>> Good morning everyone and

welcome to how EHDI services providers

can facilitate the best outcomes in

young children.

So that's all this says so I want to

introduce you to Donna lar skin and

Andrea Warner-Czyz who will entertain

and enlighten us this morning. Thank

you for coming. This is a two hour

session, they're going to go straight

through so if you need to use any

facilities please feel free to raise

your hand and ask -- no, just kidding,

just go at your own will.

Have a great day.

>> Thank you for spending your last

moments in Cincinnati with us, and I

just want the introduce two speakers,

Andrea Warner-Czyz is an associate

professor at the university of Texas at

Dallas, so she works with students and

gets them ready to serve? All

kinds of capacitieses this audiology so

she's really great. She brings a wide

knowledge of audiology and how to teach

things to adult learners, so I'm really

happy to have her be so enthusiastic

about redth spreading the word. I'm

Donna zero Sorkin and I have about 30

years in this field in different

capacities. I work for different

nonprofits and we are a nonprofit and

I've also worked on the industry side

for one of the cochlear implant companies

so I have a range of different

perspectives about how -- what you do

and how to do things in the world. And

I'm trying to figure out how to

advance this. There's something he did

before when he was here. Ye, that.

Okay. So we are kind of a unique

organization in the field and we just

think about access to care so there are

audiologist organizations and E north

organizations but who found as a

community that cochlear implant often

fell through the cracks, so ten years

ago, actually 11 years ago we were

incorporated as a nonprofit and we use

research awareness and advocacy to

advance what we're doing, and we're a

membership organization so we have as

part of our membershipphysicians and

audiologists, speech language

pathologists and others on cochlear

implant teams and this should include

early interventionists because

we have a number who are op our

membership and consumers and parents.

They typically join to us -- to advocate

so we would love to have you involved if

you would like to be. We have a website

that has a lot of information on it and

it's just for you as professionals

as well as parents and're on

social, so join us on social.

so what we're going to talk about today

is the parent journey and what that

looks like as member parents move

through this process and we're going to

also look very much at the relevance of

age at the time of device fitting, we're

going to be talking about both hearing

eights and cochlear implants because

those are both part of this process and

key factors for spoken language

outcomes. And our learning objectives

you've seen but heartly they are, we're

going to describe the parent journey,

share data on cochlear implant age and

key factors.

So let's talk about the parent journey

and these are the seven items I'm going

to be sure to cover, this is my part of

the workshop today and I should also

mention that we really want this to be

interactive, so if you have a question

or a comment that you want to make, you

know, we're close all together, just

raise your hand and we'll call on you

and we'll both pause at different

point that

facilitate that kind of interactive

activity, and you all come with your own

experiences and knowledge, so I

hope you will do that. So the first

three items all have to do with

information is we're going to talk about

inform and how to get information to fans

.

We're going to talk about goals because

a lot of times we don't make eight clear

to parents that they do have

optionings and

they can create their own goals.

Tele-health -- and I have

blue tooth so I went right into my

process and I couldn't hear

anything else so I had to turn it off.

I should have mentioned that I have a

cochlear implant and have had one for 30

years so I'm going to bring some of that

experience into my discussion today.

Really important facilitating

connections to other parents. And then

the last item has to do with cognitive

and linguistic stimulation and sensitivity

of a parent but specifically

moms. So let's start out and talk

about information. Information is power

.

And information helps someone move

forward at the right time to make

decisions. And I'm going to speak from

my own experience on this, so I was

implanted 30 years ago, think about

where we were 30 years ago with

information on hearing loss. It's --

some of you are too young to know but

there was no internet and

where I used to look for information

was in books in the library, physical

books. And when I was searching

for information that's where I would go,

I would go to the public library and

guess what, there was testimony anything

there. I was very fortunate to have an

audiologist who said to me after fitting

me with three sets of hearing aids, you

know, I've just given you the most

high-tech hearing aids on the

market and you're still not doing very

well I think you should explore cochlear implants. She didn't

tell me I needed one, she just said I

think you should explore it. And she

did that by giving me the names of

patients who had been through her

practice and had been able trayful gain

a lot of B. from a cochlear implant. So

that's what I did, that's how I started

looking at this. I talked to her

patients and it really let me see what

the potential was for me with this at

that time very new technology. In the

whole world there were only 7,000 of us

so very hard to find information, and I

talked to people and it made me realize

I could do a lot boater than I was doing,

and I had another member of my team who

was fantastic, my internist and his wife

had a hearing loss and uses hearing

aids. And Dr. Newman made the calls for

me because I had no idea where to go. I

mean, think about it, no internet, you

go op the internet to find the

information you needle but there was no

way for me to get information. I didn't

know where to start but he did and he

told me where to go and he even called

the program and talked about to the

surgeon so he could then talk to me

about what the process looked like, so I

was really fortunate to have that kind

of a team that once I realized there was

something for me to help me move forward

and that's your role as early

intervention professionals to help

families that information and

you know what, the law requires it. The

most recent version of the early

intervention law, the omnibus act

encourages professional to work with

partner to advance awareness about the

rain of modalities for children who are

deaf and hard-of-hearing it

specifically mentions the modalities.

So that's really important that we are

supposed to be talking about all those

according to the law. And it also notes

the full rain of assistive hearing

technologies that should be discussed

including hearing aids and cochlear

implants so it specifically mentions

cochlear implant in the law, and it

mentions that you know getting

information is important and we know

that getting that in a timely manner can

delay the fitting of hearing technology

and impact out comes and Andrea is going

to talk about that. So this is all this

the law. So how best to share

information? There's a variety of

formats way better than when I went

through this 30 years. And

certainly we awe turn to

electronic formats and there's been

research that shows in fact moms

in particular use the internet to get

health information, a very large number,

and there are some differences across

different socioeconomic groups and

education, et cetera but even with those

differences on average 75 percent of

mothers go to the web for information on

health and that includes hearing

loss. So really important.

I love videos of teams that demonstrate

what's possible baa you look at baby you

really can't get the too much from

that, but I also really love hearing

first. How many of you are familiar

with hearing first? So they are an

organization, not too old, I think

they've been around about five or six

years, maybe a little more than that,

and they're web basses and they have

beautiful videos and information, I'm

going to share some of that with you and

we have given you some of that cop tent

from hearing first and we work with them

a lot because we think they have really

great materials. The other

thing that's important is the planned

rollout of information to avoid

overwhelming people. There's a limit to

what people can absorb initially so

you want to make sure that you're

continuing to give them information but

you don't want to overdo it at the first

meeting. And you just plan what you're

going to give them over time. So ensure

your website includes the information

that they need. Sitting in the back of

the room is Nicole west and I should

have introduced her earlier. She's our

advocacy manager, and Nicole did a

studies that she presented

yesterday about EHDI websites

and she went on and looked at all of the

EHDI websites and determined whether or

not they were in compliance with

what's required and some are -- I think

39 percent, Nicole found were

comprehension expensive that means the

rest were lacking investigation. So you

want to make sure your website has the

information that people need. And I've

listed there what those are, what is

hearing loss, what the communication

options are, a bit about technology and

resources. So those are the four things

that the federal requirements include.

Which are not on every website, so

really important to do that. We also

have some great materials and everything

is -- we've given you some of them and

all of those these are also online but

we have information on cochlear implants,

and we have recent guidelines on how to

determine candidacy and assessment for

children with bilateral deafness and for

single side deafness. And Andrea

was the first author for the one on

bilateral, so she's going to work from

that. But these are

materials that we have for you and you

can ask us to send you additional printed

versions of these and we'll take care

of that.

>> [indiscernible] there's also a bunch

of them in the back and you're welcome

to take some with you so we don't have

to talk about them all home, I mean, you

can enjoy them.

