Exploration of Language and Communication Opportunities Process

>> the time is 2:32 we will get started the next session I am Lauren, the moderator for the session titled eblowing of language and communications opportunities process. I will turn the presentation over

>> Hello everyone, we are here from the Maine Educational Center for deaf and hard of hearing Gov. Baxter school for the deaf and wanted to show this acronym because we will have it in the presentation.we do provide services and early intervention we have some site-based programs, a preschool program and provide outreach services statewide. Educational audiology and family events as well.

Today we are here with a few different people, myself, Amy Spencer, and a parent here and I will have her introduce herself.

>> CLAIRE JEFFERS: Hi, I am Claire Jeffers a mom to a three-year-old who is deaf and we communicate using both ASL and spoken English with the aid of hers cochlear implant. I also work as a writer and PR professional, I've been doing some substitute teaching at the site-based programming within the MECDHH organization in ASL student at the University of Southern Maine

>> I am Amy Spencer ASL Family Services Ct., I do serve on some boards and coordinating councils and part of the maine grant team and I initiated thisprocess and with the support of a lot of the community members I will get up and talk about some of that I do live in Maine and we enjoy the outdoors and do all those things. I will let Karen

>> KAREN HOPKINS: I'm the executive director for the Maine Educational Center for deaf and hard of hearing and the principal investigator of HRSA Grant, made deaf adult with a hard of hearing 19-year-old and I'm the author of Maine's memorandum of understanding which is the original intervention process about 20 years ago and we decided that in 2016 for an MOU in my doctoral student at the University of New England researching this process.

>> The ELCO exploring language and communication opportunities process it is a way of empowering families to explore language and communication opportunities for their child who is deaf or hard of hearing. Today we wanted, so can identify the process for education opportunities, and think about some ways to empower families through this process, and ways to incorporate parents and deaf and hard of hearing it all to the process of exploring language and communication opportunities.

Our purpose and philosophy is that families need and information to promote growth and develop it of their child and we really want to facilitate positive early interaction whether those early interactions are between themselves and their baby, or between them and their audiologist, or pediatrician, just those earliest interactions trying to help foster positive early interactions.

We support the process all the way from hearing screening through language literacy, cognitive emotional development, and we really want to provide comprehensive information to empower families to make informed decisions and that was our impetus for developing this.

The evolution, Karen will talk about the history.

>> KAREN HOPKINS: In the past way back our approach was very professionally driven, not family centered, family center to point what was led by professionals. We had direct referrals given from the audiologist to the agency of their choosing, so the audiologist if they were connected to the listening and spoken language or oral agency what their if they were connected to the school for that effort what their or some other agency they thought it should go to. There was no process so services were offered provided on who connected with the family first and never really crossed or connected. This is usually ran parallel to the part C agency we would go in and do our intervention, part C would do their version of their early intervention and it was conflict, mixed messages for families, and totally doubled the burden on these families. It was that inconsistent process statewide because it was depended on the audiologist and who the referral went to and who was working with the families. There was no process no messaging, no forms that were consistent statewide. It was disempowering, the system was not a system that empowered families to make choices on their own without comprehensive information. Communication options at the time were a checkbox on a piece of paper. Our Department of Education, part C was under the time required early intervention to bring a paper that was a checkbox that said do you want to sign or talk? And that was hard because families were not ready and they did not know what that meant. Some had never heard of sign, some new it was some visual language but did not really know and most of them were just checking the spoken language box because that is what they thought they wanted, that there was no process or other way for them, to get information so I was struggling with this based on a lot of challenging visits with families and the trauma of seeing the disempowering, and it just struggles they were having to make these decisions before they even were ready.

When we really started thinking about what was bothering us at the time, we needed to focus on parent-child attachment, not checking a box and we had to follow parents lead we needed a statewide consistency and we really wanted family centered early intervention we wanted families to lead the process. So we began the process of building a new system and five years later, it took us five years, we had a memorandum of understanding with our part C agency. And in connection to that we developed what we called a six visit process, and that process was partially a way to give us time to do some of this parent attachment focus, slow it down but at the same time it all those things in that you are supposed to get an early at all the other agencies wanted to make sure that families knew about, the services, the communication options, all those things but it was hard because it was a package and it was way better than before and it was family centered and our staff was following families lead, they had a lot of training, they had a semi-script but it was missing things but it was better than it was. In the MOU we detailed who was doing what and state wide involvement on early intervention teams so we had our early intervention staff on teams throughout the state of Maine so that really increased our consistency statewide. We had a primary service model, and we were bringing in specialists throughout the state, who specialized in one communication opportunity or another but not consistently, we were doing it but we did not have enough providers and it was not happening in a way we know it should. Department of Ed wanted us to find the number from the ISS P so we went with that as a steppingstone and we really wanted to focus on the moms and dads and babies to ensure the families had opportunities to meet other parents and deaf and hard of hearing adults and that was written in the MOU and it happened inconsistently so we were making process but progress takes time and as Amy will share, we made more steps towards this progress of making early interventionists we have now being led by Amy.

