

HIV Housing Care Continuum Webinar 3 August 3, 2016

Rusty Bennett: Welcome to the HIV Housing Care Continuum Planning Webinar Series. This is webinar three, creating your own housing care continuum and how you would use it. My name is Rusty Bennett. I'm with Collaborative Solutions and I'm joined with Amy Palilonis, Office of HIV/AIDS Housing.

Amy Palilonis: Hi, everybody.

Rusty Bennett: Thank you for being with us. This is the third webinar in a series of webinars about building an HIV housing care continuum. And so, in this, we've already over the past two webinars talked about the importance of the HIV care continuum overall, its connection to the White House initiatives, talked about the intersect with housing and housing as a structural intervention, gave you an example of a community, New York City and how they built their own HIV housing care continuum.

And now, today, this webinar is all about building it yourself. And so, we want to spend some time, go into some of the major decision points that we found that communities went through during the regional meetings where they really wrestled with specific decision points to help them build their HIV housing care continuum.

And so, what we're going to do throughout this webinar is actually go through some of those discussion questions with you that are found in your workbook and so, those will begin on page 17 of your workbook. And so, we'd encourage you to go ahead as your team and pull that information out. Some key points about the webinar today that if you want to stop and pause and have that discussion, feel free, if you want to just keep on moving through until the end and have one final discussion, please feel free to do that.

The main point I would encourage you to do is to create the space, make sure that you are having team discussions, so bringing your whole team together, your HOPWA grantee, Ryan White, surveillance data people, whoever you need to really have that full team discussion and we have found that that has been the most useful – is to have everybody together. And so, we can't emphasize that enough.

So, to begin the conversation, we're going to be really looking at some – as I said, some major decision points. And so, this first one is really about the level on which you're going to create your HIV housing care continuum, so, to have that conversation, Amy is going to lead us through some of those questions.

Amy Palilonis: Thanks, Rusty.

Rusty Bennett: Sure.

Amy Palilonis: So, the first decision point that you will really need to make when you're creating your HIV housing care continuum is whether you are going to create the continuum on an agency level or a community level.

With a community level model, you will use surveillance data to provide comparison of all of the people living with HIV/AIDS in your community to those that are receiving HOPWA funded services in the community. If you're a HOPWA grantee and can get data from all of your project sponsors, this might be your option.

With an agency level model, you'll use agency data that can provide a comparison of all of your agency's clients that are HIV positive to those clients that are receiving HOPWA-funded services in your agency. Please see page 17 in your implementation workbook for more information regarding this decision. And now, you should take the time to discuss this with your team.

Is a community agency or combined approach the best? If you would like, you should pause the webinar right now, so you can start, you know, having

those conversations with your team. If not, you can just keep going through this webinar and make sure that you have that conversation at a later time.

From our regional meetings, this decision point really helps each of the teams to conceptualize and define their strategy for building their continuums. And much of this decision is based on your access to and the availability of the data, and making this decision will help you as you go through your next – the next discussions and decision points. And our next step is actually thinking through your access and the availability of the data sources that are necessary to create an HIV housing care continuum in your community.

So, the worksheet that's on this slide is featured on page 18 of the workbook, and what it does is it really maps out the possible paths that you can take in developing your HIV housing care continuum. So, after you decide whether your HIV housing care continuum will be at the community or the agency level, you're going to need to decide where you're going to get the data and how you're going to build your model. Again, this worksheet is on page 18.

And as a team, you should walk through each row to decide where your community sits from the options that are presented on the worksheet. And as you determine the path that you'll take, you need to think about who you will need to partner with to build your model. Will it be the local surveillance department or will it be local Ryan White providers, or will you need to partner with, you know, both of those options in order to create your continuum?

And what we learned from the communities that participated in the regional meetings is that you might not, you know, end up fitting into just one of these paths. Your path might end up having elements of a couple of different paths. The key difference with what path you take is really, you know, your access to data across the multiple systems in your community.

And so, now, we're going to turn things over to Rusty and he's going to walk us through a community example to really illustrate, you know, how you would decide which path that you should take in order to create your continuum.

Rusty Bennett: That's great. Thank you, Amy. I can't overemphasize it. You're exactly right. You know, some of the decisions that we saw many of the communities making really had to be decided basically on the access to data. And so, those relationships they had established in what they have access to and availability of that.

So, if you want to follow along, this is, I think, a good example that you can kind of walk through together with your team on page 19 and it kind of is the worksheet that Amy was just talking about. So, actually, as I'm walking through, you may go ahead and circle and kind of identify the access points that you have related to the information.

