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Topical Session 5 & 6: Capitol 5

March 19,    2024

9:40 AM – 12:00 PM (MDT)

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9:40 AM (MDT)

CAPTIONER: Standing by for audio/video link. You can communicate with me via the chat ==>>

JACE WOLFE: Good morning, everyone.    I know everybody's happy to see each other this morning, but it is 9:40 and I have planned a ton of information I hope I get in in 25 minutes.    I better go ahead and start as people are still coming in.    My name is Jace Wolfe and I'm an audiologist and the senior vice president of innovation at the Oberkotter Foundation.    I want to start by thanking you so much for being here because always my biggest fear is I will spend a lot of time preparing a presentation and I will go a long distance from home to deliver it and there won't be anybody who shows up to hear it.

Thank you so much for being here.    I will say normally I try to start these kind of talks with a joke or an interesting or funny story, but I do have so much to share that I'm going to forgo that today, which is not a big loss on your part because all of my jokes are dad jokes and I'm not that funny.    I will say in all seriousness that at the end of this presentation I'm going to ask you to volunteer for what I feel like is a really important endeavor that I think can potentially benefit children with hearing loss.

I know you're probably thinking I have no time already.    I have no extra time or energy ‑‑ ask to volunteer more?    Not mandatory, but hopefully when you hear about this it will get you excited and you will want to get involved and support this effort.    What I'm going to talk about today, we face a challenge in the US.    You may not realize, but compared to other countries that are resourced and have resources like the United States does, we have far fewer children who receive cochlear implants when they really probably could benefit from a cochlear implant.

Or they get one and they get one way too late.    That is a challenge because that is preventing children from reaching their full potential in their lives and reaching their and their families dreams and aspirations.    There are a number of different barriers, and I'm going to summarize those barriers that impede access to cochlear implants for children, and then I'm going to introduce you to an initiative called the CI Path which stands for the Cochlear Implant Patient Access to Hearing pediatric initiative and that is a mouthful but we will revisit it several times over the next 20 minutes and I will tell you what this group is doing to hopefully try to identify some solutions to this challenge we face and identify ways you might want to get involved.    Keyboard is frozen.

A quick introduction to the problem.    We know in the U.S. there are two to three children out of 1000 who are born with moderate hearing loss or greater.    Unfortunately, we also know that of all these children who potentially could benefit from a cochlear implant, only about 50% and of getting one, and I will point to a study and I will describe the study and just a second that speaks to that.    This is in stark comparison to countries like New Zealand and Australia and many Western European countries, especially countries where they have government‑funded universal healthcare where often times children who could benefit from a cochlear implant, about 90% and up getting one and have access.

We have a challenge here in the United States, and that was the impetus for the development of this CI PATH group and we defined it and this group was formed in 2022.    Our goal was in 10 years by 2032 70% of children who qualify or benefit would get one.    We hope to improve that number from 50 to 70%.    One thing we also know the scruple take this to heart is that we know that research tells us there are specific groups in particular who don't have good access to cochlear implants.    These are typically families who have really limited limited financial resources, living in rural areas, transportation concerns, and often times in many parts of the country minorities have poor access to cochlear implants.    I heard a presentation a year ago by gentlemen, a cochlear implant surgeon in Florida, and he did a review of all the children who receive cochlear implants in a Florida and there was not a single black child at that time who receive a cochlear implant before one year of age in the entire state of Florida.    It underscores the challenge we face and the importance of this work.

Why is this so important?    I know it seems like an abrupt pivot but I want to point to a study some friends of mine did at New York University at the cochlear implant program where they looked at each perception of cochlear implant recipients and have a large cochlear implant clinic.    They looked at their records over a 10 year period from 2005 to 2014 and they found 165 children who have cochlear implants and they included everybody except those for whom English was not their primary language because they test speech recognition with English materials.    Those who had malformed cochlea or incomplete insertions.

They wanted to determine how many of these children achieve ceiling affect performance or ceiling scores of speech recognition tests with their cochlear implants and a defined ceiling score is 90% or greater.    What you can see here and all these children for the most part get their cochlear implants really early, had early access, and you can see depending upon the test that was administered, somewhere between 75 to 90% of these children in this cohort scored 90% or better, so that underscores again cochlear implant technology has improved so much and if we provide a cochlear implant at an early age and support the family in being able to create a language rich environment and support that child using the implant during all waking hours, excellent outcomes are positive and probable and we can expect age‑appropriate listening and age‑appropriate outcomes.    This challenge we face is really just an opportunity because if we can improve access to children with cochlear implants and get them to children earlier, the sky is the limit.    We can shoot for the limit.    Let me introduce you to the CI PATH initiative and it's a large group of professionals and their family members represented and audiologists, deaf educators, ENT physicians, early intervention providers.    All walks of life but all with the common interest of really helping children with hearing loss reach their full potential in life.    We did a literature review before we got together and looked at a number of different articles that looked or examined the barriers that children face in getting good cochlear implants and I will share one with you that was published in 2020.    They did a systematic review themselves of all the literature on the topic and what they found was the barriers could be broken down to six categories.    One was timely referral.    Children were referred but they were referred really late and the number one reason for that is providers out to the community outside of CA programs often times were not comfortable with what the modern evidence‑based cochlear implant candidacy criteria are.

They thought children either had too much hearing loss or not enough hearing loss and they were too young or too old and it was all over the place but they really weren't aware what the criteria were that we use today to determine if the child would benefit from a cochlear implant.    Distance was a big one in the fact that often times we operate in silos AND we don't operate in a coordinated fashion, that audiology does not speak to early intervention or speech language providers or whistle providers or ENT providers and they don't speak to deaf educators.    We have a challenge and we have to start communicating.

We have to work together in a coordinated fashion.

That was a big barrier, for sure.    Lack of exposure to cochlear implants both from professionals and families.    There is a lack of knowledge of it.    Many people had never met an individual with cochlear implant so that makes it hard to make a personal basis decision on how to proceed.    Lack of awareness was another big one.    And this was particularly true for families who speak English as a second language or they don't speak English because we often times don't have good materials in languages other than English, and sometimes these materials that we do have are just translated from English and they are not culturally sensitive or culturally specific.

The process takes too much time.    There are too many visits involved.    If you are a family who works hourly and you are just barely making ends meet and you might lose your job if you take off work or you don't have that income supplemented, you don't have days off that you can take without forfeiting pay, it makes it really difficult to get in.

The thing I think we should start to do as professionals at Vanderbilt is to coordinate.    And this is in a medical center where they have all the programs in one place they try to coordinate all the testing that needs to be completed in one day so you could take one day off to get all that testing done.    Fear of surgery, that the complication rate is really high, that it might harm their child.    The complication rate for cochlear implants is really low.    It is a safe procedure for six ‑month‑old children and also what about new inner ear therapy developments like gene therapy or inner hair cell regeneration.    Should we wait for that?    Or give the child the ability to make that decision later and wait for that.    Lack of funding.

Many think cochlear implants will be expensive when in reality almost all insurance providers and Medicaid will cover it, and social barriers.    Often times over and over again we see inequity to access.    Minorities or individuals who don't speak English don't have good access to information that they need to make a good decision for their child.    I want to point out this study.    I think it is a great study.    Lisa Park at the University of North Carolina looked through all of their audiology databases at the University of North Carolina with all their affiliated audiology clinics.

