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AUCD

Introduction to the AIR-P

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KASHIA ROSENAU: Hello, everyone. Welcome to the introductory webinar for the Autism Intervention Research Network on Physical Health. I'm Kashia, a project scientist on the AIR-P. We are beyond excited to share our vision with all of you, and I would like to thank all of you for joining us today.

So before we begin, I would like to address a few logistical details. We will provide brief introductions for each of our speakers, and we will also reserve time to answer questions at the end of the presentation. Because of the number of participants, you can submit questions at any point via the chat box on your webinar console, as everyone will be muted.

This webinar is being recorded and will be available on the AIR-P website in the near future.

There will be an evaluation survey at the close of the webinar. We invite you to provide feedback and suggestions for future webinars, as the AIR-P will be hosting monthly webinars beginning in January, so this is the first of many.

In the interest of time, let's get started.

It is my honor to introduce the executive director of the Association of University Centers on Disabilities, Mr. John Tschida.

JOHN TSCHIDA: Thank you for joining us today for this introductory webinar. We are thrilled to be partnering with UCLA and more than a dozen other AUCD members on these apprenticeship grants. We are excited to see the research that will be produced, the collaborations that will result from it, and ultimately the benefit that it will do for the broader scientific and disability communities.

It's my honor to introduce our funder for this project, the Health Resources and Services Administration, and thank you to Laura Kavanagh at HRSA. They have been great partners, and we look forward to working with them on this project.

LAURA KAVANAGH: Thank you so much, John. It's a pleasure to be with you. Good afternoon or good morning. I'm Laura Kavanagh, Deputy Associate Administrator for the Maternal and Child Health Bureau at the Health Resources and Services Administration.

Before we get started, I would like to introduce and acknowledge your project officer for this research network, Dr. Jessica Deberry. First and foremost, congratulations on successfully competing for the autism intervention research award. I want to really thank you for your commitment to moving the field forward.

I'm going to tell you a little bit about the history and background of our agency, put a little context around where this research network sits within our agency and what I hope we will achieve together in the coming years through this research network.



As you may know, HRSA is the primary federal agency to improve healthcare for geographically isolated economically or medically vulnerable populations. The Maternal and Child Health Bureau's mission is to improve the health and well-being of America's mothers, children, and families. In fiscal year 2019, the MCH services block grant, the public healthcare system for maternal and child health population in the United States, served an estimated 60 million women, infants, and children, including children with special healthcare needs. That included 92% of all pregnant women, 98% of all infants, and 60% of all children nationwide. Our programs rely heavily on data, and your research makes the difference in the critical contribution to that evidence base.

The AIR-P is funded through our division of research in our office of epidemiology and research within the Maternal and Child Health Bureau. The MCH research programs inform practitioners, the scientific community, as well as the general public. The division of research administers four broad grant competitions. These include the first, which you're a part of, the research network program. The second is a field initiated innovative research studies program which we call the first grants. Next is the secondary data analysis research studies program, known as our SDARS grants, and finally, single investigator innovation program, or SIP.

Roughly half our portfolio focuses on the child emphasis and the other half is specifically focused on autism. The AIR-P research network falls in the autism research network grant competition, and it's our largest research network investment at \$3 million per year.

The maternal and child health research network program has contributed to improving the lives of mothers and children in enrolling approximately 10.1 million participants in 250 research studies, publishing over 1100 peer reviewed publications, developing and distributing 281 clinical guidelines, tools, and tool kits to service providers and families, and leveraging over 116 external grants.

I encourage you to familiarize yourself if you're not already familiar with the other autism research investments that are part of your family of research programs within the Maternal and Child Health Bureau. There's the Autism Intervention Research Network on Behavioral Health; the Developmental Behavioral Pediatric Research Network; the Healthy Weight Research Network; the Autism Longitudinal Data Project; and the Autism Data Research Project.

