



ELEVATING CONSUMER VOICES

Michelle. D: Hello, everyone and welcome to today's webinar, Elevating Consumer Voices. My name is Michelle Dawson and I'm a Technical Assistance Coordinator for the Planning CHATT Project. Before we get started, we want to go through some technical details. First, attendees are in listen only mode, but we encourage you to communicate with each other and ask lots of questions using the chat box. Make sure that you click the drop down and ensure that you're clicking all panelists and attendees so that everyone can see what you have to say. If you have questions during the call, you can submit them at any time or during the question period at the end. Our presenters along with Planning CHATT staff will take as many questions as we can at the end of today's session. If you think of a question after the webinar, that's always fine too you can always email us questions at planningchatt@jsi.com.

Michelle. D: The easiest way to listen to our webinar is through your computer, but if you can't hear very well check to make sure that your computer audio is turned on. If you still can't hear us or if you experience a sound delay at any point, try refreshing your screen. Finally, if you need to, you can mute your computer audio and calling using the telephone number that you see on the screen, only to use the passcode as well, which is also listed on the screen. This is going to go into the chat as well, you'll have record of that a little bit later.

Michelle. D: As I get into today, we'll start off with a welcome introductions and objectives. Then, we'll move into a discussion the value of consumer voices of how meaningful involvement of consumers requires intentional effort on the part of the Planning Councils and Planning Bodies, strategies and promising practices and elevating consumer voices and examples of all consumer involvement. We'll be taking questions through the chat box throughout the webinar and will aggregate them for response at the end.

Michelle. D: By the end of today's webinar, you'll be able to understand the value of consumer voice. Voices on the Planning Council and Planning Body, people to name three strategies to elevate consumer voices on the planning counselor Planning Body, understand the value of a Planning Council or Planning Body culture that supports consumer engagement and identify a means by which to



improve your jurisdictions training programs to improve consumer's ability to participate in the Planning Council.

Michelle. D: I'd like to introduce our Project Officer, Lennwood Green who works for the Division of Metropolitan HIV/AIDS Programs in the HIV AIDS Bureau at HRSA. Thank you for your continued support of the Planning CHATT Project and of the Ryan White HIV/AIDS Program Part A Planning Council and Planning Body. As you know these webinars, like the one that we're at today are put on by the Planning CHATT Project. Planning CHATT builds the capacity of the Ryan White HIV AIDS program, Part A Planning Councils and Planning Bodies across the United States. Our goal is to help Planning Councils and Planning Bodies meet legislative requirements, strengthen consumer engagement and increase the involvement of community providers in HIV service delivery planning.

Michelle. D: With me today, I have our wonderful presenters coming from Atlanta and from San Francisco, I'll take a moment to introduce them. First we have Sandra Vincent, who is the Project Officer of the Metropolitan Atlanta HIV Health Services Planning Council. She is a strong advocate for the continued support of Planning Councils and the implementation of the Ryan White Part A Program. Morris Singletary is a 13 year survivor and thriver living with HIV. He currently serves as the Vice Chair of the Ryan White Planning Council Consumer Caucus. Trevor Pearson is the Chair of the Metropolitan Atlanta HIV Health Services Planning Council. Mike Shriver is the HIV Care Consumer Chair for the San Francisco EMA. You'll hear from all of them a little bit later in today's presentation.

Michelle. D: I'd also like to take a moment to thank our colleagues with EGMC, who provided so much thoughtful guidance and input into the development of this presentation. I want to start today by highlighting that Planning Councils and Planning Bodies are the direct result of the advocacy of people with HIV at the beginning of the epidemic through today. People advocated not just for services, but for the services and care that they needed and for involvement in determining what those services were. Advocates work together to offer the Denver Principles, which outlined the rights of people with HIV and powerfully stated that people with HIV have a right to be active participants in their care and leaders and the decisions made regarding HIV care and services.

Michelle. D: The beliefs articulated in the Denver Principles are inherent in Planning Councils and Planning Bodies, which strive to ensure a mechanism by which consumers



are actively involved in decisions about Ryan White HIV AIDS Program service delivery. Something we really want you to come away understanding is that consumers do not speak with one voice each represents their own unique perspectives, Planning Councils and Planning Bodies need to diverse consumer voices and perspectives in order to be representative of experiences of the whole community. Many jurisdictions need to be really intentional about elevating and valuing the voices of people of color, immigrants, people trans experience and young people.

Michelle. D: The effective Planning Councils and consumer involvement and Planning Council has been just really taken and run with by other organizations. It's inspired consumer health center advisory boards, and family involvement for children with special health care needs that we see this influence going into other areas as well. The original Ryan White comprehensive AIDS resource emergency Care Act of 1990 mandated that Ryan White HIV AIDS program Part A Planning Councils include among their membership affected communities, including individuals with HIV disease. The 2000 amendments added the requirement that not less than 33% of the council shall be individuals who are receiving HIV related services through Part A and are unaligned. They're not officers, employees or consultants to any entity that receives amounts from a grant and does not represent any such entity and reflects the demographics of the population of individuals with HIV disease in the service area.

Michelle. D: Planning Councils and Planning Bodies are required to have consumer input on needs assessment and PSRA that's Priority Setting and Resource Allocation activities. Though, other programs like the ones I mentioned a little bit earlier have seen the effect that consumer involvement has had on people for HIV and have started to adopt this model. Legislatively mandated consumer involvement is unique to the Ryan White HIV AIDS program Planning Councils and Planning Bodies. It's really a special thing we have. It's required and an absolutely integral part of Planning Councils and Planning Bodies, meaningful consumer involvement requires intentional and dedicated action.

Michelle. D: At this point, I'm going to turn it over to Mike, who's going to talk to us a little bit about a dedicated effort that it takes. Yes, I'm going to hand that over to him now. Thank you. Are you muted, Mike? Well, you work that out I'm actually going to-

Mike Shriver: Are we better now?



Michelle. D: Perfect. Thank you.

Mike Shriver: I'm sorry about that I was unmuting. I'm not very telephone savvy. I think, I hit the wrong button.

Michelle. D: That's okay.

