Looking to the Future on National Youth HIV & AIDS Awareness Day

Adolescent Health & Well-Being

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This blog post has been adapted from comments made by Dr. Nadia Dowshen for a conference call with Congresswoman Barbara Lee (D-CA) and Advocates for Youth in recognition of National Youth HIV & AIDS Awareness Day.

Many people in the U.S. think that HIV is an issue of other countries. What they don't realize is that we have about 1.5 million people in the U.S. living with HIV, and there are 50,000 new infections each year. What's more shocking is that almost 40% of these new infections are among youth, despite the fact that they make up less than 25% of the total population. Also, for new infections among youth, more than two-thirds of new infections are among Young Men Who Have Sex With Men (YMSM) and Young Transgender Women (YTW). More than two-thirds of new infections are also among youth of color. In addition to new infections, youth face major inequalities across the continuum of care. HIV positive youth are two to five times *less* likely to be diagnosed, linked to care, prescribed medication, and achieve viral suppression.

As a pediatrician and adolescent medicine doctor, I provide care for youth living with HIV. What I see every day in the Adolescent Initiative at The Children's Hospital of Philadelphia mirrors these national trends. For over five years, the clinic has seen about one new patient per week, and more than 85% are African American YMSM and YTW.

When it comes to prevention and ending the HIV epidemic, I believe we need to address larger structural issues as a society, like racism, homophobia, poverty, and discrimination based on gender and gender identity. While

these are longer-term fixes, there are actions we can take in the short-term. For example, many of the youth I care for tell me they never learned about how to have safe sex. To address this issue, we need to ensure that all youth are getting comprehensive sex education in school that is inclusive of and respects LGBT identities, and that focuses on how to have healthy relationships.

We need to address the problem that so few youth are aware of their HIV status. We know from recent CDC Youth Risk Behavior Surveillance System (YRBSS) data that fewer than 25% of high school students who are sexually active have ever been tested for HIV. My colleagues – pediatric care providers – need to do better. Despite recommendations for routine sexual health screening and HIV testing, providers are not spending confidential time talking about sex and other psychosocial issues. For example, in CHOP's large hospital network of over 29 practices, a survey showed fewer than 25% of our providers ever talked to teen patients alone. We also need to do a better job of supporting parents to talk to their kids about these sensitive but critical issues.

We also need to improve what happens to youth after they receive an HIV diagnosis. For young people who test positive for HIV, instead of receiving unconditional love and support from family and friends, many instead experience stigma and shame from loved ones and others in their community. While we always strive to involve family and loved ones in care, it is often not possible for those youth who experience stigma and shame or, even worse, violence or homelessness because of their diagnosis, sexual orientation, or gender identity. For these reasons, it is vital that programs like the Ryan White HIV/AIDS Program and the AIDS Drug Assistance Program survive and thrive. While the Affordable Care Act has made great strides addressing issues of access to health care because of confidentiality issues and other barriers for youth who may be covered under their parents insurance, we still need a safety net for the young people that I often see falling through the cracks.

Because young people living with HIV often face so many other challenges in addition to their diagnosis, we need comprehensive multi-disciplinary care teams that are trained to meet youth needs in a way that is culturally and developmentally appropriate. At CHOP, our multidisciplinary care team is made up of nurses and social workers, an adherence specialist, and a mental health counselor. The team focuses on meeting young people where they are. Given that the recommendations are to start all HIV positive youth on treatment, it is a great challenge to help youth prepare for taking a medication every single day when they are also facing so many other challenges like stress and depression due to trauma, homelessness, or not having enough food to eat. The expert care teams need more resources and support to help youth navigate through these complex and sometimes life and death situations.

Finally, we need to ensure that our national HIV research focuses specifically on the needs of youth. As a researcher interested in using mobile technology to improve adherence to medications and care, I was part of the first international guidelines on treatment adherence and retention in care. In reviewing thousands of studies for the guidelines, there was not a single intervention that met the highest levels of evidence for youth. Therefore, we need *more* resources to develop and test evidence-based interventions and programs to support youth to be engaged in medical care and to take their medications. We also need more resources for youth-

focused research on the rollout of biomedical and other prevention strategies like Pre-exposure Prophylaxis (PrEP), which involves taking a daily pill to prevent HIV infection.

I chose to specialize in adolescent medicine because I see this as a time of growth, optimism, hope, and creativity. The young people with whom I have been privileged to work with are incredibly resilient and inspire me every day. My patients, and young people like them, are the key to solving the HIV epidemic, and we adults must listen carefully to them and be prepared to provide the education, support, resources, and access to care that will allow them to grow up to be happy and healthy adults themselves.

The Adolescent Initiative at CHOP provides sexual health education and HIV prevention and treatment to thousands of Philadelphia youth. If you are interested in supporting the Adolescent Initiative, please click here.

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