As you will be hearing shortly, the purpose of AIR-P is to establish and maintain an interdisciplinary multicenter research forum for scientific collaboration and to have a shared infrastructure to build upon. This research network will provide national leadership in research to advance the evidence base on effective interventions for children and adolescents with autism spectrum disorder and other developmental disabilities, with a particular focus on addressing physical health and well-being across the life span.



Thank you so much, and again, congratulations on the award. We really look forward to learning more about the great work of this research network. Take good care.

KASHIA ROSENAU: Thank you.

Next I am pleased to introduce the principal investigator and the director of the apprenticeship, Dr. Alice Kuo. Dr. Kuo is a professor and Chief of Medicine-Pediatrics at UCLA and the director of the UC-LEND program. So please welcome Dr. Kuo.

ALICE KUO: Thank you so much. I am so excited to be able to share with you our vision for the AIR-P.

As Laura mentioned, this is one of the investments of the Maternal and Child Health Bureau focused on autism. For our particular project, the AIR-P, our hope is to establish and maintain this interdisciplinary multicentered research forum in order to address physical health related questions that impact autistic individuals. We hope to provide national leadership in research in this area and to spur on more investigators to join our efforts. And I want to go over a lot of the ideas that we had for how to do this.

Our overall goal is to develop effective interventions for autistic individuals with a focus on addressing their physical health and well-being across the life span.

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So this is the structure that we have set up so far. We were awarded at the beginning of September, so we've been quite busy over the last 3 months. At UCLA is our national coordinating center. This is really the administrative core or the hub that is overseeing the development of all the different little components in the network. The national coordinating center comprises of myself, Kashia, Dr. Emily Hotez who you will be hearing from a little bit later on, and a small staff to help us with website development, communications, and so on.

Our partnership with AUCD is an extremely important component of AIR-P, and we are building upon their networks of over 133 university centers that have either a LEND program, a UCED, or IDDRC. I know that's a lot of alphabet soup but these are basically university efforts to address either training of professionals in neurodevelopmental disabilities, advocacy efforts, policy efforts, as well as basic science research in the IDDRCs.

So with that existing network, we're hoping to leverage those relationships and introduce this field of AIR-P more broadly.

The other thing, so network management is one component that AUCD is doing for the AIR-P, and the second is the data repository. Many of us who have been funded on either a LEND, IDDRC or UCED project is aware of the national information and reporting system, NIRS, that have been set up by AUCD to help with collecting data for reporting purposes to the federal government.



And what our vision has been for AIR-P is to develop an analogous reporting and information system for research. One thing that NIRS does not do right now is capture research information. And we have been in many conversations over the past month with data experts and security and compliance experts because research information is maybe a higher bar, especially if we're talking about protected health information. And we've been trying to figure out how to create this platform that would make it easier for researchers to not only collect data for their studies but then also have that data be able to be combined for purposes of additional analyses.

We're also looking at supporting with some of our efforts genetic syndromes. And the desire of families who have children with rare diseases or orphan syndrome to create registries. So we're looking at having the ability to do that as well through these powerful data structures.

So that's one component of AIR-P. The second is the Autistic Researcher Review Board. We have a couple members from that board who will be giving a presentation and explaining what they do. I have found them extremely powerful and important collaborators in this effort. And already in the short time that we've been working together, I have learned so much. So I'm excited for you to learn also the part that they play in the AIR-P in the next presentation.

The third component of the AIR-P are the research nodes. We've identified six which I'll go over. These are a result of pretty significant literature reviews and expert interviews to identify what were the priorities regarding physical health of autistic individuals. And the leaders of those research nodes comprise our steering committee, and these investigators are really trying to guide the direction that the AIR-P is headed.

I will say that through a research agenda, a national research agenda for AIR-P, our hope is that the agenda is fluid and dynamic and can modify over time based on the direction that research goes. And so I guess we will hear a little bit more about that later on in the presentation, but the main point that I would like to make is to say that this is an iterative process and we welcome input from members of the network, the entire network, which includes all of the attendees on the webinar today, and anyone listening. So we really do want to hear from a diverse group of stakeholders and opinions on where research on physical health for autism should go.

