

>> [The Pointer Sisters'
"Yes We Can Can" plays]
>> Now's the time for all good
men to get together with one
another.
We got to iron out our problems
and iron out our quarrels
and try to live as brothers.
And try to find peace within
without stepping on one another.
And do respect the women
of the world.
Remember you all have mothers.
We got to make this land a
better land than the world in
which we live.
>> Good morning, Virgin Islands.
This is "Ability Radio --
You and Your Life," brought to
you by the Lottery Commission of
the Virgin Islands, as well as
the Disability Rights Center of
the Virgin Islands.
Our show today's gonna focus on
the children of the
Virgin Islands.
School is about to start.
Little excitement about the
children going back to school.
And getting ready is a big, big
issue.
We got classrooms to deal
with, teachers to deal with,
parents, making sure that
they're ready to also have their
children back in school.
And in regard to parents, we
have a parent here this morning.
Chevell Simeon, right?
Did I get it?
>> You got it correct.
>> [Laughs] Okay.
>> [Laughs]
>> And, Chevell, how are you
this morning?
>> I am doing fine this morning.
I'm really happy to be here with
you and talk about our group,
the Virgin Islands Parents of
Autistic Children, and the
things that we'd like to see in
the community.
So thank you for inviting me.
>> Oh, my pleasure.

Pleasure of the Disability
Rights Center of the
Virgin Islands.

We've worked with parent groups
over at least 20 years, and
various aspects of parents
interacting with the department
of education and school
districts.

And at the present time, you
mention a certain group of
children.

And we were talking about
autism and autism spectrum
before the show began.

Want to give us a little brief
history of your understanding of
autism, and how the condition,
that generally affects children?

>> Sure.

Like you said,

Attorney Jennings, my name is
Chevell Simeon, and I am -- some
might say the founder for
VIPAC, which is Virgin Islands
Parents of Autistic Children.
The group started back in March
of 2017 with about seven
parents.

All our children are seeing the
same speech therapist, and we
got a call list together, and we
decided to get together and
chat, you know, share stories,
situations, experiences,
strategies.

And for about a year, that's
what we did.

We were mostly providing support
for each other, encouragement.

'Cause the children are
different ages, and so parents
whose children were older could
kind of give other parents an
idea of what something would
look like a few years later.

And so it was really
encouraging.

We decided to meet up
occasionally.

We had play dates to the water
park, to McDonald's.

Just social gatherings to
provide that opportunity for the

children to socially interact.
'Cause sometimes, when you have
a child on the spectrum, it's
hard to go on a regular
play date.

It's hard to do things that
other parents do with their
children that's seemingly easy.
For us, because our children
have these sensory obstacles,
certain things are too much for
them.

>> Could you sort of explain
that for the general public?

>> Sure.

Well, I am a parent of two boys
with autism.

So my journey might be different
from some people who might have
one child, or whatever the case
might be.

But for my one son, for example,
he has some sensitivity.

So when he goes into, let's say,
someplace like the movie
theater, although he might want
to be there -- he loves popcorn,
loves all the other things --
once the movie comes on, he has
to block his ears.

It gets to be too much for him.
Once the lights go off, he gets
anxious.

He doesn't know what's going to
happen next.

And so because he has those
sensory issues, something as
simple as going to a movie
is overwhelming.

My other son, he's completely
different.

He doesn't have those specific
sensory issues with sound and
light.

But he has what's called pica.
So, he will constantly be
picking up things, putting them
in his mouth.

He has low muscle tone,
so he'll be flopping on the
floor and doing all these other
things that draw attention.

And people say, "Well, what is
this" -- you know, he seems big,

'cause he's 3, but he's pretty tall for his age.

"Why is this big boy flopping on the floor and putting stuff in his mouth and..."

So it makes it challenging, because on one end, I try to support the one child who's having the sensory issues...

>> Right.

>> ...and then, on the other end, I'm trying to prevent the other one from, you know, not picking up stuff, putting it in his mouth, flopping on the floor, and all this different stuff.

So, that could be, like, a day in my life, what it's like to go out with them and try to have them have these experiences.

But in other groups, it wasn't as easy.

Whereas with the PAC group, parents had similar experiences, and so they could understand,

"Okay, it's not that these children don't want to be here.

It's not that these children don't know how to 'behave.'

It's just that it's challenging for them."

>> Good. Correct.

>> Yes.

>> And when would the symptoms or signs of, perhaps, a child having some measure of sensitivity or issues with regard to autism sort of manifest themselves?

>> [Sighs]

I've read some research and heard some parents say as early as a year, they could see there was a difference.

You know, some people earlier.

My children -- I can only speak for my experience -- they were both diagnosed at 18 months.

It was clear that there were some developmental delays, and within that time period, they were both diagnosed with autism.

So it's pretty recognizable

early on.

And all the research would say that early intervention is the key.

