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EHDI 2019

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If You Build It, Will They Come?

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>> All right. Hello. My name is Michele. I'm going to go ahead and introduce the session. If you build it, will they come? A regional approach to establishing effective learning communities.

>> Thank you so much. Good morning, everyone. We are so excited to share what we have to share this morning. So we're trying not to curb our inus that yam. My name is Valerie Abbott, and first and foremost, I am the parent of a child with hearing loss. She is 13. I am also a 1‑3‑6 family educator and the learning community coordinator for the Center for Family Involvement at Virginia Commonwealth University, and I support the EHDI program.

And today I'm here with several friends and colleagues who have played a instrumental role in the learning community program in Virginia. I will be asking them each to introduce themselves. But in the meantime, we know some of you may have questions. If you could write them down and hold them until the end, we have a fair amount, a large amount of information we are going to share in a short period of time, and we think that will be best. So with that.

>> And my name is Deepali Sanghani, and I'm the follow‑up coordinator for the Virginia EHDI program.

>> I'm Ashleigh Greenwood. I am a pediatric audiologist and a clinical director of audiology for pediatrics audiology serves of services at a children's hospital in Virginia, and I am one of the co‑chairs for the Virginia EHDI advisory community.

>> And I'm Mona Iskander, I am a general pediatrician in northern Virginia and the Virginia chapter champion for EHDI.

>> So our objective today is to provide you with an overview of how we establish the learning communities regionally in Virginia. We'll start out with a short video. Okay. One second.

>> Technical challenge.

>> All right. So we I apologize, there should be sound, but it's not coming through. So that video is much more ‑‑ a little bit better if there's sound coming through, but we do need sound for the end. We have another video that we would like sound for.

So when each state EHDI program was asked to create a learning community by the HRSA grant, we sat down in Virginia to figure out how we were going to do this. So we collaborated with the center for family involvement at Virginia commonwealth university and we hired a learning community coordinator to help us do this. And in Virginia, it's so diverse, regionally, culturally, and geographically, based on which part of the state you're in. And so we thought it would be best to divide the state up in six regions and we would start the learning communities regionally and then with the hopes that we would combine in to one learning community at the end.

So as you can see, those six regions are, it's really loud, so I'll step back a little bit, if you can't hear me, then I'll get louder. But the six regions are northern Virginia, central Virginia, Hampton Roads, Blue Ridge, Roanoke and Southwest.

So I'll just highlight a few key things about each region and what makes them diverse. So the northern Virginia region, or what we call NoVa, is a dense population but they have limited access to pediatric services. The central Virginia region is where our he'd program is based and where the Virginia EHDI advisory committee meetings are held. So that region of the state has a greater number of key stakeholders that are residing there and involved in the EHDI program.

The Southwest region is the most rural part of our state and so we anticipated in this region we were going to have difficulty recruiting parents and professionals to be a part of our learning community and then that's the region of the state where there is extensive, and we mean like upwards of two hours travel, to get access to pediatric services.

And then the Roanoke region is, there is scattered pockets of access, so some areas of that region don't have to travel very far at all, but then other parts of that region have to travel very far to get services.

This is essentially the same except they are a mix of urban, suburban, and rural, but they also have those pockets of access.

And then Hampton Roads is where we have a high military population so it is a very transient part of our state, we have people coming and going in that part very often.

>> Super. So our program launched in September of 2017 with the establishment of the northern Virginia learning community, that was kicked off in September, and as of right now, there are about 65 people on that distribution list, 15 of them are parents. There's also an ENT and a pediatrician. The pediatrician is with us today.

I should mention that that list has doubled since it was initiated in September, so each quarter we seem to grow.

Average meeting attendance, when they meet quarterly, is about 18 to 20 people at each of those meetings. The second region we launched was the central Virginia region, and we did that in May of 2018. That, again, as Deepali mentioned, has a group of key stakeholders in it just because it's located in the same space at Richmond. And as of right now, there are about 42 members on that distribution list, a strong pocket of parents, about eight of them, and EENT and a very involved neonatologist. And those meetings are quarterly and they bring in anywhere from 12 to 20 people when they meet.