One really important part is the reflection. For the past 20 years, we have reflected and changed and evolved and never been stagnant because it never will be finished. Amy and I have talked about this six visit process we never really printed it and sent it out, some people saw it at conferences into pieces and now we have ELCO processes and four editions later we have, I guess we can share – but it won't be finished it never will be finished. That is where we are waiting on research and discussion in family feedback.

The part C model is changing as well changed from a therapy model to routine early intervention so the six visits did not fit that model and there was no magic in number six it was limiting, and after more robust discussion the tool that Amy will share with you is where we are now. We needed visuals and we really needed more than a program to it than what we had and the foundation behind the six visits and the philosophy for the past 20 or 25 years has not changed. Those of us in early intervention of followed philosophy for years and we've been challenged with the state system and staff in the right staff and diversity and Amy will bring you now to where we are now and who knows where we will end up!

>> AMY SPENCER: I think are really, I think we were missing was real statewide continuity and ensuring that everybody was getting the same types of information and providers understood what information should be shared because that is challenging if you don't know and you don't have that direction. Why do we develop ELCO to empower families to make informed decision and focus on the parent-child interaction because we know that predicts language and comes even more than which type of language you choose. Family culture and values are different for all different families. And we know the importance of accurate and comprehensive consistent information. And we also really want to focus and let families know early on about critical language. And how important language access and exposure is for children.

The how of the ELCO processes meeting families where they are. Being able to read families and follow their lead and develop trusting partnerships. We really need those proficient early intervention specialists that know about deaf and hard of hearing children and families. And also I feel proficiency specialists being people really comfortable being on visitors, that is a huge component, being able to make families feel comfortable and trusting. And those continuity, parent to parent support comes up a lot to ELCO process and ongoing assessment.

ELCO is now available at the early actions maine website so if you pull it up it is available there.

Also another way we are trying to have more continuity in resources as having our early interactions website and having for both families and professionals there and like Karen said it was always evolving and it is a new website so we are still adding to it and figuring out how we wanted to look and what resources we want to have there so it will be changing over time.

Some guidance for ELCO, it is not a script so when you pull it up it is a professional guide and it is not intended to be read or have the papers shared with families, we have other resources for that but it is more of a guide for professionals to know what information to share with families at certain points in the process and maybe not deviate too much from that so you are not pulling in, expressing your bias through the process.

We know many pieces are happening simultaneously and that is my pinball analogy we never know when we walk into a families home which way the ball will go so you have to respond to that. We want to hit all that information? Do we want to get all that information in, of course you do, and the guide can help you know, it looks back after your session and you missed some key points to remember next time. And by following parents lead we are fostering that empowerment and being explicit about our role as an informer and guided their role as you explore and expert on their family.

Will use this as a visual for that foundational language and those earliest interactions. And we do of course visit some audiological understanding and go through the process with families but it is really by following the families and what their questions are and deciding when that topic is coming up and when we are talking about different things is dependent family to family.

This is a really visual views early on to support families and understanding that whether language is spoken or visual, children will develop all these skills. And access to language is the most important component.

This is our professional approach and it looks at, it is a cyclical approach and will group be repeated over time because we really want families to understand that this is not a one and done we are not just saying let's develop language and communication plan and never revisit it, we will revisit this every six months prior to the ISSP we know things happen so with families, but that is our focus is to complete assessments and review of language and communication plans prior to every individual family service plan meeting.

We start with an overview of the language and communication opportunities utilizing this, and talking to families, do you want to start on the spoken language visual like , so following them and the guide specifies these are some components that to talk about American sign language, listening spoken language, all the different approaches and we let families lead that and then once they get some information of the overview of communication and language opportunities we move on to some more in-depth exploration and really these visuals that they represent our, one needs to be in place for this approach to be successful so you will notice on here skilled providers is always on there, for that approach, the type of access needed for that approach is always represented, deaf and hard of hearing role models or mentors, parent to parent support, developing strategies and skills for that approach in using that approach in your daily routines.

Do you want to talk a little bit about this?

>> CLAIRE JEFFERS: This is my family, this is our sign at about three months of age, this is March 2020, and we, I think we look pretty tired because we were. We were at this stage we were only a couple of weeks from his identification as profoundly deaf. We were very much still in a processing stage. For our particular family, we really dove into wanting to learn as much as we could from the deaf community and wanting to learn about deaf culture and those two terms are used we were not even using other time, I just wanted to understand what we did not understand. We were day by day, hour by hour, and then simultaneously as any parent could understand we were also dealing with daily new parents challenges from sleep deprivation to weird things in the baby's diaper to whatever and trying to hold down two jobs and increasingly feeling like, COVID was happening, so that isolation cut us off from what would normally typically be available to us through the Maine program and we are able to access those things pretty seamlessly through zoom, of course not an ideal situation and nobody had that so that is what we were able to do. We were just processing and asking a lot of questions, trying to dive inasmuch as we could and simultaneously learn a new language. That is that slide.

