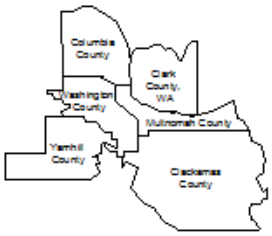
Portland Area HIV Services Planning Council

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

Ryan White Program, Part A



Meeting Minutes

Meeting Date: March 4, 2020

Approved by Planning Council: May 5, 2020

Grantee: Multnomah County Health Department

Multnomah County

Approved by Co-chairs: 4/28/2020

Portland Area HIV Services Planning Council
MEETING MINUTES

Tuesday, March 4, 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	Lorne James led the lighting of the ceremonial remembrance candle.
Mindful Minute	Emily Borke led the Mindful Minute.
Welcome & Introductions	Emily Borke welcomed everyone to the meeting and introductions were made, with Council members declaring any conflicts of interest. Welcomed Sandra Poon (Clinical HIV Pharmacist) to her first PC meeting!
Announcements & Review Graphic Cycle / Year	Announcements: • March 31st Trans Day of Visibility • March 26th City of Portland is holding an event, panel being put together- 9 people testifying to the city council; Quest holding community event after, a flyer will be provided by Quest • March 11th Meaningful Care Conference • National Trans Testing Day is Saturday, April 18th, 1:30-8:30, at Portland Community College's NE Cascade Campus o Events include wellness activities, drag, testing, storytime • HGAP held Focus groups to close out Client Satisfaction Survey o 5 different groups o HGAP will report back to the PC when information is analyzed o Up to about 25 people o One last one happening • Research project through University of Oregon documenting the demographic composition of advisory boards across the state o Email will be sent out with request for info, aggregate numbers will be sent back to them o Purpose is to ensure that programs are engaging foreign born populations • Reminder: Planning Council meetings are recorded for notetaking purposes
Agenda Review and Minutes Approval	The agenda was accepted by unanimous consent.

Approved by Co-chairs: 4/28/2020

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	The meeting minutes from the January 2020 meeting were approved by unanimous consent.
Meeting Logistics	Check-in from Co-chairs/Operations Committee • Concern has been expressed that there is not enough time for all topics- this has been specifically adjusted for this meeting and will keep this in mind going forward • Meeting the needs of the council includes: balancing agenda time, data presentations, many different needs of different people. Feedback welcomed! • Community garden is new. This is a way to provide feedback and questions that can't get addressed during the meeting. It's not intended to be a replacement for Q&A, but an additional way to provide info. If possible, leave your name for follow up if needed. • Request: Handouts for yearly cycles at next meeting? Quick poll about desire to have paper printed docs- slides specifically. • About 25% say yes please print slides • Comment: printing not needed, as long as things are emailed beforehand
Public Testimony	Joyce Holland: I've been positive since March 17 2008, and part of the community off and on since then. I engage in WOW, clean and sober treatment centers, have been getting care at the clinic and case management, make use of the Day Center, engage in long term survivors group. I've been engaged in Positive Steps which has helped me follow through with small goals that I've had in the past and haven't followed through with. I've learned I can make them smaller so I can eventually follow through with them. I met a family being positive, even when using drugs and alcohol, people still tried to help me, including other clients I've met. People have still been there for me even when I disappeared for an amount of time. I was in another state for about a year and they didn't have the services, or acknowledge I was HIV positive. I wasn't tested for lab work. This was in the south so people weren't aware of the HIV thing, I wasn't taken care of when I was there. I want to recognize there is a lot of stigma around HIV, including doctors, DHS. I want to acknowledge that it's women too, not just a gay thing. Lots of women out there who are HIV positive and we need just as much services as any other person does.
FY 19-20 Preliminary Expenditures Report	*Presenter: Jesse Herbach* *Summary of Discussion:* See slideshow. Questions / Comments: • Q: Do we see that all these categories will be spent out? A: Yes, programs have plans to spend out. Waiting to get all February invoices and half of January.

