` Philadelphia HIV Integrated Planning Council (HIPC)
Comprehensive Planning & Needs Assessment Committees
Meeting Minutes
Thursday, October 19, 2017
2:00-4:00pm
Office of HIV Planning, 340 N. 12th Street, Suite 320, Philadelphia, PA

Present: Katelyn Baron, Keith Carter, Mark Coleman, David Gana, Peter Houle, Gerry Keys, Nicole Miller Jeannette Murdock, Ann Ricksecker, Joseph Roderick, Adam Thompson, Leroy Way, Jacquelyn Whitfield

Excused: Lorrita Wellington

Absent: Karen Coleman

Guests: Jessica Browne, Ronald Lassiter

Staff: Mari Ross-Russell, Nicole Johns, Stephen Budhu

Call to Order/Introductions: A. Thompson called the meeting to order at 2:03 pm.

Approval of Agenda: A. Thompson presented the agenda for approval. **Motion:** D. Gana moved, L. Way seconded to approve the agenda. **Motion passed**: All in favor.

Approval of Minutes (September 21, 2017)**:** A. Thompson presented the minutes for approval. **Motion**: (L. Way) moved, P. Houle and G. Keys requested for their attendance be updated as "excused". After the addendum, A. Thompson presented the minutes for approval. P. Houle seconded to approve the updated September 21, 2017 minutes. **Motion passed**: All in favor.

Report of Chair: A. Thompson stated Co- Chair leadership was added to his report because he wanted to address some issues. A. Thompson informed the committee his clinic was in the midst of a merger and it has affected his work load. He apologized for his recent absences and explained after the merger he will be able to attend meetings consistently again. He thanked K. Baron for chairing meetings in his absence. He admitted he considered resignation from the chair, but after deliberation with K. Baron they reached the conclusion instituting a co-chair would be best for the committee. A. Thompson stated a co-chair would function just like other committees and the work load would be evenly distributed. He stated the committee would be actively recruiting a new co-chair, and he invited committee members to communicate with himself or OHP if they were interested. He recommended that anyone who has a desire to be in a position of leadership should look to become a co-chair. He acknowledged that it is a learning process and he noted he had to learn Robert's Rules of Order. He stated K. Baron and he would be more than happy to mentor the new co-chair. A. Thompson suggested nominations should begin in the November meeting. K. Baron noted she is still learning new things every day and she encouraged committee members to either nominate someone they feel is a good candidate or inquire about co-chairing for themselves.

R. Lassiter inquired if K. Baron was the chair for the committee or the HIPC. K. Baron replied she is the co-chair for the HIPC, however; she has been helping chair this committee in lieu of A. Thompson's absence. She explained she was not the chair for the Comprehensive Planning Committee. N. Johns noted OHP would give support to the new co-chair. She explained co-chairs have open communication with staff at OHP, and she would be willing to work with the new co-chair to bring them up to speed.

Report of Staff: N. Johns informed the committee building management has requested no smoking in front of the building or near the side entrance. M. Ross-Russell noted there maybe fines by management.

Discussion Items:

- Consumer Survey Report

N. Johns explained the Consumer Survey report was in progress. She noted OHP has hired an intern to work on the data analysis, while she and S. Budhu are working on what to include in the write up. She noted the report should be completed by December, and the hopes are the sneak peek of the report would be viewed in the November Comprehensive Planning Committee meeting. She encouraged the committee to ask questions about the survey and survey analysis. She asked the committee to suggest points of interest that may not have been mentioned or need to be emphasized more.

N. Johns presented a slide show to the committee about the Consumer Survey. N. Johns explained the consumer survey was launched by OHP in December 2016 until April 2017. She informed the committee the purpose of the survey was to evaluate Ryan White services. She stated in total OHP distributed 2915 surveys over the 5 month period and received 392 completed surveys. She stated the survey was distributed both in English and Spanish, and the breakdown of distribution was: 805 mailed in English, 280 mailed in Spanish, 1600 hand delivered in English, and 230 hand delivered in Spanish. She noted 28.1% of surveys received were mailed and 41.3% were from an agency. She stated OHP relied on providers to distribute the survey to their clients. She noted the low number of received surveys could be attributed to the decline of providers using mail services.

