

GENDER & SEXUALITY DEVELOPMENT CLINIC 2018 UPDATE



Dear Friends,

As we look back on 2018, we are pleased to share some incredible milestones accomplished in the clinic's fourth year of life. Our multidisciplinary team has continued to grow, which has allowed us to reach the point of providing medical care and other services to more than 1000 children, adolescents, and their families!



Innovative Multidisciplinary Medical Care This year marked an expansion of our clinical capacity by adding a nurse practitioner to our existing team of three physicians. We are proud to welcome Ms. Lazar to the clinical team, who has many years of experience in caring for LGBT adolescents. We have also increased partnerships with pediatricians across the region so that they can provide the most support possible to children and families in their own communities. We hosted several visits for institutions across the country so they could learn from our youth- and family-centered multidisciplinary model of care. With the goal of constantly improving quality of care, we worked this year to streamline referral processes for other essential medical services such as fertility preservation and masculinizing chest surgery.



Support Services This year, adding extended family to our support group has been a huge success. Each quarter, we had more than 30 grandparents, aunts, and uncles attend. Due to popular demand, we will be increasing the frequency of these meetings to monthly. We also expanded to include a new Tween group and the Littles (our youngest participants, ages 4-9) have renamed themselves the *Mightys*. Overall, our support groups are convening 100-120 people every month!



Education and Training With generous funds from CHOP and a local foundation, we expanded our training and education efforts in schools to reach more than 35 schools throughout the region. These trainings were both focused on ensuring a safe and comfortable school environment for our transgender patients as well as un-gendering classrooms, which is better for all students. As a result, more of our patients are staying in school than a few years ago. We are thrilled that some of our youth are working with their schools to start Gay-Straight Alliances, running for student government, and leading the way to create gender-affirming policies in their schools.



Innovative Research This year we have taken on new projects in areas most relevant to improving the health and well-being of our patients and their families. Together, with our collaborators, we are studying a broad range of issues including describing the impact of school bathroom policies on nutritional outcomes and school attendance; measuring patient reported outcomes of implants for puberty suppression; understanding the experiences of our patients on what may challenge or facilitate gender identity affirmation; and improving the understanding of transmasculine youth's experiences of chest dysphoria and potential benefits of masculinizing chest surgery. We have presented our findings at more than 25 national meetings and published more than 35 peer-reviewed manuscripts, book chapters, blogs and op-eds.

As we near our fifth clinic birthday, we reflect in the following pages on the vision that we had when we started this clinic – to create a safe space where gender diverse youth can be healthier, happier and their true selves with the support of their families. We quickly learned that this must also include efforts outside the clinic walls, to make the world better for the children and adolescents we care for and their families. Please join us in celebrating our team's accomplishments as we look forward to another year of this great and humbling work.

Sincerely,

A handwritten signature in black ink that reads 'Nadia Dowshen'.

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

A handwritten signature in black ink that reads 'Linda Hawkins'.

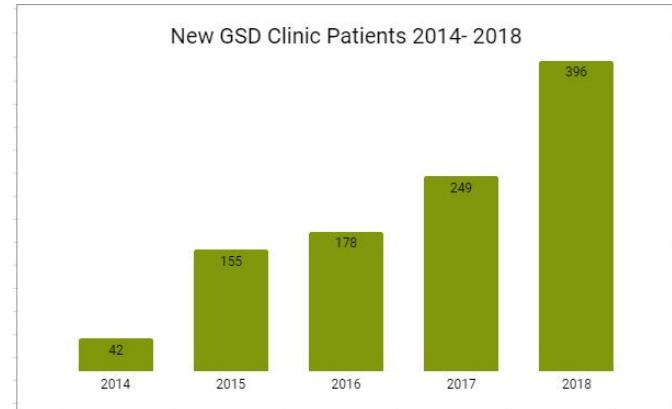
Linda Hawkins, PhD, LPC

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

STATE-OF-THE-ART MULTIDISCIPLINARY CARE

In order to meet the needs of the families we serve, our clinic uses a multidisciplinary approach to care and our team includes specialists from multiple disciplines – behavioral health, social work, pediatric endocrinology, and adolescent medicine. In this past year, we have added a nurse practitioner to our team of three physicians expanding our clinical capacity, and we continue to work with multiple physicians in training to ensure that we educate the next generation of providers to be competent clinicians for transgender children and adolescents. In addition to our growing clinical team, we host social work interns and have added a chaplain as a resource for families. Through this approach, we continue to build supportive services for our families on all levels of care – medical, emotional, and spiritual.

