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00:00:05,678 --> 00:00:23,878

Tony Hernández Pumarejo, writer and author, professional and motivational speaker, television presenter, life coach and ambassador

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00:00:23,878 --> 00:00:31,998

international for autism and mental health.
He is proud to invite you to his podcast, My Time,

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00:00:31,998 --> 00:00:33,678

with Tony Hernández Pumarejo.

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00:00:39,630 --> 00:00:46,990

Hello, welcome to this new episode of My Time with Tony Hernández Pumarejo.
This is your affirmation, Tony Hernández Pumarejo.

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00:00:47,190 --> 00:01:02,350

And today we are, today I have a very special interview
with Mrs. Lucia Barbet. Lucia is a mother of an autistic young adult and she has a
story that is,

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00:01:02,550 --> 00:01:14,358

which maybe you can say is common because she is the mother of an autistic person,
but at the same time I always say that in autism there are different stories.

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00:01:14,558 --> 00:01:26,998

We have common things, but it is always important to learn
about how autism is experienced, especially from the perspective of parents and

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00:01:27,198 --> 00:01:42,798

mothers. So Lucia has her professional
with BCBA who is Assistant Behavior Analyst.

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00:01:45,158 --> 00:02:00,238

She can work, she knows how to work, that's not what she is, it's ABA therapies.
Exact. And Lucía is, she is a member of the Board of Directors of the Autism Society of
Florida,

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00:02:00,238 --> 00:02:11,654

which is an organization... that advocates for the rights of people with autism in the state of Florida and is an organization with which I am very familiar. I was previously part of

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00:02:11,654 --> 00:02:20,914

the Florida Autism Society organization, so I have the honor privileged to be presenting Lucia Barberto today. Lucia, thank you for coming.

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00:02:20,914 --> 00:02:27,234

today to this episode of MyTime with Tony Yendandes Pumarejo. No, thanks to you for the invitation. A pleasure.

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00:02:27,854 --> 00:02:36,374

And I am happy to be here with you and share part of my experience and my history with people to see if it can be of any use to them.

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00:02:36,574 --> 00:02:45,294

Well, the mission is accomplished. Exact. And that is the purpose of this podcast. I always say that if you can learn,

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00:02:45,494 --> 00:02:55,454

especially when we talk about different topics, but I always have a possible approach with what autism is, the reason which is because autism is

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00:02:55,654 --> 00:03:11,054

my main job. being what an advocate or defender of autism is and not only being a defender, but having lived with autism since when I was reviled, at the age of three.

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00:03:11,254 --> 00:03:19,694

In other words, autism is part of my life, it is part of who I am. And that is why I know that autism is very important to me and there is

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00:03:19,894 --> 00:03:32,950

We have to talk about it and not only do we have to talk about it, but it is a mission that both you and I have.

of our society to advocate, to create awareness, acceptance of human beings

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00:03:33,150 --> 00:03:43,670

autistic humans and create action in our society to help other beings
autistic people and their families in giving them the tools and support to fulfill the

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00:03:43,870 --> 00:03:54,270

mission that we all have in autism, quality of life.
So I have no no. Perfect. So again, Lucia, thank you for coming and Lucia, let's get
started.

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00:03:54,470 --> 00:04:06,254

I always ask this question. to all my invited guests.
And I want to ask you, how would you define the life of Lucía Barberto,

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00:04:06,254 --> 00:04:17,694

especially being a mother of a professional autistic son?
How would you describe your life in a few words?

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00:04:17,694 --> 00:04:24,966

I would define my life in a before and after.
A before, well, as a woman, as an immigrant, as a Hispanic,

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00:04:25,046 --> 00:04:32,686

In a country where I did not speak the language when I arrived, 25 years ago,
where I had many dreams and many goals to achieve.

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00:04:32,966 --> 00:04:39,686

I fulfilled many of them because I became a professional,
I became an executive in logistics companies.

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00:04:40,486 --> 00:04:47,166

And, well, after a lot of effort and sacrifice
and to achieve a professional career in the world of finance,

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00:04:47,246 --> 00:04:56,942

Well, in 2004... my son came, my oldest son was born.

and really that meant, as I say, a before and after.

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00:04:57,022 --> 00:05:07,702

So, not only did he come with autism and at that time, obviously, we couldn't measure the severity of the degree of autism he had,

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00:05:07,782 --> 00:05:16,702

but also his autism is quite severe.

So... due to the severity of his autism and having developed epilepsy,

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00:05:16,782 --> 00:05:29,102

Well, Lucía Barbeito had to rethink her personal and professional goals.

So once we were able to, say, control Hector's seizures to a certain extent,

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00:05:29,182 --> 00:05:38,142

I wanted to reintegrate into the working world again,

but, obviously, not paying the price of continuing in my professional career.

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00:05:38,222 --> 00:05:45,254

So what I did was go back to university.

get some credits in early childhood education

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00:05:45,334 --> 00:05:55,174

to embark on a project... I was in a children's center...

That is, we had neurotypical and neurodivergent children.

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00:05:55,854 --> 00:06:03,414

I spent three years in that early childhood education project.

And being in that project, well, really...

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00:06:03,774 --> 00:06:13,670

That's where I think I really discovered the mission that God had for me.

In the... in the earth. I believe that we all come with a mission to this world

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00:06:13,750 --> 00:06:20,870

And mine, well, until that moment I don't think there was one...

or I had not been aware of what my mission was.