They have eight CI clinic and a number of audiology clinics that don't provide cochlear implants and what they wanted to do was determine or look at all the audiograms of all these children across all these clinics to determine if they were getting referrals for children who maybe had hearing aids who were served at other clinics outside the CI program.    If they were getting appropriate referrals when these children might benefit from a cochlear implant.

How they define whether these children should be referred were on three different criteria.    One, if they have a pure tone average of 65 dB HL or poorer.    You might think well, that is not a cochlear implant candidate that is a moderate to moderately severe degree of hearing loss.    But there are multiple research studies that show if you have the five dB HL hearing loss 80% or greater of cochlear implant users will score better on word recognition and their ability to look (Inaudible) when you have a 65 dB HL often times you'll have a lot of inner hair cell damage and so that starts to distort the message that the ear sends on to the cochlear nerve and the brain.    A speech intelligibility index of 65 or poorer, that means that only 65% of speech is available to the child when they are using the hearing aid, so obviously we can't expect children to shoot for the moon and reach all their goals if they are missing out on 35% or more of the speech signal.

And then aided word recognition scores of 60% or poorer word recognition scores of 60% or poor under earphone.    We know that 90% of children with cochlear implants and large research studies like the one I just showed you, will score better than 60%.    All these criteria, even though they may be seen a little more proactive compared to FDA indications, they are evidence‑based and they are actually pretty conservative if we refer up those criteria.    There is a high likelihood that the child will do better with the cochlear implant than they are doing with hearing aids if they meet any one of those criteria.

They defined a number of different groups.    Traditional candidates were defined as those with hearing loss in both ears of 80 dB or greater, single‑sided deafness was hearing loss of 80 dB and the four year, and normal typical hearing in the opposite ear in bilateral nontraditional was hearing that was better than 80 dB but they still met the referral criteria, an asymmetric which is the poor ear of greater than 80 dB hearing loss with a better ear that did not meet the referral criteria, and traditional nontraditional where one ear was poorer than 80 dB and the other ear was better than ED but it met the referral criteria.    They found 869 children that met these guidelines with only 48% referred were CI evaluations.    It is along the lines of ‑‑ not enough children are being referred for cochlear implants.

92% of children with profound hearing loss were referred, so North Carolina they are doing a good job in that group.    Only 82% were referred if they only had a profound hearing loss in one ear but they met referral in the other.    If they had single‑sided deafness only 26% were referred and if they were bilateral nontraditional, this is the group that probably could take the best benefit and take the best advantage of these evidence‑based modern referral criteria, only 27% were to referred.

Asymmetric candidates, only 34%.    Interestingly, of the children who were not referred often times the provider stated they did not think the child was a candidate, so they are operating off FDA indications of these more conservative criteria, and often times the families said they did not feel like their child would be a candidate.

When they looked at all the children who were referred and evaluated, 97% ended up receiving cochlear implants.    That tells us that there is probably not an over referral of children who aren't good candidates.    That tells us that we probably still should see more referrals and there are a lot of kids out there that probably need a cochlear implant and they are not getting into the clinic.

When we look at the reasons for why children don't get in, often times it is because families and providers are making decisions against implantation without a formal evaluation or counseling by CI providers.    So if they meet those criteria the 65, 65, 65 criteria, it would be a good idea at least to get acquainted with the cochlear implant team for an evaluation and determine what would meet the best needs or best meet the needs of those children.

With CI Path initiative, we did to tackle this initiative a we all met together for a full day and we implemented the A3 process.    This was developed by the Toyota corporation when they would have recalls or manufacturing problems to identify exactly what the root cause of that problem was and to identify solutions, they would go through this A3 process.    I don't have enough time to describe it all today, but typically or primarily what you do is you identify your specific problem which in this case is reduced access to cochlear implants and to identify with the current condition is associated with the problem, which is only 50% of children in the US receiving cochlear implants who might benefit or need one, and then you identify a goal which is by 2030 to 70% of children who would qualify or potentially benefit from a cochlear implant would receive one.

So after going through that A3 process and our literature review and brainstorming the barriers, what we decided is there are multiple problems or multiple barriers, but we identified four that we felt would be the best dominoes to tip over first because they might knock over other dominoes after that.    One, the cochlear implant candidacy or referral process is complex.    It is unclear what referral criteria should be and there is no coordination between specialized hearing care professionals and people who serve children outside of cochlear implant clinics.

There is a general lack of awareness of safety, what is involved with families and children.    There is a lack of timely referrals.    The process takes a long time.    Economics.    Countermeasures, we decided we would develop three countermeasures.    One will be to establish simple and referral criteria in a standard test battery to guide professionals to determine when to refer.

The other would be to define and amplify a consistent, fact‑based message for both professionals and families, and the third would be to develop training programs that could be provided for professionals or students to help them understand more about cochlear implants, the benefits, limitations, and criteria ‑‑ we have three different working groups working on these three measures and it is really exciting.

You might recognize some of the names on this list.    We have three projects that I think will really make a difference just with our first pass at this.    In Group 1, Vanderbilt, University of North Carolina and Texas and Dallas are reviewing their entire databases of children with cochlear implants and looking at speech recognition scores to establish good evidence‑based referral criteria that we can hopefully spread across the field and across professionals working with children with hearing loss to help it be easier to identify those who might benefit.

Group 2 is doing a literature review on a number of different areas or components that basically are important information that professionals and families would want to know about cochlear implants.    Is it safe, efficacious, beneficial, pros and cons.    They are going through a Delphi process to craft evidence‑based informational statements that can be provided for families and for professionals to acquaint them with cochlear implants and the referral process and whether or not a cochlear implant could be beneficial for a particular child.

Group 3 is serving you audiologists and AUD students to determine what they know about cochlear implants so we know what to include in training programs so we can help provide information that is most beneficial to them.

With that said, this is the portion where I am asking for you guys to volunteer.    If this rests on your heart, if this seems like an initiative that you might want to get behind, it would not require a lot of time but we are going to need a lot of help and support reviewing the statements, reviewing the training programs, giving feedback on referral criteria.

If you are interested in this initiative and being a part of it, I would ask you to please contact me.    My e‑mail is on the screen.    We need everybody.    It needs to be all hands on deck.    We need to be working together to solve this challenge that is unique to US compared to other countries who are heavily resourced and have good healthcare systems.    I encourage you to continue to shoot for the moon when you're serving children with hearing loss and I thank you for your presence and attention today.    Any questions, comments?

>>: I will try to get around the room as best I can.    It is really full.    We have two minutes.

>>: I'm wondering if your group has done any looking into the shortage of pediatric audiologists in the country?

JACE WOLFE:    We identified that for sure and we have more long‑term goals for trying to address that.    Related and unrelated.    I am working at Hearing First and that is on our roadmap as well, to try to provide good training opportunities and continuing education opportunities for audiologists who might be interested in working with children, but that is a major barrier.    There are not enough audiologists who are specialized in working with children.

>>: I am not a CI audiologist but I like attending these talks to make sure I am referring appropriately.    How much do you think the under referral rate is due to kind of the segmentation that we have created in pediatric hospitals with the CI group versus everybody else?    I feel very comfortable talking about CIs because it Stanford everybody was on the CI team even though I was not a CI provider.    We were all part of the determination process on who is a candidate, and the second part of my question is how much do you think under providing is due to bias of providers who are not necessarily identifying children, particularly children of color, as candidates for these kinds of devices versus behavioral problems or intellectual delays?

