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SCHOLARS & PILOT AND FEASIBILITY FUNDING Q&A SESSION

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>> MADELINE HALEY: All right. Can you see my PowerPoint presentation?

Yes. Okay. Perfect!

Okay. We'll give it a few more minutes, because I think we have -- we had a few more people sign up. So I will give it maybe -- at 12:02 our time. So 3:02 Eastern Time I will go ahead and start.

>> Hi, Maddie!

>> MADELINE HALEY: Hey. I think we're going to start in just a minute. I just want to make sure that everyone who signed up is able to join. So I will give it just another minute and then I will go ahead and get started.

>> No worries. Thank you, Maddie.

>> MADELINE HALEY: Mm-hmm.

All right. I will go ahead and get started. So good afternoon, everyone. Oh, Anna is the meeting recording? I can go ahead and record, if not.

No? Okay. I will just go ahead and press record.

Okay. Good afternoon, everyone. I hope you are all doing well. So today is -- we are going to be talking about the AIR-P Scholars Program and the pilot and feasibility funds. So thank you for those of you who were able to join. I'm assuming if you are joining, you have some more questions. So hopefully we will be able to answer those questions. Let me just do an overview first.

We are supported by HRSA, the health resource services administration. It's to provide pilot and feasibility funding to early to mid-career researchers for most -- mostly secondary data analysis. We also want to give an opportunity to provide mentorship training and professional development for those early to mid-career researchers and we obviously want to foster collaboration and expand our AIR-P network because we are -- we're at the -- since we have



started the UCLA -- since UCLA received the funding for AIR-P, we want to try to expand the network and we're just finishing up our first year of the -- what is supposed to be a five-year grant. So we want to definitely continue to expand that.

So a little bit about our organizational structures right now. We have the National Coordinating Center which is basically out of UCLA. Dr. Alice Kuo is the PI at UCLA. So the AIR-P grant is under her name. A couple of our activities and our organizations within the -- the -- you know, report to the national coordinating center, we have AUCD, who is -- they help a lot with our social media. They help a lot with our engagement, and they are also working on our database that we will hopefully have some more information updates about soon. We have the Autistic Researcher Review Board, which is our group of self-advocates, and we meet with them pretty frequently. We meet with them twice a month to make sure that our aims are aligned and that we are getting, you know, positive participatory community research in our studies and what we are doing.

We have our steering committee with the six research node leaders and some other faculty, and then we have the collaborating research entity. So those are the 15 -- I'm sure some of you are already from those research entities, that was what the last year's scholars -- the last year's program was open to only the CRAs but now we are extending it to serve.

So a couple of activities we do are the -- so we have obviously the pilot and feasibility funding programs. We have two research days per year. So we just did one in July. We have one coming up in November. We have our annual supplemented pediatrics that we are -- we are working to get that published, our first one and then we have our monthly webinars which AUCD also helps run.

So just an overview of our six research nodes. So we have primary care services; and quality, community-based lifestyle interventions; gender, sexuality and reproductive health;



health systems and services; neurology and genetics. These are the six areas that we have identified are most effective to help improve the physical health of autistic individuals and if you are an applicant, these are kind of the areas where you want to try to -- you know, focus your research. You want to try to tie it back to one of these six nodes. You know, one or more of these six nodes.

So who is eligible? Early-stage investigators or anyone who is interested in starting to do autism research. We do give some -- we want to -- you know, we encourage those who are underrepresented in gender and racial and ethnic groups and obviously autistic individuals are welcomed to apply. And US citizens or like a green cardholder, noncitizen national.

So we award -- what type of funding? We award up to \$50,000 per award, per application. So you can request, depending on what type of project you are going to be funding or applying for, you can request anywhere between 10 to \$50,000.

So a little bit about the type of funding that is going to be awarded. So it's direct costs only, unless you are a University of California institution. This is kind of just an administrative, I guess, loophole that we have identified. We can't use it for food or beverages because it's HRSA, it's federal funding. So we are not able to do that. So what we can use it for is research support, again direct costs. We can't do it for tuition fee remission. And we can't do it for salary or benefits of anyone who has academic appointment.

So yeah, when you apply, there are two kind of leaders and mentors that you want to identify as a scholar. So there's the project advisor and there's the career mentor. So project advisor is primarily the person who is involved in the, like, more detailed aspects of project. The career mentor is going to be just, you know, providing support and also help with the long-term goals of what you want to do with your research and what you want to do with your career.

So, yeah, the project advisor should be helping the scholar -- they should be working



together in the applications. That can be both the project outline which is due on the 7<sup>th</sup> and also for the full application once you would be invited to apply for the application.