I know parents tend to shy away from getting the evaluations done because they don't want their child to be labeled, but it's not really in the label.

It's in the support.

And so, like I said, the delays, you're able to see them as early as a year.

Some children even earlier.

The child might not make good eye contact.

Most babies, they crave your attention.

They love the sound of your voice and things like that.

So if you're seeing a baby that seems like they don't want to be cuddled, they don't look at you when you're talking to them --

>> Eye-to-eye contact.

>> Yes.

>> Yeah.

>> You know, those are things you want to look out for.

'Cause I was one of those parents, I was checking off that milestone chart.

And at a certain point, my older son, he was hitting all the milestones, but he wasn't speaking.

At about a year old, he didn't have any words, really.

I was like, "Well, you should be saying 'mama,' 'dada,' something by now."

And he wasn't.

So for him, that was my signal that, "Okay, I need to pay closer attention."

My younger son, again, he was very different.

He was more floppy.

He wasn't sitting up on time.

He wasn't crawling on time.

So his was more of a physical-type thing that I

realized, "Okay, there might be some delays there."

But it's important to know the milestones...

>> Right.

>> ...and to check and make sure your child is meeting the milestones, and, if he or she isn't, to talk to the pediatrician about it and see if there's something you should be concerned about.

>> Well, for those parents who may not have their own pediatrician, isn't a Department of Health, through early periodic screening, diagnostics, and testing...

>> Yes. Mm-hmm.

>> ...they can take their child there to watch those -- like you say, the first two years, have that monthly or every-other-month check for the child.

>> Right.

There's a group that recently started.

It's VI Act Early.

And it's a territory team that is working on identifying the milestones and what children should be doing at each stage of development.

And they're working close with the Infants and Toddlers Program, which I think is something that you were talking about.

Once you have a concern and you either need to get a diagnosis or you need to get some support, the Infants and Toddlers Program is amazing.

Both of my sons went through that program, the 0-to-3, they call it.

>> Okay.

>> And they provide parents with speech-therapy support, developmental therapy.

Pretty much what your child would need to close that gap, to close that delay.

And so those are two agencies that I know of that are there to help parents with those first steps -- recognizing that there might be a delay and what you do next.

>> And what sort of support did you have after that?

Is it Head Start, or is it the school system?

>> After 0-to-3, there's a transition for most children. And, of course, throughout the child's experience, they have several evaluations to see where they are, to see what supports they might continue to need, or to see if they've made progress enough to discontinue certain services.

So, after the child is determined to be aging out of the 0-to-3 program, so when they're making 3, there's a transition meeting where you decide if you want to put your child into Head Start, what do you want to do with your child based on his or her needs.

Your child then transitions to what they call the Part B Program, and that's under special education.

So now, instead of the services being provided through Infants and Toddlers --

>> Which is Department of Health?

>> Right.

The services now are provided through Department of Education, the special-ed program.

And that is in conjunction with Head Start.

So, if you want your child to go to Head Start, you could definitely continue the services there.

But they do provide services with private preschools up until age 5.

>> Okay.

>> So you could continue to receive speech, developmental,

resource, OT, physical therapy, whatever your child has been determined as eligible for, through Part B.

>> Okay.

>> Now, when your child turns age 5, now, there is a little difference.

If your child continues on in private school, the services become limited.

I think what I was told is that if you're eligible for speech, you may continue that, but your child would have to go to a site school -- so a public school that provides speech services. In terms of the other services, like physical therapy, OT, those are discontinued after age 5 if you're in the private school. But if you continue on in public school, the services are still available on each public-school site, base.

>> Okay. I see. Okay.

And so that was the first point, that a parent has to make a decision with regard --

>> Right.

>> And I assume -- correct me if I'm wrong, 'cause I'm wrong a lot of times -- is that the private insurance, if you have it, can cover those services that are not provided in the private school?

>> Yes.

With my experience, my two sons receive ABA therapy -- applied behavior-analysis therapy.

So, it helps them with some of their behavior issues, how to handle certain situations.

It's a one-to-one type therapy, so each son has his own therapist.

And they work with the child specifically on what their needs are.

That is covered through my insurance.

>> Uh-huh.

>> So, that's not covered through any special-education or any other type of program. They also receive occupational therapy, which also helps them with some of their sensory issues and so on and so forth, how to kind of manage that. That's also something that's provided through insurance. So, if a parent has insurance, he or she could decide to go through their own insurance.

A lot of the services can be provided through insurance. Speech, OT, and ABA specifically I know you can do through insurance.

>> Okay.

And otherwise, if they're in public school, they'll get those services through special-education services.

>> If the child has an IEP and is determined eligible, they will receive services through special education.

>> Okay. All right.

And one of the aspects of what you already mentioned was early intervention.

>> Yes.

>> Okay.

I'll give you an example what it was like when I first encountered children with autism.

It was way back in 1976.

