become an active, contributing member.
- 7. Effectively communicate with community leaders to establish rapport and credibility to collaborate in a shared vision.

These learning objectives, once completed, revealed a need to address three pressing issues, which became my project goals:

Goals of Project

- 1. Create a setting where gender variant children can receive culturally-appropriate care for their specialty and general medical needs.
- 2. Educate pediatricians and other health care providers about gender issues.
- 3. Teach gender variant children/families the tools to self-advocacy within the medical setting

Activities (organized by goal)

Goal #1: Create a setting where gender variant children can receive culturally-appropriate care for their specialty and general medical needs.

I initially started my PLUS project by approaching local community organizations that were seeing gender variant youth and asking them what their needs were. Dimensions clinic, a local biweekly organizations at Castro-Mission Health Center providing care to LGBT youth (ages

roughly 18-25) for over a decade, responded that they were seeing more young adolescents presenting to their clinic with supportive parents who were looking for interventions to block puberty, and Dimensions was not sure how to provide this service and where to refer. The typical Dimensions clientele are marginally housed and independent young adults, and they felt unprepared to deal with this younger population, and had had some negative experiences referring to UCSF for care given the lack of sensitivity and training among providers and staff.

I next approached Gender Spectrum, an education and training organization located in the East Bay focused on working with schools and other professionals to increase support for gender nonconforming children. Their typical clientele are elementary-aged children and they work mainly in the schools and community organizations to support children with gender nonconforming presentations and prevent bullying and exclusion. They also spoke of the need to increase access to medical care for these younger children and were interested in approaching UCSF to create, what they put as "a single phone number where a parent or provider could call and reach someone on the other side who knew what they were talking about and could connect them with the care they need." While they knew there were providers at UCSF interested and skilled in seeing their population, they weren't sure how to access their expertise. As the intervention for younger children is hormone blockers to prevent puberty, they were interested in connecting specifically with the Pediatric Endocrinology program at UCSF and knew that Dr. Stephen Rosenthal was interested in getting their referrals.

I next approached Dr. Diane Ehrensaft, a developmental psychologist living in Oakland who is an international expert in the care of gender nonconforming children and their mental health needs. Her philosophy is "listen, and the children will tell you what they need," and she is often compared to the controversial and harsh reparative therapies espoused by Dr. Ken Zucker, a Canadian psychiatrist. However, recent mental health literature has been supporting her philosophies and Dr. Zucker has lost some standing in recent years.

The UCSF providers interested in working with this population initially got together in the fall of 2009, organized by Stephen Rosenthal and Shane Snowdon around the visit of Normal Spack from Boston Children's Hospital GeMS (Gender Management Service) clinic to UCSF to do endocrine grand rounds. Then movement stalled for a few months as we discussed politics and challenges of starting this project. Then, in the summer of 2010, with the support of Stephen Rosenthal from the endocrine department at UCSF, Diane Ehrensaft, Gender Spectrum, Dimensions, and the addition of Shane Snowdon, from the chancellor's office at UCSF, we put together an initial meeting of Bay Area providers interested in creating a "gender clinic" or network of care for all trans and gender-nonconforming youth in the Bay Area. The first major meeting took place in July 2010 and in attendance were over 30 individuals and representatives from organizations from as far as Santa Cruz and Fresno and covering mental health, political advocacy, legal issues, spiritual issues, medical health from adolescent medicine, psychiatry, and general pediatrics, and medical educators. We decided that this network of care should provide access to all the above services and we broke down into subcommittees to discuss further issues. I was chosen for the steering committee, and also to coordinate the medical committee.

The steering committee, consisting of the core community partners listed above (Dimensions, Diane Ehrensaft, Gender Spectrum, Stephen Rosenthal, Shane Snowdon, and me) in addition to UCSF psychiatrist Dan Karasic and representation from the UCSF Transgender Center of

