

West Virginia University - Center for Excellence in Disabilities  
Ability Grand Rounds Webinar  
Access to Care for Families of Children with Orofacial Clefts  
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>> Dr. Lesley Cottrell: Christine has joined us from Home Team Captions. Here they come so it must be working. She's going to be providing the captions for us today. So anyone that would like to see those stream, if you will just click on the right-hand side where it says participants and chat, there is a dropdown that says multi-media viewer. You can click there and that will be where you can see the caption streams.

Dr. Marshall is connected but she's going to call in, too. We can't hear her.

>> Dr. Jennifer Marshall: Good afternoon. This is Jennifer. Can you hear me?

>> Dr. Lesley Cottrell: We can hear you. Hi.

>> Dr. Jennifer Marshall: I decided to go the old-fashioned way and call in with my phone.

>> Dr. Lesley Cottrell: That works out well. Welcome. I'm glad you could join us. I'm going to go ahead and give everyone your bio, maybe read a couple of pieces off of it if you don't mind, and then I'll turn it over to you.

>> Dr. Jennifer Marshall: And do you have the PowerPoint up or do I need to --

>> Dr. Lesley Cottrell: I have it. I can bring it up or if you want to be able to forward for the slides, I can share the desktop with you.

>> Dr. Jennifer Marshall: That would be great.

>> Dr. Lesley Cottrell: Ok. In fact, if you want to do that while I'm reading, you should have a quick start in your top left corner. If you click that, it will turn blue. And the middle part says "share screen." If you push that, you should be able to see your desktop.

A-ha. Ok.

So while Dr. Marshall is bringing up her slides -- so, Dr. Marshall joins us from University of South Florida in College of Public Health. She's talking to us today about access to care for families of children with orofacial clefts. I have the privilege of knowing Dr. Marshall through the American Public Health Association. She attends a lot of our annual meeting sessions around children's special healthcare need areas and presentations, as well as oral presentations.

A little bit more about her. She's an Assistant Professor at University of South Florida. She's a lead evaluator for Florida's Infant and Early Childhood Home Visiting and Early Childhood initiatives. She conducts community-based research, assessing infant mortality

prevention programs as well as family care and access to services for families of children with birth defects. Her bio is wonderful. I will send this to everyone. But I'm going to turn it over to her now. We have the privilege of hearing about some of her initiatives.

Dr. Marshall, if you don't care, start when you're ready.

>> Dr. Jennifer Marshall: Ok. So, I don't think I have the same view that you have. Can you see my slides? Can you see my webcam also?

>> Dr. Lesley Cottrell: We can see your Cisco WebEx information but not your PowerPoint.

>> Dr. Jennifer Marshall: Ok. Something's not -- I was trying to share my slides but it's not showing here for you. Ok. Sorry. I didn't realize I needed to set up that PowerPoint. If there's a way even for you to put those slides up, that might be -- might make it easier for us.

>> Dr. Lesley Cottrell: Ok.

>> Dr. Jennifer Marshall: That way we can launch into it.

>> Dr. Lesley Cottrell: Ok. You just tell me when you want to advance. Ok?

>> Dr. Jennifer Marshall: Ok. Ok. So you'll have to click my slides for me. All right.

Well, thank you. It's great to be here this afternoon. I'm excited to share this research project that is underway here at my office. I wanted to talk with you a little bit about our Birth Defects Surveillance Program here in Florida which this is a part of and then I'll share some preliminary results from this study.

So we can go ahead and advance.

Ok. I work -- part of my position is with our Birth Defect Surveillance Program. We work with our state partners, the Florida Birth Defects Registry, which [Inaudible] the main function of the [background noise interference] to help with surveillance with the Birth Defects Registry, making sure that we have active surveillance. And I'll go into that.

[CART NOTE: Please mute your lines when not speaking]

A little bit of support for services and hopefully we also work alongside clinicians to impact clinical care.

Let's go to the next slide to tell us a little bit more.