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	• Q: What is the value of this since it is just preliminary? Suggested notes be added if there are areas of concern. A: PC will get a final close out report. PC requested more expenditure reports throughout the year. • Q: How is this in line with past years? A: Will need to review and get back to the PC. • Q: What is the carryover process for program income for Part B? A: We see what is left over, then based on all the various things we take into consideration for Part A, Amanda makes a proposal for the carryover to Heather at Oregon Health Authority. • Q: Why does Part B have program income? A: It has to do with insurance rebates from the ADAP program.
Long Term Survivor (LTS) Panel	*Panel: Jim Clay (Aging Well, CAP), Chris Eves (Empowered to Thrive, EMO), Christian Messer (Quest Men's Group), Glenn Larson (longest-term survivor)* *Summary of Discussion:* See slideshow. Short description of program you're representing: • Christian - HIV Men's Group, meet for 2 hrs every Friday (?) • Chris - EMO Empowered to Thrive Workshop series, 4 per year, held in winter months to try to bring people out, held in variety of locations, usually food is part of it. Shyelle Rutter has been facilitator. Originally were partnering with Let's Kick ASS PDX to do outreach and recruit participants; this year partnered with Jim Clay and Craig at Aging Well program at CAP. • Jim and Glen – Aging Well (a program of Cascade AIDS Project) supports the well-being of aging adults living with or affected by HIV. We do this by encouraging health and wellness, hosting social activities and events, creating opportunities to give visibility and a voice, engaging in activism and advocacy, and community service. Key needs and gaps of Long-Term Survivors (LTS): • Christian - support amongst each other. Groups like the one I'm a part of at Quest were not available 5 years ago. Community is everything - it fights depression, does all sorts of good. With support of group members, the past two years have been incredible, I couldn't be here without them. More support groups along that line • Chris - hard for me to speak on behalf of LTS. From what I've witnessed at Day Center, there's been a lot of discussion around ways that people can get involved in larger community. People will talk a lot about their experience / how things have changed over the years. Storytelling, meaningful connection - more venues to educate around current needs and how those relate to the history. Sometimes there is a generational divide between those who did and did not go through the 80s. We know of many

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	people who choose to self-isolate. Many know of peers who aren't doing so well, how can we draw them into the fold? Doing home visits for those who can't leave home or other reasons. I've been thinking about how we can engage that population and meet their needs. • Jim - I was commissioned to speak to 100+ LTS. Today I'm relaying what I heard. Need improved availability, accessibility. Need assistance navigating workforce development without risking benefits. Need psychosocial support. Important to recognize that loneliness is different from isolation. • Glenn - groups that Jim and I founded, started with 2, a month ago was 35+. I have a question to ask you: is there any funding for the aging PLWH? o Emily - from my knowledge (part A funding), Empowered to Thrive, mental health, medical care, several other service categories. There is a stipulation for all contractors regarding serving long term survivors. That's why you're here, to provide input. How have you see service needs for LTS evolve in the past five years? • Christian - other than the HIV men's support groups, there's also the peer supports. Without my peer support for 2017 and 2018, I would not have survived my heart attack, cancer, chemo, radiation. As far as evolved, my HIV hasn't been an issue, so medically hasn't been a thing for me. • Chris - I feel like I answered that a bit in last question. I can speak to evolution of Empowered To Thrive workshops. This past round there was an attempt to restructure / solidify some of the changes to that program. Wanted more consistency - same time, same place, trying to vet those locations / times with people interested in attending. We knew that the content was going to be engaging / worthwhile. Also moved towards more of a panel discussion model. A lot of those needs came from discussions Glenn was having out in community. Topics - volunteerism, connection (technology, dating, social networks, in person places), healthy coping habits (incorporating SUD recovery topics, but making very universal) • Jim - Note: Perhaps this group here is talking about a subset of LTS, those who are RW eligible. Important to understand that there is a larger group of people who are not eligible. Response: The demand for service is expanding really fast. Not well recognized. "Who are LTS? I thought everybody died." Huge misconception, huge opportunity. We can talk about programs available. There are services / supports unique to LTS that this group needs to understand. Not very much is available for this aging population. • Christian - LTS is not a clinical definition, it is a sociological definition. We can point to five different definitions, we may not be talking about the same thing. Historically, started with "long