>> Absolutely. Anybody have any

questions, comments? Seven

challenges of getting information to

families? No? So then I mentioned

don't give it to them all once, break it

down and you want to think about adding

information as you go along, and we Al

need to think about the the fact that

adults access

information in different ways and some

people prefer written things and

photographs and diagrams. That's me. I

prefer visual. If your parent has a

hearing loss they're probably going to

prefer visual, and some people like kin

esthetic which basically means they want

to interact with it and sometimes things

that are on the web that have options

for you to interact are what people like and our most important

information is presented in two ways,

my favorite way which is the flow chart

-- I like flow Charlottes and it shows

you the steps to a cochlear implant, but

then some people like the interact with

it so we have one where you can interact

with that flow chart and it can take you

to different parts of the processment

SOS the good to have things in both ways

and system some people like auditory the

best, they like to talk in groups and

they like verbal repetition so if you

have a parent that prefers that that's

what you should do. That's not me but a

lot of people prefer that mode and you

need to think about it. The other thing

really important is the opportunity for

social and personal relationships, linking

parents up with other

parents and there's been a lot of

discussion at this meeting about what

they keep calling deaf mentors and I

think mentors need to be both

deaf and hard-of-hearing, people who use

spoken language and technology but

talking to other parents is important.

We have a parent in the rooms. Do you

want to talk about that?

>> So I have three children, my first

two were born typical hearing same as me

and my husband. My third child was a

surprise and she was born deaf and is

she uses bilateral cochlear implants.

Tempt we had no parent support, there's

no one in our community who had

experience of children with cochlear

implant and now nine years later we're

doing parented supports so I support

other parentings as they explore all

the options and decide what's best for

their child, so I think parent to parent

support is so valuable. As long as it's

accurate and unbiased because I would

never persuade another family the choose

cochlear implants, I would rather listen

to what they know and make sure they get

all the accurate information.

>> Thank you. I really agree with

everything that you said.

So the third topic also has to do with

information, and it's the whole issue of

identifying pediatricically in thises

that are trained to work with young

children with hearing loss. This in

some ways is the most difficult of all

depending on where the parent

lives and how farther from centers. So

who are the member of the team and how

do you finder them and how do you the

find a quality listening and spoken

language team and that's

an issue we hear about all the time.

Again I go back to the hearing first

materials and this is just off their

website, and so we have just stolen from

their site which they're happy for us to

do, they're members of the team which

are listed there. This is all new

terminology for most parents so it's

good to give it to them in writing so

they can see or send them to the web and

it goes through all the members of the

team, and who their early interventionist

is. I'm sure you find parents that

have no clue what an early interventionist

is. That's a brand new term for them,

so giving them in information in

writing so they can see who it is

they're supposed to be interacting with

is important. I'm sure they don't know

who a speech pathologist is and a teacher

of the death, what's that and in many

areas of the country they don't have

teachers to have deaf, this is all on

the hearing first website. Then the

next question that parents often have is

how do I find a quality program. How do

I judge who's a quality provider. And

is there may not be enough of them

around but then to even think about how

you choose that person is really key and

this is all hearing first materials

again, so I'm not going to go through

all of this again but you can go to

their website and find it and share it

with families because I think it's

really instructive and all of it's done

in a way that make the information

understandable and accessible. It's

been tested with parents at different

education levels and I think it work

really well, so this is just a real

quote from one of the Facebook pages for

parents. It's called parent

offense children with cochlear implants

and the mom was venting and she said hey

everyone, just wanted to vent, my almost

two and a half-year-old will have

activated for two years this July and

we struggle to find support in our area

due to insurance and high turn over rates

and we don't have any near us and the

one provider that is good doesn't

accept my insurance and here's had four

SLPs since April and none seem to stay

this this area of how many of you have

this issue? Yeah, really common, so

very frustrating for families. Trying

to do the best thing their child and

they can't find the right people, so

there are some places they can

look. Are you familiar with EHDI

pals? So that's the main one for

audiologists and there may be that there

aren't any nearby. Pediatric

audiologists are who we tell families

to go to, they're even harder to find.

I went on the websites to see what was

on them and this particular one for

[indiscernible], I don't think

I would send parents there, but I'm telling

you look at this stuff. On the Otol

gists that's what we encourage you to go

to.

And many of them have no knowledge of

technology and the importance of starting

early with kids. So some other barriers

are the child's health status which can

really slow down a child's starting on

the path and we have had a lot of

discussion, a can recollectMV at this

meeting, and the foundation of CMV

foundation talks about how sometimes

clinicians will stay to the parents you

can wait on the hearing loss part

until you get through this other part

and the the foundation doesn't feel that

way, but they're still often told that

by other professionals. And then in the

prejudices of some other issues maybe

going on and then family related factors,

the education, transportation

issues, health insurance has been

mentioned and English is a second

language to be a barrier, and I mentioned

before qualified pediatric audiologists

and the ability to get in and have an AB

R within three months is often very

difficult. Then this is

Andrea's work or student's work, and

what they did but take the state of

Texas and mark off where they were

pediatric audiologists who could serve

children zero to five and if you're in a

big city you'll probably be ability to

find someone, and otherwise you're going

to be quite a distance from a pediatric

audiologist. So that's another barrier

and you got to figure out a way to help

them access those people. And then

parent centered Lizotherapy we

really know that children need auditory

therapy with the involvement of a parent

or family member, it has to be a

partnership and this is really different

from when I first got into this field.

I for a short time was at HE bell and

saw how we were forming therapy at that

time and the mom would go with her child

to see an SLP and the mom would sit in

the waiting room and the kid would go in

with the therapist and then the

therapist would come out with the child

after an hour can it's and the mom would

say how did he do? So that's the way we

used to do therapy, the provider of

the services was the therapist. So how

much things have changed. We

don't do therapy like that anymore. We

have the parent in the room and the

client is the parent, so that's really

different and really important and it's

what's made a real difference.

So who are those providers? So HE bell

has a listing of certified auditory

verbal therapists or AV Eds and I went

on their directory to see what it looked

like. Just in athlete states so in the

state of Alabama there's one, in Florida

there's two, in California there's

seven. So have you begin to see parent

think they have to have a

certified person and they go to find

them and they're not there and they have

it in their head it has to be a cert AVT

and we have to change that and I think

the hearing first materials really

address that in terms of helping a

parent find someone who's trained to

help a family with moving along with

listening and spoken language, who

perhaps doesn't have that certificate.

In the whole world there's a thousand

and a lot of though people are not

practicing. I know them. They're

doing other things, they're teaching,

they're running hearing first, they're

danger great stuff in the field but

they're not available for

therapy so I think your job is finding

families who may not be a cert AVT but

inspection can be a valuable member of

that family's team. And we think an

audiologist should be able to support

that. So big question, how

much therapy does my child need to

appropriately spoken

language? Do you get that question?

How long should he go for therapy? We

hear it a lot and it's also an issue

that come up with insurance because

insurance has an arbitrary definition of

what it should be and they cut it off t.

Someone just agreed with me, exactly

right.

so what we did a few years, ago, one of

the things in your packet is the

position paper that our board sponsored

a few years seeing ago, it have

done by a group of certified therapists

in the field and it goes through what is

best practice in terms of providing a

child who is receiving a cochlear

implant with therapy to achieve their

listening outcomes. And just to

summarize on average children need one

to two one hour speech sessions per week

and when a child is delayeded and all

children are delayed at some level even

if they're implanted at nine months of

age they're going to be delayed nine

months, if they are 18 months old when

they get their cochlear implant

typically they need three years of

rehabilitation so there's a direct

relationship there and that's been how

long in studies in literature. And

after stimulation of the auditory corps

tech of the brain with the cochlear

implant there's urgency in getting that

rich and consistent auditory based

habilitation and time is really of the

seams so that rehabilitation for

children needed to happen really quickly.

Any questions or comments on

that?

>> Do you have any comments?

>> I do, I don't have a comment but I --

you nodded your head when Donna talked

about insurance, and I wondered if maybe

there was something that you did to help

get insurance to cover something when

they weren't? Hold on, wait. I'm coming

to you.