Birth defects really impact about one in every 33 births in the U.S. You probably know that. But one in 28 in Florida. There are about 41 states that track birth defects in some way but around 14 are supported by the CDC, CDC funding, manage the population-based registries.

I'm going to start with the big picture and then zoom in on families.

[CART NOTE: Please mute your lines if not speaking]

These registries including ours really track about 50 different conditions, syndromes, anomalies, and various conditions impacting heart, brain, gastrointestinal, abdominal wall, including cleft.

So Florida is the fourth most populous state in the country with about 225,000 births every year. It's a big registry. It's a big state. A lot to track. We essentially compile the records, birth and death, vital statistics records, combine those with our AHCA healthcare data which includes hospital discharge, emergency room and outpatient care and our regional and perinatal centers. Those are the data that kind of contribute to this registry. And for some of our years, we have early intervention children's medical services data. So it's a passive registry where all of this information gets compiled and we have basically information about any child born in our state with any of these conditions. We also do a little bit of active surveillance, which means go out and actually check those records to make sure that the case is, in fact, a case.

So I wanted to start with the registry because it's really only as good as how timely, how complete, how accurate it is. And that gives us a bird's eye view of how many cases and the trends, the prevalence of different conditions in our state. That's a big piece of what we do. And then we can look at risk factors. We can look at patterns and prevalence. We can look at services access and utilization and costs and things like that to help ultimately plan for services.

A small piece of what we do, in addition, is some community-based research. So we're interested in not just assessing the prevalence of these conditions but to look at the services and supports for families who are -- who have children born with these conditions. And that's some of what I'll talk about today.

Next slide.

So from the epi side, again, it's a lot of the registry, making sure that it's accurate, some environmental studies, some specific projects looking at specific conditions. And most recently is our -- they've included some surveillance of neonatal abstinence syndrome. Even though that's not a birth defect, it's something we're really following in Florida, as well as our team here created that Zika pregnancy registry.

As far as community-based research, we're also working with Zika care. But I want to tell the story today about our Family Experiences Surveys and how those came about because we want to kind of follow the after story of what happens with families from the moment that the child is diagnosed and how they navigate Florida's systems of care.

Our website is there on the page, too. So you can read a little bit more about us.

So, let's -- yeah, let's move forward. Thank you. And I'm going to talk about basically Aim 3, which is how we use our surveillance data and then connect to healthcare services.

When I talked about -- you can go to the next slide, actually.

Orofacial clefts, I'm going to start with our study that we did. Actually about four years ago, five years ago we started actual actually with Down Syndrome because it's one of the relatively more common birth defects. It's relatively more well-known among all the conditions that we track. And it has medical and social and developmental implications and so we really wanted to understand families' experiences in accessing services.

We did a number of focus groups to ask about services in the first three years of the child's life. What the families talked with us about was their experience in receiving their child's first diagnosis. That's really where their story began and kind of continued from there, throughout their child's lifespan. So that really helped us understand parents' views.

What we decided to do from that study was create a survey that really followed the journey of parents prenatally throughout childhood and see what lessons could be learned about the system of care for Down Syndrome. And then this past year we adapted that survey for parents of children with orofacial clefts, for some of the same reasons; relatively more common than other conditions, has developmental, social, and medical implications, and it's one of those kind of conditions that maybe we could have some actionable improvements we can make to the system.

I wanted to share with this study, I have a wonderful team of masters and doctoral students here in Public Health. We have one physician from Nigeria. We have three dentists from India. One is here joining us. And we have one parent of a child with chronic complex conditions. So this is our team that meets with families to distribute the survey and to help them complete that survey.

All right. Go ahead, next slide.

So I am by no means an expert in orofacial clefts nor am I a physician but I'm a public health systems researcher. So I'm just going to give a little bit of background on orofacial clefts just to provide some context before I talk about the families experiences study.

So clefts occur when that boundary between the nasal and oral cavities, the roof of the oral cavity, are incompletely formed four to 10 weeks after conception.

