

	Time	English
Tony Hernandez Pumarejo	00:00:03,920 --> 00:00:16,850	Hello, my name is Tony Hernandez Pumarejo and thank you for tuning into a new episode of the podcast for our Hispanic community on autism called "Hablemos Autismo".
	00:00:17,000 --> 00:00:31,000	And today I have the honor and privilege of a lifetime to interview the only representative for Puerto Rico in the United States Congress, Resident Commissioner Jenniffer González Colón.
	00:00:31,560 --> 00:00:45,000	Jennifer González Colón was elected to the U.S. House of Representatives in November 2016 as Puerto Rico's only representative in the U.S. Congress, as Resident Commissioner.
	00:00:45,850 --> 00:00:49,280	González Colón has broken records throughout her career in public office.
	00:00:49,290 --> 00:00:59,330	She first entered elected office in a special election in 2002, becoming the youngest member at that time in the House of Representatives from Puerto Rico.
	00:00:59,720 --> 00:01:09,930	She then rose through the ranks, becoming Speaker of the Puerto Rico House of Representatives for four years and then Minority Leader for another four years.
	00:01:10,290 --> 00:01:16,710	By winning her seat in Congress, she also became the first woman to hold the office of Resident Commissioner.
	00:01:17,040 --> 00:01:40,680	Her priorities as Puerto Rico's voice in Congress include spearheading the island's economic recovery, especially after the two hurricanes, Irma and Maria, in 2017, as well as ensuring equal treatment for

		Puerto Rico's 3.2 million American citizens in terms of federal laws, regulations, services and funding.
	00:01:41,010 --> 00:01:54,240	Representative González is a product of Puerto Rico's public schools and holds a Juris Doctor and a master's degree in law and, as a lifelong Puerto Rican statehood activist and Republican,
	00:01:54,390 --> 00:02:10,040	she has also served as Chairperson of the Puerto Rico Republican Party from 2015 to 2021 and first Vice Chair of the New Progressive Party. She recently announced her pre-candidacy for Governor of Puerto Rico.
	00:02:10,250 --> 00:02:20,810	So I'm honored and privileged to have on my podcast today, Resident Commissioner Jenniffer Gonzalez. Commissioner, I'm honored to have you here on my podcast.
	00:02:21,050 --> 00:02:23,150	Thank you very much for your participating.
Rep. Jenniffer Gonzalez Colon	00:02:23,930 --> 00:02:32,390	Thank you for being aware of how this affects families in Puerto Rico and the Nation, adults with autism, and children as well,
	00:02:32,390 --> 00:02:39,380	and I think it's very important to discuss these things and what can be done, what's being done in Congress and what we can do in Puerto Rico.
	00:02:39,380 --> 00:02:40,850	Thanks to you for the opportunity.
Tony Hernandez Pumarejo	00:02:41,210 --> 00:02:41,870	Thanks to you.
	00:02:41,870 --> 00:03:00,560	As a Puerto Rican, I'm honored to have you on my podcast, but before I learn a little bit about

		your efforts for our autism community, especially in Congress, and also in Puerto Rico, I want to congratulate you also on your pregnancy, because you're going to be a mom of twins, so congratulations.
	00:03:00,560 --> 00:03:03,020	Blessings to you, your husband and his family.
Rep. Jenniffer Gonzalez Colon	00:03:03,440 --> 00:03:03,830	Thank you.
	00:03:03,930 --> 00:03:05,250	Many thanks for that.
	00:03:05,250 --> 00:03:08,400	That means a lot to me. I'm happy.
	00:03:08,400 --> 00:03:10,350	I think it shows, doesn't it, the happiness?
	00:03:10,740 --> 00:03:12,510	So it gives me all the more reason,
	00:03:12,510 --> 00:03:17,220	as these issues are important when you're going to bring children, right, into this life?
Tony Hernandez Pumarejo	00:03:17,760 --> 00:03:18,590	Exactly.
	00:03:18,600 --> 00:03:28,590	Before I go into your current efforts, I think there may be people in the audience who are not from Puerto Rico, from other parts of the United States, from Latin America,
	00:03:29,040 --> 00:03:34,020	I'd like to find out a little about you and your background, before jumping into your current efforts in Congress.
	00:03:34,020 --> 00:03:36,300	What inspired you to run for public office?
Rep. Jenniffer Gonzalez Colon	00:03:36,870 --> 00:03:54,660	Look, when I ran the first time in 2002, I wanted to represent my community in San Juan Precinct