Mike Shriver: I wanted to thank you all very much for the opportunity to talk about some of the things that we've done here in San Francisco around prioritizing the voices of people like myself consumers of HIV services. When, in fact San Francisco decided to merge its care council with AIDS prevention Planning Council, I would as a forward say that it was the HIV positive consumers on the Planning Council who actually were the driving force behind a lot of the safeguards around the intentionality and the visibility of people to do with HIV on emerge Planning Council. That becomes important because while we merged three years ago, when we were joining Planning Council, what we saw after the first year of the merger, was that the PLWH are caucus of people living with HIV caucus. That caucus had begun to meet less frequently, and the Planning Council itself actually took notice of this and was greatly concerned that they thought that they were losing a very important voice to the entire planning process.

Mike Shriver: The Planning Council itself came to the leadership of the co-chairs, they're five coaches of our Planning Council. They said to us, "We need you to change this, we need you to improve the mechanism by which the PLWH caucus has its meetings, and has a regular and consistent input into our planning processes. It was actually the Planning Council itself that really stepped in front of the issue and said, "We value the role of people with HIV. It's up to the co-chairs and the steering committee to figure out what the problems were that were preventing an active and consistent participation, people living with HIV. Then, find out from people living with HIV on the Planning Council, which change that dynamic to actually incentivize and really bring a more robust voice back to the table."

Mike Shriver: What we did as a Planning Council is we took our dedicated staff and had our dedicated staff go ahead and interview every person living with HIV on our Planning Council to find out what were the barriers and obstacles, as well as what would improve participation in the PLWH caucus process so that we could have a more robust PLWH caucus. After the staff did all those interviews with all the members of our Planning Council who are HIV infected, then we sat down as

PLWH caucus itself and look at the results of our survey, and then actually did a very deep dive into what was preventing us from being there was it the meeting time? The meeting day? The meeting frequency? What would actually be a specific concern to the consumers that would actually make it worth their while to come to a dedicated PLWH caucus?

Mike Shriver:

One of the things that we discovered is that we have mandated work group so the Planning Council, our membership work group, our steering committee, et cetera, that all of our Planning Council members are required to attend. It's part of our contract as a Planning Council member. Many people with HIV thought that they were being doubly hit because they not only had their mandatory committee to be at, but they also had the PLWH caucus, which often center that a burden to them above and beyond every other Planning Council members requirements. What we did is for all people living with HIV who attend the PLWH caucus, we incentivize membership by giving them a get out of jail free card, that if they did attend the PLWH caucus meeting, they could actually have an excused absence from one of their required council committee membership committees.

Mike Shriver:

That seemed to actually help alleviate the idea that they were being doubly pressed duty, when no other Planning Council members being double impressed. The second thing that we did with PWL HIV caucus is we took our first meeting this robust new meeting, and actually used it as a retreat. Where we actually looked at the topics that the people living with HIV on the Planning Council, we're looking to either get more information about, be brought up to speed about over important to their advocacy and there's participation on the Planning Council. We just finished this last year did it again this year and we came up with an agenda, we have a topic focused and it says on the same topic focused and agenda driven quarterly meeting for our consumers so that they can actually time these meetings for major milestones in the Planning Council year. Time these meetings and that it actually benefits that participation in major Planning Council meetings, for example, our quality control Planning Council meeting or our summit where we actually do our prioritization setting.

Mike Shriver:

Just in that specific episode, it was really how the council valued our input and debate extra input back to the PLWH community to say okay, that you tell us what you need from us, so that you could actually be a much more robust member, Planning Council member.



Michelle. D: Thanks so much, Mike.

Mike Shriver: Welcome.

Michelle. D: I'm going to go ahead and handed over to Atlanta and talk about their experience with intentionality.

Morris. S: The consumer caucus gives the opportunity for the recipient of Ryan White services to help us be a part of helping ourselves and that's really important. Some of us who have entered our journey with HIV had come from a couple of very different spaces and very independent spaces. Helping ourselves was really big. We also are the first contact with as it concerns community engagement. As a member of the consumer caucus here the opportunity for people to say, "We want to hear from the community." I love to say, "Well, here we are." To be the consumer that has a voice that is able to be heard, makes a world of a difference when someone says, "Where's the community?" I am the community come to us.

Morris. S: Number three, we range from ages to spectrums and race and various education levels, which is super important because in Atlanta, we have such a wide variety of consumers. In our meetings, you can hear things from what I call \$10 words to what we like to now call education. Where we often get a chance to mention that we had a verse and explaining things to one another, as well as how we speak to our providers and care. In the end, having our voices as not only leaders but as a part of the community, lets us be invested in our own health and our destinies.

Michelle. D: Great, thank you. Thank you so much for that. We can see that those both required and valued, it does take effort to ensure that consumers are meaningfully involved in Planning Council and Planning Body operations. We're now going to walk through some strategies that your Planning Council or Planning Bodies can take and used to help promote and elevate consumers voices in your jurisdiction. Consumer involvement is essential to the success of the Planning Council and there's not just one way for consumers to be involved and consumers should be encouraged to explore and partake in any Planning Council or Planning Body activities that are of interest to them.

- Michelle. D: The slide that you see here shows a variety of different activities that consumers can be involved in. This list is by no means exhaustive, but can provide some good ideas of ways to get consumers involved in or learning about different activities. On the side, the activities are grouped into two categories input and leadership. Of course, these categories input and leadership are not mutually exclusive and consumers should always be made to feel welcome to provide input and to feel that they're a leader even if they don't have a formal leadership position.
- Michelle. D: Consumers can provide both formal and informal input into Planning Council and Planning Body activities, regardless of whether they're full members of the Planning Council or planning board. Consumers can participate during town hall meetings in conducting needs assessment activities such as performance sampling methodology, recruitment, et cetera. Consumer committees or caucuses open to the public in issue specific task forces, and of course, an open Planning Council and Planning Body committee meeting. Consumers should also be encouraged both in words and actions to take on leadership roles.
- Michelle. D: Consumers can hold many different formal and informal leadership roles. Examples include, Planning Council co-chairship, leadership of the Consumer Advisory Board, clinical quality management, committee chairperson and the leader of communication or marketing initiatives. Consumer participation these roles can ensure that consumer voices and needs are at the forefront of activities. It's important to recognize that consumers may need support or training to help them be successful and feel confident in their role as leaders and respond to that need.
- Michelle. D: One of the best ways to ensure consumer voices are heard and valued is to make provisions for consumer involvement in your Planning Council or Planning Body bylaws. On this slide you see some ideas for things that you can put into your bylaws to help ensure that consumer voices are at the forefront of planning counselor Planning Body activities. First suggestion is that Planning Councils and Planning Bodies make provisions for committee for people with HIV or are caucus with open membership. That way there's an opportunity for non members to make their voices heard and be involved with the Planning Council.