And then finally, our fourth component are the collaborating research entities. These are members of the existing AUCD network that have made a commitment to helping us get started. So these 15 research centers, university research centers, are giving us input already and meeting on a regular basis and forming committees that others can join. So there's a lot of interest and activity going on in that component as well.

So with those four components and a national coordinating center, our goal is to accomplish the three bullet points in the orange box. So those include launching and AIR-P scholars program,



as I mentioned. We would really love to focus our energies on cultivating new investigators in this field. This includes doctoral students, postdoctoral fellows, and junior faculty. Along with existing researchers who may be pivoting or developing a new interest in physical health. So all of those investigators can come together in our scholars program and network with each other. In the scholars program, we hope to be able to fund with some pilot and feasibility funds, you know, pilot studies so that they can lead to bigger awards, as well as identify mentors not only in the scholars own institution but throughout our entire network. This is a newer field and not every institution may have researchers who are doing research on physical health for autism.

Once we have our scholars, we need opportunities for them to present their work. So we are hoping to develop an AIR-P Research Days in conjunction with the AUCD annual meeting in the winter, November-December and also the annual HRSA CARES conference in the summer. So an additional research day focused on health in autism, then investigators will have an opportunity to present their work and spur on conversations and collaboration.

And finally as a place to publish their work, we are planning for annual supplements in the journal of pediatrics as the AIR-P previously have done in the past. Our goal to produce a supplement every year with 15 or so research articles. The presentations from these Research Days and the work from the AIR-P scholars will have an outlet to be able to disseminate this, their projects to others.

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So these are the research nodes that we determined through our proposal process. And I'll just speak briefly on each one.

In the previous work that I did as the director of the healthcare transitions research network for autism, we had conducted a number of stakeholder interviews trying to identify what were the issues facing youth and young adults with autism and what their families were facing when it came to their physical healthcare. And the number one thing they identified was finding a good primary care provider. And so we recognize that primary care is an important aspect to addressing the physical health of everyone, and that much work can be done in primary care to improve the patient experience of care as well as making sure that the quality of primary care is appropriate, that patients receive all of the appropriate, you know, routine health recommended services. So cancer screening, immunizations, those types of services. And so I'm actually leading that node as a primary care provider myself, with a background in health services. So those are the types of projects that we're looking for in that node.

The second node is a community-based lifestyle interventions node. When it comes to physical health of everyone, many lifestyle behaviors can affect our cardiovascular and cancer risk.



So for example, nutrition, physical activity, stress reduction, sleep quality, those are all lifestyle behaviors that impact our physical health. So that node is going to be looking at programs and interventions that can help autistic individuals improve their physical health status.

The sexual and reproductive health node I think is a very exciting one because there has been a paucity of research in this area, and it is very important to autistic individuals, not only sexual education in traditional sexual health issues such as contraception and screening for sexually transmitted infections, but also sexual and gender identity, pregnancy and women's health issues I think have intersectionality with autism. So more research is needed in this area to improve the experience of pregnancy for autistic females, and to address many of these issues.

The fourth node of healthcare transitions is pretty standard and has been identified as an opportunity to ensure that autistic individuals over the life span have a good start into having good health as an adult. And so typically autism has been considered a pediatric condition because it's developmental. But we recognize that autistic children turn into autistic adults and that the transition of the systems, in between the two systems can be somewhat difficult. For many autistic children and their families, there is this reference to a service cliff where because so many of the services are wrapped into K-12 education and special education services, that in adulthood, there's no analogous structure. So families sometimes are a little bit at a loss as to how to navigate that transition into adulthood. And so care coordination, thinking about postsecondary education and employment, and then the benefits, the public benefits that can be available are all areas that are important and need additional research to understand how we can better address these issues.