Go ahead and flip through the slides. It will keep you busy here.

And a lot of times some might perceive it's just a simple surgical repair and that's all that's needed. But in addition to a lot of times these co-occurring conditions, such as hearing problems, there might just be, even with an isolated cleft, there could be comorbidities. So associated complicated with a cleft such as feeding or speech problems. And this is really important because in infancy, especially the first three months of life, the fourth trimester, a lot of development in early childhood. Brain development is happening. The foundations of our sensory system, developmental processes, feeding and speech specifically forming within the brain. The hospitalization, the medical procedures, the feeding challenges, all of these different things you see on this slide here can impact many aspects of development. So it becomes more complicated, as you'll see, than some might perceive when they are thinking about cleft.

Next slide.

So this is a couple of slides about the prevalence of orofacial clefts. It's about 12 per 10,000 births, so about 4,400 babies born here in the U.S.

Next slide.

And then in Florida, again, about the same rates. Most common are isolated cleft palate or cleft lip and then sometimes we have both.

So these are the rates and the problems with each of those.

Next slide.

I did want to mention the cause of the clefts, it's multi-factorial. There's not one specific cause but it could include smoking, diabetes, certain medications. It could be part of other conditions. And non-Hispanic white mothers have the highest prevalence rate.

I'm not really here to talk so much about trends and prevalence of clefts but about what happens next. We really wanted to know descriptive, qualitatively what families' experiences are in terms of the services and the supports in Florida. We're using a framework called Family-Centered Care, which probably many on the call are familiar with.

Why don't we just go to the next slide and I'll talk a little bit about the survey and Family-Centered Care for anyone who is not necessarily familiar with it.

So this is an approach, Family-Centered Care, is an approach to delivering and evaluating health services. It's grounded in mutually beneficial partnership between parents, healthcare providers. So it's a way of describing the relationship among providers and families. And we made some progress in contributing or kind of developing systems that are family-centered but we still have a long way it to go.

So Family-Centered Care respects a role that family plays in ensuring the health and well-being of their children and acknowledge the emotional, social, and developmental support is an integral part of healthcare. As I mentioned before, especially in early childhood, we can't separate health and development. And that's something we want to consider. The Family-Centered Care framework shapes policy, programs, design of facilities, staff, day-to-day interactions with patients.

Go to the next slide.

Specifically, Family-Centered Care uses a framework when talking about children

and youth with special healthcare needs because this population has a lot more interaction with healthcare systems, utilize a lot more health services, and it's really been found in some studies to be -- to contribute this approach to more efficient use of services, more satisfaction with services and utilization and follow-up, communication, and ultimately outcome for kids.

So the context of this study, we really believe that this family-centered approach beginning with family-centered prenatal care would consist of early and regular appointments, really good, clear, accurate communication about testing options and recommendations, risks that results are delivered in a sensitive manner in a family's primary language, by a consistent provider and a culturally competent provider. So there's an example.

So family-centered prenatal care could result in earlier recognition, diagnosis, quicker linkage to services, and greater satisfaction with those services and participation. So continuing on with that, receiving that prenatal diagnosis is helpful and also having a positive birth hospital experience or primary care provider experience, again, can help families learn about and actually utilize the supports and services that are available such as early intervention or therapies support groups.

We can move to the next slide.

Very simply, I described Family-Centered Care and this is a framework that you'll see core concepts repeated as I go through the preliminary results of the study, to kind of four main components.

So the first is information sharing. So that's clear, complete, unbiased information about the child's condition and the services available so that parents can engage in informed decision making.

The second component, at the top there, is dignity and respect. So thinking about sensitivity to families, cultural competence, again, recognizing and respecting families' knowledge that they have, their values, their beliefs, their cultural backgrounds.

The third component is participation. We think about that as team care in which the family is part of that care team, that medical care team. So we encourage and support families in being part of that decision making team at the level that they are comfortable with.

