

Improving Quality and Access to Gender-affirming HIV Prevention Care for Transgender Youth

Statement of Problem

As many as 1% of individuals in the U.S. identify as transgender or gender expansive, and among adolescents and young adults, estimates are as high as 2.7%. Transgender children and adolescents often lack access to appropriate care, including affirming identity through appropriate use of preferred names and pronouns, puberty blockers, hormones, and other recommended medical and surgical treatments. In fact, in a large national survey, nearly half of transgender individuals reported delaying or forgoing medical care due to concerns of being treated poorly.

Transgender youth also experience significant challenges to their physical and mental well-being, including alarming rates of HIV infection. While new HIV infections in the U.S. are decreasing, the rates of infection among young transgender women are likely stable or increasing. Compared to the average individual globally, transgender women are 49 times more likely to become infected with HIV. There are a multitude of factors that contribute to HIV infection vulnerability among young transgender women, but lack of gender-affirming medical care and lack of provider respect and supportive care environments are cited as two major barriers against young transgender women seeking care. While awareness of Pre-Exposure Prophylaxis (PrEP), a daily pill that prevents HIV infection recommended for people at high risk for contracting HIV, varies among young transgender women, many perceive that they cannot afford this treatment.

Description

Improving Quality and Access to Gender-affirming HIV Prevention Care for Transgender Youth

Disparities faced by transgender youth, our team will:

Improve and test a youth-driven model to increase rates of getting care and use of PrEP; policy

Improve practice and provide information to transgender youth to help them receive and use PrEP; policy

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The team will partner with local leaders to improve the ability of local systems and policies to support the health and well-being of transgender youth.

Given the health disparities faced by transgender youth in accessing quality care, Dr. Dowshen, a Stoneleigh Foundation Fellow, and her team will develop and test a youth-driven method to evaluate experiences getting care and use what they learn to impact policy, improve practice and provide information to transgender youth to help them make decisions when accessing care. Specific aims for this project include:

- Adapting and validating an existing quality assurance checklist to assess aspects of HIV prevention services for use with young transgender women populations, and creating additional quality measurement methods that will be best suited to the unique health care needs of this population.
- Recruiting young trans women in Philadelphia to evaluate the quality of HIV/STI testing and counseling, as well as PrEP-related and gender-affirming care referrals made to young transgender women within local HIV/sexually transmitted infection (STI) testing sites. Our youth-led quality evaluation process will involve mystery shopping visits and other new methodologies we develop. Feedback reports will be provided to clinical sites and youth care evaluators will offer training and technical assistance when areas for improvement are identified.
- Exploring the impact on self-efficacy and health care knowledge of trans youth quality evaluators.

Additionally, the team will partner with local leaders in the Philadelphia area to apply similar methods and learnings to improve the ability of local systems and policies to support the health and well-being of transgender youth. Beyond embedding and sustaining the intervention locally, partnering with other policymakers outside of HIV care, who are responsible for the health and well-being of transgender youth, will allow for broader impact.

Next Steps

As of summer 2022, Dr. Dowshen and her team have completed the first aim as well as recruitment of youth quality evaluators, who are currently conducting mystery shopping visits and facility audits at local HIV testing sites. After data collection, the research team will create the site-specific feedback reports and work with the youth quality evaluators to identify general improvements in gender-affirming HIV testing and prevention. Their hope is that the findings from this study will lead to the development of a framework for future research on the quality of care for young transgender women.

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PolicyLab Leads

Nadia Dowshen
MD, MSHP

Faculty Member

Nadia Dowshen (she/her) is a faculty member at PolicyLab at Children's Hospital of Philadelphia (CHOP) and serves as Director of Adolescent HIV Services in the Craig Dalsimer Division of Adolescent Medicine at CHOP. She is also an associate professor of pediatrics and the Associate Director of the Masters of Health Policy Research at the Perelman School of Medicine at University of Pennsylvania and a Stoneleigh fellow.

In addition to specialized care for youth living with HIV/AIDS, Dr. Dowshen also provides general adolescent medical care at CHOP and Covenant House, PA, a youth shelter located in Philadelphia. She recently co-founded the CHOP Sexuality and Gender Development Clinic which now provides medical and psychosocial support to more than 2,000 gender variant children and adolescents. Dr. Dowshen's research focuses on using youth-friendly technology to improve adherence to antiretroviral therapy and improve other health outcomes for adolescents living with HIV/AIDS. She is also interested more broadly in research around issues of STD and HIV prevention and treatment as well as achieving health equity for other marginalized youth including LGBT and homeless adolescents.