N. Johns continued onto the next slide of the presentation, geographic distribution. She stated 62% of survey responses were from Philadelphia, 19% from New Jersey counties, and 18% from Pennsylvania counties. She stated Philadelphia was actually under- represented in the survey since it is 72% of the EMA's PLWH population. She explained OHP used a new color coded system to designate geographic area.

N. Johns moved discussion to the demographics of the survey population. She informed the committee from the sample the mean age was 52.8, and almost ¾ of the population was older than 50. She added only 2.4% of the population was between the ages 18-24, and 62.1% of the sample identified as Black. She stated from the sample, 65.9% were male, about 50% reported they had income of less than $1000 per month, and 10.4% reported they had no income. She stated many of the survey sample was living at or below the Federal Poverty Line.[1]

1. FPL is used to measure a household's poverty status. It is adjusted each year for inflation; FPL for 2017 for a household of 1 is $12,060. From the Affordable Care Act Medicaid is available to those who fall up to 138% of FPL. Note that FPL increases about $4000 per household member.

She noted the majority of the sample did have a high school degree, however the rate for unemployment was 17.8% and 10% were retired, while 27% were employed.

N. Johns moved committee discussion to housing status in the sample. She stated from the survey 62% rented or owned their home (without subsidy), 9% HOPWA, 7.7% Housing Choice voucher, 14.6% staying with friends/family, 2.1% in a shelter, and 1.3% were in transitional housing.

N. Johns stated from analysis the following were statistically significant:

1. African Americans were more likely to be from Philadelphia
2. New Jersey PLWH were significantly more likely to report an income of at least $1000/month
3. New Jersey PLWH were also less likely to report using rental assistance or to be marginally housed/homeless
4. No significant difference between male and female in terms of age, employment, housing females were more likely to earn less than $1000/month and more likely to have below a high school level of education.

N. Johns mentioned OHP has included new questions about incarceration experience, other chronic health conditions (besides HIV) and Hepatitis C. She noted 75 people or 19.1% were incarcerated since their HIV diagnosis, and those who were incarcerated were more likely to have income less than $1000 per month. She explained from analysis hypertension was the most common chronic condition in the sample at 48%. She noted in America on average, 30% of adults have hypertension. She stated the next most common condition was high cholesterol at 30.9%, she added on average 13% of adults in America have high cholesterol. She stated all chronic conditions were over represented in the sample compared to nationwide averages except for cancer. She explained in the sample only 8.4% of the responses said they have had or have cancer. She stated the nationwide average for lifetime cancer is about 30%, according to the CDC. D. Gana replied as of recent news cancer treatment has incorporated the use of HIV treatment to destroy tumors; he noted the research was still new but preliminary findings have shown HIV treatment has been an effective cancer treatment. D. Gana suggested that having HIV maybe protective of acquiring cancer due to HIV treatments.[2,3]

N. Johns directed the committee's attention to the slide about mental health. She stated more than half of respondents reported they were ever diagnosed with depression, and 11% were

2. This is in reference to recent cancer treatment that uses antiretroviral treatment to delay tumor proliferation. The treatment is very new and it involves taking a daily dose of antiretroviral drugs for cancer remission. Preliminary results have suggested that the ART treatment has been successful in cancer remission. Francoise Barre-Sinoussi the co-discoverer of HIV, told BBC during an interview: "One of the mechanisms why [latently infected cells] persist is the fact they are proliferating very similar to tumour cells." General consensus of the scientific community has acknowledged that the HIV expresses the same molecules found in cancer cells. For more info http://www.bbc.com/news/health-40700770