So -- I'm sorry. I just -- yeah. So that's pretty much that. Career mentor, so I believe these people can -- the project advisor and the career mentor can be the same person. If you -- if you are kind of not really sure how to identify a career mentor, we can -- AIR-P can help, and assign one. We can use members within our network to see -- identify somebody who would be willing to serve as your career mentor. And the career mentors will meet twice a year with the steering committee, with the node leaders of those six nodes and the National Coordinating Center, UCLA, basically the administrative side.

And so these findings will be disseminated in a few different ways. We will be showcasing them at the Research Days. We -- ideally, it would be amazing if we would be able to have those -- some of those findings in our AIR-P supplements, our annual supplements in pediatrics. We can present them in our monthly webinars and eventually we would use it with our database that we are working on. Yeah, basically get the network more engaged.

Sorry. I see there's a question in the chat. I will finish my slides and then I will go -- most of this will be time for questions.

So application requirements. So we have the project outline which is going to be -- which is again, due September 7<sup>th</sup>. That's the 250-word abstract and essay-style questions and then once we review the project outline and we notify you of whether or not you, invited to apply for the full application and the full application has a little bit more information, description of the project, you will include bio sketches and your budget proposal and some letters of support.

So once you are actually awarded the AIR-P scholars funding, you will be responsible for providing a mid-year report which is 15 -- basically the halfway point and then the final report, 45 days after the project period.



We have some attribution language that we would like to you include on any kind of, like, materials published or disseminated. We basically need to acknowledge that HRSA is our funder for the AIR-P project. And plain language is required at the end of the project.

So you might be asking how will you be judged for these applications? So we have three different -- three different groups are going to be reviewing your applications. We have the National Coordinating Center here at UCLA; we have the steering committee and then the Autistic Researchers Review Board, and they will all be assessing on these different criteria. So it will be significance, approach, innovation, investigators, environment, ethical issues and community involvement and accessibility.

And this should also -- I believe this is already in the RFP.

So for community involvement, there are some resources that were also listed in the RFP. So we have -- we have articles on improving participatory research. We have Arnstein's ladder of participation if you are not familiar with that. We have some different guidelines, and we also have our ARRB did a presentation on autism acceptance month, on how to conduct quality participatory autism research. We have a lot of resources if you are stuck on how to include that in your application.

So how do you apply?

You submit -- so you submit the outlines by a survey that's going to be due, again, September 7<sup>th</sup>, 2021. So in -- just in, I believe, under two weeks. So here's the full timeline. So the outlines are due September 7<sup>th</sup>. We're going to notify you of whether or not you can pass on to the full application stage by September 22<sup>nd</sup>, and then you have a month to complete -- to submit your full application based off the project outline depending on what kind of feedback you receive, you might have to change a few things around based on the original idea for the project outline and then we will notify our awardees by December 15<sup>th</sup>, and then we want to have the



start of the project year and the start of the funding by January 15<sup>th</sup>.

And that is pretty much everything from my end. I'm sure we have a lot of questions.

If we would like help finding a career mentor, should we do this before the proposal due September 7<sup>th</sup> or can we include the request in the proposal?

Good question. Kashia, do you have any input?

>> We want to know what research node it falls in and a little bit more background information about it so that we can reach out to the ARRB network to try to find a good mentorship match, but definitely let us know as soon as you can.

>> MADELINE HALEY: Yes. What is the balance between the mentorship and career development versus the research plan?

So I think -- again, I think there's a little bit of overlap and I think -- I think in our previous scholars -- our previous applications, there was -- there was the same person who was the career mentor and the project advisor. So, you know, there is probably a fair amount of overlap. I think that the career -- the career -- oh, in terms of judging the proposal. Okay. I'm sorry.

>> KASHIA: Help me understand the question a little bit more. Are you asking how much the, like, mentorship aspect is judged versus the research plan of the proposal?

>> KAREN: Yes, yes, I'm thinking I served on like NIH committees and like a K award, where -- when we review, it it's equally judged between the career development, the need for and the plan for that. I mean this wouldn't be a plan for career development, as well as the research. If it's not, like, you know the best quality research project, it should be good but that's what I'm wondering where is the balance in terms of how it will be judged?

>> KASHIA: Yes, there needs to be a level of rigor in the research and then we are looking for in the mentorship that there's somebody that can help to support and pull that project across the finish line so to speak, right?



