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Lora M. Church

Term: 2008–2012

Ms. Lora M. Church is a member of the Navajo Nation, Bitterwater Clan born for the Black Streak Wood Clan. She is the Senior Program Manager for the Acoma-Canoncito (To'Hajiilee)-Laguna Teen Centers. These school-based health centers are associated with the University of New Mexico Health Sciences Center and serve youth and families who reside on three American Indian reservations and in two Hispanic communities west of Albuquerque. Her key responsibility is helping define the interface between the primary prevention program and clinical/behavioral health, focusing on prevention and early intervention. She has more than 23 years' experience working in the health and human services field. In a previous position, she managed Native American Community Services, a nonprofit American Indian health and human services agency in Grefa cuo4 T 6.69 0 Td[()6.1(c)1.2xpfds,[()6.1 Mfchfg8.1(2c 0 Twsu- 6k9 a)]TJ0k204 Tc 0.0041 Tw -5.6995

Services Administration, Center for Substance Abuse Prevention (CSAP). In particular, he offers technical assistance and training to support cultural competency efforts, strategic planning, and evidence-based prevention programs and strategies at the regional, state, and local levels. Mr. Pavão also provides technical assistance to CSAP's Minority AIDS Initiative grantees.

Mr. Pavão has extensive experience with diverse communities, especially newcomer and underserved populations, and he has worked in both clinical and nonclinical settings. His subject and skill expertise includes more than 16 years in community development, evaluation, and public health programming. His interests include examining the cultural experiences of a population rather than race or ethnicity as a framework for developing health promotion tools.

Before joining EDC, he worked as community provider and project manager in HIV, substance abuse, violence prevention, tobacco control, youth development (especially sexual risk behavior), healthy school initiatives, and cardiovascular health and nutrition education.

Mr. Pavão has served as a board member for organizations that advocate for the needs of underrepresented segments of the population, including the Fulton County Commission on Disability Affairs, Georgia Equality, Atlanta Area Evaluation Association, and the Atlanta Lesbian Health Initiative. He presently serves on the institutional review board for Emory University and Morehouse School of Medicine. He has also been Commissioner of the Massachusetts Governor's Commission on Gay and Lesbian Youth.

Mr. Pavão received a master's degree in public administration from Bridgewater State College in 2004. He speaks English and Portuguese fluently, as well as conversational Spanish. Mr. Pavão resides in the historic section of Grant Park in Atlanta, with his partner James H. Doster and two dogs. In his spare time, he enjoys reading, theater, traveling, spending time with family an

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)

JUNE 8, 2012

COPR MEMBERS PRESENT

DONNA APPELL, R.N.
GARDINER GORPHAN) C.)TH(TT1R1NTf-0.0123 T0 -0.0009Tw 008(JU 0 LYNN 2> OLSO

J U N E .

WELCOME AND DISCUSSION

DR. TABAK: All right. So, I am assuming we are live for the cameras since you have all already had a chance to chat briefly.

I am Larry Tabak. I am the Principal Deputy Director. I am here today because Dr. Collins is in London, of all places, not London, Ontario, but London in the UK. He does send his regrets, but he is looking forward to hearing a summary of what has been discussed today.

I know you have already begun discussions about the COPR origins and the various ways that people receive and share and, importantly, act on information. Over time, obviously, all of those modalities have evolved and have changed.

So, the internet, for certain, has had a profound impact on our society. I am told social media does, too, although I confess that I am not up-to-date on any of that.

But, certainly, we are always looking, regardless of what the technology is, we are always looking at better ways to broaden public engagement. And so, it seems opportune to sort of pause and say, how can we, going forward, gather and consider input from the public in the

broadest possible way?

This morning I understand you heard from a number of folks, Jon Carson from the White House Office of Public Engagement, where I hear they bring in -- how many people a day?

MR. BURKLOW: A hundred and fifty every day.

DR. TABAK: A hundred and fifty every day? Boy, that would be quite a challenge.

And then, Justin Hermann from the GSA's Office of

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Again, we will have

were quite a few places it was brought up that that question itself is probably too broad. It is, how should NIH seek broader public input on...?" And unless there is some specificity to that "fill in the blank" -- so, you need to know what the issue is and you need to know what the audience is before you can really develop a meaningful strategy.

