What Works in HIV Care & Services Podcast Transcript

Episode 4 – Text Me, Girl!

Narrator (00:01): You're listening to What Works in HIV Care & Services, a podcast by the Ryan White HIV/AIDS Program Best Practices Compilation. This podcast and the Best Practices Compilation are supported by the Health Resources and Services Administration's HIV/AIDS Bureau. HRSA's HIV/AIDS Bureau funds the Ryan White HIV/AIDS Program, which provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV. Join us to hear success stories from leaders implementing best practices in HIV care and services across the nation.

AJ (00:44): Hello, everyone! Welcome to today's episode of What Works in HIV Care & Services. My name is AJ Jones, I am a content developer on the team that brings you the Ryan White HIV/AIDS Program Best Practices Compilation, a free-to-use online collection of established and emerging approaches that work to improve care and services for people with HIV. In today's episode, we're talking about *Text Me, Girl!* a program aimed at improving HIV health outcomes for young transgender women. Joining me today to talk about their intervention is Dr. Cathy Reback. Dr. Reback is a Senior Research Scientist at Friends Research Institute, the Executive Director of Friends Community Center, which is the community-based research center, and a Researcher in the Department of Family Medicine at UCLA. Finally, she is also the Core Director at the UCLA Center for HIV Identification, Prevention, and Treatment Services. She's been developing behavioral interventions for sexual minority men and transgender women with multiple health disparities for over 35 years. Dr. Reback will be sharing her experience as the Principal Investigator, designing and implementing the *Text Me, Girl!* project. Dr. Reback, welcome. Thanks so much for joining us today.

Dr. Reback (01:55): Thank you so much for having me, it's quite an honor to be here.

AJ (01:58): We're very happy to have you. So to start out, could you tell us a little bit about the Friends Community Center?

Dr. Reback (02:04): I'd love to. Friends Community Center is a community-partnered research center in the heart of Hollywood in California. We work with sexual minority men and trans and gender expansive individuals with multiple health disparities. Primarily, those who are unhoused, engaged in the street economy, have experienced long or short cycles of incarceration, have untreated substance use disorders and/or mental health disorders. All of our intervention staff are peers. They are from the community with lived experience similar to our participants, some of them are even former participants.

AJ (02:46): Great! Thanks so much, Dr. Reback. In terms of the *Text Me, Girl!* project in particular, what inspired you to develop this program?

Dr. Reback (02:53): Well, HRSA put out a request for applications focusing on social media among young adults living with HIV. And I had just completed a text messaging intervention with a different population, and it showed efficacy and superiority with unidirectional text messages as opposed to bidirectional text messaging conversations. And it occurred to me that if it worked with one population, if we redesigned the text messages, it could work with another population, and it would be very cost-effective. So based on the previous studies, I started to develop the *Text Me, Girl!* intervention.

AJ (03:40): Great! And can you tell me a little bit more when you say unidirectional, what do you mean by that?

Dr. Reback (03:45): It means that the text messages are transmitted out, but there is no text messaging conversation. And we actually were quite surprised at the outcomes of the previous study and also the *Text Me, Girl!* study, because one would assume that if you're engaged in a text messaging conversation, there is greater opportunity to work with an individual. But in fact, we found that when there was a text messaging conversation, when we did a content analysis of the messages, it tended to get off of the subject, and the text messages that were unidirectional that they just were pushed out to the individual. They had a greater effect because they were very on target, they were very precise, and they were very specific to the population.

AJ (04:36): Got it! That makes a lot of sense. So then diving in particular for the intervention, so what is the *Text Me, Girl!* intervention exactly?

Dr. Reback (04:45): You've got to visualize a grid. And when you visualize the grid, think about the first row being along the HIV care continuum. With the first column, HIV positivity, physical and emotional health, and then the next column specific to linkage to HIV care and retention in HIV care, and the third column being HIV med adherence and viral load suppression. So, you have the top row with three columns. Then you go over to the second row, the third row, and the fourth row, and those are theories, the first being social support, the second social cognitive, and the third health belief. So, when you put this grid together, you have a text message that is along the HIV care continuum, and it has its theoretical foundation. So, the participant receives three messages a day at five-hour intervals. We had the default, which came from the community, came from the CAB that we worked with.

AJ (05:55): That's a community advisory board, as we call it, a CAB. We love to use our acronyms.