JACE WOLFE:    All great statements and in some ways your questions probably would be my answers.    I would rephrase them like Jeopardy and give the answers back to you.    I think the siloed care models that we have in many communities is a really big reason for that and University of North Carolina, Ton of respect.    That is a center of excellence, one of the best places to get pediatric healthcare in the world but their cochlear implant clinic is a standalone.    The article described that it is where children go for further diagnostic testing outside of that cochlear implant clinic and even though that is one cohesive center and it is all at one University, over 50% of children were not being referred to the cochlear implant clinic in that university.

So I think it is a big part of what is happening.    Also inequities are real thing for sure.    You can go across ‑‑ I did not have time to mention ‑‑ Park study that was a significant factor of whether children got referred, whether they were white or anything but white.    Yes?

>>: So do you think the current system can sustain this increase in referrals and what can we be doing now to make the systems more robust so we can handle that increase in patient load?    A lot of our CI centers are booked out a fair ways and involved a hefty process.    My secondary process is how do we shorten the appointments to create less of a barrier to care for families without skimping on information?

JACE WOLFE:    I will tackle your second question first.    I think we need to look for innovative and disruptive ways to shorten appointments.    It is funny because depending upon which side of the bed you go to sleep on, you can go to bed thinking I have great job security, you know?    Our clinics are booked out six months so they really need me, or you can go to bed and say machines are going to take over and someday a robot is going to do my job and obviously the reality is somewhere in the middle.

But I do think there are a lot of things audiologists do now that can probably be automated, so I thing we need to look for opportunities to do that.    I think remote care, virtual care is probably a huge opportunity to do that.    I also think that we need to provide more training opportunities for audiologists and work together where you might have pediatric specialists who could do the really challenging things or work with the patients with the most challenging needs.

You could partner or coordinate with other audiologists who have training to help in areas that are maybe more vanilla or not quite as specific.    The other thing that I think is really tough nut to crack, I think the economics of pediatric care in healthcare is a major barrier.    Reimbursement is so poor.    It is super time intensive to provide good care for children with hearing loss, and if you serve adults you could see four adults in an hour if you crank them through hearing tests.    You schedule 1.5 hours with the child to make sure if they are coming a long ways you get everything done, but at the end of those two different types of appointments you build the same CPT codes and there is no way we continue to make things sustainable.

It is also expensive to get a college degree and a AUD degree and often they are paid the poorest out of all the different audiology subdisciplines you can go into.    You have to figure that out.    I'm not pretending I have the answers.    I have some ideas, but I think the economics of pediatric healthcare was one thing we mentioned and we felt like we could tackle those other three problems more realistically than not one.

>>: Thank you everybody.    I apologize, but we have to get moving to the next session.

JACE WOLFE:    E‑mail me if you have questions or you want to help.

>>: Thank you.

>>: It is 10:10.    I'm an audiologist with Children's Hospital Colorado working out of Colorado Springs.    I also want to acknowledge my colleague Decker Stern.    She unfortunately could not be here today but she has been my partner in completing this study and we have also completed the stock together so most of the time if I seem a little winded it is because I'm talking for two today.

This morning and want to share with you about early implantation for children with complex medical needs and how we take a multidisciplinary approach at our center and what the timing looks like.    I do not have any financial disclosures besides the salary from children's.    Research has long supported spoken language outcomes in children with congenital and profound hearing loss implanted at an earlier age.

In 2020 the standard of care shifted to consider implantation at nine months instead of the previous 12 months.    It is worth noting that centers across the country and across the world have been implanting prior to 12 months for many years, doing so off label.    It is lot of those experiences that if inform the research I will share with you today and that is what led to the change in care.

One such study was out of the University of North Carolina.    In 2022 they conducted a retrospective study that looked at children who were implanted and those who were implanted prior to nine months and those who were implanted after nine months of age.    All of the children included were typically developing.    They found children who were activated prior to nine months at a faster acquisition of a greater quantity of auditory skills than those reactivated after.

By two years of age children implanted prior to nine months reached expected performance of typically hearing children.    While children were activated after nine months of age still showed improvement in their skills, their skills did not reach their age‑matched peers with typical hearing.    It is worth noting data past four years of age was not included in the review, so the authors are marked it is possible that some skills may match children with typical hearing just at a later time.

Another study out of a different CI center looked at the relationship between age of implantation, surgical safety, and language acquisition.    Obviously when we are talking about surgery and small children we want to make sure it is safe, so they followed 100 children on average for 10 years.    The ages range from five months to 29 months when they were implanted.    They found there was no relationship between the age of implantation, surgical complications.    Indicating that yes, surgery is safe for children under 12 months of age.

They also found that language outcomes were improved for the younger groups.    This graph is directly from the paper.    Across the bottom on the X axis you can see the age of the test and the Y axis is the language understanding.    Typical progress is on the dotted line, 1:1 relationship and the colorful bars represent the children broken up into different age groups.    Those were implanted between five and 11 months and you see they get on that dotted line with the typical process.

The older children make progress ‑‑ why timing is so important.    There is clearly hearty evidence that supports implantation prior to 12 months of age for these groups of children and at our center this has certainly been our goal.    Nine months has been our goal and however we were finding that this was sometimes difficult to achieve in a very large medical center serving the state of Colorado and surrounding states where we tend to have a high proportion of children with different medical complexities who require specialized care.

Historically this population has not always been readily considered for cochlear implantation.    It wasn't until studies from mid‑ 2000 and early 2010s when it became readily considered.    So one study reported that about one third of pediatric cochlear implant recipients have an additional disability or diagnosis.    I've seen this number range from one quarter to almost half.    Clearly a sizable proportion.

They looked at children and evaluated their outcomes using the categories of auditory performance.    With that outcome measure, 0 to 4, they had awareness of sound but not necessarily using spoken language or any kind of verbal language whereas from 5 to 7 indicates some use of spoken language and they found 96% of the children that they looked at without additional disabilities, 4 to 7, indicating they use some kind of verbal language where 52% with an additional disability score 5 to 7 scored that additional spoken language.

Developmental delays, cerebral palsy, visual impairment, ADHD, autism.    Cochlear implant outcomes are often very much focused on spoken language measures for a good reason, but that may not be inclusive for all children with additional diagnoses.    The researchers from the study did report on the variability of outcomes in children with additional diagnoses and the importance of this point should be counseled with families.

With earlier and earlier implantation we may not know if there is going to be an additional diagnosis later on.    So at our center we take a multidisciplinary approach when working with all cochlear implant patients, whoever comes through.    Our core CI team is made up of ENT, audiology, speech pathology, child life, social work.    We found that having open lines of communication between providers really streamlines the process and makes things easier.    I think a lot of folks are familiar with audiology ENT and speech as part of the CI team, but for those who are not familiar with child life, we are lucky to have them on the team and that is a specialty where they take medical concepts and make them kid friendly.

They tailor their approach to that clinic or whatever procedure needs to be done and our child life specialist has a teddy bear that she has a picture or picture book and goes through the whole implant process whether that is coming in for the hearing test, getting your mold impressions, anesthesia, she has an anesthesia mask, to make the process less scary for kids and families.