So I think that while we are evaluating the mentorship and like the goodness and fit of the mentorship with the application, I think we're also really looking at the research itself, and the research plan and how it relates to autism and physical health and with the greater goal of the AIR-P and trying to promote overall well-being for autistic individuals and making sure that their voices are included within research.

But let us know if you have any additional questions. That's a good question. Thank you for asking.

>> MADELINE HALEY: There was another question about whether or not primary data collection will be funded or if it's just secondary data analysis.

I am not positive on this.

>> KASHIA: Yes, definitely both. Especially on some of these -- we know in some of these areas that the research nodes fall into -- or actually, all of them, there is not enough research. So sometimes secondary data analysis, going through and seeing what has been collected in some other areas can be a really good start and our team at Drexel, the health services and systems node, they work on quite a bit of secondary data analysis. If anyone is interested in that and has additional questions or needing to connect with some -- with the team about possible data sets or anything like that, we can also connect individuals with -- with the team at Drexel and the health systems and services node.

>> MADELINE HALEY: Have any of the steps to apply for funding changed since first round?

Yes, for this RFP, we are including a project outline phase. This is to mostly help our side, the AIR-P network evaluate the outlines before moving forward, and also hopefully, you know, if you do -- or if you do not get approved, then you would -- you wouldn't have to submit a full application. So, yeah, that's the primary thing that's changed.

The full application steps, however, are essentially the same as they were.



>> QUINN: So there's no need to submit bio sketches and all of that information until the initial survey response is set?

>> MADELINE HALEY: Correct. Correct.

>> QUINN: Okay. Thanks.

>> MADELINE HALEY: Good question, Samantha. If the data is free for secondary analysis, what might we plan for the funds to go towards? I believe usually, it's some kind of analyst or someone who can help do the data analysis. That's usually what it would be for.

If the data is free, that's a good point. I would assume mostly towards an analyst.

What is the percent you expect to fund?

Well, can we say what percent we funded this past year was, Kashia and Emily? Do you have any problems with me saying that?

No? Okay. Well, we received 16 applications -- we received 16 applications last year, and we funded nine. So about 56. It's 56%. That being said, we only had those applications open to our Collaborating Research Entities, those 15 institutions that are collaborating with our network. So we're not sure how many applications we'll be receiving this round. So that percentage might change. I hope that answers your question.

Wouldn't that be salary support if you fund an analyst.

Yes, but it's salary support -- sorry, the funding -- what you are not supposed to be funding for is salary support for those who will have an academic appointment. So like a faculty, you wouldn't want to be doing, that but if it's like a staff member, then you can -- you would be able to use the funding for that.

>> KASHIA: Another thing is to fund the projects. I know in some different instances, you can use quite a bit of funding towards percentage FT of individuals on the project, and our goal -- that isn't really the goal of this program. We really wanted to fund projects that wouldn't



otherwise be possible without -- without more support.

There also have been some different ones -- or some secondary data analysis projects where they engage with individuals, autistic individuals, and they will provide support for individuals that are helping with the project in different ways.

Would a graduate student be considered an academic appointment?

Yes, so there's not any salary support offered through the project for those that are -- that have an academic appointment. So somebody who was going to be working as like a study coordinator or something on the project is possible. And then in the past, we did have -- there were small stipends that individuals did give to graduate students within the Scholars Program, but there wasn't any percentage of tuition or anything like that funded. Again, we are really trying to focus on the things that would be absolutely necessary in order for the project to -- to be able to happen, and aren't really able at this time to be able to, you know, fund somebody for a year or something like that.

Does that -- did I answer your question, Samantha.

>> MADELINE HALEY: My understanding was I don't believe a graduate student would be considered an academic appointment. I believe it's just faculty members that have academic appointments; is that correct?

>> KASHIA: There wouldn't be an FTE to give to a graduate student, or act as a study coordinator to push the different administrative and perspectives of the project along. As we all know, oftentimes the project coordinators and the program managers are the ones that really keep everything -- keep everything going.

So I think that that had been done in the previous year, which I think worked out well. But when you are funding a certain percent FTE, then there are other additional benefits that go along with it, that adds additional cost. And then getting into things like tuition when we are



talking about graduate students. So stipends, I think is the best way to be able to -- to include a graduate student in a paid roll on the project.

One note about the mentorship, so the career mentor and the project mentor, it can be either. There's not really a focus of it being two person or one person but rather who is adequate to fill that role. You may have an individual who has a good career mentor who is helping them figure out their place in the research world, and in guiding them and scaffolding them along the bigger picture career, but that person might not be really that good of a fit for the specific project that they want to work on for this application.

