Dr. Matthew Gillman

Behind the Mask

April 23, 2023

Barr: Good afternoon. Today is April 21, 2023. My name is Gabrielle Barr, and I'm the archivist with the Office of NIH History and Stetten Museum. Today I have the pleasure of speaking with Dr. Matthew Gillman. Dr. Gillman is the Director of the Environmental influences on Child Health Outcomes [ECHO] program at NIH. He is going to speak about how ECHO approached the COVID-19 pandemic. Thank you very much for being with me.

Gillman: You're welcome. Pleasure to be here.

Barr: Will you please shed light on how you and others at ECHO pivoted in 2020 to fund new COVID-19-related studies as well as incorporate COVID-19 in existing studies and projects?

Gillman: Let me first tell you a little bit about ECHO. ECHO consists of two parts. One is observational or cohort studies. The other is an intervention network called the IDeA [Institutional Development Awards] States Pediatric Clinical Trials Network [ISPCTN]. On our observational side, we harmonize data on a platform from 69 ongoing maternal child health cohort studies. We have data from over 100,000 participants. We're following 34,000 or more children actively, and these data range from a few decades ago to the present day. They're about what happens at the earliest stages of human development that gives rise to perinatal outcomes like preterm birth, obesity, neurodevelopmental outcomes like autism spectrum and ADHD, airways conditions like asthma, and positive health, which is another name for well-being. That's what our program is about. Everyone was marching right along collecting their data in the cohorts until March 12, 2020, when we suddenly experienced the shutdown. Of course, we weren't sure how long it would be-- would it be days, weeks, months? Or would it be years? Many of our investigators recognized the unusual opportunity that COVID-19 brought to the table to do some innovative science. The investigators created a working group, a subgroup of our steering committee, to very rapidly put into place a questionnaire, not so much about the infection, although that was part of it, but about parents' and kids' experience of being in a pandemic. We quickly envisioned we would have data before the pandemic, during the pandemic, and after the pandemic because these are ongoing longitudinal studies that are following the kids and their parents.

Barr: That is a very unique position to be in. Very lucky that you have had that breadth of data.

Gillman: Yes, that was one of the great opportunities. We were able to turn this ocean liner pretty quickly into developing this new questionnaire within weeks, which is really unusual for a program with this size, and were able to share it with other programs across NIH or outside, in addition to our asking ECHO participants to complete it. As I said, the questionnaire really was about people's experience of going through COVID. What were their stressors? What behaviors increased? What decreased? How did they view their experience of the pandemic? What were the effects on the families, what were the effects on the kids? Our cohorts collected

those data through 2020 into 2021, and we have a revised questionnaire that brings questions up to the present. In addition to developing this questionnaire and fielding it in a rapid fashion, our cohorts and our trials on the clinical trial side, had to pivot to do epidemiology in a new way, because most of our cohorts were collecting data in clinical settings, or at least in-person research settings. As you recall, there wasn't in-person activity for quite a long time. We already had set up a remote assessment working group. That group along with our COVID-19 group got rapidly to work on how we could do things in a remote fashion that we used to do in an in-person fashion. It turns out that's going to be kind of the future of field epidemiology anyway, and thus the COVID-19 pandemic catalyzed some thinking that we were doing already. Pretty quickly, our cohorts were able to transition from doing in-person to doing remote work, including remote informed consent, which is something that most of them hadn't considered before. I had previously thought, well, we need to do it on paper. Why?, because we've always done on paper. In addition to informed consent form, surveys, and even for tests, like respirometry, which is a lung function test, some of our cohorts were able to pivot to do that, by sending materials to people's homes, doing trainings online, and having the kids and the parents do the tests and then either send the result back themselves or upload them automatically.

Barr: How were you able to get that together so quickly? It's a whole different way of doing stuff for you all.

Gillman: Well, I would say, everything didn't go as smoothly as ideal, but we didn't want the perfect be the enemy of the good. Some of our cohorts were able to do the transition a little more quickly, and some took a little more time, but it was all hands-on deck. All our cohort investigators, our coordinating center, our person-reported outcomes core, data analysis center, all did their best in a very brief time to pivot to do things more remotely. Still, even to this day, there are new ways of doing things that we are implementing within the cohorts.