Social work is helpful to have on our team just to navigate any barriers to care, and also it helps if there is a tricky social situation and again, make everything more streamlined for the family.    This is a visual that we provide for every single family, going through the process.    It is a little bit blurry.    We do prepare them that they will meet the members of the core CI team and additional groups as well.    I have a couple of learning objectives for you.    The first is I'm hoping you'll be able to recognize the difference in time between ‑‑ second I hope you'll be able to describe the core members of the CI team.

Then identify at least one conservative factor that leads to the difference between CI evaluation time between the two groups.    So given our patient population and our goal to lower the age of implantation, our aim was to determine the difference in candidate evaluation time between patients with additional medical diagnoses and those without.    We hypothesized that children with additional medical needs would have extended time period compared to patients without additional techno sees.

Some factors might include the need for more providers, prior to determining if a child is good cochlear implant candidate, as well as additional appointments.    We also expected that due to the variability and outcomes, some of these patients might need more counseling appointments just to talk through what their trajectories would look like.    So we obtained IRB approval and conducted a retrospective review of medical records from 2017 to 2022.

inclusion criteria was a diagnosis of bilateral hearing loss by three month of age with at least one year in the severe profound range.    (Inaudible) guidelines.    Our exclusion criteria was diagnosis of hearing loss greater than three month of age, etiologies of hearing loss including meningitis (Inaudible) conceivably made the nine months and we know for some of those other etiologies we need to do more follow‑up and track moving forward.    Given the strict criteria the data represented ‑‑ additionally, much of the data collected was prior to that 2020 shifting care so just keep that in mind.

For every patient who met our inclusion criteria, we looked at their age of diagnosis of hearing loss, fitting, age of the consultation, surgery, age at CI activation.    We evaluated outcome data.    43 patients met our inclusion criteria and underwent a retrospective review as previously described.    Of the 43 patients, 20 or 47% had an additional medical diagnosis and 23 patients or 53% only had a diagnosis of hearing loss.

We calculated cochlear implantation time for each patient which we defined as age of the surgery minus age of hearing loss diagnosis.    Here you can see a breakdown of some of the additional diagnoses.    Of note, congenital CMV accounted for law ‑‑ almost half of the patients.    Other diagnoses included diagnosis (Inaudible) deletions, various symptoms, cerebral palsy (Inaudible) delay.

Here's a breakdown of our results.    The ages are presented in months and moving across the chart you can see the age of hearing loss diagnosis, the age of the initial CI consultation, age of CI surgery, age at CI activation.    We also have that evaluation time as we calculated.    The top row shows patients with additional diagnoses in the middle shows patients with hearing loss and at the bottom can see the difference between the two groups.

Of note we found a difference in the age of hearing loss diagnosis between the two groups.    This is to be expected since we had that strict criteria by three months.    As hypothesized we did find a difference in CI evaluation time between these groups and results show that children with an additional medical diagnosis had a CI evaluation candidacy period of almost six months longer than those without an additional diagnosis.

Once we determined that these patients did indeed have a long candidacy period we wanted to look into a little bit more of the why behind that and what was causing that difference.    We started by looking at what appointments patients have.    We began by counting how many audiology only appointments the patients had.    That included newborn hearing screens, ABR fittings, evaluations, and we included any CI related appointments such as initial consult and (Inaudible) selection.

We did exclude ear mold fittings and impressions from this count because we know ‑‑ and we are working with small children with significant hearing loss ‑‑ we did not want to artificially inflate that count.    Both groups had about seven audiology appointments prior to their CI surgery.    After that we opened it up into that core CI team and so I included the core audiology appointments that were related consultations and ENT consults and we found social work and child life typically did not have their own appointments with these patients, and they usually would meet in conjunction with a speech appointment and ENT audiology.

Both groups had five appointments approximately before implantation.    We could see a significant difference.    The children with an additional diagnoses had greater than 17 appointments.    This is prior to cochlear implant surgery.    Then the patients with no additional medical diagnoses on average one appointment with an outside specialty.    Quite a big difference there.

This very well could be contributing to (Inaudible).    This very well could be contributing to the change in time.    On top of additional points we also found there were times when a care conference will be needed to consult with the different specialties just to make sure patient is medically stable enough and kind of trying to figure out what their outcomes could be meeting with another member of the team and get coordinating schedules to have these important conversations also (Inaudible) difference in time as well.

Significant findings were the difference in CI evaluation time and number of appointments with specialties, but unlike what we hypothesized there was no significant difference in number of appointments with the core CI team.    Given that we are finding there is a longer candidacy evaluation period with numerous appointments with many medical specialists.    Why are we continuing to strive for early implantation?    We did review outcome data for children with a medical diagnoses but it was quite limited from what we could find.    At our center we follow the pediatric minimum speech test guidelines or the PMSTE recommends use of little ears auditory skills questionnaires for outcome measures.    In a review these were not consistently pleaded with this population and those that were, we did see some improvements.

Then I have a couple of comments from families as well to go through.    Some families continue these measures whereas others were able to go to closed or open set speech outcomes or speech reception measures, so outcomes really did vary.    There's also studies that do support early implantation, so one is from (Inaudible) 2013 and they explained spoken language acquisition may not be the ultimate goal for some of these more medically complex children.

Early access to sound, even with those with additional diagnoses, can lead to develop many of language and cognition and improvements in behavioral adaptability (Inaudible) skills have been noted.    Families in the study also reported benefits and sound awareness, ability to communicate needs, interest in their surroundings, and improvements and getting along with their peers and siblings.

Another great review that looks at this population is from (Inaudible) 2015 and this is with the comments of literature review that reviewed all of the research available on implantation in children with numerous medical needs and their outcomes.    In the review of the authors describe the most common types of additional diagnoses in the pediatric CI population and these included autism spectrum disorder, developmental delay, cerebral palsy, charge, usher, learning to civility, (Inaudible) syndrome, ADHD.

Of the trends, particularly autism spectrum disorder, and cerebral palsy, the more severe (Inaudible) or outcomes and slower language acquisition.

There are other benefits recorded.    In a study from children with several policy they received cochlear implants and found they had decreased externalized decreasing behaviors such as aggression over time.    Children with autism spectrum disorder, with study included in the review indicated increased responsiveness to sound, vocalizations, and eye contact following their CI activation.    Other positive outcomes included interest in music, and it improves self‑care skills and socialization.    Outcomes ‑‑ handful are listed it was everything from (Inaudible) parental questionnaire, ESP early speech perception test which is closed at task in CNC so all over the place.    While the PMS TB is our guide, it seems that there may not be a sub standard of care on how to determine benefit.

In addition to spoken language outcomes there are other considerations that support early implantation in this population and these include safety and sound awareness, receptive leg which development, opportunity to connect with family and friends, and at the end of the day we will also consider the families communication roles.    In doing this review we were able to go through the charts and find some fun quotes from families that it was nice to see some of those.    Indulge me and let me share a few.

Family reports improvements in his eye contact.    They also report he is attempting signs of communication.    He is no longer hitting his head.    She has been making nice progress developmentally.    Her parents have noticed much more cause and effect play, improved mobility, and environmental awareness.    His mother feels he hears better while using the speech processor because he will smile, laugh, and make more sounds when wearing it.    He displays some ‑‑ decreased when he is wearing his processor.

