>> You know how these conferences work

and you have a picture of what you're

going to have done, so this is one of

those camps. We thought we would be

further along in the project by the time

we got here. So this is what we are in

the process of doing, not what we've

already done. You're building the

 suspense, Karen.

So I'm Sarah and this is Karen didty and

we are both audiologists by training,

although we have had very different

trajectories in terms of our career.

Karen has been much more into the

clinical diagnostics, she does a lot of

work with enChan and my work is

focused on intervention and family

support. I'm sorry. Testing, testing.

One, two, three. Perfect. We did have

it set up but thank you. You can also

see that we are audiologists but we are

not coming from an audiology center, we

are coming from Texas Hands and Voices

which is a family based organization,

so even though our background's in

audiology I do have a parent

sticker on my tag, I'm a mom of two

deaf kids and we are coming at this

from the perspective of a family based

organization, so these are the objectives

 and these can still the same. So go

ahead and click, Karen. You can see how

the region is all highlighted there and

that's our focus. So as we go through

looking at the different individuals

that make up a region and how that guides

 the nature of supports they need and

also determines the kind of barriers

they encountser and as we start to think

about how we're going to provide support

we want the use a variety of data sources

 so inform our supports and we're also

going to go into some

assessment, because you're not going to

provide intervention unless you figure

out what those regions need. And a

little orientation to Texas, because

Texas is like whole different country,

it is about the size of France. We have

the second largest birthrate. We birth

nearly 400,000 babies a year and

269,000 square miles. Record levels of

immigration and that was the case before

things had started to shift and if

you've been watching the news you know

that we continue to have record levels

of immigration and a lot of those

families have babies. More than a

third of our children are on Medicaid.

We have the highest number of uninsured

families of any state. We have 1600

audiologists and is that sounds a like a

lot until you realize there are

30 million theme in Texas, and under

1600 that's not pediatric, so it's change for the point of diagnosis

with the babies born in 2020 we

lost 52 percent at diagnosis, and that

compares to the national average of

21 percent.

And 61 percent we lost at early

intervention compared to 16 percent

nationally so we've entered into a

partnership with the department of state

health services and as with any

partnership there's sort of a dance.

We're going to figure out where our

priorities are the same and where

they're different and as the state came

in what they were looking at is the

leveraging the resources that are

already on the ground but developing a

model of support that is

replicaable. We also wanted this to be

sustainable so we didn't want to provide

training and then exit, we wanted to

develop robust micronetworks and we wanted

 to think about what our best practices

so not to think about let's do it the

way we've always done but

what's working now, what are current

best practices, what do we know.

Probably the reason we're all at EHDI

and as our own organization we are a

family based organization, and so while

that state is really looking at fixer

and systems and out completes we are

invested in the families. That'ss who we know and what we do

so provide timely informed parent

decisions, optimal outcomes for children

and families. And as a family based O

we're also cognizant of what we bring to

the table a ever as stakeholders but

also thinking about we want to build

credibility and we're excited for that

opportunity. We want to demonstrate

that it's effective to partner with us.

