

UNC Chapel Hill CEDI Lecture Series: D. Jones, Matthew Schwab, and Michelle Schwab

January 31, 2019

Working in Community

Thanks for joining us today.

Today's guest speakers are D. Jones, Matthew Schwab, and Michelle Schwab.

D. is an individual with autism who shares her tools for living an independent life with other individuals with autism through guest speaking events at the ECU department of occupational therapy, TEACCH, and other programs across North Carolina.

She provides personal insights to help professionals understand how to better serve people with disabilities.

She has been a Physical Therapist Assistant for more than years and is a provider for in-patient and out-patient care services.

She has also served as an adjunct professor at Craven Community College in its Physical Therapist Assistant program.

D. received her bachelor's degree in psychology from Rutgers University, a second bachelor's degree in liberal arts Science from Neumann College and her associate's degree in physical therapy assistance in Union County College.

Matthew is a -year-old native North Carolinian who lives with his parents, two brothers, and his dog, Daisy, in Holly Springs.

He graduated from HSHS in June with an occupational course of study diploma.

He is currently enrolled in Project Search through Wake Tech, an internship-based educational program.

He has worked at the Holly Springs Chick-fil-A for almost years as a dining room host and food runner, and volunteer at the Museum of Natural Sciences in Raleigh.

Michelle is a wife and mother of boys, all of whom are closer to being men than boys.

Her oldest is Matthew, and he has Down Syndrome.

She has a bachelor's of social work and has worked as a social worker before going back to graduate school to earn a master's of education in early childhood education.

Michelle has been involved in the special needs community since Matthew was born and she helped form the Triangle Down Syndrome Network years ago and has served in a variety of roles over the years.

Michelle was part of the start-up team for Gigi's Playhouse Raleigh and serves on the board.

I'll tell
you that being a part of disability
rights North Carolina is passionate to
my heart.

You may see me tear up and that's okay.

Because I was told that when your
tears form in your eyes, it's your heart
actually speaking because you can't take
your heart out of your body.

Just know that's the way the heart speaks.

And this is a passion for me because
I'm old enough to have lived -- actually
I was living around that time.

The difference is that my parents
disagreed with the physician, so I lived

at home versus probably in one of the institutions.

I don't know in you know about temple Granden.

A well known person, more so than I. She's older than I am.

But just like her mom refused to put her in an institution, my mom and dad decided not to listen.

I was point

-ounces, the size of a tissue box.

My dad used to put me on top of it on top of the pillow to keep me safe.

This is truly that video brings tears to my eyes because if you have ever been to a nursing facility, some of the bigger ones remind me of that.

Some of the little ones don't.

And I'm always an advocate regardless of who I'm treating.

And as a physical therapist I sit about the, I tend to go to places like that and make a difference and I'm glad I can do that.

So the whole purpose for disability rights in my eye is that they put a stop to discrimination.

In various settings for people with various disabilities.

An example with that would be in February a

greenville, North Carolina dentist and department of health and human services were sued by disability rights because of discrimination with Medicare.

So their legal representation is a powerhouse.

Public works, public policy changes work.
We can't go out and do the grass roots work.

We can't but they can because they receive the federal funding.

But you can help fight the causes at the grass roots level.

They investigate neglect and they're like P -- it's psychiatric residential facilities and they investigate those.

And that's whether you have a person or people who are living in a facility because their parents or the schools, public school can't take care of them so they send them off.

But then they don't do justice so we have to investigate that.

You would be surprised at how much we see.

I personally haven't got to a PFRT, I'm messing up the acronym, because I'm a board member.

But as a physical therapy assistant I can go in and treat if I have A contract to treat.

The other thing they do is training and education.

This is disability rights.

They go out and train.

If you want them to come talk more.

I already spoke to them.

Just let them know and they'll come out and talk on a topic.

They go out to different schools, different facilities, different offices and talk and educate.

Educate not only the people higher up

but also the students who are advocates for themselves, they do training.

That's how I got involved.

I got involved with -- it was called the date training.

When I saw the flyer, I was like, take a date.

It said D.

A.

T.

E.

And I'm like hmmm.

Why do we have to schedule a date.

I didn't understand it.

I was inquisitive, I think I'm using the right word.

I was inquisitive and I signed up and went.

It was a training to teach people how to be advocates across the state and you help the individuals on the phone and talk to them about a contact.

So that was really good.

And that's how I got -- I didn't plan on being on the board.

It just happened and I had moved because I have a support team that said you can't do X, Y, Z, but I missed that cue because I became the chair.

Not because I was told they was going to do that.

On here it says, like I said, the law enforcers.

I consider them law enforcement.

They go in without physical guns but they do go in blazing with words.

And as attorneys, they use a lot of briefs, if you know what a brief is, it's pretty big.

It took me a little while to figure that out.

They help change policies throughout the state.

I have examples of those too.

Besides the dentist being sued, there was a settlement on behalf of children with complex needs.

That's where a child can have a physical disability and a behavioral disability and that's considered complex needs.

Why would a school give them a hard time, a child?

If you need the help, you need the help.

But they were giving him a hard time, not accepting the IEPs.

And then there's a behavior IEP.

Strictly behav

behavior and they won't honoring it.

Everybody drive?

They filed a lawsuit and won in with the department of motor vehicle.

Now, I'm going to explain it to you.

I see you got an idea.

It's like, everybody drives.

So people who have physical disabilities, and you walk in with a physical disability, they automatically singled out you.

And you had to go by the expense of your own pocket go get medical reports, had to be filled out by the medical doctor, bring that back and they only gave you a license for a year.

Most of us have license for six years or ten years -- I think ten is the most.

I really don't know.

I'm from New Jersey.

So people who had a physical disability were discriminated by that because the person at the desk who was saying here's your license and you got it for a year because they saw you with

a physical disability.

Regardless of the adaptive equipment that cars are able to have, that's what they were doing for people with disabilities.