Michelle. D: This may help them to become familiar with Planning Council or Planning Body activities and operations, and may eventually lead to their membership on the Planning Council or Planning Body. You might also consider stipulating that all committees must include consumer members. Many Planning Councils and Planning Bodies require that at least one of the Planning Council or Planning Body co-chairs be a consumer or another person living with HIV. This intentional provision ensures that consumer needs are always at the forefront of Planning Council operations.

Michelle. D: Another provision might be to create quorum requirements in your bylaws. Though many Planning Council or Planning Bodies have overall quorum that are necessary to conduct business, it can be really valuable to create quorum requirements that require a certain percent of consumers to be present to conduct business at both full Planning Council and committee meeting. Doing demonstrates that consumer input is essential at every step along the way, and ensures that consumer voices are always present. Your jurisdiction might also consider establishing procedures for non Planning Council or Planning Body members to serve on non governance committees.

Michelle. D: People may not had the time or availability to be a full member and a committee member, but perhaps they could be a subject matter, expert brought in for a specific expertise. This is permissible. It's just important that there be policies and procedures such as conflict of interest policies around doing this so that folks know that it's allowable and how to do it appropriately.

Michelle. D: I'm now going to hand it over to Atlanta, talk about how they've changed their bylaws in order to help improve and ensure consumer input and involvement in Planning Councils and Planning Bodies.

Sandra Vincent: Thank you, Michelle. Morris its reference earlier, who's the wonderful Consumer Caucus Vice Chair, I might add. He talked about the diverse involvement of our caucus members and I will say that the changes that we made to our bylaws were directly the result of the consumer caucus and requests which were coming out of that body. In November 2014, through series of meetings with both PC members, the community consumer caucus and the council procedures committee. The Planning Council amended its bylaws to require to the greatest extent possible that either the chair or vice chair position will be filled with an HIV positive non-aligned consumer.

Sandra Vincent: Additionally, the chair and the second vice chair would meet the same criteria. Presently, the PC chairs nine committees one caucus and two task forces, we only have two vacancies and we're working to get those positions filled. The other thing that I like to highlight is the caucus and Council's decision to have a consumer caucus instead of a consumer committee. Membership of the consumer caucus is not limited to members of the Planning Council. I think, that there's repeating, they are not limited to members of the Planning Council. This has proven to be very effective model because many individuals continue to be intimidated by the Planning Council meetings, and many of the acronyms and other formalities that are associated, as much as we try to train and educate and provide information in advance. Some still don't feel comfortable at first.

Sandra Vincent: Through the consumer caucus, we are able to create a safe environment without the formality of a Planning Council. Our caucus recently participated in the development of the consumer survey, which will be used in various Ryan White funded agencies. The goal was to develop a tool that would be user friendly and would yield maximum feedback. The Ryan White epidemiologist in conjunction with the Planning Council support office presented several questions, asked for responses on the language that was used, the amount of time that took, whether some of the questions should be removed or questions added. The response was overwhelmingly successful and the outcome, a consumer survey crafted by consumers. Nothing for us without us.

Sandra Vincent: I will take the liberty to add here that our caucus is diverse as I stated earlier, I will take the liberty to further indicate that the questions which were fashion to reflect the rating, some of them were emojis instead of numbers. This is primarily the result of millennial input, but all of them agree. There is one last point that I'd like to make and it is very important, please make sure that you look at your county and city requirements and understand whether or not they create barriers to consumer involvement. In some jurisdictions, there are local policies which impact the involvement of members as an example, some jurisdictions, the county or city requires that individuals disclose their financial status, home ownership status, and in some instances, even their HIV status.

Sandra Vincent: There has to be a conversation with the CEO, so that there is a clear understanding of the statute with a government Planning Council. Please take the time to review what information is being requested by the clerk's office of



the judge's office or other entities which may prove to be barriers to membership.

Michelle. D: Thank you so much. The Planning Councils and Planning Bodies should at every step of the planning process, be looking to find ways to bring in consumer voices. There are lots of ways to do this both outside of meetings and during meetings. Outside of meetings, you can work to ensure that consumers and people with HIV in your community are aware of the Planning Council and Planning Body and how they can get involved, whether that's with a needs assessment as a member of the consumer committee or consumer caucus or some other way. Be sure to advertise in multiple ways because, people get their information from different places. Consider advertising using flyers, social media websites, direct phone calls, texts.

Michelle. D: You can also work with other groups for people with HIV that might exist in your communities such as groups for young people with HIV, to make sure they're informed about the Planning Council or Planning Body and know how to and are encouraged to make their voices heard. Your Planning Council or Planning Body can hold community feedback and input sessions in different places in your service area to make it easier for people to provide input.

Michelle. D: During meetings, Planning Council or Planning Body can report out on the findings from needs assessment surveys, focus groups, and any special studies you conduct in order to share the voices of consumers with the whole Planning Council and inform the PSRA process. You could consider holding structured public comment periods at all meetings in order to allow both members and non members to raise issues and concerns and share their ideas on how to overcome these challenges. You can also permit telephone or other electronic access to meetings if that's permitted in your state or locality, which can help to make meetings more accessible to people who may have challenges and getting to the meeting due to transportation childcare issues, healthcare issues, et cetera.

Michelle. D: I'm now going to hand it over to Mike to talk about Health Care Francisco has used their evaluation to improve Planning Council and Planning Body meetings and improve consumer involvement.

Mike Shriver: Thank you. One of the things that I did talk about earlier around the revitalization of PLWH caucus was in some part because of evaluation from the



full Council. We take our evaluation process of our meetings and our committee meetings very seriously in San Francisco. A couple of years ago, we discovered in particularly coming from the PLWH caucuses input was that even the format of our meeting was actually not conducive for maximum consumer input or appropriate consumer input. What we also found in one of our evaluations at the end of one of our meetings is that several of our consumers felt the need to introduce themselves to the Planning Council and have the Planning Council introduce themselves to the consumers, so that everybody was operating under the same basic level playing field of what brought them to the council and expertise they brought to the council and what their vision for the council was.

