



**LIVE UNITED**

**Needs Assessment for  
Youth Living with HIV/AIDS and  
Youth at risk of contracting  
HIV/AIDS**

**March 5, 2014**

**Strategic Assessment & Planning Committee  
Nassau-Suffolk HIV Health Services  
Planning Council**

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## EXECUTIVE SUMMARY

The Strategic Assessment and Planning (SAP) Committee of the Nassau-Suffolk HIV Health Services Planning Council authorized a survey to study Youth among People Living With HIV/AIDS (PLWH/A) and Youth at-risk for contracting HIV/AIDS. The age parameter of Youth was defined as ages 13 to 29. This parameter allowed the study to examine college age participants, transitioning youth and older PLWH/A (ages 20 to 29) with whom younger PLWH/A (age 13 to 19) have sexual relations. The classification of responses by age strata informs the reader about differing attitudes and behaviors among age groups of PLWH/A

The survey is designed to gather comprehensive information from consumers. The information has been collected in order to assure that Ryan White priorities are responsive to the changing needs of Youth in the Nassau-Suffolk region.

A total of 120 surveys were completed by respondents. In order to ensure that results were for only Nassau-Suffolk region's consumers, the responses of two people whose zip code could not be identified as in the Nassau-Suffolk region were removed. Thus, the total samples collected for the consumer survey was 118. The number of respondents that were HIV positive totaled 104 and the number of respondents at-risk for contracting HIV was 14.

Totals for individual questions are sometimes fewer than 118, since some people left questions blank. Percentages may not add to 100% due to rounding. Some sample sizes were so small that information is not provided for these groups since percentages might be misleading and confidentiality might be compromised. Because no meaningful comparisons can be made between various sub-populations due to the sample size, these are not presented.

### **YOUTH** (ages 13-29):

This group incorporates adolescents (age 13-19) and young adults (ages 20-29). This Youth Needs Assessment conducted in 2013-2014 polled 104 PLWHA respondents and 14 high-risk youth respondents.

*Epidemiology:* The average percentage of new AIDS cases from 2010-2012 in the NS EMA is 20%, with new HIV cases higher at 40%. This compares to the national average of 39% of all new HIV infections among Youth. Comparison to the general population is that this age group is only 21% of the total. The Youth study contained 31 newly diagnosed HIV cases or 30%.

The study identified three groups with growth in newly diagnosed HIV cases: Males having sex with Males of color (MSM's of Color), Injection Drug Users (IDU's), and Foreign Born teenage mothers. These groups reported different reasons why the HIV virus is spreading.

*Unique Challenges:* In Nassau County, an epidemic largely fuelled by lower socioeconomic status, with high rates of drug use (crystal meth, prescription drug abuse) and ostracization due to sexual identity, bullying about sexual identity and cutting as a frequent practice. Nassau County responded with higher incidence of suicidal thoughts (56%); problems coping with sexual identity (67%); and cutting or self-harm (61%).

In Suffolk County, an epidemic largely independent of socioeconomic status with high heroin use reported, extreme pressure to succeed academically. Suffolk County reported all of the use of searching for Internet sex partners mainly by gay youth. Suffolk County respondents comprised all of the anger problem responses.

*Service Barriers:* Transportation, assistance paying for health insurance, co-payments or deductibles, mental health services and substance abuse services.

*Service Gaps:* Knowing where and how to access services, support groups for youth only and assistance integrating school or work with HIV care.

### **MSM's of Color**

MSM's of color engage in unprotected sex often exacerbated by the use of crystal methamphetamines. Black young MSM's are disproportionately affected by HIV.

Current epidemiologic data does not provide race/ethnic nor transmission detail, but the State of New York reported that:

*Male-to-male sex.* CDC data have shown that young gay, bisexual, and other MSM, especially young African American and young Latino MSM, have high rates of new HIV infections. Another CDC study showed that young MSM and minority MSM were more likely to be unaware of their HIV infection, a situation that puts their health and the health of their partners at risk. Young MSM may be at risk because they have not always been reached by effective HIV interventions or prevention education—especially because some sex education programs exclude information about sexual orientation. A CDC study of MSM in 15 cities found that 80% had not been reached in the past year by HIV interventions known to be most effective. Young MSM may also have increased risk factors for HIV (such as risky sexual behaviors) due to isolation and lack of support.

Factors increasing risk factors for HIV included:

- Sexual abuse. Young adults, both male and female, who have experienced sexual abuse are more likely to engage in sexual or drug-related risk behaviors that could put them at risk for HIV infection.
- Sexually transmitted infections (STIs). The presence of an STI greatly increases a person's likelihood of acquiring or transmitting HIV. Some of the highest STI rates in the country are among young people, especially young people of minority races and ethnicities.
- Substance Use: Young people in the US use alcohol, tobacco, and other drugs at high rates. CDC's 2009 National YRBS found that 24.2% of high school students had had five or more drinks of alcohol in a row on at least 1 day during the 30 days before the survey, and 20.8% had used marijuana at least one time during the 30 days before the survey. Both casual and chronic substance users are more likely to engage in high-risk behaviors, such as unprotected sex, when they are under the influence of drugs or alcohol. Runaways, homeless young people, and young persons who have become dependent on drugs are at high risk for HIV infection if they exchange drugs for sex.

*Service gaps* for MSM's of Color include Transportation (29.5%), assistance with integrating services with work or school (25.8%) and support groups (12.9%).

## **Injection Drug Users**

Injection Drug Use among Long Island youth is at epidemic proportions, where addiction counselors are treating youth as young as 12. The drug epidemic's causal factors include proximity to New York, to major airports and transportation centers, and a statewide crackdown on prescription painkillers, which has had the unintended effect of pushing more kids to cheaper and more accessible heroin. The Centers for Disease Control and Prevention states that U.S. drug poisoning deaths involving heroin increased 45% from 2006 to 2010. The Drug Enforcement Administration reports that the amount of heroin seized each year at the southwest U.S. border increased 232% from 2008 to 2012. Among the four age groups reporting "drug poisoning deaths involving heroin" from 2008 to 2010, the only increase was among those in the youngest group, ages 15 to 24. For the other three age groups, the number of deaths was steady or went down, according to the CDC.

*Epidemiology:* Injection Drug Users (IDU) accounted for 18 or 15.1% of Youth that are PLWH. Including 15 (64%) of Youth Living with HIV/AIDS (YLWH/A) and 3 at-risk youth. Unlike the other special population groups, the majority of the IDU respondents (51%) were female. The youngest respondent was 14 years old with the oldest being 25. The average age of the IDU respondent group was 21. Among the IDU participants, 50% were African American, 17% were White, 11% and 3% were Multi-racial. 98% were currently in care while 2% were new clients. The majority (61%) of IDU respondents reported living in Suffolk County.

*Unique challenges to the service delivery system.* Unique challenges include the extreme poverty and significant challenges to housing stability and employment related to legal histories of narcotic possession and/or sale. All IDU respondents reported a diagnosis of a substance abuse disorder in addition to prior (75%) treatment of mental illness

*Service gaps.* Service gaps reported by IDU respondents were transportation (23%), behavioral health services (39%) with substance abuse services at (21.9%) and mental health services at (17.8%).

## **Foreign Born Pregnant Women**

Foreign born women often arrive pregnant and with HIV in the United States from Central or South America or the Caribbean due to the same proximity of major transportation centers. A total of five foreign born pregnant women in the 20-29 year age group participated in this study and cited needs of food, child care and assistance in obtaining insurance. The survey facilitator observed the status of these women as no questions covered their origin of birth or condition of pregnancy.

## Study Findings

Youth face enormous challenges and stress, with a diagnosis of HIV and possibly Hepatitis C increasing this stress. Social networking via smartphone, cell phone, tablet, laptop or computer can provide counselors and health care providers a medium to reach HIV youth or at-risk youth. This study confirmed that texting is a preferred contact method via cell or smartphone with respondents having access to tablets, laptops or computers than cell or smartphones. The most popular websites and social networking sites were Facebook, Twitter and Google (plus). Responses were collected from both counties (53%) Nassau and (47%) Suffolk.

At risk behaviors differed between the counties with alcohol, sexually transmitted diseases, marijuana, alcohol and prescription drug use and domestic violence and childhood poverty reported in Nassau County. Suffolk County was more affluent, with the heroin injection drug use epidemic more prominently experienced. Reasons given for initial use included the enormous pressure for academic achievement. At Risk Youth reported frequent histories of jail, prison and juvenile detention, primarily among age groups from age 10 to 16 in the Nassau County Juvenile Detention Center.

The risk factors reported for HIV acquisition by county were:

**Table 1: Risk Factors reported by County in Youth Needs Assessment**

| Topic                                       | Nassau  | Suffolk  |
|---|---------|----------|
| <b>Bullying over orientation</b>            | 42%     | 58%      |
| <b>Bullying over HIV status</b>             | 40%     | 60% (5)  |
| <b>STD's</b>                                | 55% (6) | 45%      |
| <b>Substances Used Ever:</b>                | 62% (3) | 38%      |
| Alcohol                                     | 56%     | 44%      |
| Tobacco                                     | 50%     | 50%      |
| Marijuana                                   | 20%     | 80% (3)  |
| Heroin                                      | 0%      | 100% (1) |
| Cocaine                                     | 25%     | 75% (2)  |
| Prescription drugs                          | 67% (2) | 33%      |
| Crystal methamphetamine                     | 86% (1) | 14%      |
| Club drugs                                  | 38%     | 63% (4)  |
| <b>Internet sex partners ever</b>           | 50%     | 100% (1) |
| <b>Unprotected sex</b>                      | 50%     | 50%      |
| <b>Anger Problems</b>                       | 0%      | 100% (1) |
| <b>Suicidal thoughts</b>                    | 56% (5) | 44%      |
| <b>Problems coping with sexual identity</b> | 67% (2) | 33%      |
| <b>Cutting or self-harm</b>                 | 61% (4) | 39%      |

Shading indicates top 7 risks contributing to HIV acquisition.

Bullying attributed to HIV positive status occurred more often (60%) in Suffolk County than Nassau County (40%). Nassau County showed a higher rate of prescription drug abuse and crystal methamphetamine use, while Suffolk respondents reported higher use of marijuana, heroin, cocaine and club drugs. Suffolk County reported all of the use of searching for Internet sex partners mainly by gay youth. Suffolk County respondents comprised all of the anger problem responses, while Nassau County responded with higher incidence of suicidal thoughts (56%); problems coping with sexual identity (67%); and cutting or self-harm (61%).

Almost one-third (32%) of respondents reported graduating with a college degree or reaching a more advanced educational level. The stress of the Common Core standards was offered by key informants as a contributing factor in alcohol and substance use and a mental health stressor.

Most respondents (48%) lived in their own apartment or home and 36% lived with their families. Respondents working full time reported at 42% and part-time at 33%.

Risk identifiers for Youth that were People Living with HIV or Youth at-risk for contracting HIV were: sex, alcohol/drug use, school, parenting, bullying, trauma, encounters with juvenile justice, male to male sex, foreign origins, and coping with sexual identity and gender.

The recommendations of this study mirror the comments of the key informants

The stress of youth coupled with an HIV diagnosis constitute a challenge to healthcare providers, counselors and educators to best treat youth living with HIV/AIDS and at-risk youth.

Recommendations for healthcare providers and counselors include treating the child where they are, both in location and in their developmental stage, incorporating the needs of an LGBT individual in their treatment, exploring the co-existence of substance abuse and mental health issues, and if present, intervening early. Medical practitioners, “should aim to meet parents, families and caregivers “where they are” to build an alliance to support their LGBT children and to help them understand that family reactions that are experienced as rejection by their LGBT child contribute to serious health concerns and inhibit their child’s development and well-being.”<sup>1</sup>

Recommendations for educators are to educate youth early about safe sex, inform them of the risks of unprotected sex and discuss the emotional aspects of sex. Sex education was recommended by key informants to start at age 10 and 11 in the 5<sup>th</sup> or 6<sup>th</sup> grade. Programs to combat bullying, with peers standing up to bullies should be incorporated into each school curriculum. Responses from this study showed the presence of bullying, especially to those who disclose their HIV positive status. Every key informant recommended that the Common Core curriculum be examined, and that the pressure on youth for academic achievement be lessened. A toolkit for an effective school-community partnership can be accessed at: <http://www.3boldsteps.promoteprevent.org>

Recommendations for parents included involvement in youth health and treatment, being aware of substance abuse potential and mental health and accepting the sexual orientation or gender identity of the child. Acceptance of an LBGT child’s sexual orientation or gender identity is crucial to their well-being, and can prevent suicide attempts, depression, substance abuse and unprotected sexual intercourse. Key informants commented that parents need to be educated to parent better to provide structure and guidance to their children. One resource is Triple P Positive Parenting Program, a multi-level system of parenting education and support strategies for families with children ages 0 to 16.

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<sup>1</sup> “A Practitioner’s Resource Guide: Helping Families to Support their LGBT Children.” SAMHSA. Accessed online at: <http://store.samhsa.gov/shin/content//PEP14-LGBTKIDS/PEP14-LGBTKIDS.pdf>

Recommendations to the community include providing leadership and support to shape community responses that promote recovery, prevent behavioral health disorders, reduce the impact of behavioral health problems when they occur and ensure needed treatments and services are available. The Mayor's Resource Guide on Behavioral Health Issues from the Substance Abuse and Mental Health Administration (SAMHSA) contained in Schedule 7 of the Appendix is a resource to assessing community needs and implementing programs that promote healthy, responsive communities.

The top two ranked services for service need and use were Family Doctor and HIV/AIDS Doctor. The third service listed was Case Manager for Need with a ranking of fifth for service use. The third ranked service use was Medications. This is consistent with the Youth mindset that medications are okay, but talk and coordination is not as critical.

Services that represent gaps, and were reported to be unavailable to obtain are Transportation, Support Groups, assistance integrating services with school or work, and assistance paying for health insurance, co-payments or deductibles, followed by mental health services and substance abuse services. The main reason Youth that are PLWH/A failed to obtain HIV medical care in the last year was lack of knowledge about where to access care.

## Study Parameters

**Table 2: Geography**

| <i>Geography (County)</i> | <b>Sample Size</b> | <b>Actual@ 2/28/14</b> | <b>Variance</b> |
|---------------------------|--------------------|------------------------|-----------------|
| Nassau                    | 42                 | 62                     | <b>20</b>       |
| Suffolk                   | 58                 | 56                     | <b>-2</b>       |
| <b>Total</b>              | <b>100</b>         | <b>118</b>             | <b>18</b>       |

**Table 3: Race/Ethnicity and Gender**

| <b>Race/Ethnicity</b>           | <b>Sample Size</b> |                   | <b>Actual at 2/28/14</b> |                   | <b>Variance</b>      |                      |
|---------------------------------|--------------------|-------------------|--------------------------|-------------------|----------------------|----------------------|
|                                 | <b>#</b>           | <b>% of Total</b> | <b>#</b>                 | <b>% of Total</b> | <b>Under /Over #</b> | <b>Under /Over %</b> |
| Black, not Hispanic             | 35                 | 35%               | 40                       | 34%               | <b>5</b>             | <b>1%</b>            |
| American Indian/Native American | 1                  | 1%                | 0                        | 0%                | <b>1</b>             | <b>1%</b>            |
| Hispanic                        | 7                  | 7%                | 21                       | 18%               | <b>14</b>            | <b>11%</b>           |
| Asian / Pacific Islander        | 1                  | 1%                | 4                        | 3%                | <b>3</b>             | <b>2%</b>            |
| More than one race              | 3                  | 3%                | 15                       | 13%               | <b>12</b>            | <b>10%</b>           |
| White, not Hispanic             | 50                 | 50%               | 38                       | 32%               | <b>12</b>            | <b>18%</b>           |
| Other                           | 3                  | 3%                | 0                        | 0%                | <b>3</b>             | <b>3%</b>            |
| <b>TOTAL</b>                    | <b>100</b>         | <b>100%</b>       | <b>118</b>               | <b>100%</b>       | <b>18</b>            |                      |
| <b>Gender</b>                   |                    |                   | <b>#</b>                 | <b>% of Total</b> | <b>Under</b>         | <b>Under</b>         |
| Male                            | 56                 | 56%               | 58                       | 49%               | <b>2</b>             | <b>7%</b>            |
| Female                          | 42                 | 42%               | 55                       | 47%               | <b>13</b>            | <b>5%</b>            |
| Transgender                     | 2                  | 2%                | 5                        | 4%                | <b>3</b>             | <b>2%</b>            |
| <b>TOTAL</b>                    | <b>100</b>         | <b>100%</b>       | <b>118</b>               | <b>100%</b>       | <b>18</b>            |                      |

**Table 4: Age Strata**

| Age (Years)  | Sample Size |             | Actual at 2/28/14 |             | Variance      |               |
|--------------|-------------|-------------|-------------------|-------------|---------------|---------------|
|              |             | % of Total  | #                 | % of Total  | Under /Over # | Under /Over % |
| 13           | 1           | 1%          | 2                 | 2%          | 1             | 1%            |
| 14           | 2           | 2%          | 4                 | 3%          | 2             | 1%            |
| 15           | 2           | 2%          | 6                 | 5%          | 4             | 3%            |
| 16           | 2           | 2%          | 1                 | 1%          | 1             | 1%            |
| 17           | 2           | 2%          | 2                 | 2%          | 0             | 0%            |
| 18           | 5           | 5%          | 1                 | 1%          | 4             | 4%            |
| 19           | 4           | 4%          | 5                 | 4%          | 1             | 0%            |
| 20           | 2           | 2%          | 6                 | 5%          | 4             | 3%            |
| 21           | 4           | 4%          | 4                 | 3%          | 0             | 1%            |
| 22           | 9           | 9%          | 4                 | 3%          | 5             | 6%            |
| 23           | 8           | 8%          | 5                 | 4%          | 3             | 4%            |
| 24           | 11          | 11%         | 11                | 9%          | 0             | 2%            |
| 25           | 8           | 8%          | 17                | 15%         | 9             | 7%            |
| 26           | 20          | 20%         | 19                | 16%         | 1             | 4%            |
| 27           | 8           | 8%          | 17                | 14%         | 9             | 6%            |
| 28           | 8           | 8%          | 12                | 11%         | 4             | 3%            |
| 29           | 4           | 4%          | 2                 | 1%          | 2             | 3%            |
| <b>TOTAL</b> | <b>100</b>  | <b>100%</b> | <b>118</b>        | <b>100%</b> | <b>18</b>     |               |

**Table 5: Transmission Mode and Sub-Population**

|  | #          | % of Total  |  | #          | % of 2/28/14 | Over Under # | Over Under % |
|--|------------|-------------|--|------------|--------------|--------------|--------------|
| <b>Transmission Mode<br/>Exposure Category</b> |            |             |  |            |              |              |              |
| I had sex with a man who is HIV                | 33         | 33%         |  | 75         | 72%          | 42           | 39%          |
| I had sex with a woman who is HIV              | 30         | 30%         |  | 12         | 12%          | 18           | 18%          |
| I was born with HIV.                           | 8          | 8%          |  | 10         | 10%          | 2            | 2%           |
| Through a blood transfusion.                   | 25         | 25%         |  | -          |              | 25           | 25%          |
| By sharing needles or works.                   | 3          | 1%          |  | 6          | 6%           | 3            | 5%           |
| I don't know.                                  | 33         | 35          |  | 1          | 1%           | 32           | 2%           |
| <b>Subtotal</b>                                | <b>100</b> | <b>100%</b> |  | <b>104</b> | <b>100%</b>  | <b>4</b>     |              |
| Injection Drug Use                             | 15         |             |  | 18         |              | 3            |              |
| Pregnant Woman, Foreign Born                   | 3          |             |  | 5          |              | 2            |              |
| Males Sex with Male, Males of Color            | 38         |             |  | 40         |              | 30           |              |
| <b>Total</b>                                   | <b>56</b>  | <b>100%</b> |  | <b>59</b>  |              | <b>35</b>    |              |

## DEMOGRAPHICS

### Age

**Table 6**  
Age of Respondent

| Age Strata   | YLWH/A             | Youth at Risk for contracting HIV/AIDS | Total   |
|--------------|--------------------|--|---|
| 13-15        | 2                  | 8                                      | 10  |
| 16-18        | 5                  | 4                                      | 9   |
| 19-21        | 15                 |  | 15  |
| 22-24        | 16                 |  | 16  |
| 25-27        | 41                 | 2                                      | 43  |
| 28-29        | 25                 |  | 25  |
| <b>Total</b> | <b>104</b>         | <b>14</b>                              | <b>118</b>  |
|              | <b>High School</b> | <b>College or Early Work Years</b>     | <b>Late Twenties, Graduate School or Post-College</b> |

Respondents that are newly diagnosed YLWH/A total 11; 6 (55%) age 19 to 21 and 5 (45%) age 22 to 24. No out of care respondents completed the survey.