We won that case, yay.

And that was in February of .

I was excited about that.

And the importance -- the question was what was the importance -- I'm glad we have an organization like this.

Because having an organization helps me because sometimes I lose my voice.

It's hard to believe but sometimes I can't talk.

And knowing that I have a group of people that I can reach out to and say help me, help me, that makes me feel really strong.

I don't know if everybody has had anything to do with the department -- you probably have and just don't realize it.

But the idea that we can sue them and make them do things right and not put us on hold for minutes and come back, oh, you got the wrong number.

That bothers me.

Pet peeve.

I'm going on a tangent.

Story.

Sorry.

We go out to all of the areas and when we have board members, we pull board members from each region.

We try to get at least two, sometimes three from each region.

And we're in the process of revamping that to see what number we really need.

But having representation from each one of these locations speaks volumes.

The reason why I say it speaks volumes

is I had the privilege, the opportunity, the excitement of going to the listening sessions.

And what the listening sessions is -- was -- they're going to have another one coming soon.

Where they would go to different parts of the state covering every county -- like I've traveled all counties and I'm not even from North Carolina.

Go figure.

But it was curiosity to hear what people were saying and what they were dealing with and experiencing.

And I have a few examples.

So like in the mountains, because you go far far, there's a place called Murphy.

Have you ever heard of that.

Back there a lot of people in that area had trouble -- imagine being in the emergency room.

We go because we have an emergency, correct?

Going to the emergency room and spending three months minimum in the emergency room on a cot on their stretcher because they don't have place for you and you suffer with mental illness.

That pulled really hard at me because people with mental illness -- I'm sure all of you have been in the emergency room and you hate being there not being served.

Imagine sitting on a cot and somebody is bringing you a bedpan.

It's not even a closed curtain.

You're behind the rest of the people -- they see this as the back area.

You're right here and we see you because we're workers.

We're

nurses and doctors.

We get to see you, pass by you every day.

But the other community people don't get to see you but you're on a cot.

You're being bathed hopefully getting bathed.

They may pull a sheet to cover you as they bathe you.

But that takes away your dignity.

That bothered me a lot.

Not having the services they need for people with mental illnesses on the west, far far west.

Then when we went to -- into the far east, down by the shore.

People were saying that they were independent, physically impaired.

We were at the outer banks.

Way out there.

One of those cities.

I can't remember.

They were way out in the water.

Have you ever driven there?

Oh my gosh.

That was horrible to me.

I'll tell you why real quick.

When you drive there's only one way in and one way out.

You got cars going this way and cars that way.

What if somebody's car breaks down, you're in the middle of the ocean, the water.

How are they going to get to you.

Nobody will answer that question for me.

I will not drive there again.

It doesn't make sense to me.

There one of the complaints that I heard visually impaired individuals were completely independent daylight hours.

So after : in the morning they were independent.

If they didn't get back home before
: they, stranded because there was no
lighting, there was no transportation
and there was no way to get home.

So imagine the campus here, first day
in class :, bright lights, :, it
starts to get dark and you're visually
impaired and can't get off campus.

That's what that was like.

And to hear their passion as they
expressed it was more wrenching to my
insides, my soul.

And then we had -- I guess it was
Charlotte region area, up there, their
complaints was transportation.

Belief it or not, Charlotte is pretty
big but there were issues with
transportation.

So all of these areas, for me, I bot
to hear that because I don't live there.

And to know as a board member I could
voice my opinion and help make change
and that was the beauty of being on the
board.

And I will always remember that.

Not even board member went to every
one but that's okay.

My desire is to go see what am I doing
on this board and how can I help.

So we have, coming up -- and I gave you
guys a handout on that.

And I can give you one because they
didn't make it back this way, okay,
Matthew.

They're around here somewhere.

I'll make sure you get one.

That we have an upcoming conference,
and it's going to be on May st.

Everybody can come to it and I wish
you would.

They break out in different sessions of different issues that are affecting people, or concerning -- I shouldn't say affecting.

Concerns people with disabilities.

So I think if you get the opportunity to go on the st of may, that would be great.

The other thing, we just had a launching -- I don't have -- I don't know if I can -- let me show you this video.

This is pretty cool too.

Watch this.

This one is really cool.

[Music playing].

It looks better bigger.

It doesn't want to go bigger.

Sorry.

And it looks better bigger.

I hope I didn't stop it.

The music is great, too, right?

Makes you want to move.

>> A service animal can change the life of a personal with disability allowing for increased independence.

Federal laws give a person the right to have their service animals with them in almost every setting.

The Americans with disabilities act requires that all public entities allow service animals.

Animals must be allowed in all buildings they own and run.

Private entities provide goods and service to the public, hotels, movie theaters, grocery stores, restaurants and medical facilities.

The ADA covers almost all of our daily

interactions.

The best strategy is to assume that you have a responsibility to allow service animals absent one of the exceptions that we'll discuss in a bit.

What animals qualify as service animals.

Here are the rules according to the ADA.

First, the animal must be a dog or miniature horse.

Second it must be individually trained to do work or perform tasks for the benefit of a person with a disability.

That disability may be physical, psychiatric, intellectual, sensory or some other disability.

Third, the work or task the animal performs must directly relate to the person's disability.

Service animals can be trained to do a wide variety of tasks.

A seeing eye dog can
o a hearing dog.

A service dog with transport things or open doors with someone with mobility issues.

Some animals were trained for medical alerts.

They can let their owners know about a dangerous seizure.

These are just a few examples of the many tasks service animals can do.

If you work in a business, nonprofit organization or government office and you want to know if someone's dog or miniature horse is a service animal, there are two and only two questions you are allowed to ask.

You can ask, one, is this a service animal required for a disability.

And two, what task or skill is the

animal trained to perform.

You cannot ask the person what his disability is and you cannot demand proof that the animal is a trained service animal.