Barr: What are examples of some of those things that you've learned throughout the pandemic?

Gillman: That some participants actually like to connect remotely more than in-person, but others build trust better with an in-person approach. In the future, we aim to have hybrid approaches to try to meet the participants where they are and the types of data collection approaches that they want. Also as an aside, we'll do more in the future about returning individual results to participants. They gave us information, and we owe some back to them. For example, how did their individual data compare with the rest of the people in the cohorts? Giving individual participants their results is one way, among many, of engaging participants. Others are to meet them , where they are; to provide incentive for participation; institute individualized approaches for collecting information.

Barr: What is involved in planning for a hybrid model? Some people have said that they feel that hybrid is the most complex of all because it got all the difficulties of remote and in-person. And all the benefits.

Gillman: By hybrid, in this case, I don't meet that there will be some people at the same time in-person and online. Rather it means that one participant would be online, and another participant would be in-person, at different times. So that doesn't get into the issue that you're talking about, which is people sitting around a table and some people on the screen. This hybrid means instituting flexibility so that some people get one thing and

some people get the other. It requires a very personal touch, which, I think is more and more part of research endeavors, a reflection that when our participants are really partners in the research.

Barr: Definitely. How many cohorts do you have as part of ECHO?

Gillman: There are 69 cohort studies that are part of ECHO. Most of them started before birth and follow the children. Our researchers initiated some of them 30 years ago, whereas others began just before EHCO got off the ground, seven or eight years ago.

Barr: Are they all over the world you look at participants?

Gillman: They're all in the US, and they represent a diversity of geography, of age groups within pediatrics, sex of socioeconomic status, and race/ethnicity.

Barr: Can you share some of the efforts that ECHO has supported in understanding how the pandemic has affected both pregnant women and mothers in general in regard to mental health?

Gillman: One thing we were able to do was to carve out some funding early in the pandemic to support, through a competitive process, half a dozen special projects related to COVID. They covered a wide variety of things: some about pregnant women, some about kids, some about chemicals, some about stress, some about biological function. None of them were about COVID-19 infection; they were all about the experience of being in a pandemic among pregnant people and children. Let me give you an example of some of the results. As I mentioned at the very beginning, one of our outcomes is positive health or well-being. We measure that in terms of life satisfaction, global health, meaning and purpose. In one particular analysis that our investigators published recently, they looked at COVID-related stressors, and then they related that to parental perceived stress and child perceived stress. As you might imagine, some of the stressors like financial hardships or social isolation, did result in the parents and the kids feeling more stress. When the kids felt more stressed, they also had less life satisfaction, which you might expect, but there wasn't a one-to-one correlation. Stress and life satisfaction measure different things, but they are related to each other. One of the interesting things is that the families who had more connectedness within the family and the kids who have more social connectedness actually buffered that link between stress and life satisfaction. It tells us that during an emergency health crisis like this, the family and social connectedness are promoters of life satisfaction and protectors against stress among children.

Barr: How can you ensure that that could be more widespread in the future?

Gillman: That would not be part of the ECHO cohort program per se, but rather an example of our results informing interventions. This is the kind of result from ECHO that is solution oriented, which means in this instance informing policies and practices and programs to increase social connectedness. That could be done in several ways; one is through the clinical care that the kids get; their well child care checks could include relevant information. Another is via social programs as we saw during the early years of COVID-19. One of the things that

we try to do in ECHO is to have our results be as solution oriented as possible so that we can inform actions that actually enhance the health of children for generations to come.

Barr: Can you comment on some of the other studies that ECHO has supported or had a role in during the pandemic, which included but wasn't limited to: looking at the effects of increased screen time, how family situations affected children's behavior, changing sleep patterns, changes in body mass index, or obesity? Other tests looked at stressors, during the pandemic and how they affected the development of babies. You really focused a lot on marginalized communities. Do you want to shed light on any of those?

Gillman: Let me give you a couple of examples. Some of our investigators looked at the effect of the pandemic on changing maternal depression or maternal stress, and in turn on the length of gestation, or how long babies stay in the womb before they're born. They also looked at birth weight for gestational age or fetal growth, how big they got when they were in the womb. They found in that particular study that there wasn't that much difference in the depression or the stress between pre-pandemic and during the pandemic, which was a bit of a surprise.

