

Dr. Sonia Lee
Behind the Mask

May 7, 2021

Barr: Good morning. Today is May 7th, 2021. My name is Gabrielle Barr and I'm the archivist for the Office of NIH History and Stetten Museum. Today I have the pleasure of speaking to Dr. Sonia Lee. Dr. Lee is the Acting Branch Chief of the Maternal and Pediatric Infectious Disease Branch at the National Institute of Childhood Health and Human Development. She is a trained psychologist and has been a part of a lot of behavioral components of studies at NICHD. Thank you very much for being with me.

Lee: Good morning. It's nice to meet you and to be part of this. Thanks so much.

Barr: Absolutely. As a psychologist can you shed light on a very hotly debated topic surrounding sending children of all ages back to school in a COVID environment and the different elements both pro and con that need to be addressed in order to understand this issue?

Lee: Sure. It's a great question. I think what is driving decisions about returning children back to an in-school setting is a lot of fear and a lot of unknowns regarding COVID-19 transmission as well as how schools will be able to keep their children safe. It's on many levels a personal decision and a family decision on what to do with their children, but I think it's also a discussion and has relevance to how schools are implementing ways to keep children safe in school as well. When we think about it from an NIH side of things, we want to make sure that children are receiving what they need from school—academics, nutrition, physical activity, and social support with their friends and their teachers—but also, it's an environment where parents are also hoping that they're safe. So, when we are living within a pandemic with a lot of uncertainty about the spread of COVID-19 inside a school setting, we want to make sure that families are feeling comfortable, and the students and teachers are feeling comfortable as well, so that they can receive their education. It is, as you said, hotly debated because there are so many different people that need to be involved with these kinds of decisions including the kids themselves.

Barr: Yes. That's a good point that often doesn't get recognized.

Lee: Yes. I think it's helpful to talk to the children of all ages about what it's like to be in school, what they like about school, and talk to them about how they're feeling about going back to school in person knowing that there is a disease that is having effects on lots of people; not just children but parents, grandparents, and teachers. It's a good discussion to have with the kids.

Barr: Have you felt given your line of research that children's attitudes have shifted over the course of the pandemic, such as maybe more fear in the beginning, but now maybe they're sick of being home with their family so it's worth going back to school to be with friends?

Lee: Yes. That's an excellent question and a great assessment too. In the beginning of the pandemic there was just so much that was unknown. The thought behind a lot of things that we did—it wasn't just schools that closed down. Work environments sent workers home to do remote work if that was possible. Businesses closed their doors or limited the amount of people that could come back to work. So children were probably seeing this all around them and staying at home to do school at home is a brand-new experience for many kids.

It probably seemed a little bit exciting at first or learning about Zoom or learning about other platforms to interact with their friends and their teachers and learning their skills. But I think over time what was missing was what we don't necessarily think about all the time: talking with their friends in between classes; having lunch and spending time with their friends and teachers; recess. Just those kinds of breaks with their friends and with other adults, they probably missed over time. Those kinds of interactions and opportunities are things that aren't as able to be provided on a computer. I think adults feel that too. It's not just the children. I think adults miss that interaction and the ability to do that as well. The other thing I'll mention is after school activities that are part of school, so whether it's sports or after school programs, a lot of those stopped as well. Children weren't able to participate in art classes or, as I mentioned, sports or other opportunities to really grow their development.

Barr: Physical school closure has impacted children in underserved populations considerably more than children in more affluent environments. To get an idea how many children in underserved populations have returned to school nationally on average. It seems like those populations are more hesitant and lagging for a variety of reasons more than other types of schools in other areas.

Lee: NIH is funding research to try to get to some of those answers and to see what those rates are in different communities. The thought is that underserved and vulnerable communities are having lower rates of participating back to in-person school, but that also participating in virtual school as it's called or remote school, is also more difficult for underserved and vulnerable communities as well. Whether it's due to lack of internet access or lack of the ability of families to help their children in remote learning, is also difficult for a lot of families.

I will say, for example, I am fortunate that I can remote work full-time virtually, but the ability to then also be responsible for helping my kids participate in full-time remote learning is difficult. I think it's an extra responsibility that a lot of families just don't have the ability to do. What NIH is trying to understand is what those rates are, as you've asked, in what communities and then how can we address some of those difficulties as well.

Barr: When did you and your team begin planning the Return to School Diagnostic Testing Approaches initiative, which is a RADx-UP project, and what considerations did you and your team need to make to get this multi-part initiative off the ground?

Lee: This program was probably started in development over a year ago. I think when things were starting to close down, at NIH we understood that this was going to affect children not being able to go to in-person school. How to address that was always on many NIH staff's mind. The actual

implementation—meaning getting the funding, getting the research opportunity announcement written—all of that started at the beginning of this year.