I would also say that I will raise the question, and now this is related to what is the role of COPR going forward. I think that, at least the way I remember it, it is that COPR has been looked at with the communication possibly both ways. So, it is getting input, advising on that, and, also, advising on pushing information out, which I think is a different question which might use different strategies. So, I think that is part of the question on the table here: what is the role?

DR. TABAK: So, information in versus information out?

DR. OLSON: Right.

DR. TABAK: Obviously, they are not mutually-exclusive, but they are different.

DR. OLSON: Ex12 and it gets back around to that specificity issue. Because if we are not clear about

COPR.

MR. BURKLOW: It is just, how does NIH use social media to engage the public?

MS. LAPHAM: Right. So, that is one question. How does NIH use social media to engage the public? And then, the other question is, what is COPR doing? So, there is this fundamental issue of what COPR's role is. And they are two very different questions, I guess is what I am saying. Whether it is information in, like just giving advice, versus spreading it back out, your membership might be very different.

DR. TABAK: Let me ask you to elaborate a little bit about pushing the message out. Because I appreciate input in is in some sense member-specific.

MS. LAPHAM: Uh-hum.

DR. TABAK: You can have certain input. You can provide certain input. If you have a sufficient number of people, you eventually get a very broad range of input. That is great.

But pushing information out, is that also member-specific or is that a more generic possible function or role? I mean, I am just asking. I don't know the answer.

So, I know your background with dental. So, I will give you a dental example. We know that periodontal disease, if you have it, they said it is like the sixth risk factor for diabetes. If you have periodontal disease untreated and diabetes, you are likely to have difficulty controlling your blood sugar. So, there shouldn't be a health center out there that is not making sure that all their diabetic patients are getting dental care, and yet there is.

And so, I see pushing information is to say, you know, we need to use these discoveries that we are investing in as a nation, and we need to put it to work in our clientele. That is one way I would see COPR collaborating.

We all have our own, you know, and let's put that information to work and let's find ways of collaborating better across these associations and to get that information out in usable form.

DR. TABAK: Right. Let me push you a little further, though. I think that is a very outstanding example. Get a little bit more into the weeds for me. So, here is the information. You review it. You know it is germane to the Community Health Centers around the nation. So, then, what

DR. TABAK: Right.

MR. NYCZ: So, then, I would be saying I would be lobbying within that Association to get a push from the Association that would make it receptive to a presence coming from the agency.

MR. BURKLOW: And, Lynn, you had a comment?

DR. OLSON: Well, related to this, yes. I agree with what Greg is saying. I think, though, that the potential value of the kind of folks who have sat around this table is that they are these conduits to the public. So, now I am talking about the pushing information out, pushing findings out.

So, you know, you have had really fantastic patient advocate group2dpatient advocate g(ng)TeTd(had)Tj-0.0126Tc

So, I think what I would have to say about pediatrics probably applies to a lot of medical societies in terms of mechanisms, how things work. So, it is a way of learning from that and amplifying.

I will give what is one of our favorite examples

MR. BURKLOW: I am curious; Donna has commented before on this whole issue. Donna, can you comment on it, please?

MS. APPELL: Well, just from what we were talking about before, I think that there is so much social media, so many ways that you can get a pulse of the people. I worry, I want to be valuable, too. I want to look for how I am most valuable.

And so, when I think about your biggest needs, personally, having a lot of experience being at NIH, it is that the NIH is terrible at playing their own trumpet. They just aren't really great -- they are humble researchers -- and they aren't really great at getting the message out.

So, my real desire to help is trying to get the message out. Even there is such a wealth of stuff going on at the NIH, and I have a circle of trust and I have these people that, if I send a message out, it is going to be a pebble in a pond; it will go out further.

But I live in a world where people don't even trust research, nevertheless, NIH. Like research isn't even a friendly word in some cultures.

DR. TABAK: Yes.

MS. APPELL: So, we have a lot of work to do with making the NIH palatable, not just in a scientific breakthrough from some enzyme or something, but research in general, and making it user-friendly and huggable and warm, which I know the NIH is.

DR. TABAK: Right.

MS. APPELL: I know that side of the NIH. And I really am struggling to figure out how we can best be most usable to make it seem like the world's friendliest place.