>> no, I work for Michigan EHDI so I

hear from parents because I'm the

follow-up consultant and the provider

of education so I kind of do a role

there. But I'm also administrator of

camp Williams for deaf and

hard-of-hearing kids and campers,

they're very delayed, they will inch

never catch up so they use sign language

but primarily because they could not get

those type of services there or the

cochleares were absent but the

[indiscernible] was was still pushing

spoken language, so there's some trauma,

but yeah insurance denice everything if

they can.

>> Request Rachel St. John is a

pediatrician, a developmental pelted

trigs where I live and one to have

things she talks about is always keeping

that get open so if one avenue isn't

working for your communication modality

making sure its stays open but I know

we're talking about spoken language here

but sometime it doesn't always do the

best for the child

>>> Thank you. Someone just told me I

was standing too close to the mic, so

tell me if I'm too loud. So I think

it's really important that parents know

that they have options and when I go on

some of these Facebook page for parentses,

parents don't realize that they have

the opportunity to choose the option

they want and select their own goals.

So one of your key roles as a

provider of services to families is to

let them understand is that and support

all those options without bias or

judgment. And not ever let someone say

this is what we offer S and I hear that

from families all the time that they've

been told wither provider often it's at

school, when they're looking for

specific accommodations at school this

is what we offer and that's not part of

the law, so really important. And how

many of you are familiar with that when

on in Los Angeles, the school district

there? So they passed a resolution in

Los Angeles in the school district that

basically says that all children in the

earlier intervention program would be

placed in an ASL

environment unless the family asked to

opted out so that actually is not in

bottom line with IDA and some of us have

tried to call them on it. It's actually

very difficult to argue with a school

district, and even the U.S. department

of education has to go through the state,

they don't work with local school

districts. But you may see some of that

coming up. There's been discussion of

it at this meeting and it's not

compliant with the law, so I'm just telling

yo to be aware of it. Let's talk about

tele-health and that was a topic that

came up at this meeting and it may be a

way that we can address some of these

difficulties of physical distance, and

we're not there with everything yet by

we are there with some aspects of it and

we are seeing that it's a viable option

for service delivery and COVID showed us

that, in a really well -- it was one of

the positive outcome of COVID. Some

clinics offer their via tele-health even

before COVID, U.N.c, university of North

Carolina's been doing for years ago

because they have families who lived in

the mountains three hours from Chapel

Hill and they still required those

families to have therapy once a week, so

they have been doing virtual therapy

forever, so it can overcome the

challenges of weekly therapy sessions

which we know are so important. It can

be very helpful even between in person

sessions and what those who provide it

say is that it's more reliable in terms

of attendance and being on time to

meetings and some schools for children,

your deaf and hard-of-hearing like the

option schools there's some actually

close by to here. There's three in St.

Louis. They provide tele-health therapy

to children who are both in or outside

the state so is that may be something

for you to think about if you can't

find someone to embroider provide they

were.

There was a presentation I believe it

was mortgaged by Arlene brown and

they did a study of in person can

tele-health they were and they had 70

children, they did this in Colorado and

guess what they found? There was no

difference in terms of the outcome.

They did this for six months with

children and what they found in that six

month period was both groups of children

on average improved their language

outcome by nine months so they did nine

months of progress in six months' time

which is the catch up we're looking for

and parents tented to be two hours away

and loved the fact they had that

opportunity. So that's another option

to be looking for. St. Joe's institute

for the deaf in St. Louis has a program

calmed I hear teletherapy and they work

with children zero to 18 using the try

actic approach, that is the therapist

and the parent and the child and they

find it work very well and it's

convenient for the families. The issue

is insurance, and this is something

we're working on organizationally but we

have to resolve that insurance part of

it but in some occasions there are ways

to take care of it and the early

intervention will pay for it.

Thetracy center which has been around

forever -- are you all familiar with the

is John Tracy they are center in Los

Angeles? They do virtual programs can

they do 12 therapy for families if

you're overseas and I don't know if they

do teletherapy for Michigan or wherever

you all are from. But I know St. Joe's

does so I think we'll see more of those

popping up. So want tele-health if

ever audiologist? It's complicated.

In fact the V.A. in New England used

materiel health programming for their

clients because there's one center in

new haven and then they are there are no

other V.A. that provide CI services in

New England other than that one center

so they use it routinely and they have

the audiologist who's in new haven and

then equipment in another center with

someone who can then hook the person up

to the mapping equipment. So the

problem with when we try to during COVID

and there were centers that tried it is

you have to ship the equipment to the

family and then they have to ship it

back, it's expensive and time consuming

and depending on the experience of the

family it may not work that well. So

we're looking at the V.A. program and

it's a service we believe may happen in

the future. And then troubleshooting

device and oh issues via tele-health,

this technology is complicated. I've

had mine 30 years but every time I

upgrade there's some aspect of the

technology that I can't figure out how

to pair with the processer, like blue

tooth I couldn't figure out

how to pair it so in this case all three

cochlear implant companies have taken

up the charge and troubleshooting is

something they will do and they're all

really good at it and they will do it

with a virtual, you make an appointment

and there's no charge, it takes the

burden after the clinic so that's

available for your child's

specific device. Yes?

>> Hearing aid company need to take this

advice and do this as well because so

many older people can't pair and they're

taking up the audiologist's time doing

that.

>> I used to work in adult -- I'm an

audiologist, I used to work this adult

ENT and that is the majority of my time

was experiment doing that and thenty

couldn't counsel on other things

that could benefit them, I don't want to

say more but I couldn't -- no, so that

was just -- you know goodness of the

heart, so . . .

>>> I'm going to bridge it to you but

I'm going to talk, so do you think

audiologist assistant that that could be

something that would talk about up that

time or something like that that it

doesn't take up the audiologist's time

but it addresses the issue that -- I'm

it addresses some of the issues that

they're having but maybe not the global

issue?

>> No, not sure with all the hearing

eight companies but I know

[indiscernible] they're very short and

simple, I don't know if they talk -- I

don't think the videos they talk, it's

very, this is what you do, they lay it

out and they're very slow about it so

everybody has time to see it so if

there's something specific, how do you

this hearing aid pair to something and

you might be able the find something

pretty simple. They've getting better

at it.

>> I know our center started doing

social stories also, Michelle had her

hand up and that's been helpful too

but anything that takes the words away

and good because you can use it for if

different languages.

>> I'm an audiologist as well and the

manufacturers do the calls but I think

when you get to a certain age they

don't want to call, they want a person

to prop thing so we get a lot of that.

>> Any other comments from the other

side of the room? We're going to make

you guys talk too, you know that,

right. I think it's also useful place

to go just in thinking about the

logistics of how you wear the technology.

And I see on the parent sites a lot of

times they ask questions about how do

you keep the processer on the head, shing

keeps taking off and so

they can provide help with that, and

even using the waterproof product as

knowledgeable as I am about the

waterproof people's republic the first

time I went to use it I put the batteries

in with addition disposable batteries

can as you all know they need

air and I got in the water to snorkel

and I didn't have any sound. It cults

off all the air so some of that kind of

stuff even a knowledgeable user can

really benefit from some help, so just a

little bit on connections to other

parents and we all know the talking to

other parents is critical and

hearing how they walk the walk, and

it comes up all the time as an unmet

need, I recently surveyed adults on

their perceptions of the cochlear

implant process and for people who had

some uncertainty about moving forward

or people who didn't move forward, the

number one thing that would have help

them was to talk to other adult

recipients. It came up time and time

again and I asked some of our clinicians

about whether they in fact use some of

the resources do exist. All three

companies have people -- they are

volunteers and a lot of the clinics are

hesitant to do that because what

happens is it becomes a branded

discussion and the clinicians don't want

that. So I think it's helpful just to

have parents around who have been

through the process like yourself who

can talk parents through that process.