3. Note that in activated HIV cells have been used to treat those who are terminally ill with cancer. In this form of treatment the patient is intentionally given an inactivated form of HIV that is reprogrammed to feast on cancer cells instead of cd4 cells. For more info visit https://optimizehiv.com/hope-study/the-goal-of-hope/

diagnosed with PTSD. She stated only 8% of the general population had a depression diagnosis, and only 8% of the general population has had a PTSD diagnosis. She stated that some populations are more susceptible to PTSD; she noted recent studies have shown HIV+ women can have PTSD rates around 30%. A. Thompson mentioned for people to get PTSD diagnoses their doctors have to screen them. He explained in many cases mental illness has been under diagnosed and some studies have shown the rate of PTSD of PLWH to be as high as 60%, which is on par with the rates of soldiers returning from war. He added New Jersey was taking a trauma-informed approach that will expand on physician training. He noted he's curious to see if the rate of PTSD will increase or decrease over time with the new approach. D. Gana stated those who were diagnosed with PTSD could have been misdiagnosed and they are likely to have AIDS Survivor Syndrome[4] . He stated the AIDS Survivor Syndrome is not yet inclusive of modern day HIV + persons; he noted it relates to those who received HIV diagnoses in the early 1990s and unique experiences to PLWH, when HIV was terminal.

N. Johns moved discussion to Hepatitis C; she stated that 30% of respondents reported a Hepatitis C diagnosis. She stated of that 30%, 24% have received treatment since their diagnosis. She stated those with Hepatitis C were more likely to have income less than $1000 per month, and in turn they were also less likely to receive treatment. A. Thompson inquired about the amount of individuals who stated they had Hepatitis C versus the amount of individuals who reported they have liver problems. He stated only 15.1% of respondents said they had liver problems but 30% reported they ever had Hepatitis C. A. Thompson inquired if the year of Hepatitis C diagnosis was included because of the difference in past treatment to present treatment. N. Johns replied no, the survey did not ask year of diagnosis, but she stated that should be included for next time.

N. Johns steered community discussion to insurance. She stated the majority of the study participants were insured at 95.9 %. She noted 46.4% have Medicaid, 10.7% use Health Partners, 31.4% use Medicare, 4.6% get insurance from the Affordable Care Act, 9.9% receive insurance through work or a union, 1.5% through the VA, and finally 1.5% have insurance through an individual market place. She added 7 of the 16 people who were uninsured had their insurance change in the last year. A. Thompson inquired about those who were uninsured. He asked if the 7 who have had their insurance change in the past year were included into the uninsured percentage. N. Johns replied yes the 4.1% who were uninsured is inclusive of the 7 who have had their insurance change. M. Coleman inquired about individuals who used Keystone health, and where they were categorized. N. Johns replied all data was stratified into the appropriate categories. M. Ross-Russel explained she put all Medicaid insurances together as well as the different Medicare insurances.

N. Johns went over some of the characteristics of the survey population with the committee.

4. AIDS Survivor Syndrome describes the spectrum of sustained trauma survivorship. It is psychological state resulting from living through HIV/AIDS pandemic, especially vulnerable are those who became HIV+ in the 1980s and 1990s when having HIV was considered a terminal diagnosis. AIDS Survivor Syndrome is a "syndemic" of psychosocial health problems that exist on a spectrum. It varies by degrees of intensity, and it affects HIV Long-Term Survivors differently at different times.

She stated the mean number of years with HIV diagnosis was 16 years, 10% of the participants having had HIV diagnosis for 1 year or less, 81% reported entering HIV care within 30 days of diagnosis, 48.9% have had an AIDS diagnosis, of those 67.5% received AIDS diagnosis at HIV diagnosis, and 83.3% report being undetectable. In reference to slide 14 of the presentation, N. Johns displayed a frequency versus years living with HIV histogram. A. Thompson inquired if the x axis was the number of years living with HIV, since some of the data points went up to 40. N. Johns stated yes the x axis does denote the number of years living with HIV and there were some long term survivors in the sample.

N. Johns moved onto clinical outcomes of the respondents. She noted most of the participants have access to Ryan White services and are using the services to get treatment. She stated 96.8% of respondents have a regular place for HIV care. She stated only 2 PLWH reported not seeing an HIV medical provider in the last 12 months, while 56.6% reported 3 to 5 visits, 24.2% reported 6 or more visits, 11% reported 2 visits and 4.1% reported 1. She informed the committee 92.8% of respondents are taking HIV meds, and 18 people reported they were not. She noted that many of the respondents also have a good relationship with their HIV care provider. She stated 86.9% said that their HIV medical provider had always taken time to explain their lab results, diagnoses, treatment plans and answer their questions. N. Johns added that 91.3% of the survey respondents have had not issues accessing care. She stated those who did not receive care, the 8.8% were more likely to be younger and non-white. A. Thompson commented that this finding is in contrast to what people say about providers. He stated that people are always claiming providers can't offer good service on a time limit. N. Johns noted that those who were incarcerated were less likely to have access to HIV medical care. A. Thompson inquired if the survey asked if those who were incarcerated had access to their medications while being incarcerated. N. Johns replied the survey did not ask that but the survey did have a follow up question if PLWH after incarceration were offered help to access services. N. Johns noted only 19% reported being incarcerated in the survey so M. Ross-Russell would be able to obtain more information about those who were incarcerated upon further analysis. She noted the survey did not ask if those who were incarcerated were in jails or prison. A. Thompson stated that prisons and jails are two separate environments, and those in prisons would be more likely to receive their treatment over those who were in jails.