So then in that case, it would be better to have a different project mentor who is more knowledgeable in that area, and could really provide more specific expertise. So it's really up to what would be the best fit for your project, and then the individuals that you have as to whether or not it would be the same person or one person. And either one is fine. It just needs to be explained.

Jennifer, let us know if you have any other questions about the mentorship. It's detailed a little bit more in the RFP, kind of about what we're looking for from each one of those roles, but the gist of it is what I had just provided.

>> MADELINE HALEY: Oh, example projects? Sure!

Give me a second to pull them up.

I dot no have them off the top of my head, but --

That's a good question, Quinn. So not necessarily. We didn't get a ton in the genetics or neurology node. It was primarily in the other -- it was primarily in like the gender, sexuality, reproductive health; health systems and services; and then the primary care services and quality. It was primarily in those nodes but, again, we -- that might change with this round of applications.

>> KASHIA: I know from the last round -- the example projects, there was one related to the



genetics node that was doing some secondary data analysis. There were a few that were related to increasing access to diagnosis. There were some really interesting ones related to getting out the experiences of autistic individuals that were in the gender, sexuality and reproductive health node that were funded that, you know, you will be hearing more about.

And then Maddie can probably give some other examples of the ones from last round.

>> MADELINE HALEY: Yes, sorry, give me one second to pull them up.

>> KASHIA: I think we did get one from at least most of the nodes. I think we got one application from most of the nodes, but as Maddie said, it was much more heavily focused on those four.

>> MADELINE HALEY: Sorry, everyone. Let me just share my screen really quick so I can show you what some of the example projects are.

So yes, as you can see, a lot of them are about, like, increasing access to care. So these are some examples. Informing the design for minorities. We do, you know, sexuality education. Developmental assessment for next infant. It can kind of vary. There's a lot of different ideas. I hope that answers the question.

>> KASHIA: And I think we did have, Maddie, individuals reach out about a particular idea. Whoever was asking that question, they were asking what node it would fit into. Correct me, I remember we had a few people, hey, is this along the lines of what you all were looking for?

>> MADELINE HALEY: Yeah, and, again, if you have like a general idea of what Kashia said, feel free to contact us and we will hone in on the scope and how it relates to one of our nodes.

>> KASHIA: The questions are really helpful because it gives us an idea on what we need to provide more clarity on.

Does anybody have any other questions about the Scholars Program that you would like to discuss?



>> MADELINE HALEY: No?

Oh, that's a very good question. Direct clinical application.

Kashia or Emily, do you want to weigh in.

>> KASHIA: I think these research nodes, really there's not a ton of research in any of these areas. We are trying to spur any research along these lines in the specific areas of autism and physical health. So I don't think that it has to be something related to direct clinical application, right? There's great secondary data analysis giving a baseline or giving information about -- about kind of what is occurring and the experiences of autistic individuals and I think that that is -- is obviously also really helpful right now to have in the field. Emily, I'm not sure if you have anything else to add.

I think we value both types of research.

>> EMILY: Right. Agree. And we understand that it may be challenging with the resources provided to have a really robust clinical application, but we would like to see at least ties to how it relates to translation or clinical practice or anything like that.

>> MADELINE HALEY: All right. I think -- I'm hesitant to wrap up early, in case there are people who have those questions, but maybe I will just give it -- we'll give it a couple more minutes and let's see if you all can think of any burning questions or if there's any stragglers.

I will send the slides -- and, again, this is also recorded. Again, thank you for coming to this and thank you for asking your questions. This helps us as well. I will give it a few more minutes and if we have to any other questions.

>> ELIZABETH: I'm sorry, I came in from a meeting and so I came in late. I was going to ask where the recording is going to be held as well if there's a point person for follow-up questions since this meeting is getting ready to adjourn.

>> MADELINE HALEY: Yes, this meeting is recorded. We can put it on our AIR-P website



and we can also send it to AUCD.

For the questions, you can email our AIR-P email which I will put in the chat right now.

>> KASHIA: And we have time, Elizabeth. And feel free to ask your questions in the chat or out loud. We had planned for an hour. So if you have additional questions, we are happy to answer them. You are actually not late. You are right on time.

(Chuckles)

>> MADELINE HALEY: Okay. I think we'll probably be good to go then. Again, please --

>> One more question.

>> MADELINE HALEY: Oh, yes okay.

>> I was typing it in the chat.

>> MADELINE HALEY: No worries.

>> I had one more question related to just thinking along the lines of the genetics node, how autism specific does the research have to be, just because there's a lot of genetic mutations that are -- have a certain percent associated with ASD, but in studying it, you also have ID or other sort of developmental disabilities. So it may be like mostly autism, is associated with this genetic condition that we want to study. Is that okay if it's mostly autism?

