

STI TESTING IN PENNSYLVANIA HEALTH DEPARTMENTS: YOUTH-RELATED ISSUES

A planning report submitted to the Pennsylvania Department of Health, Division of HIV/AIDS

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DOCUMENT BACKGROUND: This report is a planning document developed for the use of the Pennsylvania HIV Prevention Community Planning Committee (CPG). It relies on program planning information generated by the Pennsylvania Young Adult Roundtables (YART), a set of continuous discussion groups of young adults ages 13-24 that are facilitated by the University of Pittsburgh with the support of the Pennsylvania Department of Health, Division of HIV/AIDS. YART functions as a part of the CPG planning body, with 18 Executive Committee members and 4 youth co-chairs as voting members. Since its inception in 1994, YART has helped inform the state CPG of HIV-prevention issues specific to youth populations and has provided reports to the Commonwealth of Pennsylvania in this capacity, including a Consensus Statement. These reports are intended to foster dialogue with HIV prevention planners and providers and, wherever possible, to indicate contextual and cultural domains that might inflect HIV transmission among youth. They are not intended to constitute research that can be generalized. This latest document, "STI Testing in Pennsylvania Health Departments: Youth-Related Issues," relies on information provided by participants to inform the state's HIV and STI prevention and treatment planning processes.

SUMMARY: In the United States, youth ages 13-24 are disproportionately affected by HIV and other sexually transmitted infections (STI). In Pennsylvania, youth account for over 70% of new

STI diagnoses. Youth barriers to STI testing and treatment have historically included issues related to perceived confidentiality, access to care, poor interaction experiences with STI test providers, feelings of high stigma and shame about getting tested, and dissatisfaction with testing technologies employed. The Pennsylvania Prevention Project convened discussions with six diverse Pennsylvania Young Adult Roundtable groups, constituting a non-random sample of at-risk youth that assists the Pennsylvania Department of Health in HIV prevention planning activities, in order to explore recruitment and retention barriers associated with STI testing at health departments. Data saturation and constituent authenticity were attended to with three feedback meetings after initial discussions. Grounded theory was used for qualitative analyses. We found that at-risk young adults in Pennsylvania indicated barriers to, and identified solutions for, STI testing and treatment across five domains: (1) privacy and confidentiality; (2) access to care; (3) clinic atmosphere; (4) differential treatment and attitudes; (5) existing alternatives to health departments. Pennsylvania county and municipal health departments are urged to more carefully enforce confidentiality; maximize privacy within public spaces such as clinic waiting rooms; establish youth-friendly operating hours at pre-existing facilities; assiduously clean, redecorate, or even remodel existing facilities; mandate annual cultural competency trainings for personnel on youth sexuality, including LGBT-specific issues; and model their services on and/or partner with agencies that are currently being used as alternatives, such as free medical clinics and Planned Parenthood. Health departments are encouraged to partner with at-risk youth through the development of youth advisory boards in order to effectively implement these suggestions.

CONTEXT OF REPORT: American youth ages 13-24 are disproportionately affected by HIV and other sexually transmitted infections (STI), especially young men who have sex with men (YMSM), young transgender people, African American young women, and Latino/a youth. Previous research has demonstrated that, in the United States, young black women ages 15-24 suffer the highest Chlamydia and gonorrhea rates (CDC, 2010). Almost 1 in 4 (24.1%) young women 15-19 years old suffers from an STI, and almost half (43.9%) of young black women 15-19 have a current STI, with human papillomavirus (HPV) the most prevalent infection (Forhan et al, 2009). Nationally, half of all new STI infections occur among youth 15-24; and 62% of all new syphilis cases in 2009 occurred among MSM, a significant uptick: in 2000, only 4% of new syphilis cases occurred among MSM (CDC, 2010). Domestically, black YMSM suffer the highest HIV incidence of all race, risk, and age subgroups (Prejean et al, 2011). A meta-analysis of domestic HIV infection among TG estimated that 56% of black male-to-female transgender people surveyed were HIV positive, one of the highest HIV prevalence rates of any sub-population in the world (Herbst et al, 2008). Though little age-specific information is available related to HIV among transgender youth, it can be surmised that incidence is very high.