You know, I am thinking stupid things, like it would be great if there were a way for the social media to actually be able to interface with these COPR members. Like wouldn't that be cool if somebody could send an email to me, as a COPR member? I am supposed to be representing the public to the NIH. Does the public have anything, any questions or something that they would like to ask or something like that? And so, making us available to the public; does the public know that the public is being represented?

DR. TABAK: Interesting, yes. That is interesting. Okay.

So, in other words, be sort of beacons. You

know, here we are, if you have any questions or --

MS. APPELL: I am supposed to be representing you, and you know I am here, No. 1.

DR. TABAK: Right, right.

MS. APPELL: And do you have anything you would want me to talk to them about? Or do you have any questions about what the NIH is, about what I am representing? Start there.

DR. TABAK: Yes. Well, that's interesting.

MS. LAPHAM: Just building on that, what you just said, Donna, in the presentation from the man from GSA, he talked about COPR could serve as, we could monitor sort of some of the public feedback that comes in, just sort of sift through and try to distill, a little different take, I think, on what you are suggesting.

MR. BURKLOW: And that is just my idea of it, is that the monitoring or pulse-taking or getting a sense of what is going on that we may not otherwise know, but you would be the filter of it.

MR. NYCZ: I guess the issue for me with the monitoring is, again, we are just a few number of people with only so much time. You guys have lots of folks. So, the

value of the monitoring, if there is a value to the monitoring, it

So, the reason I am raising all of this is the right venue is when you are in the village perhaps or when you are with a group, and so forth. And that is portable to any set of issues, but this in particular, where you have communities where service is so dominant in terms of concern and thinking.

So, yes, maybe targeted outreach where you have people's attention, because the venues that we often have at our disposal, it may not be optimal.

MR. BURKLOW: So, just to encourage you to look at the questions. It doesn't have to be in order, either. So, if you see other questions you want to address --

DR. TABAK: Right. You know, it would be very interesting for me if people would comment on face-to-face versus other approaches. Because I am a self-confessed luddite; I already said that. But you are all probably doing this other stuff. So, I am just interested in what you think about it.

MR. NYCZ: Well, I will just say I am with you.

(Laughter.)

And I liked your comment about the gold standard. And we heard that, also, from the White House.

MR. BURKLOW: Actually, you heard it from everyone, including Greg Albright whose business it is to be in social media. He asked of everyone, "Who is on Facebook and Twitter?" And a number of us raised our hands. And then, he said, "Who is very active in the area?" And it is a smaller percentage.

And his point was that everybody is talking as if everybody is totally engaged in social media, and the reality is you may be to certain degrees or not. So, not to look at it as a panacea.

MR. NYCZ: And I would also say that kind of keeping in the eyes and ears thing, we are your eyes and ears in the community.

agency, and that agency was going out in the communities and handing out that free food to all the communities, everybody would say, "Boy, I really love that agency." And the agency never said who gave them the food. There is a problem with that. And that is what I see.

And so, I come back here and I say I urge you that your grantees should take up the flag and they should help be out there. And that is a natural thing for them to do, rally around. Let's circle the wagons, and we can all grow, if that happens.

DR. TABAK: Well, I know it was a metaphor, but we don't do food anymore, as you know.

(Laughter.)

It is a miracle that you even have --

MR. BURKLOW: We do water.

DR. TABAK: I brought my own, let the record show.

(Laughter.)

Yes, certainly I take your point. This is one of the things that drives me crazy and keeps John up at night, I'm sure, is this lack of willingness to share in the glory, if you will.

You know, the research was done at the University of X, and our great investigators did it because we have this wonderful research facility in the proud State of Y. And, oh, the money -- "And we are wonderful," you know.

see, their frequent face-to-face meetings, playing in the overall goal of public engagement?

I don't want to talk the whole time. So, I would encourage you all.

MS. APPELL: So, I will help with that.

MR. BURKLOW: All right. Thank you.

MS. APPELL: He was just mentioning that doing social media is certainly where it is at and stuff, but he actually felt that he got more out of it, then, once he has engaged people in social media, to invite them back to the White House for a face-to-face. And it was the face-to-face meeting that actually congealed, that made it all more palpable.