The third region that we launched was the Southwest region, and that was in October of 2018, just a few months ago, again, a very rural part of our state. We have about 22 members on that distribution group right now. At the kick off meeting in October, we had 12 participants, all of them very, very engaged. And solid representation from early intervention and early childhood education. And the Roanoke region we also kicked off in the same month, October of 2018, they are there are 24, 25 members on that distribution list right now, a good strong parent group of about five very interested parents and audiologist and a midwife that's very excited to be part of that group, and that group at the kick off meeting brought in about 15 people. These groups are meeting about quarterly.

The Blue Ridge and Hampton Roads communities are going to be launched in April and May of this coming here. What's interesting is we already have parents and professionals in those regions who have heard that this is coming and they're very, very eager to get involved. So that is a wonderful position for us to be in.

So let's talk for a minute about the needs assessment. Prior to the kick off of each regional group, we conducted a needs assessment to determine what might be the learning gaps and interests within those communities. So prior to launch, about six to eight weeks ahead of time, we circulated a survey, we sent it out every way we could possibly do it, through social media, e‑mail, we sent out a paper notification to pediatricians and PCPs, and then we tabulate the results and brought that to the kick off meeting to talk about what is the community saying are the needs within the region. For example, in northern Virginia, we found that of those who took the survey, many of them had limited knowledge about the EHDI 1‑3‑6 time line and risk factors for late onset hearing loss and that many healthcare providers rarely refer parents to any type of parent to parent support. So, in general, the survey identified a need for supports for families.

In central Virginia, that needs assessment, we were able to identify that they have an increased knowledge about EHDI systems compared with northern Virginia, and that's not a surprise given that so many of the key stakeholders that attend the EHDI advisory committee meetings live and work in the central Virginia area. But we also identified that this group has limited knowledge of risk factors, care coordination, and culturally competent family‑centered care. So those things helped drive the first few agendas of each of those groups.

>> So I'm really excited to tell you guys about all of the successful outcomes from the Virginia learning communities. So first the learning communities were able to foster an atmosphere of learning between peers. So this was people learning from each other, which was huge. I can give you an example. So in the northern Virginia learning community that I'm a part of, we identified through one of the needs assessments that we didn't know which providers in our area were accepting infants and children with Medicaid and then which of those providers were able to fit hearing aids on Medicaid patients. So we had two volunteers within the learning community research Medicaid providers, they made phone calls, they sent e‑mails, they met people in person and then they came back to the learning community and presented all of that information to the group, so an entire group learned from the work of two people.

Secondly, another successful outcome of the learning community was the ability to connect with providers. So giving providers the ability to connect with each other, strength be not only their interpersonal relationships but also the benefits were felt on a broader spectrum when providers were saying nice things about each other and the environment and in front of mutual patients.

Additionally, giving parents the opportunity to ask questions to these providers that they otherwise might not ask in a busy clinic day was very beneficial to the parents.

We also had increased parent leadership. So these learning communities have empowered parents to become comfortable sharing their child's story, they have become comfortable around the various professionals that work with their child, and it has given parents a platform to hold leadership positions not only within the local learning communities but we actually have had some join us at the say the level at the Virginia EHDI advisory committee meetings. So finally, one of the most successful outcomes of the learning community is the development of products. So we, as a community, ask, and we received. So the best example of a tangible outcome is our shared plan of care. Yay. This is very exciting, guys.

So what you see up here is the parent version of the shared plan of care, and so you all probably understand that didn't exist before we had our very first learning community meeting. So Virginia EHDI came to us and said to the learning community and said, you have to make a shared plan of care, and we all looked at each other, and we were like what? What is that? What is this going to look like, okay? So we had discussions right there in the room at the very first meeting, what do we think this will look like? What's it going to entail? And we talked out loud, at each other, with each other, we all brought different perspectives, different backgrounds, and over several learning community meetings, we refined our ideas and this is somewhat we came up with, the Virginia EHDI shared plan of care for children with hearing loss. This is very exciting.

So we have ten of these parent versions in print currently. And they have been mailed out to the first ten families identified with hearing loss in 2019. And so we're in our first PDSA cycle, planned use study act.