The steps to get that started were in development for quite some time, but I think more formally earlier this year in 2021. We were lucky in that we were able to obtain some funding from Congress in order to get this program off the ground and then get the opportunity for our team to really work with amazing research investigators, who are already working in school settings with children and to start thinking about some of these questions and how to safely make sure our children are returning back to school.

Barr: How are you dealing with such a variety of communities?

Lee: It's where we have the opportunity to make awards to different communities around the country. I think the hope is that we will be able to do more, provide more funding in different settings around the U.S. We currently have eight projects that are funded during this first round of applications. We are now currently working on a second round of applications to hopefully fund some more communities in order to think about how to do COVID-19 testing in schools and with families in order to provide data that it's safe to return back to school and understand what's the best way to do it, and how to address questions or concerns that families, kids, teachers, and school communities might have about returning children back to school.

Barr: What were some of the projects that were funded? What were some of those first eight projects that have been funded? Has what you learned from that informed what you are looking for in the second round?

Lee: Some of the projects in public school settings, for example, and working with communities that predominantly are made up of African-American or Black students. There are other projects that are working with children who have intellectual and developmental disabilities and participate in special schools. There are also some projects that are working with Native American or Navajo Nation tribes within Arizona for example. I just wanted to also highlight another project that is focused on children with medical complexity. They may be children who have more than one medical condition that makes it difficult, for example, to wear a mask all day or they have therapies that they receive through school that require close physical contact with their therapists. So, making sure that COVID-19 testing with those kids and those teachers can be done to keep them safe when other things like mask wearing and physical distancing is not always possible.

Barr: Is testing done the same in each of these studies? Is it the same kind of test like the nasal swab or the oral things? Are there differences depending on the location of how testing is done? What kind of tests are used, like the intervals of testing?

Lee: I think one of the great things about these projects is that they are in collaboration with their communities and with their schools. Oftentimes the schools have input into what kind of testing they think is best for their community. It's not all the same. Some schools are doing, as you have mentioned,

nasal swabs. Some schools are doing saliva testing. Kids apparently are good spitters, so they are happy to provide saliva samples, more than having something put up their nose on a weekly basis. Other schools are testing more often, maybe weekly, maybe every other day or maybe even based on just exposure to somebody who might have had a positive test result. The main thing is though for these projects all the testing that is done are with tests that have been authorized or approved by the FDA. We are not using any non-validated tests in these settings with these communities. As I mentioned from the start, really working in collaboration with what folks on the ground would like to see for their students and their families.

Barr: That was going to be my next question. How do community norms and feelings influence the approaches of the awardees and if they are tailored for the particular communities you are working with?

Lee: Yes. They are tailored. So the communities, whether it's school settings or medical settings, are part of these projects. It was required that strong relationships between the researchers, the schools and other relevant community partners are all working together to design part of these testing strategies. Then on the other side, how the results of the testing are shared as well. We are hoping that depending on the COVID-19 testing strategies and results, those will be important in determining when children come back to school, how they can stay in school, decisions about how many children they can bring back, and as more information and data come in, how often to do testing and how to do it.

Barr: Has there been any pushback by anybody about these tests; children or families that refuse to get tested?

Lee: Since these are NIH research projects and with all research there has to be consent. The parents and the families and oftentimes the students as well have to agree to participate in these research projects. How those decisions are made on a personal level, I think we're trying to better understand as well. We're trying to encourage testing, of course, through these projects. I think we'll get some more information about what are some of those concerns—or as you said, pushbacks—are. And then how to address them to ensure that this is a safe thing to do, for the children to go back to school.

Barr: Do you worry—I mean, these are willing participants who consented—so do you worry what might happen when it's mandated by the schools, like masks, what kind of pushback or attitudes might there be towards testing, especially people's feelings that the pandemic is over and they have reached herd immunity, or they have already been vaccinated or the stigma around things such as not complying with school rules about having to quarantine? Do you worry about that?

Lee: I do worry about it and I think that's part of these projects as well. It's trying to understand those worries. Is there stigma about testing? Some families might be worried if there's a positive test result in my family, what does that mean? Is my child going to be isolated from all the other kids? You also mentioned hesitancy as well. Misinformation is still out there and I worry about that as well. What are other folks thinking about in terms of COVID-19 and what are they hearing and what can we do in

terms of our research findings to provide help, to reassure some of these misgivings or some of these doubts about the pandemic in general? And specifically with children and in schools. I think that's a great opportunity to learn more about COVID-19 and to have it be an environment where data and science and results can really be shared at a school level and address some of those misgivings about testing and vaccination.

