

**Ryan White Planning Council (RWPC) of the Philadelphia Part A EMA
Positive Committee Meeting Minutes
Monday, December 14, 2009
12 p.m. - 2 p.m.
Office of HIV Planning, 340 N. 12th Street, Suite 203, Philadelphia, PA 19107**

Present: 23(PH), 1(PA), 0(NJ)

Staff: Nicole Johns, Briana Morgan

Call to Order/Moment of Silence/Mission Statement/Introductions:

M. White called the meeting to order at 12:09 p.m. and a moment of silence followed. W. Walters then read the mission statement. Those present introduced themselves.

Member Check In:

None.

Approval of Agenda:

M. White presented the agenda for approval. The agenda was approved by general consensus.

Approval of Minutes (9 November 2009):

M. White presented the November 9, 2009 minutes for approval. The minutes were approved by general consensus.

Report of Co-Chair:

M. White welcomed those present to attend an RWPC meeting to better contribute to the process.

Report of Staff:

N. Johns stated that they had been working on the committee newsletter for several months, and she had not received any articles from committee members. She went on to say that they hoped to have a newsletter ready in February, and asked for contributions for articles. She noted that they would likely have a newsletter twice a year, and that it would be helpful to have the newsletters available at the town hall meetings in the spring.

N. Johns stated that anyone interested in participating in a volunteer activity would need to commit to attending, and that they would discuss further details in future meetings.

N. Johns then stated that there would be a consumer empowerment training event on March 9, and that she would have more details forthcoming. She added that this event would be open to all PLWHA, and that it would be held at St. Luke's.

N. Johns stated that anyone interested in joining the Positive Committee mailing list should see her after the meeting. She went on to say that everyone needs to RSVP for the

Positive Committee meeting each and every month so that they would be able to have enough lunches available.

N. Johns then added that the RWPC would be prioritizing service categories in coming months. She encouraged the group to attend Comprehensive Planning Committee meetings as well as Planning Council meetings to learn more about the process, adding that it was very important to have consumer input in Priority Setting.

N. Johns also thanked the group for their participation in 2009, pointing out that participation had greatly increased throughout the year.

Discussion Items:

- **Group Training/Discussion: HIV and People over 50**

N. Johns stated that the group would be watching a short film about the 50+ population and HIV. She asked the group to think about the different needs for an aging population in both care and prevention. She then played the movie.

After the movie ended, a community member stated that many people think that older adults cannot contract HIV. Another community member stated that it was important for those with multiple partners to get tested several times per year, and that even those that are married should be tested regularly. W. Walters stated that older people use drugs and are sexually active, even though younger people do not think that they engage in these behaviors.

N. Johns pointed out the statistic from the film that stated that 1/3 of PLWHA in NYC were over 50, and 3/4 were over 40. She then stated that 10% of PLWHA in the Philadelphia EMA were over 50, while 45% were over 40. She noted that some PLWHA were long-term survivors, while others were contracting the disease later in life. A community member stated that some people think that HIV is curable, or that it is a gay disease. H. Bennett asked if there was information about this age group in the epidemiological profile. N. Johns agreed, noting that it would include other demographics as well. She noted that she had CD-ROMs of the epidemiological profile available. H. Bennett asked if the epidemiological profile included information about when PLWHA were diagnosed. N. Johns replied that they do have information about the newly diagnosed. She then stated that she could show this data to the group in their next meeting. She added that they now have information on HIV cases, AIDS cases, and when people pass away.

M. White stated that it would be interesting to determine the cause of death for all PLWHA, since they may not pass away due to HIV-related diseases. N. Johns replied that the Health Department might have this information. W. Walters stated that no one dies from HIV/AIDS, and that they would all die from other diseases. She went on to say that H1N1 shot contained live virus, so that PLWHA should not get this shot.

J.M. stated that, as a community, they needed to be very protective in regard to disclosure issues. He went on to say that there should be no exceptions to this rule, and that many people take liberties with other people's HIV statuses. R. L. stated that his fiancée was positive, and that he got tested every three months and he was still negative.

Another community member stated that it was important to have an open mind with other people's concerns, and that disclosure was a private issue. He went on to say that no one should disclose another person's status, and that PLWHA should have the right to disclose on their own terms. He emphasized the importance of sticking together as a community, adding that these meetings could really help people.

D.H. stated that she was not aware that the Positive Committee meeting was open to the public. N. Johns replied that the Positive Committee is for those infected and affected by HIV, and that she cannot ask everyone for their status. She went on to say that anything they talked about should stay in the room, and that full names were not published in the minutes unless the person speaking was a co-chair or a Planning Council member.