Previous research has demonstrated profound, persistent barriers that inflect youth access, uptake, and retention relative to STI testing and treatment. These barriers have been found to include perceived lack of confidentiality (Blake et al, 2003); experienced or perceived shame and stigma related to uptake (Fortenberry et al, 2002); logistical difficulties affecting access, such as hours of operation, location of clinic, and transport problems (Nwokolo et al, 2002); and health providers' occasional preference for outdated technologies, such as genital swabs, instead of contemporary urine tests (McKay, 2006). While these issues have been

predominately culled from urban youth experience, rural youth have expressed similar barriers in addition to poor interactions with sexual health care providers and geographical barriers to sexual health clinic access (Goldenberg et al, 2008).

Within Pennsylvania, there is little specific information available relative to youth access to and uptake of STI services at health departments. Youth face tremendous disparities in STI diagnosis within the state. In 2007, youth ages 15-24 received 38,419 diagnoses of chlamydia, gonorrhea, and primary and secondary syphilis. This age group comprised 72.5% of all diagnoses among those 15-44 (Pennsylvania Department of Health, 2008). Chlamydia among young women ages 15-24, with a case rate 7.5 times that of the Pennsylvania population as a whole, appears to be a key driver of the overall disparity in infection burden. To better plan services for young adults in the state, STD Field Officers from the Pennsylvania Department of Health asked the Pennsylvania Prevention Project (Graduate School of Public Health, University of Pittsburgh) to conduct discussion groups with the Pennsylvania Young Adult Roundtables (YART), a pre-existing set of continuous youth groups that inform and serve on the state HIV Prevention Community Planning Committee (CPG).

TOOLS WE USED: A qualitative needs assessment was undertaken in April 2011 to examine two primary issues: 1) determining barriers to youth testing and treatment and 2) to explore solutions to determined barriers. Six discussion groups were held with high-risk youth involved in YART, covering each Ryan White AIDS Care Coalition area in Pennsylvania (excepting Philadelphia and its AACO coalition). YART members are recruited annually as part of the state CPG. Groups are can be considered non-random convenience samples recruited via community

partners and existing members (via social network strategies and online recruitment). Youth representatives screen new members for eligibility: members must be sexually active; thinking of becoming sexually active; or injection drug users. Each group has a distinct, epidemiologically defined target population (e.g., black YMSM, young white substance users, Latina/o heterosexuals). Meetings were facilitated by trained facilitators at the Pennsylvania Prevention Project with experience conducting discussion groups with young adults. Each of these six discussions lasted more than 15 minutes and less than one hour. Conversations were continued until youth participants believed they no longer had anything new to say. YART participants assented to tape-record the conversations with the understanding that they would not be identified and that recordings would be deleted after thematic coding. Discussions were recorded via digital voice recorder; simultaneously, trained recorders from the Pennsylvania Prevention Project recorded themes on laptop computers to heighten the reliability of the information provided by participants.

We asked the following three questions in all six groups:

(1) Can you talk to us about the experiences you have had or your friends have had getting tested for STI or HIV at the health department? You can talk about both positive and negative experiences.

(2) Can you talk about some reasons that sexually active young adults might not go to the health department for STI or HIV testing and treatment?

(3) If you were put in charge of the local health department, what changes would you make to it that would benefit young adults?

Interviews were recorded and coded for themes. Pennsylvania Prevention Project staff conducted qualitative analysis of discussion points based on a grounded theory approach. Results were first shared with select youth representatives at a presentation for the state's STI Field Officers in April 2011. Results were then shared with each group's representatives at a biannual Executive Committee meeting in May 2011, with an emphasis on maximizing constituent authenticity. Finally, results were shared again with each whole YART group in September 2011 to probe for further themes uncovered during the grounded theory approach, and to minimize the inadvertent omission of important information from the final report. None of the constituent authenticity discussions were digitally recorded; however, trained staff from Pennsylvania Prevention Project typed relevant discussion themes onto laptop computers.