		4 and put myself forward, because I was criticizing the person who was doing it at the time and a politician told me: well, if you don't like the way I do it, you run.
	00:03:55,080 --> 00:04:01,860	And that obviously awoke in me a responsibility that you can't criticize unless you're prepared to do the job.
	00:04:03,510 --> 00:04:27,810	So obviously, I believe in equality, and Puerto Rico lacks equality in many federal programs. The opportunities for our children, for our people and, in fact, autism is one of those areas where Hispanic communities, because of their lack of English proficiency, don't necessarily have the same access to therapies or resources in order to work on these conditions from an early age, never mind also caring for them as adults.
	00:04:27,810 --> 00:04:36,300	So those disparities we see in percentage terms, where we see that children with autism, if we talk about autism today,
	00:04:36,300 --> 00:04:39,030	Hispanics are the most affected, aren't they,
	00:04:39,060 --> 00:04:44,520	at the national level, then it's the black or African American community.
	00:04:44,520 --> 00:04:49,860	The numbers show it clearly, how it can affect
	00:04:49,890 --> 00:04:54,630	a person due to this type of disparities. In Puerto Rico we don't have additional Social Security,
	00:04:54,870 --> 00:05:04,970	right? That would be one of the aids also for other conditions that children, adults and under-18s have on the island.

	00:05:05,710 --> 00:05:09,380	So there are many areas where I think we can raise our voice,
	00:05:09,650 --> 00:05:12,770	to seek that equality, to achieve working alliances.
	00:05:12,830 --> 00:05:20,180	And I put myself forward on that occasion and here I've been first in the House, Speaker of the House, spokesperson,
	00:05:20,180 --> 00:05:23,690	and today, as Puerto Rico's first female Resident Commissioner in Washington.
Tony Hernandez Pumarejo	00:05:24,350 --> 00:05:25,030	Excellent.
	00:05:26,090 --> 00:05:31,250	And I know that you've been very committed to my autism community, especially in Puerto Rico,
	00:05:31,610 --> 00:05:35,240	and before going into what your work is for our community,
	00:05:35,720 --> 00:05:37,400	I ask you, Commissioner,
	00:05:37,430 --> 00:05:38,660	how...
	00:05:38,660 --> 00:05:41,000	you know, you represent our island of Puerto Rico,
	00:05:41,600 --> 00:05:46,160	can you describe for us what it's like to represent more than 3 million American citizens?
	00:05:46,160 --> 00:05:54,200	And also, maybe there are other people in the United States and Latin America who may not be very familiar with your position as Resident Commissioner,
	00:05:54,200 --> 00:05:56,180	if you could explain a little bit about your role.
Rep. Jenniffer Gonzalez Colon	00:05:56,630 --> 00:05:59,180	That's great, because you're absolutely right. Not everyone...

	00:05:59,180 --> 00:06:04,680	Everyone asks me, why Resident Commissioner and not Congresswoman?
	00:06:04,770 --> 00:06:09,330	The reality is that both terms are used, but the law identifies my position
	00:06:09,330 --> 00:06:17,400	in the Puerto Rico Federal Relations Act of the United States as the office of Resident Commissioner, which is the equivalent of a congressman or woman.
	00:06:17,820 --> 00:06:32,010	The only two differences are that congressmen and women represent approximately 750,000 residents per congressional district nationwide, while the Resident Commissioner represents the entire island.
	00:06:33,160 --> 00:06:46,410	Being a territory of the United States and not a State, I represent 3.2 million American citizens residing on the island, when there should be at least 4 congressmen or women and 2 senators.
	00:06:46,830 --> 00:06:49,770	Puerto Rico has no senators and no delegation,
	00:06:49,770 --> 00:06:57,570	so my responsibility is to do the work of what four congressmen would have done for the population.
	00:06:57,570 --> 00:07:02,100	So I'm the person who represents the most people in the United States Congress.
	00:07:02,490 --> 00:07:07,230	I have the right to participate in all the committees, all the commissions.
	00:07:07,230 --> 00:07:13,150	I'm assigned to vote in them, to discuss, to present bills, to be just like another congresswoman.
	00:07:13,170 --> 00:07:27,810	The only difference is the number of people I represent and, secondly, that I don't have

		the opportunity to vote on the floor of the House for the approval of measures, resolutions or motions.
	00:07:27,990 --> 00:07:39,330	Yes, I can vote on amendments to bills, but I can't vote on the bill. So that diminishes the political power and takes away the power of enforcement from the island
	00:07:39,330 --> 00:07:44,120	when decisions are made that affect the lives of all Americans,
	00:07:44,130 --> 00:07:47,840	not only those who live in the nation, but those of us who live in Puerto Rico.
	00:07:47,840 --> 00:07:56,400	And this creates a territorial, colonial situation, where we are subject to the will of Congress.
	00:07:56,400 --> 00:08:01,050	We can discuss any legislation that's passed, but we can't vote.
	00:08:01,050 --> 00:08:09,270	And that diminishes our strength when it comes to negotiating, it diminishes Puerto Rico's strength when it comes to participating in the discussion.
	00:08:09,270 --> 00:08:17,970	You don't know how many times I have to eradicate measures so that Puerto Rico will be included in the federal legislation, which wouldn't automatically be the case;
	00:08:17,970 --> 00:08:27,780	or, on other occasions, to try to rectify behaviors made towards the territories, which in the case of Puerto Rico affects us more.
	00:08:27,780 --> 00:08:29,250	And I'll give you an example of this.
	00:08:29,580 --> 00:08:32,640	We don't qualify for Supplemental Security Income.
	00:08:33,120 --> 00:08:47,640	This measure, which helps to raise people out of poverty and generally helps the population aged 65 and over, also helps