Barr: That is a surprise.

Gillman: They also compared during the pandemic to pre-pandemic and found slightly shorter gestation. You might have expected bigger effects, but what we found is while mothers actually felt some of the stressors that we anticipated during the pandemic, there were other countervailing issues that seemed to protect them against some of the worst effects of the stress. Another example is chemical exposures that changed from before to during the pandemic. It's true that things like hand sanitizer, you might not be surprised, increased. That gives you more exposure to certain chemicals that might be deleterious to pregnant women or babies. On the other hand, some other sources of chemicals, like cosmetic use, decreased quite a bit during the pandemic. So there seems to be these opposing forces in a number of areas that bear more study because when you have such a shock like the pandemic, you might assume everything's going to be bad, but some things improved. Another example of improvement is air pollution, primarily because we had much less traffic. You've also asked about the effects of the pandemic on child obesity. That was another project of ECHO investigators. What they found was that in the months before the pandemic, BMI, body mass index, which is a measure of childhood obesity, was pretty flat, but during the early months of the pandemic, it rose quite substantially. This is consonant with some other studies in the literature that childhood obesity seems to have gotten worse during the pandemic. BMI increase was higher in the lower income and in the black versus white sub populations of ECHO, suggesting that there are disparities in the effects of the pandemic on important health outcomes. We know that to be true for many other health outcomes, in adults especially. Another set of investigators was interested in if obesity rose, what might actually explain the rise. There are, I would say, four main risk factors for childhood obesity that we talk about a lot. One is diet: quantity and quality of the diet. One is physical activity. One is sleep duration and quality of sleep. And the fourth is screen time--how much kids are using their screens, small screens, big screens, shows, social media, etc. We again took advantage of researchers' fortune in that we had participants before and during the pandemic, and thus could look at the change within individual people. What they found was that screen time increased quite a bit, which might not surprise you given school closures and social distancing. Some of the increase was in educational screen time, but most of it was

recreational screen time. Again, our black and Hispanic participants had greater increases than the white participants, suggesting inequities in the effect of the pandemic. Interestingly, they did not find any changes in physical activity, sugary foods and beverages, or in sleep duration. The screen time was the only one of those four risk factors for which they could demonstrate increases during the pandemic, maybe because of a relatively small sample size. Other studies might find different things, but that's what we've found in ECHO.

Barr: White participants were also on screens a lot or had the opportunity to be. Was it because of not having a parental figure who had the time to engage with the child and so they were on more, than maybe a child with other means whose parent could engage with them more? Or why exactly are there disparities like that?

Gillman: That's a really good question. It's important not just to characterize disparities but to try to explain them. We don't actually know the reasons because we didn't measure those things in ECHO, but that would be a great set of ideas for additional studies. You could think that it might be due to family issues, but it might be more societal issues. For example, if people don't have other good outlets for their recreational time, screens are ubiquitous, available, and can be somewhat addicting. It might not be just about the parents but about the broader environment.

Barr: Are subsequent studies going to be done? It's so interesting.

Gillman: It's really interesting. I don't think we'll have the opportunity in ECHO because what happens with these shocks to the system is they come, and they go, although I'm not saying COVID itself is over! But that early period is when we had the greatest shocks, socially, in employment, in families, etc. We didn't measure these potential explanations before the pandemic.

Barr: Will you please talk a little bit about ECHO role in the Improving Pediatric COVID-19 Vaccine Uptake Using an mHealth Tool that is also known as MoVeUp study to explore parental attitudes about COVID-19 vaccines and test the effectiveness of a mobile application to help parents learn more about the vaccine for children. What was involved and how often was this app used and by whom?

Gillman: Great questions. Now I'm going to turn to the intervention part of the ECHO --the IDeA States Network. This is a network of institutions in 18 states plus a central coordinating center in the IDeA States, which are states with historically low rates of NIH funding. The purpose of the ISPCTN, as we call it, is to give children from rural or underserved areas access to state-of-the-art clinical trials. One of the things that we knew is that uptake of childhood COVID vaccines was fairly low overall and perhaps even lower in rural or underserved areas. We thought this was a really good opportunity to see if access to information might increase the uptake of vaccines in these populations.