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00:06:20,950 --> 00:06:29,510

And then, well, I became passionate about working with children,
I became passionate about the world of education and returned to university again.

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00:06:29,590 --> 00:06:36,390

and got a certification in Positive Behavior Support,
in positive discipline strategies that are basically focused on the field of education.

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00:06:37,838 --> 00:06:46,358

And making that certification, well really...
I think that's when I also arrived and thought

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00:06:47,038 --> 00:06:51,878

that it was a way to be able to not only advocate
for the rights of people with disabilities

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00:06:52,598 --> 00:07:00,758

and be able to help my son, but I could also equip myself with tools
so that I can help other families from field work.

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00:07:00,838 --> 00:07:11,494

So, I started a master's degree in Applied Behavior Analysis,
in ABA therapy. which I graduated now in May, God willing, and I became a BCABA.

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00:07:11,694 --> 00:07:25,094

Now I hope to soon be a BCABA so I can help more families first-hand.
Exact. And not? And you have a mission and you mentioned a key word which is
mission.

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00:07:25,294 --> 00:07:33,234

So autism entered your life when your son was diagnosed in 2004.
How old were you when you were diagnosed?

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00:07:34,126 --> 00:07:41,886

Well, I realized that my son had a developmental delay.
since he was nine months old. The thing is that, of course, you know perfectly

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00:07:41,966 --> 00:07:48,766

that the doctors here always try to downplay it to parents' concerns in this regard

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00:07:48,846 --> 00:07:57,286

and then they tell you no, that all children do not develop the same, that children, especially boys, are more delayed in language, etc.

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00:07:57,366 --> 00:08:10,286

So, well, the diagnosis... The official diagnosis was at five years old through the Agency for Persons with Disabilities or APD, but a neurologist actually gave an impression of autism

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00:08:10,486 --> 00:08:26,322

on the autism spectrum when he was 18 months old.

Or that then we are talking for a while also that terms of resources and supports in relation to autism were not so.

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00:08:26,990 --> 00:08:35,230

I don't know whether to say the word abundant, but it's not like now.

Nowadays there are more tools and more supports

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00:08:35,430 --> 00:08:45,110

to support families in the process of an evaluation.

It was not like this in the past. I mean, many people may say that the rate of autism has increased, but there are

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00:08:45,310 --> 00:08:56,146

to have, that is, there may be different factors and these different studies.

But one thing that must be taken into consideration is that

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00:08:56,462 --> 00:09:09,262

The processes of making autism diagnoses have been improved and...

I think... What do you think? Well, I think it is true that we have made progress

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00:09:09,342 --> 00:09:15,862

in these last 20 years, let's say, my son is going to turn 20 this year.
I think there has been progress in terms of awareness.

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00:09:15,942 --> 00:09:23,422

I think that society knows more about the word autism,
which does not necessarily mean that you know more about autism,

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00:09:23,502 --> 00:09:33,774

But he has heard much more. talking about autism.
And we have made progress in that sense. In the field of education, in terms of
resources

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00:09:34,294 --> 00:09:43,654

for people to be able to educate themselves about autism,
I also think it has been improved somewhat. But I think there is still a lot to do in terms
of...

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00:09:44,774 --> 00:09:57,942

really have tangible resources, which translate into services that people have,
because... Although it is true that now Medicaid, for example,

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00:09:58,022 --> 00:10:11,422

here in Florida it covers HABA therapies, but then we have in the world within what
education is,
The public school system is sincerely deficient,

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00:10:11,942 --> 00:10:20,942

At least here in Miami-Dade County, which is where I live,
Well, it's unfortunate. I say this from experience.

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00:10:21,198 --> 00:10:33,398

as a mother and from my own experience as a health professional because I go to
schools and see how
education is being carried out in special education classrooms and sincerely

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00:10:33,398 --> 00:10:45,518

It's devastating. The situation is devastating because we see people, that is,
professionals

of education, teachers, who do not have the resources they need. We see children

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00:10:45,518 --> 00:10:58,198

in classrooms where there are an excess of children from my point of view.
and where, obviously, they do not receive the education that they are supposed to receive,

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00:10:58,198 --> 00:11:08,358

Not to mention that many times these classrooms are located in the back of the building.
or what they call portable, here, which are like classes of these portables,

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00:11:08,358 --> 00:11:19,398

That is, they are classrooms that are not part of the physical structure of the building, but they put them aside and that is where they educate these children.

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00:11:20,366 --> 00:11:27,086

The issue of special education is devastating,
although, as I say, resources in terms of therapies,

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00:11:27,166 --> 00:11:39,126

Yes, there has been a certain improvement, but there is still much to do.
And a lot to do, I would say. Because, you know, the case of schools of education

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00:11:39,206 --> 00:11:53,070

has been deficient. And many regrettable cases of abuse and abuse against the population.

We are not going to go to a recent incident step out of many that has occurred

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00:11:53,270 --> 00:12:03,830

unfortunately in the school system of a teacher in Tampa
that he abused and gave to a student with autism recently, for example.

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00:12:04,030 --> 00:12:12,150

Yes, I can talk about my own case. That is, I have my own first-person experience.
If you can share this one, because

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00:12:16,846 --> 00:12:25,646

who are listening and who are watching this podcast.
Yes, please, can you share the experience you had?