In the neurology node, I think this is very firmly physical health. I think autistic individuals sometimes have cooccurring neurological conditions such as seizures. Dr. Wilson is also very interested in the neuromuscular issues. So fine motor, gross motor development as well. And so she is leading up that need to look at these maybe a little more typical comorbidities or cooccurring conditions that are associated with autism.

And finally, our genetics node I think is very exciting. Dr. Julia Martinez is leading that one. I made some reference to rare and orphan diseases. As more genetic research is done, there is identification of more and more conditions. And families needing to connect with other families for support and also to spur on more research in those particular conditions. But also just the value of genetic screening and identification of additional genetic risks that are associated with certain mutations and so on and so forth. And so there's a lot of need for more work in that area, and we're working on this node very closely with the autistic researchers review board to make sure that the research in this genetics node is done in a very ethical way that addresses the concern that many autistic individuals have.



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And so I just wanted to go through our vision for the research engine. I know that I have just a few minutes left. This is the main piece of it, which is that a research study would go from step 1 to step 5 through all the different components that we're building. The proposal can come from anyone throughout the network, and we will help to packet that proposal into an implementable study. And that data collection can be also from anywhere in the network.

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So when someone submits a proposal, it would go under three reviews: Administrative review by us at UCLA to make sure all the pieces were there. Content review by the steering committee. And a review by the autistic researchers review board to ensure that the study is of relevance to autistic individuals.

The package includes creating things like an IRB template, research protocols, data collection, survey methods, things like that. And the package would then be uploaded into this electronic platform that we're creating at AUCD.

When the package is uploaded, then any network member who wants to participate in that particular study is able to then download the package and then start data collection in their site. The idea is that, for example, if you are a new investigator, and I'll just pick a random place, at Washington University in St. Louis, just as an example. If you're a young investigator there or new investigator there and you want to collect data on 100 autistic patients with a particular focus, it would be harder to collect data in one site to try to identify 100 autistic patients who fulfill a particular criteria. But across our entire network of 133 research centers, maybe 20 research centers are interested in the same particular study and each one would only have to recruit five autistic patients. And then the new investigator in Washington University could compile all that data for their analyses. So we are building the infrastructure that would make that kind of data collection possible.

Then the researcher gets their data and can analyze it, can create presentations for our Research Days or any national conference or any research conference and then also publications for our supplement or any journal.

And this basically sums it up, the finding, presenting, and publishing.

So this is the engine that we are in the process of creating. I hope to accomplish this. We are all working diligently on this and hope it have this in place, many big pieces of it, by the summer.

So basically anyone can join us. I think that's the main message that I want to say is we value your input. There will be opportunities for network members to get involved through our committees and through the CREs. We're especially interested in supporting, as I mentioned, the new investigators and autistic researchers and individuals are encouraged to join us.



Thank you very much.

I'm so excited to introduce two of the members of our autistic researcher review board, Jackie Ryan and Patrick Dwyer. I will just say that I have really enjoyed working with them over the part of 3 months and look forward to a long collaborative effort here.

So take it away, Jackie and Patrick.

JACKIE RYAN: Thank you, Alice.

Today Patrick and I are going to talk to you about the Autistic Researcher Review Board and our role in the AIR-P. I want to first acknowledge the other members of this board, Heather Brown, Dena Gassner, Steven Kapp, Ari Ne'eman, TC Waisman, and Zach Williams.

We are all autistic researchers at various points in our careers. Some of us are grad students while others are professors and lecturers. And we are an international group. There's a few of us in Canada, all across the United States, and we have one member in the U.K. as well.

We bring unique perspectives to this work as researchers and as having lived experience as autistic people. We recognize that we have privilege as researchers and that we don't represent all autistic people. And this is one of the reasons why we encourage collaborations and participatory autism research.

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So one of our values and the perspective that we take is neurodiversity. And quite simply put, this means that all brains are different. However, we also use the term to denote a political movement that opposes cures and normalization for autism. Instead, we advocate for acceptance, supports, respect for autistic people's own goals, and promotion of quality of life.