And what that school district did was give them one special-ed teacher for that district.

But at that time, the numbers were 1 in about 2,000 children were diagnosed as a child with autism.

The term "spectrum" probably didn't come up until later.

But my understanding now, even with the commercials that you hear, with Toni Braxton and all that, is 1 in 68, a child may be born with autism.

>> It's even less now.

It's 1 in 58.

>> 1 in 58. Oh, my.

>> When my sons were first diagnosed, it was 1 in 63.

Now it's 1 in 58.

>> Oh, okay.

>> So it's becoming more and more prevalent.

And I think it has something to do with more people being aware of the signs, and more people having their children evaluated. I don't necessarily think that it's some new phenomenon, I just think people are more aware, in a sense, and so they're noticing things, and so they're having their children evaluated, and then eventually diagnosed, if that's the case.

>> And then once they're diagnosed, then, from your experience, or from your knowledge, the child then is eligible for special-ed services through the public-school system?

>> Right.

So, with us, with my children, we had the evaluations done privately first.

So, after I brought my concerns to their pediatrician, she referred me to Dr. Wagner, who did their evaluations.

And so Dr. Wagner gave me the results for each child when, you know, their time came.

And then I took that information to Infants and Toddlers at the time, and so on and so forth, and then that's how it came about.

So, we went about it through getting a private diagnosis first, and then we took that information.

>> About how many parents are participating in your organization?

>> We started with seven parents.

Now we are up to 19, within the course of a year.

And I think the number grew because we started talking about what we were doing.

Before, it was more about just supporting each other.

>> Okay.

>> But sometime last March, one of our parents had a negative experience in the community, and so she approached a radio person and asked if she could come on the air to talk about, what is autism, how do you treat a child who, you might not understand what's going on with them, but you see them in the community -- you know, how you treat that child.

And so she went onto the air, and we heard so much feedback, and we realized there are people who do want to support individuals on the spectrum, and then we realized there were some people that just had no clue. They didn't understand, just from the comments that they made, and that kind of birthed our whole idea.

Like, "Okay, supporting each other is great, but we now need to get the word out.

We need to advocate in the community.

We need to do things to create some more awareness."

And so we started talking to people, and then this person said, "I know somebody we could add to the group," and so it started to build from there.

And that also was the catalyst for our Autism Awareness Month activities that we had last April.

So, like I said, we started with seven.

We're up to 19 members.

And we're hoping that it will continue to grow.

'Cause we know there's more than 19 families affected by autism here in the territory.

So, we're hoping to spread more

awareness so that more individuals realize that there is a group, there's several groups and organizations here to assist families.

>> Okay.

>> Mm-hmm.

>> And when you say "bad experience," I've seen issues where, in public, the child may have a behavior issues, and a lot of the public may think, "Oh, that's just a bad child." And they're reprimanding the mother, not understanding that the child has a sensory overload.

>> Exactly.

>> Right.

>> Especially in the Caribbean, where discipline of your children is such a big thing. Like, you know, it's like you go out in the public, and people expect that you're gonna handle situations a certain way. And they don't even consider, maybe the way that they're accustomed to handling situations might not work for this child or this family. So, it was something as simple as, I think, the child was giving a gentlemen his shoe. 'Cause some of the children have what's called "stimming" behaviors...

>> Uh-huh.

>> ...and so they will obsess over a certain thing, whether it's flapping their hands or spinning something around, tinkering with things. And so this particular child, he has a thing for shoes. So he takes them off, he plays with the strings. You know, it's his thing.

>> Right.

>> And so he was giving the individual a shoe, and the individual, you know, was like, "What's wrong with you? You don't do that."

What are you taking off your shoe for?
What are you giving it to me for?"
You know how we tend to "grouch" at people?
And so the mom was like,
"Well, if you didn't know, I'm right there.
You could have asked me.
I would have explained why he's giving you his shoe."
And all of us have that story. Every parent with a child on the spectrum has a story like that, where we were somewhere with someone who just did not know, did not understand.
And, you know, we like to say "Ignorance is bliss."
Sometimes you just don't know. But when it causes you to react with someone who just doesn't know better or can't help themselves, then it's not bliss.
>> Well, again, that's why this show -- so we can educate the public and let them know children who have autism -- and actually will be adults with autism at one point in time or other.
>> Yes.
>> And unfortunately the image of giving the shoe goes back to me thinking about President Bush in Iran, where somebody gave him a shoe by throwing it at him.
[Laughs]
>> [Laughs]
>> But the images that they have with autism, or the public has with autism, otherwise, you also got to realize, or the public should understand, sometimes children shut down, right, because of the sensory over-stimulation.
>> Mm-hmm.
>> You have those children who don't react.
Are some of those children in the community as well, within our...?

>> Of course.

>> Yeah.

>> And even children who have sensory overload who might "overreact" to a situation might be the same child, you're speaking to them, and they're not responding.