N. Johns moved onto medical case management. She stated 82.1% reported they have a medical case manager. She explained that PLWH with medical case management were more likely to be women, African American, Hispanic/Latino or of another race, poor with income less than $1000/month, less than a high school education, and unemployed or disabled compared to those with medical case management. She informed the committee PLWH with a medical case management are more likely to have slightly worse clinical characteristics than those who do not have medical case manager. She noted more people with detectable viral load report medical case management. N. Johns explained people were more likely to have worse clinical characteristics because those with worse health outcomes would be more likely to seek medical case management. She stated this was a sign that people getting services that they need. A. Thompson stated this finding was interesting because most medical case management function as system access points, and actually do not focus on treatment adherence.

He noted you would expect those in medical case management to have similar demographics to what was in the analysis. He stated those who were less likely to receive medical case management: women, African American, Hispanic/Latino or of another race, poor with income less than $1000/month are potentially groups with biggest need for case management, so that was very concerning. A. Thompson stated those who have been HIV+ for a while more than likely have had an AIDS diagnosis at some point, and as the HIV+ population ages the care becomes more complex. He noted this analysis brings up the argument for risk stratification and viral load suppression. A. Thompson recommended this should be looked into more in depth.

N. Johns moved discussion to sexual practices of the survey participants. She stated 69.9% reported not being sexually active in the question related to sexual partners, and 42.9% reported no sexual activity in the past 12 months. She noted the two responses were from 2 separate questions. She reported 4.3% of respondents have a partner on PrEP, and 12.8% reported partner HIV+ and on HIV meds. She continued to say 1.8% reported HIV+ partner not on HIV meds and 15.6% reported partner not on PrEP. She stated 12% respondents reported vaginal sex without a condom in the last 12 months and 15.6% respondents reported anal sex without a condom.

N. Johns talked about internet access of the respondents. She reported 60.1% have their own computer or smart phone with internet access,16.4% report having a place they can go to access the internet (friend's house, library, etc.),16.4% report not having any way to access the internet, 4% report it is too difficult to access the internet so they only use it when they really need to. She explained since the majority of people have access to the internet OHP will look to expand resources available online.

N. Johns discussed the common barriers to care from the survey with the committee. She explained poverty was a major factor, because it limited people's accessibility to basic needs let alone health care. She stated transportation is often unavailable or unreliable, and noted Medicaid transportation was mentioned a lot. She stated housing costs are too high for people with low/no income and staying with friends and family is not always the best choice for health/well-being of PLWH. She stated other health conditions, including mental health (depression, anxiety) make going to appointments and getting out of the house difficult.

N. Johns ended discussion with 3 quotes taken directly from open ended survey responses, and a synopsis of the analysis. The quotes are:

1. I don't always have money for co-pays for medication because of housing costs. Right now I could use a housing voucher.
2. Need help getting housing help paying bills, rent, getting low income apartments. 1 bedroom for $500 a month in Glenolden. Daycare for people with depression. Give us something to do during the day and places to go 12:30pm to 5:30pm so we can meet people and talk to people and do other things. We can make things, sew, cook, play cards, read, play games. We need to get out more. We are lonely, bored, sad. Need a daycare for adults.

> 3. I never accessed housing assistance because I don't know where to go, and I was never told. I don't go to the orthodontist due to financial issues. I don't use mental health therapy services because of the cost with my current insurance provider some of my other non-HIV medications are not covered due to me having no prescription drug coverage.

