

Donna Long with MaryBeth Bergren

>> MARYBETH BERGREN: Hello, everyone, and welcome to "Disability, Inc." I'm MaryBeth Bergren, Family Educator at INCLUDEnyc. I'm a native Staten Islander with over 10 years' experience in higher education, and an avid member of the special needs community here on Staten Island. I have two children with autism spectrum disorder classification; and my first-born, diagnosed at 18 months old, was my first experience with autism. I know firsthand the struggles of navigating this world, but could not imagine life without the supports and services that are available to my children, myself, and my family. INCLUDEnyc has been a lifeline for families like mine.

It gives me great pleasure today to welcome our guest, Donna Long, the woman who built the advocacy movement for children with autism on Staten Island since the early '80s. When I first got a diagnosis of ASD for my daughter, Kate, almost seven years ago, I was told by my mom, "Call Donna, she can help you," and I did just that. Welcome, Donna.

>> DONNA LONG: Thank you, MaryBeth, and thank you for your kind words.

>> BERGREN: We appreciate you being here so much. Before we begin, I'm sure you'll all enjoy learning more about Donna. She is a dynamic Staten Island community leader who has been advocating for the needs and services of individuals with intellectual disabilities and autism since the early '80s. And her first impact is still felt fiercely today by families like mine.

She began her journey of advocacy when her daughter, Jeanine, was diagnosed 40 years ago with, at the time, PDD, which was Pervasive Developmental Disorder -- now known as

autism spectrum disorder. There were no options for her daughter and others like her at the time. Donna took action and through tireless advocacy, created a movement of service on Staten Island that speaks volumes.

Donna's dream was to become a New York City police officer, but life's circumstances took her in a different direction. She recently retired as Executive Director of the GRACE Foundation, a non-profit organization established to improve the lives of individuals and families impacted by autism spectrum disorder. And presently, she serves as Director of External Affairs for Crossroads Unlimited Inc, an agency that provides comprehensive services for individuals with intellectual developmental disabilities.

Donna, you have been a long-time advocate for Staten Island individuals and their families living with autism. Staten Island Borough President James Oddo even referenced you as “one of the true unsung heroes in this community, directly and personally helping the lives of so many Staten Islanders.” How did this journey begin for you?

>> LONG: Well, it's been a long journey, and just let me thank you for the introduction, MaryBeth. As you mentioned, the journey began for me over 40 years ago. Jeanine is now 43 years old. I guess I started when Jeanine was two. I noticed Jeanine was not hitting certain milestones, and I had friends who had children the same age as Jeanine, and they were speaking and they were communicating, and Jeanine was not.

And when I spoke to my pediatrician at the time, he told me not to worry about that. Wait until she's four years old and still not speaking, and then we will discuss it. The reason being back then, autism wasn't known the way it is today. I didn't wait until she was four. I

started reaching out to different doctors, and taking Jeanine on many – unfortunately, many kind of visits, and getting so many different diagnoses.

And one was that Jeanine was not hearing at 100%, so they wanted to put tubes in her ears. Which at the time was a big thing to do. That didn't sit very well, and I realized that Jeanine, in addition to not speaking, was exhibiting other behaviors also. She wasn't giving eye contact. She would have screaming fits. We really couldn't go anywhere with Jeanine. People who know Jeanine now, it's hard for them to believe that she had those kinds of behaviors when she was younger.

I thought it might be a good idea at the time to put Jeanine in an inclusive environment. Maybe that would help with her picking up on cues from other children her age, and maybe she would pick up some language and some positive behaviors at the time. So I put her in -- there was a program at the YMCA called Toddling Around, so I put Jeanine in there.

And I also reached out to Staten Island University Hospital at the time to inquire about early intervention for Jeanine. I did get that, and the therapist came to our home three times a week to give Jeanine speech therapy, physical therapy, occupational therapy. Jeanine had hypotonia as well, which was low muscle tone. And I have to say how instrumental early intervention was for Jeanine. The way it helped Jeanine, I know from speaking to many colleagues, many parents and advocates, that it is a lifeline, and it has helped countless children. And they benefit tremendously from early intervention.

At the Toddling Around program, the teacher one day called me aside and she said, "You know, Jeanine is really not interacting with the other children at all. She just kind of goes in a

corner and just sits there, or occasionally would do parallel play. But not interacting." And I realized that all the other children, when their moms came into the room to pick them up, the children would run to their moms and they would go on their merry way. And I'd have to go into the room, and pick Jeanine up, and take her out, and bring her in the car.

