HIV Health & Human Services
PLANNING COUNCIL OF NEW YORK
A Mayoral Council established by the Ryan White C.A.R.E. Act of 1990

Meeting Minutes
NEEDS ASSESSMENT COMMITTEE
Jennifer Irwin, Chair

June 24, 2009
Cicatelli, 505 Eighth Avenue, Sky Blue Room
10:00 am – 12:00 pm

Members Present: Felicia Carroll, Guillermo Garcia-Goldwyn, Lee Hildebrand, DSW, Jennifer Irwin, Rebecca Kim, Don McVinney, Jan Carl Park, Glen Phillip, Kate Sapadin, PhD, Roberta Scheinmann (alt. for Mary Ann Chiasson, DrPH), Robert Steptoe (alt. for Rosemary Lopez), Melissa White (alt. for Angela Aidala, PhD)

Members Absent: Julie Lehane, PhD, Frank Machlica, Freddy Molano, MD, Troiyle Sanon, PhD, Ricardo Vanegas-Plata, DDS

NYC DOHMH Staff Present: Paul Kobrak, PhD, Nina Rothschild, DrPH, Anthony Santella, DrPH, Jessica Wahlstrom, Darryl Wong

Public Health Solutions Staff Present: Sandra Greer, Lauren Feldman Hay

Others Present: Carrie Davis, Paul Graham, Kalvin Leveille, Mallory Marcus, Elana Redfield, JD, Tina Wolf

Material Distributed:

- Agenda
- Minutes from the May 27th Meeting
- Presentation on Trans-Care: HIV Conversations: Is Anyone Listening? (LGBT Center)
- Handout on Social and Legal Issues Affecting Transgender Individuals (Sylvia Rivera Law Project)
- Presentation on Transgender Populations and Syringe Exchange (ACQC)
- Presentation Summaries: Transgender Populations/Proposed Recommendations for IOC

Welcome/Introductions/Review of the Meeting Packet/Moment of Silence: Jennifer Irwin welcomed participants to the meeting. Committee members introduced themselves. Nina Rothschild reviewed the contents of the meeting packet. Felicia Carroll led the moment of silence.

Review of the Minutes: The minutes from the May 27th meeting were accepted by all present with no votes in opposition and one abstention.

HIV/AIDS Prevention, Care, and Treatment Services for Transgender Populations: Carrie Davis of the LGBT Center gave a presentation on transgender (TG) populations. A copy of the presentation is available on the Planning Council website at nyhiv.org. She made a number of points:

- TG clients are experts in their own history and experiences.
- Outsiders – i.e., individuals who are not part of the TG community – often experience a fundamental disbelief in TG identities and see TG people as transgressive and as gender aggressors.
- Providers routinely misidentify TG individuals in paper work.
- People outside of the TG community often have double standards about who is and who is not really male or female and don't believe that TGs are who they say they are.
- We need to define the term "TG" before attempting to answer the question of the size of the TG population. TG, however, is an umbrella term and eludes easy definition. One possible estimate of the size is 12,500 individuals in New York who have undergone a gender transition.
- According to four studies, 28% of TG women tested HIV+. Among African American TG women, 56.3% tested HIV+.
- Most HIV prevention interventions for the TG population are based on an MSM model. Unfortunately, the assumption that interventions for MSM are readily transferable to TG population members means that most such interventions are poorly adapted.
- Identities are erased during reporting: TG individuals are routinely converted back to MSM by state epidemiologists when examining data. One year, for example, New York City's own LGBT Center was told that, according to NYS data, it served no TG individuals.
- TG individuals and their care providers may have differing health care priorities.
- Prevention interventions for TG individuals focus on risky behavior and may downplay the contribution of co-factors to infection.
- Vectors for HIV transmission include STD infection and homelessness.
- Strong HIV prevention models for TG individuals are lacking. TG men, in particular, experience barriers to participating in HIV prevention because research focuses on TG women.