After N. Johns shared the quotes with the committee, she stated from the consumer survey analysis we can say the Ryan White population is aging, incarceration history can play a huge role in access to services, and poverty is a large factor in access to service. She noted the aging population of Ryan White clients would have an effect on health planning. N. Johns asked the committee for their feedback in the future. A. Thompson thanked N. Johns for the report.

- **November and December Work Planning**

A. Thompson stated the next part of the agenda is November and December planning. N. Johns reminded the committee in the last meeting the committee looked at the integrated plan and noted objectives to complete before the end of 2017. She stated the first objective was to determine the feasibility of a housing first model under Ryan White and the second was to create a report about barriers to care. She noted the retention barriers like transportation could be potentially fixed with planning. She stated transportation issues can be addressed and potentially alleviated unlike poverty. She suggested the committee could make some recommendations about transportation reform and take them to HIPC or the recipient . A. Thompson stated housing access was just reviewed in New Jersey, and the plan is being augmented. He added now in New Jersey, PLWH can call about housing and within 2 hours later they are picked up and offered full housing assistance after their case is reviewed. He noted the process usually takes about a day. He suggested that maybe some of the representatives involved could attend upcoming committee meetings. He stated New Jersey is setting up an online system to track open beds, he noted this was called a housing-beacon system. He stated with this system individuals would know when beds were open almost instantaneously via the internet. He explained there was housing for things like domestic violence and woman's shelters that PLWH may be eligible for. He recommended that the committee explored the different characteristics of someone who is HIV+ that will make them eligible for other kinds of housing. He explained using this method would decrease the number of PLWH who were homeless. He noted New York handles housing pretty well, and he suggested the committee should emulate some of New York's housing programs. A. Ricksecker inquired about the purpose for the plan, and is the focus something that can be done. She stated she agreed with A. Thompson and felt the housing option should be explored, but she noted she was concerned with the funding. A. Thompson explained the funding could come from 340b money from the states ADAP[5] programs. A. Thompson recommended the committee invite those from New York who have an established housing program to speak to the committee. K. Baron noted the pathway to housing project[6] is doing similar housing objectives. A. Ricksecker agreed, and added that the opioid epidemic is so vast Pathways to Housing would be using a model that could be helpful to review

> 5. The 340B Program provides discounts on outpatient drugs to certain safety net health providers, including Title X agencies. The program's intent is to allow safety net providers to increase patient services with the savings realized from participation in the 340B program. Providers typically save 25-50% on outpatient drug costs through participation in the program. These savings can be used to reduce the price of pharmaceuticals for patients, expand services offered to patients, or provide services to more patients.

A. Thompson stated the committee could reach out to the AIDS Resources Foundation, Pathways to Housing, and HASA[7]. A. Thompson suggested the committee ask representatives from those agencies about key elements like cost. A. Ricksecker replied the recipient is sometimes in attendance and they could be asked for a cost estimate. K. Baron stated Pathways to Housing talked about their expenditures on their website, and how their cost of services compare to hospitals. K. Baron stated the committee could examine the expenditures and obtain the cost savings. A. Thompson agreed and stated the committee could explore some cost saving options from the Pathways to Housing website. G. Keys inquired about the partners who would be involved. A. Thompson replied he was unsure of the partners who would be included in the housing reform for Pennsylvania.

A. Thompson moved committee discussion to transportation. He stated New Jersey just gave community health workers UBER accounts in case their clients were late to appointments. He noted there is no cost data for the program yet. He stated New Jersey took that transportation model from Missouri and other private agencies like Hyacinth[8]. D. Gana noted North Carolina is trying to figure out an UBER program. D. Gana explained North Carolina was trying to make a peer based UBER system where the driver would be someone who maybe HIV+ or is knowledgeable of HIV and experiences of those who are HIV+. A. Thompson stated New Jersey was using health workers. He noted Hyacinth was using a peer based UBER system. A. Thompson stated he was curious to know how the UBER program worked specifically when it was appropriate to use UBER when someone is on Medicaid or Medicare. M. Ross-Russell stated the biggest issue is the requirement that those on Medicaid have to use Medicaid transportation. She added in Philadelphia the issues are the transit day passes and when the transit day passes are received. She noted the committee acknowledged there are issues with the day pass system, but the real issue is when people begin to miss their appointments due to their transportation. She stated there needs to be a protocol for the number of missed appointments. She acknowledged in this instance the problem is who is going to the pay for transportation. A. Thompson stated this pushes on the Medicaid transportation program. He stated there needs to be protocol on what is appropriate for the number of minutes to be late and when is it appropriate to use alternative forms of transportation like UBER. M. Ross-Russell replied it depends on not whether Medicaid would still get paid if their services were not used.