The neurodiversity movement is not just about autism. It includes all neuro minorities such as those with ADHD and learning disabilities. We also learn adaptive skills to help improve our well-being. So we're not just completely against any intervention. And of course we want our cooccurring medical issues such as epilepsy and GI issues to be treated.

Next.

So we are evaluating many of the projects as we're reviewing them in terms of does it improve well-being for autistic individuals. And so we are looking at what do we mean by well-being. And since it's subjective and dependent on the individual, we have adopted this model, the five pillars of well-being, that we're going to use to evaluate projects. So we recognize that that may mean different things to autistic people than to nonautistic people, and that it will mean different things to autistic people.

The five pillars are positive emotions, engagement, positive relationships, meaning, and accomplishment.



Next, please. So as a group, we have identified some research priorities. We're very interested in intersectionality. Growing in to adulthood. And then aging which is a very underresearched area. And then we're also really interested in looking at systemic barriers for individuals with autism for medical care. We're looking to understand not just that there are cooccurrences but looking at what contributes and how we can improve things at multiple levels including at the individual patient, the provider, the system, and population levels.

PATRICK DWYER: We've identified goals for our review board. Jackie covered the first of promoting autistic people's health and well-being. We want to also promote an evidence base that is scientifically rigorous, as well as making sure to include all of the heterogeneity of the population and what the community needs.

And we're also very excited by everything that the AIR-P is doing, adopting the neurodiversity approach, forming our review board, and we're hopeful these practices can be models and inspiration for other research organizations.

Another primary goal is making sure our results are communicated in a way that is both respectful and accessible to the community. So in addition to dusty journal articles, we really want to encourage people to try using additional media and formats. For example, there's great guidelines about how to write a good lay summary. We can use video presentations to reach people. Or perhaps even better, adopt a less lecture style and have video discussions and interviews. There are many possibilities here. Also in journal articles, it's important to use language that is appropriate and respectful obviously. It is true that not all autistic individuals agree about what constitutes appropriate terminology, but it's still usually possible to show that we're making a serious effort to be respectful and sensitive. And it's important to bear in mind here, I think, that just because something is in the DSM, that does not necessarily mean that it is the correct terminology to use. In fact, this is my personal opinion. I think a lot of the terminology that's in the DSM is kind of value laden and unscientific. And often adopted disability instead of disorder, for example, is more neutral and appropriate.

Our last primary goal is that we really want to foster collaborations between different AIR-P sites and projects and nodes, and autistic people and community stakeholders beyond our review board, because as Jackie was mentioning earlier, we do recognize that our academic perspective makes us fairly privileged. And of course it's better to have more community collaboration than less. For example, in the area of information and training interventions, specifically in the postsecondary context, it's been found that developing these information and training resources in a way that is participatory that includes these community perspectives makes them more effective. I'm sure you would see similar things in a lot of other domains. So I do want to encourage these collaborations,



and if there are barriers that people are encountering, we would encourage them to let us know what those barriers are so that we can work to further encourage those collaborations.

On that note, we'll just very quickly run over some key points about engaging with the community and research. There's a number of different approaches that you can use to do this. Community-based participatory research is a very demanding but very, very cool approach in which community collaborators are equal partners with the academic researchers from the very beginning to the very end of the project. Now, we do recognize, as I said, that this is a more demanding approach. May not be feasible or appropriate all the time, but there are other approaches like stakeholder engagement, community advisory boards, and other models. Whatever people do end up deciding to use, if they want to collaborate with the community, we would encourage them to be transparent about that when they're recruiting community collaborators to prevent misunderstandings, and of course to be transparent about that with our review boards.

There's some really wonderful guidelines about collaborating with the community that were published by Christina Nicolaidis and colleagues last year, the guidelines for autistic adults. And actually a lot of what we're saying right now is taken directly from those guidelines, so look those up and read them more thoroughly. But some key points: Consider compensation. If the academic researchers are getting something out of the project, the community collaborators should as well.