Excellence Jamison Greene, has been meeting monthly since July 2010. We have created a mission and vision statement for the network, initially named Bay Gap, and now with the provisional name of the Child and Adolescent Gender Center, and a model of accessing care. We agreed that Gender Spectrum would act as an intake center for phone referrals from parents, patients, or providers, but we are currently working on a hiring someone to take over this responsibility. Once a patient has been referred, they will be seen in a multidisciplinary clinic housed at UCSF that will occur once monthly and have providers present from endocrine, general peds, social work, psychology, and psychiatry to start, and others may be added later. They will have their educational, mental health, legal, and medical needs addressed in this clinic, which will then serve as a consultation resource for their primary care providers and schools. We have already started to see about 15 patients through this portal and will continue to expand when we "officially" open our doors this summer. We are currently working to iron out details on space, funding, and creating a web presence and print materials to advertise our services. Ideally this fall we will start by meeting one morning or afternoon per month where we will have a full panel of patients scheduled to see medical and mental health providers and the clinic will be followed by a multi-disciplinary providers meeting. However, we anticipate that demand will quickly overwhelm infrastructure and so we have been delaying the start of the clinic until we are sure that we have the appropriate trainings and facilities in place to accommodate the patients. In addition, Dr. Rosenthal has reached out to pediatric endocrinologists around Northern California—in Sacramento, Central Valley, and as far north as Seattle, who are interested in working together to design a multi-center study to look at outcomes data.

Since our initial meeting, we have had several other larger meetings, the last of which, in April, was funded by **UCSF Community Partnership Grant** that Dimensions received. The purpose of this meeting was to hear from each of the individual committees and to approve our organizational name, mission, and vision statement, and project plan.

The medical committee has been meeting quarterly to establish medical protocols to treating the children and adolescents who encounter our medical providers, and I have coordinated the one meeting that we have had as of yet, with another scheduled for later this summer. There is still a significant amount of information to be determined and we anticipate that we will need ongoing meetings to figure out how to best meet the needs of patients who don't necessarily fit within the protocols set out by the Endocrine Society guidelines. We are also working to develop enhanced education for primary care providers. We are also working on determining how to best measures outcomes for our patients.

In addition to the achievements of the steering committee and medical committee, Diane Ehrensaft has been heading up the mental health committee "Mind the Gap," and they have had monthly meetings of 20-30 mental health providers who give each other professional support and development as practitioners for these patients.

My direct outcomes in this area are summarized as follows:

- a. Networking and creation of "resource map" of Bay Area professionals and organizations interested in improving care for gender variant children.
- b. Establishing strong partnership with community advocacy organizations and acting as liaison between UCSF and community organizations until Dr. Rosenthal could be identified.

- c. Working within UCSF to find home for medical clinic for gender variant children that would serve the needs identified by community organizations.
- d. Establishing institutional structure of The Gender Center
 - i. Serving on steering committee
 - ii. Coordinating medical committee (meeting quarterly)
 - iii. Writing mission/vision statement
 - iv. Composing project plan and logic model
 - v. Collaborating with Dimensions on UCP Grant application
 - vi. Networking with other clinics worldwide and serving as advisor and expert on various projects, including:
 - a. Advising/editing consents for hormone therapy for minors used by Planned Parenthood, Santa Cruz
 - b. Meeting with director of GeMS clinic in Boston (model for our clinic), Dr. Normal Spack during his visit to UCSF.
 - c. Serving as content advisor to Trans Bodies, Trans Selves book project
 - vii. (Inter)national presentations of BayGap's work at professional conferences:
 - a. Transgender Health Summit, UCSF April 9, 2011 "The Child/Adolescent Gender Center: A Model of Care for Gender Variant Youth."
 - b. Panel Presentation: "Bay Area Youth Gender Acceptance Project: A Gender Clinic Without Walls." World Professional Association of Transgender Health International Conference. Atlanta, GA: September 2011 (Planned).
 - c. Panel Presentation at American Psychiatric Association Institute on Psychiatric Services. San Francisco, October 2011.
 - d. Other presentations summarized below at PAS, GLMA, APA, Gender Spectrum family conference.

Goal #2: Educate pediatricians and other health care providers about gender issues.

When I started to present my work with BayGap to my residency colleagues, I soon realized that there was a huge need to educate other pediatricians about this population. An informal survey revealed that the majority of residents had little to no knowledge about this population, but felt that it was an important topic and one that they would encounter in practice. This point was hammered home for Raul and I when we presented at the APA regional conference in Monterrey in January 2010. Our assigned mentor, instead of giving us the feedback we desired on our project plan, instead asked very basic questions about "what is transgender?" and we realized that we could not begin to talk about our clinic model without first answering that question for all pediatricians. I realized that as a general pediatrician with strengths in public speaking and community organizing, I was in a unique position to take on this goal, especially in the setting of the BayGap group that had assembled. As most of the other providers were specialists and experts nearing the end of their career, I was the only generalist who could speak to primary care providers and trainees.

