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2018 EHDI Annual Meeting

EHDI & UNIVERSITY COLLABORATIONS –

LEVERAGING THE PARTNERSHIP TO ENHANCE

PROGRAM IMPLEMENTATION AND OUTCOMES

Topical Session 5

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>> CATHY LESTER: Good morning, everyone. My name is Cathy Lester. I'm the EHDI Coordinator from the State of Kentucky. We're presenting on the EHDI Program and University Collaborations: Leveraging the Partnership to Enhance Program Implementation and Outcomes. So our objectives for today are discuss a few ways that this collaboration can benefit the EHDI Program, to discuss ways that this collaboration with benefit the University, as well as to give some examples of different ways we have collaborated in hopes that you all might be able to implement those in your states. Our team today is myself, the EHDI Program Coordinator.

I have previous experience in social work. I have masters in social work and as such have done social work research classes and have taught research so I have a little bit of a very minor background in research. Liza Creel is an Assistant Professor at the University of Louisville School of Public Health and Information sciences. Gosh, that's more of a mouthful than my organization. And she's a Commonwealth scholar with the Commonwealth initiative institute of Kentucky. We have Julie Jacobs from the University of Kentucky's college of public health and she's a Project Manager.

So we'll let Liza talk a little bit about her role in this.

>> LIZA CREEL: Thanks everyone for having us and giving us a chance to really talk about fun things we're doing in Kentucky and just how excited we are about this partnership and this collaboration, and the things that are coming out of it and the differences we're really trying to make. We're going to talk some about the research we're doing but we're really here to tell you more about how we made all of this happen and how we think it might relate to activities or inform similar partnerships in other states, so part of this is telling my background story and how this collaboration really even started from my perspective.

So I hail from Texas. Never imagined ending up in Kentucky, yet I did. And let me tell you, it's been pretty great. But my whole background is in public health policy. Have an M.Ph. in Health Policy and a Ph.D. in health research. Before I got my Ph.D., I worked for Texas Health Institute and in 2007, I literally lucked in to working on a grant from HRSA for the Regional genetics collaboratives. Vicki Thompson is in here. There are other mountain states Regional collaborative members at this meeting and that project really changed the trajectory of my entire career. I had a lot of exposure and practice and experience in Health Policy and doing state Health Policy work but it was until that grant that I got a lot of exposure to newborn screening. Metabolic bloodspot screening and congenital heart disease screening and all those things and so.

So as I went into back into higher education to get a Ph.D. I thought, well, I want to ‑‑

>> LIZA CREEL: I do talk really loud. But I know the mic is important.

>> LIZA CREEL: So when I went back to get a Ph.D. I to the I need to find a way to continue in some of this work even though I'm not as involved programmatically as I was in my previous job and it turned out I once again lucked into a great experience and environment where I had access to some data and my dissertation work is on newborn hearing screening in the NICU setting and long‑term outcomes. We did a longitude y'all study in a single center that had a lot of follow‑up data for the NICU babies. We looked at outcomes of that program pre and post universal screening in the state of Texas, so when I finished that, I had to get a job, and so I worked pretty hard at trying to get a job, and ended up at the University of Louisville in the School of Public Health and Information Sciences as a brand new junior faculty having never worked in academia, and with a goal of doing the kind of research that I really like to do, and doing it on topics that were really important to me.

And so I spent 6 months, probably, at the start of my job at U of L basically cold‑calling a lot of people that did things that I was really interested in, and, you know, called everyone I could and said: Can we partner? Do you have data? This could be really beneficial. I have some time to give you.

And ultimately I ended up getting connected with the Kentucky Commission for Children with Special Health Care Needs, with the state EHDI Program, and ultimately with Cathy and truly, the rest is history.

It's been a learning experience, certainly, on both sides, but it's also been a really powerful collaboration for both me, as an academician, and my University, as a University that's very engaged in sort of community collaboration, but also for the EHDI Program, because we've been able to just provide some support they didn't otherwise have.

All right, that did not...

>> CATHY LESTER: All right, what happened?

So as Liza said, she got connected with my agency. Our EHDI Program in Kentucky is part of our Title V agency, which is the Commission for Children with Special Health Care Needs, which is why I said her title is even longer than ours. We are a relatively small state. We have about 53,000 births a year, and we have a small EHDI Program. I'm the only full‑time person that's dedicated to actual grant work, CDC HRSA grant work. I have a full‑time follow‑up Coordinator, a part‑time follow‑up Coordinator and a couple of other really small percentages of other staff.

So we have a really good EHDI information system. We have, it's really a two part system. It's home grown. There's the part that's set in the hospital, called KY CHILD and CHILD stands for: Certificate of birth, hearing, immunizations and lab data. Once CCHD was implemented that was added but it was after the fact so they didn't make the acronym. But we count them anyway.

So through KY CHILD, we get all of the information from all of those different modules, and electronically it is then transferred into the EHDI information system, my database each night. I get specifically the hearing screening data along with some other demographic stuff. The state lab gets their piece. The immunizations, the birth certificate people, they all get their pieces of it but because it's all integrated at the hospital level we can sometimes get extra data from that. And that's been really beneficial. And the fact that it was born in Kentucky and created by Kentucky programmers, we have a lot of flexibility with being able to adjust and modify and enhance that system.