W. Walters stated that there was no confidentiality when she was first diagnosed. She told a story in which she went to an AIDS walk soon after being diagnosed, and a newspaper published a picture of her face under a banner that said AIDS the next day. She explained that she was ushered out of churches and asked to leave restaurants, as well as assaulted. H. Bennett then told a story about a positive minister that faced discrimination in his own church. He added that many people are ignorant about how HIV is spread.

D.H. stated that black clergy had been doing community outreach, including HIV/AIDS testing. She went on to say that many PLWHA are afraid to go to church because they were rejected many years ago. R. Hayward then stated that there are two large churches with AIDS ministries, and that ASOs had gone to do presentations at them. He went on to say that African-American women were the most affected population.

A community member the AARP addresses HIV/AIDS. R. Hayward replied that he had not heard anything about it. W. Walters stated that AARP takes submissions from their clients, so they could suggest this. N. Johns stated that the group could possibly write them a letter on this topic.

W. Walters stated that a local provider did a great deal of work with seniors and HIV, and suggested that they have him as a guest speaker. N. Johns stated that it could be helpful for the group to do outreach to get older people involved with the process. M. White suggested revisiting this topic at a later date. N. Johns agreed, noting that she would be bringing additional data to the next meeting as she previously mentioned.

- **Brainstorming for Activities for 2010**

M. White stated that they had already discussed visiting MANNA, and that he was asking for additional suggestions on what they might do in the coming year. N. Johns stated that she would be passing around a list for anyone interested in volunteering, noting that the volunteer activity would probably happen in 2010. She then suggested volunteering at MANNA first, and then volunteering at other organizations if they get good participation. W. Walters suggested volunteering either on Monday or Tuesday.

W. Walters suggested having a cookout. N. Johns replied that the Office would not be able to pay for a cookout, but that it could be a possibility if committee members gathered donations. J. Malloy suggested collecting toys over the coming year to give to a charity around the holidays. W. Walters stated that Toys for Tots had changed their rules this year, requiring a social security number for each child. She explained that this meant that providers that serve mostly PLWHA are unable to participate. J. Malloy added school supplies to their list for donations.

H. Bennett suggested having a subcommittee to discuss long-term activities for the coming year in order to be better prepared for large events, including AIDS Education Month and World AIDS Day. W. Walters suggested organizing a health fair. N. Johns replied that this could be a great activity, but that they were restricted on what they could do. M. White suggested finding pre-existing health fairs and having a table at those. D.H. stated that employment for PLWHA was an important issue. N. Johns replied that they could have a guest speaker come to speak on this issue. R. Hayward stated that it would be important to revisit the newsletter, and have some people commit to writing articles. He went suggest having a subcommittee dedicated to the newsletter.

W. Walters suggested that they have a social event. N. Johns replied that they could only plan an event if there were an educational component. W. Walters stated that they should have a retreat. N. Johns replied that the Office was unable to pay for travel.

N. Johns asked the group who would be interested in participating in the subcommittee for long-term planning. Several of those present volunteered for the subcommittee. J. Whitfield suggested meeting on January 21st or 28th. The group decided to meet on Thursday, January 28 from 11 a.m. – 1 p.m. W. Walters asked if they could have lunch. N. Johns replied that lunch would be available.

N. Johns stated that they next needed to discuss the newsletter meeting. W. Walters asked what they would do in the case of a snow day. N. Johns replied that the Office typically closes for bad weather when Philadelphia schools close. R. Hayward and J. Whitfield volunteered to help with the newsletter. W. Walters suggested having everyone come to the same separate planning meeting. N. Johns suggested discussing the newsletter at the subcommittee meeting on January 28th. The group members agreed.

- **Community Planning Trivia Game**

N. Johns explained the rules for a trivia game surrounding the community planning process. The group then took turns answering questions about Ryan White, HIV, community planning, and other related topics.

Old Business:

None.

New Business:

None.

Announcements:

None.

Member Check Out:

None.

Adjournment:

The meeting was adjourned at 2:13 p.m. by general consensus.

Respectfully Submitted by,

Briana L. Morgan, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- Meeting Minutes from November 9, 2009
- OHP Calendar

RYAN WHITE PLANNING COUNCIL (RWPC)

Positive Committee

Meeting Agenda

Monday, December 14, 2009

12:00p.m.-2:00 p.m.

Mission Statement- The Positive Committee supports and enhances the role of people with the HIV infection to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the Community Planning Group.