Given that many of our families come to us from across the region, this year we have focused on increasing our partnerships with primary care pediatricians and other healthcare providers beyond the CHOP network. To do this, we conducted trainings with local providers and their teams, as well as developed mentoring relationships to support the development of high quality clinical care throughout the region. Our goal is to help other clinics learn more about our model and build up their own gender clinic.



Leader in LGBT Healthcare Equality

In 2018, the Human Rights Campaign (HRC) designated CHOP as a leader in LGBT Healthcare Equality. HRC uses its LGBT Healthcare Equality Index, based on four criteria, to evaluate healthcare facilities' policies and practices related to the equity and inclusion of their LGBTQ patients, visitors, and employees. We are proud to share that CHOP received a perfect score in each category which led to a citation from Pennsylvania Governor Tom Wolf. Dr. Hawkins also continues to serve on the Committee for Transgender Pediatric Care, hosted by the HRC, that identifies best practice in medical and mental healthcare for transgender and gender expansive children and youth.

Resource Mapping

We recognize that our families need resources and support that extend past our clinic services. To ensure that our families are able access additional resources, we:

- Vet mental health therapists that are close to home for our families in order to ensure a referral to a kind, caring, gender-affirming and competent provider. This year Katelyn Regan, MSW and Nadia Dowshen, MD, MSHP have published this model in the American Academy of Pediatrics Adolescent Medicine State-of-the-Art Reviews.
- Find gender-affirming clothing and prosthetic items and strategize ways to make them as cost-effective as possible.
- Cultivate a list of surgeons who are experts in gender-affirming care.
- Find resources according to family needs, including LGBTQ-inclusive gyms, hair salons, estheticians, after-school programs, support groups
- Connect with local pediatricians to see what education they need to provide gender-inclusive care at their offices

New Team Member

We are thrilled to welcome Nellie Lazar to the gender clinic team! Nellie joined the GSDC in 2017 following many years of clinical experience working youth and adults living with HIV, including many transgender individuals, at multiple health centers in Philadelphia. She has been a Family Nurse Practitioner for 15 years and completed the prestigious Leadership in Education and Adolescent Health (LEAH) adolescent fellowship with a focus on HIV care and women's health.

Nellie received her Master's of Science in Nursing from the University of California, San Francisco and her Masters of Public Health from the University of Massachusetts, Amherst. Nellie was a Peace Corps volunteer in Guatemala and speaks Spanish fluently. She is now faculty for CHOP's HRSA-funded LEAH multidisciplinary adolescent health fellowship and lectures at the University of Pennsylvania School of Nursing.



“Working with families and patients at the GDSC has been a privilege and extremely rewarding. I have a chance to support and connect with youth who are going through an amazing journey, and I am humbled to be a part of their medical team. We know that if we affirm youth in their transition, they have the opportunity to thrive and achieve their dreams. It not only benefits patients and their families, but all of us and society. Working at GDSC has made me a better provider.”

IMPROVING HEALTHCARE SYSTEMS AND POLICY TO SUPPORT TRANSGENDER YOUTH

New CHOP Policy

To address the needs of our patients beyond our clinic and throughout our large hospital network, we have implemented, in collaboration with hospital leadership, a new policy: Caring for Transgender and Gender Non-Binary Patients, Families, & Guests Policy. This policy will address the best practices for supporting gender expansive and transgender individuals in all areas of care – from the first intake call to interactions with providers and clinical staff at an outpatient visit to the logistics of room assignments when a patient is hospitalized. The goal is to provide the most competent, seamless, and supportive care possible. This policy officially rolled out in June 2018, and our team has been diligently developing and leading trainings to ensure its implementation.