So we don't have given the fact we're a small program in a small state, we don't have epidemiology support in Kentucky. The Department of Public Health, which is in our Cabinet but not my Department, has epidemiologists but they do their thing and we're kind of left out so we have no epi support. We have all this great data but no ability to do anything with it.

So when Liza called our Executive Director, just kind of out of the blue, they met, had a really good conversation that we weren't ‑‑ the EHDI Program wasn't part of and then our Executive Director at the time sent an email to our boss and I said and said we have this new Professor at U of L, y'all need to meet with her. Yes, ma'am, we'll do that. We met with her one day and it was truly, if it was like, I envisioned the Pac‑Man, and this Pac‑Man where the little bubbles come together, it was like fate. We had this great meeting and started working with her. We got her oriented to the agency.

You all are in government agencies, a lot of you, so you know what it's like to share data with people. We had steps to go through. We had to get her documentation from HIPAA at the University, she had to sign consents for ours. We did orientation, gave her explanations, showed her our data systems, let her know what data elements we have available, how we collected them, what the variables were, what the different labels were and then started talking about, how can we bring you into this process?

So she came to our, one of our Advisory Board meetings to kind of see not just what we were like in‑house but then what the rest of our system is like and we have a really high functioning Advisory Board. And I'm bragging a little bit. I am a little biased too. So we have really good representation from state stakeholders. We have audiologists. We have pediatricians. Our EHDI Chapter Champion who is here in the audience. Say hi, Judy.

[ Laughter ]

We just have, we have birth hospitals and ENTs and just really, really strong Advisory Board. And we're doing a lot of really good things, so we immediately, after Liza came in, we started talking about some things because in our first meeting, we had some questions about, what's the incidence rate in Kentucky of hearing loss? So we all have that statistic that 1 to 3 in 1,000 kids have a hearing loss, but where in that 1 to 3 did Kentucky fall?

So we worked out a way to get Liza some data, and we were able to ‑‑ I think I was too quick ‑‑ we were able to get her, I think our first set was five years, wasn't it five years, 11 to 16? Okay, so we worked out to get all of our data for kids that referred, and all the demographics and all this different information, and then we were like okay, that's not enough so we'll give her more data. So she started doing some just kind of easy ‑‑ easy for her ‑‑ data analysis on our incidence rate and did information on our risk factors as well which we'll talk more about in a minute.

So Liza will start talking about some of the other things she was able to do because I don't know those things like she does.

>> LIZA CREEL: So if anyone in here is a quantitative researcher, you know when you hear that there are multiple years of data available to you, that's like the best news in the whole wide world.

[ Laughter ]

So you can imagine my excitement as a junior faculty member really interested in this, I have a longitudinal data set that can be used to answer research questions I care about. This was like the best thing that ever happened.

But before we kind of start talking about the specific projects, I want to just highlight some of the factors that I think really facilitated this working well for us. Some of which will translate to other University settings and some may not.

The first really being my association with the Commonwealth Institute for Kentucky, of Kentucky. So when I was hired at U of L, there was a relatively new Research Center, the Commonwealth Institute, that was just being developed, and it used some conversion funds from a hospital merger to sort of do some infrastructure building across the years and part of that was supporting faculty salaries to some extent.

So I was able to really leverage time that was covered under this research infrastructure to support and protect time to work on EHDI‑related research. And I think that is really one of the key factors, because I didn't have to go and do this on my own time, because it was unfunded. So we have great leadership in there, and I think it really made a difference in allowing me to dedicate some time to this work, at a time when the EHDI Program itself didn't have funding to support my time and role as a researcher. So that salary support and protected research time was, of course, really important.

It also helped I was an early career faculty member who's very motivated by tenure to do a lot of this stuff. And so I was willing to invest a lot of time and energy into this, number one because I care about it. Number two, because it helps me meet some career goals and so I think that really helped.

In other University settings, not every School of Public Health, not every school of education, has a Research Center with dedicated research dollars that you don't have to apply for.

[ Laughter ]

So, you know, I think there's a lot of awards available. They're small but important awards for early career investigators through my professional association, Academy Health. They have a junior investigator award, and there are lots of organizations that do that. March of Dimes is very supportive of that through Academy Health, so I think there are opportunities to get small but important funding to help early career investigators if there's not research funding available otherwise.

I think partnerships with early career investigators, with people with backgrounds like mine who have maybe worked on the program side of this and sort of ventured into the research and implementation side, can also be really, really useful.

So Cathy mentioned our first project. So out of that first advisory committee meeting, everyone was really interested in understanding the incidence rate across years in Kentucky, and I said, well, I can totally do that. Let me ‑‑ give me a week or so, and I'll take a look at this and report back to you guys on what we're observing in Kentucky across these four years at the time of data.

And so I get into the first data set that Cathy had shared with me. I will say this was also IRB approved. We did go through IRB process at my University and at the Cabinet before any data were given to me.