Call to Order/Moment of Silence

Introductions

Member Check In (*voluntary*)

Approval of Agenda

Approval of Minutes

Report of Chair

Report of Staff

Group Training/ Discussion: HIV and People over 50

Discussion Item: Brainstorming for activities for 2010

Community Planning Trivia Game

Old Business

New Business

Announcements

Member Check Out (*voluntary*)

Adjournment

Please turn Phone to Silent or Vibrate

Don't forget to sign in by 12:30pm if you need tokens. Thanks!

Please RSVP at 215.574.6760 to ensure that there are enough lunches.

Please contact the office at least 5 days in advance if you require any special assistance.

The next meeting date and time of the Positive Committee is January 11, 2010. It will take place at the Office of HIV Planning, 340 N. 12th St. Suite 203, Philadelphia PA 19107.

**Ryan White Planning Council (RWPC) of the Philadelphia Part A EMA
Positive Committee Meeting Minutes
Monday, November 9, 2009
12 p.m. - 2 p.m.
Office of HIV Planning, 340 N. 12th Street, Suite 203, Philadelphia, PA 19107**

Present: 15(PH), 1(PA), 1(NJ)

Staff: Briana Morgan, Mari Ross-Russell

Call to Order/Moment of Silence/Mission Statement/Introductions:

M. White called the meeting to order at 12:14 p.m., and a moment of silence followed. W. Walters then read the mission statement. Those present introduced themselves.

Member Check In:

None.

Approval of Agenda:

M. White presented the agenda for approval. The agenda was approved by general consensus.

Approval of Minutes (5 October 2009):

M. White presented the October 5, 2009 minutes for approval. The minutes were approved by general consensus.

Report of Co-Chair:

M. White reviewed the agenda for the benefit of the group.

Report of Staff:

M. Ross-Russell stated that N. Johns was out of the office, so she would be acting as the staff support for the day.

Special Presentations:

- **Grievance Process**

E. Torres explained that AACO refers to this as a feedback process for consumers to utilize when they have a problem with a service organization funded by AACO. She went on to explain that AACO is a part of the Philadelphia Department of Health, and they fund most HIV services in the area (*see – attached slides*). She noted that their budget is about \$46 million, and that over half of that funding comes from Ryan White. She explained that all services are free-of-charge and targeted toward uninsured and underinsured consumers. She pointed out that no one funded by AACO should be turned away for lack of insurance, so if this were to happen, a consumer ought to complete the feedback process. A community member stated that he needed services but that he did not have insurance. E. Torres replied that someone in this situation would need to contact the Client Services Unit (CSU) to help him find a case manager.

E. Torres went on to discuss the Client Services Unit. She noted that there was currently a waiting list for case management in Philadelphia, but typically consumers were on the waiting list because they would like to be linked with a particular agency. She explained that CSU provides intake services as well as information and referrals, processes requests for housing, handles complaints and suggestions about funded providers, and provides oversight for the Case Management Coordination Project. She went on to say that there is a two-year wait for housing, and that housing is funded through OHCD. She explained that a person has to be AIDS-defined or receive Social Security for HIV in order to be eligible for AACO housing. She noted that this was a permanent rental assistance program where the consumer would contribute 1/3 of his income to rent, and the balance would be paid by the government. She pointed out that, while a two-year wait for housing seemed to be a long time, there was approximately a ten-year waiting list for Section 8 housing.

E. Torres moved on to discuss the purpose of the feedback process. She explained that process gave clients an opportunity to give feedback on their current services, and that there is also a feedback process within any agency funded by AACO. She noted that they could not take feedback about unfunded agencies. A community member stated that he had been in and out of shelters while on the housing waiting list. E. Torres replied that they only have 600 housing slots. She noted that a homeless consumer would only have to wait six months for housing if they were in the shelter system. H. Bennett asked if a consumer would qualify as homeless if sleeping outdoors. E. Torres agreed, explaining that a person in this situation would need to get verification from Project HOME.

E. Torres then moved on to review the steps involved in the client feedback process. She explained that consumers should be specific in their complaints. She noted that complaints could be anonymous or confidential, but that it was more difficult for AACO to help with an anonymous complaint. She explained that they send a password-protected complaint to the provider, and then the program analyst works with the provider to come to a solution. Then, once a solution has been found, CSU will contact the caller with the outcome. She noted that those consumers that were not satisfied with the outcome could submit an appeal to the director of AACO.