### Ethnicity

The survey asked respondents to provide information about their ethnicity and their race. Because of federal requirements with reference to categories of race and ethnicity, these were asked as separate questions, and are presented in different tables. Table 3 provides information about ethnicity for respondents, and Table 4 provides information about race.

**Table 7**  
Ethnicity of Respondents

| Are you Hispanic or Latino(a)? | YLWH/A     |             | At-Risk Youth |             | Total      |               |
|--------------------------------|------------|-------------|---------------|-------------|------------|---------------|
|                                | #          | %           | #             | %           | #          | %             |
| Yes                            | 20         | 19.3%       | 1             | 7.1%        | 21         | 16.8%         |
| No                             | 84         | 80.7%       | 13            | 92.9%       | 97         | 83.2%         |
| <b>Total</b>                   | <b>104</b> | <b>100%</b> | <b>14</b>     | <b>100%</b> | <b>118</b> | <b>100.0%</b> |

**Table 8**  
Race of Respondents

| Race/Ethnicity          | YLWH/A    |             | At-Risk Youth |             |
|-------------------------|-----------|-------------|---------------|-------------|
|                         | #         | %           | #             | %           |
| White, Not Hispanic     | 33        | 39%         | 5             | 36%         |
| Black, not Hispanic     | 34        | 40%         | 7             | 50%         |
| Asian, Pacific Islander | 4         | 5%          |               |             |
| More than one race      | 13        | 15%         | 2             | 14%         |
| <b>Total</b>            | <b>84</b> | <b>100%</b> | <b>14</b>     | <b>100%</b> |

Gender

With respect to gender, there were 58 male respondents (49.2%), 55 female respondents (46.6%) and 5 transgender respondents (4.2%). This information is included in Table 4.

**Table 9**  
Gender of Respondents

| Gender       | YLWH/A     |             | At-Risk Youth |             | Total      |             |
|--------------|------------|-------------|---------------|-------------|------------|-------------|
|              | #          | %           | #             | %           | #          | %           |
| Male         | 51         | 49%         | 7             | 50%         | 58         | 49%         |
| Female       | 48         | 46%         | 7             | 50%         | 55         | 47%         |
| Transgender  | 5          | 5%          | -             |             | 5          | 4%          |
| <b>Total</b> | <b>104</b> | <b>100%</b> | <b>14</b>     | <b>100%</b> | <b>118</b> | <b>100%</b> |

The transgender respondents consisted of 3 that were born a male, but feel they are a female, and 1 respondent that was born female, but feels she is a male. Transgender respondents reside in both counties, with 2 in Suffolk and 2 in Nassau counties.

**Table 10**  
Transgender Information

| Gender at Birth | Gender Preference | Number | County                |
|-----------------|-------------------|--------|-----------------------|
| Male            | Female            | 3      | 2-Nassau<br>1-Suffolk |
| Female          | Male              | 1      | Suffolk               |

**Table 11. Mode of Transmission**

| Mode of Transmission                        | #          | %           |
|---|------------|-------------|
| I had sex with a man who is HIV positive.   | 75         | 72.5%       |
| I had sex with a woman who is HIV positive. | 12         | 11.3%       |
| I was born with HIV.                        | 10         | 10.0%       |
| Through a blood transfusion.                | -          | 0.0%        |
| By sharing needles or works.                | 6          | 6.3%        |
| I don't know.                               | 1          | 1.3%        |
| <b>Total</b>                                | <b>104</b> | <b>100%</b> |

Awareness of HIV

**Table 12: HIV Positive Respondents by Ethnicity and Sexual Orientation**

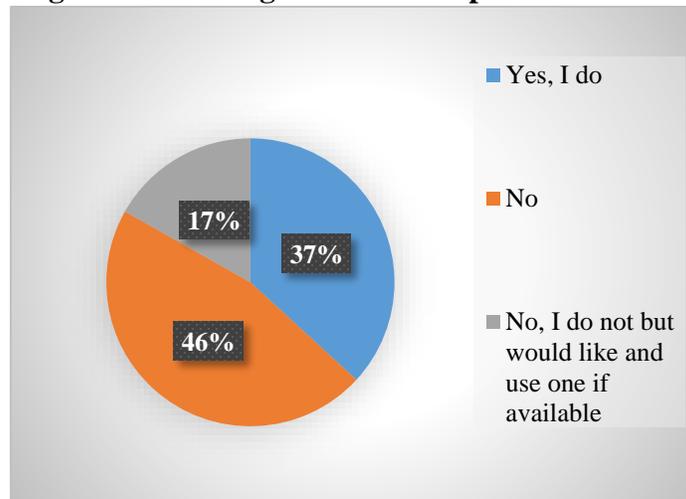
| Sex Orientation                | Hispanic  | Asian/Pacific Islander | Black, not Hispanic | More than one race | White, not Hispanic | Total      | %           |
|--------------------------------|-----------|------------------------|---------------------|--------------------|---------------------|------------|-------------|
| Bisexual                       |           |                        | 1                   | 1                  | 3                   | 5          | 5%          |
| Straight (Heterosexual)        | 12        | 1                      | 6                   |                    | 19                  | 38         | 37%         |
| Lesbian                        | 1         |                        | 1                   |                    | 1                   | 3          | 3%          |
| Questioning (Please describe)  |           |                        | 3                   |                    |                     | 3          | 3%          |
| Gay (Homosexual)               | 7         | 3                      | 31                  | 4                  | 10                  | 55         | 53%         |
| <b>Total</b>                   | <b>20</b> | <b>4</b>               | <b>34</b>           | <b>13</b>          | <b>53</b>           | <b>104</b> | <b>100%</b> |
| <b>Percentage by Ethnicity</b> | 19%       | 4%                     | 40%                 | 5%                 | 32%                 |            |             |

The largest group affected is Black non-Hispanic MSM’s at 30% (31), followed by White non-Hispanic heterosexuals at 18% (19).

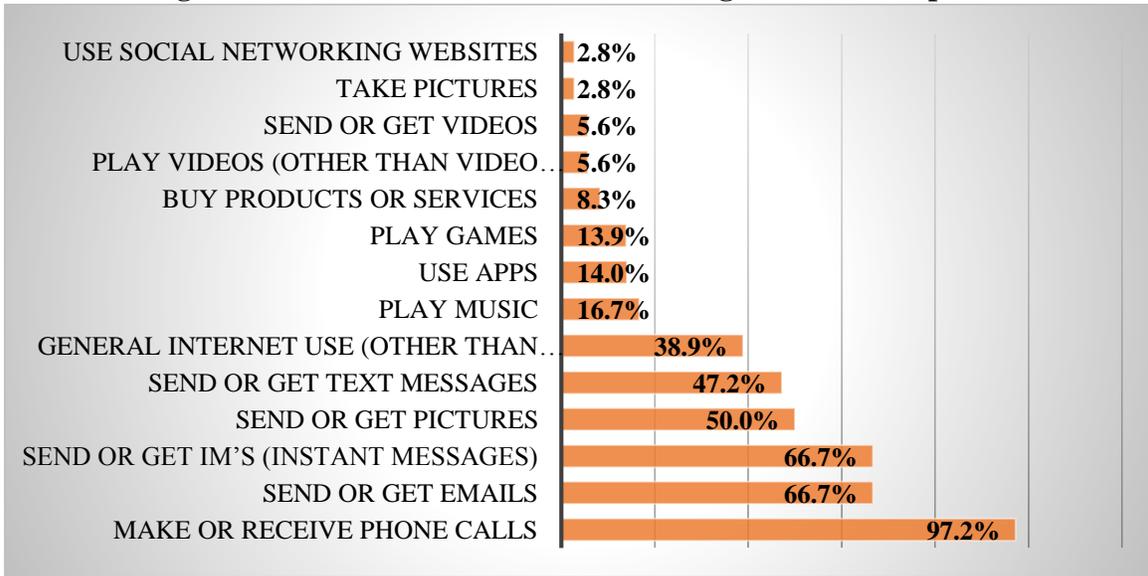
**Communication Methods**

When asked if the respondent had a working cell or smartphone a total of 54% either had a cell or smartphone or would like and use one if available for use. A surprising 46% reported that they did not have a working cell or smartphone.

**Figure 1: Working Cell or Smartphone**

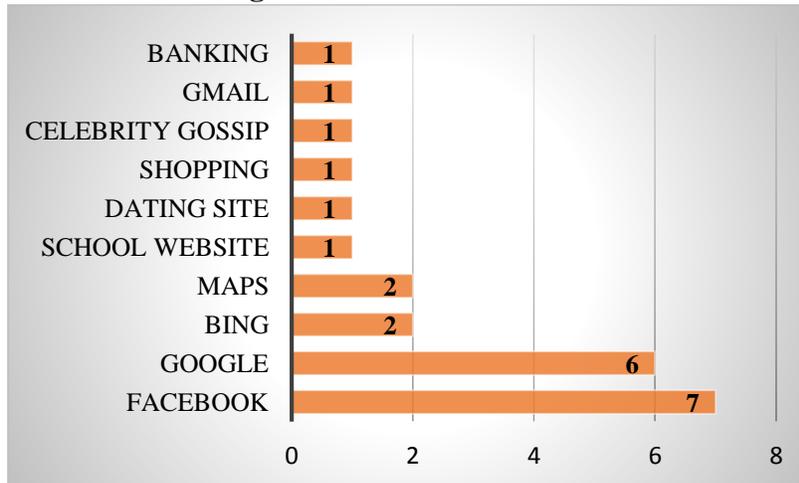


**Figure 2: Activities Performed on Working Cell or Smartphone**



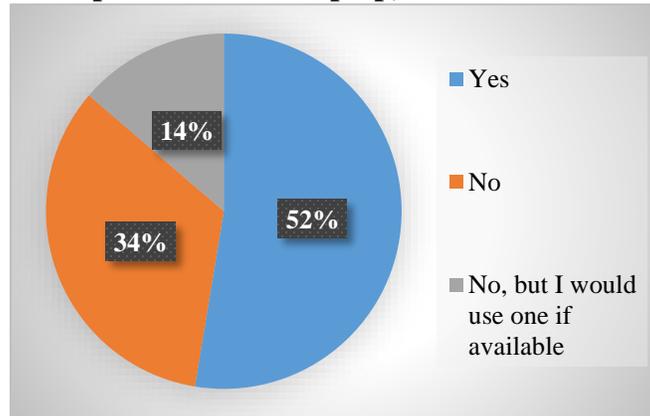
The 37% of respondents (44) who owned a cell or smartphone use the phone mainly to make or receive phone calls (97%), send or get emails or Instant Messages (67%), send or get pictures (50%) text messages (47%) or general internet use (39%).

**Figure 3: Websites accessed**



Respondents accessed Facebook most often, followed by Google, then Bing and Maps.

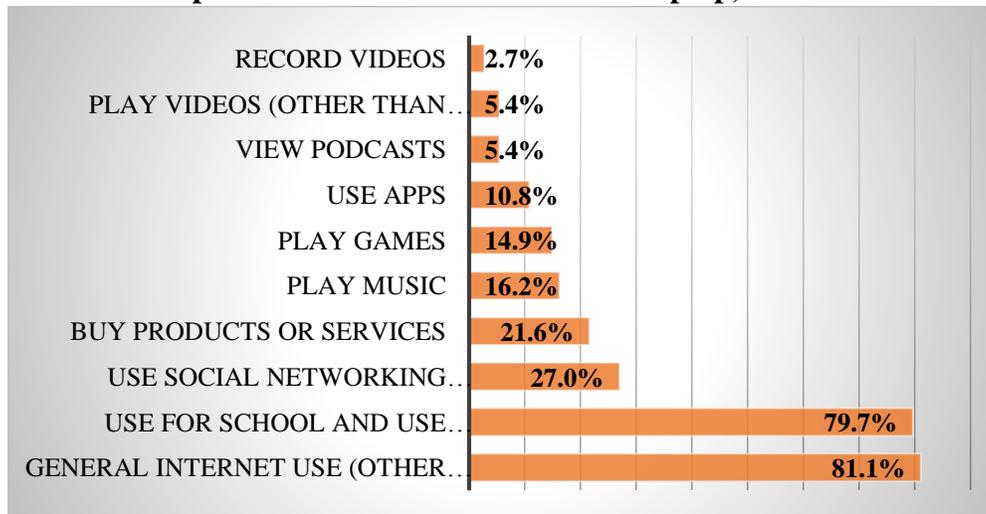
**Figure 4: Respondents with Laptop, Tablet or other Computer**



More respondents (52%) had laptops, tablets or other computers than cell or smartphones (37%) with a total of 66% having a laptop, tablet or computer or that would use one if available.

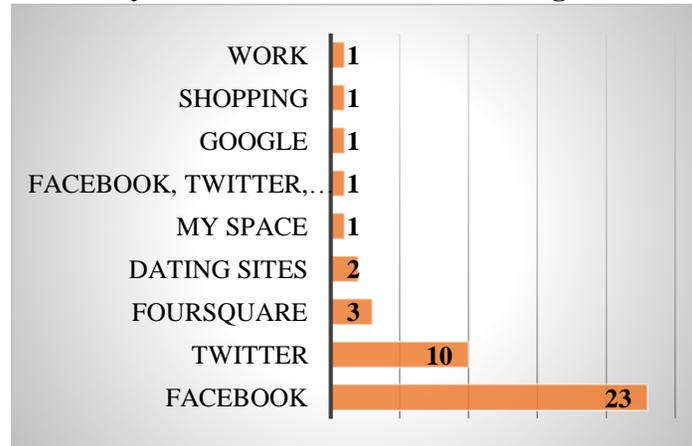
Access to the internet was available to 79% of all respondents with the following activities performed on the internet:

**Figure 5: Activities performed on the internet with a laptop, tablet or other computer**



The 52% of respondents (61) who owned a cell or smartphone use the computer, tablet or laptop for general internet use (81%), for School or Work Use (80%), for Social Networking sites (27%) and to buy products or services (22%).

**Figure 6: Which websites do you access for social networking?**



Facebook is the social networking website most often accessed at 53% (23), followed by Twitter at 23% (10). Those two websites account for 76% of social networking websites accessed.

Apps listed as used by respondents were mainly game apps, followed by banking, maps and shopping apps.

## ENVIRONMENT

### Residence

Information about where the consumers lived when diagnosed with HIV and where they live presently is provided in Table 7. Appendix Schedule 2 shows zip code, town and county for all respondents. Schedule 3 in the Appendix lists the “Other” responses (47) for residence when diagnosed with HIV.

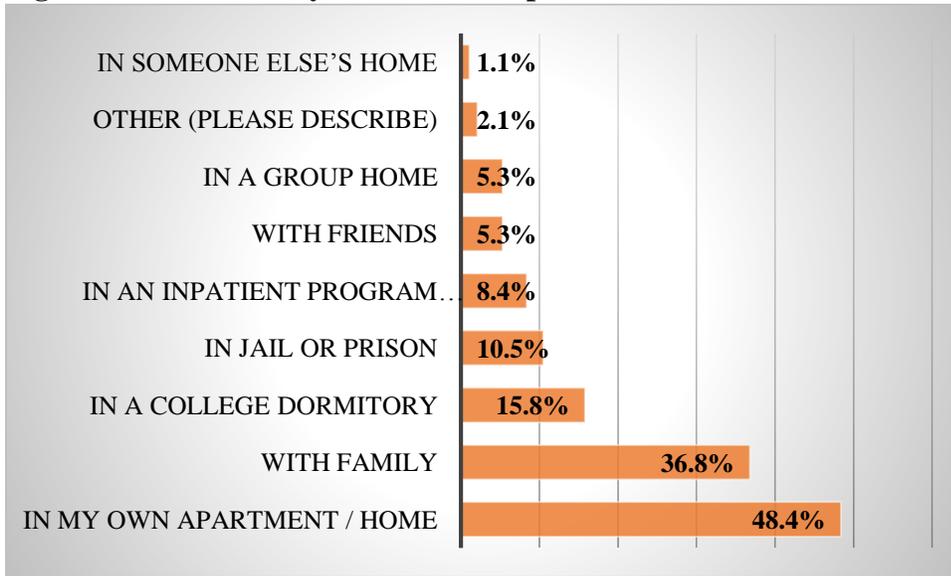
**Table 13**  
Residence when diagnosed with HIV and present residence

| Residence when Diagnosed with HIV |            |             | Present residence |            |             |
|-----------------------------------|------------|-------------|-------------------|------------|-------------|
| County                            | #          | %           | County            | #          | %           |
| Nassau                            | 32         | 31          | Nassau            | 49         | 47%         |
| Suffolk                           | 25         | 24          | Suffolk           | 55         | 53%         |
| Other                             | 47         | 45          | Other             |            |             |
| <b>Total</b>                      | <b>104</b> | <b>100%</b> | <b>Total</b>      | <b>104</b> | <b>100%</b> |

### Home

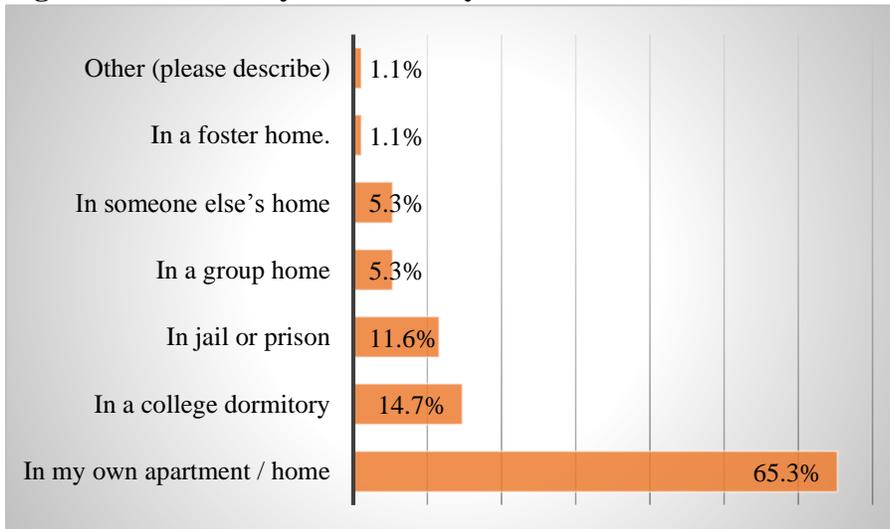
Respondents lived primarily in their own apartment/home (48%), followed with their family (37%), in a college dormitory (16%), in jail or prison (16%), in an inpatient program (8%), with friends or in a group home (5% each) in the past 12 months. Note that the Jail or Prison residents are mainly reporting from the Nassau County Juvenile Detention Center, are age 10 to 16 and are primarily At-Risk Youth who have not tested positive for HIV.