- TG individuals are often low-income, likely to be refused treatment by MDs, and experience violence.
- Many TG individuals are not interested in HIV and prevention; HIV is simply not their priority.
- Many TG individuals want to seroconvert and become HIV-infected so that they can access benefits.
- Trans-amorous is a term that describes people who partner or date TG individuals.
- Outsiders often want to pathologize the TG family model and see the TG individual as a bad fit. TG families, however, can include people who come from a variety of communities.
- The time during which an individual is transitioning between genders is somewhat like adolescence – a time of increased risk. TG-adolescence is typically delayed. Very few TG individuals have a gender-appropriate puberty. Many delay the transition until adulthood.
- The transition period may involve disconnection from family and from work.
- TG sex workers have a high HIV prevalence. A lot of TG individuals feel that sex work is their only resource. They may see it as providing money to survive and to pay for TG health care.
- Some TG individuals don't use a condom with their primary partner because that would feel like a violation of the relationship.
- Less research has been conducted on TG-men than on TG-women.
- If research is relevant to the needs of researchers but not to the needs of the TG population, then the researchers are abdicating their responsibility.
- Systemic oppression of TG people includes economic barriers, structural barriers, and cultural concerns.

Nina Rothschild asked about the situation when a young child expresses a very strong wish to dress as a member of the opposite sex and, in fact, to be a member of the opposite sex. What approach should families take? Should the parents work with a therapist to try to help the child to reconcile with his/her biological identity? Carrie Davis responded that reparative therapy at any age, including during childhood, does not usually work. A child in such a situation might engage in gender-appropriate behavior following therapy in order to gain family approval but may be traumatized. A transgender child can, however, be helped by becoming part of a TG children's group.

Anthony Santella focused the conversation on Ryan White services: are there specific medical and social support services that address TG-related needs but are not covered by traditional payers? Ms. Davis noted that traditional payers do not cover transition-related health care expenditures and that many barriers exist to involving TG individuals in the medical and social support

system. Historically, in fact, TG individuals could not enter the shelter system. The system is perceived as hostile, and TG people try to avoid it.

Legal Issues for Transgender Populations: Elana Redfield of the Sylvia Rivera Law Project provided some recent survey data on health issues affecting TG individuals and distributed information on a variety of social, structural, and legal issues. The Sylvia Rivera Law Project provides legal services to transgendered and gender non-conforming people who are low-income or people of color and also works with individuals who are undocumented. Most of the clients are transgendered women, and roughly one-third are HIV-positive. A copy of her material is available on the Planning Council website. She noted in particular the following points:

- TG individuals confront barriers to education, including harassment, violence, and discrimination.
- TG individuals often have trouble with identification: the legal name of a TG individual may not match the name or gender by which he/she lives. The best way to change a name is usually through a court order, and that isn't always easy.
- The HIV/AIDS Services Administration (HASA) has no real policy for housing TG individuals with symptomatic HIV or AIDS.
- HASA case workers can be very insensitive, and the agency doesn't have a policy regarding TGs: one HASA worker, for example, told Ms. Redfield that only god can change someone's gender.
- Medicaid does not cover TG-related health issues.
- TG individuals experience problems when accessing hospitals, and doctors do not affirm their adopted gender identity.
- TG individuals fear disrespectful treatment when accessing services and feel unsafe in women's shelters.
- Private housing is also a concern for TG persons because landlords don't want to rent to them.
- The Sylvia Rivera Law Project also works with TG individuals who are incarcerated and who are denied access to hormones and to gender-affirming health care.
- Victoria Arellano, an HIV-positive TG woman in immigration detention, was denied healthcare, treated disrespectfully, and died when she was finally taken to a hospital.
- Tyra Hunter was very ill and needed resuscitation. The EMTs started to treat her but stopped when they realized that she was TG. She died, and the courts determined in a wrongful death lawsuit that she would not have died if the EMTs had continued to resuscitate her.
- TG individuals experience cycles of poverty, homelessness, and criminalization.

- Providers working with the TG population should look not just at the conditions of their lives but also at why the TG individuals are in these situations.
- When trans persons go to the hospital, they may try to conceal their identity. Often, when they are identified, they are viewed as having mental health concerns. They may be given a gender identity diagnosis and turfed to psychiatry. The description of the TG population in the upcoming *DSM-V (the Diagnostic and Statistical Manual of the American Psychiatric Association)* will remain pretty similar to the description in the *DSM-IV*.

Transgender Populations and Syringe Exchange: Paul Graham and Tina Wolf of ACQC discussed TG populations and syringe exchange. A copy of their presentation is available on the Planning Council website.

