>> My name a Janna and

I'm the family engagement lead for the

national center on deaf blindness. I

welcome you all here today and I'm glad

that you are joining us and the

number of people, we have got some

cheerleaders here on the right side that

we may or may not make mention of, I

don't know. I'm going to set the stage

but really it's Amanda and Heather

that are going to be able to apply the

concept of family leadership through

their own example of telling their story.

Family leadership means many things to

many different people. To parents, to

organizations, and professionals. I

believe wholeheartedly that the family

leadership starts with a family simply

trying to navigate the systems

that are surrounding them. Systems that

we as all families, we're all part of a

family have but families with children

with special needs are required to

navigate in a more intensive complicated

 way. So think about yourself, your

family, and as a member of that family,

the systems is that support you. Some

of these systems you may take for granted.

Many of you it's glaringly an

issue in terms of the support that's

needed by them. So we'll begin with the

medical system in leading your family.

The educational system. Massive. The

legal system. The financial system.

And more important, the system of your

individual social network for your

single family to help support you, so

that would be your extended family,

friends, neighbors, church, synagogue,

whatever fills your family with

connection and key relationships. And

then the stronger that these supports

systems are, the stronger the family

can be. So then think of those families

that don't quite have good support

systems within these systems. Families

who a child when I say deaf blind, and I

may say this more than once, combined

vision and hearing, those differences

along with the fact that when a child is

considered deaf blind, they typically

have other

disabilities as well. It impacts how

they learn S and you'll hear this

through the family's story and

their journey. We also know through

family leadership that their voice

becomes very critical especially since

this is a low incidentals

population. Another component of family

leadership besides navigating the

systems, for us and what we are trying

to have others understand is

processing one's story. So that's

reflecting back to see, think about and

reframe the highs and lows as they

find insight in how much they've learned

over the years in looking back, they've

learned the strength that they've gained

as they look back. And then of course,

throughout the whole thing they learn

that it's reinforced the immense love

that they have for their child and their

family as they lead them. So besides

family engagement my

colleagues provide support to the state

deaf blind programs and are fund there

you had office of special education

programs under the department of Ed.

These are our initiatives. And the

we'll talk about more about the state

deaf blind programs but every state has

a deaf blind program. Our

30ives are 's of deaf blindness, the

qualified personnel and transition to

adult life and as you hear the

complexity of our needs through this

family story you know those initiatives

become that much more important for our

families. And Amanda and heather will

be introducing themselves in more

detail about how they have grown in leading

 their family and you'll hear about

the family and the systems that were key

and intense in trying to navigate.

They've worked together, these two ladies,

 to pause, to process, to write and to

present the story that you'll hear today.

All about the journey of their child

with combined vision and hearing

differences along with the complexities

of that what entails for them and their

child. You'll hear about the diversity

among children who are considered deaf

blind and this diversity is alls the

uniqueness and the isolation that it can

present. Most importantly we want you

to be able to focus on the power of

story and that in and of itself empowers

families and their family voice, sow

there this family voice we hope that you

will understand deaf blindness as a

unique disability, one with unique needs

as relates to access to learn can going

can living. We hope you'll recognize

the shared perspectives of families

who are here today and that you'll able

to realize the complexity of family

systems I spoke of which includes grief

and loss associated with the journey

while navigating the unknown for

the child. If you're new to understand

the complex of deaf blamedness there are

resources at the end of this PowerPoint

that are a part of the website that you

can upload. We have highlighted from

our website also rain showers from NCDB

that you can go to national DB.org. And

you can see that things a link within

this PowerPoint as the number of

etiologies of deaf blindness which is

diverse. And we also want you to know

that the term deaf blamed is often the

misunderstood, so it covers a wide rain

of combined vision and hearing loss, so

that's why we find it very important

that you contact your state deaf blind

program to refer and learn more about

deaf blindness and the impact it has on

learning.

We don't hold you responsible to decide

what deaf blindness is so I encourage

you to do that. So being said I will

let the families tell their story,

heftier heather will speak first,

southeaster a family engagement program

for the state deaf blind program in Iowa

and also workser edit did I and Amanda

Campbell is a leader in southbound and

carve the South Carolina deaf blind

project. Heather?

>> Hey everyone, excuse me. My name is

heather and I live in Iowa with my

husband and our four kids. Like

Janna said I'm avenue I'm the family

engagement coordinator for our deaf

blind project so today I want to share

with you about my daughter laneny. So

this is layny shortly after she was born

in the hospital. She was born via

traumatic delivery and went straight to

the Nicu where she had a brain

bleed so severe that she would not make

it. This would be if first time we were

left in the unknown without answers and

that would continue for many years to

come. We also came the find out that

she was profoundly deaf with multiple

brain abnormalities. After taking her

home and watching more grow and miss

every single milestone wees in something

was wrong with her vision so at six

months we discovered he had functional

vision loss. But laneny this meant her

left eye was not able the move up our

down, she had a drop I eyelid, the

little peripheral vision, where eye

movements near sitedness and more

and they incorrectly doinged herry

condition because her eye

movements were so rare nobody understood

it. We opted not to move forward with

any more surgeries, where at best they

would be guessing at an outcome.

She also went through trial organization

of patching and we were able the

reverse is that but her ophthalmologist

decided we would no longer try to

correct her vision in her bad eye at the

Rex of her good eye. It would take six

more years for a diagnosis but we would

learn that she was born with two rare

genetic mutations one that only three

ore people this world have and one that

nobody has been diagnosed with yet,

both of these together caused multiple

 tall disabilities

and many more medicals. She's been

hospitalized more times than I can

count. I use to think we would get past

the days when he would be uncertain

about whether or not she would live. We

didn't know where to turn to for

resources. She didn't fit in the deaf

box because she had all this other stuff

going on. She was so complex doctors

were turning us away because they

weren't sure what to do with her. We

had to start traveling out of state to

find care for her. Because she could

see she wasn't referred to our deaf

blind project. I didn't know she would

qualify. I think she was in second

grade by the time her teacher of the

deaf said she has a lot of vision stuff

going on, let's make you a referral and

get you connected.