		children under 18 who suffer from Down syndrome and cerebral palsy, among other conditions,
	00:08:47,640 --> 00:09:07,920	including some related to autism, which impedes their verbal and communications development, among other things, and they could then receive, as part of this program, a monthly allowance that would help them to have an independent life, to be able to pay for their house, electricity or water.
	00:09:08,220 --> 00:09:20,850	So Puerto Rico doesn't qualify for this Supplemental Security Income that could represent the independence of a person living with these conditions.
	00:09:20,850 --> 00:09:47,730	This is one of the many federal programs that aim to raise people out of poverty, as well as the Snap program, Supplemental Nutrition Assistance Program, which would also allow greater opportunities for people to have access to buy food. We only have a portion, which is the NAP, which is a reduced portion of funds that are approved for Puerto Rico, but it isn't the same as what would be approved for a State.
	00:09:47,730 --> 00:09:49,920	So these are some of the things.
	00:09:49,920 --> 00:10:00,450	We could spend the whole podcast discussing the rest of the differences, but for what we're discussing, I think that's one of the most graphic in terms of disparity.
	00:10:01,170 --> 00:10:10,090	No, and exactly, and since I'm Puerto Rican, our current status has a lot to do with that, which

		is another part of another discussion also.
Tony Hernandez Pumarejo	00:10:10,270 --> 00:10:24,520	Commissioner, we're grateful to you for your support both in signing letters that support increased funding for autism research and services, as well as being a co-sponsor of the Autism Cares Act in 2019.
	00:10:24,700 --> 00:10:33,040	Can you tell us what inspired you to support these efforts to support people with autism and their families, especially in Puerto Rico?
Rep. Jenniffer Gonzalez Colon	00:10:33,640 --> 00:10:39,390	Look, I have a cousin, who's now a senior, with severe autism.
	00:10:39,400 --> 00:10:54,510	He already lost his sight as part of the blows he gave himself and had to move from Puerto Rico at an early age in order to receive better care in the State of Maryland.
	00:10:54,520 --> 00:10:56,860	And this should not be the norm.
	00:10:56,860 --> 00:11:06,170	We should have access to the resources, therapies and research that are available at the State level.
	00:11:06,440 --> 00:11:10,940	This is one of the great limitations in Puerto Rico,
	00:11:11,060 --> 00:11:16,010	but also because there is a large autistic population in Puerto Rico,
	00:11:16,010 --> 00:11:27,470	and you have centers like SER of Puerto Rico that have helped many young people, many children, not only with autism conditions, but with other types of physical conditions, to try to overcome these.
	00:11:27,470 --> 00:11:47,420	So when I was Speaker of the House, I worked together with Maritza Casiano and other people, who brought to us the

		situation of autism in Puerto Rico, and we legislated so that the money from the <i>Marbetes</i> could be allocated to these causes, so this could be discussed.
	00:11:47,420 --> 00:12:16,070	I remember that on that occasion we took the artist, Cristian Castro, and Gloria Estefan to Puerto Rico to support these autism measures and a legislation was approved that laid down some requirements, of study, that Puerto Rico would have the facilities, that the research would be done, at the level of the Puerto Rico government, and it was one of the autism laws approved, which I had the opportunity to manage, and that were approved unanimously at that time.
	00:12:16,070 --> 00:12:19,480	And I believe that we must maintain this mandate
	00:12:19,490 --> 00:12:32,660	with the agencies for research and statistics, which are so important when it comes to providing treatments or therapies aimed at the affected population.
	00:12:32,990 --> 00:12:44,250	You were telling me about the 2019 law, which is the Act on Autism Collaboration, Research and Education.
	00:12:44,300 --> 00:12:56,300	I was co-author of that law and that law, for the national level, at the federal level what it did was reauthorize, throughout the 2024 fiscal year, review all programs and activities related to the autism spectrum,
	00:12:56,600 --> 00:13:13,510	and specifically authorize this provision of this Act, all that was related to expanding research

