



Meeting of the  
**NEEDS ASSESSMENT COMMITTEE**  
Lee Hildebrand, DSW, Chair

April 11, 2013  
Federation of Protestant Welfare Agencies  
281 Park Avenue South  
9:00 am – 11:00 am

**Members Present:** Angela Aidala, PhD, Randall Bruce, H. Daniel Castellanos, DrPH, Carrie Davis, Guillermo Garcia-Goldwyn, Lee Hildebrand, DSW, Natalie Humphrey, PhD, Jennifer Irwin, Rosemary Lopez, Frank Machlica, Antonio Munoz, Jan Carl Park, Glen Phillip, Rob Shiau

**Members Absent:** Terri Faulkner, Graham Harriman, Sabina Hirshfield, PhD, Anne Lyster, Tamella McCowen, Ariel Negron, Marcy Thompson

**NYC DOHMH Staff Present:** Amber Casey, Julie Cohen, Elena DiRosa, Rafael Molina, Nina Rothschild, DrPH

**Public Health Solutions Staff Present:** Derek Coursen

**Others Present:** Felicia Carroll, Ron Joyner, Mallory Lowenstein

**Material Distributed:**

- Agenda
- Minutes from the March 14<sup>th</sup> NA Meeting
- Planning Council Calendar for April 2014

**Welcome/Introductions/Moment of Silence/Review of the Minutes/Review of the Meeting Packet:** Committee Chair Lee Hildebrand welcomed meeting participants. Attendees introduced themselves. Randall Bruce led the moment of silence. The minutes from the March NA Committee meeting were accepted for posting on the Planning Council website at nyhiv.org. Nina Rothschild reviewed the contents of the meeting packet.

**Ryan White Update:** Jan Carl Park noted that HRSA recently finished a site visit, including a review of fiscal and program issues. A robust meeting of Planning Council leadership included the HRSA team and Finance Officer Robert Cordero, Community Co-Chair Dorella Walters, Governmental Co-Chair Jan Carl Park, and Consumer-At-Large Randall Bruce.

Grantee staff member Amber Casey noted that the HRSA visitors went on site visits to APICHA and Bellevue, Public Health Solutions, the Research and Evaluation Unit, Care and Treatment and Housing, and engaged in a review of e-SHARE to ensure that data is complete. HRSA looked at our financials: how do we do procurement and how do we ensure that contractors are paid quickly and adequately? The grantee has to pay the contractors, but we want to make sure that we do not violate payer of last resort (POLR) rules.

Mr. Park noted that we received half of our award and will receive the rest in late June or early July. We will probably not see as big a reduction in our award as we were anticipating. If we do receive a reduction, it will likely be 1% or 2%. Other states are being penalized for not transitioning from code-based reporting to names-based reporting, and we will benefit. The President released his budget on May 10<sup>th</sup>. It was dead on arrival but included a good sign for us – increased funding for Ryan White Part A – and reflects an awareness of our work. We are currently operating under a Continuing Resolution and will probably continue to do so for the near future.

**Delayers, Dropouts, and the Unconnected:** Dr. Angela Aidala, Co-Principal Investigator of the CHAIN longitudinal cohort study at the Columbia University School of Public Health, presented on delayers, dropouts, and the unconnected. What policy or program interventions, she asked, can reduce delays in accessing care and support retention in care? She examined qualitative and quantitative data for 319 subjects in New York City and 302 subjects in Tri-County, looking at expanded questions about the testing experience, first entry into HIV care, and experience with care over time. The definition of a delayer is someone who has more than 3 months between diagnosis and first evaluation for treatment. In the most recent cohort, 40% have a history of delayed entry into care. The definition of a double delay is someone who has delayed testing and delayed first entry into care. These delays affect clinical outcomes and quality of life.

Some individuals fall in and out of care. They do not meet the clinical practice standards of being in care, but in their minds they are in care, even if they are not broadly adherent. Committee members discussed the need to have a broader way to manage entry into and retention in care and to figure out places for intervention. Jan Park commented that focusing on an in-care vs. out-of-care dichotomy is misleading. The HIV+ population is a fluid mix of persons who may receive some services such as housing (and, therefore, may

fit their own definition of being in care) but not all services, including medical care. Early on after diagnosis, patients may be in denial and not ready for care services. Mr. Park stated that as a Committee, we do not have to buy into a black-and-white definition of what being in care means. Some reasons for falling in and out of care include departure of a particular doctor from a treatment program or the closing of a program. On average, patients are out of care for a year. The care system is doing better at linking people to care, but maintenance is still a challenge.