**Figure 7: Where have you lived in the past 12 months?**

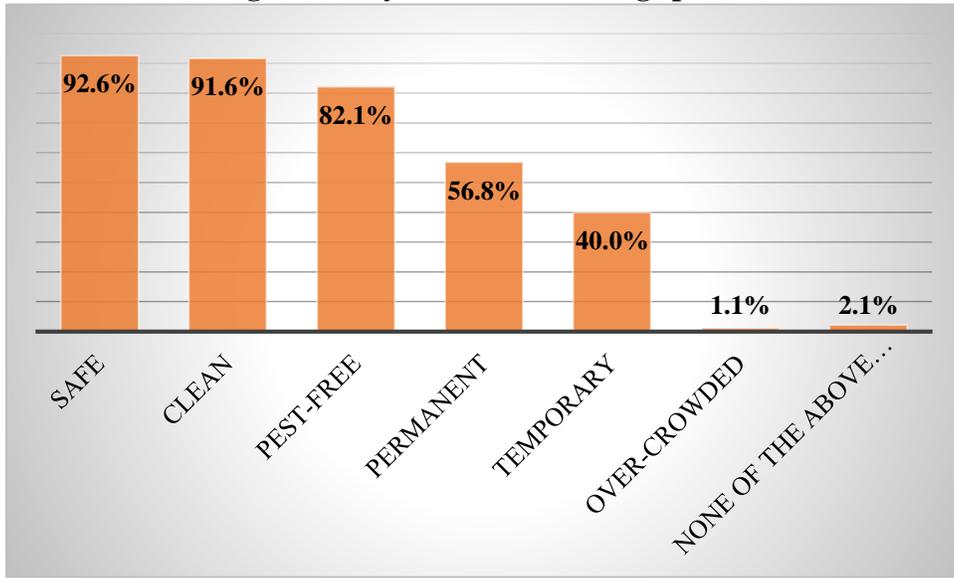


Residents live in their own apartment/home (65%), in a college dormitory (15%), in jail or prison (12%) or in a group home or someone else's home (5% each). Again, note that the Jail or Prison residents are mainly reporting from the Nassau County Juvenile Detention Center, are age 10 to 16 and are primarily At-Risk Youth who have not tested positive for HIV.

**Figure 8: Where do you live Today?**

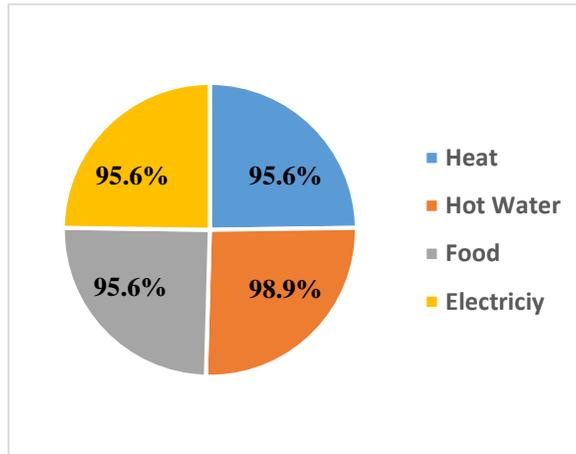


**Figure 9: Is your home or living space?**



Respondents reported that their homes were safe and clean. Pest infestation was a problem with 18% of respondents, and 40 to 43% of respondents only had temporary housing.

**Figure 10: Utilities and Food**

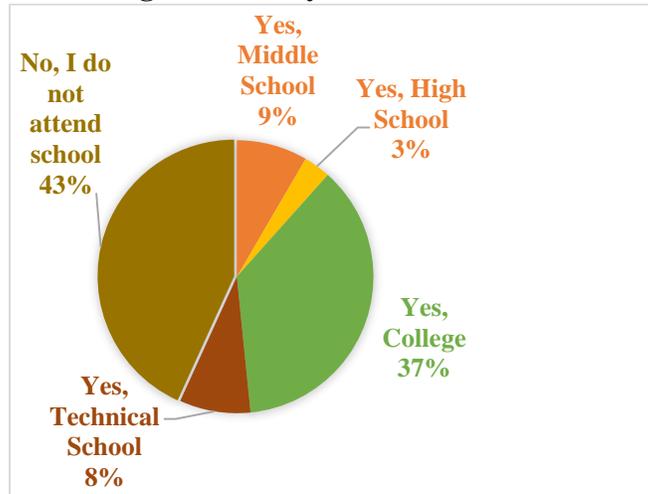


Utilities and Food were almost universally reliable, with hot water ranked highest.

### School

Over half of all respondents attend school (57%), which would be expected for their age group. The 43% who do not attend school are largely working or unemployed. Details on what level of school the respondents are currently attending is shown below.

**Figure 11: Do you attend School?**



Cross-tabulating the highest grade level reached to the age strata shows that the highest grade levels is age-related and consistent with attainable levels till the age strata of 22 and over is reached. Respondents report 27% (6) of the 22 to 24 age strata, 11.9% of the 25 to 27 age strata (5) and 42% (8) of the 28 to 30 age strata attaining a college degree or higher.

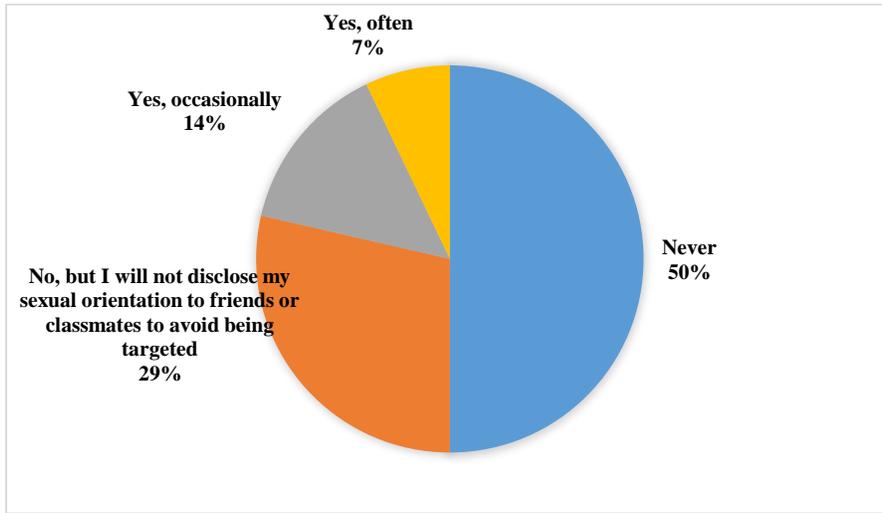
**Figure 12: Educational Levels**

| Highest Grade Level Reached | 13-15     | 16-18    | 19-21     | 22-24     | 25-27     | 28-29     | Total      |
|-----------------------------|-----------|----------|-----------|-----------|-----------|-----------|------------|
| Grade school                | 5         |          |           |           |           |           | 5          |
| Middle school               | 7         |          |           |           |           |           | 7          |
| Some high school            | 2         | 5        | 2         |           | 3         |           | 12         |
| High School degree/GED      |           | 2        | 2         | 4         | 12        | 6         | 26         |
| Some college                |           |          | 10        | 12        | 22        | 5         | 49         |
| College Degree              |           |          |           | 6         | 3         | 8         | 17         |
| Some graduate school        |           |          |           |           | 1         |           | 1          |
| Graduate school degree      |           |          |           |           | 1         |           | 1          |
| <b>Total</b>                | <b>14</b> | <b>7</b> | <b>14</b> | <b>22</b> | <b>42</b> | <b>19</b> | <b>118</b> |

If you are in school now, do you ever feel picked on or “bullied” due to your sexual orientation or due to your HIV status?

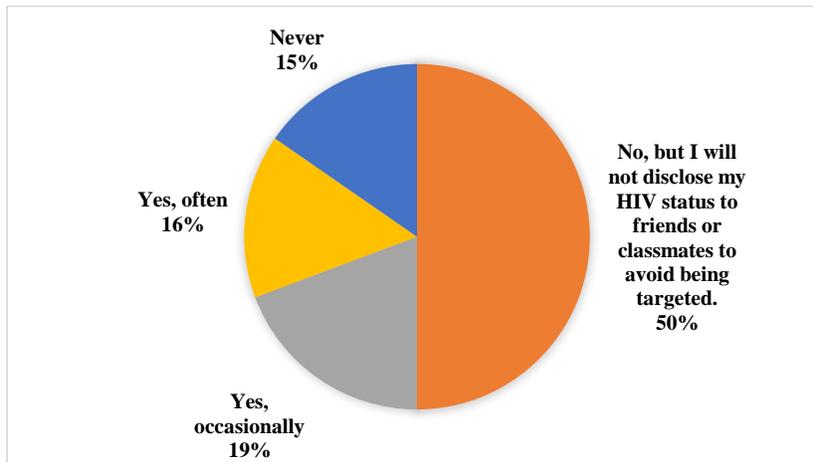
Respondents reported that 21% of those did feel bullied or picked on due to their sexual orientation with an additional 29% choosing not to disclose their sexual orientation to avoid being targeted by friends or classmates.

**Figure 13: Bullied or Picked on due to Sexual Orientation**



Respondents reported that 35% felt they are bullied or picked on due to their positive HIV status with an additional 50% choosing not to disclose their HIV status to avoid being targeted by friends or classmates.

**Figure 14: Bullied or Picked on due to HIV status**



Sexual Orientation

**Table 14: Sexual Orientation by Age Strata**

| Sex Orientation               | 13-15    | 16-18    | 19-21     | 22-24     | 25-27     | 28-29     | Total      |
|-------------------------------|----------|----------|-----------|-----------|-----------|-----------|------------|
| Bisexual                      |          |          | 3         |           | 1         | 1         | 5          |
| Gay (Homosexual)              | 1        | 2        | 6         | 7         | 20        | 19        | 55         |
| Lesbian                       | 1        |          | 1         |           | 1         |           | 3          |
| Questioning (Please describe) |          |          |           | 2         | 1         |           | 3          |
| Straight (Heterosexual)       |          | 3        | 4         | 9         | 17        | 5         | 38         |
| <b>Total</b>                  | <b>2</b> | <b>5</b> | <b>14</b> | <b>18</b> | <b>40</b> | <b>25</b> | <b>104</b> |

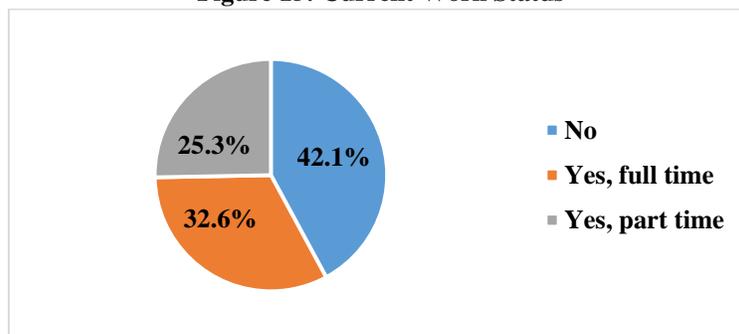
**Table 15: Gay/Lesbian/Bisexual disclosed to Family & Friends**

| Out   | 13-15    | 16-18    | 19-21    | 22-       | 25-27     | 28-29     | Total     |
|---|----------|----------|----------|-----------|-----------|-----------|-----------|
| Not out to anyone   |          | 1        | 1        | 2         | 5         | 1         | 10        |
| Yes, out to both family and friends                               | 1        |          | 5        | 4         | 14        | 4         | 28        |
| Yes, out to family but not friends                                | 1        |          |          |           | 1         |           | 2         |
| Yes, out to friends but not family                                |          |          | 2        |           |           |           | 2         |
| <b>Total</b>  | <b>2</b> | <b>1</b> | <b>8</b> | <b>6</b>  | <b>20</b> | <b>5</b>  | <b>42</b> |
| <i>Not Disclosed=Total of Sexual Orientation less Total "Out"</i> | <i>0</i> | <i>4</i> | <i>6</i> | <i>12</i> | <i>20</i> | <i>20</i> | <i>62</i> |

Literature notes that “coming out”, the process where a person recognizes, accepts, and shares with others their sexual and gender identity is a difficult and emotion-filled undertaking. Survey responses support this assertion with fully 60% (62) respondents not yet disclosing their sexual orientation to their family and friends. The fear of bullying or non-acceptance is reported with many LGBT individuals citing a struggle with prejudice, discrimination, family disruption and other traumas placing them at high risk for suicide, drug and alcohol use, depression and physical abuse.<sup>2</sup>

Work

**Figure 15: Current Work Status**



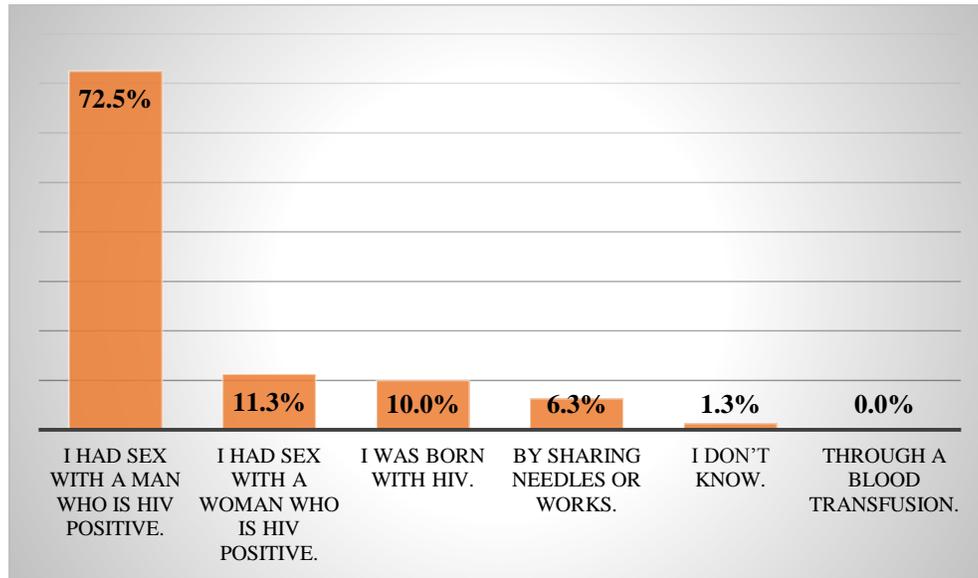
<sup>2</sup> Building Bridges: LGBT Populations. SAMHSA HHS Publication SMA 13-4774. P. 8.

Many of the older YLWH/A work with this schedule often posing a conflict as noted by the frequency of the need for assistance with integrating services with school/work. This request is needed and received by 6 respondents, and needed and cannot be obtained by 12 respondents.

## MEDICAL CARE

### Mode of Transmission

**Figure 16: Mode of HIV Transmission**



Respondents acquired HIV mainly from men who were HIV positive (72.5%). A significant 10% reported that they acquired HIV prenatally, and 6.3% reported acquiring HIV by sharing needles or works. The female respondents reported heterosexual or needle related transmission.