E. Torres next explained that there are three types of calls on the hotline: crisis, priority, and non-priority. Crisis calls were for emergencies, priority calls included situations such as denial of essential services, and other calls were non-priority calls that could take up to 15 days. She noted that any decisions would be communicated to the consumer, agency, and CSU manager. She went on to say that consumers would also be able to have feedback about CSU. She explained the feedback line had been developed to help them provide the best services possible, but they needed feedback to do that.

E. Torres went on to say that they had had 20 complaints in 2009, and most were about DEFA. T. McCoy stated that it impressive that there were only 20 complaints during the whole year. E. Torres noted that they were also conducting a case management survey for consumers where they would get a \$10 CVS gift card.

- **Civil Rights and HIV**

S. Wyche introduced herself and L. Schembry, noting that L. Schembry would be presenting on the Federal Civil Rights Laws for Individuals with Disabilities (*see – attached slides*). L. Schembry explained that they were both in the Office for Civil Rights (OCR), as a part of the US Department of Health and Human Services (HHS). She stated that OCR enforced civil rights laws protecting persons on the basis of race, color, national origin, disability, age, gender and religion. T.U. stated that he did not see sexual preference listed. L. Schembry replied that there are no federal laws protecting sexual preference, so any violations would be referred to the state. T. McCoy asked if they included anything for transgendered persons. L. Schembry replied that this group was not covered. She then stated that there had been recent ADA amendments, and that HIV was now included in the ADA. She explained that they had previously had difficulties addressing HIV as a civil rights issue. She stated any allegation that was filed after January 2009 would be covered under the revised law, and any issues that were related to discrimination had to be ongoing or within the last 180 days.

L. Schembry explained that OCR focuses on programs funded by HHS, noting that if an agency gets as much as \$1 from the federal government, they have to comply with civil rights obligations. She went on to say that OCR mostly deals with case investigations, compliance reviews, pre-grants, and outreach/technical assistance. She noted that their regional office was located in Philadelphia, but that they cover 5 states. She then stated that all Medicare providers have to go through a pre-grant process that includes a review of the agency's policy and procedures. She added that this was the only HHS funding with a screening process, while others have to sign assurances of compliance. She noted that state policies can sometimes be discriminatory. M. White asked about hate crime laws. L. Schembry replied that OCR does not handle criminal activity, adding that a criminal complaint could be enforced through the Department of Justice.

L. Schembry then stated that she would be discussing Section 504 of the Rehabilitation Act of 1973, which covered anyone receiving federal funds from the HHS directly or indirectly. She next reviewed the Americans with Disabilities Act of 1990, which covered discrimination regardless of whether or not the agency received funding from the federal government. She noted that OCR had jurisdiction over Title II. She stated that the "individual with a disability" definition was the same in Section 504 and ADA, and was available in the slides. She noted that a person associated with a person with a disability can also be discriminated against. She then reviewed the concepts behind both Section 504 and ADA. A community member stated that he had recently moved to the area from out-of-state, and that he had had been kicked out of hospitals for pre-existing conditions. L. Schembry replied that the laws around discrimination would not give him that kind of immediate service or solution. E. Torres asked the community member to speak to her about his situation after the meeting.

Discussion Items:

- **World AIDS Day**

M. Ross-Russell stated that they had previously discussed handing out AIDS 101 cards, but that the committee would not meet between the current meeting and World AIDS Day. She noted that there would be a sign-up sheet available for anyone interested in receiving information about possible group activities. T. McCoy stated that many consumers already participated in various events for World AIDS Day. B. Morgan stated

that she would be passing around a volunteer list, and asked anyone interested to supply a name and either an email address or a phone number.

• **Volunteer Activity**

M. Ross-Russell stated that the group had previously suggested volunteering at a church, MANNA, or BEBASHI. She explained that a church might be more restrictive on volunteers, while MANNA and BEBASHI might be more open. She noted that this would probably be a 3-4 hour commitment. T. McCoy asked what would be involved in volunteering at BEBASHI. M. Ross-Russell replied that BEBASHI typically has a clothing drive, and they would have to contact the organization about this. She stated that they would need to know how many people would definitely be interested in volunteering. She noted that MANNA would also likely conduct their Pie in the Sky fundraiser again. T. McCoy stated that this would be a good opportunity to keep an ongoing volunteer list from the Positive Committee.

Old Business:

None.

New Business:

None.

Announcements:

None.

Member Check Out:

J. Whitfield stated that she had gotten housing.

Adjournment:

The meeting was adjourned at 1:52 p.m. by general consensus.

Respectfully Submitted by,

Briana L. Morgan, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- Meeting Minutes from October 5, 2009
- Philadelphia Department of Public Health AACO Feedback Process
- OCR Folder
- OHP Calendar