He is doing well with his cochlear implants and his mother reports he alerts and attends to sound and speech and more vocal.    He is vocalizing using approximately 20 spoken words and using 20 or more signs.    He understands complex and multi step phrases and directions and he is also becoming more opinionated and determined to do things himself.    That's what we want for all of our kiddos.

With universal newborn hearing screens and the adherence to JCIH guidelines we are able to identify ‑‑ young ages.    The average age of identification was about 1.4 months for both groups.    This gives us 20 of opportunity to meet the nine‑month marker cochlear implantation if that is the route the family wants to take.    With that does come some unknowns.    So we may not know what the developer told trajectory of a child is going to look like and this is something we have started to be diligent with families when counseling.

Just to make sure there may be things that come up later that are not ‑‑ still need to be addressed.    A study in 2020 looked at 92 children who were implanted prior to 12 months of age and of those children 12% had an additional diagnoses at the time of surgery, but 9% went on to receive an additional diagnoses in the months and years following surgery.    The families were surveyed and they found the knowledge and additional diagnoses would not of change their mind in terms of their decision to implant and they were glad they still did so early.

This review prompted discussions on future directions and as I talked about, so many measures are focused on spoken language and finding a good questionnaire to use with families can sometimes be challenging.    Outcome measures don't always capture the whole picture and we may need to find a better tool for kids with additional diagnoses whose goals are not entirely spoken language.

We also may benefit from having neurology ‑‑ evaluate all patients.    We found a lot of the specialties were already seeing some of our kids and it may be nice to have them be part of our monthly discussions to be on the same page and have a better idea of what things will look like for these patients.    We will continue to strive for nine months.    For all children wanting cochlear implants.    In addition to looking at an outcome measure that does not only emphasize spoken like which process, we were also curious about finding a tool that can be used for longer period of time.

We presented early data ‑‑ received feedback that the functional listening index pediatric or FLIP, may be a good study.    It examines a wide range of skill sets in terms of auditory development.    It is also nice because it can be used up to seven years of age and we know sometimes development looks different in these kids so it is nice to be ‑‑ have something that can be used for longer period of time.    Some limitations included a small sample size.

This was in part due to district inclusion criteria but we found in reviewing medical records there were a number ‑‑ (Inaudible) also did not evaluate for socioeconomic status or demographic information for the purposes of the study, however given that we are learning more about an equitable access to care and social determinants of health this is an area we are interested in for future considerations and finally the variability of doubt it was also a limitation.

Again, we found that additional appointments with other specialties did add time to the overall CI candidacy period for the additional diagnoses, however, patients did not require additional counseling appointments and it took place in their normal candidacy appointments.    A medical diagnosis in addition to hearing loss should not preclude a child progressing through the candidacy evaluation process.    It is important to remove that early ‑‑ some of these kids and with appropriate counseling, families of children with complex medical needs can have realistic expectations and overall satisfaction with their child's cochlear implant journey.    Here are my references and thank you for your attention this morning.

>>: We may have time for one question.

>>: That was such a comprehensive overview.    So much literature and I think what we saw was a lot of families at are patient centered care coming together.    I think we all kind of took a gasp when we saw that number, 17, and I think it is so powerful for thinking about how we train our next generation of clinicians.    You have any thoughts about how to get that out in the world or do you have any plans to publish this data and get that out there in a way that really does drive that impact?

>>: Yeah, we have done this presentation at a couple of conferences and we are working up a manuscript.    This stuff is shocking and jarring to see some of the numbers.    Yeah, we take students at Children's Hospital of Colorado and try to incorporate them in these discussions, that it is important to have family centered multidisciplinary care focuses on the patient.

>>: Thanks, everybody.

[20 MINUTE BREAK]

>>: Hello everyone.    Welcome to our session.    My name is Thea Cabral and I am the Badavas Parents and Partnership coordinator and educator.    I was in a PIP program myself with my family at the age of 1.5 and later I became a parent in partnership parent myself and I have to my deaf children and this is my son who is now nine and this is my daughter Zoe who is now four.    And I'm now a PIP coordinator.    Hello my name is Claire LaBarre Miller.    I am an SLP.    I do have two children who are twins who will soon be 15.    Pray for me.    And I am hearing.    I am also a certified teacher and ASL English interpreter and in the Parent Infant Program, that is my primary role, SLP.

I hope we have an exciting program for you today.    In 1979, The Parents and Infant Program established its first coordinator and was founded by the first coordinator, a person by the name of Nancy, and I am the third deaf coordinator in our state now.    Our mission statement is that we want Deaf and hard of hearing children to become adults who thrive by having the knowledge, the opportunity, and the power to design their own future.    In our program we have been ASL first philosophy.

ASL is something that is viewed as a human right in our program.    We also allow access and provide access to fluent deaf role models as much as possible, including deaf leaders.    Some deaf children have a spoken ‑‑ their first language is English, but ASL can remain a valuable part of their identity and all families to receive a well‑rounded wealth of information that is based on research from both hearing and deaf professionals.

In the end, they leave with a wealth of information they can apply.    So we have a balance of deaf and hearing people.    Mostly deaf.    We do have quite a few deaf people on our team.    Some of us were formally involved in PIP as a family liaison when we have had parents in PIP as well.    Our demographics, we have should be 19 families, one family with deaf parents, one family with deaf child and hearing parents, and 17 families with hearing parents and eight of the children have hearing aids, hearing devices.

Eight children have no hearing aids.    Three have cochlear implants.    Three are deaf plus and some have a half deaf family and have hearing family so there is quite a variation in our demographics.    Historically we have had different participants with deaf plus, autism, deaf blind, physical disabilities, and other global delays.

How do families find us?    It is usually through DPH, Department of Public health.    It is usually correlated to the newborn hearing screening.    We have a lot of state‑sponsored resources, like the newborn screening where they provide a packet if they are identified as deaf, in that appointment for a follow‑up appointment.    If the family, when the family as a deaf member of the family they are presented the information in the hospital at that time.

DPH also has people that connect the families to make sure they have follow‑ups and early intervention and other specialty programs.    The resources are available in English and Spanish.    We have one person who connects with families.    He is a father of a deaf child himself, so he is creative and figuring out who to connect them with.    He will connect parents with other parents.

Families find us through early intervention, EICS system, an online program that we can use for resources to have people referred to us.    People can also reach out to us by e‑mail or a phone call, and once we are connected we can go ahead and schedule an appointment for the family to visit and see the program in action.

If the family wants to be involved in the program, we would add our programs to an IFSP for the family and we are not limited to one program.    We have more than one program.    Some programs are a bit more oral based and we encourage the families to do more than one program if they are interested in that.    Funding.    We gather funding through the learning center.    We do not get any salary through early intervention.

We do get reimbursed for our services.    We bill early intervention every month for all of our services.    We have a reimbursement contract, rates are set every year, but they are not a lot.    They are not a lot of money, just a little bit.    So we do operate in deficit every year.    Our services.    I want to show you what they look like and what we provide.    We have playgroups three days a week, Tuesday, Wednesday, Thursday.    They are about 90 minutes, 1.5 hours each day.    9:30 to 11:00.    The family will pick one or two days to join the playgroup.