		on the autism spectrum in all national health institutions.
	00:13:14,620 --> 00:13:25,060	Secondly, that it would be possible for data to be collected at state-level on the autism spectrum by the Centers for Disease Control and Prevention.
	00:13:25,860 --> 00:13:51,910	A third reason for this legislation was to provide education on the early signs of autism spectrum, screening and intervention activities through the Federal Department of Health and the U.S. Human Resources Administration and to create an interagency committee on autism at the federal level.
	00:13:52,120 --> 00:14:07,970	That law also revised the scope of all programs and activities: one to include for the first time the autism spectrum at all ages rather than just for children.
	00:14:08,420 --> 00:14:22,640	Second, because we have a large population of people with autism who are adults and for whom you may not have the same research, the same strategies, as you have for children, on whom they are much more focused.
	00:14:22,970 --> 00:14:41,840	Second, to focus the budget on programs in areas where you have staff and health service shortages; and secondly, to reduce the disparities that are related in terms of health across the different populations at the national level.
	00:14:41,840 --> 00:14:47,410	That's why, when this legislation was passed, we couldn't leave it there.
	00:14:48,000 --> 00:15:10,660	In 2022, last year, in my case, from the budget that was allocated to me, we set aside \$180,000 for Puerto Rico to have its first children's intensive care center for behavioral

		interventions, so as not to have to wait until they're adults.
	00:15:10,760 --> 00:15:38,100	And this behavioral center, the Intensive Center for Behavioral Studies, is going to provide the strength to carry out a comprehensive development of children diagnosed with the autism spectrum in Puerto Rico from the ages of 18 months to six years old, obviously based on the principles of behavioral analysis;
	00:15:38,610 --> 00:16:05,030	And the main objective of this program for those of us who allocate the money, and it was approved and they're already working with this, is to impact the mental development, the cognitive development, of all these children with autism spectrum and to stimulate education and knowledge and adapt those behaviors, so it is easier for them to integrate into different environments.
	00:16:05,030 --> 00:16:11,660	This program that we assigned was also... it wasn't my idea, this was the idea of SER of Puerto Rico.
	00:16:11,660 --> 00:16:38,720	We only gave the funds to the proposal that they presented to us, which also seeks to achieve significant changes in the social contact, in the social interaction, of these children diagnosed with autism spectrum, and to assist them and help the caregivers, to also give them the tools, and to obtaining data related to autism in Puerto Rico.
	00:16:38,720 --> 00:16:45,020	So this is already an exultation, a visit.

	00:16:45,200 --> 00:16:56,240	And the other thing we did recently is that, by fiscal year 2024, we will... you mentioned, just now, a letter to explain it to the people who are listening to and see us.
	00:16:56,480 --> 00:17:03,050	That letter is to the chairs of the Health Department's committees and subcommittees,
	00:17:03,060 --> 00:17:19,520	at the level of the House of Congress, requesting and requiring increases in the investments or funding for research on autism,
	00:17:19,520 --> 00:17:23,120	because I believe that the federal government has this, it continues growing.
	00:17:23,120 --> 00:17:29,180	We can't leave it there in the same way as for research on erectile dysfunction, among other things.
	00:17:29,180 --> 00:17:34,550	I believe that we should allocate more resources to investigations and research for autism.
Tony Hernandez Pumarejo	00:17:35,570 --> 00:17:49,610	Excellent, and I thank you very much for explaining to us these different measures that have been proven to be underway in order to help and support the community, families and human beings impacted by autism.
	00:17:50,090 --> 00:17:51,170	Let's talk about these laws,
	00:17:51,170 --> 00:17:56,720	Commissioner, and with all due respect, I'm Puerto Rican, but also here's a bit of my history:
	00:17:56,720 --> 00:17:59,450	I was diagnosed with autism at age three.
	00:17:59,450 --> 00:18:01,070	This was in the early 90s.
	00:18:01,460 --> 00:18:06,290	At that time there wasn't as much awareness about autism as there is today.

	00:18:06,920 --> 00:18:11,090	Autism is different, some autisms are more functional than others.
	00:18:11,090 --> 00:18:16,050	Mine was Asperger's at the time, a more functional autism, but I cried until I was four years old,
	00:18:17,380 --> 00:18:25,040	I faced challenges in social communication, in social interaction, especially at school, and this led me to face different bullying situations.
	00:18:25,220 --> 00:18:35,790	I mean, I was raised... I went to public schools in Puerto Rico and then I went to private schools, and it was a challenge growing up with the condition,
	00:18:35,790 --> 00:18:44,550	but what helped me were the therapies and the support my parents gave me so that I could move forward and graduate after high school.
	00:18:44,550 --> 00:18:55,980	And then, in employment, I was able to graduate from college, and now I'm working full-time as an autistic person, Commissioner, and I talk to this community every day.
	00:18:55,980 --> 00:19:05,700	I get calls from families, especially in Puerto Rico, who are desperate, frustrated and feel...
	00:19:05,700 --> 00:19:07,440	I don't know if you understand me.
	00:19:07,890 --> 00:19:12,830	It's felt that these initiatives are being talked about, but where are the results?
	00:19:12,840 --> 00:19:14,220	We're not seeing the impact.
	00:19:14,220 --> 00:19:21,000	In other words, we're talking about the BIDA law, which will establish the public policy on autism in Puerto Rico,