One of the things we really

appreciated in that plenary session

from Dr. Bosco he had that nice graphic

way of looking at leaks in the system and the leaks are going

to be different in the system than they

are in grand valley or Waco so we want

to find where the leaks are and see what

we can do to plug them. So I just got

done saying we're the parent

organization, but we're going to talk to

providers how do those things align and

are we saying two different things, and

we're not. We want to support providers

 to help communicate effectively with

families so families can make an

informed decision, so because we know

when the communication barriers that are

experienced by families

really compromises how effective our

system is and you know that. We also

want the encourage best practice related

to early identification because're not

just preaching to the choir we realize

 there's a lot of different providers

 within that service continuum and

what supports they're able the provide

and also what the families need. We're

very invested in facilitating

the transitions for families so helping

identify what the system barriers are

and the recognition of risk factors

because we're getting broader. We're

not just looking at the zero to three,

we're following the recommendations of

JCIH and can we monitor the risk factorses

 and who are we going to inform and

bring alongside with us. So the

question hey what are family based

organization, why us? What makes you a

 partner that would be

well equipped for that and going back to

our plenary session he made some great

statements that I wanted to echo that

family engage testimony promotes

self-efficacy so thinking about providing

 families evidence and building that

family to family support and of course

we think this is a good idea because

that's what we are we're a family based

organize, so if you're not familiar with

the FL three resources those have been

developed through national Hands and

Voices and funded through HRsa so this is a federal initiative and

they say aborganizational culture that

prioritizes and facilitates family

leadership is vital to sustain and

improve mechanisms for family engagement

and partnership over the long-term and

across the EHDI system. Similarly from

that JCIH document equitable partnerships

 between families and early

intervention programs and systems are

critical to the success of EHDI programs

and the achievement of optimal outcomes

for church. Family leadership and

involvements are critical when

developing policies and

 programs so that's the page

that we're on. And how do we do that?

First of all we put families first and

so as we're going into these

regions as we're planning what we

continue want to do is let's engage all

the providers and bring them together

because we're the professionals, we want

to the to the families from the beginning

 so what we do is identify people that

we already know, people that are already

on our team. These are individuals that

have worked with our guide by your side

program, so they are parent offense

children that are deaf and hard of hearing

 but they're only experienced parent

guides and they are boots on the ground

in that region, and what they are

working to do is each what we call an

informant family and that sounds a

little covert but the idea is that you

know those families and those providers,

 the ones that you worked with for two

years and three years and five years and

20 years but the deal is families that

were ten gauged in that system ten

years can inform us about how the system

is working today so what we want our

 families to do is to go into the

community and find out what are the

stories on the ground from the people

that are there now. We want them to

look at different experiences within

that age range and across demographics.

What they're working to do is organize

focus groups to hear their stories

about what worked and what barriers they

encountered and we want to do that in

English and we want to do that in

Spanish. We're also using what we call

snowballing and that sounds a little

preschool but we refer to snowballing

when we do research as a method to get

to new sources and the

idea is I engage with you and I say who

else would have information or resources

and you send me to the next person and

it expands in a way I can't get from

just pulling occupy a data base so we're

using that snowballing

technique. And again what do we no?

Are we making this up as we go is this

San Francisco? This is echoed in

other documents so our international

consensus statement on early deintervention

 for deaf and hard of hearing and

this was published from some big names

in our field in the journal of early --

I'm, no, deaf studies and deaf

education. But Mary moller and a lot

of those folks that you know of but what

they looked at is parent provider

pretty muchs and research based best

 practices in EHDI so

parent and provider partnerships,

and this isn't deaf specific but looking

at why would we not send the

 parents a vary? What we know is

qualitative data really helps To

understand patterns of health behaviors,

describe system experience and design

health interventions and develop health

care theories and that's where we're

going in this gathering of the family

stories across the different

regions.

So here's the map and it is a big place

so we're start with three regions and

this is under the direction of our

department of state health

services and it's seven, sate can 11 so

that middle to bottom. And one of the

things our state is doing is saying

let's leverage the people that are

already there. And what we're doing is

having our boot on the ground, our team

members who are in these regions go

through that map with some intention, so

we're the population center, where are

the county line and a little

Texas lore, as Texas was established the

rule was we had to have a county seat

that was within one day's horse ride of

everybody that lived in Texas, so

that's why everything sort of looks the

same. We have all the little boxes. So

they're looking, where are the counties;

 about EC.I N Texas those services

are contracted and every region has a

different contracts so they needs to

know what are the players, where

are the birthing hospitals, the clinical

providers and the

audiologists and we have our state

divide into another numbered map,

regional service centers can the

educational service centers so they need

to be familiar with those. We have a

program called the regional day program

for the deaf and so because this is a

low incidents it's a high need

population we cluster in co-ops so they

need to know who the regional preschool

programs are.

Military basings you know that navigating

 those systems is a whole different

challenge and each one has a major

military base so we want to know who are

the players there. And trying to think

more broadly who are the people we

haven't thought of so some of them are

looking at the mid wives and, what about

WIC? There are some interesting -- I

know jetty had an article using the WIC

services to link with families so

identifying who we should be talking to

and looking beyond the audiologists. We

 review

ed the data and there's a lot of data

available so this is a small smidgen

that gives you an idea of the things

we're looking at and what patterns we

should be paying attention to and of the

three regions that we're looking at that

makes up about a quarter of the

population and what you're able to see

is what percent were we North American

 in terms of loss-to-follow-up; I'm

sorry, out patient screening can then to

diagnosis, so you see region seven, babies

 born in 2019 and babies born in 2022,

register eight, 2019, 2022 and likewise.