Here's an example of how the interaction should go.

>> Welcome, is this animal required for your disability?

>> Yes.

>> What is she trained to do.

>> A seeing eye dog.

>> Wonderful.
Come on in.

>> It is the responsibility of the business owner to honor the right.

There are specific situations in which you as a business owner or employee can prohibit a service animal.

If the animal would present an actual objective significant risk to health and safety that you can clearly articulate, or if you have a valid reason to believe that this specific service animal will behave aggressively.

That means it has to be about the animal in question not about the breed of dogs or dogs in general and not based on your previous experiences with other service animals.

>> Any questions?

>> Does a service animal have to wear a vest or have an ID?

>> No.

A service animal may have a vest or an ID but it's not required.

>> Does a service animal have to be trained by professional dog trainers?

>> No.

Someone with a disability can perform their other service animal to perform a task.

>> Can a small dog like a Chihuahua be a service animal?

>> Yes, service animals don't have to be a specific size or breed.

A small dog might be as effective as a big dog when it comes to assessing changes in blood sugar.

>> Wait a minute.

I'm a doctor.

Do I have to allow a service animal to go anywhere in my medical facility?

>> You must allow a service animal to accompany a patient anywhere you would allow a human companion to go without taking extra precautions.

If you were the allow a patient's parent or spouse to accompany them into and exam room , you must allow the service animal.

But in an emergency room, the service animal can be excluded.

>> Is it okay if I pet your service animal?

>> Great question, no you should not pet a service animal.

Try to avoid them.

Remember these are working animals and you should not touch, distract or pet them.

Just as important, treat the handler just like you would any other clients.

>> The ADA is a civil rights law for access to opportunities for persons with disabilities.

Knowing the rights is casual to every business owner and employee.

Thank you for taking the time to watch this video.

>> The reason why I put that up there is because there are so many individuals out there using an emotional support animal to the point where everything you could think of is considered quote an emotional support animal.

They don't -- they're not certified, they're not approved.

Airlines are cracking down on them.

And to me that hurts people who really need them and it's because it's become our fashion and our social -- I don't do social media.

I use that phrase but I don't know anything about social media other than it exists.

So I think bringing awareness to you guys so you can share with others who may say, I got my dog, taking him into the supermarket, that's not right.

It should only be for people who really need it.

Yes, you got a fashionable poodle, whatever they're called.

People belong where they belong.

I shouldn't be mean.

It's one of my pet peeves because I think that people who need them can't get them.

You know how much they cost in places -- like , dollars to , dollars.

And you know, getting everything approved open going through the process, that's why the question, can you have your own is a wonderful thing if your dog is that in tune to you.

But they have to prove they're capable of doing work.

And then you have individuals who can't get that because they one, can't afford it and desperately need it, two, because of our -- like I said, social media -- what's her name, Parker?

The pocket pooch?

And I'm glad it says no cats so people can't have cats.

I'm terrified of cats.

When they talk about -- I am terrified of cats.

I'm so glad nobody has a cat.

I'm so thankful.

When they talk about for autism, yes, I could have one but because of the work I do I don't want to bring them into the environment.

So I wear my bake pack which is extremely heavy when I'm talking and out in public and I have multiple layers on regardless of the temperature outside.

I have compression garments from head to toe on that help keep my sensory system in check for the most part unless something causes me to have a meltdown.

Yes, meltdowns are not just for little people.

I have serious meltdowns especially when a police officer pulls me over for no reason.

And I cannot use my voice and call for help.

That's my routine.

Help and then I pass the phone to the police officer.

I hope that you can share this information about service animals to anybody that you may need or know that may need it.

People don't realize someone with diabetes, it would be beneficial to have because your blood sugars can drop in a second and we don't know it.

Sorry, I'm health care.

So that's why I put that there.

I don't know if I can open up the website, but the top one where they launched just happened on the th where disability rights is now doing the educational series for students and whoever want to read it, it's on that website and they talk about different events for education purposes.

So these the newest thing.

And I wanted to make sure I put that out there because this is a school and it's my special interest.

And I don't know how many of you know someone who was affected by Matthew and Andrew?

Disability rights staff has been on the ground from day one trying to help people with disabilities and prevent them from displacement.

We're having a forum on March th, a Saturday.

I'll be there.

So if you know of someone who lives in

the area or who wants to drive out there to voice their concerns, the latest thing I heard is that people -- bless you.

There are people still living in tents.

Didn't the temperature drop down in the digits last night?

They're sleeping in tents.

Why are they sleeping in tents.

They should not be sleeping in tents.

But that's what's happening in some of the areas that were hit pretty hard.

We're going to have a forum.

If you know anyone, bring them in.

And the conference, like I said, come to the conference.

You'll have fun.

I always have fun.

I'm overstimulated more than I am right now.

Because I am.

When you see me in that, I'm more stimulated.

That's some of the events, current events like coming up right now.

This question was about what other organizations that help me.

And I don't know if you know because I'm awe tissic of course I'm going to give you the autistic one.

The first is teach associated with the school.

They're well-known.

Do a lot of research, what's going to help a person with autism.

For me it doesn't do a whole lot because I'm older and a lot of -- they say they have adult programs but when I

go and look at the routines of what's acceptable for the adults, I don't fit in that category.

So I pass the information along to others.

The autism society can go out against the lobbyists and stuff like that.

Disability rights can't.

But knowing there is another organization that can, the organization itself can do that.

But it's best to have families and people and people that care to voice it.

ECBC stands for east Carolina vocational center.

This is an employment, they have a commercial on TV.

I disagree with the commercial because it doesn't give you the details.

It says it so that people can call them.

However, it's supposed to help people with disabilities find and maintain and keep a job.

I'm going to leave it at that until the next job.

I disagree.

They couldn't help me.

They tried to give me a burger job.