& let them have a parent to parent

discussion some really part of the

information progression and it can also

happen through organizations, like Hands

and Voices which has chapters in 39

states, wow they're all over the place

and HE bell which has fewer

connections. HLL A is locally based

and thing primarily adults but some

chapters are parent sections and then

clinics need to step up to the plate and

provide parent sharing opportunities.

The early interventionists should

encouraging the clinics that you work

with to do that.

I think it's really important and

something we shown doing more. And the

online communities which I think are

great. They're really important and

it's a new speak of how we can supports

or community. Parents of children are

cochlear implants, how many of you have

been on that site? Couple hands. It's

fantastic, it's moderated by parents

who are very knowledgeable, very

equitable, and they keep the discussion

going in a very positive way. people

post questions, other parent respond.

It's a supportive environment with all

modalities represented. They've very

careful about that, they don't let

people get on a grand stand and say it

has to be this way or that way and it's

mostly from the U.S., and there are

16,000 members of that group so I'm a

big fan of it, I go on a lot and hang

questions. And there's families

of children with hearing loss and it's

a Facebook group. It's offered threw

through hearing first and they have 806

members and in this case only members

can see the posts and it's

staffed so it's different parents of

children with cochlear

implants so they have excellent staff

that answer questions and they offer

materials which they have developed

they're all electronic.

I've given you examples of some of their

print material askings and their

somebodies are by design Lisl focused

and LSS

0. They're both great consent to search

then one last topic that I wanted to

mention was something we don't talk

about very much. Which is parent

cognitive linguistic stimulation and

sensitivity and this is study that was

done ten years ago and what debt did was

take a look at 188 children and looking

at how the mom reacted -- interacted I

should say with her child and they were

looking at whether maternal sensitivity

impacted or language learning,

cognition and social developments, and

they founder that it did and that sensitivity

was measure and videotaped with

children and they were looking for warmth

and he motional support of a child and

children with nurturing mothers

developed language faster with shorter

time to catch up to hearing peer so it

suggested is that should be part of

parent training and it something that we

may not be thinking about very much but

it was a factor this the study that

probably we need to pay more attention

to. So can you teach it? Actually,

this is something that's been looked at

outside of hearing loss and there's

actually when I went online to look at

it there's quite a bit that's written

about it and sensitive parenting is a

associated in general with improved

cognitive outcomes in children and using

praise, teaching children problem solving,

encouraging feeling words and providing

rewards, settling limits and using

logical consequences, this is just good

parenting but it's something we also

find is tied to outcomes with children

with hearing loss. I'm done. We can

stop and have any questions or just on

things that you think need to be inserted

at this point. Anything you want to

add.

>> Over to you.

>> Thank you. So the good thing is

Donna and I are about the same height so

I don't have to change the mic, normally

I'm turning it way down. So as Donna

said I'm a associate professor at

university of Texas at Dallas, I've been

in this field in this area for over 20

years which closer to 25 but we're just

not going to talk about that part of it.

And what I want to do is talk about the

research so you know why we're doing

what we're down. So I'm going to

talk about it, like I said I'm a

profession so for me it's about what

does the research say so I want to do

that part, and then we're going to have

some interaction here so we have some

lovely colors and we're going to pull

from you as far as what you're seeing

too.

What did you have to do to make this

work? So if we think about age

device fitting we're all in EHDI so last

the mantra of EHDI? Why do we do what

we do? Last the effect of age on

outcomes?

>> earlier is getter right, and

that stems from a study in nobody 98 and

I so vividly remember when this came

out because it was such a big deal, it

came out in the journal of pediatrics so

all the pediatricians saw this and what

she showed was that if children receive

their devices bisections months of age

that and they were involved in early

intervention that their outcomes, their

language outcomes at four years of age

was signal significantly better so that

was -- so they had to be identified and

facility and they had the higher

developmental function and it was across

everything, it didn't matter if maternal

education, socioeconomic status, like

all the doctors, you can tell for all

the parents it was the age and

identifies that was such a big deal and

that's when new born hearing screening

started to take off in places

outside of Rhode Island and Colorado.

So I just want to go through what the

data looked like on the age of device

fitting across the four different

parameters. And I'm going to do this so

my field I've been studying cochlear

implant, the whole time that identify

been doing research but I want to talk

about hearing aids too bass I think

we work with kids who either have hearing

aids or cochlear implant or maybe they

have both so I was talking to sunny and

I can't -- I want your name to be Laura

but I don't remember.

>> Lori.

>> And it would have been things we're

trying to get away from is a cochlear

implant audiologist and a hearing aid

audiologist that we're just audiologistings

and we need to work with both. So

before I show you the data what do you

think the data show for age at hearing

aid fitting on out comes, like on

language, on speech recognition outcomes?

What do you think that says? For hearing

aid fitting? Because I was shocked and

I reach you had out to my friends who

work with hearing aid asks there's no

studies is that say the earlier

you're fit with a hearing aid the better

your speech recognition out comes. I

know! I have the same look on my face

so I reach out to Beth walker and I'm

texting different people and I'm

like do you have any articles that show

this? Because I think everyone assumes

is that we're fitting them and but this

is what we assume, we assume the earlier

the fit the better the speech

recognition but they're actually -- the

fact that Beth and Ryan don't know a

study that shows this I was floored. I

was floored. I don't hide things very

well but there's not an actual study but

we assume that it's true, right? Were

cochlear implant we do have data so Sean

knee debt man in Australia has done this

study so it's a lot on the slide, I'm

hoping there's something I can do to

point. I'm going to walk you through

this. So on the l it's cart

entry and then oen the left is early

high school and so across the bod Tom

it's the different stimuli so we have

phonemings on the right and open

set speech recognition out come on the Y

axis and you can see there's for each

group there's five different categories

and if you look at the bottom, then you

can see what the groups are, so group

one was implanted -- that should be less

than 12 months and then we have 13 to 18

month, they were implanted, 19 to 24est

252042 and 43 toe seven to so basically

the kids who were implanted youngsest

are on the far left and the kids

who were implanted older is are the on

the far right so what Shawnee shows

was that at school entry can

kids who were I believe planted by

anticipate months had significantly

better outcomes for speech recognition

so this is just speech recognition only.

When we get to late primary and early

high school it's the kids who are

implanted by age two had significantly

better speech recognition out comes than

the ones implanted after two, so this --

I like data so I like that we have data

that shows early is boat better

for speech recognition, if we look at

speech production, this is a study where

they had kids who were implanted and --

not implanted, this is hearing aid

data so they forker with fit by six

months or fit after since months ago

what is on the right side of that figure

and they tested this many them at age

two and they one thing

they showed was that vowel production

was boater than consonant production.

Are there any SLPs out there.

Yeah I'm not one but I want to be one so

my early research was speech and

language, and a lot of my research has

to do with the the and part so I fit

everywhere and nowhere at the same time.

But for speech production, so vowels are

more accurate than consonances but the

things they found, on this one I told

you it's on the punishes acquisition, on

the Y axis that's the percent of

consonants correct. And what Sophie and

her group found was that children who

had their hearing aids fit by six months

had significantly better speech

production than those fit after six

months and I put other things up there

that they found, the degree of hearing

matters so those who are on the mild

side had better consonant and vowel

production than those with greater

degree of hearing loss and if they had

stronger vocabulary scores and if they

were female some. So this is something

that keeps coming up, if they have the

access to sound so better speech

recognition, they're going to have

better vocabulary. So from an

audiological perspective if they have

better vocabulary they're going to be

better able to guess on the speech

recognition tests so it goes both ways.