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	term non-progressers" who did not move from HIV to AIDS. Now we have a variety of understandings of LTS. One very important one is "longest term survivors" - people who lived through the trauma of the 80s, lived through trials of early medications. Not minimizing experiences of LTS, but longest term survivors are unique. Consensus is that self-identification is most important factor. • Comment: some people experience LTS label as excluding. People who were diagnosed 4 years ago are as deserving of attention as "LTS." At what point do people get to earn the mantle of LTS? What other health considerations or factors related to health do providers need to address? • Chris - complications from earlier medications, unresolved trauma that are triggered by current situation and how they are related to experiences earlier in diagnosis • Christian - stigma is a huge problem, U=U getting the word out about that and having a bigger outreach (I'm volunteering now) • Chris - housing, this is how trauma is manifested as how they are treated on the street • PC Comment: In long term care, when you've been taking medication for 15 years, impact of meds on systems can be very severe; need more information on impact of early meds • Jim - in last 6 months or so has been research on impact of early meds; also issue of polypharmacy (taking meds for both HIV and other conditions). Many people are not finding support - very important to understand. There are many people who have no long term survivor community. The Surgeon General has said that loneliness can be just as lethal as smoking 15+ cigarettes per day. • Glenn - I've only been involved in last 3.5 years. Had partner / husband for 46 years. I know what it was to be lonely and experience loss. My social worker came and kicked my butt out of my apartment and said "you're going to Kick ASS." I went and found a new family. I now volunteer. Is there one thing you would want the council to know? • Jim - Per Oregon Health Authority, 5682 people who could be considered LTS lived in Oregon in 2016, so probably 6000 LTS living in Oregon today. Aging Well program has aggressively to reach these people, but have reached very few. We have reached 182 of 6000. Likely those not being reached are those with highest acuity and most need. In many cases, they are the oldest. In many cases, they don't have access or knowledge of texting, email, internet. They need not just texting, social media, web, but also postal mail. Are we willing to do basic outreach? I would argue that we need to do that extra work. How are we going to do that? Questions / Comments:

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	• Q: How do you see a way to move forward with dichotomy of LTSs?
	• Q: Did you really define any unmet needs that we can fund?
	  o Jim - Five core needs:
	  ▪ Strengthen mental health services (by far the highest priority) - accessibility, availability, variety
	  ▪ Providing legal & financial advising
	  ▪ Returning to work without jeopardizing benefits
	  ▪ Assuring age-appropriate transportation
	  ▪ Building community & developing psychosocial supports
	  o Christian - mental health is number one, because if you don't take care of your mental health, you don't adhere to your drug regimen. Art therapy offered here - need for that to be offered in the evening.
	• Comment from Scott Moore: It sounds like Aging Well is sitting on a wealth of information on non-RW-eligible LTS. I'm curious about what CAP is deciding to do with that information. Are you working with other programs? I think there are resources out there who would be willing to work with Aging Well, even beyond RW. Seems to be a lack of getting that information out. We should have a meeting; I (Scott Moore) would be happy to put together a group. I think peer support specialists could help, as well as psychosocial, using Ryan White funds. Then using other funding (insurance, etc) for other things like groups & workshops.
	• Q: As we gather and coalesce the Aging Well community, is there an ambassador, someone to direct people to your program? A: Our program principle is this is largely community / peer driven. Is there a professional that could be a part of this? Absolutely, but that has not been the focus of our attention.
	• LTS experience advanced aging and develop conditions often decades before the general population.
	  o Inflammation from medications
	  o Per Dr. Karpiak at Gay Men's Health Crisis in New York, there are two issues in accelerated aging
	  ▪ Perception of aging at a faster rate (accelerated)
	  ▪ Accentuated aging - extremes of aging process are higher and lower (balance, neuropathy)

End HIV Oregon Updates	*Presenter: Linda Drach (Oregon Health Authority)* *Summary of Discussion:* See slideshow Questions • Q: In Testing Is Easy, what does GC stand for? A: Integrated testing for 4 STDs at the same time - HIV, syphilis, gonorrhea, chlamydia. GC = gonorrhea. Now patients at public health departments can get a rectal GC swab and get it paid for through state laboratory, which had been a problem previously.