Barr: How are you going to share some of this data? Can you speak to that a little bit?

Lee: Yes. It's similar to what you asked earlier about tailoring approaches. The researchers for these projects are working with their communities about how to best share those testing results. In some cases, they're through a dashboard. Maybe there's a place on a school website where de-identified results can be shared. We wouldn't have students' names or anything like that, but we might have if you did testing for a month, what the results were, what they showed, and how often the tests were done. Other projects might be doing a newsletter as part of their school as well as provide some of this information. Then there's also some efforts to have not just researchers but folks who are working within the school—trusted teachers, trusted superintendents—really talking with the students and their families through meetings, for example, about how the COVID-19 testing is going as well.

I think depending on what best serves the communities in the schools, we are trying to tailor some of those approaches to sharing the data. On the NIH side, as well, all the data that is collected through these projects will be shared with NIH, again de-identified. We are trying to collect all the data and really work through a coordination data center to also share some of these findings again to help schools make some of these decisions.

Barr: What age children does your study include?

Lee: As of now it is inclusive of children who are 16 years old and younger. That was based on the understanding at the time that vaccinations weren't available for children 16 and under. So that may change as vaccinations change and we'll be able to integrate those changes within vaccinations in these projects as well. So [ages] 0 to 16 [right now].

Barr: How many awardees do you hope to sponsor ultimately?

Lee: The budget for these projects was originally 50 million dollars and that was through the American Rescue Plan Act. As I mentioned we were able to fund eight projects. We are in the second phase of funding projects through this effort. Hopefully, we will be able to fund several more. I don't know the answer to that question quite yet but in a couple more months we'll know.

Barr: Is the second round of projects similar to the types of initiatives of the first round or are you looking for some slightly different types of projects or reaching some different communities than the first one?

Lee: It's an excellent question. We are looking at what we funded in the first phase, making sure we are not funding projects that are doing exactly the same thing. I think, as you said, being able to address other vulnerable and underserved communities through the second round is a goal. Making sure also we are serving potentially other states or other types of school settings will also be part of the second round of projects. I think at the end we will hopefully be able to cover not only a lot of the geography across the U.S., but as you mentioned a lot of underserved and vulnerable communities.

Barr: Was there a lot of conversation when you are setting this initiative up about what should be defined as an underserved community or things of that nature?

Lee: NIH has some definitions and it is through the RADx-UP program what those definitions are. The ability of investigators to apply—to use in their application and they had to include that information as well. So, it's hopefully really reaching communities that haven't been able to really get a lot of COVID-19 testing strategies as well. But the definitions are on the RADx-UP websites.

Barr: Okay, that is good to know. What are some of your hopes as you move into these next stages of the project?

Lee: My hope on the science side is that these projects will really provide the evidence and the data of what it will take to have children in person, in school safely and be able to see what those concerns are about having the children in school so that we can then address them. My hope is that children who want to be back in school, are back in school, and have the ability to do that and to have that sense of comfort in being in school so that they could get back to a sense of normalcy that I think school settings really provide.

Barr: You know science always wants to do data-driven experiments that sometimes can take a long time. But there is also a bit of a time crunch with school starting back in only just a couple of months and the desire across the country to get everyone back in no matter what happens. Does your team feel that kind of pressure?

Lee: We do. When there are great research questions that need to be answered, we want them answered as quickly as possible. So yes, there is that pressure, but I think as schools, as you said, are already back to in-person in many ways, it does provide a great opportunity for us to start working together to answer those questions. We are in May already and these projects for the first round were started last month. They're already working with their communities to get some of these questions answered.

Barr: Do you worry that some schools who don't have funding, will not do the testing and bring them back anyway?

Lee: I think there is a lot of pressure from many different directions about having children back in school. I worry on the research side about how we can make sure that those pressures are alleviated and how we can lessen those pressures by providing some of this science and data. But I do think there are other factors that we have to think about and address as well at the same time to make these decisions. I personally believe that children are better off being in in-person schooling, but I understand that families have to make these decisions with their schools on what's best for their kids as well. If we on the NIH side can try to address some of those questions, some of those concerns, some of those worries, then that's my hope is for the outcome for these projects.

Barr: Interesting. We are going to transition from you as a scientist to you as a person. What have been some personal opportunities and challenges that have arisen for you due to COVID-19?