Accessibility. Will there be a research meeting? If so, you don't want to expect people to naturally be able to navigate through a conversation, think on their feet, and interject comments verbally. It's better to have multiple modalities for participation, communicating in a clear way, so not using jargon. There's all sorts of accessibility considerations and there should be an ongoing assessment of what's needed and changes as necessary.

And then this point here about trust is not necessarily the most pleasant point, but unfortunately because autistic people and community stakeholders have been marginalized from research and many are concerned that research has done things that have perhaps harmed the community, there's a lot of bitterness, frustration. So it's incumbent upon us as academic researchers to actively work to build and maintain trust. For example, if we do run in to problems, not dumping explanations like oh, it's the autistic black/white thinking but bearing in mind these complex issues and thinking about what we could do being mindful of those to address the problem.

And then of course one really important consideration if you want to collaborate with the community is who are you wanting to collaborate with specifically. What are the appropriate people from the community for your project. So I mention one relevant anecdote. When I was initially approached about perhaps joining what became the Autistic Researcher Review Board, I was a bit concerned because my physical health is quite good and I wondered do I have lived experience that



would be relevant to this network. Eventually it became clear that for the review board, it was the research experience that was key. But I wouldn't really be an ideal fit if it was lived experience of physical health that was important. So it's important to consider what specific kind of lived experience you need for your study.

And I will turn things back over to Jackie here.

JACKIE RYAN: So questions around representation are of great interest to me. We've put some situations here where we need to think about who do we need representation from. And I think it's probably best determined by what your research question is, and also then a need to get sort of a broad base of diversity of experience.

A couple of areas that tend to come up, certainly within my sphere of experience, what about non-speaking people who don't communicate fluently? Should they be represented by their caregivers? Or should they be represented by other non-speaking autistic people? Or do we need to figure out how they can represent themselves using some novel methods like photo voice or arts-based methods?

And then autistic children. When you're involving children in any research, the same questions come up. Should they be represented by their caregivers, parents, guardians, or by autistic adults, or can they represent themselves.

As I mentioned, I think that's best determined by what the research question is.

Next, please.

So in conclusion, we are really excited that the AIR-P has included an autistic researchers review board. We think that this will be an exemplar for other autism research networks, and I would just like to share a little bit about my personal experience so far, that I found it to be one of authentic inclusion, not tokenism. I observe that each node is genuinely interested in learning from us to ensure that their research, practice, and language all reflects respect for autistic people.

Thank you.

KASHIA ROSENAU: Thank you very much, Patrick and Jackie. Even in the short 3 months since the AIR-P began, the ARRB has been very active and has been a great experience as we learn from each other.

So finally we have Dr. Emily Hotez who will present on the AIR-P scholars program. Dr. Hotez is faculty in the department of medicine at UCLA and a project scientist on the AIR-P. So please welcome Dr. Hotez.

EMILY HOTEZ: Thank you so much.

Today I will speak to you about the AIR-P pilot and feasibility program and corresponding scholars program.



So the AIR-P will support a scholars program beginning in 2021 and lasting throughout the duration of the grant. The overarching goal of this work is to launch and support the next generation of researchers seeking to promote the health and well-being of autistic individuals across the life span.

Through the scholars program, we will seek to do the following: First, we will seek to provide pilot and feasibility funding for research projects. These are research projects that may set the stage for applying for larger external funding. These funds may also be used to conduct research that will inform the development of a larger scale intervention research project in the future.

Second, we will seek to provide opportunities for mentorship, training, and professional development. And really beginning at the proposal writing stage, we knew we wanted to develop a research network that would provide an infrastructure for training and professional development, particularly for new or early investigators, just as Dr. Kuo mentioned. And our hope is that the scholars program will be a mechanism for accomplishing this.