And we were purely in survival mode for

years at that point, my sole identity

was being her mom and casework it's

caretaker.

I had the quilt my job because of all

the appointments. Id ha no idea how to

speak up for myself let alone my

daughter and we added three more kids

terror mix in the meantime. I didn't

know who I was outside of caring for

her. I lost nearly all my friends

because they didn't understand what we

were going through. That feels like a

complete overtype of lime ago so now

laneny is 13 and our lives are looking

much different. Our health is much

better managed, she's the sweetest kid

I've ever met, makes us laugh every day

but our struggles are still there they

just look different. We're still adding

new conditions to her ever growing list

and she has another surgery next week.

When you have a child that's extremely

complex, nobody knows what to do with

them. Many doctors are turned us away

over the years, teachers didn't want her

in the classroom because they didn't

understand. We learn tot speaks up and

advocate. We had the fight for what

feels like every little thing, sometime

basic human rights. We had to hire a

lawyer to get her interpreter at school

because they didn't sheaf the need for

it the even though she only communicate

through ASL. We had the fight for

interpreter as at doctors visits when

they tried to deny it many times.

We had the research ourselves and fight

for diagnosis and treatments when the

doctors gave up. We had the fight

insurance company toss cover needed

 equipment like wheelchairs t. We have

had the fight highway to first thing out

how to communicate with our own child.

Hade to pay someone to teach me how ho

read toe my daughter. I had the find

grants to find college courses to learn

her large. Even in the deaf world she

didn't fit in. She's been turned away

from activities because she's not just

deaf, her vision loss and other

complexities make it so she doesn't fit

in anywhere. Caring for a medically

complex child is both rewarding and

exhausting and as parents we're so busy

 managing all of the moments

therapies and hospitalizations, school

things, our Johnson there was little

time to care for ourself. We put

ourselves on the back burner and the

other children, the siblings of children

are disabilities have a much different

life than kids their age. Nobody talk

about that and the toll it takes on them.

There are many things people don't see

going on behind closed doors. You

don't see the mom gift I have whiff to

miss other children's activities

because laneny is in the hospital again

or I feel like I haven't spent enough

time with them to know what's going on

in their lives. You don't know the

struggle my husband and I have to spend

time together. Or the guilt it's I feel

went I don't realize my daughter's need.

 Recently I was getting frustrat

ed with laneny because she kept falling

 asleep at the food of her bed and falling

 off.Ty had to ask her the she

couldn't reads the contaminations on her

TV so I know what hero vision is but

even sometimes I don't what her needs

are, how can I expect everyone else to?

We're at a point now where we're having

to take step back and let laneny start

advocating for her own milds and this

is so much harder than I ever thought it

would be. I also never would have

anticipated is that laneny would

be age to do that for herself but here

we are this. Picture is overleavenny at

a pageant for people with disabilities

where she sang a song and went on to win

is it state title to represent our state

at nationals. I try not to share too

much about her personal life new that

she's older because it's not my

story to tell, how far she does give me

permission the share certain things.

Laneny is getting older and she's March

aware of the differences when her and

her peers.

Middle school is rough. Laneny

set is the only deaf blind child in her

building. The communication barrier is

huge. Add in all the other complexities

 in it seems impossible to have true

friendships. Kids don't understand

she's different. Some seem like they're

scared to talk to her. Who and while

she has an interpreter nobody wants to

have an adult following you around when

you're trying the make protects.

Her mental health started struggling

because of this. She talked on how

isolated she was the and he was asking

us us to move to a different state. How

lonely she felt not having any friends

or family members who are line her. And

just when we feel like we're overcoming

the medical things this part of life hits

 her and I don't have answers. While we

do all we can to help her as a family

and get her the things she needs we

can't do it on our own. We did put

together a team to lessen her isolation

and encourage friendships. And while we

are still working through these things

and figuring out how to make them

happen I'm already seeing a huge change

in laneny.

So we're helping laneny be her

own advocate and letting her start take

the lead. We found new ways to connect

with her peers and she finally has a

really great friend, her last birthday

party was a really big deal to laneny.

She was turning 13 and in typical

fashion she demanded a fancy

party.

We took her and a couple friends out and

did just that. My husband and I went

along for the ride. Usually we have to

step in and become interpreter and help

her. This very small but very kind

group of friends were singing and

dancing in the limo and taking pictures

and finally having fun. Laneny signed

to me mom you're a mess. I tried to

pull myself together can be cool and it

was the first time maybe in her life I

know she seemed like a normal kid. A

normal 13-year-old girl just having the

best birthday ever. Two friends for the

first time in her life. Sorry. As a

mom I can't begin to tell you how that

feels. I didn't think that was ever

possible. I now it's not perfect but

it's something. So I want to share with

you one of my favorite quotes from

Elenore. Life is amazing and

then it's awful can then it's amazing

again and in between the amazing can

awful it's oared and mundane and routine.

Breathe in the amazing, hold on through

the awful and relax and exhale there

thank you ordinary. That's just living,

 heart breaking, amazing awful

ordinary life. So we're exhaling

through the ordinary. I snow we have a

long way to go and a lot of bumpiness if

road to come. I'm just grateful if ever

the breadth takingly beautiful life

together however that may look. Thank

you.