So, the community example is basically a community that's completing the chart and basically, in this case, we have a HOPWA grantee that has three project sponsors and they're all funded through HOPWA and Ryan White. And the grantee utilizes CAREWare for all the HOPWA project sponsors in which each project sponsor reports client level information. They might even work with your local surveillance department to get the HIV surveillance data and they're going to import that information into their CAREWare, partly to do the match that we're looking for. And they're going to request this information from the health department to make sure they can do this.

And then, the HOPWA grantee will actually do the data analysis and do the deduplication necessary to be able to build out the HIV housing care continuum. So, in this scenario, let's just walk through which path this community may choose to help them make some of the choices and hopefully this will help you as you're making your own choices. So, just looking across in the chart, we have six columns, I guess, the first one being the option, the data option available. And then, there's A through E columns that tell us each kind of decision point if you will.

And so, as we go through this, kind of identify for your own community where you might fall and then just circle that one and that kind of creates your path. So, you'll have a bunch of circles that kind of guide you.

So, the first one is the HOPWA data source. In this case, does a HOPWA grantee have a database? The grantee have a database that has the client level information in it provided by the project sponsors. And in this case, we're going to say yes. And so, you'll notice looking across the road for HOPWA data source, that kind of flows through the first four options, with the fifth option saying from Column B that the data actually sits with the project sponsors and not the grantee.

So, part of that question right now, you have to answer is where does the data sit. Who has the HOPWA data and who has access to it? Is it client level? That's the next one. Is it client level information or not? In this case, they have access to client level information. So, they kind of fall in column B, possibly column A. So, we're trying to work through the different choices to come to the right path.

HIV surveillance data accessible to the grantee. Does the grantee have it? The difference between column A and column B, column A assumes that there's direct access to line level information. In this case, this should be like the example that we provided in the earlier webinar around the city of New York where the health department actually had access both to the HOPWA data and the surveillance data in the same department. So, that's direct access.

In this scenario, we had to have the HOPWA grantee requesting surveillance data from a third party that then is getting provided over to the grantee. So, we're going to choose indirect access. So, it really requires a data access or a data request to make that connection. The process from linking program data with surveillance is an internal matching or a data request from HIV surveillance.

I think we've answered that one. It's going to be a request that's going to come in that the grantee's making and then will import that into their CAREWare to create the matching necessary. Clinical data source, so, who has the clinical data source? So, this would be access to care, questions that may constitute that definition. We're going to talk a little bit about how to define this a little bit later. It could also mean your health outcome so viral load.

Where does that information sit? In this case, we're looking at it from surveillance. And so, in this scenario, we're going to select again column B. It could have been column A, but definitely in column B since we're going down that path. And then, who's going to prepare the HIV care continuum? In this case, it's going to be the HOPWA grantee.

And so, we end up finding that it's kind of a joint effort between surveillance and grantee, but the grantee is doing it. So, we ended up with column B. You may not be a straight path like our example is here. You may be as Amy said a little bit between A and B or maybe B and C, but just be honest and try to have that conversation as your team to decide where along this path are you as you're trying to find the direction you're going to go and what partners are going to need to be at the table.

So, this really is the next series of questions, and if you want to follow along with us from page 20 of your workbook, that really are the discussion questions now that we're going to ask you to answer. The first one being what path are you going to choose? And the reason why we're doing that is because it really prompts to the two follow up questions, one being who needs to be involved based on that decision.

So, who needs to be involved in the conversations in order to create the connections necessary to have the data points and to pull the information together. And then, how do you plan to get these individuals involved and invested in building the HIV care continuum? And I really would encourage you to think through the partners that are at the table and how to keep everybody engaged in the process, but also consider people outside that may not be that you want to encourage to be a part of the process as you develop this for your community.

I think you could use this information from the workbook, tools and resources available on the HUD Exchange that talk about the importance of building an HIV housing care continuum, the importance of housing as a structural intervention, the important connections between housing and health, and group health connections – all of that could be resources that could help bring

people to the table I think around this topic, and I think we found that in the regional meetings, that helped. And I think they got excited when they were building their teams. I hope you're getting excited with your team about the possibility of really demonstrating to the community the effectiveness of your programs and really creating a baseline for that.

So, these three discussion questions are found on page 20 of your workbook. If you want pause now and have those conversations, certainly do so. If not, we're going to continue and I would encourage you to have those discussions as your whole team.