Yeah, because of COVID western looking

to see what happened to the babies born

before COVID and what happened

and looking toss if things

improved and of the three only one was

screening more babies. Even though the

population creeped up so that's a bit of

a flag. The other flag is that last to

follow up across the regions

is up. It's transcribe can I because

when you're looking at 2019 babies they

had a longer period of time to get to

where they're supposed to be so there's

still hope that some of our 2022 babies

won't still be on those bars but this is

one example of the way we're looking at

the data. And then I want to ask the

right questions so [indiscernible] I'm

going through can and looking at a needs

assessment for our providers.

So we're asking them things like, what's

your role? Where do you live?

Representation, so how often do you a

deaf or hard of hearing kit? That your

wheelhouse? What's the background

knowledge and those are the sample

questions that you have here so we're

asking questions like what age should

our child's hear loss

be diagnosed what levels of hearing can

negatively impact language and hearing

and you would think any provider should

know that we're looking at the nurse

 practitioner, we're looking

at wide variety of

providers and how confident they feel

serving these families with what the

referral process is and what kind of

training and resources they want because

again before providing support we want

the find out where they are and what

they need. And I should also mention we

have two parallel instruments, one looks

at the more clinical providers that are

focused on the diagnostic piece and the

other more on the intervention people.

And then identifying the players so as

you start to think who do I want to

reach out to. Some of the people you

know so of course EHDI; so as we start

identifying who are we going to reach

out to Hands and Voices we know the

players so we've gone through all the

lists.

We have gone through state registries and professional

organizations, we've looked at screeners

and contractors, who are the provider

that pop up in MI S. Who were the

PCPs that actually bought equipment.

Would that be a place to look. What

about nurse practitioners, what about ECIs

 and regional day programs for the deaf

and gunshot the idea of snowballing.

This model we use it in psychology

sometimes, a model of ecological

development but the idea is to start

with the child and then you have

different systems that child works in so

you have that immediate family and that

school and that connection teen the

school and the family, and what

about government agencies, what the

social centrals and you see it get

broader and broader and that's where

we're going. Let's get away interest

the child and the medical model but who

does that child engage with and who

engages with them and who engages

 with them, so what we're trying to

think big and broadable who are the

stakeholders and thinking of expanding

our target. I know in this room

yesterday there were some conversations

about reaching out to prenatal folks,

what if we engage with the providers

before the baby is born and the

recommendation and what about the late

identified kids instead of zero to

three can we think about prenatal to

five? And then but tame staying on

target, who are we and what are we doing

.

Our focus is really family ingaugement

that appropriates self efficacy.

Because the goal is preventing

loss-to-follow-up. Then that idea of

getting to work, so what are we working

on now? We're

working getting the parent guides in

place and well equipped. And

sending they want out to gather

information. We're really trying to

make real connections with stake holders

so we're on the phone and we are traveling

 within the next few months going out to

visit them ahead of time. We're trying

to engage in some authentic conversations

 with them. One out of our aims is to

host what we call summits where we're

bringing the stakeholders together and

that community of learning and really

engaging a broad rain of parents and

professionals but not to finish and take

off but to build some connections that

are sustainable, and again that's why

we're using an instrument that's a

 needs assessment. We do

recognize that we are going to have to

be willing to be dynamic and flexible

and responsive and you know that

already. And that this is a long-term

 commitments. We have talked

 within the EHDI system about moving

the needle but these are incremental

changes that we hope we do well so they

are again replicaable and sustainable,

and our objective again enabling the

families to navigate the system and

enabling the system to adapt to and

engage with the family. So that's the

end, that's where we are up until now

but really the beginning of where we

hope to go, so our hope

is this time next year we can tell you

how that evolved, and we have five

 minutes, so happy to

take some questions..you guys are so

easy. All right well thank you for your

attention.