So I get into the data set, and something is just not right. Like, the numbers don't look right. I didn't really understand what was going on. Well, it turns out that the first data transfer was just a sample of kids who had risk factors for ‑‑ documented from the hospital, for hearing loss. And that's quite clearly not the right data set to answer questions related to incidence.

And so we very quickly figured that out, and Cathy was able to pull a full data set of all births across those years where we could accurately measure and estimate incidence in the state of Kentucky. So that was really fun. It was a little bit of trial and error but we totally figured it out, and I think from my perspective, working with a smaller state agency has been really valuable, because there's some nimbleness that's there that we don't always see in some of the very large state agencies so we could sort of respond to challenges related to data pretty quickly.

We've done quite a bit of other work. Cathy mentioned risk factor surveillance, so the ‑‑ at the time of birth, hospitals in Kentucky report on 15 different risk factors that may be present for mom or baby, and the Advisory Committee was of course very interested in understanding the prevalence of these risk factors and also their Association to an event you'll diagnosis of hearing loss. And this was really important to the Advisory Committee because for some time they've been working on and are just finalizing some guidelines for primary care physicians following up, and treating patients who have one or more risk factors for hearing loss.

And so we've done a lot of reporting and testing for associations between risk factors, family history, congenital CMV, NICU stays, all of those things, to look at whether or not certain risk factors that are already reported are relevant to the Kentucky population. Many of them are based on the JCIH recommendations, and we anticipate actually making potentially some changes to those, given new recommendations coming out and other things that the Advisory Committee is doing.

The other thing I will mention on this is as the professional provider work group on the Advisory Committee has been talking through some of this in their meetings, I sit in on those meetings on my computer and run analyses as they are talking about this. What was the association between this and hearing loss? And we can run that pretty quickly.

And so I think in that way, I think it's really valuable to have some realtime analysis, because I've already cleaned the data and it's already available, and this is running chi‑square tests basically on a lot of it, so it's fairly easy for us to do within the statistical software programs we're using and informative in real time for decision makers who only get to meet in person every quarter.

One of the more exciting things we've been doing is looking at hospital scheduling of follow‑up appointments for infants that refer on their Newborn Hearing Screen. We have hypothesized that hospital scheduling follow‑up appointments improves documented follow‑up for infants, and wonderfully, the Data System that hospitals report into actually has a variable, where they can mark whether or not they scheduled a follow‑up appointment for the baby.

So that makes our analysis pretty fun and so we can actually test for these things. We presented some preliminary results on this last year at this meeting. We've since added in 2016 data, so we have a full 5 years of data, where hospital scheduling was actually being phased in so there's some time variables that are really important there.

What we're doing is really controlling for things like the fact that hospitals are different organizationally. There are things that we can't measure about hospitals that we think probably matter to whether or not they do this and so we can adjust in our statistics for those things, and it does seem to be that hospital scheduling can make a difference which has also been reported in other studies, most recently the one out of Louisiana. So now we get into some grant related fun stuff.

So in 2016, Cathy, as part of several of her I think both the CDC and HRSA grant, had been wanting to implement stakeholder surveys targeting different stakeholder groups around the state to identify things like: What's working really well for you? What opportunities do we have for improving this? How can we do better around data sharing and data reporting? What are the opportunities for quality improvement in our program?

And I'll mention here that I've worked with a lot of state agencies over the years in my career and I will say, I think one really important point to point out, and I think this is true of many and probably all EHDI Programs, is this desire for better service delivery, and wanting to use data to inform quality improvement, and recognizing that not everything is great all the time, and where there are challenges identified, using those to do better, to find ways to do better.

And, you know, as a researcher, to do stuff and realize that someone's actually going to do something with it makes you feel pretty good, and so it's been really nice to work with a group of folks who are really, really interested in quality improvement, and using data to drive quality improvement.

And that's what the goal of many of these surveys are. And so in 2016, I and some students actually of mine at the University ‑‑ graduate students are wonderful too ‑‑ helped develop some set of five different stakeholder surveys targeting hospitals, audiologists, physician providers, families, and Early Intervention providers, asking similar questions across those, but also specific questions to those stakeholder groups so we could get at many of these things we cared about understanding.

Thanks to Cathy and y'all's great network of EHDI Coordinators, we didn't have to start from scratch because many of you have been doing surveys and asking really important questions for sometime and so we were able to take those and then build on them and put together surveys that were specific to our goals and needs in Kentucky.

[ Off Microphone ]

Special thanks to EHDI Chats.

[ Inaudible Comment ]

[ Laughter ]

And so we implemented those in 2016. They were not perfect. We definitely found some things we wanted to change after the first iteration of those surveys. It was a mix of both web based surveys and also paper surveys that were entered in by wonderful interns at the Commission. And we've actually collected a whole ‑‑ a second round of data on those, and are about to launch our third round. We're now doing these surveys annually, and using them to capture data that's relevant for both the HRSA grant and the CDC grant evaluations. So they're really becoming an important data collection tool for not just knowing where we could do better or knowing where we're doing something really well, but reporting to our funders on the things that they care about.