Dr. Reback (06:00): And the default times were 12 PM, 5 PM, and 10 PM, but those could be altered if the participant wanted to receive the messages earlier or later. But they had to be three a day, five hours apart, for consistency. And each message is along the HIV care continuum, and each message has a theoretical perspective. But they were evenly distributed so that once a day the participant would receive a message from that first column, HIV positivity, physical and emotional health. Another message on linkage and retention in care, and the last message on HIV med adherence and viral load suppression. And then one of the messages would be based on social support theory, one on social cognitive, and one on health belief model. There were 90 messages in each group for a total of 270 messages. Each message was entirely unique, nobody received the same message twice, and these messages were delivered over 90 days. So I'm going to give you just a very quick example of just two messages. Here's a message that is based on retention in care and social support theory: “Stay on top of your numbers with your doctor's help. Now that's trans pride!” Again, retention in care and social support theory. And then here's a message: “HIV meds can keep your trans body strong and healthy.” That message is from the column of HIV medication adherence, viral suppression, and its health belief model. So that's just an overview of what the intervention was.

AJ (07:54): Fantastic! Thank you so much, Dr. Reback. You really helped explain that grid really well. And for those of you out there listening, I'd encourage you to check out the profile about this online. So can you tell me a little bit about how you developed the content for your text messages and outreach and how it was tailored to specifically work with transgender women?

Dr. Reback (08:12): This was about a one-year process, but it was a one year process that I loved. I was so engaged in this. We have a fantastic trans-specific community advisory board that are very, very committed to the work and were very involved in the development of this. So we started with a generic text message library that we wrote for the previous study, and we pulled out those messages that were about living with HIV, and we pulled out the messages that we thought we could adopt, and we gave

those to the CAB. And the CAB spent a lot of time rewriting all the messages. I'll also say that at this time I had, I think about five or six trans women on my staff.

Dr. Reback (09:01): About half of those were young adult trans women. And the population that we were serving for this application was between the ages of 18 to 34. So we really utilized the expertise of the staff that fell into that demographic group. So the CAB took these messages, and the staff took these messages and they rewrote them, and they made them all culturally appropriate and culturally responsive to young adult trans women with HIV. Then the messages came back to me, and my job was to make sure that we had 90 messages from each group along the HIV care continuum and 90 messages for each group along the theoretical foundation. So I had to make sure there was an even distribution, and I had to make sure that there was a theoretical foundation for each of the messages. And that took a while, and I worked with a team, and then we brought the messages back to the CAB, and they reworked it again. And they made sure that they were culturally responsive to the population. In total, we had five CAB meetings, we had two focus groups, we had trans staff that looked at these messages very closely, and then we piloted all of the text messages with eight trans women. And again, it took a year. But when we finished, we had a unique library of 270 messages that I think everybody involved is extremely proud of.

AJ (10:42): Hey, fantastic! Thanks so much for that. So now that we have a good sense of what the intervention was, can you tell us a little bit more about how you got participants into the study? What did and didn't work in terms of recruitment?

Dr. Reback (10:55): Well, let me start by saying we had five recruitment strategies that we used. Each participant that was enrolled in the study could bring three participants. They could bring more, but total of three that were eligible could enroll. We didn't want more than three per participant. We did street and venue-based outreach. We posted fliers at Friends Community Center and at a lot of collaborative agencies around L.A. County. We did online recruitment, and we did a lot of just face-to-face interactions with the trans staff going out into the field. What didn't work for us, and it could work for other studies, but for us, online recruitment did not work at this time in Los Angeles when we were doing this study. There was a lot of mistrust in the community, and looking at recruitment ads online did not prove to be effective. What did prove to be very effective was just having the trans staff going out into the community and meeting people and talking about the study. And at first there was some hesitancy because it was a study specifically for young adult trans women with HIV, and you don't want to go up to somebody and say, do you have HIV? And what we found to be very effective was at the same time, we had another study for those that were HIV negative but at risk of HIV to initiate PrEP. So we went out with information about both of these studies, and we would approach potential participants and say, "We have this study about PrEP; we have this study about linkage and retention in HIV care. Are you interested? If so, which one would you want to hear about?" So we left it up to the participant to tell us whether or not they were interested and which of those two studies they would want to hear more about. And that proved to be very effective. The other thing that proved to be very effective was the chain referrals. One participant bringing in another.