You know, I had an experience the other day where someone was telling my son, "Good morning," but he was fixating on the shapes on the ceiling, 'cause he has a thing for shapes.

And the person is talking to him, and then they're like, "Well, try answering me."

I was like, "It's not that he doesn't want to answer you.

It's just probably how he's processing the environment.

He hasn't quite gotten to what you've asked him yet."

And I think that's something we need to understand.

Autism is not an intellectual disability, per se.

That's my opinion on it.

It's not intellectual.

It's a communication disability.

It's more children have a hard time communicating.

Some of them are non-verbal.

My 3-year-old son is non-verbal.

He does not have any words.

He's, right now, communicating through what's called a PECS system -- so a Picture Exchange System.

>> Okay.

>> So, you know, it's not that these children don't want to interact.

It's not that they're not listening to you.

It's just, there's a barrier for some of them.

And like you say, they might shut down, they might not respond.

And so you have to be patient.

You might have to repeat something.

You might have to make sure

they're actually looking at you before you try to address them. Because the way their brain works, they're more concerned with whatever is around them that's interesting to them. And so, yes, some children do shut down and may not respond to you.

>> And that's one of the aspects of getting and educating the public, so they at least see that or recognize it, realize it's not all about them.

That really the child may have some different perspective on the world, what's going on around them.

And early intervention helps the children get over those barriers.

I know I was recently -- I think you've done it here.

I recently was in California for some medicals.

They have an afternoon showing for movies for mothers with children with disabilities.

>> Yes.

>> And they can go there, that matinee -- and I went with my daughter.

And children could walk around. They have the whole theater to themselves.

It was like 11:00 in the morning there...

>> Mm-hmm.

>> ...type of a movie showing.

>> I'm really excited about that.

I went to one put on by the governor's office last August or so, and it was my son's third time with us trying to go to the movies.

We've tried it other times, and it didn't work at all.

You know, either when the door closed, the lights went off, the sound came on, whatever it was, we had to leave.

So when I heard about the governor's special movie

showing, I took my son.
We didn't get to stay.
He cried.
He got overwhelmed because there
was some guests who came to
speak.
And so he was thinking he was
coming to see a movie, but then
all these people were talking,
so he got anxious.
And, you know, they had the
little princesses introducing
themselves.
And he was like, "What's this?
What's going on?"
>> "Show me the movie!"
>> Exactly.
So we didn't get to stay for
that one, either.
It was their Easter showing.
And I was like, "You know what,
there was a time where we
couldn't even sit in the
theater.
From the time the door closed or
whatever, he wanted out.
This time he was willing to
tolerate it, but it was all the
other stuff in the beginning
that made him get anxious.
But Jamila Russell, she was
there.
She was so kind.
She would say, "Don't worry.
This is for children like him.
And, you know, we want to
continue to have stuff.
So it's all about you.
Whenever he's ready to go in,
you go in."
And I'll never forget that
feeling.
And I was like, "We need to have
more of that."
So then I reached out to
Puerto Rico, their
Caribbean Cinemas office,
and I was like, "We'd like to
try to have one, our parent
group."
So during our Autism Awareness
Month activities, we hosted a
special movie showing.
And my son went.

And he went in and out of the theater, but at least he had the opportunity where it wasn't a bad thing for him to get up and want to leave.

There were other children who needed a break.

Sometimes they need what's called sensory breaks.

And so that was okay.

They could get up.

They could relax.

It wasn't dark.

The sound was low.

And after having that experience, and seeing that, if a child is exposed enough, if a child on the spectrum is exposed enough, he or she can learn how to manage those situations.

I continue to reach out to the rep in Puerto Rico and say, "Can we do this on a more regular basis?"

We need to have an opportunity where these children can come out, and it doesn't have to be an uncomfortable experience for other moviegoers or for them." And we continue to talk over the months, and then in June she was like, "We're gonna try.

We're gonna start to put on at least one matinee on whatever family-friendly movie that is out during that month, and we're gonna see how it goes."

And so they've had three since then.

>> Oh, great. Great.

>> Yes.

So, they call it Movies for All.

>> All right.

>> Caribbean Cinemas'

Movies for All.

>> Very good. Very good.

Well, got a little notice here that we're gonna take a break for our sponsors.

And, again, remember, this is "Ability Radio -- You and Your Life."