	00:19:21,270 --> 00:19:32,190	but the families, mothers and fathers, especially in Puerto Rico, are frustrated right now; and many of these families, because I receive calls, because I work in the autism response team, Autism Speaks,
	00:19:32,580 --> 00:19:47,310	and I get calls every day and they have to leave the island, especially those in the adult population, because the adult autism population continues growing and the options are very limited in terms of housing, finance and health.
	00:19:48,160 --> 00:19:58,300	I ask you what you would say to the families, especially in Puerto Rico, who are frustrated and desperate for answers.
Rep. Jenniffer Gonzalez Colon	00:19:59,020 --> 00:20:16,810	First, I understand them, I have to understand them, because receiving an autism spectrum diagnosis usually results in a strong emotional reaction from the parents of that child,
	00:20:16,810 --> 00:20:20,980	and in the case of adults, this is also the case in social terms,
	00:20:20,980 --> 00:20:25,990	and I think that the... and here are two things, adult and child.
	00:20:25,990 --> 00:20:27,550	And now more attention is given to children,
	00:20:27,550 --> 00:20:29,110	but what about the adults?
	00:20:29,110 --> 00:20:34,340	What happened during that time when there was no research, when they didn't receive therapies?
	00:20:34,360 --> 00:20:54,320	Or timely access to these services? And the daily challenges of caring for a child or adult with autism are endless and affect the entire scope of that person's daily

		development, but also of his or her family,
	00:20:54,350 --> 00:21:00,500	because the mental health of those parents of children with autism conditions,
	00:21:00,500 --> 00:21:18,800	the ability to manage and obtain the resources to provide whatever that child or adult requires, in terms of the family, also becomes a burden when you don't know what services are available, when you don't know where to turn, or don't have help.
	00:21:18,800 --> 00:21:37,640	So I understand that frustration, because it becomes the dad's job, who becomes that child's caregiver, and when he or she is an adult, but still lives with the parents, there is the worry of what will happen when that parent isn't there.
	00:21:37,640 --> 00:22:02,920	So encountering all these challenges, seeking the funds, the guidance, the support, to find the best future for that child, for that adult with autism, is a great challenge for every father, for every mother, and it becomes much more difficult in Puerto Rico when the resources are not available in comparison perhaps with the States.
	00:22:03,280 --> 00:22:29,500	However, also, although there have been many advances on the autism spectrum in the last 40 years, we were talking about the fact that services for adults are still well below the services provided for children with autism, and obviously the prospects of finding employment, of having an independent life, are much lower as well;

	00:22:29,500 --> 00:22:41,730	and while the end results are going to be quite variable because there are many individuals with autism who already can...like you,
	00:22:41,730 --> 00:22:46,540	you have an independent life, you have a full-time job,
	00:22:46,540 --> 00:22:51,340	your relationships in terms of communication, seem perfect to me.
	00:22:51,340 --> 00:23:00,400	The reality is that everything you had to go through to get to where you are today took a lot of effort and a lot of help and determination,
	00:23:00,400 --> 00:23:05,800	to move, and you had to change location as part of that effort.
	00:23:05,800 --> 00:23:14,330	So I believe that, although there are many studies demonstrating positive changes in functionality with age,
	00:23:14,330 --> 00:23:34,540	it's evident that every individual with autism, regardless of IQ, regardless of ability, remains at a disadvantage to other adults, and recent studies have shown that approximately one in almost five participants...
	00:23:35,140 --> 00:23:53,090	It may be considered that 1 out of 5 participants at the national level are able to integrate into society without problems, while the rest, half, are going to have poor or very poor performance in terms of their independent living.
	00:23:53,090 --> 00:24:03,140	Other studies have talked about the inability to obtain help for young people with autism,
	00:24:03,410 --> 00:24:09,320	once they leave school, this will cause a worse situation.
	00:24:09,560 --> 00:24:19,340	Nevertheless, the results of people who've already left school and have opportunities

		and have job opportunities available,
	00:24:19,340 --> 00:24:28,730	only a minority, less than 25% of those individuals remain engaged or working in those activities over time.
	00:24:28,730 --> 00:24:37,820	And I believe that the families have to listen, have to know, that they're not alone in this fight, that this fight needs its leaders,
	00:24:37,820 --> 00:24:46,420	not only in the public sector, but in the political sector and private sector to be fighting to obtain better resources for their loved ones,
	00:24:47,080 --> 00:24:50,680	and I would ask them
	00:24:50,720 --> 00:25:10,190	to join a support group, or what we call here advocacy groups, the groups that fight, like Autism Speaks, GRASP, the Global and Regional Asperger's Syndrome Partnership, or the Asperger's Autism Network,
	00:25:10,190 --> 00:25:22,100	that are different organizations that help to train and to provide information, because sometimes the lack of access to information is dangerous.
	00:25:22,120 --> 00:25:37,280	And I believe that being able to access quality information on these topics enables parents to be a better support for their children, to be better spokespeople for adults
	00:25:37,280 --> 00:25:59,310	with autism and to improve their quality of life within the autism community, where it's still very common for them to be disassociated from the community and they can find their space, feel useful and contribute to the joy of improving the health conditions