Our investigators came up with a really nice study using a new app that they created to try to overcome barriers to increase the vaccination rates, and compared that with a general health education app. The people included in this study were not the ones who had already decided on the COVID vaccine, either the ones who already decided to get—or not get-- the vaccine. We targeted the people who are in the middle, who might be on the fence. To inform the content of the app, we had already done focus groups among people in rural and urban environments, and different races and languages, to see how messages might land. We found that there were

differences between, for example, a White rural population and a Spanish-speaking population. The app was made to be as tailored as possible to the potential participant populations. The app thus employs tailored behavior change or motivational interviewing components, which are about asking what the barriers are and trying to overcome those barriers. We'll be getting results in the coming months.

Barr: Has the messaging in some of your pilot studies that you found differences between different populations? What were some of the things that they found? What ways were better for particular groups?

Gillman: In general, some populations respond better to engagement and shared decision-making, while others may respond a little better to trustworthy voices. Another study within the ISPCTN in that winter and spring of 2020 was 'I Am Healthy'. 'I Am Healthy' was a pilot study to see if a distant intervention could reduce relative weight in kids who have obesity. It was already being delivered on an iPad by trained psychologists, so we had that part down. But it was in-person for recruitment, informed consent, and assessments. And when the pandemic hit, the investigators quickly pivoted to not only electronic consent, which I mentioned before, but also, remote assessment of the outcome. The whole study became remote-- the consent, the intervention and the assessment. The things they learned in that project were how things work, things you just don't think about. When you're trying to send a piece of equipment to a home in a rural part of one of our states, for example, you might not realize that delivery services like UPS or FedEx don't go to every house. Sometimes you have to engage the delivery service and the US Postal Service; sometimes research staff have to deliver things themselves. Then there's the getting the equipment back when the study is over. There are some of the practical hurdles that our investigators have faced to overcome during the pandemic, so that they could actually do their research.

Barr: That's very interesting. I never really thought about that.

Gillman: It also shows that most of us researchers tend to have more experience with urban/suburban than rural populations. Even within urban areas, we tend not to be in the most disadvantaged communities. One of the goals of the ISPCTN is stakeholder engagement, to involve underrepresented communities and participants in the design of the study as well as the implementation and the dissemination. I can tell you through the ECHO program, I've learned a whole lot more about stakeholder engagement than I ever knew before, and there's plenty more to learn. One of the things we did early on in ECHO was facilitate a data sharing and use agreement between Navajo Nation and our data analysis center. Navajo Nation, like many tribes, has had a long history of being discriminated against by the majority population, and have been rightly very reserved about their willingness to share data with a national program. There was lots of give and take on both sides to get to a place where ECHO's Navajo Birth Cohort Study was comfortable in sharing data in a limited fashion with the rest of the cohorts.

Barr: That's very interesting. Given people come from all these different backgrounds, how did you deal with the technical situation? Not everybody has access to technology in these groups or reliable technology, or they share technology.

Gillman: That's right. Not everyone has a laptop. Most people have phones. Our person-reported outcomes core has been in the forefront of developing survey instruments that people can do not only on their laptops but also on their mobile phones. But even when you have a phone, you might not have Wi Fi; you might just have data. Understanding how to work in this digital environment is important. In the studies in which our participants don't have the technology, typically we offer it to them. As part of data collection, we might actually mail them a laptop. We're finding that they don't get lost or stolen; participants actually return them almost 100%. When we build this trust between the participant and the staff, there are ways to overcome some of these barriers to data collection.

Barr: What have you found to be most interesting from these studies? What do you feel needs to be investigated further or looked at for the first time at this point in a pandemic?

Gillman: If you're referring to COVID-19 related studies, I would say, the obesity findings, the birth findings, the positive health findings, all are really interesting. First, maybe the most surprising thing to me is what I was talking about before is that there have been a number of buffering elements during the pandemic that have countervailed some of the stress that we predicted. Second, I think it's really important to identify the disparities, by social class as well as by race, ethnicity, and the need to, as we discussed before, to find out the origins of those disparities, so that we have solutions. Third, I think that following the kids and the parents for longer term after the pandemic will be very instructive because, again, if you have this natural experiment, this crisis, the shock to the system, you can see something short term, but you don't know what's going to happen long term. I think we've learned from other disaster-related epidemiology that there can be long term effects.