So for example, the last couple of years, we've had some questions about the data reporting systems in Kentucky, and how well they're working for different providers who are required to enter data including audiologists for all the follow‑up stuff. And because of some of the goals and objectives of the CDC grant in this current year, we've actually added a few questions to there to ask audiologists specifically about data‑sharing‑type stuff. And so to a certain extent, we're able to customize those, but also maintain consistent questions so that we can measure change over time.

A lot of this, a lot of the 2016 survey results, were used for grant writing in the HRSA application, and also the CDC application, both of which went in about a year, somewhere around a year ago. You guys know that. So Cathy of course bears the brunt of writing a lot of that but she now has me to help write evaluation sections, and define variables and research questions and things that are important to really understand the relationship, the causal relationship, where we're able to, between the EHDI Program and the things that the program is doing, and the outcomes that we care about.

So if we talk a little ‑‑ oh, so speaking of that HRSA grant, you can tell that the investment the Commonwealth Institute of Kentucky made has really leveraged into a lot of good stuff for both me and the University, and that's because I don't know if it was paybacks or what, but Cathy wrote us in as the research and evaluation partner in the HRSA grant, and which I think was great, right, because it gives us funding to do ‑‑ continue to do all of this stuff. But I think it also solidifies this partnership that's proved valuable for both sides.

And so you can see here that under this contract we have a lot of responsibilities for program evaluation. We're doing surveys and other qualitative type stuff like talking to families and parents through key informant interviews. We're also doing a lot of quantitative data analysis to see if we're meeting the metrics we're supposed to meet through that grant. The other thing we're doing that I know is important to everyone in here who's working on HRSA related stuff is the stuff we're doing around the learning communities.

And so I have a fair amount of experience in sort of quality improvement, PDSA stuff, and have been able I think, I hope, to help think through, as the ‑‑ the Kentucky EHDI Program has implemented their learning community, what outcomes they're really trying to achieve, because we actually want to be able to measure change and incremental change, percentage changes, in this case care planning, and so we've developed surveys that we implement each time and are actually using that to test for changes in care planning from both the parent side, the family side, but also the provider side.

We just got our second round of data from the learning community, and we'll actually be analyzing that in the next couple of weeks, so hopefully soon we'll be reporting outcomes of the first three quarters of a year of the Kentucky Learning Community.

As I mentioned, we're also now actively participating in also the CDC grant evaluation. So we again collaborated on the application. The CDC grant is particularly interesting to a quantitative researcher like me, because in the expanded portion of it, we're talking about things like limited data sets and really looking at measures across states, so that we can look at short and long‑term outcomes, and so it's really exciting to collaborate on this, and this work has really just evolved into some pretty fun stuff.

So we are helping on the evaluation side of that. We're also helping in the expanded part on development of the minimum data set, and we'll be doing some of the testing when the time is there, on that piece.

The other thing is that the Commonwealth Institute of Kentucky is a lot larger than me, and they have a lot of people with more diverse expertise than I do, including people with a lot of experience in things like public relations and translating all the research‑y language that I like to write into stuff that's palatable for the general public so under the CDC grant there are some goals to do some reporting to stakeholders where some collaborators of mine at CIK are able to help us translate that for a non‑research‑trained audience.

And I think that's going to be a fun partnership and kind of a new way to work together.

We've worked really closely with CDC on developing year one evaluation measures and integrating those into our surveys. I attended the Atlanta kickoff meeting back in November and I'll just mention that there are offshoots of this happening everywhere, so at that CDC meeting, and I don't see any of ‑‑ is anyone in here from CDC? Okay. Okay.

[ Off Microphone ]

Okay. So at this meeting, everyone introduces themselves and I stood up and I said: I'm Liza Creel, I'm a Health Services researcher. I'm involved with the Kentucky EHDI Program. And at our next break, Scott Grosse came up to me and said we need to be doing some stuff together. They've been doing a lot of really great work on identifying cases of hearing loss and administrative claims data which is something I do a lot of in Kentucky Medicaid data. And so we are now sharing some code and making sure that we're doing a better job of identifying things like hearing loss in administrative data, but we're also exploring sort of co‑occurring hearing loss and behavioral health diagnoses in those data sets, as well.

So I am kind of testing this algorithm with Kentucky Medicaid claims data, while they're using different data source of both publicly and privately insured children and so it's just really fun to think about where these paths have really led us over what ‑‑ I mean, two years, two and a half years.

All right.

>> CATHY LESTER: So Liza gave a good introduction of some of the work she's done with us. From my perspective there have been a number of benefits to our program with the work she's done. Prior to her involvement in our program as I mentioned earlier, we have a ton of data but you can't just look at data and say: This is significant and this is not. You have to be able to analyze it with some kind of statistical package. And while I have done that in my past, that is not something I really have time to do in my current job. I don't have time to clean the data. I don't have time to put it together and run the tests and really examine the significance of that. And having her involved with us has given us the freedom to have that done for us.