- Programs and services at ACQC include case management, mental health, legal (including permanency planning for the care of children of PLWHA in the event of parental death), housing, education prevention, medical care (via New York Hospital of Queens), and the Queens HIV Care Network.
- The syringe exchange program is not just needles in, needles out; ACQC runs groups, has food vouchers, offers HIV and STI testing on-site, and has an ESAP.
- ACQC did not have a trans-specific space (regardless of HIV status) prior to Tina's involvement. Trans individuals presented her with a list of their needs.
- The trans women in a group affiliated with ACQC need syringes because they are injecting hormones. Some are also injecting drugs.
- ACQC has a TG group at its Long Island City site and arranges for hepatitis C, HIV, and STI testing on-site.
- Sometimes, conflict occurs between the TG women and the non-TG IDUs, and Tina has to negotiate the dynamic between the two distinct groups of people and make the environment more welcoming. The TG women would really like to have their own space so that they don't have to encounter the IDUs. Unfortunately, ACQC lost half of its Robin Hood contract and will have to lay off staff, rather than expanding to provide separate hours and separate space for the TG women.
- Unmet needs for the TG clients include legal services and, in particular, criminal defense lawyers; many engage in sex work in order to obtain money for surgery and wind up in trouble.
- The TG women feel that the police are targeting them but not targeting the straight women who also engage in sex work. Tina hesitates to speak to the police, lest they crack down harder, but also doesn't want the TG women to feel that she is ignoring their concerns.

- The TG women feel that they don't have choices; many of them feel that sex work is their job.
- The TG clients confront language barriers; lack insurance because of immigration status; may confront efforts to deport them if they are arrested for too many prostitution offenses; and face stigmatization in primary care facilities.
- Lee Hildebrand asked whether Tina has worked with the Mexican Consulate. The Mexican consulate-on-wheels project will provide documentation for the TG without any papers so that he or she can cash checks.
- Too little money is allocated to prevention services for this group.

Jan Park asked about funding: what services would individuals who work with TG clients like to see implemented or continued in addition to housing and primary care? One suggestion was capacity-building for providers. Dr. Santella noted that DOHMH's own staff will provide direct training and technical assistance for providers and that DOHMH is also contracting with an outside agency to provide these services. Jennifer Irwin addressed the need to train staff to expand their skills when working with youth who are transitioning into their identity; to bring on additional clinical providers; and to help trans youth who are transitioning out of the youth system and into adult care services.

Mr. Park addressed some legislation proposed by former Governor Eliot Spitzer concerning TG health care and asked for a copy. Ms. Davis noted that from her perspective, the goal was to eliminate exclusions on health care insurance for TG individuals on a state-wide level.

Dr. Hildebrand asked about employment opportunities for trans individuals in the health care field. TG individuals, unfortunately, often wind up at the bottom of the employment heap, according to Ms. Davis.

Asked about the inclusion of TG individuals on organizational boards, Ms. Davis addressed the importance of not having them present in a token capacity. TG members have sat on the HIV Health and Human Services Planning Council in the past, but the current Planning Council does not include any TG individuals. Mr. Park suggested doing some targeted recruitment to increase the likelihood that TG individuals will apply.

TG Data: Ms. Irwin noted that DOHMH has hired outside consultants to conduct 12 focus groups with Ryan White consumers and requested a presentation on the information derived from the focus group comprised exclusively of TG individuals. Dr. Santella noted that the scorecards produced by Public Health Solutions for the Priority Setting and Resource Allocation Committee include TG data on demographics and service

utilization, but the data is only as good as the people who collect it; if the data collection staff are not asking the right questions or are making TG individuals uncomfortable when answering, the data may be incorrect or incomplete. He agreed to bring the Base and MAI overall scorecards to the next NA meeting so that Committee members can have a rough sense of the number of TG clients served. He also agreed to check with Dr. Mary Irvine of the Research and Evaluation Unit to see whether the Bureau has TG-specific information from the consumer focus groups to share with NA Committee members. Ms. Davis addressed the problem of collecting data on TG individuals, noting that people are often asked to identify as man, woman, or transgender but may really think of themselves as male, not as TG. Dr. Paul Kobrak suggested asking TG individuals about sex assigned at birth and current sexual identity, but Ms. Davis noted that such questions can feel invasive and that people may not feel safe answering them.

Adjournment: The meeting was adjourned. The Committee will meet again on July 22nd from 10:00-12:00.