>> AMY SPENCER: And I think, I will make a comment on this but developing those trusting partnerships, meeting families where they are at, you will gain more trust by meeting them on the day that they are sleep deprived you might not hit them up with a lot of information but they mighthave a resource that day and talk more about how you will get that baby to sleep a little bit more or maybe some strategies for utilizing each other's partners and things like that so, and I think that is just going to build that relationship you are more likely to get this other information in later.

But these are more of the webs we use and I will not spend a lot of time the guide is available and we don't have a ton of time but I did want to get, ultimately we go through that cyclical approach of reviewing and doing more in-depth exploration and exploring a little more in-depth looking at some research, pulling in hard of hearing adults we have the Guide by Your Side in Maine so connecting families with other families you might know of, that might be interested in meeting someone, really interested in language can you introduce me to a family or I could say would you like to meet a family and pull in a family that could meet them.

A question I had at last presentation was about, how do you implement this on an individual family service plan and like Karen said prior, we had six visits to get this language and communication plan written, but now we have a little more flexibly, we are part of the child development service team and we do meet families right away to develop the ISSP, and on that plan really what that plan usually entails is, I want to understand how I will communicate with my baby so it is family driven outcomes so we write the plans to reflect and we will share this information and we will come up with a language and communication plan and change that IFSP to match that language and communication plan.

This is our language and communication plan we want to make sure families feel comfortable they have all the information they want about all the different approaches at that moment, because we will revisit this and that is something will come up and they will meet another family that says, I'm using sign supported speech – I want to know more about cochlear implants or whatever, that will definitely come up.

We talk about those approaches there thinking about, advantages and limitations in filling this out,and we have them choose where we are starting this journey and we're starting with a bilingual/bimodal approach, and we will usually reflect back when we know what approach we are thinking about using. What you have to have in place in order for this to be successful? We are going to revisit the IFSP, and put a trainer on the plan because I'm not an ASL family trainer but I am your provider so this person is going to be put on the plan.

Do we have auditory access to work on the listening and spoken language side? we do try to make sure that families know it is a fluid doctrine it is going to change over time. This is just a really cute picture.

Just an overview we want to make sure families have the resources, knowledge we want them to have all the information this guide is set a foundation for providers to know the information to share. And maybe on the other side of the information, in the beginning, not to go too far in the deep end either, so try to keep the information providing consistent and comprehensive but not too overboard to overwhelm families.

We know parent to parent support and deaf and hard of hearing role models has been integral in a lot of families and we really support that family involvement in caregiver- child interaction. And we know that benefits and limitations are different from family to family and very dynamic.

And that is us – does anyone have anything else?

I could have done a presentation for an hour and a half. Any questions? You are welcome to email us any questions, Claire is even welcome to put her email on there how this process worked for her family.

>> I do early intervention, it is a rare family that wants to meet deaf people and learn sign leg which, what made you predispose today?

>> CLAIRE JEFFERS: In your experience it is in rare to find a family – ? To be totally clear, neither my husband nor I had met a profoundly deaf person before our son. I'm sure we had met someone but had not had a meaningful interaction with a profoundly deaf person, my grandfather was hard of hearing, a typical experience of having an older person in your life with hearing aids and not quite understanding my pitch of voice. It is hard to answer only because I'm not sure, it was just an instinct, maybe, but our particular experience was that we were extremely isolated from the outside world so I think part of my process was we would have normally had access to playgroups, in person events, and all that was shut down for COVID. I'm not saying that is necessarily the reason why but that is definitely one reason, because we did not see anyone that we were inside our house was a three-month-old baby and we were taking walks around the block toget fresh air and keeping our masks on, in the early days of COVID, part of me was, can someone, I would have wanted someone to come over to the house and meet people and meet other families and other children and we had a week or two of that before COVID came into full force. For my personal experience as a mom, I did breast-feed so I was sitting a lot and my child also took a long time to breast-feeding her session so I was on a longer, some babies feeding 15 minutes in my child took more like 45 minutes to an hour each session so I was nursing a child for 10 hours a day daytime hours. So I was sitting a lot and you can imagine I was on my phone doing the very basic, what do I need to know here? In addition to what does getting from this program I was also doing my own research on the Internet and the Internet is so much and a lot of what I was absorbing was some deaf culture stuff I had never even looked into. I was watching videos on YouTube, following people on Instagram, but I think just being exposed to the possibilities of seeing other deaf people thrive and be proud of their culture and their language, I was curious about that.

>> I have a quick question, when you are looking at all those options in your language communication plan, I am curious how you managed the bias of what they will have access to in part B with their IEP and how you prepare families for the realities of what is available in their services and with trained providers.

Beyond the education of what is it you're able at this time to address the reality of the access to it, if that makes sense.

>> AMY SPENCER: We still write the language and communication plan to reflect what the child needs or what families priorities are regardless of what is available to them because we need to demonstrate the need too. It is tricky, and we have very limited access to speech translators so if you spend birth to three and then your child goes to his school in the middle of Maine we might not be able to get you a live transliterate or, maybe there are some virtual options but that is not even always possible. I think we all have a lot of barriers in that area. Anybody else?

especially our northern staff prepare families for that we try to provide what the child needs or what the families priorities are.

>> Thank you all for coming, please email us with questions!