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	• Q: Is genetic analysis (for spotting clusters) done with dried blood spot? No, they can't do it with a dried blood spot. They can do the genetic analysis when they do the confirmation test, which is a blood draw. • Q: Is there any discussion at state level that Oregon will follow California's lead in providing PrEP to everyone who wants it? A: Yes, but it's a little difficult, because most of our money is for services, not prevention. We've worked with Medicaid to cover PReP (they cover it entirely). It has to be a systems approach. • Q: Do we know how many want to take PrEP? A: No, and that's an important question. CAP has a navigation program, and for first 6 months of last year, they got 100 new people on PrEP. The demand is there. • Q: Has there ever been any discussion about using doxycycline as PrEP against other STDs? There's been some research about it. A: No, not discussion that I know of. • Q: Are the grants mostly in the Portland metro area, or all around the state? A: It's designed to be statewide, but most have been in the Portland metro area. Please encourage others to apply – it's a very simple application for small projects. • Q: Earlier you mentioned working with tribes. Which ones? A: NW Area Indian Health Board is the hub for working with tribes. With EISO we are funding harm reduction worker for Siletz tribes. Warm Springs also works with their local public health group. • Q: How did those local partnerships start? What are your future plans for honoring the sovereignty of those nations? What about sovereign data (how are referrals going to be made to resources outside the tribe)? A: o Our relationship with Siletz was through Lincoln County Public Health. The tribe initiated - they were interested in going this work, and we said great, we'll fund it. o Talked with NW Area Indian Health Board. We have funds that we could share where you see gaps. We're still working on how that should work. o Idea of putting out RFP for this work, for which only tribes can apply	
Portland TGA Program Upddate with Part B Funding	*Presenter: Jesse Herbach & Amanda Hurley* *Summary of Discussion:* See slideshow. Questions • Re Jenna's change, will you provide that new info to us? Yes, we'll be presenting some of that information to you.	
Time of Adjournment	7:25 PM	
Community Garden Items	QUESTION/COMMENT	RESPONSE
	Please consider using all 3 screens next time.	Will test this out for our next in-person meeting.

Approved by Co-chairs: 4/28/2020

ATTENDANCE

Members	Present	Absent*	Members	Present	Absent*
Emily Borke (Council Co-Chair)	X		Julia Lager-Mesulam	X	
Erin Butler		E	Heather Leffler		E
Tom Cherry	X		Jonathan Livingston	X	
Jamie Christianson	X		Jeremiah Megowan	X	
Carlos Dory	X		Matthew Moore	X	
Michelle Foley	X		Scott Moore	X	
Greg Fowler	X		Laura Paz-Whitmore		E
Alison Frye	X		Diane Quiring		E
Dennis Grace-Montero	X		Jace Richard	X	
Myranda Harris		L	Michael Thurman-Noche	X	
Shaun Irelan	X		Robert Thurman-Noche	X	
Lorne James (Council Co-Chair)	X		Erin Waid	X	
Chris Keating	X		Abrianna Williams		E
Toni Kempner	X		Sandra Poon	X	
PC Support Staff			**Guests**		
Lisa Alfano			Robert Kenneth	X	
Aubrey Daquiz	X		Joyce Holland	X	
Jenny Hampton (Recorder)	X		Erin Parrish	X	
Jesse Herbach	X		Jim Clay	X	
Amanda Hurley	X		Glenn Larsen	X	
Jenna Kıvanç			Chris Ives	X	
Marisa McLaughlin			Christian Messer	X	
Kim Toevs			Linda Drach (OHA)	X	

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

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