And then the last part at the bottom is collaboration. You have information, dignity and respect, sensitivity, participation, and the bottom, collaboration, I describe as a family-friendly system of care. So really thinking about our policies and our programs and our healthcare delivery that's family friendly. And the only way to follow that is by including families in our evaluation of our programs and our development of our programs.

Next slide.

So you probably are wondering when I'm going to get to the study. Now's the time. So we developed a study again to understand about the care and the service that are received of families with children of clefts born in Florida, to come look at family-centered care in a different setting. And that will help us to come up with ideas for improving service delivery.

And we did make some changes after our Family Experiences Survey was distributed over families who had children with Down Syndrome. We kind of did some things statewide to better support families. So we're hoping the results of this study will, again, kind of promote some change statewide.

Next slide.

So this survey will be or is being distributed throughout Florida through craniofacial clinics, support groups, therapy programs, dental offices, healthcare providers. It's really available to any family who has a child under the age of 18 that's been diagnosed with a cleft

lip or cleft palate or both.

Primarily at this point we've been distributing it through our Children's Medical Services clinic. So the CMS. We have a CMS, Children's Medical Services, network statewide. And this is a system of care, healthcare providers, care coordination, and clinics around the state. Primarily it's for families who qualify financially, so most are Medicaid eligible and have one of these qualifying conditions, complex conditions, preexisting conditions.

So I just want to note from here on out, right now [Inaudible] from CMS, clinics in this region. So you can see a picture here of some of our staff in the waiting room of one of our CMS clinics, getting ready to meet the families as they come in.

So I just wanted to start with that by saying some of the results so far are really from families who are receiving services in a pretty coordinated craniofacial clinic, a one-stop shop, which is a model that we really promote that you will see in a moment. They still have some needs and some concerns that I think we could take these lessons to your state and across our industry.

Next.

So the survey itself, it contains these Family-Centered Care. That's how the questions are worded and what's included, asking about care coordination and transition. Some of the questions were worded based on the National Survey Of Children with Special Healthcare Needs. They've perfected that survey so we used some of the same wording. And it has these six sections and so, again, the sections kind of follow the family's journey beginning with prenatal care, the childbirth setting, usually the hospital but it could be a birth center, their access to primary care and specialty care, and then early childhood and school experiences and family stress and supports.

And next.

The survey's available online and in paper. Like I said, a lot of the times we have found being in the clinic and helping families fill it out in person is the best way but that's pretty labor-intensive.

Out of 91 caregivers who have accessed the survey, we've had 67 who were eligible and completed it thus far. So we just started this past year, this year, attending the clinics and distributing this survey. It's available in English and Spanish.

As I mentioned before -- and I'm going to go from here on out and talk about these first 67 respondents. Our population in Florida is pretty diverse, about a quarter of our population is Hispanic and our Hispanic population is quite diverse in and of itself. About 12% to 16% of our population is black. And, again, our black population is pretty diverse, too. So we always look at that when we distribute surveys and make sure that we have a representative sample. As I mentioned earlier, clefts are more common among white, non-Hispanic families or children, so we want to make sure that we actively recruit these underrepresented voices as well.

You can see here the age range is from 3 months to 16 years. And, again, this is really a qualitative, broad snapshot of families' experiences and we really found that having that range helps us to kind of see where the services might drop off, to learn some lesson there's from our last survey.

And then you can see the income is kind of skewed here towards the lower income because, again, a lot of the respondents to this survey, a majority of them, are part of that craniofacial clinic.

Next slide.

So let's walk through this journey and some of the results that we have so far. Beginning with prenatal care, I would say that's one entry point to services. So family-centeredness or sensitivity of care is helpful in encouraging, you know, the training, of course -- screening, diagnosis, and follow-up of their concerns. And most of the respondents so far had a prenatal provider and most had a fairly positive experience.

Next slide.

We also ask about the birth setting. As you can see here, out of these first respondents, about half, the child was diagnosed prenatally. So think about our prenatal providers. The other half received the diagnosis at or shortly after birth. So that's another setting and another entry point for services. The responses don't always add up to 67 because some people didn't respond to all of these questions.