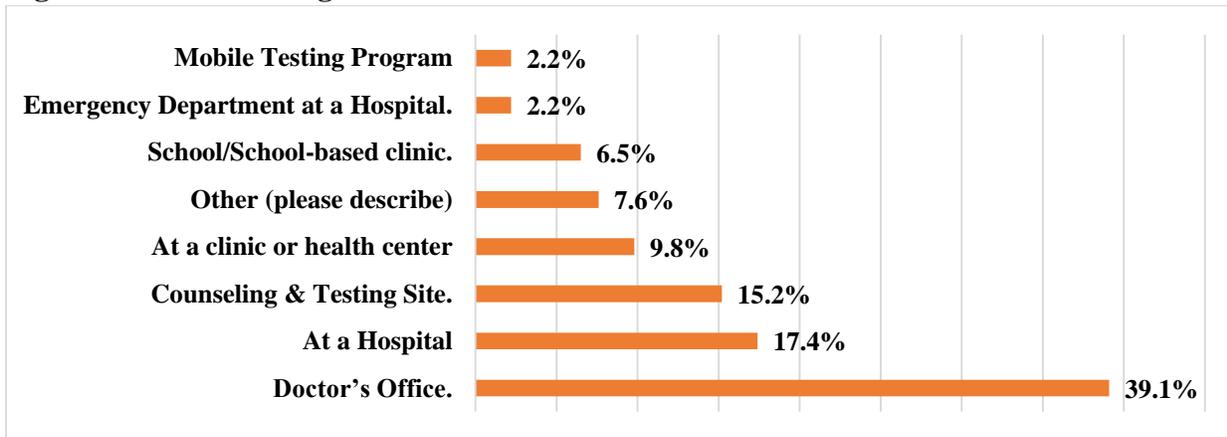
### When and Where HIV was diagnosed

**Table 16: Date of Diagnosis**

| Date of Diagnosis | 13-15 | 16-18 | 19-21 | 22-24 | 25-27 | 28-30 | Total |
|-------------------|-------|-------|-------|-------|-------|-------|-------|
| (blank)           |       |       |       |       |       | 3     | 3     |
| 1984              |       |       |       |       | 1     |       | 1     |
| 1991              |       |       |       |       |       | 2     | 2     |
| 1995              |       |       |       |       | 2     |       | 2     |
| 1997              |       |       |       |       |       | 7     | 7     |
| 1999              |       |       |       | 1     |       | 1     | 2     |
| 2001              |       |       |       |       | 1     |       | 1     |
| 2002              |       |       |       |       | 1     | 1     | 2     |
| 2003              |       |       |       |       | 1     |       | 1     |
| 2006              |       |       | 1     |       | 1     | 2     | 4     |
| 2007              |       |       | 1     |       | 3     | 2     | 6     |
| 2008              |       |       | 1     |       | 4     | 2     | 7     |
| 2009              |       |       |       | 2     | 5     | 1     | 8     |
| 2010              |       |       | 1     | 2     | 9     |       | 12    |

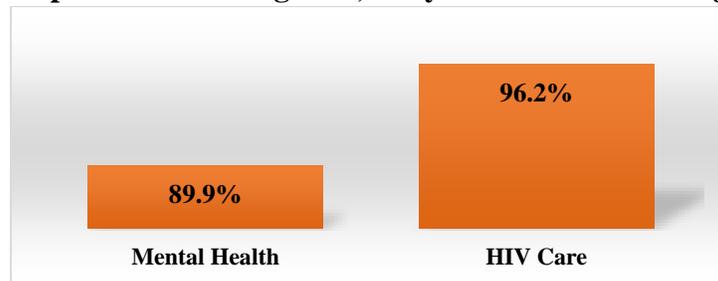
|              |          |          |           |           |           |           |            |
|--------------|----------|----------|-----------|-----------|-----------|-----------|------------|
| 2011         |          | 1        | 2         | 4         | 9         | 2         | 18         |
| 2012         |          |          | 1         | 2         | 4         |           | 7          |
| 2013         | 1        | 3        | 6         | 4         |           | 2         | 16         |
| 2014         | 1        | 1        | 2         | 1         |           |           | 5          |
| <b>Total</b> | <b>2</b> | <b>5</b> | <b>15</b> | <b>16</b> | <b>41</b> | <b>25</b> | <b>104</b> |

**Figure 17: Place of Diagnosis**

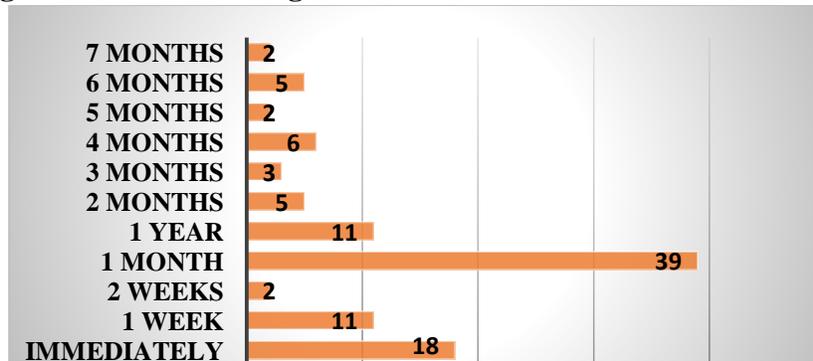


Counseling

**Figure 18: After your positive HIV diagnosis, did you receive counseling for?**

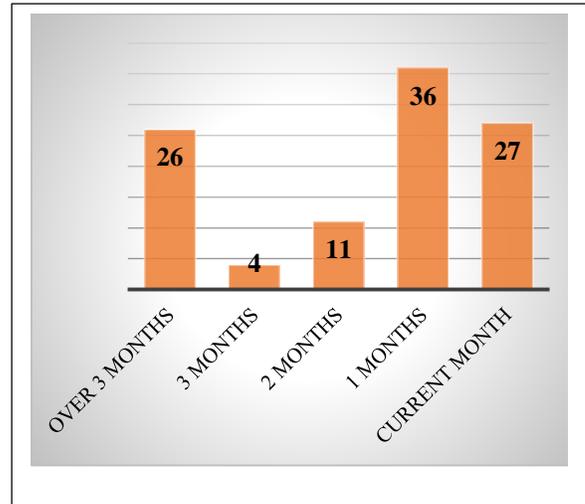
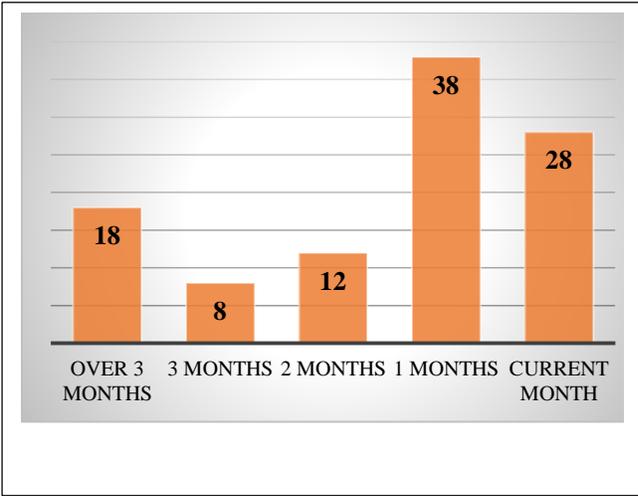


**Figure 19: Length of Time from Diagnosis to First HIV Medical Visit**



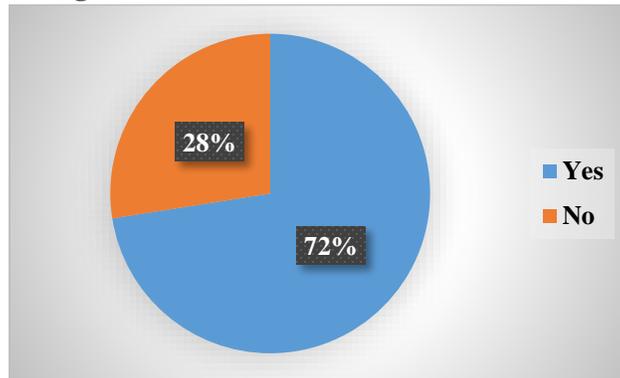
More than 80% of respondents 86% (89) saw their HIV Doctor within 3 months. Those 14% waiting over 3 months (15) cited that they did not want to admit to themselves or anyone that they had HIV, followed by being overwhelmed with the diagnosis.

**Figure 20: Most Recent Doctor Visit to treat HIV** **Figure 21: Most Recent HIV Labs**



Over forty percent of respondents are in care (42%) although 17% have not seen their doctor in over three months and 25% have not had recent lab work in over three months. When questioned by the survey facilitator, the 17% (18) replied that they saw their doctor within 4 months with trouble scheduling due to the holidays and bad weather. The respondents that had not had lab work in over 3 months also cited the holidays and bad weather and a few responded that they were undetectable and were on a 6 month lab schedule. This leads to the conclusion that all HIV respondents were in care. Respondents taking HIV medications totaled 72% of all HIV respondents.

**Figure 22: Currently Taking HIV Medications**



**Table 17: Primary HIV Physician**

| <b>Doctor</b>         | <b>Nassau</b> | <b>Suffolk</b> | <b>Total</b> |
|-----------------------|---------------|----------------|--------------|
| Dr. Elisco            |               | 5              | 5            |
| Dr. Fernando          |               | 2              | 2            |
| Dr. Hirsch            |               | 8              | 8            |
| Dr. Landau            | 9             |                | 8            |
| Dr. Lobo              |               | 4              | 4            |
| Dr. Mantingo          |               | 10             | 6            |
| Dr. McGowan           | 28            |                | 33           |
| Dr. Michaela Anderson | 6             |                | 5            |
| Dr. Yasmin            | 1             |                | 1            |
| Dr. Anderson          | 2             |                | 2            |
| Dr. George            | 1             |                | 1            |
| Dr. Nachman           |               | 26             | 26           |
| Dr. Verly             | 1             |                | 1            |
| Did not list a doctor |               |                | 1            |
| <b>Total</b>          | <b>49</b>     | <b>55</b>      | <b>104</b>   |

Co-Morbidities**Table 18: Comorbidities reported**

|   |       |
|---|-------|
| None of the above                       | 35.2% |
| Mental health issues                    | 24.2% |
| FEMALES ONLY –Abnormal pap results      | 23.1% |
| Alcohol use issues                      | 15.4% |
| Substance use issues other than alcohol | 14.3% |
| Hepatitis C                             | 4.4%  |
| Heart problems                          | 1.1%  |
| Tuberculosis                            | 1.1%  |
| Nerve issues                            | 1.1%  |
| Other (please describe)                 | 1.1%  |
| Diabetes                                | 0.0%  |
| Bleeding problems                       | 0.0%  |

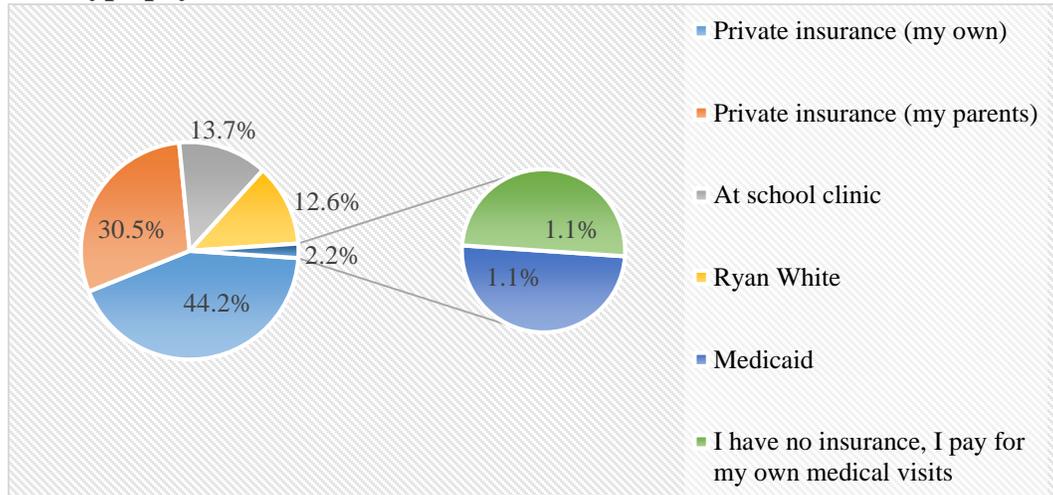
The Youth PLWH/A reported few co-morbidities, with 59 respondents listing some other health condition. The predominant other co-morbidity was a mental health issue (24%), followed by abnormal pap results (females only) at (23%) then alcohol use (15%) and substance use other than alcohol (14%), then hepatitis C (4%) and heart problems, tuberculosis and nerve issues, all at 1%. The other issues was high blood pressure at 1%.

Do you regularly see a Doctor?

This concerns the respondent’s total physical health care and refers to a family doctor or primary physician. Respondents answered that 86.3% or 102 of them regularly saw a doctor.

Medical Visit Payment

**Figure 23: Type payment for medical visit**

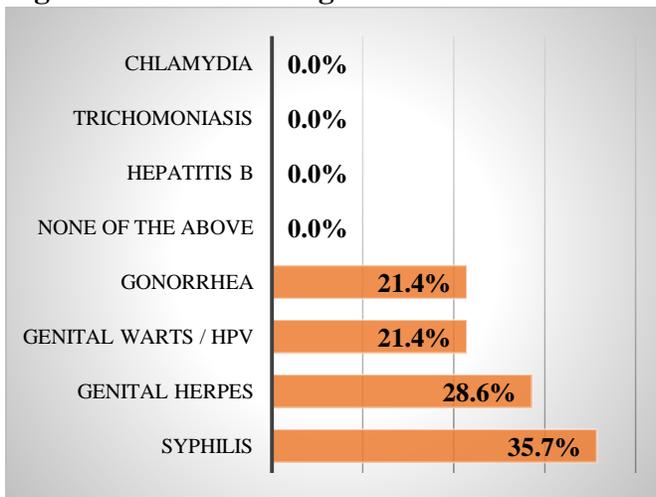


Most respondents pay their own medical bills (this 44% represented the 24 to 29 age strata), with parental insurance paying 30% (representing the 13 to 23 age group). Some college students access school clinics (14%) and 13% use Ryan White services to pay for their medical visit.

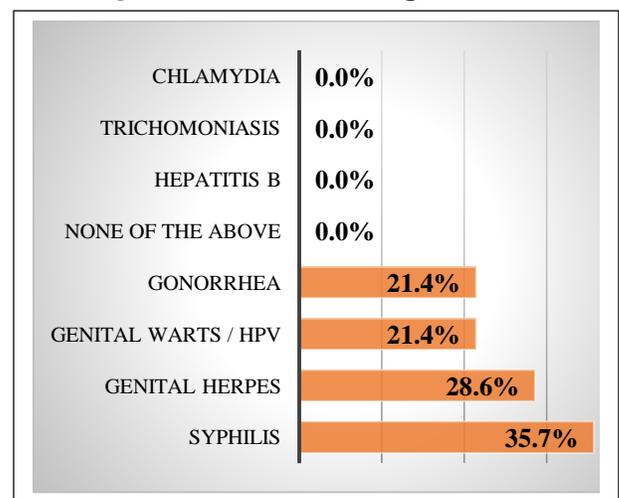
**BEHAVIOR / RISK FACTORS**

Sexually Transmitted Diseases

**Figure 24: STDS among PLWH/A**



**Figure 25: STD’s among At-Risk**

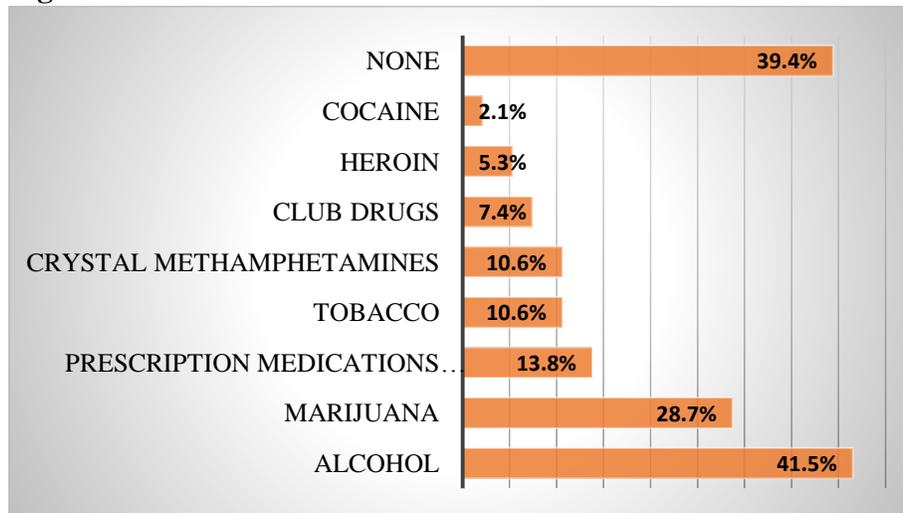


The most prevalent sexually transmitted disease was genital warts/ HPV at 22%, followed by syphilis and gonorrhea, both at 16%, then chlamydia at 14%, genital herpes at 4% and Hepatitis

B at 1%. The dominance of HPV is consistent with the female abnormal pap results of 23%, with HPV causing an abnormal pap result. Also of interest is the differing results for the at-risk population. This population reported 100% incidence of STD's among the 14 respondents, with syphilis at 36%, genital herpes at 29%, and genital warts/HPV and gonorrhea at 21%. The reasons for these high STD rates are discussed in the key informant section and include sex with older persons, no parental supervision and the attitude that sex makes these young at-risk people “grown-up”.

Substance Use

**Figure 26: Substances ever used**

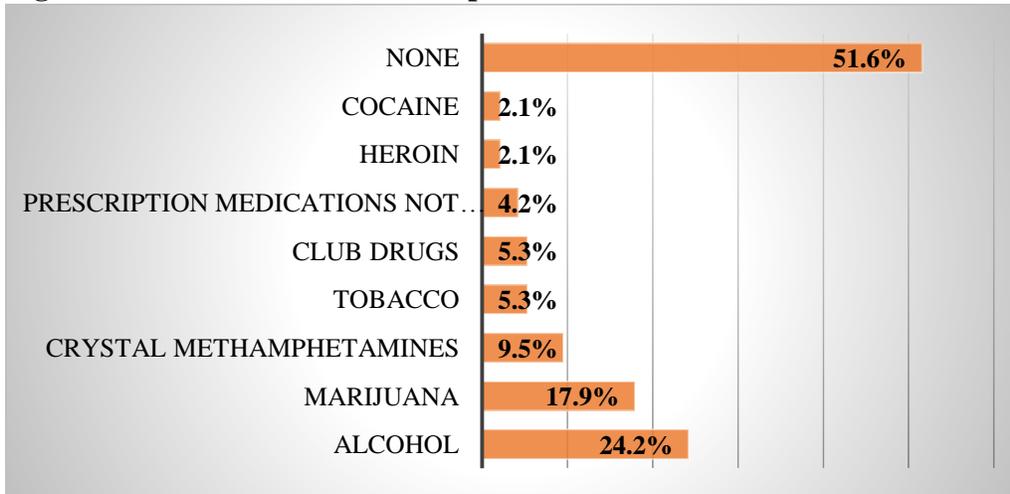


Alcohol (42%) and marijuana (29%) lead the substances ever used, followed by prescription drugs not prescribed for the respondent at (14%). Club Drug use was reported at 7%, heroin at 5% and cocaine at 2%. Respondents not reporting using any of these substances totaled 39%.

Although this substance use is concerning among YLWH/A, this phase of life involves much experimentation. The concerning aspects of this substance use are the rise in abuse of prescription drugs and the rise in heroin injection drug use.

Abuse of prescription drugs involves “Skittle parties” where teens bring their parent’s prescription medications place them in a bowl and down them without regard for what the drug is or for serious interactions, with alcohol and marijuana use also occurring. One in four teens has misused or abuse a prescription drug at least once in their lifetime.

**Figure 27: Substances used in the past 12 months**



Alcohol and marijuana still top the substances used in the past 12 months for respondents, but the use of prescription medications and club drugs is lessened. The use of crystal methamphetamines is less by 1.1%, but still high. This drug is perceived by Males having sex with males to enhance sexual feelings. Heroin use is lower by 3.4%, mainly due to improved education among those PLWH/A of the dangers of heroin use primarily contracting Hepatitis C.