I've got three or four degrees and they're trying to give me a burger job.

Why am I going to flip burgers.

I don't even cook at home.

That was really upsetting to me.

I'm not trying to badmouth them but that's what they did.

I have a physical therapy assistant job.

How can you not give me a job there.

That was really painful.

I wasn't sure what you wanted but there

are inclusion places in greenville that I know of.

The sensory friendly movie theater.

The problem with that is that they don't show all of the movies.

I couldn't go see something I wanted to go see, you know.

And then they don't show them all of the time.

It's not sensory friendly every day of the week.

On a Tuesday or Saturday morning and it's not every Tuesday night and Saturday morning.

It's two times a month.

So how is that helpful for me.

I got to disrupt my life to go to the movie theater when it's convenient for the movie theater.

One of my pet peeves.

The inclusion park in greenville, it was put together with the autism society but it's for all disabilities.

So it deals with sensory, it deals with mobility, it deals with everything and it's right -- if you've ever been to greenville, it's at the town commons area.

I got in trouble because I wanted to test it out and I was told, you're a little too old for that.

But it's there.

Swimming, adaptive swimming.

I had the privilege of having some of my patients, when I was working at the hospital in greenville who were wheelchair accessible, spinal cord injuries, so we took them out.

And it's not just for people with disabilities.

It's inclusive of anybody who wants to swim at that location.

Those are some things in greenville and surrounding areas of greenville.

There are other programs but they're specific to the disabilities.

So that I didn't think I needed to put up here because I was excluding people and we wanted to be inclusive.

Oh, I'm supposed to explain about this.

I'll get do that.

This was awesome.

Look at this.

This is about an article -- if you get a chance, the article talks about how people with disabilities are in the workforce.

I thought it was an excellent article so I wanted to share it with you.

The problem with that is it doesn't explain how people who don't have fizza disabilities are discriminated in the workplace when they're told they have a disability.

Doesn't talk about that, though.

But it happens.

And unfortunate that it happens.

You have a choice, you tell or you don't tell.

And for me I've been on both ends.

Not telling, get in trouble.

Telling, get in trouble.

Right now it's like I just recently learned the phrase fake it until you make it.

I don't really understand it but I'm trying to learn it because it was told to know do that.

I don't really understand it and I'm working my hardest to do that.

But I'm glad that people are in the workforce.

I'm glad it's working.

I'm happy.

Things that helped me.

I participated in the family group for autism and for teach

TEACH.

Even though ie mom a parent they let me come in.

And the reason they said that is because I can bring stuff to the table.

They said it was okay.

So what am I supposed to be bringing.

The reason is that me sharing what I deal with helps them with their children.

So I guess that's what I was bringing.

I thought I had to physically bring something.

East Carolina university is the school there and I say their library because it's open until :, sometimes hours and I can go.

Most people are gone.

The big people are gone so it's less stimulating

.

Pit community college.

I took a class.

If I had the opportunity right now, I would be sitting with you guys.

I just take classes just because I like to go to school.

I took a class then their disability service center staff was very helpful navigating things.

People get there saying they have accommodations and they don't have to tell you what the disability is.

But when you give that to the professor and the professor has no clue and don't feel that you need the accommodations than's what I had to deal with.

Like, really?

Prime example.

I'm going to make this quick.

I know I'm running out of time.

I took a class and the teacher gave spelling tests every week.

And I needed to take the test oops, I got five minutes, I needed to take the test in another room and they wouldn't let me.

I went over her head with their help and wound up doing self tests myself and just taking her exams because she kind of tried to single me out and I had to call her out.

Needless to say, that's it.

Carolina connections is an occupational physical therapy center at the pediatric level.

They do a great job.

A job coach in one of my jobs was confusing.

Typically they teach you how to do the work.

They were watching me to pick up social interaction and then sitting down telling me about it.

And that's the only thing that east Carolina vocational center could do for me because they couldn't find me a job.

I think I'm finished.

Oh, really quick.

Helpful places, some restaurant,

friendly atmosphere.

I don't use self checkouts.

The noise is too loud.

The touch screen I can't handle.

Public buses in Greenville only run a short time if I didn't want to drive.

I'm thankful I can.

Malls are extremely loud and they should be less loud.

I think I'm finished.

I think I am.

I don't know how to move it.

Time fine

I'm finished.

Oh, there was one more slide.

You want to see it real quick?

Look at this slide

. Okay.

I don't know how to do it.

I need help.

Oh, I did do it.

This one is really good.

You're going to like this one.

>> Inclusion of people with disabilities is good for everyone.

Meet

Sara, when she grows up she wants to be a teacher and get married.

Sara has cerebral palsy and therefore uses a wheelchair to move around.

She's an outgoing person and whenever she needs help she asks.

But why she can do most things herself she faces many barriers.

Some people's attitudes is one of the physical and economic barriers.

So far no school has accepted her.

If she can't go to school, she won't

find a job and without a job she'll always be dependent on others.

This is a waste of her schools.

What can be done.

Everybody around her can help her live her life to the fullest and gain back her rights.

We need to raise awareness, for example, in education programs.

That way her community understands the nature of her disability.

After setting up a local support group for parents of children with disabilities, her mother can share her experiences with others.

Now the head teacher know it's her right as any other child to receive education.

And we need to reduce physical barriers.

Building wider doorways and wheelchair ramps benefiting the elderly too

. Now she has the same chance as others of getting the job he wants.

Instead of depending on others, she's appreciated for what she is, a person with many abilities.

When someone uses a wheelchair, with vision or hearing problems or an intellectual or other disability, let's make sure our society includes them.

For more information.

>> That's it.

Thank you.

[Applause]

>> That was ooh good video, right?

.

>> We're going to move down.

Let me turn the lights on.

Now we have
Matthew and Michelle Schwab.

>> .

>> Hello.

Forgive me voice.

I think I'm getting better.

