

HIV Engagement and Retention Village Report

December 1, 2014

HIV POSITIVE AND HEALTHY FOR LIFE: HOW DO WE IMPROVE HEALTH FOR ALL?

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| <p>TWO DATES!</p> <p><u>In-Person Meeting:</u> Monday, November 3, 2014 5:30pm to 7:00pm Bailey-Boushay House 2720 East Madison Seattle, WA 98112</p> <p><u>Webinar Meeting:</u> Wednesday, November 12, 2014 5:30pm to 7:00pm Contact Justin or click or type this link to access the webinar</p> <p style="text-align: center;">➔</p> | <p>COMMUNITY MEETING AND WEBINAR</p> <p><u>Who Should Attend?</u></p> <ul style="list-style-type: none"> All persons living with HIV / AIDS and others interested in HIV / AIDS support services <p><u>What Can I Expect at This Meeting?</u></p> <ul style="list-style-type: none"> Information about HIV / AIDS support services Opportunities to provide input on: <ul style="list-style-type: none"> HIV / AIDS support services How to link and keep all persons living with HIV / AIDS in medical care How to help persons living with HIV / AIDS live healthy lives |
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(HIV Village meeting and webinar flyer used for event promotion)

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Introduction:

HIV Stakeholder Village meetings are part of the [Washington State HIV planning system](#). Village meetings were conceived to educate the community on current and proposed HIV interventions, strategies and policies. Village meetings receive input from the public on current and proposed HIV interventions, strategies and policies. Village input is shared with all parts of the HIV planning system, including Village participants, in order to improve HIV services and policy. Village meetings are open to everyone. Villages do not have formal members and can be convened by anyone.

The first Village meeting and webinar addressed HIV engagement and retention in care for all persons living with HIV disease in Washington State. This Village meeting theme is coordinated with the [Washington State Strategic HIV Framework](#). It specifically aligns with the HIV viral load suppression outcome found in the Framework. Future Village events convened by the Washington State Department of Health Infectious Disease Office (DOH) will continue to focus on HIV prevention, care and treatment priorities.

DOH convened two Village events in November, 2014. The Village events' purpose was to:

1. Talk about the need to improve the HIV engagement and retention services for all people living with HIV in Washington State;
2. Receive input from meeting participants about the need to improve HIV engagement and retention services meeting participants;
3. Create a Village meeting report to be shared with the public, the HIV Planning Steering Group (HPSG), and DOH.

Special Note: This Village meeting and webinar report is anecdotal by nature. The Village events were not conducted using a rigorous, robust and scientific methodology. DOH promoted Village events to be as inclusive as possible of all persons living with HIV (PLWH). Participants, their case study input and general comment are not meant to be representative of all PLWH. DOH intends for this report to inform an enhanced HIV engagement and retention response in conjunction with other core and supplemental data resources.

When and Where:

1. November 3, 2014. In-person meeting. 5:30pm – 7:00pm Bailey – Boushay House. 2720 East Madison Seattle, WA 98112-4738
 - Approximately 30 participants attended the meeting.
2. November 12 2014. Webinar meeting. 5:30pm – 7:00pm via internet connection
 - Approximately 24 participants attended the webinar individually and at participation “parties” in Spokane, Everett and Bellingham.

Meeting and Webinar Format:

Both Village events followed a similar format and sequence. Topics covered were:

1. The **need** to improve HIV engagement and retention services for all PLWH to be as healthy as possible.
2. The presentation of the [HIV care and treatment cascade](#) to show **where** we can better help PLWH be healthier.
3. HIV case studies: Participants were asked questions about fictional PLWH to brainstorm **how** to help PLWH live healthier lives.
4. General comment and questions from Village participants.

Village Report: Wordles

The following wordles attempt to show the Village meeting and webinar themes by each case study and by general comments and questions. Themes you see below were generated using Village participant input for both events. The more a word was used the bigger the font. (Images used with permission from [Wordle.net](#))

Village HIV Case Studies:

1) Paul

Paul, a 22 year old Latino man who lives in eastern Washington received a confidential HIV test at an outreach event at a bar in a city that he visits on weekends to seek sexual partners and other recreation. Paul usually stays with men he meets on these trips, or occasionally another friend who moved there for a job. Paul hasn't come out to his friend and is vague about what he does while out and about in the city. Paul was shocked when his rapid HIV test was reactive because he doesn't feel sick and none of his partners identified as HIV positive. The outreach worker explained the meaning of his result and emphasized the importance of Paul using condoms to protect his partners during all sexual encounters even though his diagnosis is not yet confirmed. The worker drew a blood sample that was sent to the state public health lab and made arrangements for Paul to come to the CBO office to receive his definitive test result 10 days later when Paul would be able to visit the city again. Paul agreed to meet the outreach worker at the CBO office to receive his results. The worker gave an appointment card with the details of the appointment and contact information for the agency. The worker strongly suggests that Paul request an appointment with a medical provider in his town, even before receiving his results, because of the importance of beginning antiretroviral therapy as soon as possible after diagnosis, but can't offer a specific referral because he is unfamiliar with providers there.

