

#### **Dear Friends**,

The Gender & Sexuality Development Clinic (GSDC) was founded in January 2014 and with our exciting growth over last few years we are pleased to share with you our first Annual Update. The clinic team provides medical care and psychosocial support for gender non-conforming and transgender children and adolescents and their families. The GSDC is a collaboration among the divisions of Adolescent Medicine and Endocrinology, and the Departments of Behavioral Health, and Social work and Family Services at the Children's Hospital of Philadelphia. Now in its third year, the clinic has served more than 500 youth and their families from our local community to as far as North Carolina. While our first priority will always be to deliver the highest quality, state-of-the-art care to our patients we are pleased to also highlight other important areas of focus for the clinic.



**State-of-the-Art Patient Care** The clinic team, with now over 10 staff members, includes a mental health gender specialist, social worker, adolescent medicine specialists, endocrinologist, gynecologist, psychiatrist, intake coordinator nurses, and insurance specialist. We offer comprehensive psychosocial assessment by a mental health gender specialist and referrals to community partners for on-going therapy and primary care clinicians locally to provide a supportive medical home. Our medical practice includes services such as puberty-blockers, gender-affirming hormones, referrals for fertility preservation, and gender affirming surgeries when appropriate. This year the clinic completed over 900 visits with approximately 4-6 new referrals per week.



**Support Services** Beyond the walls of clinic we know that the young people we care for face many challenges in their communities and classrooms and they often feel that they are going through these experiences alone. In response to these concerns, we collaborated with the Mazzoni Center Pediatric and Adolescent Comprehensive Transgender Services (PACTS) program and developed a therapeutic support group for patients, caregivers, and siblings that meets monthly. We have also created a Medical-Legal Partnership with the University of Pennsylvania Law School which recently included community lawyers creating a legal workshop where 18 families received in-person answers to their legal questions and concerns, and another 25 families were connected with low cost or free legal guidance.



**Education and Training** In addition to providing the highest quality care for our patients we want to share what we have learned with as many youth-serving professionals as possible. This year our staff has provided over 500 hours of training to practicing pediatricians and other healthcare providers, teachers, and other youth serving professionals, both locally and nationally. We are strongly committed to supporting the next generation of professionals to provide gender-affirming care. This year we have provided opportunities for more than 20 medical, mental health, and social work trainees to have on-site, intensive training at the GSDC. Many schools reach out to us to provide trainings to their leaders and teachers to improve the classrooms for transgender students. We average 2-3 trainings every month! We are also particularly proud to support implementation of the new Philadelphia School District Policy 252 by partnering with the University of Pennsylvania and the Attic to train teachers and staff.



**Innovative Research** We believe that research is critical to improving outcomes for our patients. This is especially true in the field of health of transgender youth where little evidence exists to guide us. To date the clinic has received more than 5 federal, foundation, and local grants and institutional support was provided to develop a registry to follow long-term medical and psychosocial outcomes for our patients. Together with collaborators we are doing research across a broad range of issues including HIV prevention among young transgender women, pediatrician competence in providing care to LGBT youth, health insurance and policy impact on access to gender-affirming care, fertility preservation, and understanding genetic diversity of gender expression.

In the aftermath of the recent US presidential election, many patients and families have expressed concerns about whether our clinic will continue to exist. We are proud to respond that CHOP and our clinic team are committed now more than ever to our mission. We hope you will join us in celebrating our accomplishments and the wonderful staff who do this work every day. We look forward to a new year of supporting youth across the gender identity spectrum to be their happiest and healthiest selves.

Sincerely,

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Nadia Dowshen, MD, MSHP Co-Director, Gender & Sexuality Development Clinic Craig-Dalsimer Division of Adolescent Medicine Assistant Professor of Pediatrics, Perelman School of Medicine at the University of Pennsylvania

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Linda Hawkins , PhD, LPC Co-Director, Gender & Sexuality Development Clinic Department of Social Work and Family Services

## **Community** Engagement

### Project SHINE (Supporting Healthy IdeNtitiEs) for Transgender and Gender Non-Conforming Youth

#### Why Project SHINE?

Barriers to healthcare access for transgender and gender variant youth are many. Due to their gender identity, transgender or gender variant youth are often met with rejection from family and community creating an increased risk for poor mental and physical health outcomes, victimization, and even homelessness. Compounding these individual-level barriers to care, is the lack of knowledge of care providers; few pediatric physicians and other service providers are trained to provide appropriate screening, referrals, and on-going care for gender variant youth. To address this gap, we recently formed the Gender and Sexuality Development Clinic (GSDC) at The Children's Hospital of Philadelphia (CHOP) where gender variant youth are able to access care. While this clinic is an important component of care, the majority of gender variant youth will likely not need or have access to services offered by CHOP, but rather a supportive health care environment and local resources. The purpose of this project was to gather information on ways to best support transgender, gender variant and/or gender expansive youth to inform the practices within the GSDC and ensure high quality care. We aim to provide comprehensive healthcare and other related services throughout Philadelphia and the surrounding areas.