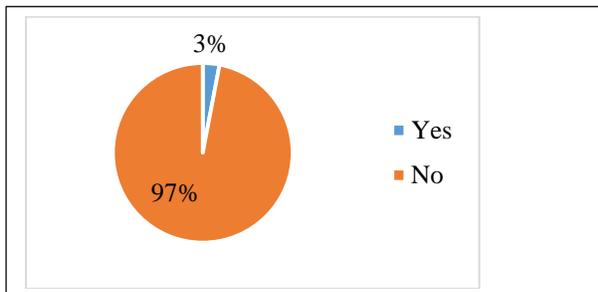
Mental Health Conditions

Respondents stating that they have been diagnosed with a mental health condition total 29.5% (35). This figure is higher than listed in co-morbidities (24.2%), and both questions ask if ever the respondent had this condition so the incidence of mental health issues is probably closer to 30%. Diagnoses listed by those replying affirmatively include depression, anxiety, ADHD, bipolar disorder and intellectual disability in that ranked order.

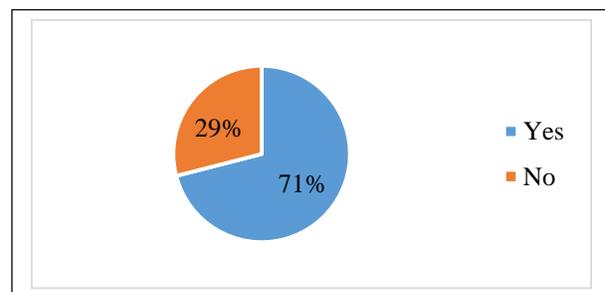
Jail, Prison History

The replies for jail and prison history ask if the respondent has been in jail, prison or a juvenile detention facility in the past 6 months or ever? Ten of our at-risk youth are currently in a juvenile detention facility so these results are skewed. Shown below are the response for PLWH/A and those at-risk:

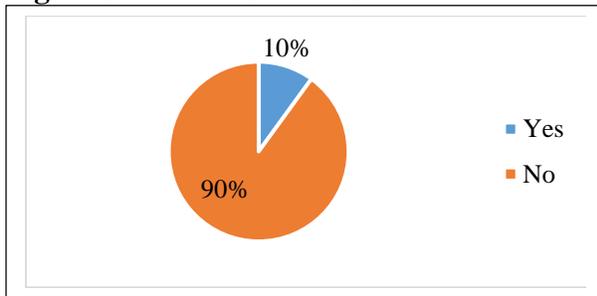
**Figure 28: PLWH/A - past 6 months**



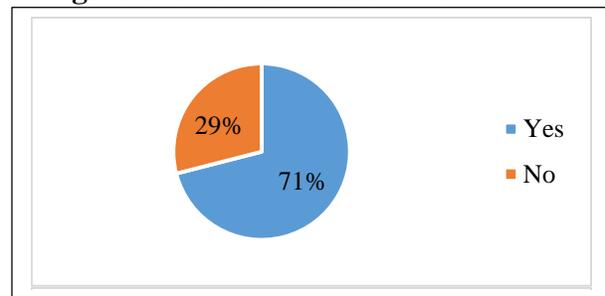
**Figure 29: At-Risk Youth-past 6 months**



**Figure 30: PLWH/A - Ever**



**Figure 31: At-Risk Youth-Ever**



The decrease of 7% in the rates of jail or prison history for PLWH/A reflect the length of distance in time from the jail or prison experience. The At-Risk youth identical results reflect the recent juvenile detention experience with 6 months equaling all history of jail, prison or juvenile detention.

Internet Search for Sex Partners

Respondents ever using the internet to find sex partners was low at 8.6% (10), with only 2.1% (2) respondents currently using the internet to meet sex partners.

Unprotected Sex

Respondents engaging in sex without a condom during vaginal or anal sex totaled 3.2% or 4. These four responses listed the following information about whom the respondents had unprotected sex with:

**Table 19: Partners with whom Unprotected Sex practiced**

|                                    |
|------------------------------------|
| Someone I Know who is HIV Positive |
| Someone who is injecting drugs.    |
| For drugs, money, food or housing. |
| Someone of unknown status          |

Age of First Sexual Encounter / Older Sex Partners

Risk factors mentioned in the Key Informant interviews included early onset of the first sexual encounter and older sex partners. Many of the at-risk youth had engaged in sex before the age of 14 and often young males with older HIV positive women. Some of these youth had children by these women by the age of 15. Another group of young, pregnant or young mothers at a group home reported first sexual relations before the age of 14, with many pregnant or mothers before reaching 16. Many of these encounters were with older men, and occurred most frequently among foreign born immigrants from South and Central America or the Caribbean. This risky behavior and often sexual trauma places the youth at-risk for HIV and for risky behavior their entire lives.

Male to Male Sex

Male having sex with males are in a risky position to contract HIV/AIDS and Hepatitis C due to poor education or inability of parents or teachers to discuss safe homosexual practices and to the use of substance such as crystal methamphetamines to enhance sexual feelings. “Gay men, lesbians, and male-to-female transgender persons experience methamphetamine use as a

significant problem.”<sup>3</sup> A multi-state study of high school students found a greater likelihood of engagement in unhealthy risk behaviors such as tobacco use, alcohol and other drug use, sexual risk behaviors, suicidal behaviors and violence among LGB students and students who report having sexual contact only with persons of the same or both sexes, than by heterosexual students.<sup>4</sup>

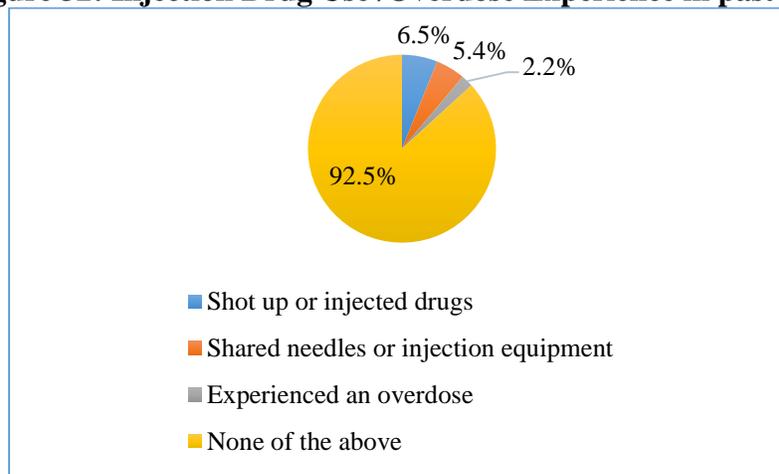
### Injection Drug Use

The path towards injection drug use (IDU) starts with prescription drug abuse then leads to heroin, which is much cheaper to obtain, but carries the risks of HIV and Hepatitis C, both risks of which youth at-risk are unaware and not pursuing any type of protection from. The heroin addiction can often lead to the exchange of sex for drugs, and at this point, the parent often kicks the youth out of the home. The exchange of sex for money now becomes survival sex. This is the new IDU.

Heroin use has exploded in what is being described as an epidemic on New York's Long Island, where addiction counselors are seeing users as young as 12 -- many from middle-class, suburban families. Several factors have contributed to this "perfect storm" of addiction according to experts -- among them, proximity to major airports and transportation centers, and a statewide crackdown on prescription painkillers, that has had the unintended effect of pushing more kids to cheaper and more accessible heroin.

The Centers for Disease Control and Prevention reported that U.S. drug poisoning deaths involving heroin increased 45% from 2006 to 2008. Drug Enforcement Administration states that the amount of heroin seized each year at the southwest U.S. border increased 232% from 2008 to 2010.. Among four age groups reporting “drug poisoning deaths involving heroin”, only the youngest group, ages 15 to 24, increased from 2008 to 2010. For all the other age groups, the number of deaths was steady or decreased, as reported by the CDC. Young heroin users consume more heroin than previous heroin users, often 10 bags daily. Respondents reported that 6.5% had shot up or injected drugs in the past year, 5.4% had shared needles or injection equipment and 2.2% had experienced an overdose. Respondents with no IDU or overdose experiences in the past year totaled 92.5%.

**Figure 32: Injection Drug Use /Overdose Experience in past year**



<sup>3</sup> Building Bridges: LGBT Populations. SAMHSA HHS Publication SMA 13-4774. P. 1

<sup>4</sup> CDC, 2011a.

### Inadequate or Non-Existent Parenting

Key Informants report parents who were teenage parents try their best to cope, but are not educated to handle a teenager with “issues”. Family Acceptance of an LGBT individual’s sexual identity or gender is critical to their feelings of self-worth and support. If rejected by their family, many LGBT individuals are homeless, depressed, and use alcohol or drugs to self-medicate or find their acceptance with sometimes dangerous groups. The acceptance of an LGBT child bestows a protective factor against suicide, depression, and substance abuse disorders in early adulthood.<sup>5</sup> LGBT who reported high levels of family rejection during adolescence were:

- 8.2 times more likely to report having attempted suicide.
- 5.9 times more likely to report high levels of depression.
- 3.4 times more likely to use illegal drugs, and
- 3.4 times more likely to report having engaged in unprotected sexual intercourse.

Better education for parents is critical to support Youth that are PLWH/A or youth at-risk for contracting HIV. Community efforts to support parents are cost-effective, engage all parties and can lead to safer towns and healthier youth.

### Stress at School -Overscheduling

Key Informants referenced issues confronting Youth Living with HIV/AIDS or those youth at-risk, with over-riding reference to the stress that the school environment and Common Core standards have imposed on our youth.

The mission and intent of Common Core State Standards is to provide a consistent, clear understanding of what students are expected to learn, so teachers and parents know what they need to do to help them. The standards are designed to be robust and relevant to the real world, reflecting the knowledge and skills that our young people need for success in college and careers. With American students fully prepared for the future, our communities will be best positioned to compete successfully in the global economy. <sup>6</sup> All key informants cited that the stress of going to college and filling student’s days with as much knowledge as possible leads to anxiety, which is coped with by substances such as alcohol and other drugs. It was also widely asserted that the main reason for poor student performance, childhood poverty, was ignored. Two key informants stated that student’s schedules are so full that any prevention programs cannot be accommodated.

### Trauma

Trauma affects youth negatively in many ways. Youth that are sexually abused or initiated into sex via rape or early encounters color their entire view of sex for life. Sex leaves both physical and emotional scars, and trauma has serious implications for mental health, alcohol and substance use and related risk-taking behaviors.<sup>7</sup>

LGBT youth face trauma through bullying, physical attacks and provocation due to both their sexual identity and their HIV status. Research shows that hate crimes based on sexual orientation

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<sup>5</sup> Building Bridges: LGBT Populations. SAMHSA HHS Publication SMA 13-4774. P. 8.

<sup>6</sup> <http://www.corestandards.org/>

<sup>7</sup> Centers for Disease Control & Prevention. (2006). Adverse Childhood Experiences Study. Retrieved from <http://www.cdc.gov/nccdphp/ace/index.htm>.

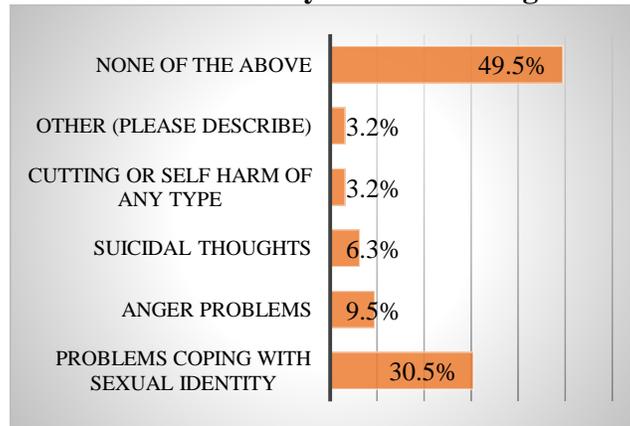
bias has more serious and long-lasting psychological effects than other crimes because of the link to cores aspects of the victim’s identity and community.<sup>8</sup>

### Invisibility of LGBT Individuals and Groups

Social stigma often leads to the invisibility of LGBT individuals to their families, communities, each other, society and to healthcare providers. The fear of family and friend’s rejection of the LGBT individual and the fear of bullying, harassment, violence and shunning is always present. Many youth, particularly youth of color, hide their sexual orientation and thus may appear even less visible than their white LGBT peers<sup>9</sup>.

In the workplace, LGBT individuals fear self-disclosure will trigger social and economic repercussions. This leads to LGBT people socializing in gay bars and clubs, which can exacerbate substance use disorders. Mental health providers in inpatient and outpatient setting often fail to tailor treatment plans to reflect the LGBT client’s unique needs. This lack of recognition sends a message that the youth’s feelings and self-identity is not important.

**Figure 33: Have you ever had issues with any of the following behaviors?**



<sup>8</sup> Herek, G., Gillis, J.R. and Cogan, J.C (1990). Psychological sequelae of hate-crime victimization amount lesbian, gay and bisexual adults. *Journal of Consulting and Clinical Psychology*. 67 (6), 945-951.

<sup>9</sup> SAMHSA News 2011b., 19(2).

## SERVICES AND SERVICE ACCESS

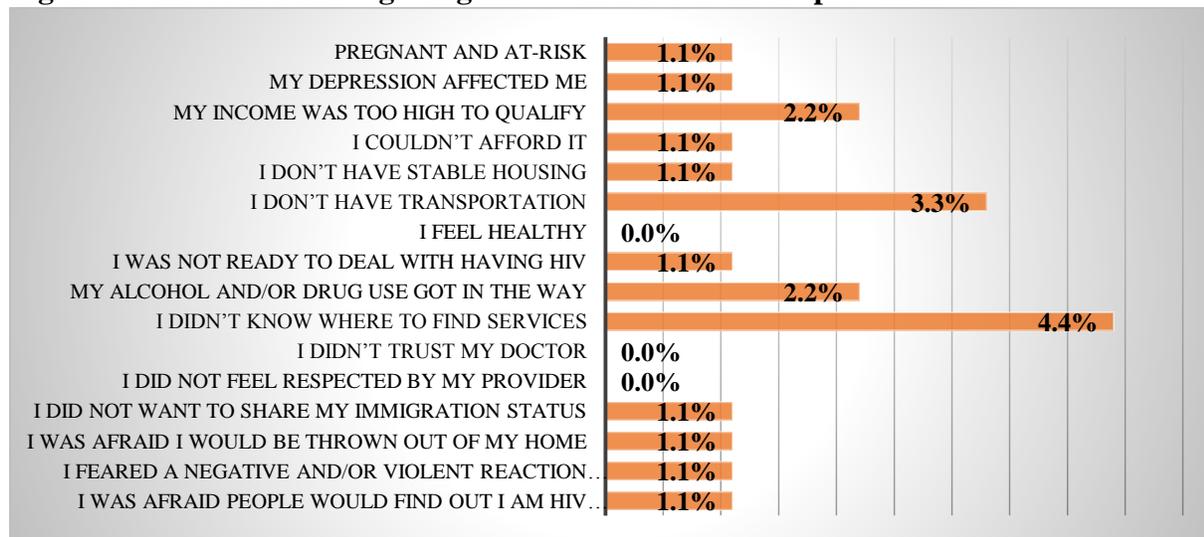
**Table 20: Services that are Needed, Used and Not Available**

| <u>Need</u>   | <u>Need &amp; Receive</u>                               | <u>Need &amp; Cannot Get</u>                                   |
|---|---|--|
| Family Doctor   | Family Doctor   | Transportation / Support Groups                                |
| HIV/AIDS Doctor   | HIV/AIDS Doctor   | Assistance with integrating services with school / work        |
| Medical case management /Case Manager                   | Medications   | Assistance paying for health insurance, co-pays or deductibles |
| Mental health services (individual or group counseling) | Mental health services (individual or group counseling) | Mental health services (individual or group counseling)        |
| Support groups  | Medical case management /Case Manager                   | Substance abuse services (other than 12 step meetings)         |

The top two ranked services of Family Doctor and HIV/AIDS Doctor are identical for services respondents need and need and use. The third service, listed is Case Manager for Need. This service ranks only fifth for service use. The service ranked third for service use is Medications. This is consistent with the Youth mindset that medications are okay, but talk and coordination is not as critical.

Services that represent gaps and were reported as unavailable or that could not be obtained are Support Groups, assistance integrating services with school or work, assistance paying for health insurance, co-payments or deductibles, followed by mental health services and substance abuse services.

**Figure 34: Reasons for not getting HIV care services in the past 12 months.**



## Key Informant Interviews

Four key informant interviews were conducted with Jeffrey Reynolds of LICAD, LaQueta Robbins-Kennedy of the Nassau Juvenile Detention Center, Dan Matos of Stony Brook Long Island Children's Hospital and Colby Povill of South Oaks Adolescent Partial Program.

All informants stressed the challenges of growing up in our fast-paced environment and the risks that Youth face regarding HIV and Hepatitis C.

Challenges include:

- Inadequate knowledge of sex, safe sex practices, HIV prevention and the risks of unsafe sexual behavior.
- Sexual trauma among those already sexually abused. These youth will inappropriately behave as they have been taught to do.
- Teen pregnancy
- Alcohol or Marijuana use
- IDU and heroin youth epidemic
- Large transmission rate of HIV
- Domestic violence
- Sexually transmitted diseases
- Poor or Non-Existent Parenting
- Early First Sexual Encounters
- Sexualization of Youth by Media
- Sex with Older Partners
- Prescription Drug Use
- Stress of Over Scheduled School Workload due to Common Core standards.
- Mental Health Issues

Recommendations included:

- Go to where youth already are engaged such as structured settings like group homes, Gay Bars, Homeless shelters, Mobile vans
- Partner with other organizations to fill gaps in services (like LIGALY for HIV testing and Syringe exchange programs)
- Practice active outreach
- Collaborate with community-based, educational, behavioral health, foster care and HIV agencies, police, juvenile justice and faith-based organizations.
- Start HIV and safe practice education early by the 5<sup>th</sup> or 6<sup>th</sup> grade
- Work on improving the American attitude toward sex and accept alternative choices and inform children about STD's and the care of themselves as sexual being.
- Realize these are young people, and they are:
  - a) Unaware of long-term consequences-long term is What will I do this weekend.
  - b) The adolescent brain is still developing-long-term planning happens last, and the short-term is all we can address them with.
  - c) They will take risks
- Parents have little control or influence but need to be engaged

- Teens do not want to be talked to, but directly addressing issues with education, available condoms and education can work.
- Fostering healthy self-esteem
- Substance and alcohol abuse prevention.
- Treating dual or triple co-morbidities
- Early Intervention
- Efforts to stop bullying
- As adults, being aware and owning our responsibility to children, even if they are not ours.
- Reducing school-induced stress
- Addressing media inaccuracies of how to be a successful person
- Owning that we all contribute to good mental health.
- Use social media
- Greater recognition of drug epidemic problem and more funded programs to address youth and IDU.
- Use of Human social worker component is essential.
- Let Youth be Youth, not mini-adults.