6. Pathways to Housing PA (PTHPA) was founded to transform the lives of people experiencing mental health challenges and chronic homelessness by supporting self-directed recovery and community integration. As an alternative to a system of emergency shelter/ transitional housing progressions, PTHPA's model is simple: provide housing first, and then combine that housing with supportive treatment services in the areas of mental and physical health, substance abuse, education, and employment.
7. HASA assists individuals living with AIDS or HIV illness to live healthier, more independent lives. The program can help clients with individualized service plans to target necessary benefits and provide support that is specific to their medical situation and that will enhance their well-being. HASA clients receive ongoing case management and are assigned to a caseworker at one of our HASA centers, located in all 5 boroughs.
8. Hyacinth was incorporated in 1985 to help fight the AIDS epidemic, there is 7 offices, and they offer prevention outreach services like PrEP. For more info visit https://www.hyacinth.org

A. Thompson noted that was a great question, and Medicaid should refund for services that were not provided. N. Johns explained currently the cost of Medicaid transportation is zero for the Ryan White System, but with alternative forms of transportation there would be a cost associated, and she suggested the services would have to be used only when necessary. M. Ross-Russell stated the issue is for every service that is provided there are a series of restrictions that need to be adhered. She stated there needs to be an explanation or protocol to justify using alternative methods. A. Thompson stated that people cannot schedule two appointments in one day because of the transportation. He explained clients going to a 20 minute doctor's appointment would have to be free 3 hours before the appointment and then wait to be picked up hours after the appointment. He stated this requires about an 8 hour day just for one appointment. M. Ross-Russell agreed with A. Thompson, and explained it's not that people are not able to get transportation for 2 appointments; it's that one appointment could take many hours, and then people could be late for their second appointment or may miss their appointment entirely. N. Johns stated there is a Philadelphia startup company that was looking into medical transportation. M. Ross-Russell stated the issue will always be cost. A. Thompson questioned if UBER could be used to take clients to SEPTA, or should UBER be used all the way.

A. Thompson recommended the committee focus on the transportation barrier first as opposed to housing. He noted it may be difficult to get representatives from organizations in November due to the holidays. K. Baron stated the barriers discussion should be in November and housing could be discussed in December, or later on. A. Thompson agreed that housing should potentially be pushed back due its magnitude. A. Thompson asked about what was needed to contact those organizations that were aforementioned. From committee deliberation it was decided that A. Thompson would reach out to Hyacinth and HASA, and K. Baron would reach out to Pathways to Housing. A. Thompson recommended in the next committee meeting the committee does a brainstorming activity for transportation. He explained the brainstorming activity requires 2-part planning: the first part consisting of what is already being done for service, and the second being what else can be done. M. Ross- Russell recommended the committee should move their 2017 deadlines. She suggested the committee should aim to have objectives worked on by the release of the updated integrated plan in September 2018.Committee agreed to this suggestion by consensus.

Old business: None

New Business: None

Announcements: M. Coleman announced the Philadelphia Film Festival is from October 19-29, 2017. He stated tickets could be purchased online and he invited all to attend.

K. Carter announced J. Murdock was a new co-chair of the Positive Committee

A. Thompson announced New Jersey has put together a network of community health workers. He stated these health workers have a shared life experience with HIV+ individuals. He stated some of the clinics in New Jersey counties were having trouble recruiting people. He invited the committee to apply or share this information with anyone they felt was qualified.

Adjournment: Motion: J. Murdock moved, J. Whitfield seconded to adjourn the meeting at 3:33pm**. Motion passed:** All in favor

Respectfully submitted by,

Stephen Budhu, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- September 21, 2017 minutes
- Comprehensive Planning Calendar