Barr: Are there any plans to look at aspects of long COVID in children themselves, although it's less prominent but it does exist? Or in children either born to a parent with long COVID or are there any effects on their growth and development?

Gillman: NIH has a program called RECOVER [Researching COVID to Enhance Recovery], which is about long COVID. The majority of our sites in the IDeA States Network are part of the RECOVER Initiative. They've been going gangbusters and recruiting children to look at long COVID symptoms in those kids. Yes, it's an offshoot of our program that's contributed greatly to that initiative.

Barr: What do you feel that you and others at ECHO have learned from the COVID-19 pandemic? What have been some of the opportunities and challenges as well?

Gillman: The answers are both in the areas of research content and the way that people actually do research. I think we learned that as a program, we have the opportunity to pivot when there's a crisis or a natural experiment. Then as we go into our second seven-year cycle of the cohorts come this fall, we want to be able to be ready to respond to whatever crisis comes next. And of course, we don't know what that's going to be. It could be another infectious disease, or it could be a natural disaster. Any of those things, we want to be able to respond to, if the ECHO design is applicable to that natural experiment. In terms of the science, we've discussed that some results have been surprising, and some are less so. What's important is working out what happens when there's a national emergency like this and how do people cope? As we go into our second cycle, we're

more interested in resilience and reversibility of trajectories that are set very early in life. So, there's this notion that a good start to life can last a lifetime and even over generations, because of what happens in early development, but not everyone who has an insult or perturbation in pregnancy or early infancy, has an adverse health outcome. Many of them don't. What are these features that allow some people to be resilient and others not as they go through other perturbations in their life, including pandemics? How can these trajectories be reversed by environmental or behavioral or social or medical interventions?

Barr: That will be really great to find out. In addition to being an administrator, a physician, and a scientist, you've also went through the pandemic personally. What have been some positives and negatives for you as an individual living through the pandemic and ways that you have coped as a person in managing a program as a leader?

Gillman: Thanks for that question. One of the pleasurable things I did during the pandemic was volunteer to give vaccines to adults and kids. I did that within NIH as well as in the community; I felt that was a way of giving back and doing service. Really, I was grateful for that opportunity. I certainly had to pivot quite a bit to learning how to do research remotely. Another thing I learned is to blur my background because my home office is such a mess! Sadly, I don't think I learned how to be neater during the pandemic. I did (re)learn, though, that one of the really important things we do in the office and try to inculcate throughout the program, is team science. By team science, we mean, the whole is greater than the sum of the parts; we mean bringing different disciplines to the table so to result in something completely new. We mean setting a vision, building trust; we mean all these things that are part of team science. We know that when teams form or reform, they have to go through a period of what some people call storming before they can get to the other side, of norming and performing. We had to do that because we were used to meeting in person all the time. Now we're meeting by Zoom or Teams or WebEx half the time. Just figuring out how to do that, while incorporating teamwork, was a challenge. Now that we're back some days in the office and some days in remote telework, it's a good mix because our teams get to meet again in person. When we meet in person, we see the nonverbal cues and the body language, and we can share things that we don't on zoom or other platforms. Zoom has its positives too. For one thing, I can see everyone's name so, if it's more than my staff, I know who's there. Also sharing documents is easy. In some ways, that can be more democratic if you do it wisely. learning how to conduct business during the pandemic was really a challenge, and I think we met it. That was hard for everybody, including myself, and now we're on a good path for collaboration and teamwork

Barr: Well, is there anything else that you would like to share about your COVID experience or work that ECHO has been engaged in?

Gillman: Just a few days ago, we had the last big investigator meeting of ECHO for the first seven-year cycle, and it's really a pleasure to see how people have come and have worked together in a collaborative environment to produce results that are enhancing the health of children. That's been very gratifying because we spent a lot of time building the plane, and now we're flying it.

Barr: It's very nice. Well, thank you very much for all the work that both you and your program have done and continue to do.

Gillman: Thanks very much for the opportunity.