So, the next set of questions really was an effort, I think, to kind of hone in on what you're defining as your housing program specifically as you develop your HIV housing care continuum. So, in the city of New York what they've used as their population was really anybody touched by a HOPWA dollar. So, they built their HIV housing care continuum based on that model. So, anybody that was either touched by services, whatever the activity was, they were included in that.

You may want to do the same thing. So, that certainly is a great way to do it. You may want to dig a little bit deeper or look specifically at a housing type. So, for example, on page 21, what we ask you here is, first, what are you funding with your HOPWA program, there's an array of housing activities that could be funded through HOPWA. And so, the question is which one are you going to focus on and are you going to focus all of those or are you going to include or not include certain ones.

So, for example, permanent housing placement, facility based housing, tenant based rental assistance, or short term rent or utility are all eligible activities that you want to include individuals in those housing program types into your HIV housing care continuum. You may, you may not, depending on what you're trying to demonstrate.

So, part of what we want you to think about now is what are the activities that you're funding and what truly represents the HIV care continuum that you want to represent to your community? One thing you may want to also think

about, do you want to include, if you have access to it, other available HIV/AIDS housing dedicated units in your community that may not be HOPWA funded, but are certainly people living with HIV, especially if you know those housing programs and you know the individuals and the client level information on them as well as the health care information. So, that's another thing you just need to consider for your own communities what that's going to represent in that – and what that population kind of looks like.

So, before we move into the next section which is really definitions and how you're going to measure some of the key elements along the HIV care continuum cascade, this is another opportunity for you to stop, think about your own program and really define what you're thinking for your own community in developing this. Related to this is really piggybacking on Amy the conversation you've just had which was is this going to be a communitywide or is it going to be agency.

And one thing we did find is that some – where communities felt like they couldn't access surveillance data or that was just too big, and they didn't think they have the political will within their community, many of them have actually decided to do an agency one. And in some cases, they focus – as we're asking you to think about here, they focused on a particular HOPWA activity because they felt like that was manageable enough that they could pilot this, build a tool that they could then demonstrate and then use that to bring others to the table to actually have a broader conversation.

So, I would like you to think about though it'd be great for everybody to build this larger model like New York City, they may not have the resources and the political will to get that done. And so, thinking about different ways you want to do it like on the agency level or activity level that could demonstrate and use that to help build some momentum in your community.

So, those are some of the conversations we'd love for you to have as a team and really find out where you are, have that conversation and then move into these indicators that we're going to talk about next. So, certainly, pause now or we're going to move on and – but make sure you have the conversation.

So, page 21 in your workbook begins in the next section which is really about the indicators and measures. So, if you remember the HIV care continuum cascade in each step along the process, you have to have a definition. You have to have a way to measure that. And part of this conversation now is to help you to see how other communities have measured it and get, prompt you to have that question based on the information you have available and the data sources, so that you can create that own measure for your self and the work of your community.

So, if you will, take a look at your worksheet and follow along with this section. I think you'll make them a little bit easier. Under "indicator and measures", we've given you two definitions. One is a definition provided by the CDC in how they developed the care continuum or the care cascade. And the second one is what New York City used in their definition.

The definitions as you can see are following each step along the care cascade. So, diagnosed – those diagnosed with HIV infections, it's also linked to care, engaged in care, in care, retained in care, and then, ultimately, viral suppression. What we'd like you to do is actually walk through these definitions and make a decision what steps along the care continuum are you going to measure. What we would recommend, you may not need or may not have access to all of the care and, you know, the engaged in care, linked in care ones – indicators, depending on your data sources.

So, for example, you may not care about linked to care or maybe you do. So, you might want to do that. Engaged in care versus retention in care, those are just the nuances that you might want to have as a community and have that conversation. What I would encourage you to do is probably to have that retention in care, because it's a great measure of people remaining engaged in care and I think that's a big part of housing – is to make sure people stay engaged. And one thing we know that research really points to is that housing certainly supports that ongoing engagement to care.

The second piece, obviously, we want to focus on is viral suppression and really showing that individuals that are receiving housing assistance or that are housed and stable actually have regular levels of viral suppression versus

those who do not or are experiencing housing crisis. So, I think that's what we're trying to show.

Certainly, work overall in the care continuum as much as you can based on the available resources that you have and the data that you have available. But, if you had to make a choice, make that retention and care and I think that viral suppression certainly are the critical ones that you're trying to demonstrate as you look at your own community.