I don't know.

>> MADELINE HALEY: That's a really good question. And it's actually something that we have been talking about internally with the network as well. We just had a discussion about this. Yeah, I again, genetics can be -- there's a lot of things going on with that. So, yeah, I think that if, you know, it's mostly autism, and other developmental disabilities, I think that that would definitely be appropriate.

>> KASHIA: Yes, definitely. One the things that's happening within the genetics node is trying to create a registry, and make registries more accessible for rare diseases and genetic



diseases that are related to autism, you know neuro developmental disabilities and so exactly along the lines that you are asking Andrea, is something that would be possible for connection with the AIR-P network and especially for the Scholars Program, because there are quite a few families and individuals that are getting more connected and information about some of these not as commonly occurring disabilities, would be really helpful for them and that's one thing that the AIR-P network wants to try to encourage and help facilitate. But definitely let us know if you have any other questions.

>> ANDREA: Thank you.

>> MADELINE HALEY: Of course.

>> QUINN: Even though we are focused on one research node, would it be helpful or beneficial to cross nodes with one -- with our focus mainly on one node? Because I'm thinking of an idea that's primarily focused in the gender node but I think it naturally also dips into multiple other nodes.

>> MADELINE HALEY: Yeah, so it's definitely -- I mean if anything, that's probably more the better, because we want something that can connect with at least one node and if it sounds like if you can find several areas where it, like, applies that would definitely make sense.

We do have -- I believe in our survey, we have an option to list a secondary node which would apply, but, yeah, I would definitely try to connect it as much as you can to one single node, and then, you know, in your application if you want to describe the ways that it connects to the other ones, that would be -- that would be good as well.

>> QUINN: Thank you.

>> KASHIA: I would agree, Maddie. I wouldn't say that we would favor one, more than others since there's so much work that's needed in each of the individual nodes but I think it was pretty common that we had ones, from the last round where they would choose a primary node



and a secondary node because as you were getting at Quinn, it would really be focused on one but it would also relate in another. So that's no problem.

>> QUINN: And I'm sorry, just one last thing. You said that there wasn't a lot of applicants in the genetics node and which -- and what was the other node that you mentioned?

>> MADELINE HALEY: Neurology.

>> QUINN: Neurology. Thank you so much.

>> MADELINE HALEY: If you have a really great idea in one of the other four nodes -- we don't have any quota to fill, so to speak, you know?

>> ELIZABETH: I actually do have a question and forgive me if you have already gone through this you can refer me to the recording if that's the case and I will happily view it. Just a little bit point of clarification. So when it comes to the application, I noticed that the mentorship piece, as far as having the career and the project advisor -- so I'm actually a junior faculty. So recent graduate student and so wanting to know when it comes -- you know, those types of roles aren't so clear anymore. And so I wanted to kind of get some more insight to -- you know, for people in my situation, what would you recommend our ideal people to ask for this type of support?

>> KASHIA: Yes, I understand and I can relate.

(Chuckles)

So I think that if -- don't feel like your career mentor necessarily has to be somebody who is an expert in autism and physical health if that guidance is helpful. Because if -- your career mentor, it could be somebody who is helping you with the kind of bigger picture along the way and I know as you are faculty and as you move into -- into different roles, that that mentorship sometimes gets a little bit fuzzier, but, even individuals who have been in the field for 30 or 40 years will oftentimes still have those that they will reach to when they need that bigger guidance,



and trusted people who they bounce ideas off more. That's more the focus with the career mentor.

And then for the project advisor, especially being, you know, an early career researcher and then it is -- it would be important to have somebody who does have some more knowledge base in your more focused area to scaffold the project specifically and help to pull it across the finish line. So that's what we are looking for in those two roles but it can be -- it could be one person or two people. If you have an idea that fills both of those roles, then it's okay for you to be able to use them as both the project advisor and the career mentor and then sometimes they -- the individuals need to pull from, you know, two different people in order to fill the kind of needs for those two separate roles.

Let me know if that doesn't answer your question, though.

>> ELIZABETH: Yes, no, that was helpful. Thank you very much.

>> KASHIA: Of course!

>> MADELINE HALEY: Okay. I think that we might be able to end it short. 20 minutes.

So, again thank you all for attending. Please feel free to email our AIR-P email if you have any questions. I will put it in the chat one more time.

And yeah, we're looking forward to seeing the applications that come through. So have a great rest of your day, and take care!

Bye, everyone!