I started to assemble the conferences I had given to educate my peers about this population into a resource toolkit, or curriculum that could be made available to community pediatricians and other trainees. I attended the AAP national conference in 2010 and spoke at a session about

LGBT youth to answer some general education questions and brought up my interest in putting together tools for providers, and multiple people approached me after the presentation to ask for these tools. I got in touch with Michelle Forcier, a physician at Hasbro Children's Hospital in Providence, RI, who has been working with PRCH (Physicians for Reproductive Choice and Health) to put together a curriculum on transgender health care needs with a special focus on reproductive health. We have joined forces and are working together now to create a single gender curriculum that we can implement and test at our home institutions and then make available publicly through PRCH and that we plan to present at conferences in 2012, once we have some implementation data.

In the meantime, I have continued doing formal and informal presentations for residents on transgender and general LGBT issues and also put together a resource guide for San Francisco on a sticker that can go in the Eddie Book and on the continuity clinic and residency webpages. Multiple residents and faculty have approached me to tell me about a patient they knew what to do thanks to my resources and teaching.

In addition, I was approached by several providers at the AAP conference (Lynn Hunt, pediatrician and professor at UC Irvine, board member of Gay and Lesbian Medical Association and Lesbian Health Fund; Henry Ng at MetroHealth in Cleveland, a med-peds provider and director/founder of the LGBT Pride clinic in Cleveland, GLMA board member; and Christopher Harris, pediatric pulmonologist and past president of GLMA) who invited me to join their effort to develop a section devoted to LGBT issues within the AAP, and also invited me to present with them on a panel at PAS on LGBT health, which I did this spring.

My outcomes and achievements in this area are summarized as follows:

- a. Educational presentations within the pediatric residency program:
 - a. Transgender Adolescents in San Francisco, 2008
 - b. Advocating for Gender Variant Children, 2009
 - c. Medical Homes for Gender Variant Youth, 2010
 - d. Challenging Gender in Pediatrics, 2011
- b. Poster at APA regional meeting Works in Progress "Improving Primary Care Medical Home for Gender Variant Children" 1/10
- c. Presentation at Gay and Lesbian Medical Assn National Conference "Challenging Gender in Pediatrics" 9/10 with Raul Gutierrez
- d. Workshop Presentation at Pediatric Academic Societies Meeting 4/11 "Cultural Competence and Quality Care for Lesbian, Gay, Transgender Patients and Families," where I conducted a one hour training on transgender health.
- e. Poster Presentation at Pediatric Academic Societies meeting Advocacy SIG 4/11 "Laying the Foundation for a Multi-disciplinary Model Clinic and Resource Center for Gender Variant Children and their Pediatricians"
- f. SFGH Grand Rounds 6/11
- g. Creation of a resource guide in San Francisco for pediatric residents
- h. Creation of a unique UCSF Pediatrics curriculum covering major issues in gender variance over different developmental stages in childhood
 - a. Development and Behavior module on gender development in childhood (planned)

- b. Adolescent module on risks and management for LGBT teens (done)
- c. Continuity clinic module on dealing with issues of family acceptance for LGBT youth (done)
- d. General module on health and mental health needs of transgender youth (done)
- e. Pediatrics in Community module on San Francisco area resources for LGBT youth (planned)
- i. Future plans: test and implement this curriculum and make available through PRCH for public use in collaboration with Michelle Forcier.
- j. Future plans: continue to work towards creation of LGBT section in AAP

Goal # 3: Teach gender variant children/families the tools to self-advocacy within the medical setting

In addition to teaching providers how to work with gender variant children and families, I also want to work with families to help them advocate for themselves within the medical system. I have been invited by Gender Spectrum to speak at their family conferences and support group meetings, and have also worked with Parents and Friends of Lesbians and Gays in San Francisco to educate at their meetings and to advise on what books they should buy on this topic. In addition, I was asked to advise on a book project called Trans Bodies, Trans Selves on the content that should be covered on medical issues in children and youth and adolescents. This is a guidebook authored mainly by trans individuals and will serve as a comprehensive tome for trans people (www.transbodiestransselves.com). My bio is online under "The Team: Advisors."