I should also say quickly that there are other shared plans of care. So this is just for parents. Audiologists are going to get their own, PCPs are going to get their own, and also early intervention providers.

So this is on the back of the parent version of the shared plan of care. And what you can see is this is just a real quick visual so that when parents are at their very first diagnosis and in the early stages, they can quickly see what professional they may encounter in the hearing loss journey. So there's the date of diagnosis in the middle. On the left side these repeating appointments that will be a part of the child's hearing loss journey with certain providers, like their audiology they're going to see often, their early intervention providers, etc. And then on the right side are recommended appointments, such as getting an eye check, heart checkup, genetics, infectious disease to look for CMV and neurology if we're looking at atypical types of hearing loss.

>> All right. And in conjunction with the patients shared plan of care, the provider share plan of care will focus predominantly on the left side of the curve of these repeating appointments. So at the same time that the parent is able to look at the inside and know what they need to do at their next step after diagnosis and what they ‑‑ they also will see what they expect from each of the providers that they see at their repeating diagnoses. And the provider gets a copy that is tailored to that particular provider, looking at the PCP, the audiologist, and the early interventionist. So the provider copy will start with a name specific child, baby Smith in your practice has been identified with a hearing loss, and here are ways that you can help.

And the provider copy will have a point of service, educational information that fills in knowledge gaps for that particular provider. It will reenforce to the provider the importance of early intervention and language acquisition. It provides a guide expectations of initial evaluation and follow‑up evaluations. And it also provides resources which would include things like websites for early intervention, EHDI pals, family to family support, case management services, as well as specific phone numbers and e‑mails where a provider can reach out and connect to somebody within the EHDI community.

So as Ashleigh had mentioned, our next step now is to implement the shared plan of care with this PDSA.

So we built it and they kept coming. Why? Well, recruitment. Members with just weird of month, people would tell each other, this is going on in our community and bring friends and bring colleagues and coworkers to the table, and it was more effective than any marketing that we had come up with on our own.

The engagement was there. People were invested. Ideas were shared. People were energy eyed to work on the next stems. And one of the things that came out of northern Virginia was an on‑line chat group or Google chats that we are still in touch with each other even outside of the learning community meetings.

Networking opportunities, it was really nice to be able to establish contacts with vested caregivers that are local. So for me as a pediatrician to show up at the meeting and be like this is the peeing ENT that's really looking for children in his practice and familiar with this, it was a great way to network with other people locally.

Transitioning to leadership, and this was, I think, a really important part of it is that they are ‑‑ the leaders that are continuing the work of the learning community are people who are from the community and know the community and are working together to better their community.

And real quick, one of the things that I had forgotten to mentioned with the shared plan of care is that all of this information does get put into the state reporting system which in our area is called visits.

>> Okay. So establishing the learning community's regionally, it allowed us to learn some lessons along the way so that we could make changes before we launched any in each newborn region. So as Valerie mentioned, we had completed a needs assessment in each region prior to launching, so when we got to the most rural part of our state, the southwest region, we realized that we weren't really getting a lot of numbers of completed needs assessment, so we sat down and thought about it and we realized that we probably should have had a pilot of the needs assessment with parents and professionals prior to launching in that very first region, the northern Virginia region, to make sure that our language that we used in the needs assessment was more friendly for every part of our state. And had we done that, we probably would have gotten better numbers come back. And then another thing we noticed is that any in each region, the way we planned our meetings, the time, the location, it deferred greatly depending on what part of the region we were in. For example, in Southwest, again, we got a lot of feedback that we would get a lot of parents if it was a very informal setting as opposed to a formal setting. So we that information to tailor our meetings in each region to that specific needs of each region.

And they ever overall we've had very minimal medical professionals like pediatricians or primary care providers and ENTs involved. So we've been working with the ones that are involved in our communities to come up with ways of how we can increase primary care and ENT involvement in the future. So we could sit here all day and tell but our learning communities, but we thought we would allow our learning community participants to tell you a little bit about that.

>> And this may be where we need some tech support.