And the timing of the diagnosis is something, too, that we sometimes might take for granted but is important. One quote here is from an adoptive parent who learned about the child's condition from the CMS nurse. And the second quote is from a parent whose child -- the cleft palate is identified about three days postpartum. So again, think about the implications of that.

The chart here that answers the question about who provided information to the family about orofacial clefts in the birth setting I think is really something that we've been really interested in. You can see here, the most commonly reported answer was surgeons. And then you can see for 10 of the respondents, the answer was none. For our Down Syndrome survey, the most common response when we asked about whether they received information at the birth setting about Down Syndrome, the most common response was none followed by the nurse. And so we are really working with hospitals to understand that system and to provide some support and guidance in terms of how to get good, solid information to families, the types of information that they need and want and the best time and figure out who is the best person to give that information.

Next slide.

So some parents had responded so far they do want information about the causes, the prevention of their child's condition, or future recurrence of the condition. They wanted information on parent-to-parent support and on available services.

Next slide.

And also about half of the children were admitted to NICU and then the other half were in the regular mother-baby unit. So that's something else that we considered, is that these are two different environments, two different systems of care. And they have different entry points to services.

So most of the respondents had a positive, sensitive positive experience. Snippets of our results here. But you can see that many did not. And there are quotes here about the stress and the challenges in the hospital setting in terms of having a really positive, supportive family-centered response to that diagnosis.

Again, I think there's a lot of work that could be done to improve this kind of touch point along the way.

Next.

So, once the child is discharged from the hospital and the family goes home, the next step I would say on this journey to consider is medical home. Primary pediatric care, again is helpful in coordinating medical services, supporting families. And once the baby is out of the hospital.

A knowledgeable pediatrician for any of these conditions, but especially for cleft, can be really helpful when issues arise. And for the pediatrician to be able to tailor that anticipatory guidance to the family and child's needs regarding feeding, development, parenting, as well as hopefully developmental screening and monitoring as the child grows.

So you can see a quote here. One parent said they were offered a variety of options on feeding in bottles and discovered that the bottle [Inaudible] several months later through the advice of the pediatrician, so they're working with the family throughout.

Next.

So there is a primary care provider, hopefully, that's knowledgeable, that's available to that family. Depending on the condition, that might take some searching. And it's really helpful to have that medical home because in addition to that, these families are really having to coordinate a lot of specialty services, medical services.

So you can see here on this chart that parents of a child with orofacial clefts may need to be prepared to have a lot of interaction with healthcare providers. And the box shows those services that were most common in the first six months, which is a really busy timeframe in development and, of course, for parenting even in the most ideal circumstances.

Next.

So we do have some systems of care that are designed to support families whose children have a variety of medical or developmental needs. I know I'm preaching to the choir here. I mentioned that most of the respondents of this survey so far, here's 55, that were -- are enrolled in children's medical services. But we also look for our IDEA-funded special education programs of which these children would likely be eligible. So that for birth to 3 would be our Part C early intervention program, we call Early Steps, or for children aged 3 and up, the school districts' special education services, Part B.

So those, we see under enrollment in the IDEA-funded special education programs across the board and there's no exception here but that's a source for families if they're able to enroll and hear about it and enroll as soon as possible, especially considering speech and feeding therapies.

Another resource which I consider one of the best kept secrets is perinatal home visiting. So disclaimer, I am an evaluator for a visiting program, but I wanted to point that out here that that's a really great source of prenatal and postpartum support for families across the board. It's conveniently at home. It's often very culturally competent and family-centered, close relationship and very holistic. So it can address all of the mothers' and the families' needs through connection to other services. So we also look for home visiting enrollment.

The other system of care, of course, is access to healthcare coverage and health insurance which we probably need to spend another hour on that but we won't. But, again, I would argue that's not a very family-friendly system and it's changing all the time. But you can see here most of the families that we've connected with have medical insurance but we're connecting with them through healthcare providers. So we really are going to cast a much wider net in trying to reach more families to fill out this survey because it's not really representative of the picture out there.