Mike Shriver:

We actually deconstruct part of our meetings as a result of this evaluation, and create a whole new panel that's consistent with all of our meetings now, with every meeting that we have in San Francisco, three of our council members now go up in front of the council, we have a 15 minute question and answer session and a get to know you session. So that everyone is operating under the same understanding of why we are all collectively there to execute all the legislative requirements of the Care Act and all the prevention requirements are merged Council. What we discovered at the end of our Planning Council meetings for evaluation was that people, particularly our consumers were concerned with the way in which we had our group discussions. As a direct result of our evaluations, we've now actually changed the way in which we do our group discussions we've gone to dyads to two people talking about a significant issue. Groups talking about specific issues. Have the Planning Council picking out to the one half of the room, half the Planning Council going to the other half of the room to figure out how we actually communicate across each other when we're getting into major priority setting, or policy making decisions for the council.

Mike Shriver:

Our evaluations were really clear that we needed to break the old fashioned traditional meeting of somebody going in front of the room and doing a presentation, taking all your questions and answers from the council, and then moving to a decision. That process wasn't working for us as a Planning Council, not just because of the size of our council. We're about 45 members, but also because of the varied expertise and unique expertise that different council members had. As a result of all that we've actually changed our calendar for the Planning Council. We devote our January Planning Council meeting as a mini retreat for the Planning Council to do an assessment of our previous year's work, and actually lay the groundwork for what is going to be our next year's



work and that Planning Council meeting is coming up this coming Monday for us.

Mike Shriver: It's been very important for us and as one of the co-chairs we take very seriously subjective evaluation that our council members have of the meetings, and in particular from our consumers the way in which they're experiencing and feeling quantified or even heard, and they want to participate back in the discussions.

Michelle. D: Thanks so much.

Mike Shriver: You're welcome.

Michelle. D: We know that some people might come to your Planning Council ready and confident to jump right in, but others might not know about the Planning Council or Planning Body and may not know how to get involved. It's important to actively publicize opportunities for participation. It's important to be proactive, actively recruit consumers from the most impacted populations such as youth, people of color, people with trans experience. Remember to draw upon your current members and the relationships that you have with other groups, for people with HIV to get the word out. When folks from these groups come to the planning counselor Planning Body, it's important that you actively work to retain them and this can include training.

Michelle. D: You'll want to work to train potential consumer members, including those who come to the consumer committee or caucus. They can be confident and active participants in their current roles and become prepared to serve in other roles such as alternate members, full planning, council planning, body members, or even leadership. In order to do so the one established procedures to find ways for non member consumers to take part in committees. The Planning CHATT training guide can be a great tool to help you educate and train consumers and new members on Planning Council or Planning Body operations.

Michelle. D: Now, I'm going to turn it over again to Atlanta to talk about their training emotion program.

Sandra Vincent: Excellent. Thank you, Michelle. I'll say Few things and then I'm going to actually ask our Planning Council Chair Trevor Pearson, if he will come in on quality management. Training emotion with coined as our name for ongoing training,



the Planning Council years the cycle is cyclical. Oftentimes, what happens is that we conduct our annual orientation at the beginning of the Planning Council year, and then another training at Planning Council refresher, but there's a host of activity which takes place throughout the planning year. Examples include roles and responsibilities at the beginning of the grant year, and the seeding of the new Planning Council, priority setting and resource allocation, evaluation of the administrative mechanism membership, et cetera. These varying processes can be confusing for both consumers and experienced members.

Sandra Vincent: We take our agenda items which reflect where we are within the Planning Council cycle, and we educate on those items through various meeting, including definitions, videos, speakers, illustrations, cartoons, charts, graphs, real time including information and examples and presentations on how the information will and can be applied. One example, which is a best practice is to re-educate the CEO recipient and members on the roles and responsibilities of the Planning Council. Everyone needs to understand the legislation and how it works, this is the basis for your consumer empowerment. Another example involves our members of the consumer caucus who also serves as the Vice Chair of our Priorities Committee Daniel Driftin.

Sandra Vincent: Daniel completed the block training and before we start our PSRA process, we reintroduce service utilization and needs assessment data from the standpoint that data saves lives. Having a member of the consumer population present a Planning Council and in consumer caucus has been overwhelmingly successful. In addition to his presentation, we also issue a list of acronyms, at the terms and information on how the decisions impact planning, and it's not unusual to see the light coming on for a lot of people. One of the indicators of success has been the questions that we now get. Sometimes people just don't ask questions, because they don't know enough about what's being asked to ask a question. Silence is not synonymous with understanding.

Sandra Vincent: Looking at various things in subject matter, we also focus on our quality management and the engagement of consumers in that process. Trevor, why don't you share more about that.

Trevor Pearson: Thanks Sandra. What Sandra has said in a nutshell is that in Atlanta, we have looked at trading in an intentional way, it doesn't happen on its own. We have ensured that our trading takes place in an intentional way. In terms of our QM trading, one of the things that we did, which I don't think a lot of other than



Planning Councils and Planning Bodies have done is ensured that our consumers were involved in leadership in quality management trading. For instance, there are three members of the Planning Council leadership, who in conjunction with a member of the funded agency, the county, Fulton County, Department of HIV elimination, actually were trained as a team to provide trading not only to consumers, but also provide training to consumers and recipients of Ryan White services.

Trevor Pearson: I think, it's the only training team in this country that's done that training, other jurisdictions were trained along with us but I think we were the first in the country to actually do a program where consumer leadership, consumer QM trainers, as well as Ryan White leadership came together and provided trading to not only consumers, but also to all sorts of funded agencies at the same time. We had no intention of trading. What was also important in that one of the things we did in terms of leadership is that we look at the ability of ensuring that leaders in QM not only trained in house but also trained out of, outside. We were able to look at training in terms of each agency that was funded on our program has community advisory board, we depended on our trading within our own group to involve training at the side. Instead of bringing people in, we went away as they were meeting and provided them the training. I think that's important to understand that you don't always have to have consumers coming to you, you have to reach out to them. Thank you.

Michelle. D: One of the things that we really like to see is for current members to be able to help get other consumers involved in Planning Council and Planning Body ever it's one of the best ways to get folks to the group and also to keep them there. Current members, who are consumers can serve as liaison to other to sub populations or groups that they might be a part of. They can encourage their friends or colleagues, the people they know to participate in Planning Council or Planning Body activities. They may also be or they are great representatives of the Planning Council or Planning Body at community events. When they become the face of the Planning Council or Planning Body, it shows the value that the Planning Council has for consumer members. That is the group intended to elevate that voice.