My outcomes and achievements in this area are summarized as follows:

- a. Invited presentation at Gender Spectrum Family Conference to teens on medical treatments and body modifications 9/10 (with Dr. Jennifer Hastings)
- b. Invited presentation at Gender Spectrum Family Conference for parents (100 attendees) on panel of physicians as part of in depth medical session, but focusing on enhancing primary care experience (with Stephen Rosenthal, Carol Milazzo, Jennifer Hastings, Joanna Olson)
- c. Created brochure for families "Finding a Pediatrician for your Gender Variant Child" 9/10
- d. Invited presentation at PFLAG meeting in San Francisco on Gender Variant youth, 1/11
- e. Editing chapter on children and adolescents in book Trans Bodies/Trans Selves, Laura Erickson-Schroth, ed.

Outcomes

- 1. Project Outcomes and Sustainability Plans:
 - Currently seeing approximately 15 patients
 - Anticipate significant increase once clinic opens "officially" this summer
 - First patient recently started on cross hormone therapy after 2 years of hormone blockers
 - Community partners managing dozens of referrals for mental health and advocacy needs
 - Coalition of approx 25 mental health providers associated with the Center formed

Sustainability

- Sustainability of the Child/Adolescent Gender Center
 - Working toward financial sustainability
 - Program sustainability provided by community partners
 - I will continue to serve on the steering committee
- Sustainability of the Residency Curriculum and Provider Education
 - Current R2 to take over
 - This will continue to be a career interest/goal of mine, took a part time job for next year so that I can continue to work on this.

2. Award: UCSF Chancellors Award for LGBT Leadership

3. Publications: Formal

- a. Sherer, I. "Oh, My Father Hit Me." Narrative <u>Matters in Health Affairs</u>. July 2011. (in press).
- b. Sherer I, Rosenthal S, Ehrensaft D, Baum J. "Child and Adolescent Gender Center: A multidisciplinary collaboration to improve the lives of gender nonconforming children and teens." <u>Pediatrics in the Community in Pediatrics in Review</u>. Submitted.

4. Publications: Informal

- a. Sherer, I. Finding a Pediatrician for your Gender Variant Child. July 2010.
- b. Sherer, I. Creating an Affirming Pediatric Office Environment for Gender Nonconforming Children. July 2010.
- c. Sherer, I. San Francisco Resources for Transgender Youth. September 2010.

5. Presentations: UCSF

- a. Transgender Adolescents in San Francisco, 2008
- b. Advocating for Gender Variant Children, 2009
- c. Medical Homes for Gender Variant Youth, 2010
- d. Challenging Gender in Pediatrics, 2011
- e. Boys, Girls, and Others: Improving Care for Gender Variant Youth. Resident Conference Parnassus and Grand Rounds SFGH, 2011

6. Presentations: Community

- a. Hastings J, Sherer I. Medical Treatments and Body Modifications. Teen Conference at Gender Spectrum Family Conference. Berkeley, CA: July 2010.
- b. Milazzo C, Rosenthal S, Olson J, Hastings J, Sherer I. The Doctor is In. Panel Discussion at Gender Spectrum Family Conference. Berkeley, CA: July 2010.
- c. Sherer, I. Invited Presentation for Parents, Family, Friends of Lesbians and Gays, San Francisco Chapter. January 2011.

7. Presentations: Regional/National/International

- a. Sherer I, Gutierrez JR. "Improving Primary Care Medical Home for Gender Variant Children" Ambulatory Pediatrics Association Regional Meeting Works in Progress. Monterrey, CA: January 2010. (Poster)
- b. Sherer I, Gutierrez JR. "Challenging Gender in Pediatrics" Gay and Lesbian Medical

- Association National Conference. San Diego: September 2010. (Platform)
- c. Hunt L, Ng H, Harris C, Sherer I. Workshop "Cultural Competence and Quality Care for Lesbian, Gay, Transgender Patients and Families." Pediatric Academic Societies. Denver, CO: May 2011. (Workshop, I conducted a one hour training on transgender health)
- d. Sherer, I. "Bay Area Youth Gender Acceptance Project: A Multidisciplinary Collaboration to Improve the Lives of Gender Variant Youth." Advocacy SIG at Pediatric Academic Societies. Denver, CO: May 2011. (Poster within Advocacy SIG Meeting)
- e. Sherer I, Baum J, Karasic D, Rosenthal S. "Bay Area Youth Gender Acceptance Project, a community collaboration advancing care for gender variant youth." National Transgender Health Summit. San Francisco: April 2011. (Platform)
- f. Ehrensaft D, Baum J, Green J, Karasic D, Rosenthal S, Sherer I. "Bay Area Youth Gender Acceptance Project: A Gender Clinic Without Walls." World Professional Association of Transgender Health International Conference. Atlanta, GA: September 2011 (Panel: Planned).
- g. Ehrensaft D, Baum J, Green J, Karasic D, Rosenthal S, Sherer I. "Bay Area Youth Gender Acceptance Project: A Gender Clinic Without Walls." American Psychiatric Association Institute on Psychiatric Services. San Francisco, October 2011. (Panel, Planned).