Her training in statistical analysis and her training in Health Policy allows us to look at what she's analyzed, and then figure out a way to change our program to respond to what we see could be beneficial. For an example, the hospital scheduling analysis that she ran, we are now ‑‑ we've always encouraged our hospitals to do this scheduling, but it's never really been required and while we haven't changed our compliance guide yet to make it required, we are actually making it a stronger emphasis in our annual reviews with our hospitals.

Kentucky does an annual site review either on the phone for high‑performing hospitals, or in person for hospitals that are struggling in one or more areas, and every meeting we have with a hospital, we are reinforcing this, and we are sharing the analysis that has been done to say: Look, this really makes a difference. Yeah, sometimes families don't show. Sometimes they have other issues. Sometimes they're rescheduled but by and large, your efforts make a difference. And who among us don't want to know that if we're going to do something, it does make a difference. So when we're able to say to them, we have data, we have analysis, it does make a difference, it really has increased their motivation to do that scheduling where it's possible.

Another way that Liza was sharing that one of the things she's done is helping us with grant reporting and this has an been an incredible benefit for us. There's many EHDI Coordinators in the room and I get to the point where I feel like I'm saying the same thing over and over again in some of these grant reports but having actual data analysis means that I get to be specific about what we're doing and how it's impacting our program and how it then impacts the children and families that we serve.

The survey data that Liza talked about, we were able to use that in both of our grant reports, and were able to say not just that we did these surveys or not just that we did this initiative, but in our surveys, parents said that this really mattered to them. And that's really critical for funding agencies to see, because then they really do get a sense of what it is that we're doing, and how it's making an impact in the community.

The last thing that I think, the last big thing that I think that is really important to the EHDI agency or the EHDI Program for us, and I think could be equally as important to other EHDI Programs is this quality improvement. And we all know quality improvement is a big deal for us. It's required by many of our funding agencies but it's also, I have found that it's really effective at changing some of the things we're doing and changing them in a strategic way so it's not just willy‑nilly. We like most of us do this PDSA, the Plan‑Do‑Study‑Act, and once we start one we start a small test of change and we start gathering little bits of data and at this point we're not really analyzing it. We're eye balling this because there's five cases or whatever. We roll it out and we start collecting more data at a bigger level and then we get data analysis on it and then we can say: Hey, this really does make a difference so this risk factor piece, the data analysis that Liza has done on our risk factors has really helped drive what our Advisory Board is doing to educate physicians on risk factors. We're in the process of taking all of the best practice documents that we can find from all of the different National agency, the JCIH and AAA and ASHA and other states' documents that they've put together that we've gleaned from the EHDI Conferences or NCHAM webinars or whatever, and we're developing a risk factor protocol for physicians, specifically for physicians, not for EHDI Programs or other people but it's a one page document, it's going to have the risk factor, it's going to have what's the first step you do and what's the ongoing follow‑up and it's going to be in language that physician understand, and it's going to be pretty clear‑cut and we're almost done with that.

But if it hadn't been for some of Liza's data analysis we couldn't be where we are with that process so the ability to do quality improvement with realtime data analysis has been huge for our program. And it really has made a big, big difference. So that's the three big guest benefits to the EHDI Program. There are many more but those are the ones I think will be easily transferable to EHDI Programs if you're lucky enough to have the ability to develop a collaboration like this.

>> LIZA CREEL: This is the last time you'll hear me.

[ Off Microphone ]

But wanted to highlight some of the benefits to the University in total and certainly for my University, it's a huge benefit to have these collaborations with both state and local communities. The University of Louisville has a very, very strong value, places a lot of value in community engagement. We as faculty and staff are actually required to report on our community engagement activities each year.

And this is a wonderful example of community engagement work that we're doing not just with the State, but with the local community in Louisville through things like the learning communities and other activities. And I'd be remiss to say that there's not value here from an academic productivity standpoint, because ultimately, I have to go through the tenure review process, and that requires academic productivity in a lot of different ways, including manuscripts. So we're working closely together on several manuscripts actually right now that, you know, help build my research portfolio, while also contributing to the larger body of literature knowledge around these important issues.

You know, probably most importantly to me, as a person who cares about Health Policy and wants good Health Policy, is the contribution I think that we can make thank you this work to both public health programs, but also to State Health policymaking, primarily. And, you know, I really think that this can inform better policymaking, better program development. We have a lot of expertise in the Commonwealth Institute of translating research into documents and reports and things that are targeted towards policymakers and we think there's a lot of opportunity to do some education and outreach in those areas, so that we can inform good policy making.

So at the end of the day, I, thank you all of this work, get to do something I really like. I get to add to the body of literature that I care about and that I read. And also enjoy the stuff that I do and try to do what I do really well.

>> CATHY LESTER: So we did identify some challenges to this collaboration, and they are something that I think, if you're looking at trying to implement this kind of collaboration in your state, that you should be aware of so you can sort of plan for that. Data sharing, we're able because we're a small program we're able to work around that and make that happen but it did take several ‑‑ we had to jump through several hoops to get that done.

It is difficult to find faculty with time in other universities, so we're very fortunate that Liza came into Kentucky at a point where she needed things to do and we needed things done. And she had the time to do it. You may, depending on the universities in your area, you may not have people in that University in that School of Public Health or whatever Department you choose to focus your efforts on, you may not find somebody like that right away so it is something you should be aware of.