Lee: Where do I start? I think like with many in March of last year through 2020 I became a full-time teleworking NIH employee, which personally was difficult for me. I will admit I like working in person in an office because I see my colleagues. It provides an opportunity to socialize, but also the opportunity to talk about the work that we're doing. And personally, my children at the same time, of which I have three, were also at home full-time trying to do remote school. The four of us on computers all day long eating up the wi-fi was a challenge; and at the same time trying to understand what was going on with the pandemic. I missed work colleagues. I missed friends. I missed family because we weren't able to see them in person in the same way so that was quite challenging.

Barr: What were your challenges and responsibilities because you have an administrative role as well for those that work with you and for you?

Lee: I think it is ensuring that the connections with work colleagues are still there and trying to best utilize technology to do that. For some colleagues it's phone calls, for others it's video calls, for others it's just quick check-ins over email. I think being available and also understanding that we are all in this similar situation, and how to adjust to that while still trying to get our work done and get the balance with personal lives as well, was something that I think we are still trying to figure out the best way to approach.

Barr: Here's another question: do you think that your different ways of speaking to those you work with may continue after the pandemic is over, because you know the classic way did not work for everybody when we were in person?

Lee: I do think that, yes, there will probably be lots of combinations of how to conduct our work better. I'm hopeful with vaccination rates increasing, a better understanding of COVID-19 transmission as more science is done and as we get a better understanding of how COVID-19 is affecting different populations, that other opportunities to return back to the office will be available to many of us. For those that it's not, again trying to be creative with technology, with other ways of making sure that contacts are still done in a way that we can work productively and work happily as well, which I think makes a big difference for the work that we do.

Barr: In your role where you involved in other COVID initiatives, research, and projects?

Lee: I think with the extent of the pandemic it's hard not to imagine that everybody's research work is not involved with other COVID-19 efforts. It has such an impact on all the work that we do. Prior to this my main focus was on HIV/AIDS in infants, children, adolescents, and pregnant women. The COVID-19 pandemic has affected that work as well, whether it's our work in terms of stopping a lot of research or it's also on the clinical side, making sure that those kids and those families were able to still receive treatment for their HIV. I think it's definitely brought new perspectives to the work that we were already doing.

Barr: Interesting. That's so true. It does get forgotten; all those other diseases that people had and still have.

Lee: Yes. The focus definitely shifted right at the beginning and now the work is trying to encompass everything; how COVID-19 is better understood, but then also how it's understood with respect to other research that's going on as well.

Barr: Yes. What has been one thing that you enjoy doing that has made the pandemic a little bit easier to bear?

Lee: I will say that getting outside has been probably the most enjoyable aspect of this, whether that means taking a bike ride with friends or a walk or a hike in the park. That has always been something that I've maintained. Of course, with other strategies in place such as masking and keeping safe distances from those friends and some of those families, it is important to get outside. Even during the winter being able to take a walk in the snow has just been a nice break from the computer. The computer, it really is, and from the screen. I think that's really been enjoyable and important and has helped maintain my sanity as well.

Barr: That's really good. This is a thought-provoking question. What steps do you think need to be taken to help children mentally and emotionally adjust to being back in the physical classroom full-time?

Lee: It's a great question. I think that one of the first steps that we can do is really to talk with the kids and ask them or discuss what their fears and their concerns are. They are hearing about COVID-19. They know about wearing masks. They know about keeping safe distances from their friends, from family. They may not have been able to see grandparents for quite a long time. The ability to have those conversations and hear what their concerns are, if there are concerns, I think is really important. As a researcher and as a parent there's a lot that we ask of children; to participate in a research project or to wear a mask all day or no, we can't see friends for a few months. It's a lot of rules on top of all the other rules that children have to follow. I think providing them a space to talk about how they feel about all

these rules and understand why is something we don't do enough of. They may have great ideas that we need to think about on how to do better or they may have questions that they don't understand. We can help provide them and help understand and hopefully that will help them get back to school in a way that they will be comfortable with.

Barr: Is there anything else that you would like to add as an NIH staff member, but also as a person who is living through this pandemic like everybody else at this time?

Lee: Oh, that's a great question. I will—I do want to say that the support of everybody, not only for their research at an NIH level, at a leadership level, and at a school level has been tremendous. The excitement about how we can do a lot of our work to return children back to school safely has always been high. I'm so lucky to have people that I work with at all levels be so supportive of all these efforts. And even being on a computer all day, I think the understanding of the support from everybody, that you take a break every once in a while, so that you can be fresh and that you can continue your commitment to your work is a balance. The examples that I've seen from others within NIH and within the communities about how to work on all of this together have been just really inspiring.

Barr: That's really wonderful. Thank you very much. I wish you the best on your research and I look forward to hearing more about it. I hope that you and your kids continue to stay safe.

Lee: Thank you so much, Gabrielle; you too as well. It's been a great conversation. Thanks.