8.Other Collaborations/Committees

- a. Content Advisor Trans Bodies, Trans Selves book project.
- b. Coalition creating Section on LGBT Issues within AAP.
- c. Advising with Planned Parenthood, Santa Cruz; Gender Spectrum, PFLAG San Francisco.

9.Direct Feedback/Surveys/Evaluations

- "Ilana gave me the tools that I needed to talk to MM's parents regarding her preference to be called "a boy."
- "Dr. Sherer has been tremendously resourceful in identifying LGBT resources for teens in my continuity clinic, providing the beginnings of a strong, enriching support system that is so critical for any young adult."
- "This was the best workshop I have ever been to. Ilana Sherer is absolutely outstanding and her presentation on transgender issues was superb—I wouldn't have guessed in a million years that she was a resident"
- Ilana is a brilliant, knowledgeable and fantastic presenter. Great interactive session.
- Dr. Sherer's presentation was outstanding, she should definitely present it again in the future.
- Present more sesions on issues with gender orienation in pediatrics.
- Life changing. Eye opening. Enlightening.

Lessons in Implementation

• A controversial issue can be de-politicized by emphasizing that supporting and affirming children prevents suicide.

- In the case of a topic like this where there is very little research or consensus, and virtually no demographic information, creating opportunities for research can be a type of advocacy in and of itself.
- While we don't know much about gender variance, we do know that family acceptance and early intervention are critically important to reducing later adverse health outcomes.
- When working on policy, timing is critically important and somewhat out of individual control. You have to wait for a policy window to open before pushing an agenda, but timing can be very serendipitous.
- When working with multiple stakeholders with much more experience than myself, it
 was important to carve out my own individual niche and identify my own area of
 expertise to contribute to the larger group effort.
- Pediatric providers tend to lump gender issues together with LGB issues and consider them an adolescent issue, so it is very important to educate them about early recognition of gender variance as a developmental issue in early childhood.
- By just talking about a particular issue, other people start to consider you an expert, even if you don't feel like you deserve that reputation. However, you can use that perceived expertise to push forward goals and educate others.

Resources

- a. UCSF Residency: Raul Gutierrez, Stanley Vance, Ari Zadel
- b. UCSF Pediatric Endocrinology: Stephen Rosenthal
- c. Chancellors LGBT Committee/UCSF LGBT Resource Center: Shane Snowdon
- d. Gender Spectrum: Joel Baum, Stephanie Brill
- e. Dimensions Clinic: Dafna Wu, Deborah Brown, Michael Baxter
- f. Mental Health Network: Diane Ehrensaft
- g. Family Acceptance Project
- h. Transgender Law Center
- i. UCSF Psychiatry: Dan Karasic, Karl Jeffries
- j. Planned Parenthood: Jen Hastings
- k. Childrens Hospital LA: Jo Olson
- 1. Transgender Center of Excellence: Jae Sevalius, Joanne Keatley, Jamison Green
- m. Carol Milazzo
- n. Boston Childrens GeMS Clinic: Normal Spack

References

Brill, S. and Pepper, R. The Transgender Child. (2008) Cleis Press. San Francisco.

De Vries, A., Cohen-Kettenis, P., Delemarre-van der Wall, H. "Clinical Management of Gender Dysphoria in Adolescents." IJT 9.3/4 (2006): 83-94

Hembree, W., Cohen-Kettenis, P, et al. "Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline." JClinical End & Metabolism 94/9 (2009): 3132-3154

Ryan, C., Huebner, D. et al. "Family Rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults." Pediatrics 123/1 (2009): 346-352.

Ryan, C. "Helping Families Support their Lesbian, Gay, Bisexual, and Transgender Children." (2009) Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

"Harsh Realities: The Experience of Transgender Youth In Our Nation's Schools. Gay Lesbian and Straight Education Network. 2009

Olson J, Forbes C, Belzer M. Management of the transgender adolescent. Arch Pediatr Adolesc Med. 2011 Feb;165(2):171-6.

Ehrensaft, D. Gender Born Gender Made. In Press.