>> We got to make this land
a better land
than the world in which we live.
>> Oh, yes, we can.
I know we can, can.
We can, can.
Why can't we if we want to?
Yes, we can, can.
Yes we can
I know we can, can.
Yes, we can, can.
Oh, why can't we
if we want to?
Yes, we can, can.
>> Sometimes it's hard.
>> Yes, we can.
I know we can, can.
>> Times is hard.
>> Oh, why can't we
if we want to?
Yes, we can, can.
>> Good morning again.
This is "Ability Radio --
You and Your Life."
Archie Jennings here from the
Disability Rights Center,
with Ms. Chevell Simeon.
>> Yes.
>> A good parent who's talking
about -- we're talking about
autism, and children with autism
in the territory.
And part of what we've been
discussing is how the general
public reacts to children with
autism.
Again, with putting in mind that
these, again, will be adults
with autism in our community.
What are some of the other
services?
I know we talked about --
Usually there's an annual
conference for autism in the
territory.
>> Yes.
>> And could you go over, what
have been some of the subjects
or topics at the last couple
years?
>> So, VIUCEDD puts on an autism
conference every year.
The conference topics are
different every year.

So, this past April, their topic was geared towards disaster, and how to help individuals with disabilities in the case of a disaster.

How do you help them prepare?

What do you need to do?

Because let's face it -- trying to prepare for a disaster as a neurotypical, average-developed person is already difficult.

You add a disability to that, whatever that disability might be, whether it's physical, whatever the case might be, it becomes exponential.

It becomes even more overwhelming.

So this year's autism conference was about how to help those individuals prepare for the disaster, what should be in your disaster-preparedness kit, how do you help them to be able to identify themselves if you have to go to a shelter or something like that.

And so the autism conference this year, it was timely.

It was something that we might not have thought about here in our community before two cat-5 hurricanes, but we realized that there's a lot that we need to do in our community to help individuals with disabilities prepare for disasters, and how to function after a disaster.

So that was a topic for this year's conference.

I learned at the conference that we wanted to see in the community first responders be more prepared to interact with individuals not only with disabilities, but individuals, let's say, with autism.

Because we know someone with autism might not respond in a disability -- they don't realize that, "Okay, this is an emergency.

How do I speak to this policeman

or this EMT?"

And so educating our first responders as to how do they engage with a person with a disability.

And, so at the conference, there were different strategies that were talked about.

I think the one presenter was from Texas, and so she was talking about how they created a tips sheet for first responders.

>> Okay.

>> And I immediately thought, "That's something that we should do here."

If someone has ADHD, autism, whatever, and their tip sheet wrote down different disabilities that first responders might come in contact with, and how do you respond to that person, how do you help that person.

So that would be something great to see come to fruition here in the community.

So, at the conference, there were a lot of different strategies that were discussed as to, "Okay, what can we do here to help individuals not only with autism, but with other disabilities in the instance of a disaster?"

>> Okay.

So, I mean, the idea of tip sheets is good.

>> Right.

>> As well as, some communities call it crisis-intervention programs.

>> Mm-hmm.

>> So, they have fire, emergency, police are all given the same type of training in regarding to responding to persons with disabilities.

>> Right.

>> Not only children with autism.

But in regard to children, it's an issue of trauma.

>> Mm-hmm.

>> A person with autism already has perception problems and, again, getting overwhelmed. Did they talk about activities that children could perform...

>> Yes.

>> ...in order to overcome the traumatic event in regard to the hurricane, or preparation for the hurricane?

>> They did.

Two of the presenters were from Island Therapy Solutions, out of St. Croix, and their discussion topics specifically were activities you can do as a family to prepare, and how you can debrief after the disaster to -- they call it "check in," and see how individuals, everyone in the family was doing.

And they also talked about the persons in the family without the disability, because you're so focused on making sure that the person with the disability is okay, is taken care of, you know, you forgot about yourself.

>> Right, right.

>> And I thought about that. I was like, "Oh, my goodness. After the storm, I was like, "How are my children gonna get this service and that service?" And I couldn't get this person on the phone.

And I was so concerned about them, I didn't realize I was exhausted.

>> Right, right.

>> I was completely exhausted and depleted.

And so they talked about that after the storm, and I could relate.

>> Yeah.

One of my friends, after Marilyn, when I called him -- 'cause I had two daughters at the time.

He said, "Well, you got to take care of yourself if you want to be able to take care of anybody

else."

>> Exactly.

>> Just like the same thing they give you on an airplane -- make sure you put your airbag on first before you turn to help others.

>> Anybody else. Mm-hmm.

>> Yeah.

>> So, they did talk about that, and that was especially helpful. And they give out a lot of information at these conferences.

When I went to the 2017 conference, it was the same way. The presenters who came from away, they gave you all the materials.

So you're able to learn.

You're able to learn more about it even if you're living it day to day.

You get information that helps you to be more informed about what you can do as a caregiver. Because, I mean, while I belong to a group that's called Parents of Children with Autism, there are some people in the community who might not be a parent, but they're in the life of someone with autism.

They might be a caregiver for someone with autism.

So it's important for everyone to be aware of what's available.

>> Have you ever thought about expanding that to caregivers of people with autism, as far as your core group?

>> We have.

Because we realized that, as a parent, sometimes we are so busy taking our child to this therapy, that therapy, sometimes we don't even have enough time to devote all that we should to our organization.