Michelle. D: Consumer members can serve as mentors or partners or bodies for new consumer members or participants to say, "Yes, I've been in your shoes, I know what that's like. We're going to move together through this learning experience,

that you're going to have and help lift each other up and move each other forward." So that everybody can be involved to the extent that they want to be and elevate their own individual voice. Speaking for members that are other people that they know. Also, members can speak positively about people involved, the benefits of consumer involvement and the benefits of this community planning.

Michelle. D: We know that sometimes it can be challenging to bring consumer members in for a variety of reasons. It's a complex process. It's a group that has rules and traditions and so once we have somebody that decides to become a part of Planning Council activities, it's important to help the consumer stay engaged. Once we have them engaged, we want to help provide training on the processes of the next meeting in advance so that they know what to expect. They can prepare, they can ask any questions they need, they can effectively participate in the next session. If there's going to be data that's going to be presented in the next meeting, or the next committee meeting provide training on that. What does this data mean? What does it tell us? What are we going to be talking about? When people understand those things, and they're able to be active participants in the process.

Michelle. D: You want to ensure that data and materials are written at an accessible literacy level. We know that people come to Planning Council or Planning Body with a variety of experiences and we want to make sure that everything is provided in a way that is equitable and gives everyone access to the same information. We're going to make sure that there's time for questions and that everybody is aware that this is an appropriate thing to do and encouraged thing to do. Asking questions helps to build understanding and shared ownership of the process and that's what they're doing.

Michelle. D: It's also important that Planning Councils and Planning Body members reflect in words policies and actions, that consumers are the pathway to ensuring a successful service continuum. It's important that it be clear that all members of the Planning Council or Planning Body are equal regardless of their position, but that consumer input should be raised and valued by all members, as consumers have a purpose for the Planning Council. Now, I'll hand it back to Atlanta to talk about being status neutral in terms of employment and position.

Sandra Vincent: When the membership committee establishes its community, every effort is given to make sure that there are consumer based on their interest assigned to

every committee. It's important that there is respect and equality among the members. The issue of whether or not someone is HIV positive, never comes up. The member to have no idea who is or who is not, unless the individual is openly disclosed, or in those rare instances when a member says, "In essence, timeout I've been living with HIV for X number of years and this is what's missing in this conversation." Those are very, very powerful moments. I've seen this happen several times in our QM committee meeting, when we were developing standards of care. If you can imagine a room full with agencies, practitioners, doctors and consumers and sometimes there is a misperspective, the consumer perspective and the most beautiful part of this exchange is that when this happens, it's like EF Hutton was speaking, everyone stops and listens.

Sandra Vincent: I know that Morris has been very engaged in some of these types of meetings, I'd like for him to comment a little more about that perspective.

Morris. S: Wonderful. I remember last March, coming to my very first Planning Council meeting, not knowing what I know now is, it's seeing all these people that were active and speaking and knowledgeable about so many things. Again, not knowing their status, they're going to the consumer caucus, and some of those very leaders who are chairpersons of other committees who asked consumer caucus. That made me go, "Wow." It opened my eyes up to see, not only were they looking at helping us with how much money is spent out, but we were a part of making that decision and that changed my whole view. Right now, while we haven't got membership drive, it is so exciting, because I get an opportunity to see that we must mirror 33% that 33% less looks like people with HIV and again, have trans experience, women who are living with HIV/AIDS, African Americans who are living with HIV/AIDS.

Morris. S: It's so amazing to be a part of the process again, it helps me invest in my own future and my own destiny. That status neutral has played a major role, I don't know Atlanta is different. We have a very bowed atmosphere here, we have a very open atmosphere for people to be bold and in other places that is not so. When a consumer steps forward, who is open and honest about their status for that person will then be, like I said before be the face of the consumer caucus, I'll be the face of the Planning Council itself. That changes how the Planning Council then gives the view and attended by those who live with HIV/AIDS.

Michelle. D: Thank you. I think that's really important. We know that Planning Council and Planning Body members work to get consumers involved. There are some things

that Planning Council and Planning Bodies do that may look like consumer involvement but may actually be holding consumers back from fully participating or might mask a lack of meaningful participation. We're going to go through some of these examples in order to help you think critically about the value you and your Planning Council are planning value placed on consumer involvement and what you might consider revising in your operations.

Michelle. D: One of the first things we'll talk about is that the membership might include the required number of consumers, but many are not actively participating because they receive minimal training or support. They may be here without actually being present or participating. Consumers should be speaking voting, making motions, et cetera. As an example of consumers not participating, Planning Council or Planning Body might have full consumer attendance, but the consumers abstain from voting because they don't understand the topic being discussed or what they're voting on or what the options are.

Michelle. D: Roll Call voting can help get Planning Councils or Planning Bodies the data that they need to critically look at and understand who's abstaining from voting. So that you can figure out what you need to do to make it easier to actively and independently participate. Another example is that a jurisdiction has a core requirement to conduct business but the quorum is based on total members only, and doesn't specify a required level of consumer attendance. This can result in only a very few consumers being present but business still being conducted. This can be true for both hold Planning Councils are Planning Bodies or for committees, to make sure that consumers are involved everywhere that they can and should be.

Michelle. D: Sometimes there are no consumers in leadership positions. For example, there are no requirements that one co-chair or one or two committee co-chairs be consumers. This can sometimes be results of a requirement that at least one of the co-chairs be a person with HIV, but it's not required that, that person to be a consumer of Ryan White Services the leadership includes primarily people with HIV who are not consumers. While it's good that the group is being led by a person with HIV, they may not have the same understanding or experience as a consumer.

Michelle. D: In some instances, consumers are involved, but the input that they provide is not valued. We see this play out in a few different ways. In some instances, consumer participation on a committee is not required or enforced. We see that

the groups that do most of the actual planning work have very limited consumer involvement. In others consumers are encouraged formally or informally to look to non-consumers for guidance and voting rather than being encouraged to make their own decisions. You may hear other members talk about consumer input rather than full consumer participation in decision making. Consumer input is received but largely ignored. This is unfortunately easy to do and can happen on a regular basis because consumers are almost never the majority on the Planning Council or Planning Body or committee. Easy to overlook, if not intentional.