Linda Hawkins has completed trainings throughout the CHOP network of primary and specialty care providers, including the Emergency Department and at Karabots Pediatric Care Center in West Philadelphia. In 2018, Linda trained nearly 300 CHOP staff. In addition, Katelyn Regan, our clinic social worker, has completed three training for more than 90 Advance Practice Providers (APP) who care for patients in inpatient and outpatient settings. APPs include Certified Nurse Midwives (CNMs), Certified Registered Nurse Anesthetists (CRNAs), Certified Registered Nurse Practitioners (CRNPs), Clinical Nurse Specialists (CNSs) and Physician Assistants (PAs). These trainings have been critical to ensure that staff not only are able to implement this policy, but also understand the importance for all patients and families.

Steps to Improve Health Systems and Access to Care for Transgender Youth

Informed by our research and clinical expertise, we partnered with Policylab, a research center of emphasis at CHOP, to design two policy briefs led by Nadia Dowshen and Siobhan Costanzo, that outline recommendations that health systems, policymakers, and providers can use to improve quality and access to care for transgender and gender-expansive youth.

Ensuring providers have the knowledge and support needed to care for transgender youth

Like most young people, transgender and gender-expansive youth often have a pediatric primary care provider (PCP) who is their first or only point of contact in the healthcare system. Unfortunately, many of these providers feel they do not have the training or experience needed to manage the unique healthcare needs of this population. This policy brief outlines these barriers, the resulting hardships for patients and families, and recommendations on how to improve care.

You can find this policy brief here:

<https://policylab.chop.edu/policy-briefs/ensuring-providers-have-knowledge-and-support-needed-care-transgender-youth>

Importance of improving insurance coverage for transgender and gender-expansive youth

Transgender and gender-expansive youth face unique challenges. Restrictions on accessing evidence-based, gender-affirming health care may lead to more youth experiencing more severe preventable mental and physical health problems. This brief outlines evidence-based recommendations that states and insurance payers can use to expand access to coverage and, ultimately, improve the health and well-being of this population of children, adolescents and young adults.

You can find this policy brief here:

<https://policylab.chop.edu/policy-briefs/importance-improving-insurance-coverage-transgender-and-gender-expansive-youth>

COMMUNITY ENGAGEMENT & ADVOCACY

Education and Training

As our patient population continues to grow, we have continued to support our families outside our clinic walls. This past year, we focused efforts on creating inclusive and affirming school environments. At the end of 2017, we received a grant to fund a full-time educator. Our own Samantha King, MSW, M.Ed, has hit the ground running as the Education Coordinator. In this role, Sam designs and leads trainings for teachers, administrators and other school staff on language and terminology related to gender, how to establish trans-inclusive policies and gender-inclusive environments, and what the impact and outcomes are for students who are not affirmed in their educational setting. Based on her efforts, we have received an increase in demand for these trainings and, our patients report positive changes in their experience in schools – youth and their families feel more supported by educators and administrators in their school district and more schools are recognizing the need to increase their competency in supporting transgender students.

Over the past four years we have completed more than 80 trainings. This year alone, Samantha provide 45 trainings to schools in Pennsylvania and New Jersey.

“The gender clinic at CHOP has given me the educational tools to become a partner with my child’s school in our combined efforts to protect my son. When you have a transgender child, you need allies. CHOP has opened doors to me so that I never feel alone, whether it is through the support groups, friends, social workers, or doctors.”

- Parent of GSDC child

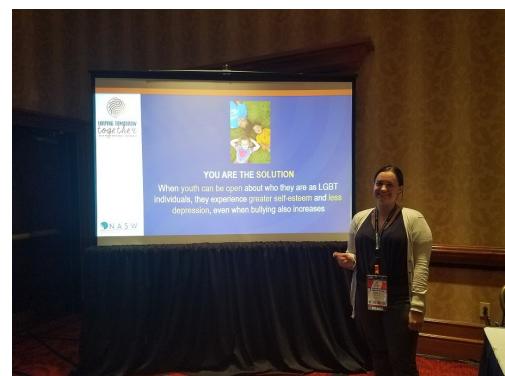


In addition to this success, we also were awarded a grant from the Pennsylvania Office of Mental Health and Substance Abuse to expand our training efforts throughout the state of Pennsylvania. These trainings will focus on supporting mental health clinicians throughout the state with knowledge and skills to better support their transgender clients. We are very excited about the opportunity to expand the reach of our trainings, especially in more rural areas of the state where fewer resources may be available for transgender youth.