Mr. Park also commented on the potential conflict between public health and a person's life. The premise of linkage to and maintenance in care is to help the individual patient and reduce community viral load, but this overarching goal is not necessarily in synch with people's lives – they may simply not be willing to remain constantly in care. We may need to query the test-and-treat strategy. Dr. Aidala also raised the question of whether we should deploy resources to track down people who have temporarily dropped out of care. The length of time, however, before the first primary care visit for someone who didn't go within the recommended 4-month time period has dropped.

Dr. Natalie Humphrey asked about the impact of delayed entry into care on development of drug resistance and infection of partners. What are the consequences for functioning?

Jennifer Irwin noted that the numbers for in and out of care are artificial – sometime people come back to care after a year-long lapse. Derek Coursen also noted the pressure to close out a case: administrators may try to impose order on a messy reality so that they can make statements about numbers tested and treated. The care coordination protocol calls for reaching out and helping to ensure that people do not fall out of care.

A few findings:

- Generally, men are more likely than women to be delayers and dropouts.
- People who are foreign-born are less likely to delay entry into or drop out of care.
- People with more serious mental illness tend to be engaged, possibly because there are more services for them and they are more used to navigating the social welfare system.
- People with a history of substance use tend to be more connected to the service system.
- Persons who are older at time of diagnosis are more likely to be engaged in care.
- Not surprisingly, persons with a regular source of medical care prior to diagnosis are less likely to drop out of care.

- There is no difference by insurance status in terms of dropping out of care.
- We don't see a trend regarding engagement in care according to age and year of diagnosis.
- Experience with homelessness in the year in which an individual is diagnosed increases the likelihood of delay.

We know that a big factor in retention in care is what happens at the test site – more helpful than simply recommending an appt. is actively scheduling the appointment.

PLWHAs offer a number of reasons for not being in care including:

- Not wanting to take medication
- Not wanting to deal with the illness
- A sense of fatalism about what will/won't happen
- Being told by a doctor that medical care is not needed at this time (a situation that occurs more frequently when a PLWHA speaks with a family doctor than with an HIV specialist)
- Not being aware of how the illness plays out

Reasons for delay include:

- Active drug use
- Homelessness during year of diagnosis
- Lack of supportive relationships

Reasons for dropping out of care include:

- Relapse into drug use
- Feeling fine and not experiencing symptoms
- Being tired of treatment and wanting a break
- Not being ready to deal with HIV

PLWHAs in these groups (delayers, dropouts, and the unconnected) in the CHAIN study generally conveyed the sense that the push for widespread testing and treatment is a bit limited. Guillermo Garcia-Goldwyn noted that housing is the major reason why some PLWHAs are not in care and that lack of housing can exacerbate mental health issues. Housing is health care and can have a measurable impact in reducing money spent on crisis care services. Efforts are underway to develop acuity scales to measure the impact of housing issues on illness.

Services are needed to facilitate entry into and continuity in care – there is a definite need for navigators and peers. Dr. Humphrey stated that the linkage

programs with which she works are in outreach, counseling, and testing – but counseling and testing don't have much coordination with mental health services – a fact that should be relayed to the members of the Planning Council's Integration of Care Committee, who develop service models.

Randall Bruce underscored the importance of looking at the PLWHA as a whole person, not just as a number. We should look at the characteristics of the care setting and the connection between those characteristics and dropping out of care. Amber Casey reminded the group that we have to look at the big picture and that we have to create a good system and work with agencies that use good providers.

Dr. Hildebrand remarked on the tension between quantitative and qualitative data. Dr. Aidala noted that she tried to do a mix but that working with qualitative data is actually harder. It has to be coded, after which interpreters try to extract findings.

**Adjournment:** The meeting was adjourned.

**Highlights:**

- Close to 50% of PLWHA in NYC delay testing, entry into medical care, or both testing and entry into care
- 25% of PLWH in NYC are diagnosed at an advanced stage of infection
- 20% of PLWH who test promptly delay entry into medical care for more than 3 months following diagnosis
- Approximately 19% of PLWH who are ever linked to care are not maintained in care over time
- Focusing on in-care vs. out-of-care is not the only way to look at the data. PLWHAs may receive some services but not others, including medical care, and may float in and out of the care system.
- Reasons for not being in care include not wanting to take meds, not wanting to deal with the illness, a sense of fatalism, not being aware of how the illness plays out, or being (incorrectly) told by a doctor that medication isn't needed at the present time.
- Reasons for delay include drug use, homelessness, and lack of supportive relationships.
- Reasons for dropping out include relapse into drug use, not experiencing symptoms, wanting a break from treatment, and not being ready to deal with HIV.
- Testing site is of major importance in linkage – it should provide treatment education emphasizing the importance of routine care, and post-test work should actively link PLWH with care, providing direct contact between location of test and location for receipt of medical care.