I think that discussion, if I remember correctly, came up when we were also talking about how social media can be difficult and problematic sometimes, certainly in pediatrics where people worry about vaccines or those kinds of things. He was saying that there is a great deal of benefit to bring the people to the campus, let's say, to meet the investigators, to meet the researchers. And that is when they get into this circle of trust.

Did I do that well?

MR. BURKLOW: Yes.

MS. APPELL: Thank you.

DR. TABAK: And I w

great value in increasing the granularity of the outreach. I mean, in my former life, I did a fair number of these types of talks, you know, community talks, Rotary-type talks, and so forth.

It is always amazing; yo13

that does great disservice to science, to take you back to one that was a while ago, it was, well, women should get mammograms after age 50. Now they should get mammograms after age 40. No, no, no, it is 50. Now it's 40. And then, the public doesn't see that.

than I think NIH would.

MS. LAPHAM: They are structured differently.

MR. NYCZ: They are structured differently, yes, but what I am saying is, to me, this is an opportunity.

DR. TABAK: See, in fairness -- I mean, I don't disagree with what you just said; in fact, it is very accurate -- but it is not our mission. See, CDC's mission is to reach out and do the public health outreach. What we do is we support the research that informs the public health approach.

Now, as an aside, a little inside baseball talk, I don't know if it is still true, but for year

but certainly one of the preeminent spokespersons.

So, there are examples of that, but it is an interesting point, when do we choose to step out and when do we choose to stand behind our mission. So, it is an interesting --

MR. NYCZ: Let me give you another one that involves dental.

MR. BURKLOW: I can't believe it. Dental?

(Laughter.)

MR. NYCZ: The American Heart Association --

DR. TABAK: Yes.

MR. NYCZ: -- just came out as a result of a recent publication in circulation.

You are familiar with that.

DR. TABAK: Oh, yes, of course. I funded the work.

MR. NYCZ: So, NIH maybe should step out on this one. Because the way they came at that made average people and even clinicians think, oh, all that stuff about connectivity, gone, because there is no causal relationship. Yet, there were a couple of people who felt that they had to write a disclaimer on some of this and say it, basically.

So, I am trying to convince our physicians that dental and mental should be integrated for all these good reasons. And then, I get blowback because, oh, the American Heart Association said there is no connection. Well, you didn't read it carefully enough. Let me help you.

DR. TABAK: The general principle that you are raising is a good one. And when does NIH make the decision to step out versus not?

MR. BURKLOW: Perhaps it wasn't a crisis or it is a crisis in a way. The obesity in America and the HBO series, you could argue that, well, we could tell the story without NIH. Well, NIH funds the research that informs all the public health practices and the clinical applications. So, we actually have an extremely important role in it.

And so, we certainly will remain one of the main players in it. So, it is a public health issue, but we were bringing the science behind the health or the science that will contribute to the health. And we do that in other ways, Alzheimer's earlier last month.

MR. NYCZ: But I guess my point is -- and this is getting us back to some of our past -- if you want to select some people from around the communities, and you want them to

as a group. And I wonder, like when we go around the table, when you are here or when Dr. Collins is here, and we have to give our little bit of three to five minutes -- you know, it gets lengthy for some -- that is not leaving our hat at the door, right?

But it gives much more color to the world we come from. So, I kind of struggle with, is that really what we need to be sharing? I think the more sort of focused we can be around a specific topic, whether it is obesity or whether the issue you discussed at the last meeting about race and diversity among researchers, I think it is much easier to leave your hat at the door when we have some kind of topic to ground us on.

DR. TABAK: Right.

MS. LAPHAM: So, it doesn't really answer it, but I think it is a very valid --

DR. TABAK: Well, no, no. No, it

many organizations that I leave my hat at the door, so I understand the whole idea not going to your own agenda specifically. However, when you are with a group of people that come from all different areas, my frame of reference and my knowledge -- for instance, I work a lot with Puerto Rican people and Hispanic people. I am not sure you need me to leave my hat at the door in a way. You need me to bring my perspectives, which is why I came to the table.

So, I understand that I don't want to talk specifically about one particular disease process, but there are some hats that I wear that you actually need to hear from. So, I kind of try to temper that leaving that hat at the door because you really need me, I hope someday. Maybe someday I will prove to be needed in something like that.