## **FINDINGS**

Social networking via smartphone, cell phone, tablet, laptop or computer can provide counselors and health care providers an easy medium to reach HIV youth or at-risk youth. Study results show texting to be a preferred contact method via cell or smartphone, although more respondents have access to tablets, laptops or computers. The most popular websites and social networking sites were Facebook, Twitter and Google (plus).

Responses were collected from both counties (53%) Nassau and (47%) Suffolk. At risk behaviors differed between the counties with alcohol, sexually transmitted diseases, marijuana, alcohol and prescription drug use and domestic violence and childhood poverty in Nassau County. Suffolk County is more affluent, with the heroin injection drug use epidemic reported and linked to the enormous pressure for academic achievement..

At Risk Youth had the most frequent history of jail, prison and juvenile detention, primarily reflecting the youth age 10 to 16 from the Nassau County Juvenile Detention Center.

School was a source of education achievement with 32% of all respondents graduating with a college degree or reaching a more advanced educational level. However, the stress of the Common Core standards were repeated by every key informant as a contributing factor in alcohol and substance use and a mental health stressor.

Most respondents (48%) lived in their own apartment or home and 36% lived with their families. Respondents working full time reported at 42% and part-time at 33%. Most living spaces were safe, clean and permanent with reliable utility service, but pest infestation was listed as a problem

Risk identifiers for Youth Living with HIV (YLWH/A) or Youth at-risk for contracting HIV were: sex, alcohol/drug use, school, parenting, bullying, trauma , encounters with juvenile justice, male to male sex, foreign origins, and the coping with sexual identity and gender.

## **Recommendations**

The recommendations of this study mirror the comments of the key informants, with a few additions.

The stress of youth coupled with the increase from an HIV diagnosis constitute a challenge to healthcare providers, counselors and educators to best treat youth living with HIV/AIDS and at-risk youth.

Recommendations for healthcare providers and counselors include treating the child where they are, both in location and in their developmental stage, incorporating the needs of an LGBT individual in their treatment, always exploring the co-existence of substance abuse and mental health issues, and if present, intervening early. Medical practitioners, “should aim to meet parents, families and caregivers “where they are” to build an alliance to support their LGBT children and to help them understand that family reactions that are experienced as rejection by their LGBT child contribute to serious health concerns and inhibit their child’s development and well-being.”<sup>10</sup>

Recommendations for educators are to educate youth early about safe sex, the risks of unprotected sex and the emotional aspects of sex. Sex education was recommended by key informants to begin at age 10 and 11 in the 5<sup>th</sup> or 6<sup>th</sup> grade. Programs to combat bullying, with peers standing up to bullies should be incorporated into each school curriculum as responses from this study showed the presence of bullying, especially to those who disclose their HIV positive status. Every one of our key informants recommended that the Common Core curriculum be examined, and that the pressure on youth for academic achievement be lessened.

Recommendations for parents included being involved in your youth’s health and treatment, being aware of substance abuse potential and mental health and being accepting of their sexual orientation or gender identity. Acceptance of an LBGT child’s sexual orientation or gender identity is crucial to their well-being, and can prevent suicide attempts, depression, substance abuse and unprotected sexual intercourse.

Recommendations to the community include providing leadership and support to shape community responses that promote recovery, prevent behavioral health disorders, reduce the impact of behavioral health problems when they occur and ensure needed treatments and services are available.

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<sup>10</sup> “A Practitioner’s Resource Guide: Helping Families to Support their LGBT Children.” SAMHSA. Accessed online at: <http://store.samhsa.gov/shin/content/PEP14-LGBTKIDS/PEP14-LGBTKIDS.pdf>

# Appendix

## Schedule 1: Survey

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

Thank you for participating in this survey to assess the status of care for young people (age 13 to 29) in Nassau and Suffolk County, Long Island. This is a confidential survey. The data will be used to improve prevention of HIV and services and service delivery to you for your HIV.

Facts about you:

**1. When were you born?**

DOB  /  /

**2. Are you aware of your HIV status?**

Yes, I am

I am not sure

No, I am not aware

**3. If you answered I am not sure or No, I am not aware, when was the last time you were tested for HIV?**

Approximate Date  /  /

**4. Are you Hispanic or Latino / Latina? Please check one answer.**

Yes

No

**5. Which of the following best describes your racial background?**

Black, not Hispanic

American Indian/Alaskan Native

Asian/Pacific Islander

White, not Hispanic

More than one race

**6. Are you?**

Male

Female

Transgender

Page 1

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

### 7. If you checked transgender were you:

- Born a male, but feel I am a female
- Born a female, but feel I am a male

### 8. Do you attend school?

- Yes, Middle School
- Yes, High School
- Yes, College
- Yes, Technical School
- No, I do not attend school

### 9. What is the highest grade you have reached in school?

- Completed grade school-5th grade
- Completed middle school-8th grade
- Some high school-please state grade level you reached below
- High school or GED
- Some college or Technical School
- College Degree
- Some graduate school
- Graduate school degree

If you answered 'Some high school' above, please state grade level you reached.

### 10. If you are in school now, do you ever feel picked on or "bullied" at school because of your sexual orientation?

- Yes, often
- Yes, occasionally
- No, but I will not disclose my sexual orientation to friends or classmates to avoid being targeted
- Never

Page 2

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

**11. If you are in school now, do you ever feel picked on or “bullied” at school because of your HIV status?**

- Yes, often
- Yes, occasionally
- No, but I will not disclose my HIV status to friends or classmates to avoid being targeted.
- Not applicable
- Never

**12. I consider myself . . . . (Please choose one.)**

- Gay (Homosexual)
- Lesbian
- Straight (Heterosexual)
- Bisexual
- Questioning (Please describe)

**13. If you identify as gay/lesbian/bisexual, are you “out” to your family and friends?**

- Yes, out to both family and friends
- Yes, out to friends but not family
- Yes, out to family but not friends
- Not out to anyone

How do you Communicate?

**14. Do you currently have a working smart or cell phone?**

- Yes, I do
- No
- No, I do not but would like and use one if available

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

**15. . If you answered yes to Question #14, please check the following activities you do on your mobile or cell phone. (Check all that you do.)**

- General internet use (other than using social networking websites)
- Make or receive phone calls
- Play games
- Play music
- Access podcasts
- Play videos (other than video games)
- Buy products or services
- Record videos
- Send or get emails
- Send or get IM's (instant messages)
- Send or get pictures
- Send or get text messages
- Send or get videos
- Take pictures
- Use social networking websites
- Use apps

**16. . Which websites do you use?**

**17. Do you have a laptop, tablet or other computer?**

- Yes
- No
- No, I do not but would like and use one if available

**18. Do you have access to the internet?**

- Yes
- No

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**19. If you answered yes to Questions #17 and or #18, please check the following activities you do on the internet. (Check all that you do.)**

- General internet use (other than using social networking websites)
- Use for School and use applications like Word, Excel
- Play games
- Play music
- View podcasts
- Play videos (other than video games)
- Buy products or services
- Record videos
- Use social networking websites (Facebook, Twitter, etc.)
- Use apps

**20. Which websites do you access for social networking?**

**21. If you said you use apps in response to Q #19, what apps do you use?**

School or Work

**22. What is your zip code?**

zip code

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**23. Where have you LIVED in the PAST 12 MONTHS? Please check all that apply.**

- I was homeless
- With friends
- With family
- In my own apartment / home
- In a college dormitory
- In a hotel, motel or renting a room
- In a shelter or transitional housing
- In a group home
- In an inpatient program (substance abuse treatment or psychiatric facility)
- In someone else's home
- In jail or prison
- Foster home
- Other (please describe)

\_\_\_\_\_

**24. Where do you LIVE TODAY? Please check all that apply.**

- I am homeless
- In my own apartment / home
- In a college dormitory
- In a hotel, motel or renting a room
- In a shelter or transitional housing
- In a group home
- In an inpatient program (substance abuse treatment or psychiatric facility)
- In someone else's home
- In jail or prison
- In a foster home.
- Other (please describe)

\_\_\_\_\_

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**25. Is your home or living space?**

- Safe
- Clean
- Pest-free
- Permanent
- Temporary
- Over-crowded
- None of the above (Please describe)

**26. Do you have reliable:**

- Heat
- Hot Water
- Food
- Electricity

**27. Are you currently working?**

- Yes, full time
- Yes, part time
- No

**28. Would you be interested in sharing your opinions on HIV and youth by becoming a member of our HIV Planning Council?**

- Yes, please contact me (Please supply contact details and name below)
- No, thank you

Contact details and name

HIV and your Medical Care (Complete only if HIV Positive)

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

### 29. How did you become infected with HIV? (Please check all that apply.)

- I had sex with a man who is HIV positive.
- I had sex with a woman who is HIV positive.
- I was born with HIV.
- Through a blood transfusion.
- By sharing needles or works.
- I don't know.

### 30. When were you diagnosed with HIV?

Approximate date of diagnosis      MM    DD    YYYY  
  /    /    /

### 31. Where were you tested for HIV?

- Emergency Department at a Hospital.
- At a Hospital
- At a clinic or health center
- Doctor's Office.
- Counseling & Testing Site.
- A Home HIV test I purchased at a local drugstore.
- School/School-based clinic.
- Mobile Testing Program
- Other (please describe)

\_\_\_\_\_

### 32. After your positive HIV diagnosis, did you receive counseling for: (Please check all that apply.)

- Mental Health
- HIV Care

### 33. Please list the city and state where you were first diagnosed with HIV.

\_\_\_\_\_

### 34. How long after your initial HIV diagnosis was it until you saw a doctor for HIV?

\_\_\_\_\_

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

### 35. If you waited to see a doctor for your HIV more than 3 months, why did you wait?

- Not Applicable, saw doctor within three months of HIV diagnosis.
- Felt healthy, did not think I needed to go.
- I didn't want to admit to myself or anyone else that I had HIV.
- Did not know where to go.
- I was overwhelmed when diagnosed with HIV.
- I did not want to deal with HIV.
- Other (please describe)

### 36. Who knows you are HIV positive? Please check all that apply.

- Family
- Friend or Friends
- Parent or Parents
- Partner or Partners
- Sibling or Siblings
- Co-Workers
- Classmates
- Teachers
- Other (please describe)

### 37. Who is your primary HIV doctor?

### 38. When was the last time you saw a doctor to treat your HIV?

Approx date      MM    DD    YYYY  
                         |    /    |    /    |

### 39. When was the last time you had labs for HIV?

Approx date      MM    DD    YYYY  
                         |    /    |    /    |

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**40. Are you currently taking HIV medications?**

- Yes
- No
- Don't know

Health

**41. Have you EVER had any of the following other health issues? (Please check all that apply.)**

- Alcohol use issues
- Diabetes
- Heart problems
- Hepatitis C
- Substance use issues other than alcohol
- Mental health issues
- Tuberculosis
- Bleeding problems
- Nerve issues
- FEMALES ONLY –Abnormal pap results
- None of the above
- Other (please describe)

\_\_\_\_\_

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**42. Have you EVER been told that you have ANY of the following sexually transmitted infections (STI's)? (Please check ALL that apply.)**

- Chlamydia
- Genital Warts / HPV
- Genital Herpes
- Gonorrhea
- Hepatitis B
- Trichomoniasis
- Syphilis
- None of the above
- Other (please describe)

**43. Which of the following substances have you ever used?**

- Alcohol
- Tobacco
- Marijuana
- Heroin
- Cocaine
- Prescription Medications not prescribed for you
- Crystal Methamphetamines
- Club Drugs
- None
- Other (please describe)

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**44. Which of the following substances have you used in the past 12 months?**

- Alcohol
- Tobacco
- Marijuana
- Heroin
- Cocaine
- Prescription Medications not prescribed for you
- Crystal Methamphetamines
- Club Drugs
- None
- Other (please describe)

\_\_\_\_\_

**45. Have you ever been diagnosed with a mental health condition?**

- Yes (please specify below)
- No
- Don't know

If yes, what was the diagnosis?

\_\_\_\_\_

**46. If you went for a medical visit today, how would you pay for the visit? Please check all that apply.**

- Medicare
- Medicaid
- Private Insurance (my parents)
- Private Insurance (my own)
- At school clinic
- Ryan White
- I have no insurance, I pay for my own medical visits
- I have no way to pay for my medical visits

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**47. Do you regularly see a doctor?**

- Yes
- No

Behavior

**48. Have you been in jail, prison or a juvenile detention facility in the past 6 months?**

- Yes
- No

**49. Have you ever been in in jail, prison or a juvenile detention facility?**

- Yes
- No

**50. Have you ever used the internet to find sex partners ?**

- Yes
- No

**51. Do you currently use the internet to meet sex partners?**

- Yes
- No

**52. In the PAST 12 MONTHS, have you had UNPROTECTED (without a condom) vaginal or anal sex? Please check ONE answer.**

- Yes
- No

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

**53. If you answered yes to Q. # 52, please provide the following information about the partner with whom you had UNPROTECTED vaginal or anal sex. Please check ALL that apply.**

- Someone I don't know
- Someone I know is HIV negative.
- Someone I know is HIV positive.
- Someone who is injecting drugs.
- For drugs, money, food or housing.
- While using drugs and/or alcohol.
- Someone I met on the internet.
- A man who has sex with other men.
- Someone of unknown status
- None of the above.

**54. How often do you use condoms or sexual protection?**

- Sometimes
- Never
- Always

**55. In the PAST 12 MONTHS, have you? Please check ALL that apply.**

- Shot up or injected drugs
- Shared needles or injection equipment
- Experienced an overdose
- None of the above

**56. Have you ever had issues with any of the following behaviors?**

- Anger problems
- Suicidal thoughts
- Problems coping with sexual identity
- Cutting or self harm of any type
- None of the above
- Other (please describe)

## Nassau-Suffolk HIV Health Services Planning Council-Youth Needs

HIV Services And Service Access (Complete only if HIV Positive)

**57. In the PAST 12 MONTHS, which of the following HIV care services: (Please check ALL that apply)**

|   | Need                  | Need and Receive      | Need and Cannot Get   |
|---|-----------------------|-----------------------|-----------------------|
| HIV/AIDS Doctor   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Family Doctor   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Medical case management /Case Manager                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Health Care professional to teach me how to take my HIV medications | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Substance abuse services (other than 12 step meetings)              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Mental health services (Individual or group counseling)             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dental care   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support groups  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance getting food   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Nutrition services (Ensure/Boost and food pantry)                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Help paying for HIV/AIDS medication                                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance paying for health insurance, co-pays or deductibles      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Translation/Interpretation services                                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance paying for housing                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance paying for utilities                                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Transportation to medical or to support services                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Legal assistance  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance with integrating services with school / work             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other (Please describe below)                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you answered 'Other' above please describe.

**Nassau-Suffolk HIV Health Services Planning Council-Youth Needs**

**58. In the PAST 12 MONTHS, I did not get the HIV care services I need because . . . (Please check ALL that apply).**

- I was afraid people would find out I am HIV positive
- I feared a negative and/or violent reaction from my partner / family / friends
- I was afraid I would be thrown out of my home
- I did not want to share my immigration status
- I did not feel respected by my provider
- I didn't trust my doctor
- I didn't know where to find services
- My alcohol and/or drug use got in the way
- I was not ready to deal with having HIV
- I feel healthy
- I don't have transportation
- I don't have stable housing
- I couldn't afford it
- My income was too high to qualify
- Other (please describe)

\_\_\_\_\_

## Schedule 2: Provider Directory

| Provider  | Contact                              | Task                                      | Day/Date/Time                           |
|---|--------------------------------------|---|---|
| Long Island Council on Alcoholism & Drug Dependence | Jeffrey Reynolds<br>(by phone )      | Provider interview                        | January 7, 2014: 9 am                   |
| Stony Brook Long Island Children's Hospital         | Dan Matos                            | Provider interview                        | Tuesday, January 7, 2014: 10 am)        |
|   |                                      | Facilitate surveys                        | Sent February 20, 2014                  |
| Nassau Juvenile Detention Center                    | La Queta Robbins-Kennedy             | Provider interview                        | Wednesday, January 8, 2014: 12 noon     |
| North Shore University Hospital                     | Barbara Martens                      | Provider interview and facilitate surveys | Thursday, January 9, 2014: 9:30 to 5:00 |
| Nassau University Medical Center (NUMC)             | Martine Michel-Toure and Hope Sender | Provider interview                        | Week of February 17, 2014               |
|   |                                      | Facilitate surveys                        | Wednesday, February 19, 2014            |
| South Oaks Adolescent Program                       | Colby Povill                         | Facilitate Surveys                        | Week of February 17, 2014               |
|   |                                      | Provider Interview                        | February 20, 2014                       |

### Schedule 3: Zip Codes of Respondents

| Postal Code  | Number of Respondents | Town               | County   |
|--|-----------------------|--------------------|----------|
| 10977  | 1                     | New Hempstead      | Rockland |
| 11232  | 1                     | Brooklyn           | Kings    |
| 11520  | 7                     | Freeport           | Nassau   |
| 11550  | 10                    | South Hempstead    | Nassau   |
| 11551  | 1                     | Hempstead          | Nassau   |
| 11553  | 2                     | Uniondale          | Nassau   |
| 11558  | 4                     | Island Park        | Nassau   |
| 11563  | 3                     | Lynbrook           | Nassau   |
| 11565  | 1                     | Malverne           | Nassau   |
| 11566  | 4                     | Merrick            | Nassau   |
| 11572  | 2                     | Oceanside          | Nassau   |
| 11575  | 8                     | Roosevelt          | Nassau   |
| 11580  | 2                     | Valley Stream      | Nassau   |
| 11590  | 2                     | Westbury           | Nassau   |
| 11592  | 7                     | Rockville Center   | Nassau   |
| 11594  | 1                     | Westbury           | Nassau   |
| 11597  | 3                     | Westbury           | Nassau   |
| 11701  | 1                     | Amityville         | Suffolk  |
| 11704  | 1                     | Babylon            | Suffolk  |
| 11719  | 1                     | Brookhaven         | Suffolk  |
| 11720  | 1                     | Centereach         | Suffolk  |
| 11722  | 8                     | Central Islip      | Suffolk  |
| 11730  | 1                     | East Islip         | Suffolk  |
| 11746  | 6                     | Huntington Station | Suffolk  |
| 11747  | 2                     | South Huntington   | Suffolk  |
| 11749  | 1                     | Ronkonkoma         | Suffolk  |
| 11750  | 2                     | Melville           | Suffolk  |
| 11758  | 3                     | Massapequa         | Suffolk  |
| 11760  | 4                     | Hauppauge          | Suffolk  |
| 11763  | 2                     | Medford            | Suffolk  |
| 11767  | 1                     | Nesconset          | Suffolk  |
| 11772  | 1                     | Patchogue          | Suffolk  |
| 11790  | 1                     | Stony Brook        | Suffolk  |
| 11794  | 7                     | Wildwood           | Suffolk  |
| 11950  | 3                     | Mastic             | Suffolk  |
| 11971  | 1                     | Southold           | Suffolk  |
| These 2 surveys were not included as the respondents do not live in Nassau nor Suffolk counties. |                       |                    |          |

**Schedule 4 (Table 7)**

Responses to question “Where did you live when you first tested positive for HIV?” for those who selected “Other” and provided this information

|              |           |
|--------------|-----------|
| Manhattan    | 30        |
| Queens, NY   | 10        |
| Brooklyn     | 5         |
| New Jersey   | 1         |
| Denver, CO   | 1         |
| <b>Total</b> | <b>47</b> |

**Schedule 5: Key Informant Interviews**

Jeffrey Reynolds, Executive Director  
Long Island Council on Alcoholism & Drug Dependence  
Tuesday, January 7, 2014  
9 am

Jeffrey stated that the Long Island Council on Alcoholism & Drug Dependence is an organization that provides a wide array of addiction services including assessment, screening, interventions, referrals to treatment, assistance with relapse into addiction, school-based prevention programs for 20,000 youth primarily in elementary and secondary schools and a mentoring program to youth with parents in prison.