It just sounds like I'm not.

I apologize in advance because I didn't really understand what a panel discussion was and I just found out other day we were supposed to have something prepared by Dee did and it was awesome.

>> They're all different.

>> We're happy to answer any questions you have and seriously any question is fine.

If it's just about Down Syndrome or growing up with it or going to school with it or how he has done what he's done or -- he's much more exciting than I am.

Anything like that.

And humble.

But when we -- he was a surprise to us when he was born.

And it has been a journey, but it has been an entertaining one, enlightening and we've enjoyed almost all of it.

He's exceeded our expectations, I think every expectation we ever had.

It's been a great learning experience for his dad and I and everybody who is associated with him.

Amelia said that I had been involved with the Down Syndrome network.

When he was born -- he's , there was

nothing in the area.

We live in holly springs, North Carolina and there wasn't anything.

Through some great fluke of events we got introduced to some other parents who had kids at the same time he had just been bonder and decided to form the tribal Down Syndrome network.

It with us a lifeline.

It was great.

I wouldn't have -- I would have made it through but it wouldn't have been nearly as easy as it was.

One of the questions was the things that are most helpful and honestly it's other parents.

People who have gone through it before, going through the same journey.

Similar journeys.

There is nothing better than networking with other parents.

And so that's what we were able to do.

But at the time I remember just desperately wanting a place to go, a physical brick and mortar where I didn't have to explain why he wasn't doing what the other -year-olds were doing yet, why certain things affected him certain ways.

Why I would burst into tears sometimes when some other kid was doing something he wasn't doing.

All of those things.

And there wasn't anything like that.

Nothing existed until when Gigi's play house -- you all have a handout.

Gigi's play house was created in the Chicago area.

And her daughter was born, named Gigi, with Down Syndrome.

And I think that Gigi is the youngest

of four.

And Nancy just thought, I want the same thing for her that I had for my other kids.

I want a place to go.

I want there to always be support for the parents.

She started saying I need some money, need a place.

Very grass roots.

And it grew.

And that was .

We just opened our st -- there's one in Mexico and the rest are across the U.S.

Most of them -- well not most of them.

I believe there are ten in Illinois, that's where it started so people have exposure to it, they walk in the door and they're like, I really want one of these.

It's all grass roots.

The corporate office does not look around going on oh, we need one in Raleigh, North Carolina.

Parents or community members get together and form a startup committee and decide, have to prove that we can fund it and the need is there.

We were able to do that.

It took us a year from when we formed the startup committee to when we opened our doors.

And it's been wonderful.

Even though we missed out on it when he was young, there are so many opportunities for him and his peers now as they're entering the workforce and social outlets for him.

We have fantastic friends.

He can talk about a bunch of that stuff in a minute.

But Gigi's meets the needs from the

prenatally diagnosed wanter that walks in not knowing what to expect all the way through the life span -- I think our oldest in Gigi's Raleigh, is he in his s?

Oh, Frank.

We do have a fellow who is , I think, who comes and does the social programs.

He lives with his brother or sister and he's hysterical and has a great time.

We have another gentleman named Bobby, he's in his mid s and his goal -- he couldn't read.

His goal when he started Gigi's was to be able to read Harry potter.

He cannot read it yet but in a year and a half of literacy tutoring, he's now reading Dr.

Seuss.

He's getting to his goal.

The ability to do that opens so many more doors for him.

He can read signs in the airport now and in the grocery store, you know.

It opens up so much.

We have tutoring and we have internship opportunities.

Some of our adults come and do jobs at Gigi's also within the community.

Local establishment that we've made great partnerships with.

We have promise for the littles, they come in and do ion language and music.

It's great for them but it's even better for their parents, mom to come in and hang out with other moms, exactly what we wanted when he was born.

What else do I need to say about Gigi's?

It's free.

We raise a lot of money but it's free to all parents.

That's one of Nancy's criteria was that finances could never be a barrier for parents getting support or families getting support.

So if you've never been, you should come and do a tour.

It's a lot of fun.

>> It is a lot of fun.

>> It is fun, isn't it?

Matthew, do you want to tell a little bit -- I'll do a little more and then let you take it away, okay?

I think that we've had a fairly unusual experience in that he was fully included all the way through seventh grade.

We had a one on one.

We had a principal go to bat for us who said he can keep up with the class, he just needs a little bit extra help.

We got the one on one every year, wake county gave it to us.

Academically the struggle became a little greater once he hit middle school.

It was so much reading.

Really hard for him -- school all day and then three hours of home work with me sitting beside him every day and that's in way to live when you're in middle school.

So we went resource and then when he went to high school, he left the one on one behind and went into the occupational study program.

It's

different in different places.

In wake county it's academics and hours of work experience.

on campus volunteer, in the community volunteer and then out in the community paid.

So he wept and got his own job at Chick-fil-A at holly springs, he had to go in, got an application, I think he went in four different times asking had they made a decision, are they going to give him an interview.

He was very persistent.

They finally gave him an interview, gave him a chance.

He had a job coach through Easter seals and now he works independently.

His list of volunteer gigs rivals anybody.

I would put him up against anybody for the things that -- he has been a volunteer since sixth grade and does all kinds of really cool interesting things . His goal in life, one of them is to speak publicly and advocate for people in Down Syndrome.

We told him in first grade he had Down Syndrome and explain to him what it is.

You have blue eyes, you have blond hair, you have Down Syndrome.

We thought sometimes somebody might say something to him on the playground and we wanted to give him the language to explain why he was hard to understand sometimes.

I don't think he's ever had any serious issues with anybody picking on him.

You can talk.

No?

Okay.

What do you want to say?

Would you like to say something?

>> Yes.

Like what my mom said, that even though I have a disability, which is Down Syndrome, the stuff I do besides my disability rivals anybody.

I have a grateful life.

One of the first memories I had was when Mom -- I got held back in first grade, I don't know why.