>> I'm going to try it and see if it ‑‑

>> Is there any volume?

>> All of the details may not have been in perfect alignment. But we knew we couldn't do it without a ‑‑

Like many other states and territories when, we sat down to write the HRSA grant in 2016, we had many ideas on how we envisioned the learning community and such a uniquely diverse state. All of the details may not have been in perfect alignment, but we knew we couldn't do it without a parent and professional partnership.

Everyone who comes to these meetings, the parents, the professionals, they are coming from a wide variety of settings and they all come with a unified mission of trying to make things better for these babies that are born with hearing loss. And they come to the table not only eager to share what they think should be changed and improved but also looking for ways to improve how they go about their support of children and what they could be doing better. Everyone is coming looking at ways they can improve the system but also ways that they can be improving themselves.

By the end of 2019, Virginia will have established six regional learning communities and, in 2020, the hope is to connect them all in to one statewide community, recognizing that each region has its own challenges to address and that each of them can learn from each other too.

>> Virginia, all regions have very different needs and different supports and different things like that, and so I think having the regional aspect allows the community to tailor things specific for the parents that live in that area. So I think that's been a good approach.

>> I am thrilled to be a part of the northern Virginia learning community. It has been a wonderful experience as a parent and as the cochair of the community, I have learned so much from the professionals and I am hoping that the professionals learn a lot from the parents.

>> One of the most important aspects of the Virginia EHDI learning communities is that everyone is both a teacher and a learner. Members contribute their expertise and come ready to share their ideas, experience, and knowledge with others. The direction and interests of each regional learning community is balanced between the needs of the Virginia EHDI program and the needs of the region which are established through a needs assessment survey and frequent group discussions.

>> Everybody comes in with kind of a common goal of trying to provide better outcomes for children with hearing loss. And then you also have professionals coming to the meeting because they want to meet parents and find out better ways that they can help these families that have children with hearing loss.

>> As a healthcare provider, it is easy to be focussed only on the medical aspect, but these kids need a lot of resources and a lot of community support to really grow and develop well, and there are a tremendous number of opportunities and support out there that are available that sometimes gets lost in the shuffle and that we don't necessarily, you know, see day to day. So coming together in this kind of a community where you're able to see all of these people and learn about the resources that are available has been very enlightening to me. In EHDI learning communities across the country, we all have a common goal, and it is centered around supporting families.

>> CFI and EHDI will continue to work together in Virginia to ensure that parents and professionals are working together to close the gaps for children diagnosed with hearing loss.

>> To learn more about Virginia's Early Hearing Detection and Intervention learning communities, please contact Daphne Miller at Daphne.Miller@vdh.Virginia.gov or Valerie Abbott at vjabbott@vcu.edu.

>> So thank you all for joining us. We'll take a few questions at this time. Do we have a microphone for them?

>> Oh, that one.

>> I commend you on all of your work. That's wonderful, and you've done such great stuff, and I really like your needs assessment theory. Did you develop the needs assessment or did you already have a tool?

>> So the needs assessment was developed with the center for family involvement at VCU.

>> And are you willing to share that?

>> We'll share.

>> Yes.

>> Okay.

>> We're sharing people.

(Laughter)

>> Any other questions?

>> What's the main difference in between your advisory committee versus this and where does the educational ‑‑ I guess our understanding of what we read the grant, there was an educational aspect, so are you guys ‑‑ does the meeting start with education or are you using those educational topics to spark conversation? So it's ‑‑ I guess what are the two differences? What's the difference between your advisory committee and these learning communities and then how are you implementing that educational piece?

>> So our EHDI advisory committee meeting meets only in the central region of our state, and with the learning communities, we've been going to those specific regions, so we have a lot of different parents and professionals that are involved in the learning communities, and the topics, we are covering those educational topics that HRSA recommended, but we're really tailoring it at one point to what those professionals and those families in that region need. And so the topics are focussed on the need of that community. So it does vary from our advisory committee meeting. And you know, because not just regionally but the people that are involved in the topics that are covered.

>> So it appears we are out of time, but we can meet folks outside if you have other questions.

(Applause)