We do have a limit to the Department of Health and the time we are allowed to provide in which they can, ‑‑ I wish they can come all three days, but they can't.    We do also at home visits or center visits depending on the distance they live from the center.    We can do at home at our center or we can go to their home once or twice a month and that will be with me.    We have a family discussion group where we provide support to families about various topics and I will explain a little bit more about that later.

Twice a month for one hour we have two Wednesdays a month they come to the learning center to visit and twice a month we have one half hour and this is a supplemental visit, so if the family is already getting services they can supplement with this additional visit.    That means speech therapy services, just to clarify.

Everything we do supports the child as a whole.    Their cognitive abilities, their gross and fine motor skills, social development.    Our playgroup is also an opportunity for the families and staff to connect, to provide sort to each other, answer questions, and also the parents can connect with each other as well.

We also have pictures and videos and have a lot of ASL print pictures, some sign language, and that is something we feel is very important for access to language.    For the visual access.    So my group looks like a lot of playing, imaginative playing, different themes, cause and effect playing.    We have an infant reading area.

Most of the time we have side‑by‑side play, so maybe we have something in the beginning and we will start to play with the kids.    They will also develop their social skills through playing.    The staff is able to interact with families as well, and talk about their playing skills, their language skills.

We try to do some field trips.    We go to different places and we have been to farms, orchards, a public playground.    Splash pad.    The library.    Museums.    We have a play space as well, and we do try to have that set up for free as much as possible.    If we have to pay like for an indoor place, we usually try to get something as low‑cost as possible for free is usually what we prefer in the community.

So if families are unable to afford something, we try to cover the cost for that.    And we collaborate with the early childhood center with older kids that are 3 to 6 or school to kindergarten age.    We collaborate with them for some events so that our kids can look up to older kids and families also have an opportunity to see their kids and the older kids in action.

I also realize I forgot to mention that our families actually stay in the PIP room the whole time.    We don't separate them except for when we go to the family discussion room.    We have interpreter services as well.    This year we are trying to do it a little differently.    In the past we have the interpreter staying in the room the whole time and now we are trying to do it differently where we have the interpreters come for the first 15 minutes and the last 30 minutes there is no interpreter, so we can encourage full immersion for the family for them to practice their communication as adults with each other.

We ask the interpreters to take a step back and if they need to step in they can.    Mostly to step back.    For home visits we do provide a first or second home visit if needed.    We also try to encourage the families to directly communicate with me to increase their ASL skills.    For new family visits, that means it is the first time the family is coming to our center to learn about the program and we usually have an interpreter there the whole time for that appointment, for the whole hour.

We do also provide foreign language, spoken language interpreters, if needed.    We have had Spanish and Portuguese and we do pay for the interpreters out of our budget.    But if there is an IFSP meeting run by early intervention, early intervention will pay for the interpreters, not us.

 What our program looks like is we start with free play for about the first half an hour, we have circle time to warm up and then we have free play and then we will have circle time at about 10:00.    We will do different activities during circle time and using the bilingual approach.    Usually what we do first is a movement activity, then we have joint attention activities.    We will also recognize each other's name signs, giving everyone a turn to recognize each other's name signs and feel that sense of community.

We do have some videos of this.

[VIDEO PLAYING ‑ INDISCERNIBLE]

That gives you an idea of our circle time and how we begin.    We do the gross motor movements, we practice the starting and stopping, and giving other children a turn.    Once physical movement is finished, we move on to some hand shaped games or ASL songs or other ASL‑based games.    I do think we have a video of that, as well.

[VIDEO PLAYING] We are going to use a handshake in a circle.    We are going to pick the hand shape bug.    Everyone has to use a hand shape for a bug.    Mom, what do you think?    It looks like you are trying to get towards hand and rooster uses the three. A car going down the road.    Exactly.    That uses a handshake as a classify.    Exactly.

>>: We do use a variety of hand shapes and play those hand shape games in our circle time.    We teach about hand shapes and ASL parameters during this time as well.    We connect and we use thematic units.    In the month of March, what makes you think of the month of March?    It cannot just be hand shapes but practicing signing, as well.    We do have a variety of ASL songs that we have created over the years.

We will refer to those and use those in our circle time as well, especially with parents.    We have an apple and a family song and different ‑‑

[VIDEO PLAYING] We will do a practice round first and do it two times.    Family family, play and play.    What do you do?    Chat and chat.    Family family, what do you do Read, Read, family, family, what do you do.    Eat, eat,      What do you do? Hug, hug,    What do you do?

>>: That was a song we wrote back in 2016.    We created that song.    We have collected quite a few over the years.    We also do pre‑ teaching, so we show families signs we plan to use during circle time and we repeat them a couple of times.    Those songs are repeating, so it makes families feel good about their signing songs and what they are picking up.    In our program once circle time is finished we often move onto snack time which is right next door.    Not in the same room, but we do have a doorway we go through to go to snack time.

During that time we will talk about food.    We will talk about what they are eating and that is the time to capitalize on vocabulary.    We use classifiers and talk about the shapes of foods and the taste of foods.    We ask them if they need help opening things.    While we are doing that, they are acquiring language skills.    We also do a who's here and that is routine to our snack time.    We talk about who's here and we have a short lesson on weather and it's a small wooden board that we use to help kids visualize what the weather is today and it is another way to get language exposure in our everyday Parent Infant Program.

In our who's here, sometimes we do a song as well, so we will tap on the table and say who's here, who's here, and we pick up a card and the card will have each child's name on it individually, and we will recognize that name and help children connect printed language to their name sign to who is in the room.

It helps them get to know each other.

[VIDEO PLAYING] who's here?    Who's here?    We've got Aren. Are you Aren?    Where is Aren? You are not Aren. Aren is right next to you.    Do you want to give it to Aren? Good job.

>>: We also incorporate ASL storytime and we either will use an actual book or projected book by video.    We have an in‑house video from deaf made sources, so we do use our own videos that we have created from the books that we read.    Occasionally we will borrow from RMSD and use various resources for signed access to books.

These books also often incorporate deaf adult role models and illustrate strategies in ASL storytelling.    We also have an online archive of staff made stories and other rhymes for families to access when they are at home.    We ask interpreters to not use English and do the voicing for story time because we really want families to be immersed in that, and sometimes parents don't want that distraction, so we asked them not to voice the stories unless requested.

In this video you will hear a Portuguese interpreter in the background.

[VIDEO PLAYING] he looked up at all the giants and said come on.    (Indiscernible)

>>: This book is called Farmer Will and it has props that we can connect to the story and it helps develop ASL vocabulary.    During story time we also bring in guest speakers so we will borrow people from the elementary school or anyone that is on campus to come over and participate in story time with us.    We also use some of the caregivers who have practiced an ASL story so the parents or other caregivers come in and will share the story.

This in the top right is a hearing father was reading the Brown Bear book.    At the bottom we have a deaf mom reading Where Do Pigs Live.    In the upper left, this is a guest storyteller talking about Divali and we have at the bottom left a Spanish guest reader reading a book about siestas for Spanish heritage month.

>>: Another thing we are doing this year that is new to us is after story time is finished the children will then go on and play with staff in another room and we capitalize on that time to sit with families and caregivers and they get to have a one‑on‑one chat with me, a group chat, and they get to ask their questions and they get to talk to me without distractions.