Jeffrey added that a new cohort has emerged that puts youth at risk for contracting HIV/AIDS and Hepatitis C, middle class children. These youth have no understanding of HIV nor Hepatitis C, and most have progressed from abusing household prescription drugs and painkillers to injecting heroin. The frequency of injection for these injection drug users (IDU) is disturbing; often at 10 to 15 times daily.

Harm reduction strategies include safe syringe programs, syringe exchange programs, teaching users to not share needles and safe sex education. The frightening aspect is that these new IDU users have no awareness of the risks of HIV and Hepatitis C that their IDU habits cause. There is currently only one syringe exchange program in Long Island.

The reach to this middle class IDU youth cohort must include social media, more recognition of the problem and more funded programs to address youth and IDU. Importantly Jeffrey stated that the human social worker component must be present. A middle class young person admitting to a significant and expensive substance abuse issue will likely also have health concerns and a co-occurring mental health issue. Social media is a passive outreach tool, but human engagement is personal and can probe for co-occurring factors. Youth often prefer texting or talking on Facetime on their smart phones, which is a challenge for agencies that need to legally record conversations.

Greater coordination between HIV/AIDS agencies, Substance abuse treatment centers and Youth services is needed to battle this emerging problem and for prevention. These agencies have

historically operated in siloes and they need to collaboratively address youth IDU treatment and prevention.

A further co-occurring aspect of the middle class youth IDU use is the entrance of these youth into sex work to support their drug use. Youth will trade sex for drugs, often with no protection involved, which is termed “Survival Sex”.

Schools, with the advent of common core curriculum and standardized testing, are more difficult environments to teach prevention due to scheduling.

Schools also appear to place undue pressure on youth to succeed, and this can result in stressed out kids that turn to drugs and alcohol and then progress to street drugs.

LaQueta Robbins-Kennedy, Director  
Nassau County Department of Probation  
Juvenile Detention Center  
January 8, 2014  
Noon

LaQueta has worked with youth in the Juvenile Detention Center setting since 2009.

She says the teens she works with stay with her on a revolving basis for about 6 weeks and average 10 to 16 years old. These are highly at-risk youth with a large transmission rate of HIV, teen pregnancy, domestic violence and sexually transmitted diseases in their home environment. Nassau Suffolk Juvenile Justice has STD testing and if positive for an STD are referred to the STD Clinic at Nassau University Medical Center (NUMC). Teen pregnancies or those teens needing contraception are referred to Planned Parenthood or the Sex and Reproduction Clinic at NUMC. These youth have poor parenting examples and a general lack of structure and good adult behavior role models.

All of her clients have a sense of invincibility coupled with limited to no knowledge of safe sexual practices and the risks of unsafe sex and drug and alcohol use.

LaQueta listed the top at-risk communities in the juvenile justice system for both Nassau and Suffolk Counties as:

| <b>Nassau County</b> | <b>Suffolk County</b> |
|----------------------|-----------------------|
| 1. Hempstead         | 1. Wyandanch          |
| 2. Roosevelt         | 2. Amityville         |
| 3. Uniondale         | 3. Central Islip      |
| 4. Freeport          | 4. Mastic             |
| 5. Westbury          | 5. Huntington Station |

These children are often from single parent households or the foster care environment.

LaQueta offered that solutions would encompass free condom programs and syringe exchange programs. Also all community programs have been either defunded or have decreased funding and a concerted effort by all social service agencies that impact youth- Boys & Girls Clubs, after school programs, behavioral health providers, HIV agencies, must be made to support at-risk youth and their parents. Also police, juvenile justice and faith-based organizations as well as schools must be involved. The current School Common Core program is a detriment to our youth because it adds stress to their lives and ignores the poverty of many school age children. First, LaQueta stated you have to feed them and clothe them before real learning results can improve. LaQueta stated that young teenage boys (age 15 to 16 years) are dating older women (20 to 28)

having babies and that this is often with the knowledge of their parents. The cultural approval of this behavior for African Americans is damaging to these youth.

Dan Matos, Administrator  
Stony Brook Long Island Children's Hospital  
January 7, 2014  
10 am

Dan is involved with the Comprehensive Adolescent Pregnancy prevention program, which encompasses a group home for teenage mothers and provides emergency housing, substance abuse treatment programs, foster care agencies, Boys and Girls Clubs and has served over 300 clients in 2013.

Dan discussed young Males having sex with Males which is the largest newly diagnosed group for HIV youth followed by the foreign born.

Risk factors include:

- Teen pregnancy
- Alcohol or Marijuana use
- Other IDU drug use

Recommendations on how to reach at-risk youth include:

- Go to where youth already are engaged such as structured settings like group homes
- Gay Bars
- Homeless shelters
- Mobile vans
- Partner with other organizations to fill gaps in services (like LIGALY for HIV testing and Syringe exchange programs)
- Practice active outreach
- Collaborate with community-based, educational, behavioral health , foster care and HIV agencies
- Start HIV and safe practice education early by the 6<sup>th</sup> grade
- Work on improving the American attitude toward sex and accept alternative choices and inform children about STD's and the care of themselves as sexual being.
- Realize these are young people and they are:
  - a) Unaware of long-term consequences-long term is What will I do this weekend.
  - b) The adolescent brain is still developing-long-term planning happens last, and the short-term is all we can address them with.
  - c) They will take risks
- Parents have little control or influence but need to be engaged

Teens do not want to be talked to, but directly addressing issues with education, available condoms and education can work.

Colby Povill

South Oaks Adolescent Partial Program

Thursday, February 20, 2014  
11 am

Colby felt there is a lot of misinformation on the part of youth regarding HIV and the risks that increase their chances of contracting HIV. She feels that youth today:

- Have inadequate knowledge of sex, safe sex practices, HIV prevention and the risks of unsafe sexual behavior
- There are more mental health factors including sexual trauma among those already sexually abused. These youth will inappropriately behave as they have been taught to do.

Recommendations to change risky behavior include:

- Fostering a healthy self-esteem
- Education about sex, as early as 5<sup>th</sup> grade.
- Substance and alcohol abuse prevention.
- Treating dual or triple co-morbidities
- Early Intervention
- Efforts to stop bullying
- As adults, being aware and owning our responsibility to children, even if they are not ours.
- Reducing school-induced stress
- Addressing media inaccuracies of how to be a successful person
- Owning that we all contribute to good mental health.

## Schedule 6: Literature Review

### Literature Search

#### Facts

- Young people aged 13–29 accounted for 39% of all new HIV infections in 2009.<sup>11</sup>
- HIV disproportionately affects young gay and bisexual men and young African Americans.
- From 2008 to 2010, estimated new HIV infections rose 12% among MSM overall and 22% among young MSM (aged 13 to 24 years); black MSM accounted for over half of infections among young MSM in 2010. **Young black MSM account for more new infections than any other subgroup**<sup>12</sup>

#### Prevention Challenges

Young MSM may be at risk because they have not always been reached by effective HIV interventions or prevention education—especially because some sex education programs exclude information about sexual orientation. A CDC study of MSM in 15 cities found that 80% had not been reached in the past year by HIV interventions known to be most effective.

#### Sexual Risk Factors

**Early age at sexual initiation; unprotected sex; older sex partners.** Many adolescents begin having sexual intercourse at early ages: 46.0% of high school students have had sexual intercourse, and 5.9% reported first sexual intercourse before the age of 13. Of the 34.2% of students reporting sexual intercourse during the 3 months before the survey, 38.9% did not use a condom. Young people with older sex partners may be at increased risk for HIV. HIV education needs to take place before young people engage in sexual behaviors that put them at risk. Parent communication and monitoring may play an important role in reaching youth early with prevention messages.<sup>13</sup>

**Male-to-male sex.** CDC data have shown that young gay, bisexual, and other MSM, especially young African American and young Latino MSM, have high rates of new HIV infections. Another CDC study showed that young MSM and minority MSM were more likely to be unaware of their HIV infection, a situation that puts their health and the health of their partners at risk. Young MSM may be at risk because they have not always been reached by effective HIV interventions or prevention education—especially because some sex education programs exclude information about sexual orientation. A CDC study of MSM in 15 cities found that 80% had not been reached in the past year by HIV interventions known to be most effective. Young MSM

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<sup>11</sup> CDC

<sup>12</sup> CDC e-HAP update, September 27, 2013

<sup>13</sup> CDC's 2009 National Youth Risk Behavior Survey (YRBS),

may also have increased risk factors for HIV (such as risky sexual behaviors) due to isolation and lack of support.

**Sexual abuse.** Young adults, both male and female, who have experienced sexual abuse are more likely to engage in sexual or drug-related risk behaviors that could put them at risk for HIV infection.

**Sexually transmitted infections (STIs).** The presence of an STI greatly increases a person's likelihood of acquiring or transmitting HIV. According to some estimates, both ulcerative and non-ulcerative STDs increase HIV transmission risks as much as 3- to 5-fold.<sup>14</sup> Some of the highest STI rates in the country are among young people, especially young people of minority races and ethnicities. Approximately 25 percent of cases of STDs reported in the United States each year are among teenagers. This is particularly significant because the risk of HIV transmission increases substantially if either partner is infected with an STD. Among sexually experienced people, adolescents aged 15 to 19 years have some of the highest reported rates of STDs. In addition, particular groups of adolescents (e.g., males who have sex with males, injection drug users, and teens who have sex for drugs) engage in even greater risk-taking behavior. Condoms are recognized as an especially important form of contraception, because they are currently the only form of contraception that prevents the transmission of most STDs.

Among sexually active students in grades 9-12 in 2001, 58% reported using a condom the last time they had intercourse.<sup>15</sup> This percentage is two to three times higher than those reported in the 1970s before AIDS became a public issue.<sup>16</sup> This increase over time suggests that the emergence of AIDS and public campaigns to prevent AIDS through increased condom use have actually increased condom use.

However, condom use varies with urban area, age, ethnicity, gender, and involvement in other risk-taking behaviors, and this national average obscures wide variations in different groups. In young people, for example, condom use declines with age, and is higher among African-Americans than European-Americans.<sup>12</sup>

STDs and their contribution to HIV transmission have important implications for educational programs. First, they suggest that there should be effective HIV education programs for all young people. Furthermore, they suggest that there should be additional, more focused programs targeting those groups of adolescents who are at higher risk of HIV infection. Educational programs for school-aged males should adequately address the risks of unprotected intercourse among males who may have sex with males, while programs for young women and female adolescents in the United States should address the special threat of unprotected heterosexual

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<sup>14</sup> Cates W Jr. The Epidemiology and Control of Sexually Transmitted Diseases in Adolescents. *Adolesc Med.* 1990 Oct;1(3):409-428.

<sup>15</sup> [Grunbaum JA, Kann L, Kinchen SA, Williams B, Ross JG, Lowry R, Kolbe L. Youth risk behavior surveillance--United States, 2001. MMWR Surveill Summ. 2002 Jun 28;51\(4\):1-62.](#)

<sup>16</sup> [Kuhar DT, Henderson DK, Struble KA, Heneine W, Thomas V, Cheever LW, Gomaa A, and Panlilio AL. Infect Control Hosp Epidemiol. 2013 Sep;34\(9\):875-92. Updated US Public Health Service guidelines for the management of occupational exposures to human immunodeficiency virus and recommendations for postexposure prophylaxis.](#)

intercourse with injection drug users and the exchange of sex for drugs. Finally, programs should address drug use and needle sharing.

### **Substance Use**

Young people in the US use alcohol, tobacco, and other drugs at high rates.<sup>17</sup> Almost a quarter (24.2%) of high school students had had five or more drinks of alcohol in a row on at least 1 day during the 30 days before the survey, and 20.8% had used marijuana at least one time during the 30 days before the survey. Both casual and chronic substance users are more likely to engage in high-risk behaviors, such as unprotected sex, when they are under the influence of drugs or alcohol. Runaways, homeless young people, and young persons who have become dependent on drugs are at high risk for HIV infection if they exchange sex for drugs, money, or shelter.

### **Lack of Awareness**

Research has shown that a large proportion of young people are not concerned about becoming infected with HIV. This lack of awareness can translate into not taking measures that could protect their health.

Abstaining from sex and drug use is the most effective way to avoid HIV infection, but adolescents need accurate, age-appropriate information about HIV and AIDS, how to reduce or eliminate risk factors, how to talk with a potential partner about risk factors and how to negotiate safer sex, where to get tested for HIV, and how to use a condom correctly. Parents also need to reinforce health messages, including how to protect oneself from HIV infection.

### **Care for Adolescents Diagnosed with HIV**

#### **Anti-Retroviral Treatment**

The Centers for Disease Control and Prevention (CDC) estimates that 15% of the 35,314 new HIV diagnoses reported among the 33 states that participated in confidential, name-based HIV infection reporting in 2006 were among youth 13–24 years of age.<sup>18</sup> Recent trends in HIV prevalence reveal that the disproportionate burden of HIV/AIDS among racial minorities is even greater among youth 13–19 years of age than among young adults 20–24 years of age.<sup>19</sup> HIV-infected adolescents represent a heterogeneous group in terms of sociodemographics, mode of HIV infection, sexual and substance abuse history, clinical and immunologic status, psychosocial development, and readiness to adhere to medications.

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<sup>17</sup> CDC's 2009 National YRBS

<sup>18</sup> Centers for Disease Control and Prevention (CDC). HIV and AIDS in the United States: A picture of today's epidemic. 2008; [http://www.cdc.gov/hiv/topics/surveillance/united\\_states.htm](http://www.cdc.gov/hiv/topics/surveillance/united_states.htm)

<sup>19</sup> Centers for Disease Control and Prevention (CDC). HIV/AIDS surveillance in adolescents and young adults (through 2007). 2009; <http://www.cdc.gov/hiv/topics/surveillance/resources/slides/adolescents/index.htm>.

Most adolescents who acquire HIV are infected through high-risk behaviors. Many of them are recently infected and unaware of their HIV infection status. Thus, many are in an early stage of HIV infection, which makes them ideal candidates for early interventions, such as prevention counseling, linkage, and engagement to care. A recent study among HIV-infected adolescents and young adults presenting for care identified primary genotypic resistance mutations to ARV medications in up to 18% of the evaluable sample of recently infected youth, as determined by the detuned antibody testing assay strategy that defined recent infection as occurring within 180 days of testing.<sup>20</sup> This suggests that HIV for a substantial proportion of youth was most likely acquired from older and perhaps more ART experienced partners; thus, awareness of the importance of baseline resistance testing among recently infected youth naive to ART is imperative. Also, a limited but increasing number of HIV-infected adolescents are long-term survivors of HIV infection acquired perinatally or in infancy through blood products. Such adolescents are usually heavily ART experienced and may have a unique clinical course that differs from that of adolescents infected later in life.<sup>21</sup>

Dosage considerations for anti-retroviral medications in adolescents should generally follow the Tanner staging of puberty, with adolescents in late puberty receiving dosages on an adult dosing schedule and adolescents in early puberty receiving doses administered on a pediatric schedule. Customized dosing schedules should be used for those infected who acquired HIV perinatally, as puberty may be delayed in these children. Also youth in their growth spurt require careful monitoring as do adolescents transitioning from pediatric dosing schedules to adult dosing schedules.

HIV-infected adolescents are vulnerable to adherence problems based on their psychosocial and cognitive development. Comprehensive systems of care are needed to serve the medical and psychosocial needs of HIV-infected adolescents, who are frequently inexperienced with health care systems and **who lack health insurance**. Many HIV-infected adolescents face challenges adhering to medical regimens for reasons that include:

- denial and fear of their HIV infection;
- misinformation;
- distrust of the medical establishment;
- fear and lack of belief in the effectiveness of medications;
- low self-esteem;
- unstructured and chaotic lifestyles;
- mood disorders and other mental illness;
- lack of familial and social support;
- absence of or inconsistent access to care or health insurance; and

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<sup>20</sup> Viani RM, Peralta L, Aldrovandi G, et al. Prevalence of primary HIV-1 drug resistance among recently infected adolescents: a multicenter adolescent medicine trials network for HIV/AIDS interventions study. *J Infect Dis.* 2006;194(11):1505-1509.

<sup>21</sup> Grubman S, Gross E, Lerner-Weiss N, et al. Older children and adolescents living with perinatally acquired human immunodeficiency virus infection. *Pediatrics.* 1995;95(5):657-663.

- Incumbent risk of inadvertent parental disclosure of the youth's HIV infection status if parental health insurance is used.

## Reminder Systems

A reminder system works well for HIV-infected adolescents (e.g., beepers, timers, and pill boxes).<sup>22</sup> The concrete thought processes of adolescents make it difficult for them to take medications when they are asymptomatic, particularly if the medications have side effects.

Reminder systems based on mobile phone applications revealed that apps were infrequently downloaded (median 100-500 downloads) and not highly rated (average customer rating 3.7 out of 5 stars)<sup>23</sup>. Benefits to using mobile phone apps to provide HIV/STD prevention and care services include convenience to the user and developer because they provide a flexible way to reach a large audience at an affordable cost. Apps can provide individually tailored and interactive HIV/STD prevention interventions that are accessible and allow the user to seek information while maintaining anonymity. Intervention customization and interactivity have been found to be important for effectiveness in behavior change interventions, including those that are technology based.<sup>24</sup> The HIV/STD phone apps also capitalize on delivering an intervention in a way that is familiar, to at-risk populations including youth, MSM, and racial and ethnic minorities.<sup>25</sup> Within the United States, the black population represents the most active and fastest growing user group of the mobile Internet.<sup>26</sup> And MSM have also been shown to have greater access to and use of cell phone technologies compared to heterosexual populations<sup>27</sup> increasing the likelihood of delivering highly engaging prevention messages to this hard-to-reach population, including those who are not reached through in-person or group interventions.<sup>28</sup> Public health practitioners should work with app developers to incorporate elements of evidence-based interventions for risk reduction and improve app inclusiveness and interactivity.