		and quality of life of these people.
	00:25:59,310 --> 00:26:04,980	So we can help the autism community in Puerto Rico,
	00:26:04,980 --> 00:26:23,450	being advocates for increasing research funding, which is what I'm doing, and specifically in areas where adults with autism can be helped to have better opportunities and be more effective at living independent lives.
	00:26:23,600 --> 00:26:31,020	And we can also help in promoting more education in the general population about what autism is.
	00:26:31,020 --> 00:26:31,470	What for?
	00:26:31,560 --> 00:26:33,900	Because here people shouldn't be treated
	00:26:33,900 --> 00:26:38,880	as if they have a condition that prevents people from approaching them.
	00:26:38,880 --> 00:27:01,040	Quite the opposite, I think we need to improve how we educate about autism and talk about what are the special needs of those individuals, because sometimes what appears to be accommodating to someone can make a major difference in the life of an individual with an autism condition in something as simple as a job application.
	00:27:01,040 --> 00:27:21,890	Obviously, due to federal law, I can't talk about the employees in my office, but I know people who are 100% functional -if not more- in terms of the capacity they have, with autism conditions, to write, to investigate, and to do research, because I've been with them.

	00:27:21,890 --> 00:27:54,650	So we can help advocate for equal treatment at the federal level, equal social treatment, through the health programs, and that the people in Puerto Rico who do not have access to the Supplemental Social Income program or SSI, as we were talking about a few minutes ago, which is the only individual financial assistance program that helps parents of children with disabilities to pay for the costs of those treatments.
	00:27:54,770 --> 00:27:57,470	It's the only aid and it's not available in Puerto Rico.
	00:27:57,860 --> 00:28:02,990	And yet, the limited funds that come from Medicaid as well,
	00:28:02,990 --> 00:28:14,870	restrict our opportunities for better mental health and occupational resources, which are often needed so that the autistic population can move forward.
	00:28:16,270 --> 00:28:23,680	Perfect, excellent, and I thank you very much, Commissioner, for all this information you're giving us, especially for our family and our community,
Tony Hernandez Pumarejo	00:28:24,100 --> 00:28:33,460	and I agree 1000% with you on all these things, all these challenges that we face, but what has to be done, the action in order to help the families;
	00:28:33,930 --> 00:28:36,340	and, Commissioner, as you know, Puerto Rico is now,
	00:28:36,430 --> 00:28:45,550	it's one of only 16 places in the United States that is federally designated to monitor the prevalence of autism.
	00:28:45,550 --> 00:28:56,750	This means that, in addition to contributing to the national estimate of how many people are diagnosed with autism,

		there will be more local data available on autism in Puerto Rico specifically.
	00:28:57,050 --> 00:29:06,280	For our family, for our community, why do you think having that information will be helpful in improving outcomes for individuals and families in the autism community?
Rep. Jenniffer Gonzalez Colon	00:29:06,970 --> 00:29:12,340	Look, the first thing is that there are so many problems with obtaining data,
	00:29:13,000 --> 00:29:19,510	updated data on the population with autism among minors and adults in Puerto Rico,
	00:29:19,510 --> 00:29:27,880	and without that you can't manage a treatment, you can't allocate resources, you can't find a way to reach that community.
	00:29:27,880 --> 00:29:40,390	So this legislation, and obviously I'm very glad that the Government of Puerto Rico is seeking this data, because look, right now, if you conduct research, you're going to find different numbers for the same things.
	00:29:40,390 --> 00:29:46,450	To prepare for this conversation with you we found, for example, that in Puerto Rico...
	00:29:46,450 --> 00:29:50,720	These are data from one source, but I have different data from others:
	00:29:50,740 --> 00:29:56,490	in Puerto Rico, there are 11,247 adults with autism
	00:29:56,500 --> 00:30:03,220	and, although it says it's among the lowest at the State level, 2498 children with autism.
	00:30:03,220 --> 00:30:15,200	However, nationally, via the census page, Puerto Rico has approximately 319 children with autism out of every 100,000 residents diagnosed with autism.

	00:30:15,530 --> 00:30:17,480	But I can give you other data.
	00:30:17,480 --> 00:30:31,050	At the level of the other data that tells me that almost 7000 children out of every one in 125 under the age of 18 have autism in Puerto Rico.
	00:30:31,050 --> 00:30:34,900	We've already increased three times the amount of data there was.
	00:30:35,150 --> 00:30:35,380	Yes.
	00:30:36,470 --> 00:30:45,500	And that children from 4 to 17 years old, one out of every 110 children has autism in Puerto Rico and this leads you to the fact that the center,
	00:30:45,500 --> 00:30:54,550	the National Health Interview Survey of the Department of Disease Control, the CDC,
	00:30:54,550 --> 00:31:09,140	old numbers estimate that Puerto Rico, for these children over the age of 18 with autism, may be between 19,965 to 21,822.
	00:31:09,560 --> 00:31:10,580	All these numbers change,
	00:31:10,580 --> 00:31:18,440	and I believe that now the island can search for the information to have updated data
	00:31:18,440 --> 00:31:23,600	on the population suffering from autism -and Puerto Rico didn't have these data ten years ago.
	00:31:23,900 --> 00:31:28,910	This will enable us to provide a correct statistical report
	00:31:28,910 --> 00:31:37,460	and look, the Autism Alliance in Puerto Rico, because sometimes here we have to depend more on the community organizations that do this work than on the government data.