#### **About Project SHINE**

Because the success and sustainability of this program will rely heavily on input from the community, we interviewed 10 community stakeholders who have worked with transgender and gender variant youth. In addition, we conducted two focus groups: one with 6 youth who identify as transgender or gender variant and another with 8 parents of transgender or gender variant youth. Of the stake holders that participated, 80% were white and 20% were black; the majority identified as female (60%) and had on average 8.7 years [range 1-23 years] of experience in their profession as someone with experience working with gender- variant youth.

For the focus groups, we recruited youth and their caregivers who are clients at the GSDC and attend the youth and caregiver support groups. The parent focus group comprised 8 parents of GNC youth with their child's mean age of 15.5 (SD 1.58, Range: 14-18 years). The youth group participants (n=6) were on average 18 years old (SD 1.41, Range 16-20), 66.7% White, 33.3% multiracial, 16.7% Hispanic/Latino(a), and from surrounding Philadelphia and New Jersey counties.

## What We Learned...

#### **CHALLENGES TO CARE ACCESS**

(-) Providers, caregivers, and youth described issues obtaining insurance and approval for initial visits.

For most of the participants, the lack of providers who specialize in gender identity or the lack of knowledgeable and culturally competent providers precluded youth and families from accessing the care they need.

Many participants believed that youth feel uncomfortable or reluctant to visit with a care provider as they are afraid they will experience trans-phobia.

#### **CHALLENGES WITHIN CARE**

- (-) While a care provider may be knowledgeable, policies and guidelines for practices adhere to the binary system; medical forms still use binary language, have to select "other" for gender.
- (+) Patients are often outed in the practice office, emails, and insurance that still use old name.
- Caregivers and providers noted that due to the lack of insurance coverage for gender-related services, both caregivers and providers had to spend a lot of time working to appeal denials of coverage of medically necessary services by insurance companies.

Youth also noted that even with knowledgeable care providers, theses providers still said inappropriate things regarding their identity and were not as educated on GNC health as they thought.

#### SUGGESTIONS FOR IMPROVEMENTS TO CARE

- Participants would like to see insurance companies cover more gender-related health care and listen to their GNC clients.
- Providers need to stay up to date on gender health resources and information; they need to respect their patients by using trans friendly language and listen to their health needs and concerns.
- (A) Institutions need to be more GNC friendly--providing inclusive medical forms that are not binary, well-trained staff.

Parents would like resources and a support network– finding provider locations, learning about hormone therapy, surgery, and connecting with other families with GNC children.

## **SHINE Next Steps**



Work with SHINE Advisory board to set priorities for the Gender and Sexuality Development Clinic at CHOP together with community partners to support the health and well-being of GNC youth in the Philadelphia Area.



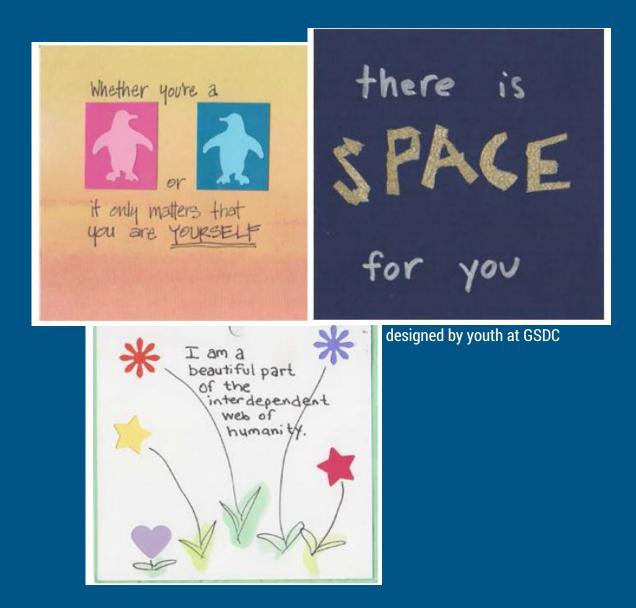
Collaborate with other centers of excellence for trans and gender nonconforming care to develop best practices and a comprehensive resource list for youth and their families.



Provide training for health care providers in Philadelphia regarding the specific health needs of trans youth and best practices.



Develop partnerships with other local community groups and resources (e.g., organizations and Philadelphia School District) to create a supportive environment.