## Adherence to Regimen

Adolescence brings rapid changes in physical maturation, cognitive thinking and life style and is

<sup>22</sup> Lyon ME, Trexler C, Akpan-Townsend C, et al. A family group approach to increasing adherence to therapy in HIV-infected youths: results of a pilot project. *AIDS Patient Care STDS*. 2003;17(6):299-308.

<sup>23</sup> Mobile Phone Applications for the Care and Prevention of HIV and Other Sexually Transmitted Diseases: A Review. *Journal of Medical Internet Research*. January 15, 2013. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3636069/>

<sup>24</sup> Noar SM. Computer technology-based interventions in HIV prevention: state of the evidence and future directions for research. *AIDS Care*. 2011 May;23(5):525-33. doi: 10.1080/09540121.2010.516349.

<sup>25</sup> Wise J, Operario D. Use of electronic reminder devices to improve adherence to antiretroviral therapy: a systematic review. *AIDS Patient Care STDS*. 2008 Jun;22(6):495-504. doi: 10.1089/apc.2007.0180

<sup>26</sup> Pew Internet Two-thirds of young adults and those with higher income are smartphone owners. Washington, DC: Pew Internet & American Life Project; 2012. Sep 11, [2012-10-11]. [webcitehttp://pewinternet.org/~media/Files/Reports/2012/PIP\\_Smartphones\\_Sept12%20%2010%2012.pdf](http://pewinternet.org/~media/Files/Reports/2012/PIP_Smartphones_Sept12%20%2010%2012.pdf)

<sup>27</sup> LGBT Market Research and Development Lab The LGBT Community Survey. San Francisco, CA: Community Marketing Inc; 2012. Jul, [2012-10-10]. [webcitehttp://www.communitymarketinginc.com/documents/CMI\\_6th\\_LGBT\\_Community\\_Survey\\_USv1.pdf](http://www.communitymarketinginc.com/documents/CMI_6th_LGBT_Community_Survey_USv1.pdf).

<sup>28</sup> Elford J, Bolding G, Davis M, Sherr L, Hart G. Web-based behavioral surveillance among men who have sex with men: a comparison of online and offline samples in London, UK. *J Acquir Immune Defic Syndr*. 2004 Apr 1;35(4):421-6. [PubMed]

challenging to develop long-term adherence to a medication regimen. The ability of youth to adhere to a regimen needs to be included as a factor in decision making concerning the risks and benefits of starting treatment. If a client will only adhere erratically to medication future regimens, this may impact resistance mutations. If an erratic adherence to a medication regimen is suspected, or initially displayed, alternative considerations include:

1. Short-term deferral of treatment until adherence is more likely, with adherence-related problems aggressively addressed.
2. Adherence testing period in which a placebo (e.g. vitamin pill) is administered
3. Avoidance of any regimens with low genetic resistance barriers.

### **Other Considerations**

Other considerations for HIV care in youth include treatment of any sexually transmitted infections, particularly human papilloma virus (HPV), addressing substance use, family planning counselling including prevention of perinatal transmission of HIV, gynecological care for the female HIV-infected adolescent, and contraception and following safe sex practices to prevent transmission of HIV to other sexual partners.

### **Transition of Youth from Adolescent to Adult HIV Care**

In most adolescent HIV clinics, care is more “teen-centered” and multidisciplinary, with primary care highly integrated into HIV care. Teen services, such as sexual and reproductive health, substance abuse treatment, mental health, treatment education, and adherence counseling are all found in one clinic setting. Transitioning the care of emerging young adults includes considerations of areas such as medical insurance, independence, autonomy, decisional capacity, confidentiality, and consent. An additional complication to this transition is that HIV-infected adolescents belong to two epidemiologically distinct subgroups: (1) those perinatally infected—who would likely have more disease burden history, complications, and chronicity; less functional autonomy; greater need for ART; and higher mortality risk; and (2) those more recently infected due to high-risk behaviors. These subgroups have unique biomedical and psychosocial considerations and needs.

Optimization of a successful transition from being an adolescent setting to care in an adult setting can be achieved through eight steps:

1. Optimize provider communication between adolescent and adult clinics
2. Address patient / family resistance caused by lack of information, stigma or disclosure concerns.
3. Prepare youth for life skills development-appropriate use of a primary care provider, appointment management, importance of prompt symptom recognition and reporting, importance of self-efficacy with medication management, insurance and entitlements.
4. Identify an optimal clinic model for a given setting
5. Implement ongoing evaluation to measure the success of that optimal clinic model
6. Engage in regular multidisciplinary case conferences between adult and adolescent care providers
7. Implement interventions that may be associated with improved outcomes, such as support groups and mental health consultations

Incorporate a family planning component into clinical care.



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**Schedule 7: Mayor’s Resource Guide to Behavioral Health-Substance Abuse and Mental Health Administration (SAMHSA)**

Accessed at:

<http://store.samhsa.gov/product/Mayors-Resource-Guide-on-Behavioral-Health-Issues/All-New-Products/PEP14-MAYORSRG>

## **Mayors’ Resource Guide on Behavioral Health Issues**

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## **What Is Behavioral Health and Why Does it Matter to Mayors?**

The term “behavioral health” refers to both mental health and substance use, and recognizes how the two are often inter-related. Behavioral health problems include the misuse of alcohol or drugs, mental and substance use disorders, and suicide. Mental and substance use disorders include conditions such as schizophrenia, bipolar disorder, depression, and addiction to alcohol or prescription drugs.

Preventing, treating, and supporting recovery from behavioral health problems is essential for communities to be healthy, safe, and successful. You can help ensure that everyone in your community has the best chance to succeed by addressing the behavioral health needs of your communities. You can do this by supporting the prevention and treatment of mental illness and supporting recovery from mental illness. Mayors and municipal leaders like you can have an important role in providing leadership and support to address the behavioral health needs of children, adults, and families in their communities.

Unaddressed behavioral health problems may have a negative effect on the economy for cities, towns, and counties. Costs may increase across systems including health care, emergency and social services, special education, services for homelessness, law enforcement, criminal justice system, and health insurance for municipal employees. They may impact the productivity of local businesses and health care costs, impede the ability of children and youth to succeed in school, and lead to family and community disruption.

Fortunately, many people with behavioral health problems can recover from these conditions and live healthy and productive lives. Many effective prevention, treatment, and recovery programs are available for mental and substance use disorders. Many mental and substance use disorders can be prevented and if symptoms do appear, and the severity of many of these problems can be reduced through programs focused on health promotion, illness prevention, and early treatment intervention.

In addition, the passage of the Mental Health Parity and Addiction Equity Act (MHPAEA) means that insurance groups that offer coverage for mental health or substance use disorders must provide coverage that is comparable to medical coverage. The Affordable Care Act (ACA) significantly extends the reach of MHPAEA's requirements. Because of the health care law, most small group and individual market health plans must also include coverage for mental health and substance use disorders as one of the ten categories of Essential Health Benefits, and that coverage must comply with the federal parity requirements set forth in MHPAEA.

Mayors and local public officials can have a unique role in shaping community responses that will promote recovery, prevent behavioral health disorders, reduce the impact of behavioral health problems when they do occur and ensure that needed treatments and services are available. As a Mayor, city or county official, you can help amplify the message that the U.S. Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA) is working to bring to communities and the nation: “Behavioral Health is Essential to Health; Prevention Works; People Recover; and Treatment is Effective.”

## **What You Can Do to Engage Your Community**

Engaging to prevent or reduce behavioral health problems in any community can help save money and improve lives by:

### Reducing

- Health care costs;
- Emergency department use;
- Prescription drug misuse;
- Absenteeism from work and school;
- Special education costs;
- Crime;

### Preventing

- Child maltreatment;
- Tobacco, alcohol, and other drug use;

### Improving

- Academic achievement, graduation rates, and college entry;
- Community environment;
- Community partnerships;
- Family stability; and
- Wages and productivity.

## **Community Conversations on Mental Health**

SAMHSA created a toolkit that can assist communities in organizing community conversations about mental health. Creating a local community conversation about mental health issues can be an effective way to bring community members together to determine how best to approach raising awareness and identifying ideas for solutions best suited for a specific local community.

Local conversations can be formal or informal, big or small, and include a group of individuals who mirror the demographics and diversity of a given community or a group of persons who are simply interested in discussing the issues and ways to move forward.

Local community organizations may be willing to organize and support these conversations and especially to collaborate with a mayor's office to follow-up on needed steps. The goal is a more informed and engaged citizenry willing to help increase mental health literacy and awareness and committed to helping those who need help are identified and assisted in receiving it.

You can get copies of the toolkit at <http://www.samhsa.gov/communityconversations/>.

## Potential Next Steps

Are you ready to implement policies, programs and strategies that promote positive mental and behavioral health and prevent behavioral health problems? The following steps could help move your community forward. Your mental health and public health agencies can collaborate together to assist with these processes.

### 1. Assess Needs

- Conduct a scan of your community to discover the risks and strengths present and how they affect the behavioral health of young people in your community.
- Conduct a needs assessment to gather current data about your community's behavioral health systems services and supports. Identify strengths, challenges and areas where there are gaps.

### 2. Build Capacity

- Reach out to others who have lead successful community efforts focusing on behavioral health;
- Identify local leaders who are committed to take steps to address this issue and who are knowledgeable about behavioral health.
- Consider convening a summit on preventing and reducing mental, emotional, and substance use disorders in your community—ensuring representation from multiple sectors that can have an active role. Stakeholders might include:
  - Members of the business community
  - Groups involving families and parents of young people with mental health or substance abuse challenges
  - Representatives with lived experience of mental illness or substance use disorders
  - Youth and family leaders
  - Local college student representatives
  - Local charitable funders and foundations, faith-based groups
  - School superintendents, board members, association/union representatives, teachers and students
  - Municipal and county law enforcement, city/county prosecutors, city/county parole and probation officers, emergency medical services and other first responders, crisis response teams and trauma resources
  - Local nonprofits (soup kitchens, housing providers, employment services, and others)
  - Local scientific experts and officials – researchers/university/college professors
  - Behavioral health providers or providers of prevention services
  - Local Tribal representatives

### 3. Plan

- Identify goals, objectives, strategies and timelines
- Convene stakeholders. Consider using an effective facilitator or process leader to engage those present. Begin by creating a vision for behavioral health in your community. Include

questions that are informed by your data regarding what to increase and what to decrease in the community.

- Consider the use of science informed community prevention frameworks such as:
- The Strategic Prevention Framework: <http://captus.samhsa.gov/access-resources/about-strategic-prevention-framework-spf>
- Communities that Care: <http://store.samhsa.gov/product/Communities-That-Care-Curriculum/PEP12-CTCPPT>
- Address the unique needs of different groups in your community paying attention to differences in culture, language, religion and gender or sexual identity
- Discuss how to build on community strengths and move or reduce barriers;

#### 4. Implement

- Determine needed next steps to address these issues.
- Engage others to help, create a timeline, and create a way to share early wins.
- Communicate with your community about successes.

#### 5. Evaluate

- Consider developing an evaluation plan from the beginning. This plan could help your community be clear about what it is working to accomplish and how it plans to achieve these outcomes. An evaluation plan can be a valuable tool to help your community implement, monitor and continuously improve and refine its efforts. For more information about developing an evaluation plan, go to:  
[http://nrepp.samhsa.gov/Courses/ProgramEvaluation/NREPP\\_0401\\_0010.html](http://nrepp.samhsa.gov/Courses/ProgramEvaluation/NREPP_0401_0010.html)
- Develop processes to continually use data to inform decisions.

## **Suggested Resources**

Below are some useful behavioral health resources that you can consider as you plan your community activities. Resources denoted with an asterisk (\*) are provided by external organizations. The inclusion of these resources does not constitute an endorsement of these organizations. These organizations and their respective websites do not necessarily represent the views or opinions of SAMHSA or HHS.

### Prevention/Promotion Resources:

#### 1. Mental Health First Aid Training\*

Description: Mental Health First Aid (MHFA) is an interactive 12-hour course that presents an overview of mental illness and substance use disorders in the United States. Those who take the 12-hour course to certify as Mental Health First Aiders learn a five-step plan encompassing the skills, resources, and knowledge to help an individual in crisis connect with appropriate professional, peer, social, and self-help care. Individuals who participate in this public education program help their community identify, understand, and respond to signs of mental illnesses and substance use disorders.

Additional Information: The MHFA training is operated and disseminated by the National Council for Community Behavioral Healthcare. They can be reached at 1701 K Street, NW., Suite 400, Washington, DC 20006; phone: 202-684-7457; email: [Communications@thenationalcouncil.org](mailto:Communications@thenationalcouncil.org) or visit [www.TheNationalCouncil.org](http://www.TheNationalCouncil.org) and <http://www.mentalhealthfirstaid.org/cs/>

#### 2. Three Bold Steps: A Toolkit for Community Leaders: Safe Schools/Healthy Students\*

Description: Schools, family, youth, and community partners are the target audience for this guide. Community and school leaders learn to address challenges such as poverty and violence; mental health and substance abuse issues; growing truancy, expulsion, suspension, and dropout rates; disproportionate rates of achievement among children and youth of color; and shrinking resources. The Actions in Bold Step 1, 2 and 3 will guide you through the process of forging an effective school-community partnership. Each action will contain an overview, voices from the field, and appropriate resources and tools.

Additional information: <http://3boldsteps.promoteprevent.org/>

#### 3. The Good Behavior Game\*

Description: The Good Behavior Game teaches children to have control over their attention and not be distracted by negative behavior from others, and it works by reinforcing appropriate social and classroom behavior by teams of children. The strategy works by

addressing early aggressive and inattentive behavior that, left unchecked, can evolve into a well-documented downward developmental trajectory and lead to multiple, costly problems in later life.

Additional information: Contact Dennis D. Embry, Ph.D., President and Senior Scientist, PAXIS Institute, P.O. Box 31205, Tucson, AZ, 85751; phone: 520–299–6770; email: [dde@paxis.org](mailto:dde@paxis.org); or Jeanne Poduska, Sc.D.; Director, Center for Integrating Education and Prevention Research in Schools, American Institutes for Research; email: [jpoduska@air.org](mailto:jpoduska@air.org); phone: 410–347–8553.

#### 4. Triple P Positive Parenting Program\*

Description: The Triple P Positive Parenting Program is a multilevel system or suite of parenting education and support strategies for families with children from ages 0–12, with extensions to families with teenagers ages 13–16. Triple P is designed to prevent social, emotional, behavioral, and developmental problems in children by enhancing their parents’ knowledge, skills, and confidence. The program, which also can be used for early intervention and treatment, is founded on social learning theory and draws on cognitive, developmental, and public health theories. The program offers parents five intervention levels of increasing intensity to meet each family’s specific needs.

Additional information: Triple P America, phone: 803–451–2278, email: [contact.us@triplep.net](mailto:contact.us@triplep.net)

#### 5. Suicide Prevention:

##### Suicide Prevention Lifeline:

Description: The National Suicide Prevention Lifeline provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week. Since its inception, the Lifeline has engaged in a variety of initiatives to improve crisis services and advance suicide prevention. Additionally, materials and resources are available to provide to your community.

Mayors can assure individuals and groups in the community that “No matter what problems you are dealing with, we want to help you find a reason to keep living. By calling 1-800-273-TALK

(8255) you’ll be connected to a skilled, trained counselor at a crisis center in your area, anytime 24/7.”

Additional information: <http://www.suicidepreventionlifeline.org/>

Suicide Prevention Resource Center:

Description: The Suicide Prevention Resource Center (SPRC) is the nation's only federally supported resource center devoted to advancing the National Strategy for Suicide Prevention ([http://www.surgeongeneral.gov/library/reports/national-strategy-suicide-prevention/full\\_report-rev.pdf](http://www.surgeongeneral.gov/library/reports/national-strategy-suicide-prevention/full_report-rev.pdf)). Your community can benefit from understanding the strategic priorities and engaging in the development and implementation of community strategies. The SPRC provides technical assistance, training, and materials to increase the knowledge and expertise of suicide prevention practitioners and other professionals serving people at risk for suicide. These resources can be helpful to your community's efforts to promote collaboration among a variety of stakeholders and organizations in your community and can play a role in developing your community's strategies in preventing suicide and self-injury.

Additional information: <http://www.sprc.org/>

#### Treatment Resources:

##### 1. Crisis Intervention Team Training

Description: The crisis intervention team model is a strategy for improving the outcomes of law enforcement interactions with people experiencing a behavioral health crisis. The model was first developed by the Memphis Police Department in response to a shooting by an officer of a man with mental illness. Training for law enforcement officers is only one component of the model. Community collaboration, integration of people with lived experience and family members, and a law enforcement-friendly crisis stabilization center are also essential elements of the crisis intervention team model.

Crisis intervention team training is intended for sworn officers of law enforcement agencies and first responder/911 dispatchers. The model has been adapted for corrections officers working in jails and prisons.

Additional information: <http://store.samhsa.gov/product/Crisis-Counseling-Assistance-and-Training-Program-CCP-/SMA09-4373>.

The SAMHSA Gains Center at <http://gainscenter.samhsa.gov/> emphasizes the provision of consultation and technical assistance to help communities achieve integrated systems of mental health and substance abuse services for individuals in contact with the justice system.

##### 2. National Child Traumatic Stress Network\*

Description: The NCTSN provides information and resources to help communities serve the needs of traumatized children and their families and raise public awareness of the scope and serious impact of child traumatic stress on the safety and healthy development of America's children and youth.

Additional information: <http://www.nctsnet.org/>

### 3. Treatment Locator:

Description: SAMHSA provides an online resource for locating mental health treatment facilities and programs. The Mental Health Treatment Locator section of the Behavioral Health Treatment Services Locator lists facilities providing mental health services to persons with mental illness.

As a Mayor, you might consider creating a locator for substance use treatment and mental health in your own community, region and state. This might be in the form of an information card of city resources with the logo from your city—perhaps a wallet-sized card that can be carried by residents of your community. These might be placed in your local health departments, hospitals, clinics, schools, faith organizations, and neighborhood settings.

Additional information: <http://www.samhsa.gov/treatment/index.aspx>.

### Recovery Support:

SAMHSA has a wide array of programs and information resources to support recovery. For more information on SAMHSA's resources and working definition of Recovery, please visit: <http://www.samhsa.gov/recovery>.