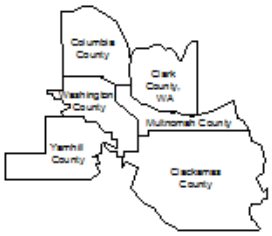
Portland Area HIV Services Planning Council

Advocacy and planning for people affected by HIV in the Portland metro area

Ryan White Program, Part A



Meeting Minutes

Meeting Date: January 7, 2020

Approved by Planning Council: March 4, 2020

Grantee: Multnomah County Health Department

Multnomah County

Portland Area HIV Services Planning Council
MEETING MINUTES

Tuesday, January 7, 2020, 4:00 – 7:30 pm
Gladys McCoy Building, 619 NW 6th Ave., Portland, OR 97209
Room 850

AGENDA

Item**	Discussion, Motions, and Actions
Call to Order	Emily Borke called the meeting to order at 4:00 PM.
Candle Lighting Ceremony	Jeremiah Megowan led the lighting of the ceremonial candle in remembrance of Peter, died last year, affected in the '80s, wrote for newspapers.
Welcome & Introductions	Lorne James welcomed everyone to the meeting and introductions were made, with Council members declaring any conflicts of interest.
Announcements	Announcements: • U=U presentation by Sherryl Lamm (see slides) o Sherryl's background ▪ Lived in isolation for 10 years due to stigma and job loss ▪ Became a policy fellow with Positive Women's Network (PWN) because they advocate for women with HIV ▪ Partnered with Toni Kempner and created fact sheet (see handout) o U=U ▪ Undetectable = Untransmittable • Based in science – multiple studies • Yes, you can have condom-less sex if you are undetectable • How many transmissions have happened during these studies? Zero. ▪ We in Oregon haven't been talking about U=U ▪ CDC adopted in 2017, but we're still not talking about it o Endorsing U=U is a message of hope ▪ Reducing fear ▪ Fighting stigma • Introducing "Community Garden"(formerly known as "parking lot") – a place for sticky notes with questions / comments, for review by Co-Chairs and use by Ops Committee when considering future agendas • Reviewed Planning Council Year Cycle graphic
Review and Approval of Agenda	The agenda was accepted by unanimous consent.
Review and Approval of Minutes from Prior Meeting	The meeting minutes from the November 2019 meeting were approved by unanimous consent.

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Public Testimony	No public testimony. Public testimony refresher • Key reasons for public testimony o identifying an unmet need o providing feedback on a type of service currently being offered (focus on service category, not provider) o giving input on where funding should be prioritized • Public testimony is not a dialogue. Don't expect a discussion session or follow up questions. o PC policy is that HGAP staff will follow up with person individually immediately (during meeting if possible) to say thank you. HGAP can determine follow up steps based on individual need
MAI (Minority AIDS Initiative) Panel – *NOTE: MAI is a service category we currently fund through Part A, as part of Medical Case Management.*	*Panel: Maricela Berumen (CAP), Robb Lawrence (CAP/Urban League), Frank Mollel & David Ochan (Lutheran Community Services)* *Summary of Discussion:* Minority AIDS Initiative (MAI) **Q: What is your role, and how do clients get connected to you?** • David Ochan (DO), Lutheran Community Services (LCS) navigator o Was involved in HIV work in Africa for 10 years o Involved here about 7 years • Frank Mollel (FM), LCS o We get clients from clinics, organizations (CAP, Lutheran communities), family members • Robb Lawrence (RL), African American HIV Services Navigator with Urban League (UL) o Position is a CAP/Urban League collaboration o Work with individuals in African American community who are newly diagnosed o Get clients from Urban League, CAP, medical case managers • Maricela Berumen (MB) o Latino Service Navigator at CAP o Built rapport with community o Referral doesn't necessarily come from case manager, but sometimes from actual doctor who has made new diagnosis, or externally or internally **Q: What are the biggest challenges you have in connecting folks to care, including any service gaps and changes in populations you serve?** • MB: transportation, cell phones, being able to get ahold of clients to set up an intake, not wanting to access mental health (#1 challenge) • RL: transportation, staying in contact with clients (sometimes can't pay cell phone bill), mental health (don't want to admit there is a mental health issue) • FM: sometimes clients don't have phones (we sometimes try to use social media, but some don't have wifi or other access), have to go to the client's home and see if they are there