WHAT WE LEARNED: 70 young adults participated in the discussions. 30% were white and 70% non-white. 43% were female, 49% male, 9% transgender. 66% identified as straight, 11% bisexual, 17% gay, and 3% lesbian. The mean age was: 18.97, the range 14-24. Five issue domains were recognized as emergent in the conversations. These included: (1) privacy and confidentiality; (2) access to care; (3) clinic atmosphere; (4) differential treatment of certain populations; and (5) alternatives to health departments. Each of these domains was analyzed within a larger context of identifying both barriers and solutions in order to make recommendations that could influence programming to maximize efficacy in reaching youth populations subject to tremendously disparate STI rates.

Privacy issues were most expressed by anticipated feelings of stigma and shame that could be experienced sitting in public STD clinic waiting rooms during open hours. One member said:

“One time I went. It’s like weird, because you go in there and you see a lot of familiar faces [in the waiting room]. It’s not bad, it’s just an awkward experience. It’s a free clinic on certain days, so you see a lot of people that you know. It’s because of the whole stigma, you automatically think that because people are sitting there they have something.”

Physical privacy was also reported as a barrier to testing – some individuals, especially male and transgender youth, were not comfortable displaying their genitalia to health department personnel. Said one transgender youth:

*“My experience there was weird. She was touching me in my private area and I didn’t ask her to.... And you got to take **all** your clothes off.”*

A straight male young adult stated that it was embarrassing to be “dropping your drawers for people. They’ll ask you about your sexual history.... They ask you the whole nine yards.”

Some youth reported hearing about unintended confidentiality breaches related to giving results. For instance, youth reported that health departments’ follow-up procedure for finding individuals who had tested positive for an STI could comprise a de facto confidentiality breach: sending a letter to a young person’s home could have the unintended effect of alerting his or her parents that their child was being sought by the health department. (This was in fact,

acknowledged during a presentation to STI Field Officers: one staffer admitted that if this situation arose in her own family, she would immediately open her son's mail and confront him about the meanings of its contents.) Even without a reason specified, youth were convinced that parents would ultimately correctly guess the reason for a letter, a phone message, or especially a visit to the residence:

“So say I’m HIV positive, if you come up with a positive result, they don’t let you leave before disclosing [your name and address], and also, they come to your house if they can’t find you. That’s how friends and family find out: if the health department is at your house, they know what it is.”

Other youth participants perceived staff confidentiality concerns due to poor training, boundary issues, or disregard of the laws, citing concrete examples of personnel misbehavior:

“The person’s who’s actually doing all of this doesn’t even do tests. He doesn’t do tests, but he does see results. That’s all it takes, a cigarette break and a smile. Girl, I seen such and such [participants mocks someone texting]. She was walking like she’s got crabs or something.”

Buttressing these claims, another participant added that “confidentiality about HIV status has been broken, period. Like, I’ve heard that from a lot of people.” Consistent with this theme, YART members were concerned about community members (including their own relatives and friends) staffing health departments and seemed more comfortable when departments were staffed from outside their own communities. Said one YART member: “You know people that work at the health department. Everybody says something.” Added another, “People can lose

their jobs for telling, but people are telling [disclosing status] anyways.” Regardless of whether confidentiality is actually being breached by individual health department personnel, the perception that it was remained strong in more than one group.

Suggested remedies to perceived privacy and confidentiality issues included creating private waiting rooms, for instance with individual cubicles. Said one member:

*“When you walk in, it’s everyone in one room. That’s what I would change.... You want people to **want** to come to the clinic. People who come for the first time, they see people they know, then they walk right out.”*

Another suggested that in an ideal health department, “You come into a room. The waiting rooms are private. You get your own little space. No one sees you. Like a doctor’s office.”

Some existing health departments allowed appointment-setting but others did not; youth recommended that they be allowed to get appointments in any county or municipal health department, in order to minimize time spent in settings where they could feel embarrassed and ashamed. Other YART members recommended a standard, statewide protocol for STD clinics within health departments that would allow youth to specify by which means follow-up contact could be initiated (i.e., through email or text messaging). Participants also recommended re-emphasizing the importance of adhering to confidentiality laws, suggesting trainings on this and both physical and document privacy for all staff, especially related to youth clientele. A renewed social marketing of health departments' commitment to privacy and confidentiality targeting youth populations was also indicated as a potential solution change youth perception.

Finally, youth recommended creating youth-specific spaces or hours, to delimit their chances of being seen by an adult family friend or relative.