The role of students, Liza mentioned graduate students are awesome. She has been through her mentorship with students in her Department, she has been able to find projects from us to give to her graduate students, which then lessens the amount of time that she has to devote to specific things, but still gets it done, teaches her students real‑life application of some of the things that they learn in class, and it's a win‑win‑win really in those situations.

But the EHDI Program piece is also, can be a challenge. We all have a lot of things on our plate and we all have grant opportunities and program administration and we all have things in our own agencies that require doing, and it's sometimes difficult to find the time to do the collaboration.

My experience is that when you push to make that time available, the benefits are just a multiple of the time that you spend, so I get so much more out of this collaboration than I've had to put into it. It's beyond compare, but finding that time up front can be a challenge. So that is something that I would definitely say be aware of.

So this has all been about the University of Louisville and the EHDI Program. Prior to Liza coming to Kentucky, we already had an existing relationship with the University of Kentucky. We had done a little bit of work with Dr. Matt Bush, who's an otolaryngologist who does CI surgeries and sees lots of patients at the University of Kentucky and is a prolific researcher. He had contacted us and requested data, and we had done IRB approval again, and shared some data with him. And he has done a number of different analyses and research projects around the data that we have shared, and Julie will talk a little bit more about that.

But the research that he has done has been really valuable, and we are able to do a lot of new projects because of that. So Julie is going to talk a little bit about some of those projects.

>> JULIE JACOBS: Hello. Hello, everyone. So I'm taking the story down the road a little bit to Lexington, Kentucky, which is only, like, an hour, hour and a half away, which proximity matters when you're collaborating and I'm going to introduce you to a new cast of characters a little bit and I came in a little bit after that relationship had already been established.

So my background is that I have a masters of public health degree, which I got about a decade ago in St. Louis, and there I worked with a faculty member who's an expert in dissemination and implementation research, which is a mouthful, and maybe not a familiar term to most, but basically, the study of taking evidence and moving it into practice, knowing that we first start with learning what works, and then ‑‑ in ideal controlled settings and try to get it into real world settings and try to understand through implementation, science research in particular, the barriers and facilitators that will help get an evidence‑based intervention or policy or practice into place. So that's my background.

I got moved to Kentucky, as well, and never expected it.

[ Laughter ]

And so I only landed in Kentucky and in 2015, I started working with Dr. Tina Studts, who is in the College of Public Health at the University of Kentucky. And her background is as a licensed clinical social worker. She had for about a decade spent time in Eastern Kentucky working in practice and then got her Ph.D. in social work and she very much has an interest in increasing the access to evidence‑based interventions, particularly around behavioral interventions in young children.

She met Matt Bush through an early ‑‑ they both had early career investigator awards, and they met through that mechanism, and identified some key crossovers in their research programs because like Cathy said, Matt does a lot of work in understanding hearing health care disparities, and increasing access and he does a lot ‑‑ he's particularly focused on rural populations and Appalachian populations which Eastern Kentucky is Appalachia and he's from an Appalachian community so that has sparked his interest in that.

So I work for both of them, and I've done that for about three years, worked for both of them. I have no background prior to that in hearing loss, or in, like, mental health and behavioral disorders, more so in, like, research management. So I've learned a lot and I've had a lot of great partners who taught me a lot but I have a lot to learn still so I'm a Project Director, and I run the day‑to‑day operations and keep all the balls in the air.

So getting to this slide, I'm going to try to go through a few of our projects and try not to be too results focused because I feel like we might be getting close on time. So I'm going to try.

But I really want to talk kind of highlight the critical role that the EHDI Program and the Commission for Children with Special Health Care Needs has played in our research so this first study is the one that was already ongoing when I showed up. It's a three year study funded by NIH, and it's investigating patient navigation, so basically this is based off of ‑‑ there's a lot of evidence on patient navigation in cancer patients, and we have taken that model and kind of adapted it to navigating families from a failed newborn hearing screening process through the diagnostic process.

So we had a randomized control trial. We had folks either randomized to a standard of care condition where they just got the typical reminders from the clinic and a navigated condition where one of our great navigators, one of whom is sitting with us, would basically talk to that family, identify barriers, help problem‑solve. I know I don't want to get too focused on results but I do like results and so it worked. Our patient navigation project, and so really, I guess what I want to focus on here is the critical relationship with the EHDI system in terms of helping us identify families, so identifying families, sending their contact information so that our research team could then contact those families, and also providing the follow‑up information, so our key outcome is, as you see here, looking at percent loss to follow‑up for the diagnostic testing.

And this study was published in Laryngoscope last year. And I'm just bouncing from ‑‑ because that's what our research is. We have a lot of different things going on.

So from the newborn period, now we're in the 2 to 5‑year‑old period and this is really the first project that Tina and Matt worked really collaboratively on. We knew from other studies that there's increased risk for disruptive behavioral disorders among deaf and hard of hearing children and those are things like aggression, non‑compliance, defiance, and so we conducted another study in Kentucky, and again, this is where recruitment was a really key issue for us.