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00:12:25,846 --> 00:12:36,246

with your child in the school system. If you can share about that, please.
Well, my son was in the public school system

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00:12:36,446 --> 00:12:44,446

where they knew perfectly well because we just had a meeting that he
He had just left the hospital because he had epilepsy and was having seizures.

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00:12:44,646 --> 00:12:51,718

frequently. And then, well, he had an accident
where he lost part of his front teeth,

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00:12:51,798 --> 00:12:59,998

They were permanent teeth, not baby teeth.
And... to this day I still don't know what happened.

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00:13:00,078 --> 00:13:10,758

Nobody wanted to take responsibility, everyone looked the other way.
I had to sue the school district. There was a negotiation, we did not go to trial,

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00:13:10,838 --> 00:13:22,702

But I did have to sue them. And, obviously, I was scared.
I got scared. A very vulnerable person, because my son does not communicate,

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00:13:22,782 --> 00:13:32,542

It is not functional at all, it does not stand on its own for absolutely anything.
In an environment where this type of incident had occurred

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00:13:32,622 --> 00:13:41,022

and no one wanted to take responsibility, because, logically, my decision was to put
him in home school,
As we say here, not at school, at home.

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00:13:41,742 --> 00:13:53,654

And... through the scholarship that exists the government scholarships, the Step Up for Students,

Well, I can give you the education you need here in my house.

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00:13:53,854 --> 00:14:05,214

Yes, and that is and happens frequently in our community, in frequency, because unfortunately

These cases are happening that remain unsolved.

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00:14:05,414 --> 00:14:15,070

I mean, I was lucky. I was lucky that.

My private therapists, who worked with my son in my home,

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00:14:15,870 --> 00:14:24,550

They went to school. So, there was a gap between one and the other and that's when the accident happened. So, somehow, between one and the other,

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00:14:24,870 --> 00:14:33,350

There was that time when it could be demonstrated that before the second one arrived, my son was perfectly fine,

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00:14:33,430 --> 00:14:46,742

He did not have any type of physical damage. But I do have testimonies from mothers who wrote to me,

that is, they have written to me, because I have been moving for quite some time

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00:14:46,822 --> 00:14:58,142

in the world of defending the rights of people with disabilities.

I became a Certified Advocate in 2016. And well, I have had mothers,

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00:14:58,222 --> 00:15:07,438

One even sent me a photograph of her son.

with a bite on the shoulder. and unfortunately nothing could be done because there is no way to prove it.

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00:15:07,518 --> 00:15:13,118

They are children who do not speak, they are children who do not communicate,

So how can we prove that this happened at school?

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00:15:13,198 --> 00:15:24,518

It is impossible to prove. So, that's why...

Audition Society of Florida... Well, that was one of the reasons I joined this organization,

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00:15:24,598 --> 00:15:30,398

to be able to promote measures at legislative level

to be able to defend the rights of people with autism.

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00:15:30,478 --> 00:15:44,358

Exact. And... And going along those lines, Lucía, if you can't speak, because these are situations that

They occur in our community, that is, from abuse in the school system.

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00:15:44,558 --> 00:16:00,078

Students escaping from the classrooms, what is and is known, unfortunately many teachers who, although they have certain

certified, but they honestly do not have the experience to be able to work with the

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00:16:01,486 --> 00:16:12,406

with disabilities, it is sad that these unfortunate cases are beginning to occur and there is a lack of resources and training. Exact. And commitment.

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00:16:12,606 --> 00:16:21,526

A lot of things are missing. So that's why, that's why it's a combination of factors.

I mean, many things. That's why I say there have been improvements, but there is still a lot, a lot, a lot to do.

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00:16:21,726 --> 00:16:37,430

And it is reality. And these are the topics that need to be talked about about the realities of living with autism.

Because these are the realities that occur every day and, as many times,

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00:16:37,630 --> 00:16:48,510

Families feel abandoned, like no one is listening to us in society.

That's why I always say. It's just that in every interview I do I always say the same thing.

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00:16:48,710 --> 00:16:56,270

My problem is not my son. My son lives in an environment of affection, understanding, in a safe environment surrounded by his family.

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00:16:56,470 --> 00:17:04,830

My problem is when I go out. Finding myself with a society that many times...

The lack of tolerance, empathy, solidarity...

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00:17:04,910 --> 00:17:13,990

Come on, that's what abounds. That is really the challenge for all families.

that we have children with disabilities. Going out into the street with our children and finding you

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00:17:14,070 --> 00:17:26,110

people who are unable to put themselves in your shoes

for five minutes and understand a situation as complex as the one we live in.

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00:17:26,190 --> 00:17:35,038

Exact. And Lucia, let's talk a little bit, I mean,

We are going to talk about your organization Autism Society of Florida and the measures

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00:17:35,238 --> 00:17:43,718

legislative measures that you are supporting in favor of our population.

But first of all, because maybe there are people, no maybe, there are going to be people

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00:17:43,918 --> 00:17:55,474

who are not very familiar with autism, with the term advocacy,

to defend rights. If you can explain to our audience that they are seeing us and that they are listening to us

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00:17:55,822 --> 00:18:01,382

What does advocacy consist of? What is advocacy?

If not, can you imagine this already, please?

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00:18:01,542 --> 00:18:14,622

Well, as Nelson Mandela said, education is the most powerful weapon to change the world.

So, becoming an advocate for people with disabilities

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00:18:14,782 --> 00:18:30,798

or, in this case, certified advocate, is a commitment that one makes when educating yourself,

to prepare and carry out... collaboration with organizations that can promote the rights of people with disabilities.