Michelle. D: Some more example for consumer involvement. Sometimes, there are jurisdictions that haven't active consumer committee or caucus, but the consumer committee or consumer caucus is not used to provide input to the Planning Council or Planning Body or prepare consumers for possible memberships retraining. The group might function mostly as a support or a social group. While support and fellowship are important, the consumer committee or consumer caucus should be a mechanism by which to raise up consumer concerns and provide a formal mechanism or place for training and development that potential members.

Michelle. D: Planning councils or Planning Bodies might have trouble recruiting and retaining members, especially consumers from populations that are traditionally underserved and reflective needs requirements might be seldom that. Consumers without prior community planning experience, which often includes people of color, people with less educational experience or people who are lower income receive no special training or mentoring which really reflects the failure to appreciate the fact that community planning is complicated. Ryan White HIV AIDS Program has many requirements and rules and not really understanding, it reflects a lack of orientation, training and support. It's really important that one brought to the table, consumers are given the tools, training and support that they need to be successful and to participate fully.

Michelle. D: Some Planning Councils or Planning Bodies may have very active consumer members but there are no terms limits established in bylaws. The Planning Council and Planning Body has largely the same consumer membership for many years and unchanged. You must agree that the jurisdiction has such enthusiastic participants and unchanging membership list, leave no room for younger, more diverse community consumers to join or become leaders. It's



important that the Planning Council or Planning Body evolves over time to meet the changing needs of the community.

Michelle. D: Another example so consumer involvement can be seen with a Planning Council or Planning Body recognizes that it can be difficult for consumers to attend meetings do perhaps to things like inconvenient meeting times, lack of reimbursement for expenses incurred and getting to the meeting or the difficulties or level of complexity at the language use at the meetings, for lack of skilled interpretation services. There's really no effort being made to overcome these challenges or just recognize those challenges. Again, these are just examples that are provided to encourage you to think critically about what you're doing, and whether those actions serve to elevate or depressed meaningful consumer participation, and to inspire you to think of ways to grow or improve.

Michelle. D: I'm going to leave this up on the screen. This is our website, where you'll be able to find all the webinar recordings from today archived on our Planning CHATT page on the target website. Also, during this time we'd like to encourage you to submit your questions via chatting. I know we've been having a nice robust discussion in the chat, and then the Q&A. We're going to take some time to let you ask more questions, and our presenters can take some time to be prepared to answer them. Please go ahead and enter the questions via chat.

Michelle. D: I think, we'll start with one of our first questions that came in, which is actually a question for both jurisdictions. I think we'll let San Francisco go first, but the question is, how many committees are a part of your Planning Council?

Mike Shriver: This is Mike from San Francisco. We have four standing committees that are in our bylaws. We have a membership committee, a council affairs committee, which actually helps develop our presentations and our agenda. Our engagement committee, which is the one that actually looks at consumer satisfaction, our needs assessment and our annual quality assurance. Our steering committee, which is actually all the chairs of all of our standing committees and the co-chairs, which actually developed the agenda and look at the review of our previous meetings. Those who were on our bylaws, and we have one standing caucus, which is our PLWH caucus, the mechanism that we had for PWA input into our Planning Council was have a standing caucus.



Mike Shriver: All of our Planning Council members are required to be on at least one standing committee. If you're a person living with HIV, especially with the consumer is strongly encouraged and incentivize that you also participate as a member of the PLWH caucus. On all of our meetings are open to the public, but if there's any decision that needs to be made, the only people that can vote on the decision are current members of the Planning Council.

Trevor Pearson: In Atlanta, we have the executive committee that's made up of the nine, the chairs and the nine standing committees, we are a very large body made up of about 115 members. We have an assessment committee, comprehensive planning committee, concert procedures committee, evaluation committee, housing committee, membership committee, priorities committee, public policy committee and equality management committee. We also have our consumer caucus which Morris is vice chair. The nine, our executive committee is made up of those nine standing committee chairs as well as the chair of the Planning Council, the first vice chair and the second vice chair. Most of those meetings are held, most of those committees have, once monthly meeting some of them are less meeting, less often because of the work that they do.

Trevor Pearson: One of the things that must be recognized particularly here in Atlanta, is that almost all of the work is done at the community committee level. So, that by the time you get to the full Planning Council meeting most of the work that needs to be done, it's already done.

Michelle. D: Thank you both. Did you mention how often your-

Trevor Pearson: Executive committee?

Michelle. D: Nope. Your consumer caucus meets?

Trevor Pearson: Definitely. Once a month, the Wednesday before... usually, the third Wednesday of every month. However, Morris can talk a little bit more because there have been changes. Go ahead.

Morris. S: Yes. Super excited about our meeting, we meet the third Wednesday of every month which follows which is immediately the day both for the Planning Council meeting. This past month, we have had our very first evening consumer caucus meeting. Consumer caucus meeting normally takes place... Well, in the past, and it still does for 12:00 PM to 2:00 PM. We wanted to hear the voices of



everybody and we know that if you are at work during that time, you can't be a consumer caucus voices. We said, "What can we do to make that happen?" We were very excited to start our evening meetings, and we had a room full of people we had standing room as a matter of fact. We meet once a month, and on that day, we meet twice so that we can ensure we get the voices of everyone.

Michelle. D: Thank you. I'm actually seeing similar things in the chat, being thoughtful about the number of meetings that you're having, and whether that could improve consumer participation. If you're not asked to go to five things, then you're to go to one, they will perhaps be more able to attend. Nice to see that happening in more than one jurisdiction.

Mike Shriver: I should have said in San Francisco, each of our member has to commit to attend at least one committee meeting.

Michelle. D: One of the questions that we were asked for was, what effective ways have groups found to incentivize participation? I know that some of the answers have come into the chat, saying that they provide travel stipend, food, bus passes or \$10 gas cards to reimburse travel expenses. Those are definitely things you can do. I know that one of our presenters mentioned that if you get to miss a committee meeting as an incentive, it doesn't necessarily has to be a monetary incentive all the time, there can be some other incentive for participation. I just want to take a moment to talk about cash incentives, because I know that there's sometimes concerns around cash incentives.

Michelle. D: Cash incentives cannot be provided but gift cards can be provided, but need to have gone through prior approval with your Project Officer and they can't be gift cards that can be used to purchase alcohol or tobacco. For example, like a credit card gift card, like a visa or American Express gift card would not be permissible because it could be used for those types of purchases. Because of the limitations recipients sometimes establish restrictions on incentives, we don't have to be so vigilant about ensuring that the incentives are permissible. To get a better understanding of what might or might not be permissible or if you have questions about what's allowable HRSA recommends that you speak with your Project Officer. In short, you can give monetary incentives, but your project officer has to approve them in advance. This is an advanced thing not an after experience, but it can be done with permission.