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	• DO: language barrier, lack of education (approximately 80% have never been to school), culture shock; clients need our help to make appointments and read the mail; don't believe in HIPAA and don't trust translators, so want to wait until we are available, but we can't always be with every client at their appointment **Q: What other resources or support do you need to do this work? (wish list)** • MB: majority of MAI participants go to a support group o Reencuentro - Happens once a month o If someone doesn't provide food, the event doesn't happen (this occurred last month) o Food budget for group – without food, the event doesn't happen o Cell phone o Life skills education programs • RL: o Funding: o Support group called RealTalk – hasn't been active, but bringing this back o Food o Cell phone bills o Things that help individuals navigate through life • FM: o Funds so we can do more support in our community for more clients (more FTE) o Currently only 1.0 FTE for both • DO: o When you help client, they expect you to help whole family – you can't tell someone I'm only here to help you o Time is never enough for what we do o If client calls and gets answering machine, they hang up the phone, they want to speak to someone o We do like our job, but the time doesn't allow us to do what we do **Q: What is a success story that you can share with us?** • MB: o Many individuals don't read or write, are more visual, so use desk calendars and color code each date so they know what clinic / provider they're going to. o Individual was previously referred to multiple specialists, but referrals kept expiring because he didn't follow through. o Using this calendar, I was able to get client to multiple specialists in 3 months. • RL: o Born and raised here in Portland, small gay black community o Challenge: I may know clients on a personal level, may have gone to school with them or worked with them o Called a client I knew

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	o Client was late arriving o Client described previous experience with CAP o Successful in re-engaging o Client said, "I'm glad I came down here. Even though I know you, I don't feel that stigma that happens in the black community around being gay and being HIV positive." • FM: o Moving clients, o Going with clients to Immigration appointments, applying for green cards o Shy young client didn't want to talk at all, but we kept in contact, became almost family, did intake with him, took his medicine, now going to school, very happy, more talkative, such a change, powerful young man, bought his own car, now has a girlfriend • DO: o Mother worried she would infect her child, o Worked with her to see her primary provider, went with her to appointments o Child HIV negative o Enrolled client in ESL classes or other programs o One now an RN, very happy o Two are now nurse assistants o Go to school, learn English, get a skill o PCC o ESL classes o Empowering clients, then they will have less needs, focus more on medical aspect of basic needs **Other Questions?** **Q: With regard to Urban League and your association with CAP, how did that come to be? And what can CAP and UL together do that hasn't been done previously?** • RL: There was an internal audit at CAP that gave suggestions about how to work with black community, one of the suggestions was that they work with an organization, they chose UL. UL mostly works with black individuals coming in looking for services. This position at CAP had a huge turnover. So they worked together. CAP is a leader in HIV/AIDS in Portland, UL has black people coming in to receive services, so why not work together? UL had previously been referring individuals to CAP. Some would not go to CAP, because no one there looked like them, so they became lost in the system. Great collaboration with both organizations to help the African American community. **Q: For those individuals already engaged in care, were there barriers to getting individuals tested? Did you work on anything to improve engaging communities and others to get tested more frequently?** • MB: o Most times when I get referral from a hospital, it's not just the client. There is always a spouse, but it's difficult to have that