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00:18:30,798 --> 00:18:42,358

At any level. In other words, not all people are good at everything, nor do all people have skills for everything.

So, to the extent of your possibilities, within what you are capable of doing and the skills you have,

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00:18:42,358 --> 00:18:54,838

Well, you must get involved to support organizations that serve our community.

In my case, I joined the Audition Society of Florida.

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00:18:55,182 --> 00:19:04,942

in my commitment to support initiatives that are carried out, especially at the legislative level. Florida Audition Society also offers other types of supports

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00:19:05,022 --> 00:19:15,502

and help, information, resources for families with autism, but especially what we do is join forces to lobby,

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00:19:15,582 --> 00:19:22,942

How can you say this in simple words, because really what we do is lobby in Tallahassee.

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00:19:23,470 --> 00:19:33,030

so that the laws that we consider necessary to ensure the well-being and independence of people with autism can be achieved.

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00:19:33,190 --> 00:19:42,190

And that is very important, lobbying or what lobbying is in English.
to be able to advocate for these legislative measures.

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00:19:42,270 --> 00:19:51,790

I've done that too, also as a defender.
I have gone to opt for Hassie in terms of fighting and...

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00:19:51,870 --> 00:20:03,534

and advocate. so that these legislative measures are approved in favor of our
population.
If not, give a little more detail about the legislative measures that are currently in place.

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00:20:03,734 --> 00:20:14,094

are under consideration in the Florida legislature.
Well, right now, as we speak, the Audition Society of Florida is doing several initiatives
in Tallahassee,

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00:20:14,294 --> 00:20:24,854

trying to pass bills that cover different points.
For example, one of them is the issue of cameras in special education classrooms.

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00:20:25,974 --> 00:20:33,094

Fundamentally, well, obviously, because of my personal situation,
I am one of the strong defenders of this measure

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00:20:33,774 --> 00:20:45,134

and well, I would love for everyone to support this measure
because I think it is very necessary. So, fundamentally, what we do is try to get that bill
passed

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00:20:45,654 --> 00:20:58,294

and is implanted. There is already a pilot project being carried out in Broward,
which will last three years. If I'm not mistaken, this was the last year in which the pilot
project was completed.

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00:20:59,254 --> 00:21:07,254

And the idea is that it does not remain a pilot project,
The idea is for it to materialize and become a bill.

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00:21:08,334 --> 00:21:19,014

Another initiative is a protocol that we want to carry out
so that schools are required to have...

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00:21:20,014 --> 00:21:30,374

Well, that's exactly what it is, right? As a protocol has been established when children,
the students, because of their... Well, because of their autism condition

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00:21:30,454 --> 00:21:37,934

or any other type of intellectual delay,
So they move away from the area where they should be.

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00:21:38,014 --> 00:21:52,718

Sometimes they do it unconsciously, other times they are not able to measure it.
the seriousness of what they do and they walk, they wander without really being
aware.

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00:21:52,718 --> 00:22:04,638

So we are trying to get a law passed in which the school has that
protocol and is activated immediately, because like the Amber code, for example, when

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00:22:04,638 --> 00:22:15,014

a child disappears. So, well, I think this measure is also very important.
Also, Audition Society of Florida is very committed

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00:22:15,014 --> 00:22:22,134

with the theme of awareness and prevention of death by agogo,
which is also closely linked to this issue of elopment,

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00:22:22,134 --> 00:22:29,254

which is said in English, the one that children run away from.
As you know, Florida is surrounded by water

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00:22:29,934 --> 00:22:40,374

and then there are cases, sadly, we have had, we know of cases that these children, when they have moved away from the area where they need to be,

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00:22:40,782 --> 00:22:53,342

Well, they have ended up drowned in canals and the truth is that they are deaths that somehow

Well, I don't know if they could have been avoided or not, but I think that every resource is

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00:22:53,342 --> 00:23:06,062

little to try to improve this situation. Then through Societal Audition from Florida we offer training, well, we try to raise as much funds as possible

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00:23:06,062 --> 00:23:13,638

possible to be able to... offer training to swimming instructors to teach people with autism to swim.

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00:23:13,638 --> 00:23:21,038

We also deliver alarms to put in homes so that if the child leaves the house without the father knowing,

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00:23:21,038 --> 00:23:34,678

Well, an alarm sounds and well, it notifies the father that a door or a window has been opened.

and then the father can take action. And we are also carrying out CPR training,

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00:23:34,678 --> 00:23:49,374

what is first aid. training parents so that, in the sad event that a time comes when that for some reason the parents have to do first aid, before it arrives

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00:23:49,374 --> 00:24:01,334

the ambulance, well they are trained for that. Basically I think they are some of the initiatives

important things that are being carried out. Also in the past, recently, Audition

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00:24:01,334 --> 00:24:12,294

What the Society of Florida did was... help pass a law so that what they call

Registered Behavior Technicians o las RBT,

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00:24:12,374 --> 00:24:23,454

who are the behavioral technicians who provide ABA therapy in schools,
Well, there is a law that somehow...

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00:24:23,534 --> 00:24:33,614

Because before it was this decision that the therapist gave therapy to the children in
the classrooms
it remained in an election of the main one.