The predominant access to care issue, mentioned in all of the urban groups, centered on the limited times and hours health departments were open. Youth participants were adamant that operant hours (usually Monday through Friday, from 9am-5pm) did not coincide with hours that youth were generally available to seek testing and treatment (usually afterschool and on weekends). “They close at five,” said one member. “They’re closed on the weekends. You have to go to the hospital [if you notice symptoms over the weekend].” Parking and transportation were also identified as issues in urban groups, particularly those with health departments located in zones where parking was difficult to find and/or expensive, and when one might be expected to wait for two to three hours before being seen but could not leave to pay the parking meters for fear of losing one’s spot in the queue. “It’s walk-in; it takes a long time. It takes hours. The clinic from 2pm-5pm, you’re going to be there the whole time,” mentioned one young adult. Another added, “That’s another thing: there’s no free parking. And we can’t park [in an adjacent commercial lot], ‘cos they’ll tow.”

A rurally-based group was insistent that they had no access to any health departments: the closest one was one hour away by car and would require youth to skip school in order to be seen. “The only thing around here is nursing homes and hospitals, birth control places in [a town 25 minutes away]. I think that one does testing. But I think it’s [only] for girls,” explained one rural youth. Meanwhile, some urban health department locations made youth fearful for their safety, as they were located in potentially dangerous parts of town. “It’s a good place for

crack addicts and homeless people,” one member opined. Another said, “I was raised in the ghetto but I have issues about [going back there].”

Suggested solutions to access to care issues included increasing youth-friendly hours and/or subcontracting to agencies with less restrictive policies on staff time policies, in order to allow testing and treatment after 5pm on weekdays or during weekend days. Other solutions that emerged during the brainstorming sessions involved parking validation passes authorized by health departments; incentives for bus and taxi transport that youth could redeem after being tested or treated; and establishing – or marketing pre-existing – mobile STI clinics in convenient locations where youth could remain relatively anonymous when entering and exiting.

Youth introduced several barriers that were loosely classified as components of clinic atmosphere – in other words, the general feeling of place that youth related to health departments in their regions. One atmospheric concern was ambience. Health departments, with some exceptions, were noted as unwelcoming: physically dirty interiors set within old, crumbling edifices: “I don’t want to come back because it’s just unsanitary.... It’s like a locker room.” Another member added, “If I ran the health department, the waiting room would be different; it wouldn’t be all dark and gloomy the way it is now.” Highlighting the effect that physical atmosphere had on YART members, a recently remodeled health department was viewed unanimously by one group as a clean, friendly, inviting facility: “It’s newly remodeled. It’s really clean. They got a flat screen.... It’s convenient for us because it’s in town.”

There were reasons beyond physical environment that caused youth to be concerned about atmosphere, including perceptions of being judged or treated coldly by receptionists and ancillary staff, even as they reported respecting clinicians who dressed them down for not using condoms with their sexual partners. Youth were particularly upset that some health departments still utilized old-fashioned, urethral swab-based testing procedures for gonorrhea and chlamydia, rather than more contemporary urine-based tests, stating vehemently that they would never get another gonorrhea or chlamydia test as long as they had to be subjected to urethral swabs. “You know the little swab they put in your penis? She was like, bam [mimics a rough and painful procedure]!” This had the effect of entirely dissuading some youth from any HIV/STI testing at all, given that some health departments refused to test only for one STI, insisting on running only the full battery of tests for each client, and given that many youth felt they had little option but to use health departments for STI testing since they did not possess private health insurance. Youth respondents also bridled at health departments’ utilization of whole blood draws for HIV testing that required extended waiting periods for results and were more invasive, instead of employing rapid HIV tests or OraSure mucosal swab tests.

YART members also reported having the feeling of being treated like a number, rather than a whole person, while at health departments, suggesting that their interactions with staff were truncated and cold; they expressed the feeling of being treated anonymously without the benefit of actually being anonymous. Layering these themes together, one member stated:

“The health department is disgusting. The lady in the cubbyhole is like, ‘Take a number.’ Then you sit in a little closet with the rest of the people there. It’s the health

department: who wants to go there? I will never go back. When I'm here, I will go everywhere else possible to get rapid [HIV] testing."