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	conversation until the client is ready to disclose. This creates a barrier, because if the client is not willing to disclose, there's not much we can do. It becomes a race against time when an individual is actually pregnant. o Education is the first piece to get people tested. As part of this, I go to the migrant camps. They are very heavily concentrated with men, but there are also women. There has to be a way, other than free stuff, to get them to come to the table. I started taking own personal nail supplies, with black board saying "free manicures … but let's talk about sex." The women had no choice but to listen, as they were in the chair getting their nails done. I'm educating them at the same time. Women in the chair, men waiting for them and listening in – I was actually educating two people at the same time. Testing rates went up! Actually had to turn people away because we didn't have the staff to test everyone. It's being creative about what's going to work. • RL: In mid-February we're turning UL into testing center, including info on HIV/AIDS, safe sex and PrEP. • FM: Clients from many different cultures. It's difficult to talk to the community, because if I talk about HIV, people will ask questions about why I am working with specific individuals. It works better to have someone else come to bring education. • DO: Many clients receive HIV status notification as part of immigration processes, either in the originating country or when they first arrive in the United States. Stigma is very big issue. To protect client, we say we are "case managers" (no mention of HIV). Education is key. I think U=U will change the whole game, because thinking HIV is a death sentence is a big part of the stigma.
VSSP (Viral Suppression Support Project) Evaluation	*Presenter: Marisa McLaughlin* *Summary of Discussion:* See slideshow. Questions: • Q: Is EPIC and CAREWare the same thing? A: No. EPIC is an electronic medical records system used by medical care providers across Portland, and we are able to have some information imported into CAREWare through the Ryan White funded medical provider. • Q: Is there a difference between "lost to follow up" and "lost to care"? A: While providers may use these terms differently, here they are used interchangeably. • Q: Does intermittently virally suppressed mean that an individual had a suppressed viral load lab, and then an unsuppressed viral load lab, or does it go both ways? A: It goes both ways. • Q: Doesn't only having one viral load test a year skew the data (not accounting for people who may be unsuppressed but not tested)? A: I wish I had a breakdown of how many clients had only one VL test during this timeframe. We found that many clients had more than one viral load lab per year.

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	• Q: Are you going to get legal permissions to get lab data for clients in other counties? A: We have ORPHEUS data from Multnomah County. We also get information for any client who is receiving Ryan White funded medical care directly from EPIC into CAREWare. We end up having lab data for 75-80% of all Ryan White clients being served. We're hoping that is greater than 90% once we have permissions from Washington and Clackamas counties. • Q: What is the total number of people that represents? A: About 400 clients had at least one test that was not virally suppressed during that time period. 227 clients that were intermittently suppressed. 169 clients that were only unsuppressed. • Q: How did you define time of diagnosis? A: Time that was given either in ORPHEUS or in CAREWare.
Reallocations	*Presenter: Jesse Herbach* *Summary of Discussion:* See handout Current reallocation proposal • Last-minute additions: o Handout shows $25,171 to reallocate o Just prior to this meeting we found out we have additional $15,000 (not reflected on handout) o Total of $40,171 to reallocate • Proposed allocation reductions: o $1500 from oral health (Medicaid and EIP covering most needs this year) o $38,671 ($23,671 on handout + $15,000 additional) from Medical Case Management (hiring delays) • Proposed reallocations: o $7,500 into housing o $17,671 into food o $15,000 into medical (not shown on handout) • Q: How are these requests determined – are these their requests, or what we have to give? A: Generally a little of both, but in these cases, what they asked for. • **Decision: approve reallocations as recommended.** End of year spend out prior approval request • HGAP requests approval to move anything up to $10,000 between service categories as needed, and anything after $10,000 to be moved into Medical to ensure end of the year spend out. • **Decision: Request approved.**
Evaluation & Training Subcommittee Presentation	*Presenter: Laura Paz Whitmore & Dennis Grace-Montero* *Summary of Discussion:* See slideshow.