I want -- one of the parents talked about CMS and just being on Medicaid and the constraints that that brings and the resources that that brings.

Next slide.

So you saw the list of services that families need to access for their children. Care coordination is present for a lot of families who are enrolled in CMS programs because there is



a nurse care coordinator that helps with navigating insurance and also navigating referrals to all of these other healthcare providers. In general, healthcare coordination support is hard to come by. If someone's enrolled in early intervention program, they can get that support, too.

But you can see some of the quotes here how parents talked about -- as the parent, it's up to them ultimately to navigate all of these medical appointments. And it can be really a full-time job. So I wanted to point out that these multi-disciplinary clinics can be a real Godsend because all the providers are working together. They can coordinate appointments and have it be a combined appointment. But these multi-disciplinary clinics are sometimes few and far between.

Next slide.

We also do ask about transitions. Care coordination is something that helps when we transition children or families from one setting to another, hospital to home, for example, from one provider to another, and from one system to another.

If you think of early intervention, birth to 3 to a special education system where that's separated out from medical care, those are big shifts and big transitions so transition planning and support is a family-centered practice and I think it's under-resourced and probably underutilized.

Next.

We also do ask about childhood experiences, kind of the broader view points. So, again, you might think that -- just the early services would be enough but some of the impacts can be longer-lasting than we might think. So, so far the respondents have prompted us to really consider the services, support systems of care, being sensitive to the fact that these are ongoing. So there could be lingering effects from early surgeries or hospitalizations or kind of the early impacts on the child's development as you can see here in these quotes.

Next.

And along that same vein, we ask about social acceptance. This was part of the Down Syndrome survey. We kept it in there and I was really surprised and dismayed to see that this wasn't 100% of perceived social acceptance. As we know, the more visible a disability is or a condition is often they are met with higher stigmatization. So this is something that parents are grappling with. It's certainly going to impact their outcomes and their access and utilization in different types of services and supports.

Next slide.

This slide just talks about childcare and respite but we do ask in the survey about parents' stressors. We ask about their levels of financial, emotional, and scheduling stress. And then we ask about different sources of support.

I just wanted to point out here that there's not a lot of consistency in terms of who these supports are for families. And that's no exception with this survey.

So the slide here talks about child care but overall families might rely on more informal supports, maybe a spouse or another family member or friends, but others may rely primarily on formal support. So we really need to have -- be able to provide access to both of those, depending on the situation. And those supports really help with accessing information, financial and logistical assistance. And, of course, emotional support and social support really can be helpful in helping parents to keep appointments, if you have a treatment plan, and overall kind of supporting their child through the process.

Next.

So the formal and informal supports, what we've learned through our past five years

of different research studies is that parent-to-parent support is really paramount. It's really helpful. Compared to our work with Down Syndrome, this has been very different. So in terms of Down Syndrome, there's a very strong parent network and parent support presence online and in person in many communities but there's not so much of a cohesive parent network for orofacial cleft. And considering all of the issues that we just kind of reviewed in this study, there's room, I think, again, to improve here.

So one example is our hospital, our children's hospital in St. Petersburg has a craniofacial clinic. They also have a large and active parent support group affiliated with it. Most of the respondents in this survey had an access support group that they relied on. The nurse or their care coordinator or someone else to support them with information.

Next.

So these all contribute to families' attitudes towards their child's prognosis and how they feel about the future, which can increase or hinder the effort, the tremendous efforts, needed to manage and coordinate children's care.

Of the respondents so far, there were many that felt pretty positive. But, again, we were sad to see that over a third, just in this preliminary sample, reported some major concerns about the future and worries about the future. So keeping this long-term view I think is really helpful and important in that continuity.

Some of the concerns are related to continuing other medical conditions, the aforementioned lack of social acceptance or perceived social acceptance, and these ongoing, lingering speech or learning problems that might have stemmed from those early complications.