We conducted this study recruiting kids with hearing aids, kids with cochlear implants and also typically hearing kids, and the Commission really was a great help in identifying those families for the hearing loss, with the hearing loss kids.

We used a validated measure called the Young Child Diagnostic Interview Schedule that addressed disruptive behavioral disorders, and so it uses diagnostic criteria to understand the frequency, severity, timing of disorders, and so these are, real quick, just some results of that study.

In the middle, you see the results of the measure that I just talked about, the YCDIS, so we see a much increased prevalence of oppositional defiant disorder, which is characterized by, like, aggression, non‑compliance, defiance, among kids with hearing loss compared to the typically hearing kids. We also asked parents if they thought their child had an emotional or behavioral problem. And you can see, that's the first set of bars over there. So you can see a big difference there.

And unfortunately, on the far right, we see that the typically hearing kids are accessing mental health services as expected in a typical population. But none of the children with hearing loss had access to mental health services. How am I doing?

[ Off Microphone ]

>> CATHY LESTER: So this is where the two U.K. and the Commission and then the other two, U of L and the Commission, become three.

We brought Dr. Bush and Dr. Studts and Julie to an Advisory Board meeting and Liza was already there and we introduced them and that really is history. We were able to set up a meeting to talk about mutual research interests that involved the EHDI Program, and our population of children. Liza and I drove from Louisville to Lexington and met at UK. We took beignets and we planned world domination in the field of infant hearing loss. It's been a wonderful collaboration. The pictures of Dr. Bush, some of you may know him and that's Dr. Studts at the bottom.

And then so we began working lots of different ‑‑ we'd already started the hospital scheduling research so we started involving the U.K. folks with that, and got some really valuable feedback, and discussion about, have you tried this and this analysis? What about this? Some manuscript feedback and it's just been a really, really valuable collaboration.

We're working on some grants together, and big grants, which will be really fun, and I think Julie's going to talk about those, right?

>> JULIE JACOBS: Yeah. Jumping back in.

>> CATHY LESTER: We've got like 10 minutes.

>> JULIE JACOBS: So I'll just back in to talk about future work. We're working on a big grant, if you're familiar with NIH. R01 is their big funding initiative, again collaborating with these fine folks here. So I got my 10‑minute warning. I'm going to try to go a little bit faster.

So basically, through the EHDI Program and Cathy's help, we need her help with compiling clinic level data, identifying the number of infants referred, timing of testing, number of visits, loss to follow‑up, so that's a critical relationship, and we need that for the outcomes, the primary outcomes of this study.

She also will play a huge role in rolling out the intervention. We're using 10 clinics throughout the state, 10 clinics of the Commission of ‑‑ what are you, Commission of Children with Special Health Care Needs ‑‑ so we'll be rolling it out to those 10 clinics over the course of that 5‑year period, and she will play a key role in connecting us to staff at each of those clinics and training a navigator to work within each of those clinics and Liza, of course, we have a cost effectiveness aim and while we have some researchers at U.K. who can do similar work to that, her expertise in this topic area is something that we ‑‑ it's incredible benefit to the project.

Okay. Jumping back to child behavior, so what I failed to mention is in that previous study where Matt and Tina were working together they tested an off the shelf behavioral parent training program, and so this is an evidence‑based program that basically helps families. The idea is to help the child, you train the parent and it's a lot of common sense parenting techniques but I don't know how many parents in the room but we all could use a little help and support and coaching, I know I can, and so there has been ‑‑ these interventions have been used and tested for decades, but despite that increased ‑‑ the increased prevalence of disruptive behavior problems in deaf and hard of hearing children, they've never been used in that population.

So we did the off the shelf version, where we basically took the evidence‑based program, made no changes to it. It worked okay, but as you would expect it didn't totally meet the needs of this population.

So as part of implementation science, we are systematically adapting that program, so this project, VI2P means nothing to you but to us it's an internal funding source so the University of Kentucky is funding a year and a half pilot study where we're systematically talking to key informants, talking to a Community Advisory Board. We're doing interviews with parents. We're doing focus groups with audiologists and speech‑language therapists, and educators, to understand what it is we need to do to change this evidence‑based program to meet the needs of deaf and hard of hearing children.

So we ‑‑ our next training ‑‑ so we've done interviews. We're understanding the adaptations which are things like incorporating common scenarios so really, we're really focused on the evidence base to the program. We don't want to mess with that but make it relevant to these parents' lives.

So we're focused on that right now, and we have also talked to parents about how they want this delivered and they've identified that the experience that matters most to them is that someone understands what they're going through, so we are training two parent‑guides and coordinating with Hands & Voices and the Guide By Your Side program, to train two parents to be interventionists to deliver this to families.

So they will have training in the evidence‑based part of it and the adaptations.

We are ‑‑ so that's our pilot and of course another R01, because we love R01s. I won't get much into it. That's taking the same child behavior project into a large five year statewide grant project. You want to jump back in?