If we look at age of cochlear implant

fitting these are data from the

childhood duodenum after implantation

study so we have time post

implant on the X axis and then we have

the percentst of articulation scores

so consonants because vowels are the

redheaded stepchild for speech

production so did I they have scores

within the normative range, so

greater than 85. And so what this is

showing is that age of cochlear implant

fitting the kid who

were fitted before anticipate months of

aim had a higher proportion of kids

within the normative range compared to

the kitsst whomp ownership planted

between 18 and 36 most and we have

vowels, consonants and word

intelligibility and here's we're

looking at the principal correct what

they found here is implantation by 12

months that that group had significantly

better out comes than any of the

other groups. If we look at language

and if effective hearing aid fitting on

language this is a study on the left

that is really just showing I like this

because it shows age of amplification so

you can see there are different

rages ranges so what's the difference

between if they were fit with hearing

aids -- each having so much trouble

talking about hearing eights, if they

were fit with hearing aids by three

month versus six months who is the

expected difference in their outcomes

for lam, so what we can see here so you

see three versus six and it's

prerogative after that and we can see

for in one there is a the significant

difference especially for 24 -- if they

were fit at to four versus three months

ago you can see actually an 11-point

additional in their language scores just

based on able at fitting alone. .

>> [indiscernible] for this one if I

remember right when we take a break I

will look it up because I have the

article here with me and I'm just blanking

but this is another study and I think

this pulls it together in a different

way so even though I don't know the

exact age for that one on the right it

showses the effect decreases over timement

so you see a bigger difference. Is

this what you were asking.

>> [indiscernible] I was just thinking

if you test them at three years of age

your obviously going to see a difference

but at ten years of age it might squish.

>> Yes, it does squish, you're right.

That's a very technical term but you're

right. I'm switching Meyers. You're

spot on because it's an interaction

between when they were fit and how long

they have had it and their cob

chronological age so you're right that

you see a bigger difference -- is huger

is a word? You see a bigger difference

with able and by the time they get to

the chronological age of six you're seeing

a smaller difference based on age at

hearing aid fitting.

I'm not going to go through all the of

these but this is what we see -- oh, I'm

sorry. It is the other side of the room.

I'm going to make you tell us your name.

>> I'm Tracy. I'm an outside

audiologist and speech that apologize

and I had a question if there was a

variable for wear time. Were those kids

kicked out?

Because I know there is some data where

time was -- for wear time but I don't

know if they take in the variables when

they were fit.

>> Yes, and I have some of that boys

town data later so Mo of the studies

were done before they were really

looking at or they were asking the

parents if they -- how much does your

child wear the device which is also

problematic [indiscernible]. Really we

mean well but sometimes we

overestimate what our children can do.

What does that -- so parents

overestimate how much their child uses

the device by an average of two hours

and up to ten hours there was one parent

who said their child was wearing it ten

hours more than they were when you

compare it to data logging so some of

the studies weren't necessarily doing

that. I think that's something people

are bringing a lot more and they do it

in different ways so you can do it by

told number of hours and you can do

parent report versus data logging and

there's a new paper that is looking at

auditory dosage in a different way so

there are different ways you can look at

it but a lot of these didn't aaccommodate that but I think

that's -- they're starting to analyze

the data in that different way which

make a huge difference.

>> So I think what I'm hearing you say

is for this study that wasn't considered?

It was just onset of able of

fitting?

>> So this is just showing age of

fitting but that wasn't the focus of

these. Anyone else

from this side? For this --

this is all on age of implantation and

the effect on language and all these are

showing that earlier -- so it doesn't

matter when you look -- and it's higher

[indiscernible] so better language if

you're fit earlier, you can see that in

the table in the middle that's organiz

ed the same way this one was with age of

amplification, if they're implanted at

24 months versus six months and if you

look at the one with the gold orange

color those are kids who are implanted

between 18 and 24 months or after that

you can see that you have a steeper

trajectory and just showing they're growing

at a faster rate and

those five studies were all showing

that implantation by 12 months of age

yields significantly better language

outcome on average for these kids so

that's something that's consistent

across all of theseT one on the bottom

left is a plastic study for childhood

development after cochlear implant and

we didn't have tons of kidst who were

implanted before 12 months in that study

but all the other ones are

showing earlier implantation is

definitely better for language. And

then I want to focus on this article,

this is the one by Cal Torp and this is

one that they reported is it's not just

implantation by 12 months but actually

nine months so it was a big deal when

this one came out really showing if

they're implanted especially before

12 -- whether it's the five to eight

month or nine to 11 month rain that they

were able to get language score within

the northerly rain so age equivalent

similar to their typical hearing peers.

If we take a look at psychological

well-being, so this is one of my swelted

spots, are you raising your hand our

just stretching? Now etch knows

that your stretching so quality of life

does not as far as what I found and

across the literature does not

necessarily seem to be affected by age

of implantation but that might be

because all the kids in our study were

implanted -- we didn't have anyone who

was inlanded super late so on average

it's about three for the kids who have

been in all of my studies they've been

implanted on a an average of

three but we've only had a handful

that are implanted late and so that

doesn't seem to make a difference. We

do show that so this is showing age at

implantation in years and you can see

the resilience so you can see that there

is a anesthetic relationship between

when they got implanted and how

resilient they are, that may be -- but

it's not a super strong correlation.

And but what we assuming is that they're

going to get me fit with is it the

technology earlier, they have better

speech recognition which means they're

going to have better quality of life

because they can interact with people.

We all know what they do in the booth as

far as speech recognition or formal

language testing doesn't necessarily

translate into the real world but that

is what we want -- we want to believe

that this is the nice stair step and it

goes in that direction but we don't

know how able of implantation affects

that. So this is a summary of what I

said; and I'm going to say across the

top three and quality of life

we're going to assume that's going to

come at some point. So any comments,

questions about this part? And then I'm

going to ask you to participate

willingly.

I'm going to get some water..I do want

to touch on one more thing, surgical

risk, is it safe to implant children

younger than 12 months of age? And the

answer is yes, so as far as the rate of

complications, we don't see a huge

difference in the rate of complications

where they were older or younger than 12

months of age. I just pulled data

across a couple different studies and

they're showing the same thing. These

are all studies that have been publish

ed in the last couple years and these

are the percentage of surgical

complications on the Y axis so you can

see this macs out at ten can & these are

kids 'em planted before nine months or

nine to 11 months and then here this is

less than 12 months and greater than 12

months so these are clearly the two

different studies and you can see

that younger than 12 months you see a

higher rate, not significantly higher of

CSF leaks but everything else is pretty

low and there's been no statistically

significant difference whether they're

implanted backward nine months

or after nine months or.

12 months or after 12 months, so just so

you know it's safe customer service a

big question.

>> I that you want the FDA didn't

approve of the surgery before 12 months.

>> That is a good questions and so the

able of implantation was stuck at 12

months for a really long time, like 30

years and it just got lowered for

cochlea to nine months ago in March of

2020 so right when the pandemic was hitting

that's when they were like, hey we can

implant kids younger than nine months so

I know that there were a lot of senate

hearings where people were hoping

that it was going to reduce it to six

months because there's a lot of data out

there so there's FDA criteria, and then

there's what's getting done in the

clinic but like FDA criteria only

applies to the states so the articles --

there's a lot of research going on in

Europe and Australia and around the

world where they don't have that imlimitation

so they can get implanted younger.

It's safe which is why we do these studies,

but that's why these studies are done

is to show safety and efficacy for this

and to show that we can show like, we

are getting better outcome if they're

implanted earlier so that's a really

good question and right now it's

considered off label but it doesn't mean

it's off the table to do it. That was

kind of rhyming and I didn't mean it

>>> One other aspect of that is if

there's a reason for a child to be

implanted before nine months, for

example if they have meningitis and the

clinical team wants to be sure that they

can get a full insertion you can do

what's called an off label surgery and

typically underage will approval it and

it can move forward and even if there isn't

a specific reason some clinics are able

to get insurance to approve it.