Local and State Advocacy

Unfortunately, this year our patients and families faced a number of potential policy challenges on the state and federal level. One such example was a state proposal to add a clause to the Pennsylvania Children’s Health Insurance Program (CHIP) bill to exclude coverage of medically necessary services for transgender children and adolescents. The CHIP program in PA provides insurance coverage for many children and adolescents and such a clause could restrict access to care for young people whose parents could not otherwise afford it.

In partnership with PolicyLab and Community and Government Affairs at CHOP, Dr. Dowshen wrote an op-ed in the Philadelphia Inquirer and spent a day meeting with state legislators on both sides of the aisle in Harrisburg about the potential harms of excluding care for transgender youth. Legislators were grateful for the information about the care we provide at CHOP and how critical it is to the health and well-being of the young people we serve. Thankfully, the CHIP bill was passed without exclusion. Additionally, Dr. Hawkins sits on the state Transgender Health Committee to advise the governor on issues related to transgender health.



SPECIAL PROGRAM HIGHLIGHTS

Support Groups

Our monthly therapeutic support groups, in collaboration with the Mazzoni Center, have continued to grow since their implementation in 2015. These groups provide further opportunity to support our families and create a community beyond our clinic walls. **Each month, we continue to hold our parent, teen, littles, and sibling groups, and on average, the groups bring in 50 parents, 15 teens, 12 littles (or mighty's!), and eight siblings.**

In addition to the continued success of our established groups, we implemented two additional groups – tween group and extended family members group. Both groups proved to be a great success with about seven tweens attending each month and 25 family members attending each quarter. Based on these results, we are excited to announce that both the tween and the extended family groups will be permanent. And based on the success of the extended family members group, these meetings will move from quarterly to monthly.



-Photo by clinic patient

SALON SERVICES

This year, we created a partnership with the new Salon Services Program at CHOP to offer education to our trans youth and families about hair styling and makeup application. Richard Cornish is the head of the program and he personally comes to the clinic to consult with our families about what services might best fit their needs. Richard has given our patients haircuts and hair colors, as well as fittings for wigs.



Richard has also connected our clinic to Doaa Sabbagh, who is a CHOP Family Hospitality Navigator by day, and volunteer makeup artist and teacher by night. Doaa has worked with patients to learn the basics of makeup application as well as help them find their "look." Our patients and families have been extremely grateful for the support of Salon Services, and the Clinic looks forward to continuing to work with them in the future to help our patients to feel their best inside and out.

-Photo by clinic patient

RESEARCH HIGHLIGHTS

Research is critical to improving the health and well-being for our patients, as well as understanding how we, as researchers and providers, can better support these amazing young people. We have completed a range of research projects in the past year and want to highlight a few.

Photovoice: Empowering Transgender and Gender-Expansive Youth

Transgender and gender-expansive youth have unique healthcare needs; however, they often eschew visiting health centers given a history of discrimination. Photovoice, a community-based participatory research method, is an apt technique to engage this population. The purpose of this study was to learn from the unique perspectives of transgender and gender-expansive youth on what may challenge or facilitate gender identity



affirmation to improve healthcare usability for those receiving care at a gender-affirming clinic. We recruited 16 transgender and gender-expansive youth from our gender clinic. Participants were prompted to take photographs for one month to explore how their gender identity affects their social relationships including their clinical care. After one month, all participants engaged in critical reflection of their photos and an in-depth interview with a study member. Of the 16 participants, six also participated in a focus group. Findings from this study will be presented at the Society for Adolescent Health and Medicine 2019 Annual Meeting.

Allison Bauer, MD, the study's lead investigator, recently graduated from the Perelman School of Medicine at the University of Pennsylvania and is currently an Internal Medicine Resident at the University of Washington. Her academic interests include community-based participatory research, LGBTQ health, and narrative medicine. She hopes to continue her career as an HIV primary care physician addressing health inequalities in resource limited settings within the United States.