So, I think along with not always leaving (ou a511 Tw

challenge. How do you come up with the right mix of individuals? And you do have a great mix here, but I don't know if we should pat ourselves on the back. We may have just been lucky that we picked the right people.

DR. OLSON: And I think this is a really relevant question as you look to the future because there will be a lot of slots to fill.

(Laughter.)

I think it does begin with, I think, some clarity on this issue of what COPR should accomplish. But I guess my observation is that what has been good about this group is that it has had this diversity. And I know I came on, and it was really, personally, being able to -- because I talk with health people all the time, but from a narrow perspective, right, a group of pediatricians mostly.

But what I think would be important to continue to have around the table is this combination of you have gotten great patient advocacy groups of different types. I think it actually depends on the individual, well, with all the members.

I think it is important to have the provider community represented, and the different types. So, I think

then he got down to 40, I think, or something like that, and, ultimately, 20.

MS. LAPHAM: Right. So, there is the application process piece, right?

MR. BURKLOW: Right.

MS. LAPHAM: There was a shared, it sounds like, responsibility and sort of going through the vetting process. So, that was one interesting piece.

But, then, the other piece about bringing together experts from the field, like to say what should COtn8RTj-0.012

DR. TABAK: I am actually going to have to excuse myself.

MR. BURKLOW: Yes.

DR. TABAK: Thank you all for being here and for all that you are doing.

MR. BURKLOW: We are going to follow up with Dr. Collins as soon as we all can get together.

DR. TABAK: Great. Okay. Thank you all.

MR. BURKLOW: Thank you, Larry. Thank you.

MS. APPELL: Thank you for coming.

MR. BURKLOW: So, to stick with that question, the measurable goals of COPR, in your mind, how do you see telling somebody, "Oh, COPR is such a success because...." or "We had this impact because...."?

Donna, you're up.

MS. APPELL: The COPR of the past, I saw their goal. I saw their measurable outcomes. They published things. They created things. There was stuff.

And I think that is because they had something they had to do and they had to produce something. And so, I have a hard time answering that question until we figure out what it is that we are doing, for me to figure out what the

measurable goal for that project is. So, that's me; it is a question I can't answer.

MR. NYCZ: As someone who has had his own advisory committee and projects, I mean, part of my measure on that would be for COPR, because Jon said so, I mean, or Francis Collins said so.

The measurement of success of an advisory committee is, did they have input that the people they were advising found of value to help them? I mean, I think it is as simple as that.

We are here to help you. If we are not helping you, then let's not waste our time. If we are helping you, then you just need to let us know. Our time is valuable. I don't need anything more than that.

DR. OLSON: I would like to echo both of the things that have been said.

MR. LEWIS: Yes, I would, too. And then, I know when we first started, an article was published. Like I think it was our second meeting, and it was exciting to see how a discussion started on something important to NIH and became a tangible product, which was then distributed in a prominent journal as well.

And so, I think I would echo what Donna says. It is kind of hard to have goals when you don't have a project yet.

MR. BURKLOW: Okay. Just going back to the questions here, I think we have identified all of them except perhaps the next steps for COPR.

Go ahead, Greg.

MR. NYCZ: Well, I mean, kind of echoing what Lynn was saying, a next step would be to kind of grow the group a little bit, I think. Okay?

MR. BURKLOW: A couple of givens, for those of you at home watching us today who wonder the size of the COPR today.

(Laughter.)

Twenty-one is the capacity. We have hovered around that for a while, but we have gone down and we haven't re-upped, in part because of why we are talking today. I felt that we needed a shift or at least an agreement causTj 19 Tj 0 0 -0.

want to do.

Oh, and that is a great point, too. There are more members than this. It is just that we had to move the date around a couple of times and probably threw several people off. So, we have a larger group than this.

MR. NYCZ: But I actually like the way you conceptualized this when we were talking before about like rearview mirrors or blind spots, and so forth. But it is another guard against that. If that is the kind of thing that would be helpful, then that helps you in determining how to select.

MR. BURKLOW: Yes, to grow the group. We certainly will grow.

We can talk about the types of folks, and I think we have already, the expertise, the background of people we

may want to call on other outside experts as well.