Mom and dad wanted to educate me on what my disability is, Down Syndrome.

But it was in first grade that I knew the information and presented and advocated.

But I didn't fully understand how it would affect me until freshman year in high school.

I remember I started balling and bawling trying to understand my disability, how it was affecting me.

A similar journey but more on an individual.

>> Personal level.

I got to volunteer at more things.

For example, I volunteered at the museum of national science in Raleigh . My favorite topic, dinosaurs.

And I've been a volunteer with county public school system ever since fifth grade, volleyball.

And a nonprofit shot with individuals with ADD

.

>> Who started it?

.

>> She saw a greater need and was impacted by the society, so the disability community and the typical community blends.

And I had the opportunity to share on the advisory board.

And because of that I am part of Gigi's play house youth advisory board.

I am copresident of.

And I love it.

Gigi's play house Raleigh, the Down Syndrome center.

In fact I attended workshops on advocacy, leadership forum, educational and also it gives me political exposure because I have the opportunity to speak to the governor, pat Mcquery annow the current governor, Roy cooper.

And I've been lifelong friends with the Mayor of my hometown, holly springs.

And I actually recently got hired as a paid legislative intern for the house of representatives.

He represented , Mecklenburg county.

>> He decided he wanted to hire -- I'm not sure why.

He doesn't have a personal connection to anybody with Down Syndrome but he wanted to hire people specifically with Down Syndrome.

So he was his third intern.

They were paid, got to go on the floor.

He had a great experience and I think you still say that's the best experience of your life, right?

>> Yeah.

>> He got to do the bills.

He can tell you what they were.

He's had these opportunities come up in his life that wow --

[Laughter]

>> For real.

True.

He was the one we were worried about.

I don't know why.

And I was going to say something about the -- oh, I know, the youth leadership.

>> Yeah.

>> Forum that you went to, that was the North Carolina youth leadership forum and it was through alliance of disability solution, right?

Something.

>> Yeah.

And he got to go and do a whole week's worth of learning about ADA and all that kind of stuff.

He enjoyed that.

>> Educational.

I liked it.

And with individuals with disabilities like me, one thing I need to start out, individuals with disabilities can have a normal life like a typical person, for example, a relationship.

But for me and others like me, my friends with my disability have to fight the barrier, I have a girlfriend who I've been dating for three consecutive years, long term.

>> Consecutive years.

[Laughter]

>> We love going on dates.

And we went to -- we always love to dance.

We always love watching movies in the

theater.

And we love going out to eat in restaurants.

>> But what is one thing that makes her very special in the Down Syndrome population.

What's the one thing she does that you don't do.

One of the things that she does that you don't do.

>> My girl friend, she is bilingual in English and Argentina.

Her mom is native from Argentina.

And my girlfriend has the ability to drive, took the lengthy process of driver's ed.

Even though she's done the test, she kept failing and failing but she passed.

>> Like yes said, she had to go see an OT and several things to see that she could do it.

Matthew isn't interested in getting his driver's license.

He has a girlfriend that can drive him anywhere.

[Laughter]

He believes his reaction time is too slow and I tend to agree.

For now we're going to put that on the back burner.

>> Yes.

And also just like everyone with disabilities
disabilities.

Be independent.

Move out on my own.

>> Me too.

>> We're looking into it.

>> We are?

>> Yeah.

>> Oh, right.

This is one of the innings that helps people with disabilities.

Briar creek, we're going to go next month.

There's an apartment -- call it an apple or something?

Do you know what I'm talking about?

>> I have heard of it.

>> Technology in all of the rooms.

>> And everything is set to a certain standard for someone with disabilities.

I've not seen it personally but aye heard about it.

>> We're going to go see it.

But apparently this apartment -- nobody lives in this particular apartment but it's got sensors in the rooms, it shows when the refrigerator opens and closes, when somebody goes in the bathroom and if they spend too much time in the bathroom.

There are no cameras but it's monitored /.

If he were to live on his own, which we anticipate, it's another level of knowing he's okay without somebody having to be there cramping his style.

>> And I really want to be a public speaker.

In fact

my mom -- I always have a set mind of ideas that I want my future.

My mom says individuals with disabilities can be entrepreneurs and one of my friends, and my mom gave me the idea of starting a public speaking business.

And I agree with her.

We haven't fully launched it but we're working towards that.

>> And you have had several gigs.

Do you want to see if anyone has any questions?

>> I have several gigs.

In when I was in seventh grade I gave my Down Syndrome presentation, the first time I actually spoke about my disability right there live.

>> Publicly to a bunch of people.

>> Yeah.

>>

And Gigi's fundraiser , Gigi's play house grand opening.

And this past year I had the opportunity to speak at the family YMCA.

And my mom's church in greenville, South Carolina , living with an extra chromosome.

The national Down Syndrome Congress conference which is awesome.

>> You spoke there about your experience with John Bradford.

>> Yes.

I spoke about my experience in the

legislature, which I loved talking about.

And I had the opportunity to speak on behalf of the Raleigh Mayor's committee on international development and disabilities regarding employment . They always have a case speaker and this year I was lucky enough to be their key speaker for the start of the teacher's administrative year.

>> He spoke to all special ed teachers in the county, individuals in the morning and in the afternoon.

>> Were you nervous in.

>> No.

I was not nervous.

That.

>> It's making me nervous, the numbers.

>> And I spoke at the middle school, my first time speaking to people younger than me publicly.

>> Yeah.

Little kids.

>>

And the one-year anniversary celebration.

>> And you've been invited back to another elmeant I have school to speak to the third grade about your disability.

>> Yes.

Does anyone have any questions?

>> We have a question from someone online, Ruth, and she would like to know from all of you, can you talk about your experience in public libraries and what

kind of programs the public library could have offered when you were either growing up or now that you're an adult.

>> The resources I have had have been numerous.