Prevalence and patterns of food and beverage restriction for bathroom avoidance in transgender youth

According to the 2015 U.S. Transgender Survey, nearly one third of transgender adults report avoiding eating or drinking in the last year to avoid using a public restroom. Knowing that bathroom safety is related to psychological well-being for transgender youth, the purpose of this study was to quantify the prevalence of food and beverage restriction for the purpose of bathroom avoidance in transgender and gender non-conforming (TGNC) youth ages 10-18 seen in our clinic. We conducted a retrospective chart review of 214 "body assessment" measures obtained during initial intake and mental health gender assessment. Mirroring the adult population, 29% of youth reported restricting food or fluid intake to avoid using the bathroom. Of those who reported restrictive behaviors 52% endorsed not eating or drinking in public, 61% endorsed not eating or drinking during school only, and 55% endorsed not eating or drinking before or during school. These data have important policy and training implications for schools, community organizations, and medical institutions serving TGNC youth.



Anderson is the 2018-2019 Nutrition Fellow for the Leadership Education in Adolescent Health (LEAH) program and is currently pursuing his Master of Science in Nutrition from Drexel University College of Nursing and Health Professions. Anderson is passionate about asking relevant research questions and gathering quality data in order to best advocate for the unique healthcare needs of vulnerable adolescents.

National HIV Behavioral Surveillance Formative Assessment

Young transgender women often face social marginalization and stigma in healthcare settings, leading to diminished access to health resources and negative health outcomes, including a significantly increased risk of HIV infection. For the first time, the Centers for Disease Control National HIV Behavioral Surveillance (NHBS) will include transgender women. A key component is the formative assessment -- an ethnographic study of the trans women community in Philadelphia aimed at investigating the issues that impact the health and well-being of the community and building a community-based framework for research and intervention. We conducted 41 in-depth, semi-structured individual interviews and focus groups of transgender women, in addition to 17 interviews with health professionals with experience caring for trans women and leaders of community organizations which serve the trans community. Findings from this study will be presented at the Society for Adolescent Health and Medicine 2019 Annual Meeting.

Additionally, based on these efforts in collaboration with the Philadelphia Department of Public Health, we established a community advisory board which will advise the NHBS-trans study team on recruitment, study operations, and dissemination; and promote community involvement in research and healthcare initiatives in the Philadelphia trans women community.

STAFF AND COMMUNITY PARTNER HIGHLIGHTS

Jacqueline Harrison, BA, joined the GSDC team in November 2017 as a clinical research intern. Jackie's work in research primarily focuses on medical chart data abstraction for the Gender Clinic Registry, a longitudinal database to track health and well-being outcomes of patients and improve clinical care. Additionally, Jackie is a sibling's group co-facilitator for the monthly CHOP & PACTS Support Group. Apart from her work at the GSDC, Jackie also works as a Clinical Research Assistant for the division of Neurology at CHOP on a study exploring the developmental changes in adolescents with HIV and what that means for the brain and behavior.

Jackie received her BA in both Psychology and Music from Muhlenberg College. In the future, Jackie hopes to continue her passion for research by pursuing a graduate degree in psychology, with a focus on the health and well-being of LGBTQ+ youth.



“With every day at the Gender Clinic, I am inspired by the team’s contagious positivity and strength. Each member of the Gender Clinic works with tremendous purpose, courage, and love. It is an environment that promotes kindness and understanding. For me, working here continues to be a source of immense joy in being able to witness the team’s approach to care, which is present in every interaction with all of the amazing young people and family members who come through the Clinic. I consider it to be an incredible privilege to be a part of this wonderful team. ”

Andrea Lamour-Harrington is a Community Activist who has been serving the LGBTQ Population for over 20 years. Her strong love and commitment to people, many who cannot speak for themselves has contributed to her reputation as being a voice for the people of her community. Being a Trans woman who has had to overcome her own hurdles and tribulations, she still stands beside those that dare to scream and yell for the rights and privileges afforded many but not to those that deserve them. Andrea is the Mother of The House of Lamour, which she proudly calls her Rainbow Tribe, as she cares for a family of different walks from young-Trans folks to those living with HIV. Andrea has stated that if she is remembered for anything when this life is over, she wishes to be remembered for LOVING people despite the condition that they are in; something that is missing from this world today.



Jen Shinefeld, MS has been with the Philadelphia Department of Public Health for 8 years and on the NHBS program for 7. Her academic and professional interests include social determinants of health, social justice, and harm reduction.



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, you can visit: chop.edu/gender to make a donation online.

CONTACT: 267-426-5980

email: genderclinic@email.chop.edu

website: chop.edu/gender

THANK YOU TO OUR FUNDERS & PARTNERS!



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