The other point I think is to come up with at least a sense of the group, issues such as inward versus outward, you know, gathering input versus your role as ambassadors, those types of things. Conveners, one option would be you have decided to hold -- it is almost like you are the planners for those meetings that the White House was talking about this morning. Is that a role of COPR, to plan a series of those types of meetings or one meeting, or something like that? But you have helped design it, figure out who comes, what they are talking about. So, it is not just coming in and giving your individual advice, but you have helped orchestrate or be the architects for another way of getting advice.

MS. LAPHAM: I like that. And would it be possible for the next meeting, between now and the fall meeting, to have a small group come up with two or three options of what COPR could look like and really think through it?

MR. BURKLOW: Yes.

MS. LAPHAM: It is hard to do this.

MR. BURKLOW: Oh, yes. Yes.

before we recruit people to be on COPR and do all that.

So, one option might be that we end up being a convening group, or at least a portion of the meeting might be devoted to a particular topic you think that the NIH should pay attention to. And we are not defensive about things. So, maybe we have paid attention to something for 30 years, but you feel like it is time for us to pay attention to it again or things have changed. So, we have to be open to whatever you see.

And Larry said -- I didn't write down the phrase -- but he did say sometimes we are so close to it, you know, our perspective isn't as broad as yours. So, you are coming in from the outside. You see things we don't see anymore. It is like things in your house. You know, if you walk by them every day, they become invisible. So, you need to say, hey, look, you have that right there. That is one of the things that I was talking about before, the blind spots. I see an important function of COPR is to point out things that are blind spots.

And a previous Director used to say we can't start believing our own propaganda. I bring that up because sometimes I think NIH needs to be not humbled, but needs to

be brought down to earth and say, yes, you are a great agency, a great organization; however, you still need to pay attention to some of these things. I think that is a role of COPR, to be candid with us.

MS. APPELL: So, I think that is a great idea. To have a focus group before the next meeting would be great, and I agree with that and I would love to be a part of that.

I would also really like to have that PowerPoint slide. I do a lot of public speaking.

MR. BURKLOW: We will make sure you get it.

And part of what we were talking about before about the NIH communications plan, we are going to be putting together a new version of that with some other messages as well.

Yes?

MR. NYCZ: When we heard from the fellow from the White House, the White House doesn't go through all that work without wanting something in return. So, what we might want in return might be a little different than what the White House wants in return, but it would be helpful to try to articulate what it is we would want. Because I could see, at some level, if all you want to do is get the word out on what

Does that capture it accurately? Okay.

As part of the proposal, would this include the types of members we are looking for? I don't see it being tremendously different, but I think that has to be part of the conversation as we look forward.

practical standpoint, to have people who understand not only what it is about, but the challenges facing it and things that have been done or tried in the past, that kind of thing.

So, okay, any other?

(No response.)

I think we are kind of coming down to a time that is sooner than 3:30, obviously. But we don't want to just talk for talk's sake. So, does anyone else have any final comments or questions?

Greg?

months and vacations, so to make sure you are available.

But it is a good point. It has to be planned when we are ready. That is the only thing. I know, yes, that is true. It is true. It is true, right. Yes, and by that time, you can invite the new members.

Greg?

MR. NYCZ: I was just going to say, it has to be kind of, I mean, if you miss the fall meeting, you have got, from what I can see here at least, three --

the fall, we would sit down with the leadership.

MR. BURKLOW: Oh, no, no, no. I am seeing it all in the summer. I would like to get it all done by August.

MS. LAPHAM: Okay.

MR. BURKLOW: Yes.

MS. LAPHAM: Okay.

MS. APPELL: Speaking as a member of the class of '14 -- (laughter) -- I really think it is important, because of this history and because of what we just listened to, and because of the kind of growing pains that we are having, I vote for keeping the class of '13 longer. I just want to put that out there.

MR. BURKLOW: There is probably a good chance of that.

MS. LAPHAM: What is the status of the current application process?

MR. BURKLOW: We have applicants. I mean, we have applications from a number of people from before. And, yes, we can go through them and, also, if there are new -- well, you would certainly go through that pool, even if you had new elements that you were looking for in the COPR members.

So, anyway, thanks again, everyone, and have safe trips home.