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Client Satisfaction Survey	*Presenter: Aubrey Daquiz* *Summary of Discussion:* Background: • Last survey was 2 years ago, when we started transitioning from all paper forms to a mix of electronic and paper; continued that this year • In addition to tonight's presentation, we will also present at Ryan White contractors' meeting, a written report within the next month, and provider-specific reports coming out closer to spring • Also plan to do community forum(s): groups to hear more from community members – diving deeper, hearing more from populations not reached as well through survey who may want to provide feedback another way • Jenna Kıvanç completed analysis of survey results and put together slides. • Thank you to TGA provider staff, community members who reviewed and finalized survey, and everyone who completed survey! See slideshow of survey results. Questions/Comments: • Q: Numbers of clients in each category filled out survey, and were therefore used to calculate slide percentages (i.e. denominator or "n")? A: o Newly Diagnosed = 60 o SUD = 75 • Q: For the "coping with stress," do you think there's some correlation with "major life stressor" from previous question? A: It's possible. We didn't do a specific analysis on what might be different about the folks who said they didn't have as much support there versus the ones who did, so it might be interesting to look more at that. There could be an argument made from some comments that maybe clients don't expect all of their providers to help them cope with stress. • Q: In what languages were the survey offered? Were there any requests for other languages? A: This year only in English and Spanish. We had no specific requests for other languages, but next time we can check CAREWare to consider clients' preferred languages. • Comment: We have mostly white men responding, then most respondents say they see their cultural identity in environment etc. – not a true snapshot o This is why we will be doing some looking at differences across different categories to see if there are differences, especially on questions related to cultural identity, sexual orientation or gender identity. o It would be nice to get a true snapshot of different cultural groups' social determinants and how they navigate o We will be doing more analysis, but we know we can't reach everyone with a survey – not everyone wants to respond that way.

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	• What percentage of which clients were using what means to respond (email / tablets / paper)? A: o 64% used email or MyChart o 15% used tablets o 14% used paper • Q: For people who are visually impaired or have literacy issues, were there any ways to complete the survey? A: Not done across the board, but Aubrey Daquiz gave out her phone number to providers and offered to walk individuals through the survey. If there is sufficient interest, we could look at what it would take to provide other options next time. • Really want to hear voice of youth (average age was in 50s) • Want to see more female representation • Missing people who are houseless • Comment: Ways to increase response for next round: incentivizing, having scribes to assist with completing surveys, providing pizza • Q: Is it possible to see within the different groups, how everything averaged out? A: Yes, Jenna plans to do this as part of the next round of analysis, dive deeper and look for differences across categories on all the questions, especially statistically significant differences. • Comment: Wondering if older white male is easier to access. Consider getting fewer clients but really digging in to harder to reach clients, instead of hanging it on how many more clients we reach. • Q: In the survey, was there a place for clients to indicate that they would be willing to give more information? A: Yes, at the end of the survey. • Comment: Low turnout from POC. Difficult to navigate cultural humility piece, to encourage providers to seek their input. • Comment: Request to provide information about who / what got missed, so we can consider how to address that • What's the next step? A: Qualitative data collection. A poll about planning feedback sessions has already been sent out. We are now working on the format, location, and timing. • Q: Will there be a one-page review of the survey results to give out to clients? A: Yes, we still plan to create this for provider distribution.
Open Enrollment Summary	*Presenter: Jonathan Livingston (CAREAssist), Emily Borke (Health Services Center), Julia Lager-Mesulam (Partnership Project) & Matthew Moore (Clark County)* *Summary of Discussion:* Jonathan Livingston(CAREAssist) • 277 clients enrolled in off-exchange programs • 524 clients enrolled in qualified health plans • Slight increase in clients unsuccessful in getting insurance (12 people) • Even harder than usual to get responses from clients • At least 7 outreach attempts per client via email, voicemail, and letters