I'm not going to go through each of the definitions, but you can see that, like I said, the CDC definition and also the New York definitions and I would encourage you to walk through those as your team, and what you're asking yourself is "Do we have access in this information". This is really where you need your data people. You really need to have somebody that understands the data points and the data that's being collected either through your CAREWare, HMIS, your surveillance, so, somebody that can really help you figure out how these definitions are going to be made. I think that would be the most helpful.

Now, we have provided some resources through that are available on HUD Exchange to help you think about these definitions and also pull out some of the information from like the HOPWA APR that could be some ways to get started on engagement and care, retained in care and also viral load. One thing we'll add in, HUD has been adding in new data elements, actually it's the HMIS standards around viral loads. And so, that will be implemented into HMIS and to create an easier way to collect this information for HOPWA grantees.

So, this is a conversation we're hoping we can have and think through, one, your data sources, how you're going to define it and really working as a team of how you want to structure that care continuum based on these definitions, based on the community level, the agency level, and based on the data sources that you have available to you, and again, a good time to stop, pause, have that conversation.

And now, we're going to move to our next major points around data sources. So, if you're following in the workbook, we're now going to be moving to page 25 of the workbook. And on page 25, this is really your opportunity to take what you did in your path and now move it over to say what do you have access to, so, what data sources do you have access to. Is that a grantee database? Is it client level information? Do you have access to surveillance data?

If you don't have access, the next question is do you need it and how do you get it? And so, this really becomes an important part of the collaboration and the partnerships that are going to be necessary to really build this story, if you will, about housing and its effectiveness within your own community. And so, one of the things we'll encourage you to do is to think about how do you get that access.

And if you don't have the right players at the table, I'd really encourage you to make this as part of your action plan and identify this as one of your action steps is, who needs to be at the table, who's going to be responsible for contacting that person, who's going to be responsible explaining what you're trying to accomplish and getting them to participate within the work that you're doing.

And so, throughout this process, I think we've said over and over to every conversation, to every discussion and every time you're answering some of the questions that we're asking you, identify those key actions steps and put those on your action plan template provided in the appendix and keep track of those, and really use that I think to help guide you because really what we would like you to do is to walk through – walk out of this process with a clear action plan that gets you to the development of an HIV housing care continuum.

Now, we recognize it may not happen over night. It may be a process of getting people together and really thinking through the data points, but I hope it's something that you can embrace as a community and really work through. We're going to talk a little bit about why we think it's so important as you go through this. So, these are some of the data conversations that we want you to

have, really want you to think through how to use that care continuum and to build it.

I want to spend a little bit of time because I think that the regional meetings really created a forum that we learned a lot. As we said in the earlier webinars, we had four regional meetings. We brought together almost 200 grantees, if not more of folks that were in the room. Many of them brought together teams of folks that we are encouraging you to have that represented HOPWA, Ryan White, HIV surveillance, really bringing them together sometimes for the first time.

And so, I think part of what – some things that I heard and when they're working in the community that, one, I think that creation of space to work together, breaking down those silos became so critical. Oftentimes, we don't have that time in our busy schedules to create that kind of space and I think they were very – it was – they found it very helpful.

This is going to be a challenge for you when you're watching the WebEx because you're trying to create that space yourselves in your own communities which I think you can do it. But, I think it becomes really important. Also, I think through this, they recognized they had to really think about the relationships that they would need to build related to this.

Also, I think that it was something about showing progress and really creating, but they really wrestled that this wasn't going to be a one-time event. Did you hear that? What did you walk away related to that?

Amy Palilonis: Yes. We really tried to drive home the point and I think it was really helpful to the participants at the regional meetings to just really hear that, you know – creating a HIV housing care continuum isn't a one-time thing. It's not a one-time effort.

It's really an ongoing process that the grantees can use to assess and monitor the outcomes of the HOPWA program beneficiaries and then really, you know, focus on any of the gaps that I identified in their HIV housing care continuum and, you know, really changing or improving service delivery in

order to really make changes that improve, you know, the proportion of the HOPWA clients at each step of HIV housing care continuum.

Rusty Bennett: Absolutely. I think in some ways, what makes some of the communities felt it was daunting when they thought, we have to do this over again?

Amy Palilonis: Right.

Rusty Bennett: But, I think that's the key, right, is that this is a – the HIV housing care continuum isn't a one time shot, right? You're getting a baseline of where you are as a community and if you really want to see your progress, it has to be repeated again.