Michelle. D: What other questions have we gotten here? I think, I've heard you mentioned this in the past. One of the questions is brought up during meetings that the word consumer is stigmatizing. I'll hand this over to my colleagues in Atlanta. Mike, you're welcome to join as well. I do want to say that consumer is a term that is a part of Ryan White policies more broadly, and so it's important to know that 33% of members must be consumers filling to those people need to be "out" about their status. That's a term that's part of Ryan White language, but there are concerns at the community level like this questioner has asked about.

Sandra Vincent: Yes, we received for years feedback on the term consumer and the connotation that it carries with it. When you talk about a consumer, it's a user of a service. Our Planning Council members have indicated a desire those who are living with HIV and recipients of Ryan White services have indicated a desire to employ a different term. Now, we have not and we don't know what that term is, but there is a desire to change it. I think, as practitioners we have to understand that what we're really talking about are people who are our customers, and when you use consumer juxtaposed to the word customer, there is a different vibe that comes from each word.

Sandra Vincent: I think, there is more of a willingness to respond to the needs of a customer, then you would to someone who is a consumer and that is the type of feedback that we've been getting. We had the pleasure of sharing that at our all titles meetings and I will say to the HRSA, persons who are on the line that this does continue to be a concern, but we do understand that it is codified in policy, but as we make policy decisions and revisions, we may want to consider the fact that there continues to be concern.

Mike Shriver: I will share that from San Francisco since we have emerged Planning Councils and PrIYA prevention and Care at the same table. We're having a different interaction with the word consumer because for us any individual at risk for HIV is part of our planning process as well as someone living with HIV is also part of our planning process. When we now band around the word consumer, we're talking about people both at risk and people living with HIV. I apologize for using the word consumer, but when we get into our care function, that's the word that we're most used to using, and living at the legislative mandate and that discussion. I know we would be open to having people living with HIV around the country, having us come up with a much better word for who we are. I love the idea about customers.

Michelle. D: Great, thank you. There was a question around youth and strategies and ideas for bringing youth and young adult to the Planning Council. The first thing, I'll hand it to Morris in just one second, but I would say that we ran a series of some webinars on that topic pretty recently. I encourage you to check out the Planning CHATT website where you can find those archived webinars, and take a listen to those. We had some really great ideas presented in there. I would certainly encourage you to take a listen to that, but I'll hand it to you as well.

Morris. S: As the Vice Chair of the Consumer Caucus, I take my job to go look, I go looking at search for those who are not already there. Then, I search for their friends and their neighborhoods and where they hang, because those people who was there, those of us who were there are aware. Again, depending on where we are with our status, they may not be able to express that same care outwardly for their community. Here in Atlanta, we have a number of organizations of young people who specify in ages from 18 to 24. Going to those meetings, introducing myself as the Vice Chair of the Consumer Caucus. They say, "What is a consumer caucus?" I educate them on that word and what it means my inbox starts to blow up, when can I come to the next meeting? Or where is the next meeting?

Morris. S: That in part also helps with developing that evening meeting, because they are working their jobs and they don't have the opportunity from 12:00 to 2:00 to come. No lunch break is two hours, that's an absolute value it. The younger people get opportunity to their income, or if we get an opportunity, as the vice chair, I can take that information to where they are. There are groups of people who no matter what the status is, they all are interested in knowing on how they could be a part of helping in epidemic. Going to where they are has been the answer, and then sometimes bringing some of them into the process is beginning to help filter young people into the Planning Council.

Sandra Vincent: I'd like to add to what more to said. We have an annual initiative called the Atlanta Area Outreach Initiative, and as a part of that Youth Forum continuously every year, I get this feedback. It is that young people want us to move away from being HIV specific, and applying more focused on health with an HIV focus. They don't want to come in with an HIV message. They want to come in with a health message with prevention as a part of that. That's something to consider as well. The reason for that is that there are still challenges with young folks, especially those who were born with HIV. There's this concern about the stigma



challenges that we experience throughout the arena. There's a great deal again of emphasis around just talking about plain of good health.

Michelle. D: Thank you. Let's see what other questions. Just reminder, you can continue to drop questions into the Q&A box. I also want to take a moment to say I'm really enjoying this robust conversation going on in the chat and the sharing of strategies. I encourage that as well because it's really excellent. I think there was a specific question around people different uses of the word committee versus caucus. I think, I would say that, that probably varies a little bit by community. I'll give our panelists and an opportunity to respond to that. I think, Mike might have had a response.

Mike Shriver: We have both. We have one standing caucus, we have four standing committees, all five of which are part of our bylaws. The way that we differentiate the difference between a committee and a caucus is that the four committees are all instrumental in developing our agenda for our full council meeting and for executing the functions of our planning requirements for HRSA. The caucus is meant to be above and beyond that works to actually look at that issues impacting people with HIV, and also consumer participation and individual participation.

Mike Shriver: Unlike Atlanta, we don't have nine work groups, but when Atlanta was talking about specific committees that they had to run housing or any other issue. We have the ability at our council to create work groups, which we do all the time that are very time specific and issues specific, and then run their course of their charge, and then bring those recommendations back to the actual committee structure. All of our processes begin with a motion or an idea that is generated by the board of the committee's, or the caucus, which then work their way through our protocol between committee to all the committee's need for the Planning Council. The issue would work its way through our standing committees, and then get to the full Council. We've chosen that as our option about not only in consumer voice but also how we structure our merge council around doing both prevention and care planning.

Michelle. D: Thank you Mike, for that.

Sandra Vincent: This is Sandra. In Atlanta, our bylaws specify that at a minimum, we will have a consumer caucus, and that caucus originally was designed to support individuals living with HIV. Who were consumers of Ryan white services and their other

related individuals to support them in a special place where they could have the freedom of asking questions, expressing concern, whatever their needs were, they would have the freedom and the safety of addressing those issues in a safe place. As it relates to the committees, the committees are actually assigned based on the membership of the Planning Council. Our caucus is not, our caucus is very fluid. The invites are sent out to the agencies for people who may want to attend. They do not have to be members of the Planning Council and I think that really is the distinction. We will say that our caucus serves as an excellent training ground and the majority of the people who are on the caucus also are on the Planning Council, but just as an entry into the system, the caucus has to be very beneficial in that regard.