Easter seals.

>> They want to know if you've had any services within the public library.

>> No services in the library for me because my disability is more mental.

>> They could provide things.

Matthew utilizes the public library all of the time.

He goes with frequency probably once a week either with a worker or with family or a brother, checks out books and everybody has been wonderfully helpful.

I don't know that's anything above and beyond other than them being extraordinarily helpful.

They've been patient and showed him several times -- I know they had to show him how to look up books and that type of thing.

They probably did that more times for him than they would have for a typical person.

>> For me, I'm a journey.

Growing up libraries, you sat quietly at a desk, you said nothing, did nothing but hold a book.

Growing up for me with a book was pretty much looking at pictures.

I currently used an overlay because paper, black and white paper looks likants on a napkin to me.

I can't afford to buy the glasses that are out there because they're very expensive so I use an overlay, a colored

tent -- I didn't bring one with me.

I didn't think to bring it.

Sorry.

And putting that over the black and white allows my eyes to adjust to see the letters.

So growing up was challenging.

I guess I was faking it and didn't know I was doing that, right?

I was trying to learn.

The library growing up was that way.

College level, again I'm a journey, I sat on the floor and I had all of the books surrounding me.

It took me an extremely long time.

The library wees would say shhh.

I had a card catalog.

And thank goodness I learned my ABC's and liking numbers helped me to find books on a shelves.

The more books around me the better I felt, even though they weren't the best book and not always the best books I needed.

Going to a library was a privilege and I guess it still is.

But it's a privilege.

It's your first library card was like getting I guess a gas card now, you know.

Because you had to go to that librarian and just like you see on TV, the old shows, the librarian sat behind the desk and you had to stand there quietly and patiently waiting for her or him to acknowledge you and then they would do some things and next thing you know, this is your library card, do you destroy it, make sure you bring books back on time otherwise there's a fee.

That's my life in the library growing up.

By the time I got to college different atmosphere.

A little changed.

Oh my gosh, nobody is available to help you.
You're wandering.
They didn't help you.
They sat behind a desk.
At least in grammar school and high school they knew that you needed help.
In college it was fend for all, you know.
You're supposed to know this already.

Now as an adult I go to the science library at ACU just because I'm in awe.
I'm not really looking up anything.
Sometimes I'm sitting there with my laptop.
Sometimes I'm there hoping somebody has a question about something so I can share.
It's painful for me -- here's the tears.
It's painful for me to go in a public library that's not associated with a college because everything is technology based.
Everything is you have to know how to download, you have to know -- granted, I know the words.
You have to know how to upload.
You have to know about different aspects on the computer, how to -- you saw me phub bling with the Power Point.
That was stressful for me.
Even putting it together was stressful.
But I had somebody in my ear saying click on this button.
I'm an older individual.
I didn't grow up with the technology that most of you have.

So going to the library, although it's extremely painful, I still enjoy going.
Do not do well with touch screens.

It's a sensory issue.

It can never change.

Hate the idea that we're forced in the community by stores to go through the self checkout and everything is touch screen.

I don't like that.

And so I'm constantly saying I need you to check me out at the register.

Going to the public library and having to sit there or try to get help is really painful.

Versus a college library.

I feel at home at a college library more so than the public library that I live at, you know.

I'm sure there are things that can change but it won't change for me because I'm an adult and they assume that adults know what they're doing.

Sorry, I don't.

And to try to explain autism to people, it's extremely hard because they say they understand but they really don't.

And the time it takes me to say I really don't know what you're talking about, you know, I don't know what that word means I can say that word but I don't know what you mean.

It's best for me to ask for help with my friends who understand me a little better.

But I still go.

I love the college science library.

I just like going there.

I
somebody helps me, how to scan a book.

I don't know anything about that.

But I know it can be done.

I hope that you guys will make a change

for the seniors like myself you know that are out there who may not say they have a disability or may not look like they have a disability but need help.

And I hope you guys are the ones who make that change because you would be surprised how many will not even touch a computer because of the experience in going to the library to check out a book, hope you can read it.

I can with my overlay.

And I go to Barnes & Nobles all of the time, even though it's not a library but I go and buy books because it's a good thing.

>> The same question but I guess for Matthew, how old were you when Gigi's was started here?

>> Our Gigi's is only two years old here.

>> .

>> Very recent.

>> So were there places that you liked to go when you were younger to do things in your community?

I guess what -- where did you hang out, with your friends or what kind of things did you learn to do?

>> Yeah.

I loved hanging out with friends and that's one of the biggest challenges for me with my diagnosis because when our Gigi's was brought out to Raleigh, all my high school friends were juniors or already accepted into colleges, universities or seniors or ones that were already in college.

Only two of my friends that I hang out

with, but only periodic cli so there was a huge social challenge for me.

But Gigi's play house, it gave me a place to interact with individuals with my type of disability, those who have a hard time in life.

>> How about growing up.

Was there any place that you went that you can remember that we did as a family or that you did with friends?

I'm not really remembering anything other than just typical family interactions and events that we would do.

When he was little he was very sensitive to noise so he wore the head phones.

Cough earplugs.

>> Yeah, in my pocket in case you guys got loud.

>> He doesn't need them as much anymore.

But so I think that we've really not had the need for that.

I have much more than he has.

>> I'm asking because like my daughter goes to Gigi's sometimes so she has her Gigi's friends and I can see that having that community of people who are like her fulfills needs that I can't fulfill for her.

Actually more for her than me.

Gigi's is her spot, right?

So I wondered like how -- if we were trying -- people who are work in the libraries going back to the question, we're trying to create a friendly place in the local community.

What kind of place -- what would that look like?

>> I think it would be -- we have a

satellite Gigi's in chapel hill near Southern village.

I don't know chapel hill very well.

And there's a church right there.

And they will generously give us some of their space so we have some programs that we run there.