And we were like, "We need to bring in other people."

The same way we need support to help with our children...

>> Right.

>> ...we need support with our organization as a baby, as a child of ours.

Right?

>> [Chuckles] To grow.

>> So we have definitely called on the help of individuals who are helping in our lives to be a part of our group.

>> Okay.

>> To help us with organizing our events.

We had a lot of individuals who helped with our autism rally in April who weren't parents, but they were a part of the support team that we parents had.

And so, yeah, we've thought about it, and we definitely would like to see it grow to VI People, right [Laughs] for Children With Autism.

So we'd definitely like to see it grow.

>> Yeah, because part of it is that the children will now become teenagers, will now become adults, and they're within the family.

So that information that you're sharing can only enhance the whole entire family in supporting the growth of the child through their various stages.

Because they're still gonna go through that teenage years, the puberty years.

>> Yep. Mm-hmm.

>> [Chuckles] Years when they want to transition and go and be on their own.

So there's a lot of different stages.

>> And like you say, they're going to need support at each stage.

It's almost scary, as a parent, because as a child, there's so much interventions that I have learned about that my sons are a part of, but I see it getting less and less as they get older.

And that's almost scary, because at certain periods in their life, they might need more support.

But that's something that I would like to see our organization partner with other organizations to do, and that's to make sure, at every level or stage of a person's life, they have the support that they need.

Because it's important. Without the right support system, where will these children be as they get older?

>> Right, right.

Have you reached out to any national organizations that may already have some of those programs in place?

So you don't have to invent the wheel, is what I'm saying. You just replicate some of these programs that are already in existence.

>> Reach out, not at this point. But research, definitely. We've been looking at other programs Stateside.

We had a parent who was local who's now in the States, and so she gives us a lot of feedback as to what she's seeing there, things we might want to incorporate.

We don't want to reinvent the wheel, but we do want to create things that are specific and unique to our community. 'Cause a lot of times we tend to adopt things that don't fit our specific needs.

So we're still in the research phase of it, and looking at what other programs are out there for different stages of individuals on the spectrum, and then we want to help to create something that's specific to the needs here.

>> Well, you want to make it culturally sensitive...

>> Right. Right.

>> ...to the Virgin Islands.
And that's all well and good.
And what I was also thinking of,
you have all the parents who are
no longer in the school system
that have children.
Have any of those been
incorporated into your
organization?

'Cause they're now with adult
children with autism.

>> Right.

In the organization, no.
I think our oldest child is 20.
We have a 20-year-old, we have a
16-year-old.

Because even though those
numbers seem like adults,
teenagers, they're still very
much dependent on their
caregivers, their parents.
So we do have some older
children in the group, but
parents who, let's say, children
have left school, we've reached
out to them.

They definitely helped us with
trying to put together some of
our activities, and giving us
some information.

But we don't have any in our
group right now.

That's not to say we don't want
any.

We want any person who's a
parent, caregiver of a person
with autism in our group,
because, like you say, you can
benefit from their experience.

>> Right.

>> I had a parent who recently
joined the group, and she was
like, "This is so wonderful,
because when my child was
your children's age,
I didn't have this.
I had to figure it out
on my own.

There was no support group.
There was no social group.
You know, I had to pretty much
figure out how to do all of this
on my own."

So we realized that their

experiences are different from what we are experiencing now, and so they have a lot to offer.
>> Right.

And as far as building sort of a directory of available services, and keeping those services in place is essential to the Virgin Islands.

>> Right.

>> Because my understanding -- I don't know where they are on speech, occupational, physical therapy -- all therapists are still here after the storms?

>> [Sighs]

No. After the storms, every agency that I can think of lost therapists, lost providers. There was a shortage. The ones that could come back probably decided not to come back.

Other people decided to leave even before the storm.

So, for example, my older son, he was determined eligible for occupational therapy.

Before the storms, the school year before, he was receiving occupational therapy, and he was doing great.

After the hurricanes, I learned that the occupational therapist had decided to relocate even before the storm.

But because of the storm, the department could not attract anyone to come and replace her.

>> Okay.

>> So he went an entire year, an entire school year, without occupational therapy.

Now, it's in his IEP, and there are goals attached to that therapy, so he was never able to work on those goals.

So that's a specific instance where there was a void.

There was a therapist that was needed that wasn't here.

I was constantly told that they're working on it, they're trying.

With the current climate of the island, people just aren't jumping to come in a disaster-ravaged environment right now.

People aren't trying to come and be without power.

And I could understand.

>> Right, right.

>> And, you know, I used my judgment as a parent to decide, "Okay, I'm not gonna push when I know that it's going to be hard for them to attract."

But I know that they have lost therapists since then, so I just want to see what this school year brings, see what they were able to do over the course of the year.

Because these providers, support staff, whatever, they are important and integral to these --

>> They're critical.

