Creativity in Uncertainty: Centering Youth as Sexual & Reproductive Health Policy Shifts

Adolescent Health & Well-Being

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*Editor's Note: This post is part of our **Blind Spots series**, exploring how current and potential future policy changes will affect children, families, and communities, and what can be done to mitigate harm.*

Adolescence is a time of rapid change and growth. It sets up young people's future health and well-being, including their engagement with the health care system. Yet this period can look quite different between groups of adolescents based on their unique experiences, intersectional identities, and existing and emerging health needs.

With the uncertainty around funding for sexual and reproductive health care and the chipping away at resources for mental health care, I [Beth] spoke with Marné Castillo, a faculty scholar at PolicyLab and clinical and research director of the Adolescent Initiative at Children's Hospital of Philadelphia (CHOP), and Bevin Gwiazdowski, a clinical research project manager at PolicyLab and within the Adolescent Initiative, about their work supporting the sexual health and well-being of adolescents with differing needs and lived experiences. In this conversation, we discuss their research and potential downstream effects of current policy uncertainty, as well as opportunities to center youth voices in future policy.

Editor's Note: This conversation has been edited for length and clarity.

Q: Tell us more about your research. What are you seeking to understand? How do you engage youth in this work?

Our team aims to eliminate HIV and prevent sexually transmitted infections (STI) among adolescents and young adults. But we know that to effectively engage young people we need to look at the whole person. We've developed partnerships to address issues like interpersonal violence, housing insecurity, gun safety and substance use, while also finding ways to provide safe spaces for young people to just have fun.

As we collect data, we also work with the community to increase access to services and institutions across Philadelphia, and find ways to expand our research questions to meet the needs of our community.

Our community advisory boards (CAB) are key to the work that we do. They are made up of members from the communities in which we are conducting our research. They meet regularly to inform us about emerging needs and issues in these communities, guiding our research and keeping us honest. Our Youth CAB, for example, meets regularly to provide feedback on all aspects of the Adolescent Initiative and, in recent years, other CHOP initiatives such as the Community Health Needs Assessment.

Just calling a meeting and asking for opinions on a research study is not engagement. Towards our goal of true partnership, our relationships with the CABs are bidirectional and asset-based, with equal consideration for institutional and community needs. We consider their lived and professional experience to set goals together. We also identify small structural wins and activities that we can accomplish together as meaningful opportunities for individual and community capacity building.

Q: How is the shifting funding landscape for sexual and reproductive health affecting or could affect the young people you work with?

Already we're hearing about economic stressors due to increased cost of living, paired with lack of job opportunities.

Both in our research projects and from our colleagues nationwide working with historically marginalized groups, there has been a decreased interest in participating in research. To better understand what the underlying causes are for reduced participation, we have been hosting listening sessions to hear how youth perceive research in our current political climate. This qualitative input will inform additional data collection.

Q: Can you tell us a little bit about what you are starting to learn in your research?

Some current research suggests that the engagement of minoritized youth with HIV care and prevention can be improved by the addition of a non-therapist or clinical provider to their care team, such as a navigator, community health worker (CHW) or coach. Having a peer as a coach or CHW helps youth feel seen and heard in a way that they do not typically experience with nonpeers. They have less to explain, so the process feels seamless.

Flexibility in how CHWs and coaches work with youth is also key to successful partnerships. The ability to meet in person, remotely, or just check in via text message increases their willingness to engage and link to services. In one of our studies examining the role of CHWs in pre-exposure prophylaxis (PrEP) uptake and adherence, these youth felt confidently informed about PrEP and how to access it in the future if their needs change because of the CHW intervention.

Q: What bright spots do you see on the horizon?

In recent years, we have created partnerships with some new agencies that provide services outside of our scope and this has proven extremely fruitful, not only directly for adolescents day-to-day, but also for funding. Internally, we have partnered with the Gun Safety Program at CHOP to provide access to gunlocks at community events and the Empower Program to provide access to Naloxone. Our most robust partnership has developed with Lutheran Settlement House's (LSH) Bilingual Domestic Violence Program. We partnered with LSH to adapt a healthy relationships curriculum with a focus on youth in the House and Ball Community, a performance and social support-based community comprised primarily of Black and Latino LGBTQ+ people. This partnership has led to additional funding for the program and ongoing connections with the community. These relationships make us nimble while keeping young people informed and engaged in services.

Taking an optimistic approach, chaos can create change for good, and we can look at this challenging time as a moment for creativity, asking new questions and continuing to listen. Young people continue to show up for care, events, HIV testing, the Youth CAB, and to tell us how we can do better.

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Q: Does your research point to any policy opportunities to support young people's need for sexual and reproductive health care??

In these circumstances, the roles of state and local leaders in preserving access to care through different funding streams, creative partnerships and innovation in health care delivery are even more important. Our research points to the role that CHWs can play in young people's engagement in care. Pennsylvania has created an important Medicaid-based pathway for CHW services through the state's requirement that its physical HealthChoices managed care organizations (MCOs) employ or contract with CHWs for their Community-Based Care Management Programs.

We can build on this opportunity by increasing community-based support, whether it is for sexual health education, health promotion, HIV screening, or being an ally, as we have seen that these roles can improve health outcomes for adolescents and young adults.

At the same time, we're seeing changes to eligibility and enrollment processes for benefits like health insurance and the Supplemental Nutrition Assistance Program (SNAP), which is already a challenging process for young adults to navigate. As researchers, we often face the reality of the limitations of our roles within the communities we serve. We have seen success when research also helps build bridges between our research participants and organizations supporting the community. Establishing meaningful partnerships to reach research goals and help meet community needs can create lasting impact that helps grow our connection to community and the community's capacity.

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