# **RESEARCH PROJECT** HIGHLIGHTS

Transgender and gender non-conforming youth have unique health needs and experience significant barriers to care due to social stigma associated with their gender identities. Further, transgender and gender non-conforming youth also face increased risk for a variety of negative physical and mental health outcomes such as high rates of suicide attempts and HIV infection. While treatment options and the availability of care has improved for this population, there is a dearth of research on health care access and outcomes for gender non-conforming youth. In order to address this knowledge gap, the GSDC at CHOP has been working on several studies.

#### Impact of Care on Transgender-Identified and Gender Variant Youth

This study was a qualitative, ethnographic study of patients seeking services at GSDC for children and youth aged 7-21 years old. The primary objective was to determine the ways in which medical and psychosocial treatments (including psychotherapy, puberty-blocking therapy, and hormone therapy) impact gender variant and transgender-identified children and adolescents. Enrolled participants were interviewed using a semi-structured format and if family members participated, they were interviewed simultaneously. With participants' consent, we also followed participants and their families outside of clinic, with additional interviews conducted in their home and school environments. These methods allowed us to explore how participants' experience the process of care and transition over time. We enrolled more than 25 youth and their families and are currently analyzing data.



Josh Franklin, a Penn MD/PhD student and the study's lead author is currently applying for a F30 (Individual Pre-Doctoral Fellowship) grant from the NIH to further explore the way that social factors such as race, class, and disability impact access to gender affirming care and the experiences of that care. His research interests include gender and sexuality, mental health, and the anthropology of biomedicine. His work at CHOP is part of a project which explores the impact of care and role of medical institutions in the lives of transgender-identified and gender nonconforming youth in Philadelphia.

#### Young Transgender Women's Attitudes toward HIV Pre-Exposure Prophylaxis

Up to 1 in 4 young transgender women (YTW) in the US are living with HIV and globally transgender women are 50 times more likely than the average person to become infected with HIV. As part of a larger study on how to improve HIV prevention and treatment for YTW we used qualitative methods to explore attitudes and experiences with HIV Pre-Exposure Prophylaxis (PrEP). The newest option in the HIV prevention tool box, PrEP is a daily pill to prevent HIV infection that, if taken properly, is more effective than most vaccines. Among the 25 young women we interviewed for this study, one-third of participants had never heard of PrEP. Participants cited many reasons they thought PrEP was an important option for their community including that it could make their relationships with sexual partners better and help them to feel empowered. Despite overwhelmingly positive attitudes towards PrEP many participants didn't think they would be able to afford it, especially if they didn't have access to other gender-affirming treatments such as hormones. This study was recently accepted for publication in the *Journal of Adolescent Health*.

Dr. Sarah Wood, MD, the study's lead investigator and an adolescent medicine fellow at CHOP recently received a University of Pennsylvania Centers for AIDS Research Pilot Grant and NIH F-32 Award to study how social support networks can improve success with taking PrEP for YMSM and YTW at-risk for HIV infection. Sarah's research interest include exploring the implementation science of biomedical HIV prevention, as well as identifying barriers to successful treatment for youth living with HIV.

# **SPECIAL PROGRAM** HIGHLIGHTS

#### **Support Group**

So many of our patients and families have described feeling isolated and alone when navigating the challenges faced by transgender youth. In response, we formed a therapeutic support group together with the Mazzoni PACT program for youth and families from both clinics. Group started in February 2015 with the aim to provide a safe space for parents and gender non-conforming youth to meet each other and collaborate for support and strength. These groups meet monthly with separate groups for children (5 – 14 years old), adolescents (15-20 years old), and parents. Each group is facilitated by trained specialists under the leadership of Erica Smith MEd. The parents have taken this as an opportunity to build a community and provide support and guidance to parents newly attending these sessions and appreciate their child's gender identity.

#### "Group is a space where we can all talk about the amazing and brave ways that our children shine. We don't have to explain or defend our child's right to be who they really are here."

#### - Parent at GSDC Support Group

The youth participants meet with other children and teens like themselves, which has had profound benefits. For example, many of the high school youth shared that they were also members of the Gay Straight Alliances (GSAs) at their schools, but they were frequently the only transgender student in the group. Youth tell us that being part of a group with peers who understand their challenges and strengths has been incredibly beneficial.

"Just having our children see other people like them is so healing. My daughter often asks if she should have been born and to see other people born just like she was is life affirming."

- Parent at GSDC Support Group



Initially funded by the CHOP Cares Grant awarded to Drs. Dowshen and Hawkins, these groups are now supported by the Department of Social Work and Family Services due to the success of the program. Each month there are nearly 40 parents, 30 teens, and 15 children who attend. In 2016, we added a sibling group as well, which hosts at least a dozen siblings each month.