>> Yeah.

...to the children's success.

So, I know there are probably some vacancies with therapists that are needed.

>> I wanted to remind the general public that if you have any questions regarding this issue, you can call in at 779-1079 or 713-1079.

We're talking with Ms. Chevell Simeon.

And this is Disability Rights radio, and we're talking about autism and the autism spectrum this morning.

In regard to upcoming things, what do you see for the upcoming school year with the children?

>> For the upcoming school year, I'm going to have a kindergartner.

My older son is going to kindergarten.

>> Okay.

>> And I'm super excited, but still anxious, because like we just said, I know that there's been some struggle to

attract the necessary
therapists.

So I'm just hoping that when
school starts, everybody is in
play, and everything is, you
know, on schedule to happen the
way that it should.

So, I would just like to see the
schools be ready to receive
these children and to provide
the supports that they need.

So, our group is planning to
meet later this month, 'cause we
meet on the third Friday of
every quarter.

Third Friday of every quarter.
And so one of the topics we're
gonna talk about is, at our
respective schools that our
children attend, what is it that
we need to see at these schools?

Now, if your child is in a
private school, you set up the
therapies as you see fit
as long as the school allows
therapists to come in,
which a lot of the private
schools do because the parent is
paying for that.

Now, at the public schools, we
need to make sure that we are
advocating for our children,
making sure that the services
they're supposed to receive,
they are receiving, and if not,
what can we do to help make that
happen?

So those are things that we're
gonna be talking about at our
meeting in a few weeks.

>> Oh, well, you want to make an
announcement about the meeting?
Where it's gonna be at, and how
to contact you or whoever's
gonna be organizing the meeting?

>> Okay.

If individuals interested in
attending our meeting, it's
going to be held at the Island
Therapy Solutions office,
and it is going to be on
August 17th, 20th.

I don't have my planner in front
of me.

>> I think its' the 17th, yeah.

>> All right.

August 17th.

And so if you would like to attend, you can e-mail us at VIPAC2018@gmail.com, and then I will be able to give you more information as to what we're gonna discuss, and other information about the meeting.

>> Yes.

Got a caller on line.

>> Yes. Good morning.

>> Good morning.

>> This is Iris.

>> Oh. Good morning, Iris.

>> Good morning.

>> Morning. Morning.

I just wanted to congratulate your guest this morning, because she's very articulate, very knowledgeable, and, wow, very, very informative.

Thank you so much for all the information you're providing the community.

It speaks well of you and your passion for getting a lot of parents involved, and for getting other people involved, too.

You reached out to me.

[Chuckles]

My comment, though, or my question is, does your group involve non-English-speaking children?

I know in St. Thomas you have many children that speak Creole and Spanish.

Are you reaching out to the parents of these children, too?

>> That's an amazing question.

I don't have anyone in the group who is not English-speaking.

>> Okay.

>> Just because it's a little bit difficult, I've learned, to get individuals who are willing to be a part of the group.

And let me say it like this --

When I first started the group, it was parents who agreed to

have their numbers on a call list.

There are several parents who did not agree to have their numbers on that call list.

>> Right. Mm-hmm.

>> And so while we would definitely welcome any parent, because it's about supporting families, we just have not been exposed, I guess, to those parents specifically.

We were working close with the State Director of Special Education, and she would help us to promote our activities in the public schools, but no one who was a non-English speaker ever reached out to us and said, "I'd like to be a part of the group. I heard through my child's special-education teacher that this group exists."

So, I mean, if there are parents out there who are not English speakers, we will find a way.

You know, if you need the support and you want to be a part of the group, we will definitely welcome you.

But in trying to get those parents and reaching out to them, it's hard if they don't kind of know that we exist and reach out to us.

'Cause most people will not share their client lists, their parent lists and all of that, I guess for confidentiality issues, and that's understandable.

>> Right.

>> Well, one way you can reach out -- Iris, are you gonna be doing the Head Start?

Iris is part of our office.

She's the lead on

"Ability Radio."

>> Okay. [Laughs]

>> She had us going.

And the Head Start, I was thinking while you were talking. The Head Start program is having

its orientation, and I didn't know if you were gonna cover the non-English-speaking part.

>> Yes.

I plan to go be there to cover the non-English-speaking.

>> Well, I'm gonna try to get some information from Ms. Simeon as to her her organization, and we could pass it out at that time.

>> Sure.

>> To reach out.

>> Yeah, we can give it to the parents, right.

>> That sounds good.

>> And that would be at least the Head Start program.

And then, generally speaking, at the beginning of the school year, I know before the hurricane -- they didn't have it last September, of course -- is that they would have a parents' day orientation.

>> Yes, they have it.

>> They're gonna have it this year?

>> They're gonna have it this year.

>> Where are they gonna have it at?

Because before, it was at Marriott Frenchman's Reef.