And finally, we really hope the scholars program can facilitate network collaboration by providing an opportunity for grantees to collaborate with researchers and stakeholders across the network, including the Autistic Researcher Review Board.

So the scholars program is open to any early investigator as well as any investigator at any stage in their career who is interested in transitioning into research on autism and physical health. As Dr. Kuo mentioned, this very much comports with our interest in being very inclusive in our network.

So the pilot and feasibility fund program will provide an opportunity for grantees to apply for any amount of funding under 25,000. These funds are meant to support one year of research activities.

The idea is that applicants will apply with their faculty mentor who will agree to provide mentorship and guidance for their project. All mentors will meet approximately twice a year with the AIR-P steering committee and other partners to brainstorm opportunities to facilitate the continued development of the scholars who are in the program.

All scholars will present their findings at Research Days, contribute to AIR-P sub elements in pediatrics, and engage in other network activities.

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Our plan is to disseminate a formal RFP in January. So there will certainly be more information to come on the criteria that we will use to evaluate applications. But here are some examples of some criteria that we will use to evaluate incoming proposals.



First, significance and merit. Does the research have significant potential to address a gap in knowledge in autism and physical health? And of course does the proposed research align with the goals of the AIR-P and the ARRB?

We'll also look at methodology and approach. These again are pilot funds. Is the project likely to be accomplished in 12 months, and are the study, concept, and design appropriate for a pilot and feasibility study?

And finally we'll look at investigator qualifications. So are the PI and other key personnel adequately trained and qualified to carry out the project? And we'll also look at whether there is an appropriate plan for supervision from the mentor.

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Here's our proposed time line for the roll out of the AIR-P pilot and feasibility funds and scholars program. So we will plan to disseminate the RFP in January. Potential grantees will apply by March. All applications will be reviewed by the national coordinating center followed by the Autistic Researcher Review Board and then the steering committee, March through May. We'll then send funding notifications by June with the goal of disseminating funds to be available for use beginning in September.

Thank you so much. We do have some time for questions and answers. Feel free to type any additional questions in the chat box, and we can read them aloud for the presenters.

I'll also be posting feedback survey link into the chat, and we would greatly appreciate any feedback that you can provide via this survey.

So thank you again, and we look forward to your questions.

ALICE KUO: So I see one question from Miya about how long does the AIR-P funding grant last. I'm not sure if it means our entire AIR-P or the small grant pilot and feasibility funds. Our funding is for 5 years. So we just started September 1, 2020, and it goes until August 31, 2025.

While we're waiting for questions to come in, I also wanted to acknowledge the members of the steering committee. I didn't name them all. So I had mentioned that I'm the head of the primary care health services node. The community-based lifestyle intervention node is headed up by Drs. Fernandez and Gruyani at UCLA. The sexual reproductive health nodes are Dr. Croyan at Kaiser Permanente. And the healthcare transitions node is headed up by Drs. Shea at Drexel and Dr. Shaddock at Mathematica.

The genetics node is headed up by Dr. Martinez at UCLA and the neurology node is headed up by Dr. Batt-Wilson also at UCLA.

KASHIA ROSENAU: We have a couple of questions that have come in. Brian asks, autism work in my opinion is community work. Does AIR-P allow for other than just ASD folks? By allow,



I'm asking, does the funding and implementation foster research that involves related community folks besides the one with autism and the primary care provider?

ALICE KUO: So if I can understand the question better, is this about like community engagement? Like from a public health perspective? Or -- so I guess the community-based lifestyles intervention node will look at interventions both at the individual level as well as at the community level. So for example, an example could be implementing some sort of parks-based intervention that could increase physical activity for autistic children through a recreation program or something like that. I'm just trying to understand.

EMILY HOTEZ: It sounds like one other component of that question may be are we including other community stakeholders relevant for autistic individuals, and we certainly are. So a lot of our research, as you said it in your question, Brian, we will be looking at primary care providers and other medical providers as well as families and other stakeholders, recognizing that physical health in autism doesn't occur in a vacuum, and we want to make sure we are accounting for those community level factors. That's a great question.