Mike Shriver: I just want to say that I'm really glad you brought that up the show because when our caucus is meeting and functioning as the caucus as advising the Planning Council process, we have our Planning Council staff there. Of course, the caucus is open to all of our meetings are public, so anybody can attend. Then, when the caucus is done with its business for the Planning Council, we always have a social or support function that happens after that. Nobody is allowed to be [inaudible 01:11:42] someone except for someone who's living with HIV, specifically for the Part A, but have been around support, training, mentorship, and a sense of community and community building.

Trevor Pearson: In addition to what Sandra just said about the committees as well as caucuses, we also have in our bylaws the task forces. At the moment, Atlanta has two task forces, one that is specifically with for health and the other one that deals with vulnerable populations. Those are set up specifically to handle those two types of issues and they're qualified in our bylaws.

Mike Shriver: I'm sorry Sandra, I'll let you say something not Michelle, I'm sorry.

Michelle. D: One more thing, our caucus seems to elevate issues and our committee can bring those issues to the planning process to incorporate an action planning. There is a slight difference in the purpose of the two different groups. I also want to... there was a request for clarification. The question is you mentioned something regarding consumer doesn't have to be receiving some type of services and they've asked for clarification. To clarify, a person might have HIV but not receive services or their services through the Ryan White HIV AIDS Program. They're not "consumer" of Ryan White HIV AIDS program services, though they are a person with HIV. If they're getting their services in some other



way, then they're not a consumer for these purposes, because they're not a consumer of Ryan White HIV/AIDS Programs services. I hope that makes it a little bit more clear.

Michelle. D: Okay, looking for your questions here. I think the last question that we have right now is, are members allowed to participate in meetings by phone or teleconference? I would say, the answer is that, that is permissible according to HRSA, but would depend a lot on the laws of your state, of your locality and the bylaws of your individual Planning Councils. That is permissible in some places and can be a nice way to make participation a little bit easier for folks, but in other places, it's not permissible. It's even in some places not permissible by law, so be sure that if you're considering this, that you consider it and you actually look into what is permissible and is not in your jurisdiction.

Michelle. D: We have another few minutes. If you have additional questions, please feel free to chat them in. Again, I want to point you to on the Planning CHATT website, the slides from today's presentation will be posted there along with a recording. You can always find archived webinars there. If you're interested in hearing past webinars that we've done, you can find them there. As well as a number of the other resources that we've talked about today, the training guide, the compendium of materials and so on.

Michelle. D: I do see that another question has come in, we'll get into that. In our jurisdiction, we're struggling with reaching and engaging consumers that are younger, that are under the under 40. Are there any methods or ways that can work with younger people living with HIV? I think, Mike has a response if you'd like to give to that, how they do it in San Francisco.

Mike Shriver: One of the cross pollination things that we've had happened in San Francisco is our community engagement committee is responsible for an assessment, identifying the populations from needs assessments every year. Now that we're doing both care and prevention, when we do our HRSA mandated needs assessment, we're actually looking at specifically now those communities that are experiencing disparities and an equitable outcome from HIV programs. This year for example, we looked at people over the age of 50 people living with HIV long term survivors for whom we're also looking at having a difficult time recruiting those individuals to our Planning Council and be members in our Planning Council, because now 65% of San Francisco is over the age of 55 and living with HIV.



Mike Shriver: What we've been doing, our needs assessments and our focus groups and going out to those communities, we've identified agencies that are working with that community and also looking at agencies from other disciplines. We're looking at mental health and substance use as well as housing, as well as a variety of other now, for us, it's aging and support services, and going to them to have them help us recruit members for our participants for our planning processes and our needs assessment. In the process of doing the needs assessment, educating consumers and new individuals who are completely unaware of the Ryan White process, and using them as a beginning of a training ground or at least an education ground for this has been the venue for advocacy and attention to the needs you're experiencing as a young person, a person who uses substances, an individual who's aging and living with HIV.

Mike Shriver: We're actually looking at some of our other committees, our standing committees and what they do with the community to actually help with some of our recruitment or at least community and forming about what we do as a Planning Council and use that as our first round of education and outreach. I will say that as a result of that we actually just recently brought on, we're looking at one of our bigger population, the disparity of persons who use drugs, of substance use issues or concerns. We actually just brought out a new Planning Council member who came in through that venue of being part of the needs assessment process, to then being identified that they thought this was an interesting possibility for them, and then going through our training program, our mentoring program, and then coming on the Planning Council.

Michelle. D: I think our final question for today before we close out, and thank you all for the robust discussion, it's been wonderful. It's the issue that we're encountering or that the non consumer committee members are not recognizing the need for robust consumer involvement. They're asking about the bylaws that we recommended. They said, "I'll be taking that back to my Planning Council, but I might experience a lot of pushback. Do you have any suggestions on how to approach this?"

Sandra Vincent: Well, I don't understand that there might be pushback, but people need to also understand that this is a necessary thing to happen. I would also suggest that may be a conversation with the CEO, a conversation with your Planning Council leadership. When I mentioned earlier on in our webinar, the importance of going back and revisiting the roles and responsibilities. That's extremely



important because sometimes in the work of doing what we do, we forget about the importance of in the fact that there is a mandate that says that consumers have to be at the table, and they have to be a part of the process. If this is taking place in your particular jurisdiction, that means that folks aren't listening to what the law says, because the power is vested in the statutes and not in anybody's opinion. There just needs to be a reminder of what statute have established in that way for a reason.

Trevor Pearson: I think more importantly, what people need to understand is if consumers are in leadership positions in your jurisdiction, then you will have a better understanding of what needs to be done. Because, if a consumer is leading, you can bet that other consumers are going to get involved. One, because they can see themselves in that person. Representation means everything in our community.

Michelle. D: Yes, thank you. To bring it back, I do love this what is said in the chat here, "Nothing about us or without us is a powerful statement to remind them of maybe." Thank you for that suggestion that came through the chat. I think that's a nice way to bring ourselves full circle for today. I'll thank you all for participating, please do remember to complete your evaluations. Check out the Planning CHATT website, sign up for our mailing list, find tools and resources and more. Of course, if you ever have questions or need support, please feel free to reach out at planningchatt@jsi.com. Thank you all.