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00:24:35,726 --> 00:24:45,566

I didn't consider that the therapist went to school, well no, no, no, I didn't let her
entered school. Now there is a law in which they cannot deny that the

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00:24:45,766 --> 00:24:54,566

therapist comes in so the child can receive the therapy services that
can help you become more independent. Excellent.

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00:24:54,766 --> 00:25:03,526

And don't we thank you for what your organization is doing for our communities in
Florida. And it is very important that our audience that is not watching, that is not

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00:25:03,726 --> 00:25:14,054

listening, keep in mind. Because we are talking about Florida, but it is very important
that this
It's everything in every country, every other state in America.

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00:25:14,254 --> 00:25:23,454

Very important when we talk about fighting for the rights of people with
disability including autism, it is not just talking about creating

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00:25:23,654 --> 00:25:32,734

messages on social networks, doing, writing a post, making videos,
talking about autism, inclusion, acceptance.

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00:25:32,934 --> 00:25:43,446

Actually. makes yes or defend is a process, it is working with agencies in the government, committees, it is a process that is not at all easy.

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00:25:43,646 --> 00:25:50,366

I can say it from my experience too.

is advocating different projects in Florida as well, such as,

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00:25:50,566 --> 00:26:02,930

training for police officers, for example, which is also a measure that is currently being considered in the

Florida legislature, but also other projects, not just children.

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00:26:03,182 --> 00:26:12,302

but also adults, because it is very important to talk about adults, because

There are gestures in children, but gestures for adults are much more.

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00:26:12,502 --> 00:26:24,782

And your son and his son are already in that transition phase.

You are no longer a child, you are a young adult. And I'm glad you touched on that point, because

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00:26:24,982 --> 00:26:33,958

One stops to think that I am not going to say the majority, but many resources. are intended for what is early intervention

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00:26:34,038 --> 00:26:42,238

or to the early stage of children. There is a lot of help,

many funds that are allocated to this cause.

154

00:26:42,318 --> 00:26:55,598

However, for the matter, once the young person or young adult passes the age of 21,

We see that aid is practically non-existent.

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00:26:55,678 --> 00:27:02,878

So, everything is now in the hands of the families.

The issue of housing is something... that worries a lot.

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00:27:02,958 --> 00:27:09,158

I mean, I know many families who have children with disabilities. who talk about these issues, the issue of transportation,

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00:27:09,238 --> 00:27:16,278

of the housing issue, of the labor issue itself. Also training for people with autism

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00:27:16,358 --> 00:27:27,726

to join the labor market, because the unemployment rate in this segment of the population is awesome. So... I think that part...

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00:27:27,806 --> 00:27:34,566

There is a pending matter regarding that stage of the lives of people with autism. Because it is important to highlight,

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00:27:34,646 --> 00:27:40,686

which is something I always like to mention, that autism is not a disease. Autism cannot be cured.

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00:27:40,766 --> 00:27:50,966

Autism is not reversed. The person can become more independent or less independent, more functional or less functional,

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00:27:51,046 --> 00:27:57,726

but the person is born with autism and dies with autism. Autism does not disappear from a person's life.

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00:27:57,806 --> 00:28:05,846

And that's what many people... And especially when... Well, when parents diagnose our children.

164

00:28:07,246 --> 00:28:16,006

I think we've all been there. The ones we already have... Our children are now of a certain age. At first, since you can't measure the severity...

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00:28:16,086 --> 00:28:24,646

Look, I just spoke with a person who told me that he could contact me.
with a mother who has recently diagnosed her son.

166

00:28:25,486 --> 00:28:37,966

and she, of course, is a little disoriented because she doesn't know the degree of
autism that her son is going to develop.
So, my answer has been, no one knows.

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00:28:38,046 --> 00:28:44,406

It's that when a child is two years old, three years old,
You are not capable of... I mean, I think there is no person, there is not even...

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00:28:44,486 --> 00:28:58,630

No professional parent who can... predict the extent of autism,
because, as a person who spoke on one occasion said, the diagnosis is not a
prognosis.

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00:28:58,710 --> 00:29:07,870

There are times when the forecast is painted black.
and then it turns out that the person manages to be quite independent

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00:29:07,950 --> 00:29:14,710

and vice versa. There are times when it seems like he is going to be a fairly functional
child.
but then develops certain comorbidities

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00:29:14,790 --> 00:29:28,342

which, as autism well knows, is often associated with other types of...
health problems or problems that go beyond the simple diagnosis of autism.

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00:29:28,422 --> 00:29:43,422

And then, in those cases, as I say, it is impossible to make a forecast of what the life of
a person with autism will be like.
And I agree with the different points you mentioned.

173

00:29:43,502 --> 00:29:55,254

What is clear is that every autistic person,
No matter the level of functioning, you can have that ability to achieve a better life
career.

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00:29:55,454 --> 00:30:08,094

All. Exact. Even level 3. Everyone.

It is again having the resources and support and giving the tool

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00:30:08,294 --> 00:30:18,054

so that they can achieve that best life career and work together, starting in
our community and together with society to provide these opportunities.

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00:30:18,254 --> 00:30:31,934

And there is still much to do. But we have to have that commitment to be able to
face these challenges that our autistic and ability progression also faces

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00:30:32,094 --> 00:30:43,254

to be able to see that those human beings can achieve that better life.

I know that there are many people who, because I have spoken with many families and
many parents,

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00:30:43,414 --> 00:30:54,246

that the issue of diagnosis is crucial for them.