Dr. Dowshen received the 2010 Society for Adolescent Health and Medicine New Investigator Award for her research identifying protective factors against HIV infection among transgender youth. She was recently named an NIH Adolescent Trials Network (ATN) Scholar and a Best Young Investigator by the National Centers for AIDS Research (CFAR). Dr. Dowshen also serves on the Board of Directors of the Sexual Information and Education Council of the United States (SIECUS), a national non-profit which promotes comprehensive education about sexuality, and advocates for the right of individuals to make responsible sexual choices. Dr. Dowshen received both her M.D. and Masters of Science in Health Policy Research from the University of Pennsylvania.



Nadia Dowshen
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Team

Marné Castillo **PhD, MEd**

Faculty Scholar

Marné Castillo (she/her) is a faculty scholar at PolicyLab and serves as the clinical and research director of the Adolescent Initiative, a multi-disciplinary program for HIV prevention, care, education and research at Children's Hospital of Philadelphia (CHOP).

Dr. Castillo is the principal investigator for CHOP's Adolescent Trials Unit, which is supported by the National Institutes of Health in addition to several other multi-site studies. From 2002 to 2017, she led the "Connect to Protect Project," the Adolescent Trials Network community-based prevention research study focusing on community mobilization and HIV primary prevention.

Dr. Castillo's work focuses on adolescent health promotion and community engagement in research, especially with the House and Ball and Kiki communities. She also has broader interests around social determinants of health, with a special interest in trauma and improving outcomes for marginalized adolescents. In 2015, Dr. Castillo received the Center for AIDS Research Red Ribbon Award recognizing her work on behalf of adolescents in the field HIV prevention research in Philadelphia. She has served on the Board of Directors of several organizations, including Philadelphia FIGHT and GALAEI. Dr. Castillo received her PhD in public health and her master's degree in education from Temple University.



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Bevin A. Gwiazdowski **MSW**

Clinical Research Project Manager

Bevin Gwiazdowski (she/her) is a clinical research project manager at PolicyLab and within the Adolescent Initiative at Children's Hospital of Philadelphia (CHOP). In her time with CHOP, she has cultivated partnerships with other nonprofits and institutions in Philadelphia with a focus on creating and expanding opportunities, access, and safe spaces for LGBTQ+ youth. She has also co-facilitated the POSSE CAB from its inception, facilitates a working group of trans health and wellness providers across the city, and serves as a member of the Philadelphia Department of Public Health Community Advisory Group focusing on the House and Ball community.

With more than 15 years of direct service work with LGTBQ+ youth she has developed a particular interest in facilitating capacity building and leadership development within the communities she works. Bevin received her MSW from Temple University.



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Related Tools & Publications

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[Barriers to Care for Gender Non-conforming Youth: Perspectives of Experienced Care Providers, Transgender Youth and Their Parents](#)
[Article](#)

Feb 2018

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[Using Chart-stimulated Recall to Identify Barriers and Facilitators to Routine HIV Testing Among Pediatric Primary Care Providers](#)

[Article](#)

Jun 2019

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[Sexual and Reproductive Health Considerations Among Transgender and Gender-expansive Youth](#)
[Article](#)

Sep 2019

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[Promoting Health Equality and Nondiscrimination for Transgender and Gender-diverse Youth](#)
[Article](#)

Jun 2020

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[Intersectionality and Health Inequities for Gender Minority Blacks in the U.S.](#)

[Article](#)

Aug 2020

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["I Think That I Have a Good Understanding of How to Protect Myself:" A Qualitative Study About HIV Risk Perceptions Among Men and Gender Diverse Individuals Who Have Sex With Men](#)

[Article](#)

Feb 2022

Related Projects

[Development of Mobile Health Interventions to Improve Adherence to Medication and Reduce Sexual Risk Behavior among HIV+ Youth](#)
[Adolescent Health & Well-Being](#)

[Positively Connected for Health \(PC4H\): Use of eHealth/mHealth tools to Improve Health of HIV+ Youth](#)
[Adolescent Health & Well-Being](#)