Other youth reported being subjected to moral judgments from clinicians related to sexual behavior. When going to the health department, "I feel judged," said one participant. Another detailed the following story: "She [the clinician] made me feel this low in there. 'You can't remember how many partners you had?' She was really getting [to] me. I felt really bad, and I'm not that bad.'"

Stated solutions to these barriers included improving the waiting room environment, with lighting, magazines, comfortable furniture, refreshments, and more frequent cleaning. YART members suggested additional staff training focused on improving cultural competency and respect for youth consumers among first contact staff; and interpersonal skills, sexual history-taking, and "bedside manner" trainings for clinicians. Youth participants recommended the development of statewide protocol for health departments to uniformly utilize the most modern, least invasive HIV/STI testing procedures (i.e. urine-based gonorrhea and chlamydia tests, rapid HIV tests and oral HIV tests).

One advantage of enjoining discussion groups within epidemiologically defined populations is that many issues, as described above, cohere until the point of saturation, suggesting that reported information may in fact be more generalizable than the sampling frame might initially indicate. An additional advantage is that it allows some comparison between groups of different genders, sexualities, races, ethnicities, and geographies. In these discussions, youth participants in each group perceived distinct differences in barriers that were

related to differential treatment or attitudes. For example, transgender youth of color reported feeling highly stigmatized when in health department waiting rooms and when meeting with clinicians. Gay and bisexual youth reported receiving unsolicited moral judgments by both clinicians and ancillary staff members, experiences that they felt made them less likely to return for testing or treatment in the future. They also expressed that their confidentiality was less respected than that of heterosexuals:

“How you’re treated is different between heterosexuals and gay people. Where if [health department staff] doesn’t know someone in the streets that may be straight, it’s like, here’s your results. [But] if they know you from the streets, it’s, ‘I’m going on break for a few minutes,’ [mimics making a phone call], ‘Hey such and such a person is positive, I just tested them.’ Nothing’s ever done about it.”

On the other hand, both urban straight male youth of color and rural white straight male youth reported believing that they were at little risk for STI and so had no need to utilize the health department for regular screenings unless they were “burning” (exhibiting symptoms). One straight male reported that getting tested was “not at the top of my list. Not one of my priorities at the moment.” Another said, “We [boys] don’t get checked. Ain’t none of my friends get checked.” Other responses from straight males included: “I do what I do but I don’t tell my business [to health department staff]” and “I don’t want to find out [if I have an STI].” These statements were not consistent with barriers noted by LGBT youth or straight female youth, who evinced greater feelings of responsibility over physical health and regular check-ups, and indicated differential attitudes toward accessing STI services. Straight girls, for

instance, were more comfortable with the notion that they should be receiving regular gynecological checkups, which might involve STI testing. They noted that straight boys might feel less responsibility to get tested for STI if their female partners did so routinely. “If their girl gets checked, then guys think they’re cool [they don’t need to get tested],” one straight female stated.

Solutions that were suggested to surmount these obstacles to youth recruitment and retention included collaboration with transgender clinics or creation of transgender-specific spaces within existing health departments, to demonstrate to transgender clients that their unique experiences were acknowledged:

“Can I put a gender clinic in my health department? ‘Girl, you can come to my facility and get tested and get [hor]mones and you can really get those levels checked so you know if you’re gonna get a mustache in a couple months or if you’re gonna still be real [e.g., still pass as a woman].”

Several participants suggested that incorporating hormone treatment into STI testing and treatment for transgender youth would be an effective marketing tool and care advent, comprising an incentive to get tested for HIV and STI. Other youth argued for social marketing campaigns on buses and billboards that emphasized the importance of STI testing for sexually active, young straight males, especially of color, that would urge these youth to take responsibility for their sexual health. Queer youth wished for mandatory cultural competency training for health department staff that would give them more understanding of lesbian/gay/bisexual/transgender youth issues; these participants proposed severe, automatic

penalties for staff making moral statements about sexuality to clients. One participant suggested that “state health workers might go for classes in how to deal with youth [in general].”