I mean, it's like... There have been people who have told me, the diagnosis gave me, I
don't know, like that...

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00:30:55,406 --> 00:31:04,686

It was like what I needed to know, right? Which was finally like an answer to all my
questions, right?

And to a certain extent I can understand it.

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00:31:04,766 --> 00:31:14,526

However, in my personal case, I honestly tell you,

For me the diagnosis is the least important thing. Because the diagnosis can help you,

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00:31:15,446 --> 00:31:23,226

maybe here in the United States, to achieve...

therapies because sometimes without the diagnosis they don't approve you, the health insurance doesn't approve you

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00:31:23,226 --> 00:31:32,742

services if you do not have the diagnosis. But on a personal level, on a family level... Honestly, I don't care about the diagnosis because...

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00:31:35,086 --> 00:31:45,366

What difference can there be between my child having a diagnosis of autism or not? If when I go out on the street, that is, my son doesn't have a label here that says, I have autism.

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00:31:45,526 --> 00:31:52,926

In other words, my son has a series of difficulties which must be answered. And I think that

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00:31:53,846 --> 00:32:01,526

It is more based on the theme of seeking, as I always say, coexistence. I don't like it, I always say that I don't like to talk about inclusion,

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00:32:01,526 --> 00:32:13,054

I like to talk about coexistence. That is, surrounding yourself with an environment of support, understanding, affection, a safe environment, that goes far beyond any diagnosis, honestly.

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00:32:13,414 --> 00:32:27,734

I mean, because... Can you have it or not? That is, you could be a person who has autism and you do not have the diagnosis. You will still face certain challenges. And even if you have it, the diagnosis, the challenges will remain the same.

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00:32:29,174 --> 00:32:44,526

So, I don't know, I think... In my case, really, the diagnosis for me is totally irrelevant. I don't understand your point, but it all leads to the same mission.

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00:32:44,726 --> 00:32:53,646

If you see it that way, the mission of everything is quality of life. Yes, of course, that's why I say that what we have to do is fight for coexistence.

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00:32:53,846 --> 00:33:01,490

In other words, what we have to do is try to generate environments that allow the coexistence of people, regardless of the diagnosis they have.

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00:33:02,190 --> 00:33:12,230

The label is the least important thing. It can be called autism, it can be called ADHD, it can be called OCD, it can be called whatever it is called.

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00:33:12,310 --> 00:33:22,670

It is creating an environment of understanding, empathy, where we create spaces that can make a person feel that they are part of the same society,

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00:33:22,750 --> 00:33:29,758

which is where we all live. To me, people with autism live in their world or... is that we have to try that in our world,

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00:33:29,838 --> 00:33:36,078

people with autism enter our world.

Sorry, I told you in another conversation I had with another person,

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00:33:36,638 --> 00:33:45,758

I precisely told him that. It's just that I don't see it as our world and their world. There is only one world here. It's the world we all live in.

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00:33:46,198 --> 00:33:55,758

And here what it is about is... do we generate spaces for coexistence or not? Do we generate hostile spaces where the person has to go through situations

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00:33:56,078 --> 00:34:04,950

That to me... are common sense that I shouldn't go through them? Because sometimes they are situations generated by people

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00:34:05,030 --> 00:34:14,750

who have no empathy, who have no sensitivity towards other people

and then, well, that lack of empathy, that lack of sensitivity,

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00:34:14,830 --> 00:34:23,830

because it creates a hostile environment in which these people have to function. So what is the key? The key is to work hand in hand, that is, raise awareness.

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00:34:23,910 --> 00:34:33,414

That's why yes, that's why... That's why, for me I tell you, for me it's more important raising awareness and working to create these spaces

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00:34:33,494 --> 00:34:39,254

more than worrying about the diagnosis we have. Because I told you, we can look for many...

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00:34:39,334 --> 00:34:52,854

We already have, look, the autism rate is already, come on, for me... incomprehensible. I mean, I don't... It's hard for me to believe that actually 36 people out of every 100

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00:34:52,934 --> 00:34:59,062

are on the autism spectrum. I mean, one in 36, sorry. I find it hard to believe that one in every 36 people

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00:34:59,142 --> 00:35:09,182

is on the autism spectrum. So what do we do with that number? What does that mean? Yes, we have a diagnosis, we have the diagnosis.

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00:35:09,262 --> 00:35:23,406

We know that one in 36 people faces a situation where, well, they have that diagnosis. And... For me it's more... I don't know... I mean, I prefer to put my energy and my time into generating that.

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00:35:23,486 --> 00:35:31,006

That's why I decided to change my professional career. That's why I decided to get fully involved.

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00:35:31,606 --> 00:35:44,966

and go down to the field. I mean, that's why I'm fully involved in the world.
of what behavior modification is to improve the quality of life of these people.

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00:35:45,566 --> 00:35:54,126

Because to me... beyond the diagnosis, what do I do with putting a lot...?

Well, yes, it is true that we must raise... awareness.

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00:35:54,206 --> 00:36:04,486

It's the same as the issue of... It's funny to me because on Autism Day, April 2,
everyone wear blue. Come on, let's go for a hike.

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00:36:04,566 --> 00:36:17,006

The \$5,000 for Autism Speaks. Yes, okay, I think it's great, great, let him be aware,
let it be done that day. But my day to day does not end on April 2, nor does it begin on
April 2.

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00:36:17,086 --> 00:36:27,886

In other words, my situation lasts 365 days a year, 24 hours a day, seven days a week.
What good does it do me if we wear blue once a year?