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	• Fewer issues with proving residency this year • High percentage of people auto-enrolled (can do that in off-exchange programs) Julia Lager-Mesulam (Partnership Project) • Enrolled 288 (increase from 257) • Increase of clients completing enrollments themselves (sometimes needs help from staff, but taking ownership) – 49 clients (increase from 31) • More Medicare enrollments (don't have to be certified application assister to do these, so encouraging all staff) • Experienced not getting call backs – people getting multiple calls from CAREAssist, case mgrs, insurance companies • Successful, but we're going to do some things differently next year • Q: How do you reach clients in outer counties? A: Texting people, go to them, offering transportation & gas cards, offering starter Thanksgiving meals Matthew Moore (Clark County) • Smaller population • Many people automatically re-enrolled • 23 people either were new ACA, switched plans, new Medicare, switched Medicare, or individual plan enrollments • Significant change – WA state health insurance pool started to close; this is one of few options for those without SSN, but there was another good option available that does not require SSN • Pretty smooth, just a matter of making sure that bills go to EIP (Clark County version of CAREAssist) Emily Borke (Health Services Center) • 328 clients enrolled • 147 off exchange • 133 through ACA qualified health plans • All MCMS and 1 eligibility spec are certified app assisters, so all enrolling people • Average of 5 outreach attempts per person • No hold times on marketplace assister lines • Went more smoothly, possibly due to fewer plan changes, more auto-enrollments	
Time of Adjournment	7:25 PM	
Community Garden Items	QUESTION/COMMENT	RESPONSE
	-Clarify "Lost to follow-up" vs. Lost in care" *Lost to follow-up* • Systematic • Care team has responsibility with consumer	*Lost to Follow-Up* – generally used to describe clients that they have not been able to reach or contact after multiple outreach attempts *Lost to Care/Not in Care* - describes clients that have not been to a

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	Lost in care • Individual • Circumstantial to individual untold story	medical provider (or had a CD4/VL test) in a set time period (e.g., 9 months, 12 months); may be active clients at a non-medical agency
	How many clients had one viral load lab?	It's difficult to truly know if each VL test we have is truly unique or not, and we are likely undercounting. That said, we estimate at least 591 (~29%) clients had 1 VL lab in the cohort time period.
	Survey – clarity on P.O.C. HIV consumers to capture data	Unsure how to respond
	Consumption trends amongst cohort/cultural etc. consideration Client Sat Survey	Unsure how to respond
	Consider phone scheduling and incentive for hard to reach and younger cohort Client Sat Survey	Will add these to our notes for our next survey.

ATTENDANCE

Members	Present	Absent*	Members	Present	Absent*
Emily Borke (Council Co-Chair)	X		Julia Lager-Mesulam	X	
Erin Butler	X		Heather Leffler	X	
Tom Cherry	X		Jonathan Livingston	X	
Jamie Christianson	X		Jeremiah Megowan	X	
Carlos Dory	X		Matthew Moore	X	
Michelle Foley		E	Scott Moore		E
Greg Fowler	X		Laura Paz-Whitmore	X	
Alison Frye	X		Diane Quiring		E
Dennis Grace-Montero	X		Jace Richard	X	
Myranda Harris	X		Michael Stewart	X	
Shaun Irelan	X		Michael Thurman-Noche	X	
Lorne James (Council Co-Chair)	X		Robert Thurman-Noche	X	
Chris Keating	X		Erin Waid	X	
Toni Kempner	X		Abrianna Williams	X	
PC Support Staff			**Guests**		
Lisa Alfano			Brandi Velasquez (PWN – State Lead)	X	
Aubrey Daquiz	X		Sherryl Lamm (PWN – Policy Fellow)	X	
Jenny Hampton (Recorder)	X		Frank Mollel (MAI Medical Case Manager)	X	
Jesse Herbach	X		David Ochan (MAI Navigator)	X	
Amanda Hurley	X		Sandra Poon (Clinical Pharmacist)	X	
Jenna Kıvanç					
Marisa McLaughlin	X				
Kim Toevs					

* A = Unexcused Absence; E = Excused Absence; L = On Leave