He typed another question in the chat: My question is whether cause for GI symptoms/disorders are considered to fall under one of the priority research areas.

ALICE KUO: So I think currently where I would say if you have -- if you are interested, if one is interested in research on gastrointestinal issues, the first node is primary care and health services. So in this case, we would be looking at referrals to gastroenterology specialists or there is some work being done around mind-body interactions. So the microbiome of the gut and that kind of thing. So those could fall in the primary care health services node.

I think this would be an area that we would have to see if there is a lot of need. And you know, I would not rule out the possibility of the development of a future node, for example, if there was to be more need and attention paid to this area, that we could go through that process and see if we would create a node for that.

For now, I would say that it falls under health services, so we would be looking at placing a study related to that in the first node.

KASHIA ROSENAU: Somebody else asked a question about is this in written format. So great question. We actually are completing the submission of our first supplement right now. So even though we started in September, it's only been a few short months which have really flown by. We've extensively described the research engine, the network, the model more objectives for each one of the nodes all within that information. And then also we're putting the finishing touches on the AIR-P public-facing website right now. So that will also be up shortly.



ALICE KUO: And as far as a listserv, AUCD and Dawn could probably speak to this, AUCD has started to set up listservs for our steering committee and CREs as well, and we can definitely create one for the entire network around AIR-P. I think we need to think about how people would subscribe to that, who that would include, but we're absolutely open to increasing communication with the entire network about what our activities are and all the different opportunities that people have to get involved.

PATRICK DWYER: I am also seeing a question in the Q&A about resources relating to terminology. And yes, we're actually quite interested in that, and thinking about adding something about that to the supplement. But in the meantime, I can definitely recommend some articles. I'll put some in the Q&A box in a second.

EMILY HOTEZ: We have one other question: Would orthopedic studies also be placed under the first node. Or other. I have observed orthopedic spine issues more than once in autistic individuals who have communication issues, from seizures, with late evaluation and treatment due to communication issues. Is anyone studying anything in this realm?

ALICE KUO: I'm not aware of anyone studying this particular issue. However, to the broader question of where orthopedic studies would be placed, I agree that it could be in the first node or in the neurology node because there is so much orthopedic issues that overlap with neurology. Oftentimes in our clinical services, the orthopedics and neurology lines are combined.

So I think this question to me harkens to would there be perhaps collaborations between nodes. So I think it depends. If the issue is more related to, for example, the actual orthopedic issue, the biology of it, the pathophysiology of what is causing the challenge, then maybe that is more appropriately placed in the neurology node.

If the issue is how do people access that service, how do they get connected to that treatment, then maybe that's where it overlaps with our first node. So the nodes were not meant to be exclusive. It was really just a way to start to organize some of the work so that we could support studies appropriately and adequately. And we have talked about collaborations in between nodes. And to be honest, if there are issues raised that don't fit neatly within a node, I think that that is a conversation that we're going to have to have to figure out how things are organized. And it could be that there are some studies that don't fall neatly or conveniently into a node but that we would still support.

KASHIA ROSENAU: So it looks like we just have another minute or so left, if anybody has any last-minute questions.

I think Dr. Hotez dropped the feedback survey into the chat. And if you want, you can hold up your camera screen and the QR code will pop up on your phone, if that's easier.



Thank you for all the positive feedback and for all of the questions as well.

Looks like we're right at time so we'll end the call now.

Again, thank you all for attending the webinar. The webinar has been recorded and it will be archived on the AIR-P website in the future. Please take a few moments to complete our survey, because we really want to hear from you what do you want to hear more about from us. So as I said, we're going to be doing monthly webinars. So we would love to hear more about the topics and things that you all would love to hear.

So thank you, everyone, to our panelists, and also to all of the participants. Have a good day.