Paul does not return as arranged to receive his results.

Because Paul's second test confirmed his HIV diagnosis, his case was reported to the public health department. Shawn, a health department staff member contacted Paul by phone and later spoke to him in person. He gave Paul information about HIV and offered help finding a local medical provider in the city who is sensitive about LGBT health. Paul shared with Shawn that he felt betrayed by the person who transmitted HIV to him. He knows he should tell sexual partners he has HIV and protect them by using condoms, but fears that no one will want to have sex with him if he does.

Shawn told Paul that if he takes HIV medicine he will be much less likely to transmit HIV to others. Paul became more interested in receiving treatment because it will help make up for times he doesn't use condoms. He says that his current jobs-- library assistant and waiter at a café don't offer health insurance and he can't afford to pay for treatment. Shawn tells Paul that he is eligible for case management services through the Ryan White Program. The case manager can enroll him in the Early Intervention Program which will cover initial medical visits

and pay for medications. EIP will eventually pay Paul's premium for commercial health insurance. Paul seems reassured by this information.

Was Paul ready to connect to care?

Paul was not ready to connect to medical care after his partner services interview. He feared that his friends, family, and community would not support him if they knew that he was gay, and living with HIV. He also wasn't sure that he would feel safer receiving medical care in the city because he was unfamiliar with the health care system, and it might find it hard to hide his clinic visits and medicines from his friend.

Paul accepted a referral to the case management service because its office was located in a community a few miles away from his town. Shawn called the case management office and introduced Paul to a case manager over the phone.

Paul's case manager helped him obtain health insurance and introduced him to a peer counselor who began working with Paul using motivational interviewing skills learned through training he received at the agency. After a few months, Paul attended his first medical visit with an HIV care provider in the town where the case management office is located. He began ARV therapy and received brief treatment for anxiety and depression. He is considering entry into substance abuse treatment. Because Paul's emotional status and risk behaviors are still issues for him, he keeps contact with his peer counselor who discusses Paul's concerns and encourages him to adhere to HIV treatment.

Paul's Questions:

1. What were the problems Paul had to solve after his HIV diagnosis?
2. How did the people in the story help him deal with those problems?
3. What does Paul need now to continue his progress toward becoming healthy?

2) Alyssa

Alyssa is a 26 year old African American single mother with a two-year old daughter, Betsy. Alyssa was diagnosed with HIV as a result of a routine test during prenatal care. Her CD-4 count was 320 at diagnosis, indicating that she has been living with HIV for some time. She received ARVs during her pregnancy and delivered an apparently uninfected baby. Alyssa is a part-time student at a community college and works part-time at a retail clothing store. Her daughter's father left the family when he learned that Alyssa had HIV—his status remains unknown. While she does not receive health insurance from her job, she and her daughter are eligible and enrolled in Medicaid. She receives food stamps and limited child care and other support through her church, of which she is an active member. Alyssa did not enroll in any case management or navigation services following her diagnosis, saying she could manage her own medical treatment.

Alyssa has been bringing her daughter for routine medical care and immunizations as scheduled for the past two years. Alyssa was referred to an HIV medical provider who practices in the same clinic as her OBGYN and attended regularly scheduled appointments for 14 months after her daughter was born. She was also treated by another affiliated provider for postpartum depression. Her depression persisted and she received some group therapy and a few individual sessions from a counselor at the clinic. Alyssa did not attend her most recent scheduled HIV care visit, or refill any of her prescriptions at the clinic pharmacy where she ordinarily gets them. She did not return a follow up call from clinic staff at that time or reschedule on her own. A letter was sent to her by the clinic stressing the importance of her medical care and offering assistance in making an appointment.

The letter was returned to the clinic as undeliverable.