The FDA is guideline it's not an

absolute and the reality is insurance

often looks at the FDA so that's an

issue that we have but many clinics the

do what they think is the right thing to

do clinically and if t strong relationships with

nursers then get it moved

forward. In some statest Medicaid

wouldn't even talk to the clinic until

the child was -- it used to be 12

months, you couldn't start the process

until the child was 12 months old so is

that meant the child would be 18 months

old before they were able to get their C

I and Andrea showed you the huge

additional so some of us argue let's get

it earlier. It's safe the surgeon is

always going to look at how much the

child weighs and because that's often a

factor so important to realize that's a

guideline, it's not an absolute. The

time is when it's absolute is under

Medicare but that doesn't apply to our

kids. Medicare won't budge on that and

they don't preapprove so clinics don't

go do CM S before hand of.

>> I thought I had this up there. So

yeah no significant difference before

versus after 12 months.

So now we're going to play a game. And

the game is and which factors do you

think influence spoken language outcomes,

whether they have hearing eights or

cochlear implants? I'm going to write

them on this lovely board. I'll try to

use my best first grade handwriting like

my mom taught me. So what do you think

matters?.you cheated from Tracy. Just

kidding.

>> Therapy, is that what I heard? The

appropriateness of the fitting..can you

repeat them all on the mic?

>> I was going to ask that you repeat

them all on the Mike.

>> Yes, so right knew we have parent

education, device use, quantity and

qualities of language input. Therapy or

intervention. Appropriateness of fitting.

Michelle? What age. What do you mean?

Like chronological age? That's a

catchall, isn't it?

>> I was going to add conversation turn

taking. I know she has quality and

quantity of language but what if it's a

TV or somebody just keeps talking at the

kid and doesn't allow them to interact?

>> Quality input.

>> Okay, so for cart we just added age,

like chronologic age and age at fitting

and then conversation can turn taking

.

>> Collaboration and communication

between the professionals,

all of a them and the parents. So maybe

speech sees a problem but that

information needs to be shared

with audiology or the parents have a

piece of the puzzle but they're not

sharing it with speech so that

collaboration among all the members.

>> It kind of goes with that -- I was

just going to say carryover of therapy

in the home, so therapy techniquings in

the home.

>> Anybody else?

>> Did cart get the last two? So we're

going to -- so I have some of these. So

that means we get to talk about

more. So I'm going to show you what I

have. I feel like also you might and

then you can show me yours so we're

going to talk about some -- what we have

data for but all of these are super

important and so we want to make sure we

can talk about these too. That's why I

like doing this. So child related

variables one is degree of hearing

access so you can -- if you just

look at the degrees, so this is a study

by Bruce Tomlin and Beth about walker

so this is showing the language score is

this is relative to spoken language, so

I want to point that out it's relative

to spoken language so we have sad

standard score here, so there's a mean

of 100 and the standard deviation of 15

and then we have four different groups

here. I'm so happy that I know this

curser works and you can see what I'm

looking at. So we have typical hearing

on the far left and mild, moderate and

moderate severe and they tested them.

There's two different box plots here so

you can see this is when they were

tested in second grade and this is when

they were tested in fourth grade and

what they found is there's a significant

defense that even though mild and

moderate didn't differ from each other

and didn't necessarily from someone with

typical hearing in children to have same

age but the children who had moderate to

severe hearing loss had significantly

poorer language skills compared to any

other groups.

And this is a isn't it true stud

by Katherine wiseman so this is also

looking at better ear tone average and

so they pull grammar, morphology

and vocabulary if I remember off the top

of my head but they but put them all

together so they had one score for

language and so instead of using 85 as

a cutoff so 15 for standard deviation

they looked at the group of children

with typical hearing because they wanted

to compare them and the reason this dotted

line here is showing I think it's

92 or 93 is that was the average of

their typical hearing group so that's

who they're caring to and what they

wanted to know is what is the level at

which the children where it crossings

the line where maybe they're going to be

below that normative range compared to

their hearing peers, so we're looking

for the place where this dark blue line

crosses this little dotted line

horizontally and that's here and what

they found is children are hearing

losed that significantly poorer outcomes

on language than those who had hearing

levels better than 65. Other things is

etiology, so what those with genetic

meaning connects in 26 they tend to do

better than those who have anatomical

malformation, so not surprising if

there's a cochlea malformation and they

complaint get the device all the way in

or this there's any call as I have

occasion, or maybe it's a common cavity

so this I love this little drawing here

so maybe they don't have all of the coils

of the cochlea or they have a common

cavity so there are challengings with

that anding macing sure your getting the

best stimulation from the cochlear

implant to the auditory nerve. If they

have

additional disabilities we know they

tends to develop slower, they tent to

plateau at at a lower rate andless

predictable out come so we have a lot

more varyingty in out comes. I like

this part at the bottom because maybe

that means spoken language maintenance

be the goal so keeping in mind which are

things we can look for that's showing

progress that may not necessarily be

spoken language, so maybe more

environmental awareness, more social

engagement. Better qualities of life

both for the kid and for the

parent. It's not the town of this study

but if anyone wants to talk about that

that's one of my favorite things to talk

about, actually so I feel like spoken

language is not necessarily going to be

the goal for every single child. I

know that's the focus of this talk but

we can talk about that later. So this

also goes with is it degree of hearing

but the residual hearing if they're

going to get an implant but here if they

have better residual hearing you can see

-- so the table here is from Lisa

Davidson's work from 2019 and they show

that every 20 D B increase in hearing

threshold you see a decrease

on their scores on language development

skills so this is showing significant

outcome that they're doing poorer if

their preoperative hearing is less and

this study found that children who had

more residual hearing actually made faster

progress.

They did not have that cheetah in

their article, and mater

education. I'm hoping that it's alls

about maternal education, we're linking

that to socioeconomic statute of

limitations, my goal is to change it's

not always on the moms because

sometimes when I raid that there's more

to it than the moms but higher maternal

education we see better spoken language

outcomes but I think paternal education

or maybe we just call it parental

education so we can focus on both of

them.

That's a me thing and I believe I'm telling

you how I feel about everything and

that's how I feel about maternal

education. Parental involvement and

this was hit on with the collaborative

approach, the parental involvement

actually accounts for a significant

amount ovarianty in the data, so this

one is looking at verbal reasoning so

this is is from Mary palleted muller's

article but that family involvement has

a significant impacts and I think you --

tell me what do you see? Do you see a

difference? Your clinics? Can you tell

me something about that? Because I'm

showing you a table but I bet you've

real stories. Lori is going to

begrudgingly tell us something.

>> So I see a wide range of families

and so the ones that you can tell that

tell you that the child is sitting and

watching tableteds and their phone and

that you can tell they're not really getting

that interaction at home versus the

ones that they're talking to the child

and that are following my advice as far

as just wear the clip, narrate that

you're washing the dishes, it doesn't

matter the child just needs to hear

what's going to be on and being exposed

all the time and you can tell those kids

do better.

>> Anyone else?

>> Anybody else?

>> I agree, I see that full range photo

too and when you see families and bring

grandparents to the appointment, so

they're trying to advocate beyond their

family and again everyone on the same

page and that's just great but I also

see the ones that do little to nothing.