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00:36:28,286 --> 00:36:36,606

I work on creating space. Yes, or talk about the day of...

In other words, like the other elastic days. December 3, disability day.

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00:36:36,686 --> 00:36:47,790

Autistic Pride, this day, the day... I am already in that line that I already care about that.
I mean, it's not... I recognize, but I'm already beyond that.

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00:36:47,990 --> 00:36:52,990

I mean, I've gone beyond those days too.

This is 24-7. Do you know what I honestly believe?

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00:36:53,190 --> 00:37:02,630

Do you know what I honestly believe? That this is being used to commercialize autism.
The thing is that an industry as such has already been formed.

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00:37:02,830 --> 00:37:15,374

Exactly. So there is a lot of interest created behind this topic of autism and
There is an interest, I don't know, created by who and for what,

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00:37:15,454 --> 00:37:27,814

But I see the topic being very commercialized and I already told you, that's why I...
I don't spend my energy on... Just like the issue of what if you are autistic, what if you
are a person with autism,

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00:37:27,894 --> 00:37:34,094

that is, getting lost in that weekly fight. Or you are a therapist.
ABA therapies, for and against ABA therapies.

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00:37:34,174 --> 00:37:42,542

Exactly. That... I don't know what you think about this.
I ask you because you work as... VCBA? The debates?

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00:37:42,622 --> 00:37:51,222

I believe... Of course, I always say it. In other words, the problem is not the therapy.
I return to the point. The problem is the people who implement the therapy.

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00:37:52,062 --> 00:37:59,582

Behavioral therapy, and especially in recent years,
where there have been great advances, because at the beginning it may be that they
were carried out, well,

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00:38:00,742 --> 00:38:08,622

the people who did this type of therapies,
because certain behaviors became unethical, so to speak.

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00:38:09,326 --> 00:38:22,846

But ABA therapy has evolved tremendously in the last 25 years.
So, it is a field of therapy that is scientifically supported, that is, it is proven.

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00:38:22,926 --> 00:38:28,366

I have experienced it firsthand in matters of millet behavior.
who have improved thanks to ABA therapy.

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00:38:29,446 --> 00:38:37,286

But of course, we return to the same thing. If there are people who enter the world of ABA therapy to make money, because here, especially in the United States,

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00:38:37,366 --> 00:38:45,206

It pays very well... Lately, at first it didn't pay so well, but now, in the last, I would say five years, more or less,

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00:38:45,286 --> 00:38:54,446

I don't know, something like that, well, the salary of therapists without experience, without preparation, without university studies,

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00:38:55,046 --> 00:39:06,446

I mean, we're talking about salary, which for me, well, I don't know, They are a little out of context. So, of course, many people come into this world...

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00:39:06,670 --> 00:39:15,550

searching, searching Well, but we're back to the same thing. In other words, the system is the system has been formed in a way that favors

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00:39:15,750 --> 00:39:25,910

this type of behavior that is unethical. So it's something that's hard to fight against. But it is true that it is a methodology that works and if it is implemented in the

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00:39:26,110 --> 00:39:34,670

so it has to be implemented ethically. It works. And the results are there. That's the reality.

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00:39:34,870 --> 00:39:47,406

This. There are many things that remain to be done in terms of the autism population and capabilities, but the important thing is to advocate, educate yourself, defend those rights.

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00:39:47,606 --> 00:40:02,006

We're talking, yes, we're talking about Florida, but you know you're in Puerto Rico, you're in the Dominican Republic,

You are in Spain, you are in other countries. It is important to advocate, know the laws

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00:40:02,206 --> 00:40:14,342

how and not only important good. Not only that laws are approved because it does not end there.

It is ensuring that the laws are being implemented.

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00:40:14,542 --> 00:40:28,702

It is very important. It is to ensure that the law is being complied with.

What happens is that what happens is that the complexity of countries that are not the United States, because here we know that

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00:40:28,902 --> 00:40:39,350

Let's say the repercussion. Eeh. Let's see how I tell you.

The issue is that here in the United States politicians have a consequence if they do not comply

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00:40:39,350 --> 00:40:48,390

what they promise. In other words, here the politicians make you a promise, if you don't keep it, they take it away from you.

In other words, people vote for politicians.

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00:40:48,390 --> 00:41:00,910

In many countries, in our countries, the political system is totally different.

So, of course, it is much more difficult for politicians...

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00:41:01,390 --> 00:41:06,590

Well, they have a consequence. It's much more difficult.

For example, I am going to talk to you about Spain, which is what I know,

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00:41:06,670 --> 00:41:12,750

because I don't master international politics,

It's not very strong. But I can talk to you, for example, in Spain.

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00:41:12,830 --> 00:41:21,630

In Spain, the political parties, the lists of politicians who belong to each political party

They don't do them like the citizens do here, that is, they are done by the same political party.

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00:41:21,710 --> 00:41:32,758

Political parties are financed by government funds.
something that doesn't happen here. So, of course... it is a much more complex system to manage.

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00:41:33,238 --> 00:41:43,318

But beyond the difficulty or challenge that all of this entails,
Yes, what you say is true. In other words, it is true that, to the extent that citizens

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00:41:43,398 --> 00:41:52,998

get involved, to the extent that citizens
Recognize the power you have by expressing your concerns and your needs to politicians.