Two months after missing her HIV care appointment, her mental health counselor found a message on her answering machine from Alyssa. She was tearful, stating that she was more depressed than before and was missing work and school. She was afraid that she would lose her job—her only source of income. She has moved in with her parents to make ends meet. As her depression became worse, Alyssa's mother was initially supportive, but then begun suggesting that the grandparents may be better equipped to raise Betsy than Alyssa. Alyssa fears losing custody of Betsy. Alyssa also says there is "something else" she needs to talk about with her counselor. Alyssa leaves a new cell phone number and asks the counselor to see her for a therapy session as soon as possible.

As a member of Alyssa's care team, the counselor knows that engagement in HIV care is very important. She knows that Alyssa missed several appointments. The counselor puts a note to

Alyssa electronic medical record, including a summary of Alyssa's message and adds the new telephone number to the chart. She sends a message to Alyssa's HIV care provider, saying that she will schedule an appointment with Alyssa ASAP and will encourage her to re-establish contact with her doctor.

Alyssa returns her counselor's call and requests an appointment for that afternoon. The counselor agrees to set aside a brief slot for Alyssa, explaining that it takes more notice to arrange a full session. When Alyssa arrives, she appears anxious, tired, and has lost weight. During her session she repeats the concerns expressed in her first telephone message. The counselor asks Alyssa what her most pressing concern is now, and Alyssa says she doesn't want to lose Betsy. Alyssa adds that she ran out of her antidepressant right after her last medical visit and her mood has deteriorated rapidly since. She didn't fill her HIV medications then either, since Betsy had needed some clothes and Alyssa didn't have money for her prescription co-payment.

The counselor acknowledges seriousness of Alyssa's situation and praises her for seeking help. She asks Alyssa if she is OK to see her HCP while she's at the clinic today to evaluate her antidepressant medication needs. Alyssa agrees and her HCP squeezes a few minutes to see her and prescribes a higher dose of her antidepressant. Her provider's nurse walks Alyssa to the pharmacy and stays with her until she gets her medicine. She tells Alyssa that the clinic staff have missed her since her missed visits and is looking forward to working with her again. Alyssa schedules a follow up appointment before leaving the clinic.

The HCP agrees with the counselor that Alyssa's depression is the main obstacle to adherence to HIV treatment and should be the first priority for the care team.

The counselor sees Alyssa for three 30-minute appointments during the following week. Alyssa describes her experience of fatigue and lack of motivation for self-care. She states that she is able to rally when it's time to care for Betsy and is angry at her mother for suggesting she is an unfit mother. Alyssa says that she is relieved to be able to share her concerns with the counselor since she has become quite isolated as her depression deepened. At this point, she only goes to work—school is on hold until she can manage better.

Near the end of the third appointment, Alyssa tells the counselor that she had begun dating a man she met at church. She worried that he would reject her when she disclosed that she has HIV. To make matters worse, Betsy's father has reappeared after being jailed briefly for an assault charge. He knows about the new man in her life and has threatened to tell him about her HIV if she continues going out with him.

The counselor suggests that HIV as well as depression may be contributing to her fatigue and depression, explaining that her immune system was already relatively depleted when she began taking ARVs, and may have moved farther in that direction since she stopped taking them. Alyssa is open to the suggestion that she resume ARV therapy and that she needs evaluation by her provider before she can start. The counselor suggests that Alyssa may be able to see her HCP in conjunction with her next counseling appointment.

Alyssa attends a joint appointment with her counselor and health care provider. They work out a new treatment plan for Alyssa that combines moderately intensive counseling with management of her medical situation. Alyssa is also introduced to a Ryan White case manager who is stationed at the clinic. Alyssa agrees work with the case manager and apply for services that may help her regain her independence from her parents. She receives new prescriptions at this appointment and begins to take ARVs again along with antidepressants.

During the next six months Alyssa's health improved and she recovered slowly from her latest depressive episode. She had several joint appointments with her counselor, HCP, and case manager in attendance. Her case manager helped her find financial assistance and apply for subsidized housing. Alyssa is looking for a roommate who is comfortable with kids so that she can afford to live in an apartment again.

She took a semester off from school but made arrangements with her instructor to make up some incomplete work. She ventured out more, including to church. The man she had begun dating is still interested, but Alyssa has let him know she wants to proceed slowly. She shared with her counselor that Betsy's father had physically abused her and she still feared him. Her case manager helped Alyssa access services for women who experience domestic violence at the YWCA. Each member of Alyssa's care team is making an effort to maintain frequent contact with her and are communicating with the others about what they observe. Alyssa has agreed to contact her care team at times when she needs extra support to lessen the chance of future care interruptions.

Alyssa's Questions:

1. What were the problems Alyssa had to solve after her HIV diagnosis?
2. How did her health care team help her deal with those problems?
3. What does Alyssa need now to continue her progress toward becoming healthy?