	00:31:37,490 --> 00:31:41,210	- Exactly. - Yes, I have to acknowledge the Autism Alliance.
	00:31:41,450 --> 00:31:49,910	Last year they detected an increase of 120% of students with autism enrolled in the public school system in Puerto Rico
	00:31:49,950 --> 00:32:00,280	and in the monitoring study, which they say will help to improve the collection of this data, which has not been updated in Puerto Rico for almost ten years.
	00:32:00,290 --> 00:32:15,740	So, the fact that we're one of those 16 States or jurisdictions that can have access to this data will enable us to redirect funds, allocate resources where there are none, and serve a population that is often invisible to the structures of government.
	00:32:15,740 --> 00:32:34,850	I believe in giving them those tools, both financial and resources, so that children on the autism spectrum today, once they are adults, can be independent, successful adults, like you.
	00:32:35,600 --> 00:32:39,260	Look at your communication and research skills.
	00:32:40,730 --> 00:32:47,150	This is more than a functional citizen, you're a collaborator in the change,
	00:32:47,180 --> 00:32:49,580	the change we need to make in order for things to really happen.
Tony Hernandez Pumarejo	00:32:50,180 --> 00:32:50,660	Exactly.
213	00:32:50,680 --> 00:32:52,730	And you said it very well, Commissioner.

214	00:32:52,730 --> 00:32:54,380	Here are the data.
215	00:32:54,380 --> 00:32:54,890	You know?
216	00:32:54,890 --> 00:33:01,400	That's what I believe we have to solve as soon as possible in order to have a clear picture,
217	00:33:02,390 --> 00:33:05,930	of what's really happening with the autism population in Puerto Rico,
218	00:33:05,930 --> 00:33:11,630	so we can then truly identify the resources and support for the children and adults with autism;
219	00:33:12,020 --> 00:33:25,090	and your knowledge of this autism issue is impressive and I know your commitment to our community is strong, so I thank you very much as an ambassador for this Autism Summit.
220	00:33:25,090 --> 00:33:31,550	And before we conclude this podcast and, again, thank you, thank you, thank you for being on our podcast,
221	00:33:32,210 --> 00:33:35,180	what final message, Commissioner, would you like to share?
222	00:33:35,180 --> 00:33:55,010	Not only with Puerto Rican families, but also with Hispanic families -because there are also challenges, in general, for Hispanic families regarding autism and access to services- about the work that you and other members of Congress are doing to help the community, and how our audience that's listening to and watching us can support your efforts on behalf of the autism community.
Rep. Jenniffer Gonzalez Colon	00:33:55,850 --> 00:33:58,160	First, thanks to you for this podcast.

	00:33:58,160 --> 00:34:14,120	I believe this is the first time I can talk and share information about autism at length, because sometimes conversations about autism become a one or two-minute question and answer.
	00:34:14,120 --> 00:34:16,100	And I believe it deserves this,
	00:34:16,100 --> 00:34:23,810	this changes your life, it changes the life of a dad, it changes the life of a child, it changes the life of an adult living on the autism spectrum;
	00:34:24,020 --> 00:34:30,050	and I've had the opportunity to meet many adults at different levels within the spectrum
	00:34:31,080 --> 00:34:40,620	that challenge me, because they ask tough questions, help with data, with ideas.
	00:34:40,620 --> 00:34:47,910	So I believe that the intellectual capacity is very high, at least in the cases in which I've had the opportunity to interact.
	00:34:47,930 --> 00:34:53,860	In fact, I can't speak in more detail, because there are federal laws that prohibit me from doing so,
	00:34:54,010 --> 00:35:07,710	but I think the community should know that we have congressmen and women, we have leaders, that this is a personal matter, that this is a condition that can be addressed and that there must be many people who are frustrated.
	00:35:07,710 --> 00:35:10,750	Young parents asking themselves, What am I going to do?
	00:35:10,770 --> 00:35:13,590	I've just been diagnosed, how does this change my life?
	00:35:14,280 --> 00:35:29,710	And it shouldn't be like that, we should have the information, the statistics, so that those resources can be allocated correctly, use the resources