>> It's hard to capture. We can sigh it

in the clinic, I'll tell you from a

research perspective it's difficult to

capture that but I think it makes a big

difference. I do want to talk about

conversation turn taking and quality

and quantity of last thing input so this

is a classic study by hart and Ridley,

these kids doughnuts have hearing loss

but this was a study that really looked

at how old the child was so a

longitudinal study so this is from tone

ten to 36 months and this is the number

of -- so when the study first came out,

children in working class families in

green and children in welfare family we

didn't -- that's a horrible

term, but in red so when it first came

out this is all about socioeconomics but

if you look at it and look at the deet

it's really about ownership put versus

out put so what they found is that the

ones in the blue -- I'm going to call

them the blue group, there was a lot

more input from the parents so there

was a lot more going on and compared to

the children in the red group so it's

input versus output so how much they're

getting in related to how much the

children say and this is from about ten

years ago and these are children who are

deaf and hard-of-hearing and some of

them were Savannahish so the ones in

Spanish are the two on the left and the

two on the right for each of these

figures are for English speaking

or English learning so they looked at

adult input and they looked at child out

put and one thing they founder was that

English language variants they terror

alerted to talk more than in the

Spanish language environmentings but

it's not about that, it's really how

much they talk, the parents are talking

is influencerring how much the children

are putting out and how much they're

learning for their vocalizing and their

later language. And somebody said

conversation and turn the taking with I

remember when Christie presented this

data at ASHA she said they were putting

devices on the kids and looking toss

hosepipe put they were getting and

remember she had this one family and she

would use this as a counseling tool, if

you talk more, dense just put them in

front of a TV but the more why talk to a

child the more language they're going to

get and the better outcomes they're

going to have but then there was this

one family and it was like off the chart

for how much the parent was

talking, it was such an outlier it

didn't fit on the chart. Why

would that be a bad thing? There's no

turn taking. That parent talked all

the time, which is great but there's no

turn taking and on the flip side the

mom would wear the baby in the sling but

she was working all the time so she

didn't talk to the baby, so it's a gay

way to use counseling tools and be res

gestae so now we can look at adult input

and child output and you can capture that and realize

that children who are deaf and

hard-of-hearing may need more time to

respond and more time to progression.

One other thing they found this this

study is that children with who are deaf

and hard-of-hearing might need super

language environments to help them, so

just what you were saying, like talking

more, talking through your thoughts and

they talked about that, I know yesterday

in some of the sessions and making sure

you're opening up different worlds to

them and really explaining things a

little bit more. One other family

related variable is appointment

adherence, so -- well you guys talked

about people coming in all the time

but sometime they don't come in and

when they don't come we're seeing basic

effects on open settle recognition and

phoneme voice and this is just looking

it would language score or the percent

correct, it doesn't really matter what's

ton Y acquisition, the point of this

figure is 20 to show that we're

seeing significantly better out comes in

the families who are attending the

sessions versus those who do not and

there are different

reasons that maybe they can't go in that

they can't come into the appointment, so

12 therapy is something that help agency

lot and the families when they can't

come in I'm going to say they can't come

in, sometimes there are other

things going on in the families and

those the families that don't come in

tend to be -- it's more likely to happen

if there are other comorbidities going

on that they need to take care of. So

thousand now todayly device use so here

this is showing different ways that we

can look at it so this is what I was

talking about we can look at mean hours

per day so you can ask the parent or do

date logging -- I've happy the share the

slides so parentings tent to

overestimate and compare a parent report

to data logging. You can look at hearing

hour percentage and this is someone

that take into account how much the

child is sleeping so for kids that's a

nice way to do it.

Auditory dosessage; takes thing in

different ways so how much is the

childbearing the device, this is

something that Katherine wiseman published

on the article that I showed you with

the blue line; this was her study is and

what they did is they said how much is a

child wearing the device so how many

hours per day using data logging and

they the took that and multiplied it by

the eighted SII and then they also

added how much time was a child not

wearing the device and multipled that

by their unsaid aided S II, so

I haven't seen that and I guess if you

had an implant that would be

nothing, but these are the three ways

that people are using to look at how

much they're wearing the device. This

is just to show you out comes of the

study that Catherine wiseman and I

published a couple years ago so on this

one the X axis goes from zero to 14

hours and this is the speech recognition

on the far left andexpressive

language in the middle and I want to

point out that the of circles are all

children who have no additional the

disabilities and the the ones in the

filled markers have additional

disabilities so if we look at speech

recognition we have parent report in the

middle and we can see the

correlation the more likely they're to

get into closed set and open

set if they wear the device more. So

for children with no disabilities we

see a nice correlation here that that

are more likely to get into normative range and same

thing with receptive language. And I

want to put this in there, so we talk

about mode of communication and we

all know the best mode of communication

satellite one that works best for that

child and that family so this shows

there's a range, this was an article

that builted on the childhood

development after cochlear implant study

is this is a studies that came out a

couple years ago and I don't think this

first thing was figure but published in

the paper but the gist is we have three

groups so one group -- I just lost my

mouse.

There it is so this group here are

children who did not sign either before

or after they got their implant. The

group in the middle had short-term sign

meaning they signed before but stopped

signing other 'em plant and the ones in

the dark blue are ones who continued to

sign post implant so here's we're

looking at standard scores and their

spoken language and reading comp

helpings and then we have early

elementary and late elementary and so in

the paper it talks about

we saw significant differences and we

were extremely conservative and accounted

for all different variablings to make

sure that what we were seeing was really

accurate so if we're looking at spoken

language we're still seeing a

significant dig in late elementary on

responsibly language teen the group who

didn't stein and the group who continued

to sign after two years post implantment

there are reasons for that, that one of

it is they have more access to sound and

so they are doing better and they have

better spoken language. You could also

argue the children are continuing to

sign because they weren't developing

spoken language as they should and mak

ing that progress so they're continuing

to sign because that's the way that they

can communicate, but the data do show if

they don't sign, they didn't sign before

or afterthe implant they have

significantly better spoken language

outcomes. And there have been studies

by Lonna Percy Smith and she looked at

auditory verbal therapy and somebody

talked about therapeutic intervention

and they did Lonna did a study looking

at auditory verbal therapy so not

necessarily focused on AVT principlings

and found a significant difference on

both general language and vocabulary

measures. So this is just a summary of

what I just said so better hearing

access, genetic etiology and no addicts

are associated with better spoken

language outcomes, higher maternal

education, more pandemic involvement and

input and turn taking, like I said I

don't have that in here and if they

come to appointments and the

wearing the device and communication

mode. So any feedback,

question you have on that? Is any of

this surprising?

>> Think some of it is voic

surprising to me because hearing

children who learn sign language

actually talk faster than hear, children

who don't so I would assume we would

have saw that with your whatever or deaf

children too but you're not so that was

surprising to me.

>> I don't -- so I know -- I mean, I

sign to my children when I was little --

I was little and so were they and but

when they were young, but I think part

of it also has to do with what does that

language environment look like. So if

we think about who -- if we think about

the 90 to 95 percent of kids who get

cochlear implant are kids hard-of-hearing I can

Lubin it to -- it would be like me

trying to teach my if congressmen

Spanish, so maybe they aren't getting a

pollutant representation of what that

language is, do you know what I mean??

>> I do agree with that and I see older

children who have implants and they're

forested to do sign language and some of

the kids got cochlear implants that

should have never gotten them. They

weren't in the state of Michigan, but

one kit had absent cochlea and they're

just dangling in their held and she's

getting some environmental sound but

obviously no speech so that's just

surprises me that they would even do

that and we're appalled here.

>> So if they have a cochlea and they're

-- if they have a cochlea to put it in

even if the auditory nerve if there's

cochlea nerve deficiency but if then see

Al shred of a nerve they think they

might be able to get something, and

sometime you current see it on imaging,

so sometimes you're just -- you know

sometime they'll do that because --

>> Right. And I don't think auditory

brain stem was available when delay did

that and then when the parent went to at

look at it if she's getting something

like that we wouldn't encourage another

surgery.

And kind of off topic, I have a home

birth mom that was struggling and found

out her daughter was deaf and the

parents are hearing and during research

and home birth moll was terrified to

make that decision for her daughter to

have that cochlear implant but when the

imagery came back the cochlea mall

formed she was not a candidate the

mom was so relieved she didn't have to

make that decision and I

think a lot of parents struggle with

that and they're implanting later

>>> There are so many nuances.

>> I have a question for the group do

you ever find a parent doesn't want to

go forward with a cochlear implant

because the child has some residual hearing

?

>> Yeah, it's a a really common factor

in adults. And in fact for adults

that don't move forward with a C I when

they're a good candidate that's a

reason, they're fearful about losing

their residual hearing I think the thing

to demonstrate to them is the data that

Andrea showed you is that the kids with

more residual hearing who are still

candidatings are going to do better

than if we wait until they progress and

have less there to work with, so there's

a challenge I know with the population.