Village Report: Meeting and Webinar Input

The following raw data comes from input from both Village events. The input is based on questions about Paul's case study, Alyssa's case study and general comments and questions from participants.

Paul's Case Study

Question 1: What were the problems Paul had to solve after his HIV diagnosis?

Meeting:

- Getting to care and treatment
- Needs to address substance abuse
- Language
- Coming out-process 2 lives going on cultural (family) (supportive)
- Feeling good, must not be sick
- Fearful of disclosure to partners unfamiliar scared- provider in area
- Arrange treatment in a place he felt is confidential
- See a Dr all the time
- Get some real help
- Get a friend to talk too
- Come to terms w/diagnosis
- Finding friendly care
- Knowledge about HIV (safe sex)
- Geographic location

Webinar:

- He had to find insurance, doctor
- address his substance abuse
- How to get treatment without being outed
- Addressing the stigma from family and friends
- Where and if he was going to seek treatment, tell anyone about his HIV status, find insurance, seek treatment for his substance abuse problem, seeking additional counseling for his depression from and substance abuse
- small town, confidentiality of his hiv status and sexual identity
- He needs transportation to see any of his care providers
- transportation to the nearby town
- he'll need a convenient pharmacy
- works two part-time jobs... where is the time?
- is his housing secure?

Question 2: How did people in the story help Paul deal with these problems?

Meeting:

- Great people-didn't go far enough 1) housing 2) getting to city
- Aggressive interventions to link to care

- Offered options outside of where he lived
- Worried about letting family know
- Condom use advised after initial diagnosis
- Provider sensitive to LGBTQI
- Health Insurance/CM services
- MH/CD substance abuse (treat whole person)
- Helped him enroll in EIP program
- Helped with HIV knowledge
- Find local provider in city/LGBT sensitive
- Received a case manager
- Peer counselor
- Get him the appt

Webinar

- they started the partner notification conversation
- got a referral to case management
- Health department referred to case management and CM then to care and then insurance
- follow-up with his case manager, additional community resources, access to art
- referred him to the cbo in the other nearby town
- got insurance and a peer to talk to
- and to treatment
- sexual health education
- peer services
- Offered convenient connection peer support
- he must have been connected to dr since he has arvs
- all these solutions must be progressively relieving his fears

Question 3: What does Paul need now to continue his progress toward becoming healthy?

Meeting:

- Peer support group
- Needs to learn about disclosure & condoms
- Mental health- Peer support in rural locations
- Stigma
- Transportation
- Move to city Education
- Risk of viral suppression good information
- Additional therapy or peer groups
- Self-esteem stigma
- Referral to PLA but for HIV
- Community education
- Going to different city/not getting support
- Stabilize mental health keep going to counseling

- Use protection & keep up with meds
- Stay educated
- Disclosure with potential partner
- Find support system friends/family
- Needs a place to live in city
- Wear condoms
- Get EIP
- Thinking about substance treatment
- Safer sex knowledge
- Social support in age group

Webinar:

- support network
- commitment support and on going education
- peer support/psycho-social support
- continued access to case management
- continue with treatment, seek peer support groups, improve lifestyle choices,
- prevention education
- treatment education and counseling
- personal commitment to his own care

Alyssa's Case Study

Question 1: What were the problems they had to solve after her HIV diagnosis?

Meeting:

- Depression
- Mothers reaction/family support
- Domestic violence
- Single parent
- Mental health
- Possible transmission to child
- Housing/food
- Single parent/violent ex-husband
- Childcare/depression/housing
- What family she has is hostile/boyfriend abuse
- Economic problems
- Husband left her
- Communication problem
- Hard to ask for help
- Afraid of losing child
- Feeling overwhelmed
- Fatigue
- No family support
- Postpartum depression

- Couldn't afford co-pay

Webinar:

- easy access to education/confidential
- Depression
- LIFE!!!
- no stable housing, no family support, DV, working and going to school and raising a child
- ability to address her DV to counselors and providers
- low-income

Question 2: How did the people in the story help her deal with those problems?