Next slide.

Ok. So I hope this gave you a little bit of insight from parents so far into the needs and challenges and opportunities for caring for children and families with clefts. The Family-Centered Care framework, as you can see, kind of helps us to guide improvements in quality of life for individuals with disabilities and specifically throughout the lifespan beginning prenatally.

Next slide.

So what we hope is that the findings, once we've completed -- received more respondents, will be used to identify some areas of strength and gaps in these formal and in informal systems and also to improve how healthcare is delivered and professional practice and medical and educational and in community settings.

The next slide I'll show you here. It's probably hard to see but we could probably send these out. This is the brochure that we pilot tested and developed. It went through our state clearance process which took about six months. So all the lead agencies in this state from our early intervention programs, our home visiting programs, Medicaid, children's medical services. So it was vetted by all the agencies and it was designed by families to be available as a one-page, nice brochure that could be distributed to all of the hospitals in the state.

So we have our first 5,000 copies being distributed now. So our hope is that at the very least, each family who has a child born in this state with any condition, including cleft, has access to the sections in this brochure, beginning with parent-to-parent support, good, quality information about the child's condition, reliable sources of information, and then access to medical and also developmental or educational services.

So that's what the brochure includes. And then we also have a resource guide that we distribute. This separated regionally and also by various conditions including sections on

orofacial cleft throughout the state. And that has medical, educational, recreational, and family supports in it.

So that's what we've done so far in response to what we've learned from families through this survey. But like I said, we're just hoping to collect more responses in a more diverse set of responses to the survey so that we can kind of share the findings from that to inform others.

I think that's our last slide. So I'm happy to respond to any questions.

>> Dr. Lesley Cottrell: Thank you, Dr. Marshall. That was really interesting. There are some similarities here in West Virginia. I don't know if you have it on. There's been -- I posted a little bit of West Virginia questions under chat in your upper right-hand corner. If you click it.

>> Dr. Jennifer Marshall: Oh, yes. Ok.

>> Dr. Lesley Cottrell: Some of it is just throwing it out there. Like your home visitation comment, we have right from the start. And it has some compliments. And I was asking a question about our birth defects. I saw Salem on here. You might have some questions.

Does anyone have any -- I don't want to monopolize. Does anyone have any questions for Dr. Marshall?

I think someone who I don't think is on the call, Laurie, in our parents program, I think she would be really interested in what you have done. And Salem is part of that.

My question to you, and you kind of spoke to this a little bit, you know, we have a lot of rural areas. Clinics are our main point of entry, like you said, the clinical base either for the survey or the services. But what do you do -- do you have plans for reaching parents and families outside of the clinic? And if so, what might that be? And then do you think their responses would be any different?

>> Dr. Jennifer Marshall: Yes. So, first of all, I neglected to mention that this state-based registry. We literally have a list of every child born with a cleft lip and/or palate in our state for the past eight years. But that registry is used only to track prevalence and trends and for epidemiologic research allowed to contact families on that registry. It's not for other purposes. It's used for surveillance and prevention. So that makes it kind of challenging.

And what we were really surprised by and kind of learned through our efforts to disseminate this survey is, again, as I mentioned, with some conditions there are strong parent networks or family support networks and with others maybe more rare conditions or not a lot of family networks. So it's a little bit harder to reach families besides through medical settings. But our healthcare system is fragmented, too. We have a lot of dental providers, for example. And our early intervention program statewide, they don't collect specific data. They can't just pull a list of families who have children with clefts because they don't collect their data that way. So it's really challenging to work within the existing system beyond children's medical services.

We have families, even here in our county, who drive -- or across the state who drive four to six hours once a year to Jacksonville to go to a multi-disciplinary clinic for Down Syndrome. When we have all the providers right here in town but they don't necessarily work together to create a multi-disciplinary clinic.