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00:41:53,358 --> 00:42:04,894

And that together... Well... obviously we can achieve many more things than individually.
So, there is strength in unity. In these countries, people have to unite.

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00:42:04,894 --> 00:42:14,334

They have to realize that we can achieve change if we unite
And if we all go together and try to put pressure on the politicians of each country.

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00:42:14,334 --> 00:42:22,454

So, the first step begins by uniting us, by having a common goal.
and for conveying those concerns to politicians,

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00:42:22,454 --> 00:42:29,998

beyond what may result after all that.
But without a doubt, because people have to empower themselves and they have to know

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00:42:30,198 --> 00:42:39,718

that your voice is important and that your voice can be heard.
Exactly, make your voice heard and work together in our community

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00:42:39,918 --> 00:42:52,198

very important to be able to advocate for these forms that are needed, needed to fulfill that mission. And Lucía, we have talked about different points and I feel that we can spend more time

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00:42:52,398 --> 00:43:01,926

talking. Because autism and what is the issue of autism and disability, The causes are... There is so much that needs to be talked about and so much to do.

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00:43:03,366 --> 00:43:18,166

Before concluding our interview, if you can tell me in a minute What more is needed for autism and to help people with autism and disabilities in our society.

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00:43:19,694 --> 00:43:29,454

Well, I'm going to talk to you honestly. I would love to be able to tell you that you have to do this, that or the rest there. But, obviously, I don't have the magic recipe.

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00:43:29,534 --> 00:43:37,174

In other words, this is not a magic recipe in which we can say Look, the ideal world would be this. Much needs to be done, of course.

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00:43:37,254 --> 00:43:46,254

But I, especially in recent years, I have come to a conclusion and it is that the world is very difficult for us to change.

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00:43:46,638 --> 00:43:55,998

It is very difficult because the countries are all different and the interests are all different. So, I think that each person should try to surround themselves,

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00:43:57,358 --> 00:44:08,958

try to create and surround yourself with an environment of empathy and understanding.

And beyond... getting involved in a fight,

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00:44:09,038 --> 00:44:21,254

to say, well, we are going to change the world, I think we have to start with our little world,
Around us. And from there, well, if our capacity allows us to expand that field and that world,

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00:44:21,254 --> 00:44:37,094

well, perfect. But start with a small quota in which we can surround ourselves with, as I told you,
because we are very vulnerable people. Families with disabilities, then, are involved in a vulnerability resulting from

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00:44:37,094 --> 00:44:45,214

all those, those services that we need for our children, right?
So, well, we have to look for those resources in our environment and do...

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00:44:45,806 --> 00:44:57,206

As much as possible what we can for what is around us.
Is what I believe. Excellent and your perspective of experience not only as a mother, but as

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00:44:57,406 --> 00:45:05,726

Atrica or advocate of the community with people with disabilities.
It speaks for itself and I truly thank you for what it does for our

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00:45:05,926 --> 00:45:14,726

community, fighting for our community every day, which is the cause that gives us unites in being able to provide those tools for our community around the world.

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00:45:15,118 --> 00:45:22,998

And Lucía, how can the people who are listening to us, watching us, get you?
How can they learn more about your organization?

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00:45:22,998 --> 00:45:37,798

How can they learn more about your work? Well, you can go look for the Audition Society of Florida in the search engines
and there you can contact the organization that...

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00:45:38,158 --> 00:45:43,518

Well, we basically focused on Florida.
So, then also, well, you can follow me on social networks,

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00:45:43,598 --> 00:45:50,238

I have an Instagram account and I have a YouTube channel
which is called Sin Tags, where I also do interviews with inspiring people.

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00:45:50,878 --> 00:45:57,598

And well, and you were part of that interview too.

So, well, you can follow me there too if you want.

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00:45:58,158 --> 00:46:09,206

And I'm going to put the links, once this episode is published,
Lucia, I'm going to put the links. of your organization and your social networks,
because people,

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00:46:09,406 --> 00:46:17,326

especially families who have children with autism,
can contact you and can learn more about these initiatives that are so

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00:46:17,526 --> 00:46:30,246

needed by our community and what you and your organization are fighting for.

So I'm going to post this on NASA. So Lucía, this has been a unique episode and this
is just a story.

272

00:46:30,766 --> 00:46:40,206

of many stories, millions of stories of what autism is and people with
disability and I thank you, Lucia, for having participated in this interview in

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00:46:40,406 --> 00:46:48,526

my podcast My Time with Toni Hernández Pumarejo.

I don't thank you for giving me the opportunity to raise my voice and power.

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00:46:48,726 --> 00:46:58,646

spread the message. Thank you very much with all my heart.

Thanks to you. Well, this is the end of another episode of Mi Tiempo with Toni
Hernández Pumarejo.

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00:46:59,342 --> 00:47:07,702

Tony hopes you liked it. If he wants more information about the job performs Tony, subscribe to his social networks.

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00:47:07,702 --> 00:47:15,622

Facebook, Instagram, YouTube, Twitter, which is now X, and its link page. You can also follow Tony on his website at

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00:47:15,622 --> 00:47:26,622

tony Also, if you are interested in getting a copy of his book, An autistic life without a script, you can purchase it on Amazon or on any sales platform

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00:47:26,622 --> 00:47:34,430

from books. or you can get a copy through their website. So, until the next time you meet us.

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00:47:34,430 --> 00:47:38,430

Thank you and have a wonderful day. Blessings.