Meeting

- Dream team-communicated with each other
- Coordinated care team
- Prevention messaging
- Help w/subsidized housing & financial assistance
- Copay
- Make appt. for her
- Tried to stay in constant contact
- All parts talk to each other (medical, case mgmt., mental health)
- Praise & encouragement
- Assessed meds/education 3-30min
- They tried to link her w/care & connect her housing, medication
- Outreach/phone calls
- Letting her know that she was missed
- Providers in the room/very important
- Walks her to the pharmacy
- Documenting lack of engagement
- Access services for women w/ DV
- Communicating with each other
- Sent her to treatment for depression
- Case manager helped with DV

Webinar:

- referral to YWCAQ
- they prioritized the depression issue
- worked together to address her problems
- referral to mental health, case management DV solution
- counseled her to cut back on school
- reassessed her insurance to pay for ARVs
- urged her to reach out support when needed... don't let things fester
- obtaining her own housing
- realizing her only support is not just her family

- childcare

Question 3: What does Alyssa need now to continue her progress toward becoming healthy?

Meeting

- Stay on ART in touch w/team & coordinated care
- Information sharing
- DV treatment
- Parenting classes
- Additional connection to services for self & Family
- Peer support group
- Getting Alyssa engaged in her own care
- A lot of professional support
- Parenting classes
- Search about domestic violence and access services for it/possible restraining order
- How to disclose /date
- Consistently attend counseling appt.
- Re-engage with school
- Childcare
- Consistently follow-up w/case management
- Talk to legal counsel about child custody
- Transportation needs
- Support group with people w/ disclosure issues
- Aggressive care with her depression/monitoring her
- Mail order pharmacy
- Talked about fear of disclosing HIV status
- Care team needs to follow up sooner not later-don't assume she is going to do it
- More group meetings with provider
- What is important to Alyssa??
- Counseling/discussion with mother
- Connectivity

Webinar

- housing
- safe housing
- positive outcomes and continued education and work
- trust of her new support system
- keeping her child
- maintaining good contact info

General Comments and Questions:

Meeting:

- Majority of folks w/HIV over 50
- Everything is mediated through an agency

- Peer support
- Community
 - Comfortable
 - Welcoming
 - Snacks
 - Open to anyone w/HIV
 - Drug & Alcohol zone
- Rural areas-billboards letting people know about services-anonymous/free
- Testing w/anonymous options
- Need to understand needs of folks who live in rural areas
 - Relationships w/neighbors local community
 - Continued support
- Give to rural CBO
- Meet folks where they are at
- Bilingual/multi- lingual
- Tech
 - Tele health
 - Tele mental health (group & Individual)
 - iPad with connection
 - Skype
- Some folks are weary of tech confidentiality/privacy
- Collapsing care-loss o services
- UCAN-PCAF

HIV and Aging

- isolation
- emphasis on youth
- elders brushed aside (assess in assisted living elder living)
- sexual identity
- were we get care
- loss of peers as folks die
- communication network disappearing
- housing older folks
- disability
- SS income/fixed income and Med copay
- Memory loss
- Dental care
- Transition from Medicare
- Insurance issues

Webinar:

- stability - acceptance and assistance - Less complicated

- People can stay healthy by having access to affordable health care and treatment.
- They can also stay healthy by UNDERSTANDING their health care
- continued funding for existing services is necessary
- change healthcare coverage to help pay the co-pays on non hiv related Dr visits and meds.
- Housing
- continuous access to medication, and confidentiality/privacy within small communities, stigma, and transportation
- Feeling save
- safe
- Question: Do we have state funding to support care for estimated 14,000 total infections in the state
- How can the state help reduce the waiting list for housing?
- EIP dental coverage and mental health
- EIP dental services are only available in very restricted areas.
- are there limitations to mental health access
- There is concern that many of the HIV specialist drs will be retiring soon. How can we proactively address this anticipated shortfall?
- co pays on mental health under Medicaid is high and not always obtainable
- *Medicare
- That is good to know. WE would love to see this availability information more accessible
- having a case manager that knows and shares the information.
- Would Dept. of Health offer EIP consumer education webinars? Or even a letter?
- QUESTION TO THE GROUP: "Peer support" was mentioned a several times during this evening's conversation. Can folks describe what successful peer support looks like?
- needs assessments were helpful and would love to see them again
- ANSWER TO FACILITATORS: Support groups
- Providing client's immediate contact with someone in a similar situation and similar experiences
- someone who is accessible and nonjudgmental to talk to on a regular basis
- Peer led would be wonderful. maybe with oversight of staff when needed
- Peer also provides support to case management
- HIV + Support Groups, care & coordination with friends and family, transportation, buddy system for med follow-up, educational workshops for community members, etc.
- It would benefit peer leaders to go through "community health workers" training - offer leadership skill, boundaries, etc. invest in our community to establish leaders
- Some clients will speak more openly to a peer knowing they are in similar situation.
- how will this session inform the planning group