After that we have an art and sensory exploration time and this also feeds into language development.    It allows children to explore the world around them.    This is me here.    I did not want to get involved but I was explaining that the ice was very cold and you can see my face.    We encourage messy play during this time and the adults back off.    This is a time when we let the kids explore.

They have plenty of sensory integration.    We do use vocabulary classifiers to show them what they are experiencing, and we have various tools, sensory tables, tables or bins, they can go to the wall or floor or do anything they need.    You can see here we have sensory areas on the floor with different textured materials taped down.

We have cotton balls, bubblewrap, and it is fun to see the children's reactions.    Some of them really like it and some of them need to get used to it.    We also have an outside play area in the bottom right.    Sometimes if the weather is nice we will play outside and do the outdoor classroom.    We have a small garden and a small kitchen out in the yard, a little stage for performances and things like that.

I would like to add that the property we use, the materials rather we use, are either inexpensive or free.    We have spaghetti and sand and flour.    We don't have an extensive budget, so the things we use our inexpensive and that is really the key.    We also incorporate cooking and science activities from time to time and this all comes back to language enrichment.

These are things they will experience in their everyday lives and cooking and science really does use all the senses and it also uses fine motor skills and it integrates sensory experiences, encourages vocabulary, and they learn procedures and directions, and they also learn ‑‑ taking and we do this one or two times a month.    It is a wonderful experience for them.    We also do science projects.

>>: We use food coloring and vinegar.    And we had pumpkins left from Halloween and we used some pumpkins.    Play‑doh.    We make our own play‑doh and have a recipe to make that and we involve the kids in the process.    We have slime as well.    They have to help poor and measure and everyone takes turns doing that.    They get to play with that and bring it home.

That is a good opportunity to use different tools and different language and discuss safety and what things are dangerous.    Here's some more pictures.    This is where we are making a tortilla.    And muffins.    We are making potato latkes. We also have some song wrap up.    We have a goodbye song.    We also have time to let them know what the transition is and they are going to be home soon so we have a song about that encourage the feeling of community connection.

And make the kids feel good.

[VIDEO PLAYING] bye‑bye, families.    Bye‑bye, families.    See you again soon.    Yeah.    See you.

>>: We do the same song each time.    That way the kids know what is going to happen next and they are familiar with the routine and what that means and what that transition is.    We have different transitions at different times and we use flashing lights to remind the kids.    We also have an ASL cleanup song, so we tend to do the same things and have the same schedule so the kids can predict what is going to happen.

We also have a picture schedule with ASL that we print out.    We have their name and their picture on a chair so they are able to find their chair.    It also helps with practicing finger spelling, the name tag on their chair.    Just to make everything visual.    The home visits with me, typically home visits are about one hour where I interact with the family and a provide different resources.    I provide information about child development, transitions for the future and what you can do and we work on language development and ASL.

We plan different routines on how to use language during those routines, like diaper change or eating, so they can improve the languages with the child.    It is a perfect time for the family to have some private time with me and ask questions, and help transition the child to going to school.    Discussing the different ideas on how we can support them.

It does not have to be at their house.    Sometimes we go to a public library or the grocery store and that helps the family understand how to grocery shop with the child.    What they can buy or what comes next.    I also attend the IFSP meetings and co‑ treatment with early intervention.    During the home visits which happen for the first two times, during the IFSP there should be an interpreter because there are other people involved as well.

One‑on‑one center visits with me, there is an option.    We have a lot of options available for the family depending on what they want, so they will use spoken English or sign language and I will use whatever accommodates that family.    We also work on bimodal development which is the goal.    Of course, skill development as well.    And prior to cochlear implant surgery we can discuss with counseling before that the goals after surgery and what to expect during surgery.

We also provide guidance and counseling information about transitioning to school and bimodal children and how to support their goals during preschool.    I am also available to collaborate with the early intervention provider but I noticed that many of you don't contact me so I try to reach out and contact you, but most early interventionist agencies are not very familiar with deaf.    They know it on a certain level, but I do try to collaborate with them more.

Thank you.

>>: Family discussion group.    This is for families and caregivers, anyone that supports the child.    I would be there and there is also a deaf social worker.    This is once a month for one hour.    We do this with the families.    The PIP staff ‑‑ so they can focus without distractions.    We also have an open discussion or in special cases, there are special topics we present about, so some of those topics are literacy, deaf history, deaf culture, transitioning from early intervention to preschool, bimodal development, education, educational audiology, and a deaf student panel which they tend to really love that panel because they are able to see older deaf kids and the parents are able to see what their child may become in the future, so it is a really cool opportunity and it is a popular one.

So we have an ASL safe space for us and the families.    We encourage the families to use ASL, which means we provide a lot of opportunities for them to do so.    When the families make mistakes we encourage that.    That is one of the ways you can learn.    Almost the only way to learn.    It is a perfect place for them to feel comfortable to make those mistakes and learn from us.

And I get it.    Language as an adult or even older adults like grandparents that are involved, it is tough for them.    And we want to meet them where they are.    We want to be able to open the conversation for them and let them learn from us.    We try many different ways for them to learn ASL.    We do a sign language breakfast every year where everyone comes together and there is no interpreter, so instead of going up to the regular room we go downstairs and have a potluck and have the families being immersed and playing games.

We show some videos with ASL stories on the screen and it is just a social time, which is nice.    We offer ASL classes for free for the families during the PIP program.    At the learning center we also offer classes for the siblings that is not free.    It is an opportunity ‑‑ they are free and that is an opportunity for the siblings to learn ASL as well.    Talk about deaf events throughout the year and encourage families to go to deaf events and we have some on campus and some off campus, as well.

We have a night ASL class and we have some that are virtual and some that are in person.    It is free for the parents or the primary caregiver, and we do connect with the ASL shop and it is a free subscription for parents or the primary caregiver.    For one year they get the prescription so they can learn ASL on their own with a self‑paced class.    And early intervention provides transportation, so of the family does not have a car they are able to get services still.

We also make sure that the families know they have a right to get transportation.    I'm not sure if everyone in our early intervention knows that, but if someone does not have a car or the distance is too far from home, it is a good idea to ask about transportation.    Other services that we provide, we provide evaluation, visual communication and sign language checklist evaluation.

We document the development.    Developmental milestones for the visual language user.    We do assess the hearing kids, too, to see what their sign language level is at.    We provide DCSL and you must be trained to provide that to become an evaluator.    We use staff observation from the PIP group and the home visits and parents as well.    We ask them questions.    We get information about the kids' skills and we collect all the data to assess that.

It is a team effort.    We do it about every 6 to 8 months and again before their third birthday.    Once the evaluation is done we type up a report and share that with the family to discuss where their child is at developmentally.    We also share that with the preschool team for their IEP eligibility.    So IEP eligibility, we also attend that meeting with early intervention and whatever family wants to be involved in that meeting.

Before the IEP meeting we will asked to observe and we invite people in and they are welcome to observe the child in that experience with their peers and the environment and what language they use so they can see what accommodations that child need.    In Massachusetts it is a little sticky of a situation.    Mainstreaming, sometimes the parents have to fight for that.    If the parents can't agree on where the student will be placed, they can go to the IEP ‑‑ if they can't agree at the IEP they need to go to mediation and we also attend that to support the families.