>> So I have a lot of families where the

child will have access to some sound but

not speech sound, so the family's he is

tenant to move forward with the cochlear

implant because the child can hear, they

tell me they hear me, they react to me

they're Funchal fine and that's when encourage to have the

conversation to find out what XYZ to

speech sounds they have with professionals

and parents to figure out what is next

step.

>> I think I just paid you to say that

because that's what's next.

I think I have a stress ball that I got

yesterday, so I wanted to go over what

candidacy determination looks

like, so hearing aids are the first

thing we usually try by but sometimes

hearing aids don't provide enough access

so what we have fallen into is this

failure based approach can we're waiting

for them to fail with the hear aids

before we say cochlear implants can help

you so thinking about this as a

continuum so that's what I want to

show you a nice easy scheme attic, but

you can hear me talking to you but you

don't necessarily have access

to all the speech sounds you need, so

this is what we used for cochlear

implant candidacy so we looked at the

data and what we came up so it was me,

Kristin Mueller in Colorado and Denise

Thomas who's an audiologist and Tom

Rolland who's -- I'm saying it that

way for a reason, if there's audio meltic

thresholds equal or greater to 70 DBHL

and/or and Donna is my Vanna white, you

have one of these, and/or their word

recognition scores are less than or

equal to 50 percent so this is not FDA

criteria, so words recognition,

less than or equal to 50 percent and/or

they have poor function Nam performance,

limited progress, and/or poor quality of life. That

doesn't mean they're going to walk into

the door and we're like we're inserting

an implant but those are kids who one

candidates. And

there are caveats and so there's a paper

that sited if their aided Sii is

less or equal to.sick eight

maybe we need to roll

that in because that tells us what they

have access to for speech sounds. So

does everyone understand what SA I does?

So I feel like this -- I'm writing a

little piece for ASHA leader and

that's something we're going to put into

that piece. And Lisa Davidson published

a paper in 2019 and she was looking toss

when the transition from bimodal so if

they have a cochlear implant on one side

and hearing aid on another when is I

would it time to transition to bilateral

so if their urn aided PTA is --

they had better segmental perception so

being able to understand consonantings

and voice mails but if they're unaided

PTA on a hearing aid ear was about 111

no question they had better boast

segmental and super segmental perception

if they had bilateral implants. The

other one is we were trained they that

need to have bilateral severe to

profound hearing loss but that's not the

case anymore, there's a lot with single

sided deafness so I want to

encourage you to evaluates each year

individually and I'm hoping that

we can figure out a way to do that here

but consider each ear individually

.

And this is what Donna was showing so

you have its but this is some guidelines

for bilateral or more traditional

implantation for kids and this is the

one for single sided deafness and here

are just some resources so I just wanted

to look toss what had resources for

parents who had resources for

professionals and only this one, that

make me sad the M and an orphan but the

resources for teachers that was the only

one that I saw that had specific

resources for -- yep for teachers.

And that's actually my last slide so I

don't have any more presentation wise

but what did we not -- so we got -- I

just want to go back to our list.

Parent education, device use, quality

and quantity and we got appropriate

therapy intervention, chronologic age, I

think we hit the age factors,

conversation turn taking, yes,

collaborative approach, assumer

important for everybody to talk about

and I think that's when they're more

successful. I didn't really --

appropriateness of fitting I think I was

trying to get to this and

carryover of techniques in the

home.

>> The one we missed was level of hearing

loss.

>> Yes and it's true whether they're a

hearing aid or implant candidate so I

think that is nice work emerging from

the OCAL study the out comes with

children with hearing loss, ORHL.org,

if you NIH OCHL and hearing loss it

will come up but they have a lot of nice

info graphics so they have work coming

out of that one too. Anything else that

we missed? I'll let Donna do -- the.

>> Just wanted to expand on parent

education, parents think once they have

the surgery and the acts Vegas is

completed they're done, the child is

good to go, no problems, they can hear

just like anybody else so I encourage

families to understand that it's a

lifelong journey in supporting spoken

language, so my daughter is nine and

she's consider as success because she

does so well with spoken language but I

still see things we need to work on to

keep her articulation clear, she's taking

care of the devices he'sst

herself is it's a lifelong journey.

>> I was just going to add to that and

also she's going to go through the

changes that typically hearing children

go through. And that's going to affect

her hearing journey as

well. They relate to one another so

that's a really point

you brought up.

>> I was going to say that's true for

the kids as well as the adult because I

growing up thought my hearing was equal

to that of my peers and it was not

until physics class in high school and

he lad had this machine and he was testing

how high everybody could hear and the

teacher didn't believe one kid and he

heard it every time and one kid that

could hear 22 but every kid could hear

by 19, and he went down to 18, 15 and he

got down to 12 and he goes do want me to

continue and I was like yeah because I

won'ted know where I can hear and he got

all the way down to seven before I could

hear I would and back then -- now these

hearing aids are just a year old and I'm

these are finally better and I think

these go up to ten, so we need to tell

our kids -- because I was mainstream too

so I had nobody to tell me this stuff

>>> I found it very interesting that I'm

not sure your name, mom, but I thought

it was interesting that you commented

that you were noticing she sounds great

but there's still things that you notice

and I work in a capacity where I have to

work with the schools and I provide

contracted educational audioI

don't go services so the school staff a

lot of times will meet this kid and they

sound wonderful and you talk to them and

their conversational skills are

phenomenal and I tell parent all the

time when you read my report doughnuts

be offended because I'm trying the pull

out the more advanced nuances of

language that they're still going to

struggle with especially as they get old

er and you might not hear it

conversationally but it's going to I

remember pact how they access the

language in the classroom, the peer

interaction, self-advocacy so I think

that's really important that you're

aware of that as a mom. Because I have

to kind of point that out to school

professionals a lot of times as well.

>> That's actually where I was going to

go with this is we see we get their

vocabulary up to a point so like

kindergarten they're like spot on,

everything is great and a lot of the kids

stop services and then we're seeing

them come back I'd like teen and because

they're missing some of the more

advanced language skills, nonliteral

language, pragmatics, so

making sure you have that conversation

is important but a lot of kids are coming

back into speech therapy but for those

reasons everything looks so pretty but

you have to make sure they now how to

use that in the real world too. All

really good things. You said something

else.

My brain is about dead gyre I wantedded

to add that I'm so glad the school team

is looking for those gaps in

communication because that hand been my

experiencer they look at my daughter

and they say she does better than her

hearing peers and I have to remind them

she's a deaf child who uses CIs, it's a

medical device, it's not changing her

hearing level without it being

functional and the teacher doing their

part with the FM. So I have to remind

them that our kids are still deaf but

they have the wonderful device that helps

them.

>> Any other -- we have two minutes left

I'm being informed. Does anyone else

have anything they want to say.

>> We didn't talk about self-advocacy

skills. There was a really great

lunchtime talk the first day by Kerry

spanninger who was here and

show was up implanted about five years

and she's a phenomenal individual. And

she did a whole talk on self-advocacy

skills which was wonderful and I think

we think we start doing that when

they're seven or eight. I think it has

to happen from the time you guy are

interacting with them so they recognize

that that's part of the equation from

the time they're little. So I think

that's something else we should add to

the mix.

>> I agree.

That is what I was thinking, and also

for them to -- if the hearing loss is

permanent. There are some kids in

middle school, am I going to out grow

this? So make a sure they understand

what their hearing loss and is getting

them involved the IEP. But

thank you so much, appreciate your

participation. This was real fun. So

thanks, have safe travels home.

>> I have one plug, we have Tuesday

talks, have you all seen those? They're

dined for parents and adults and we do

them once a month.

They're really good, they're free and

the one coming up is on what happens at

a CI candidacy evaluation, so

check them out, they're free and we

record them, so for people that have

missed them you can come back and catch

them. Some are just for parents. Some

are for both.

>>> Thank you so much.