One thing I would say for families, you know, across your state -- you know, sometimes there's regionalization of specialty service and families can travel to get those services. And like I said, even here in Florida, families travel across the state to try to get some sort of coordinated care. But really we want to continue to promote that model where providers can work together to create the multi-disciplinary clinics, these one-stop shops for families.

And then they don't need to go to five appointments a week. They can go kind of periodically and get all the consultation at once.

I don't know if that helps a little bit. You asked about the samples so far. This would be our best case scenario sample. These are families -- the majority of the families who responded are in those supported clinics. So as we move out from that, I think the story is going to get much more challenging actually and we'll really learn a lot more about what families are dealing with.

>> Dr. Lesley Cottrell: Ok. I think Russell and Salem are making comments. You were muted before. I don't want to put you on the spot but if you want to make any comments, feel free.

>> I didn't have any questions. I was just commenting on we have some of the similar issues that she was talking about with the Birth Defects Registry. We also cannot use that data for referrals. We can only use it for a surveillance.

And I do believe we also have a similar model of a multi-disciplinary craniofacial clinic in the state. I know there's one in Charleston that [Indiscernible] program works with. I don't know if there's any others. If anybody would like the information, I can get that for them.

>> Dr. Jennifer Marshall: Ok. Thank you, Salem. Thank you.

I noticed someone here said, Did you hear it took six months to finalize that survey -- or the brochure? And, yes. But you know, it was really worth it because the state is supporting -- you know, they've funded for us to print out thousands of copies. And like I said, it's been vetted through all of these agencies, the state agencies. So one, they're kind of aware of the needs, and, two, we have the ability to just get this out to all of the hospitals. So, you know, it's much more powerful to disseminate it statewide than for us to try to drive all over the state handing these things out.

What I wanted to point out, my concern about even having the brochure, which is wonderful because a lot of times parents get stuff from the internet that's not accurate, that's not helpful, providers pull it off the internet, the brochure is a wonderful thing to get out to families. Our concern and our question is -- that we'll be watching closely this year is, how does it get from that shelf in the hospital into the parents' hands?

So as you might have seen on that slide, the same story with Down Syndrome, the parents are interacting with all sorts of different healthcare providers in the hospital setting. It's not one person's job to provide the information to the parent, explain to them, you know, in a sensitive, caring way what's happening, and to hand them that brochure. That responsibility doesn't really lie with one person. We actually surveyed providers who work in hospitals. And they told us the person who is supposed to do that is the physician for Down Syndrome. But the families told us the person who gave them the information was the nurse.

So it's a little bit of he said, she said. So we'll be curious to see how that plays out but at least we've developed this and I think it's a really good product that will hopefully help some families out.

>> Dr. Lesley Cottrell: Real quickly, I noticed that you had a parent listed as an author on the project or as a partner on the project. So in terms of -- and this is for everyone but particularly you, Dr. Marshall, in terms of this multi-disciplinary clinic, in your opinion, how important is it for a parent representative to be involved? You've made some reference throughout your presentation but just in general to have a parent on that team.

>> Dr. Jennifer Marshall: Yeah. I like to think we're moving in that direction. But it's been really slow. I mean, I know the [Indiscernible] grant, the patient-centered research institute requires that you have kind of a family or patient representative that's funded, fully funded, on your

proposal in order to receive a grant from them. So if there's some ways that it's mandated within the structures.

A lot of times it's just not built within our systems. It's not a policy. But I think it's really critical and it's really helpful because, again, there are a lot of things -- assumptions we might make or things we might not be aware of. So it's helpful to get the family's input throughout the process.

>> Dr. Lesley Cottrell: All right. With that again, I thank you for your time in sharing your experiences with us. I think there are a lot things that we could take back and apply to stuff that we're doing here.

Thank you. And it was nice seeing you.

>> Dr. Jennifer Marshall: You, too. Thank you, everyone.

>> Dr. Lesley Cottrell: Take care. We'll follow up with you later.

>> Dr. Jennifer Marshall: Ok. Sounds good.

>> Dr. Lesley Cottrell: Bye, everyone.