## **Medical Legal Partnership**

Our patients experience a broad range of challenges due to their gender identity in their families, schools, and communities such as wanting to change their names or access bathrooms, locker rooms or sports teams based on their affirmed gender. Many times these goals are unable to be accomplished without legal action. In order to fill this need, together with the support of the CHOP Social Work and Family Services Department and PolicyLab we collaborated with the University of Pennsylvania Student Legal Clinic for form a Medical Legal Partnership (MLP). MLPs are designed to bring lawyers to health care teams to improve the health and well-being of underserved populations. So far the MLP has served over 25 youth and their families.

Our legal partners are also working on developing guides for addressing insurance coverage issues and the process of legal name change. Dr. Dowshen is working together with PolicyLab staff to design a robust evaluation and plan for disseminating this model to other clinics across the country which may also benefit.

# **STAFF** and **COMMUNITY PARTNER** HIGHLIGHTS

Joseph Beeman, BA, joined CHOP's GSDC in December 2015 as a clinic intern. Prior to his work at CHOP, Joseph worked and volunteered in various public health positions in Chicago. Most recently, he worked at Ann and Robert H. Lurie Children's Hospital in The Center for Gender, Sexuality and HIV Prevention as an HIV counselor and linkage to care coordinator for adolescents and young adults.

In addition to this position, Joseph is completing his senior nursing clinical in CHOP's Adolescent Specialty Clinic where GSDC is located. In these dual roles, Joseph conducts intake assessments, coordinates appointments, assists with testosterone injection teaching, insurance approval for hormones and puberty blockers, and serves as a patient advocate and resource during the medical transition process.



Joseph received his BA in Biology and Women's and Gender Studies at University of Missouri and is currently enrolled in the University of Pennsylvania's Accelerated BSN/MSN program. His graduate studies will focus on children's and adolescents' psychiatric and mental health.

"I came to nursing school because I wanted to learn how to provide health care to queer and trans youth. My work at the gender clinic has helped me to focus my nursing education on this goal. From refining hormone therapy consent forms, to navigating the complicated pathway of insurance authorization, supporting families through their gender transition processes has been my most formative and rewarding nursing experience so far."

Natasha Graves, MPH, CHES, currently serves as the Youth Care Team Manager at the Philadelphia Department of Public Health's Division of Maternal, Child and Family Health. In this role, she provides assessment, health education, referrals, and linkages to services. She offers youth goal setting sessions and birth control counseling to youth in the city's District Health Centers. Additionally, Natasha collaborates with organizations across the city to increase access to quality care for LGBT youth; increase access to effective contraception, such as LARC methods for Philadelphia women and youth; and provides workshops to Philadelphia youth about reaching goals and reproductive health. Natasha is also a committee member and partner of the Philadelphia FIGHT, CHOP Adolescent Initiative Program, and Hip Hop for Philly.

Most recently, Natasha has been collaborating with GSDC on phase 3 of the SHINE project. The goal of this project is to survey pediatric primary care providers in the city of Philadelphia to assess their knowledge, attitudes, and skills in caring for LGBT children and adolescents. The long term goal of this project is to develop trainings and education for pediatric care providers in Philadelphia so that all providers are equipped with the skills to serve transgender and gender non-conforming youth. GSDC is grateful for all the work that Natasha has done in the community and together with CHOP to serve transgender youth in Philadelphia.

Natasha received her B.S. in Health Education, focused on Community Health from Howard University and is a Certified Health Education Specialist (CHES). She received her MPH from UCLA's Fielding School of Public Health in Community Health Sciences and is currently earning her MBA at Temple University.



"Collaborating with CHOP is always a wonderful experience because I am able to work with so many brilliant people who are passionate about the work that they do. I am able to not only make a difference in the lives of others through education and empowerment, but learn from so many wonderful staff, faculty members and clients/patients."

# How You Can Help Us

#### Tell one new person about the Gender & Sexuality Development Clinic at CHOP

With your financial support, we can expand the Clinic's services and research capabilities, allowing us to serve even more children and their families. To learn how you can make a difference contact, **Matt DiBattista, Director of Development**, at **dibattistam@email.chop.edu or 267-426-6502**. You can also visit **giving.chop.edu t**o make a donation online.

**CONTACT:** 215-590-3537 **email:** genderclinic@email.chop.edu **website:** http://www.chop.edu/centers-programs/gender-and-sexuality-development-clinic

## Thank You to Our Funders & Partners

In addition to numerous individuals who support our work, we would like to recognize our funders and our partners: Divisions of Adolescent Medicine & Endocrinology @ CHOP Departments of Social Work and Family Services &

Child and Adolescent Behavioral Health @ CHOP





A program of the American Academy of Pediatrics

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