But it would be amazing if you could have -- if libraries could have some kind of work, even work with Gigi's and provide -- we could certainly provide the training if you had volunteers who would come in and run a program at your local library for the little kids, an LMNOP, sign language and music or just story time.

We have Kinder music come in and do that.

Any of that kind of stuff, it's great to have the opportunity to be just with people with Down Syndrome, although with do not exclude people with other disabilities.

Anybody is welcome at Gigi's.

But also to have an inclusive play date at a local library on a Wednesday morning, do it just all two to five-year-olds.

However it is that you design it.

But a Gigi's could certainly come and train your volunteers or your staff to run it, to run a program like that or give you some idea.

That would be great.

>> We have programs at Gigi's play house for each age level, the little kids might be more discovering mine and gross motor skills, colors, more like do that kind of thing.

And then up to the kid level, like.

>> Yoga.

>> They do yoga, like strengthening the muscles and then you have teenagers, teenage programs for social interactions.

And we also have one for adults but primarily for adults it's more, because those adults are the ones that get jobs are more exposed to the vocational rules in the program.

It helps them learn how to cook, how to eat healthy foods and how to interact with the community.

>> One of the neat things for his age at Gigi's is that because he's not in school anymore -- I mean he has this program at wake tech but he's not in a social setting like high school was for him.

All of those friends are gone.

He doesn't have a lot of that.

That's a great thank that he enjoys at Gigi's is being able to hang out with peers his age.

>> Do you guys have any more questions?

>> Y'all have very quiet.

>> Experience at other koorcheses besides disability related conferences like S.T.

E.

M.

>> Yes.

>> How has that been possible?

>> I am always overstimulated.

But I have coping skill to keep me around it a little more.

There's a book called "no more meltdowns" by Jed baker.

And some of his techniques apply to me and some of them I try to implement.

But going -- I will never go to a music conference, just so you know.

I'll never ever go to one of those because I can't control the sounds and I go to S.

T.

E.

M.

and I'm sure you're familiar with S.

T.

E.

M.

where you're rock.

Big wheels on the chair I would be spinning about.

But I stem and then ooh people look at you like you're having a nervous breakdown.

Ill's because I can't control the stimulation.

I'll never go to a music conference.

But some of the other conferences, I know I need to be there, I know I need to be there on time.

I pull out any outfits in layers.

I sometimes run up and down the stairs.

That grounds my sensory system so that I can then sit still longer.

And for me, I do physical activities obviously because my field is physical therapy and business.

That has helped me a lot to be physically active in some ways.

As a child I was a power tumbler.

So as a power tumbler I was grounded more and could go out -- because we performed a lot.

I performed for the Knicks and the giants and all of the football players.

So in order to do that, not knowing

that I needed to, you know I didn't know
I was autistic then.

And having that physical impact helped
my sensory system stay grounded.

So those are some of the things that I
still do and I have to do.

Like yesterday I presented at ECU, the
occupational therapist in charge
knows that I need to take breaks.

So I would go out and do wall pushups
in another room away from everybody
because I get so wired.

She can pick it up because she's
occupational therapy.

And

she was like, okay, let's take a break.

Sometimes I have to be reminded.

But you know how you sit and fidget in
class and
reposition, same principle just a
little more intense.

Any more questions.

>> Matthew, can you talk to us more
about or do you have any tips for us for
advocating what we're passionate about?

>> Yes.

I'm an advocate, no matter what
disability you have.

It's equally
important.

The way it's usually done is you stand
up for yourself but that's not all.

It's more like exposure out there.

And politically.

Because once you get your ideas in
that will potentially give birth to any
more potential bills which will

eventually become laws that will be accompanying both populations, disability and the typical population.

And disability population years ago, U.S. presidents, they had to physically climb up the steps of the capitol and protested on the grounds of capitol hill back then.

We need our rights to be heard.

We need accommodations.

And then it was very lengthy and a true example of awareness and advocacy.

Because of that dedication to the individuals with disabilities then, it gave birth to the Americans with disabilities act.

That came from awareness and advocacy.

>> On that same note, there's so many programs out there, especially for students who are -- and you guys are in the libraries -- that offer training.

Disability rights does offer training for advocacy, other programs for advocacy training.

What you're doing is you're standing up for a cause, something that you strongly agree with.

Like for me, I don't want to offend anybody, but I wish cats were never allowed united.

I don't push that because I would have to interact with one.

Here, even as students, you guys have challenges.

It could be something as simple as tuition going up every semester.

You may stand strong for that.

And I'm sure and the advantage you

have is social media.

And the advantage you have is library science.

You put that out there, you wouldn't be surprised how many other people agree with you and that becomes your passion and that's the cause you're advocating for.

Doesn't necessarily have to be for a disability.

It can be for anything that you personally feel strong to.

And the advantage is the social media that you guys have.

Because I never would have told people I'm an advocate.

I don't know how to spell the word, let aknow know what it meant.

But I'm constantly saying, that's not right.

I know because I'm sitting here and telling people that things are not right.

If it wasn't for disability rights for me who allowed them to have a voice.

The first day they met me say saw me in the corner and I was really quiet and now you can't shut me bawps they gave me that power.

The power to be -- it's okay to say no.

It's okay to say that things are wrong and we need to make a change.

Anybody

can be an advocate and should be because then we wouldn't have so many problems.

That's my spiel.

On my soap box.

Any other questions.

>> Last question.

>> Go ahead.

>> So you mentioned the sensory friendly theaters.

Is it the atmosphere of the theater or the movies changed in a way?

>> They change the lighting, they change the sound.

The movie itself doesn't change, it just changes those type of stimulations.

It may play at a slower speed in some cases depending on where you are.

>> But it's usually the sound and the lights.

>> Adjust them a little.

>> Okay.

We'll say thank you to our guests.

[Applause]

>> What we're going to do is we're going to take a -minute break.

Let me stop the recording.