AJ (13:09): Fantastic! And of course, we have to address everybody's favorite topic, which is how did you fund this program and do you find it sustainable over time?

Dr. Reback (13:19): Well, as I said earlier, it was funded by HRSA as part of their SPNS initiative, and it was in response to a application for social media among young adults with HIV. And we are very grateful for the opportunity that HRSA gave us to develop the intervention. In terms of sustainability, I actually think that this is an intervention that is very easily sustainable because the text messages are already developed. But also if you worked with a different population, it is very easy to change the text messages to apply to a different population, as we initially did when we developed it for *Text Me, Girl!* You just make sure that you have community representatives for the population that you're working with, and they'll help you to change the text messages to make them culturally relevant to any specific population, as long as you maintain the content and the theory, also because we clearly developed the text messages along the HIV care continuum and based on a theory, it's easy to either adopt the entire 270 text messages, or

maybe you have a HIV clinic, for example, that is already working with people that are in care but are not adherent or miss an appointment.

Dr. Reback (14:56): Well, you could adopt the text messages that are specific only to ART medication, and viral load suppression. Or perhaps you're a social service agency that wants to support their participants. You could adopt only, for example, the 90 messages that are related to social support theory. So it's very easy to take out the content that is relevant to a particular clinic or agency or to adopt the entire intervention. And again, in terms of sustainability, this intervention can so easily be translated to other populations.

AJ (15:41): Awesome, I love hearing from you about how you can tailor this intervention based on whatever your population is. Thanks so much for sharing that. So, Dr. Reback, my last question for you before we start wrapping up today is around outcomes. So how did you measure how well this intervention was doing, and what were the results of your intervention?

Dr. Reback (15:59): As I mentioned previously, we were very, very surprised at the outcomes, given that these were unidirectional transmitted text messages and nobody, including the funders, expected to get the outcomes that we did. We had an assessment for participants at baseline, all the way through 18-month follow-up, and we looked specifically at HIV care visits, ART uptake, adherence to ART, and undetectable viral load. And at baseline, those that were in HIV care were about 62% of the population, and that remained consistent. There was not any change. It remained consistent just about at every time point. However, ART uptake was at 49% of the population at baseline, and that immediate jumped to 67% at six-month follow-up. And by the time we did our 18-month follow-up, that had also jumped to 78%. Those that reported that they had excellent ART adherence, that means they never missed a pill or rarely missed a pill, was 5% of the population at baseline. And at 18-month follow-up, that was 44%, almost half the population, and the undetected viral load went from 35% of the population to 51% of the population, 51% at 18-month follow-up. So although these are admittedly far below the End the HIV Epidemic goals, it's still a remarkable improvement for where people were at baseline. So we saw that *Text Me, Girl!* participants demonstrated significant increases in ART uptake, significant improvement in ART adherence, and significant increases in achievement of an undetected viral load. And these improvements were durable and sustained all the way through the 18-month follow-up time point.

AJ (18:18): Amazing results. Wow, thank you so much, Dr. Reback, for being with us today and sharing your experience with the *Text Me, Girl!* intervention. To all of those out there listening today, we hope that you learn something new from that great talk with Dr. Reback today. To get closed out, we just have one final question for you, and that is, what does being part of the Best Practices Compilation mean to you, Dr. Reback?

Dr. Reback (18:40): Oh, it's an incredible honor. You know, every researcher wants to do their best work. And to have that work recognized is, like I said, it's such a great honor. That's the legacy that we want, is to do the work and to know that we're able to then pass that work on to others. And I so greatly appreciate HRSA recognizing the work that the whole team did on this study. And I am very grateful that I was able to lead the project. It's one of my favorite studies in a very, very long career that I've had, and I so valued the opportunity. And I also want to acknowledge the entire study team and the participants that were part of the study, and I hope people take the *Text Me, Girl!* intervention and adapt it for their population, and as I said before, pass it on.

AJ (19:41): Amazing, thank you so much, Dr. Reback. And again, for all of those out there listening, you can check out more information about the *Text Me, Girl!* intervention online at the Best Practices Compilation. You can find that at TargetHIV.org/bestpractices. Thank you so much, Dr. Reback, and to all of you out there listening today.

Narrator (20:02): That's it for today's episode of What Works in HIV Care & Services. We encourage you to check out the Best Practices Compilation at TargetHIV.org/bestpractices.