So where are they having it this year?

>> I don't know yet.

[Laughs]

>> [Laughs] Okay.

>> But I do know they're gonna have a parent orientation.

It came out in an e-mail.

But it was to-be-announced.

You know, one of those things.

>> Okay.

Well, that's when I would pass out information about Disability Rights Center.

>> Mm-hmm.

>> And I assume they have one on St. Croix, and that would be another way we can also reach out to parents with children with autism, and the

non-English-speaking parents, as well.

>> Right.

Because they have another barrier that they have to overcome, and that's why they would even need more support, in a sense.

>> Mm-hmm.

>> Because sometimes I feel for the parents who don't know how to advocate for their children, who don't know what's available. You know, my heart goes out to them.

I'm an educator.

I'm fairly familiar with the system.

So I know a little bit more.

But what about the parents who don't know, and who so need the help?

So, any way that I could get in contact with those parents or with that demographic, I would be more than willing to do that.

>> Well, and when I go in today, I will push for parents to find out more about your program. And whatever information you can share with us to disseminate there is certainly quite welcome.

You're doing a great job.

Thank you, thank you, thank you.

>> Oh, thank you.

>> Thank you for that issue, Iris.

>> You're welcome.

>> And hopefully we may have made a plan here just this morning.

[Laughter]

That's the way I like to roll.

That's the way I like to roll.

Action-oriented.

>> Thank you.

>> Take care.

>> Okay. Bye.

>> Have a great day.

have a great weekend.

>> You too.

Okay.

>> So, again, it sounds like we

got a note to go to our sponsor.
So, "Ability Radio -- You and
Your Life."

[The Pointer Sisters'

"Yes We Can Can" plays]

>> Love and understanding
is the key to the door

>> I know we can make it

>> All right.

"Ability Radio."

Back to you, and

"You and Your Life."

Ms. Simeon, we are about to go
to the final stretch here.

>> Okay.

>> I was gonna offer you,
what's coming up with your
group?

How can people make sure they
may have contact with you?

You want to give some
information of what you expect
for the next year?

>> Okay. Great.

Let me start off by saying,
the group has been in existence
for relatively a short amount of
time, but in that time, we've
really tried to make as much
impact as we can.

We'd love to grow our numbers so
that we can do more in the
community.

Last April, in Autism Awareness
Month, we put together four
activities within one month,
literally.

And we decided that we want to
continue to do this yearly.
So we would love more input from
the community.

If you are interested in working
to help us bring about awareness
of autism here in the Virgin
Islands, we'd love for you to
reach out to us.

You can contact us via e-mail.
Our e-mail address is VIPAC --
so V-I-P-A-C -- 2018@gmail.com
And we check it regularly, so
you send us an e-mail, we can
reply.

And you can just let us know if
you want more information about

the group, if you want to be a part of our planning for next year's Autism Awareness Month activities, or just if you have any questions about different things that are available here. So, again, the e-mail address is VIPAC -- V-I-P-A-C -- 2018 -- 2-0-1-8 -- @gmail.com.

We also have a Facebook page. So you can look for us on Facebook.

The name of the page is Virgin Islands Parents of Autistic Children.

You can look for us, like our page.

We put up pictures, posts of our activities, so that we're trying to make sure everyone knows what we have going on.

So, for next year's Autism Awareness Month, we're trying to do our activities a little bigger.

So we're hoping to do some really fun things.

Our rally, we want to keep that. We want to have our rally again, because we had such a great time doing that rally and fun-day.

And I want to thank Attorney Jennings for being one of our guest speakers at this year's rally.

>> My pleasure.

>> [Laughs]

So, we want to do that again, definitely.

So we're just looking for ideas. Ideas and community support for next year.

>> And you have an upcoming meeting this week, right?

>> We do have an upcoming meeting, yes, this coming Friday.

Yes, yes, yes.

So, if you're interested in attending the meeting, definitely you can e-mail us, and I will give you more information about the meeting.

It will be at the Island Therapy Solutions office, so I can let you know where that is if you don't know.

And, yeah, we're looking forward to just continuing to spread the word about autism here, and what we can do as a community to help.

>> Okay.

It's a community, and we all work.

And like I said, it takes a village to grow a child, so --

>> It sure does.

>> The whole community should be involved.

>> Mm-hmm.

>> And, again, thank you for coming.

Lots of great information.

And hopefully, parents, you got an ear to the show.

We also replay this show on our website at DRCVI.org.

We have "Ability Radio."

You can go to that category, pull it up, and listen to some of the details of this show via the website.

Take care.

Have a great weekend, Virgin Islands.

And that's a wrap for

"Ability Radio --

You and Your Life."

>> Thank you.

[The Pointer Sisters' "Yes We Can Can" plays]

>> Iron out our quarrels and

try to live as brothers.

And try to find peace within

without stepping on one another.

And do respect the women of the world.