Just to clarify, the parents, if they want to place out of the school district they have to really fight for that so mainstreaming, it is fine because it saves money so getting that placement is a challenge sometimes and so that sometimes leads to mediation.    If they want to go out of district placement, so that is where the parents have to fight if they want to go to the deaf school.    Because the districts, you know, they want to save money.

If they want to go to the deaf school they have to fight for that and explain why and we want to be there to support that.    If they want to transition to the learning center or our preschool, we do allow ‑‑ the preschool is just down the road.    We have PIP and the preschool is very close near our location.    We do want to empower the kids while they are playing.    We let them ‑‑ we support the whole child and the whole child's needs.    Oh, I am jumping.    There is a new program.

The toddler ASL immersion program.    So this is for kids that are 18 months to three years old.    It is a drop off.    The parents do not come in.    They drop off the kids and the kids stay for three days and this is out‑of‑pocket for the families.    The parents do pay for this program.    It is $75 per day I believe.    $75 each day.    Is not a replacement for PIP.    It is extra additional time, kind of like an all day daycare.    It is located in our building.    Just right next to us.

We do have deaf and hearing working together.    We always try to have deaf leadership and a majority of the staff is deaf as well.    We have story time, cooking classes, we will invite other deaf programs to, and see our program and see how it is run because we are able to learn from them and they are able to learn from us.    We use interpreters as well for full access regardless of what the persons signing ability.    We also have hearing staff modeling deaf inclusion and supporting the deaf professionals and we want to show we are including the deaf professionals.

As a hearing person working in a deaf space, my role can get a little sticky.    My favorite word is allyship.    Too much conference spelling today.    So allyship.    I like to keep that word front of mind.    That is something that is part of all of my work every time I interact with people, how I communicate with people, how I stand in the room.    My allyship is part of all my decision‑making.

Sometimes it is a simple change of behavior.    Maybe a deaf person their experience I want to look up to that first.    I will defer to them primarily.    And the primary educator in the room, I have value as well.    I am not nothing, the deaf person is first.    For example, suppose I'm chatting with a hearing parent and the baby is playing and the mom asks me how do you sign this.    I know the answer of course, probably, but I would ask the deaf individual in the room.

How do you sign cow. That way it shows respect.    It is not my language.    It is the Deaf community's language.    They should model that language and if it is available to use that.    I will not say no, I will not tell you, but I want to use representation if I can.    If somebody is not available I will show the sign.    This is the sign for cow.

Keeping allyship in mind you want to be informed.    There are many deaf people that have experienced trauma because of people like me, because a speech language pathologist ‑‑ it gets sticky.    We have to be aware of that all the time.    The two of us and our staff, we have very open communication, an open communication process.    We are very open with each other.    Everyone is open to ask questions to each other and we ask for opinions or if somebody wants to add a comment or if a situation happens, discussing what somebody noticed and being able to ask and depend on each other.

And doing check ins to say hey, how do you feel about that situation, saying I tried all these different options.    Do you think (Indiscernible) wrong, provide feedback?    We really want to lean on each other and depend on each other.

>>: Outreach.    So far for what we have been doing we have been cementing information and spreading information for EI, the Department of Public Health.    We do have a booth at the early intervention stake conference and other related events.    We visit EI agencies and we provide information about SSPs for deaf clients and families.    What we are looking forward to in the future is hosting an open house on our campus for early intervention agencies so they can come and see our program and meet the staff as well.

That way we can make connections.    We wouldn't mind posting story time at different outside locations as part of our program.    For example, we could have a Deaf and hard of hearing day at the museum and have signed story time there.    We also visit different medical centers.    We want to reach out and educate people in the medical profession and explain more about our program and our resources for deaf and hard of hearing individuals.

This is where we advertise.    We do host a biannual event.    It is a conference called Guiding to Providing Services, the GPS conference.    Early intervention has such a high turnover rate and so biannually is a good opportunity for us to have this event and our next one is coming up November 2025.    The learning center from Framingham, Massachusetts, is where that is going to be held.

Last year we had the ASL shop, and present.    We had a panel as well of different service and deaf and hard of hearing advocates.    We had Boston Children's Hospital, and explain about their deaf and hard of hearing program.    Of the ASL shop did a little bit of extra, and we had a keynote speaker as well.    We had Matt Hall presenting a keynote on love and language which was a wonderful presentation.    It was also about social and emotional learning and there were several topics ‑‑ lots of hand on activities there and lots of different things we were able to do.

So if you would like to follow us our Instagram is here of course.    And if you are ever in Massachusetts or in our area, get in touch with us and visit our program.    You are all welcome.    Are there any questions?

>>: I see you have on the screen there was a snowman.

>>: The art.    It is all made by a deaf person and there was an act that was created by deaf individual before and it was clip art, I think, and it is not available anymore unfortunately.    Yeah.    I don't know where we can actually get that from.    We have been sharing it.    We can share, but don't tell anybody.

>>: It was created by a deaf person.    They stopped because so many different people were being critical about the right sign versus the not right sign, so we had purchased that and have access to it because we purchased it previously.    Yes, we have so many different things and visuals of all those signs.    It is wonderful to have that and unfortunately it is not available anymore.    Too bad that it is gone.    We have another question.

>>: You are talking about early intervention teams and your program is in addition to that?    A supplement?    Am I understanding that correctly?

>>: Yes, speech and language is supplemental.    Yes.    So that team you mentioned you have speech therapy, a speech therapist and you might have occupational therapy, teacher of the deaf, or are you a teacher of the deaf?    How does that team work?

>>: I am not a teacher of the deaf.    I am an SSP, special support provider.    Teachers of the deaf, I don't think we have a TOD, do we?    Some of the agencies do.    Some are lucky enough to have those.    There are a couple and we are trying to get them connected with deaf children.    The Department of Public Health is trying to coordinate that, but we don't all have those relationships unfortunately.    We do have one TOD on staff, April.

But there is not a one‑on‑one service.    The teachers of the deaf are kind of involved in the playgroup and that is the concept we have them integrated into our playgroups.    And the teachers of the deaf from our preschool, we have the staff and the families knowing who that is before they make that transition.    One more?

>>: The playgroups.    What is the age range for your playgroups?

>>: 0 to 3.    Some families start at four weeks old.    Some families get an early start and some start later which is also fine.    Actually, our numbers have actually been reducing every year.    Massachusetts just doesn't have the birthrate I guess, but it was 10 and now it is 19.    We had a couple of kids graduate, three, and then two more.    The numbers have fluctuated as referrals come in.    It ebbs and flows.

There's a big effort in Massachusetts to refer to SSP services.    They don't refer to us unfortunately and the deaf kids are kind of stuck in early intervention land before they get connected with us and it is improving.    Not perfect but it is improving.    One more, maybe.

>>: It was going to be a question but it is more of a comment now.    My daughter is four and she attends a deaf school preschool and she ‑‑ it is fully ASL instruction.    She loves to talk.    She is very, very verbal and one thing that has been a struggle is how to engage her in an immersive ASL environment and I was going to ask if you had any suggestions or thought within the more I thought about it, if this existed in our state I don't think ‑‑ I feel like we are playing catch up.    If this had existed she would be in a different place than she is now, and they don't think we would be going through what we are going through, so this is my dream.    Thank you.

>>: Yeah, thank you.    I appreciate you sharing that.    Thank you all for coming.    Yes, thanks for coming.