Lastly, youth brought up some alternatives to health departments that they were often more likely to use for STI testing. These alternatives included sites like Planned Parenthood, private doctors at community health clinics that were not health departments, clinics specifically targeting young women, and student health service facilities. Youth used these facilities in order to minimize the barriers addressed above; for instance, Planned Parenthood was regarded as a place where sexual minority youth could seek care at a venue that respected privacy and whose staff were not considered morally judgmental, during weeknight hours when health departments were not open. A clinic targeting young women was cited as an alternative recommended for its continuity of care, with clinicians who remembered clients from previous visits and who had the ability to do more than STI screenings if the situation indicated it.

In order to maximize the number of youth receiving regular STI testing and treatment in Pennsylvania, and to limit youth drift from health departments to private clinics and other options, YART members thought that health departments should consider basing their youth services on models that worked, like those offered at other sites such as Planned Parenthood. In lieu of this, youth suggested that greater subcontracting by health departments to community-based clinics could help provide the non-judgmental, private, flexible, clean, and contemporary STI testing options that young adults both expect and feel that they need. “Rumors fly about people who are seen in the waiting room. When you’re in the [health

department] clinic, something's wrong – it's a last resort, compared to a family doctor or Planned Parenthood," one young adult stated. "The streets are always talking," added another.

FURTHER THOUGHTS: There are significant limitations to these findings. First and foremost, the information we collected was not based on a random sample of at-risk youth, and is not likely to be generalizable to youth in Pennsylvania outside of the diverse groups represented in the Young Adult Roundtables. Not all YART members reported accessing health departments for STI services, and so the information in this report represents unchallenged perceptions as well as real experiences. A more research-oriented approach to data gathering might include recruitment from health department clinics for focus groups, perhaps supplemented by client satisfaction surveys randomly distributed to youth who access health departments, with questions based on information reported here. For these reasons, the information provided should be considered preliminary.

That being said, the discussions reported on here were subject to basic qualitative standards. Conversations ensued to the point of saturation. Information was reported back to involved youth on three separate occasions, and results were modified according to constituent authenticity. The information gathered closely mirrored previous qualitative findings from other jurisdictions (Tilson et al, 2004). For these reasons, we believe that preliminary conclusions may still be drawn. Chief among these are barriers and solutions identified across the five domains of privacy and confidentiality, access to care, clinic atmosphere, differential treatment/attitudes to treatment, and alternatives to health departments currently being used.

Although YART members recognized significant barriers to utilizing health departments for STI testing and treatment, these issues are not insoluble and can be effectively addressed with a variety of simple and relatively inexpensive measures. Some of these measures are structural, such as extending hours and/or appending services to include a youth-only time period during which appointments can be set ahead of time. Other structural measures include using contemporary, minimally invasive testing procedures across clinics, such as urine-based chlamydia and gonorrhea tests and oral HIV tests; and establishing (or re-emphasizing) a dedicated training protocol for all staff that would cover LGBT and youth-related cultural competency. Other suggested measures involve a re-dedication to existing policies and procedures, such as monitoring staff adherence to confidentiality and privacy protocols. Attention to ambience of clinic waiting rooms (cleanliness, comfortable chairs, private areas) may also serve to improve the experience of youth seeking STI testing and treatment. Social marketing campaigns, such as posters on bus routes or billboards, that target straight male youth and attend to confidentiality concerns, could also improve youth recruitment. If health departments are interested in better recruitment and retention of youth, who account for almost 3 of 4 STI diagnoses in Pennsylvania, developing a plan that is aligned with these recommendations from at-risk youth might make for a useful starting point.

Community-based participatory programming, which seeks to closely involve youth in planning, recruitment, retention, and evaluation modes, is currently highly recommended by the CDC for HIV prevention initiatives that target at-risk youth (CDC, 2011). This program planning generally consists of dedicated youth advisory boards that convene regularly during the lifetime of a project. The Young Adult Roundtables are one example of this model, and

have been cited by the CDC as a national template for youth involvement on HIV prevention planning bodies. STI prevention targeting youth could clearly benefit from substantial young adult input and buy-in. Health departments should be encouraged to work closely with young people to develop programming that suits their needs in the most efficacious and cost-effective manner possible. We strongly recommend that county and municipal health departments in Pennsylvania adjust their programming based on the recommendations from young people in this report and the help of advisory groups convened with at-risk young people recruited for this purpose in their respective jurisdictions.

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