>> CATHY LESTER: So I think we've presented a number of opportunities that EHDI Programs and universities can collaborate. We recognize that there's some very key factors that allow this collaboration to be successful, some of which may be able to implement in other states. Others may not but on a state‑by‑state basis, it's still worth, in my opinion, the effort. And the best thing is, one of the best things is, that we're doing this work and we're doing it for the children and families in our state, and we have work meetings over margaritas.

How can you go wrong with that, right?

[ Laughter ]

That's our presentation. And we'd be open to questions for the next 6 minutes, I think, if you have any.

[ Applause ]

[ Off Microphone ]

Can you hear me? We plan on stealing both Vicki and of course and any other EHDI Coordinators who are here, the checklist, or the risk factor information as soon as you have it.

>> CATHY LESTER: As soon as it is finalized we will share seamlessly.

>> Awesome.

>> Hello. This is Tatiana [ inaudible ] from CDC. I'm credible work. I've read some of your papers, and one question: Would you be able to link some of the data to the Early Childhood education program that might offer some good insights on the impact of the Early Intervention?

And also, since I'm a CMV, working on CMV, do you have any data on CMV?

>> CATHY LESTER: So to answer the first question, we would dearly love to link our data to Early Intervention. We are fighting that same battle that most states are between HIPAA and FERPA so our Early Intervention Program does not believe that they can link individual level data with our data because of FERPA. We're continuing to address that in any way, shape or form but right now, they require signed consents of release of information from parents to do data linkage. And we don't have an electronic way to link that data, even if we have a signed agreement.

In terms of CMV, CMV is one of the risk factors we do collect and it's part of the data set Liza analyzed, and it's included in our risk factor protocol. We don't have any legislative mandates for CMV testing either targeted or universal nor do we have an education program. It is high on my list of priorities as our EHDI Champion can attest.

>> LIZA CREEL: This is unrelated to what we presented on, the University of Louisville School of Medicine is part of a new research project actually looking attesting at birth, and so, and I'm connected with a lot of infectious disease providers in the School of Medicine and so we're trying to make sure that all of these efforts that are ongoing that are important to the population we care about, at least we know what's happening, and we hope that that informs better work in the long run.

>> CATHY LESTER: And you're going to connect us at some point.

>> LIZA CREEL: Yes.

>> I am also a researcher at UMASS Dartmouth. I sort of had the moment Liza caulked the talked about when a clinical team said hey would you help us analyze your data? Then it was ahh, because it was a lot of assessment data, and they were only administering assessments when it was clinically indicated, which meant it was skewed. It's been an uphill battle to try to buy the clinicians' time to get the protocol administered. Do you have any insights to make that work? And if anyone else is looking for partnerships, I'm here.

>> LIZA CREEL: I don't know that I have any particular insights on your situation, although I sympathize. I have some other work where we're looking at some Early Intervention stuff and where the assessments are only done on targeted population just generalizations really difficult. So I don't really ‑‑ I don't know.

I'll have to think on that and think about ways ‑‑ I think in the clinical practice setting there are ways to sort of change clinical practice where they're targeting a larger population but that's a lot of burden on the providers, and there's only so much money to do this kind of stuff. So, yeah.

>> Hi. I just had a question for program. How ‑‑ I know that you're involving parents from Hands & Voices. How did you ‑‑ did you get funding? And how is that possible? Who helped you with the grant‑writing to get this program and get that implemented?

>> JULIE JACOBS: So we're just getting started with that pilot program, and we just recently identified that we want to use parents as our interventionists, so this is all a very new collaboration and actually I've made some connections here and will follow up on those to kind of understand how we'll get all that nitty gritty done. But I think in the short term for a pilot project, we're identifying parents through Hands & Voices. We will pay them probably through our University.

So that's for our pilot project, and then when we get to the R01 project, where we hope to use parents, I think we'll have 5 clinics throughout the Commission, throughout the state, for the R01 grant so we don't have those details worked out yet. The funding would come through NIH, and would help fund the position of that Guide By Your Side parent coach.

>> CATHY LESTER: So when they were planning this grant, part of the VI2P grant involves a Community Advisory Board, and because we are a small state and we know a lot of our stakeholders personally, I was involved in suggesting some parents and some other stakeholders, and we pulled in our Executive Director for Hands & Voices as one of the members of the Community Advisory Board. Coincidentally, they are one of our family support agencies through the HRSA grant, and we are funding the reinvigoration of our Guide By Your Side program. We literally just got approved last month to do Guide By Your Side all gain in Kentucky. So our first training is next weekend, the 30th and the 31st and as part of the training, we are implementing this VI2P behavior intervention, and it just very fortuitously all came about at the same time.

So I don't know that that would have been something we could have replicated as easily had the timing not be so lucky for us.

>> JULIE JACOBS: We're hoping the training component is an additional service that these already trained Guide By Your Side guides can provide, because the family checkup, the evidence‑based behavioral parent training program, is very structured and we need to maintain fidelity to that program so it's a structured program that would be offered to the family once a year and then they would have a checkup the next year so it's about a 6‑session program with a family.

>> And we are out of time. If the presenters are willing to stick around, they can answer questions one on one. Thank you.

[ Applause ]

[ End of session ]

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