And so, to really think about the work that you're doing does need to be repeated, so you have a baseline and then a comparison point. And certainly, it's also letting it be the conversation starter for your community, to galvanize your community. One, I think it could be a great way to demonstrate the effectiveness of housing, but you may also find that those gaps in there which we expect most times there are going to be some gaps and you begin to dig deeper into those gaps and, well, what's happening. And I think it does help to galvanize your community to really address that in a better way.

And certainly, one of the things I was really surprised too, Amy, about how often some of the teams said this is the first time that they talked about data integration or the first time they've really connected housing and health where they really have all these partners at the table focused on one effort. I was really taken back by that, excitedly so, and certainly, I think it's a HUD priority and something that HUD is interested in of breaking down those silos and really connecting housing and health and building those partnerships. I think that's certainly something that we see across the board in a lot of the federal planning and the work that's going on right now.

I think one of the other things I walk away with from the regional meetings is creating an opportunity for peers to come together, talk about the barriers, but also to learn from one another. Can you talk a little bit about our efforts and HUD's desire to kind of keep that moving around the peer model?

Amy Palilonis: Sure. As Rusty said, the participants at the regional meetings, you know, were really able to learn from each other and their peers and were really trying to, you know, allow a stage and an opportunity for other communities that weren't able to participate in the regional meetings to sort of, you know, be able to have that peer learning.

And, you know, many of the communities that participated under regional meetings are well underway creating the HIV housing care continuums or they've already completed them. And we know that, you know, they're willing to share the steps that they took and any pitfalls that, you know, they came up against with trying to create these models.

And so, that's why we're making some TA resources available on the HUD Exchange and we're also creating this peer online portal where communities can really share their progress and share their action plans and share, you know, where they are in the process of creating and implementing these HIV housing care continuums.

Rusty Bennett: It's awesome. And I think so often, I think it's that connecting to peers and people that are dealing with the exact same situations kind of works wonders in a way to really break down those barriers and create some solutions. So, thank you for that, Amy.

Let's talk a little bit about the next steps, kind of what we envision happening. And now, that you've kind of gone through the three webinars, you're working to the workbook. You have your team. You're all jazzed and ready to go. Let's talk about where we hope you end up and what you're hopefully able to accomplish.

First of all, we really strongly encourage you to go through all of the session questions. So, if you haven't been pausing and discussing but now have come through this, please spend some time and create that space. That space has been so critically important to really thinking through the strategies that we need to develop and take the time to write down the specific action steps that you're going to take as a team to get this project accomplished.

I think that that level of direction I think does really help many of the teams stay focused on the development of the HIV housing care continuum. And so, I really encourage you to finish the plan and implement it obviously and get to the – and certainly move towards the development of your HIV housing care continuum. I would also encourage you to share your progress, be a part of the learning portal, take advantage of the opportunity to become a part of that learning community.

Put your action plan on there, see what others have done, put your HIV housing care continuums on there once you get those developed, draw out ideas or barriers that you're facing. I think other communities would join in and help you to do – to address those. So, I hope you'll make that as a priority.

Again, just some resources that we want to make sure you're aware of, certainly, the peer portal that you can find the link on the HUD Exchange, again, it's going to have an opportunity to work with your peers and to put resources on there. There's HUD Exchange, all the HOPWA resources that are available, other work that's been going on, certainly the National AIDS Housing Coalition is a resource, Collaborative Solutions. All of those are really working as a team.

I think to see and illustrate what we know to be true and what research is bearing out, housing is an effective structural intervention and certainly helps HIV prevention, increase access to care, linkage to care, and ultimately positive health outcomes. We know that from the research, but this is such a strong tool to demonstrate that within your community. It's a strong tool to galvanize your community around that, the housing efforts. And so, it's something we really all want to see happen and look at some good examples related to that.

Certainly, if you have ongoing questions, HOPWA TA is available and ask the question, portal is available and you can submit those questions into it. So, it's been an exciting project. It's been nice to be a part of it. We look forward to hearing all the success in your community.

Any last thoughts, comments from HUD as we move forward?

Amy Palilonis: Sure. I just want to say thanks to Rusty and the CSI team and then, also thanks to Christine Campbell and the National AIDS Housing Coalition for all of their continued work on this initiative. And then, to everyone out there, I just want to say thank you for watching our webinar and I really encourage you to take advantage of the peer portal and the other resources that are available to support you in your efforts to create an HIV housing care continuum in your community.

Rusty Bennett: Great. Thank you. Thanks.

Amy Palilonis: Thanks.

END