		from universities and scientific studies, which help us to understand also how...
	00:35:30,180 --> 00:35:48,230	I was reading, now that I'm going to be a mom, several articles and books that I bought from different universities about studies of what you could do to manage children
	00:35:48,470 --> 00:35:52,830	and so they don't have conditions, not only autism, but other types of conditions;
	00:35:52,840 --> 00:36:00,370	and even though that won't guarantee it will be the case, because you can't control that during gestation,
	00:36:00,910 --> 00:36:06,760	how will I cope if my child, in a few years, has an autism condition and what help can I seek?
	00:36:06,760 --> 00:36:08,320	And I think that's very important,
	00:36:08,470 --> 00:36:15,090	and I believe that the government, in the same way that resources are allocated for things that in my opinion aren't important.
	00:36:15,090 --> 00:36:27,820	This is a family's daily quality of life, because a child with a condition impacts the mom, the dad, brother, sister, uncle, aunt, cousin, grandfather, the whole environment,
	00:36:27,820 --> 00:36:30,730	because the whole environment has to be involved and has to help.
	00:36:30,730 --> 00:36:38,140	And I believe that resources like those of Puerto Rico, that know what they have to do, are focused and have a work plan, who are looking for statistics,
	00:36:38,410 --> 00:36:44,320	sometimes what they ask for is so little: look, \$180,000 to set up a center for this.

	00:36:44,320 --> 00:36:50,110	I believe that the State should be hand-in-hand with these organizations, to walk together.
	00:36:50,230 --> 00:36:56,430	So, what I say to you is that we have many members of Congress who are interested in this issue, it affects us personally.
	00:36:56,440 --> 00:37:03,990	I wouldn't want any family or child to have to move to obtain a service that we should have in Puerto Rico;
	00:37:04,000 --> 00:37:07,960	and the other thing is that sometimes these services have a cost,
	00:37:07,960 --> 00:37:12,770	and when this happens, sometimes one of the parents has to stay at home to take care of the child,
	00:37:12,860 --> 00:37:14,860	and I don't think anyone has taken those things...
	00:37:14,860 --> 00:37:17,500	how it changes your life,
	00:37:17,500 --> 00:37:18,850	and how do you help this,
	00:37:18,850 --> 00:37:26,140	and how do you reintegrate this child once they're an independent adult,
	00:37:26,230 --> 00:37:28,840	who is 100% functional,
	00:37:28,840 --> 00:37:35,320	to contribute to the community, to society, because they have the capacity to do so.
	00:37:35,590 --> 00:37:37,510	So I want to do it,
	00:37:37,510 --> 00:37:39,430	obviously I'm in Congress.
	00:37:39,430 --> 00:37:44,830	Now, from what I want to do for Puerto Rico, this is a personal issue for me,

	00:37:44,830 --> 00:37:49,720	and I'm looking for organizations and parents involved in this issue
	00:37:49,990 --> 00:37:53,160	to send us your ideas, to communicate with us.
	00:37:53,170 --> 00:38:02,440	You've no idea how many things I legislate or present that come from the ideas of people who come from these organizations that tell us that now we've studied this, this is what we want.
	00:38:02,460 --> 00:38:06,960	That's much better than a politician telling you this is what we're going to do.
	00:38:06,960 --> 00:38:12,430	So I'm open to receiving these recommendations, to receiving data,
	00:38:12,820 --> 00:38:19,120	to receiving a comparison of how this works in other jurisdictions around the world and in jurisdictions in the United States,
	00:38:19,330 --> 00:38:21,460	and which of them we can apply to Puerto Rico.
	00:38:21,730 --> 00:38:26,080	So, Tony, thank you for your interest,
	00:38:26,080 --> 00:38:32,980	thank you for your leadership in making this conversation happen and I'm available to help and be...
	00:38:33,420 --> 00:38:34,830	you're the ambassador of the cause,
	00:38:34,830 --> 00:38:36,930	and I want to be your assistant in this effort.
Tony Hernandez Pumarejo	00:38:37,500 --> 00:38:38,040	Thank you.
	00:38:38,050 --> 00:38:41,460	Thank you for your words and support

	00:38:41,760 --> 00:38:42,890	
	00:38:42,930 --> 00:38:45,420	I mean, you said it perfectly Commissioner.
	00:38:45,870 --> 00:38:47,880	So thank you very much.
	00:38:47,880 --> 00:38:48,630	This is your home,
	00:38:48,630 --> 00:38:50,340	you can join us whenever you want
	00:38:50,340 --> 00:38:58,050	to continue talking more about this topic of autism and I will post all the information when the episode is posted so that you can contact her.
	00:38:58,050 --> 00:39:06,750	So, Commissioner Jenniffer González Colón, congratulations again on your pregnancy, best wishes to you and your family in your goals,
	00:39:06,990 --> 00:39:11,340	and continue working, not only for our autism community, but for our island,
	00:39:11,410 --> 00:39:13,200	and it's a Puerto Rican here saying this to you,
	00:39:13,200 --> 00:39:18,420	so thank you, Jenniffer, for participating in this episode of Hablemos Autism.
Rep. Jenniffer Gonzalez Colon	00:39:19,170 --> 00:39:19,620	Thank you.