After doing that so many times, it became more and more difficult. With the YMCA teacher's advice -- and her name was Pat Marcello -- and interestingly, she did not have a background in special education, but she was just very intuitive. I thank her to this day for really putting me in a position of really moving forward with getting Jeanine an evaluation.

And where I got that evaluation was at the Staten Island Mental Health Society. I reached out to them to have Jeanine evaluated. And she was diagnosed with PDD-NOS. And as you mentioned prior, it's Pervasive Developmental Disorder, not otherwise specified -- which is autism spectrum disorder. And she was also diagnosed with speech and language delay. And it was recommended that we put Jeanine in a program that the Staten Island Mental Health Society had at the time, and it was called Project 8. And it was a special ed program for preschoolers.

And so we did, we put Jeanine in this program. And she was the only girl, and she was the only girl for quite a number of years in the school programs that she was in. But at the time of Jeanine being in that program -- so she was about 3 years old at the time. It was early, early '80s. The rate of autism then was one in 10,000. Now, as we know, it's one in 54. So there's quite a significant difference at the time.

And it became a very difficult journey at that time, because there really were very little programs, and people were not really -- they didn't know much about autism at the time. I remember -- well, this was much later, but I remember being interviewed by a reporter, and after the interview, she pulled me aside and she asked me how did I feel about my daughter being artistic? Not autistic, but artistic.

>> BERGREN: Wow.

>> LONG: So it was quite interesting. But myself, and I know many others as well, in the initial stages, and especially back during this time, because autism was not so known, we went through -- I went through a period of mourning. That took about a year of me trying to process Jeanine's delays and what the future would hold, and what milestones would never be reached.

And all of these things that were quite upsetting, because I have a large family, who there's a lot of cousins who are Jeanine's age, if not very close to Jeanine's age, and being together and seeing all the things that they were doing, and it just emphasized more what she was not doing. So I opted not to participate in many things, because I found it too difficult.

So after that year of mourning, I felt that this is not productive at all. And I'm not helping anybody, especially Jeanine, by doing that. So I approached the CEO of Staten Island Mental Health Society about maybe starting a support group, because I knew that I couldn't be the only one out there feeling sad and disconnected and wondering what the future would hold.

So we started this very successful, informative support group that was very beneficial on so many levels. And interestingly enough, to this day, one of the moms in that group, and this is 40 years later, we're still very good friends. She had a son with a diagnosis of autism. And it

really helped. It helped meeting every week, and listening to people who were going through what you were going through, who would not judge.

And it lasted for a few years. It actually lasted until Jeanine then aged out of that program, and then had to go into the public school system. And once in the public school system, I also went to the principal at the time to try to get something going for the special needs families at the school. That was P.S. 69 was where Jeanine went at the time.

>> BERGREN: Wow.

>> LONG: And also, and it's interesting how we learn from one another. And one day, I overheard a teacher mention a rec program, a small rec program, that children with autism and IDD were going to. And again, very small program. And it was, believe it or not, it was On Your Mark. And it started in a karate school on Manor Road, and then it moved to St. Alban's church.

And I asked the name of the person who was doing the program. And I reached out to -- there was this gentleman, Gene Spatz and Dana McGowan (phonetic), who started the program. And I reached out to them, and I scheduled a meeting with them at my home, and invited the members of our support group to come and listen to see what they had to say and what they had to offer, and how it would be beneficial for our children. And we all enrolled our children in it. And to this day, Jeanine is still in On Your Mark programs.

And of course, there's so many additional programs. At the time, that was just a very small program, and she still was not communicating much or participating much. But as time went on, it became more and more where she was interacting more so with the other children there. And so that was the beginning of the journey.

>> BERGREN: It's remarkable to hear all of this, especially when you stop and consider that autism didn't become a classification of a disability under the Individuals with Disabilities Education Act until 1990. Because you're talking about the years from '80 to '90 where the need was there, so much so for her. And the only way to find supports and services was to ask (for it) yourself. And I love that you bring up that time of mourning, because as a parent of a child with ASD, I often think that myself, and I don't think enough parents want to address or identify that fact that they are feeling those feelings -- and that it's okay.

>> LONG: It is okay. It is okay, and it's important that you recognize that, too, I think. I recall years ago -- and my old age makes me forget a lot of things, but I don't know how long ago it was. But somebody asked me: How do you feel that your daughter will never reach milestones of she'll never get married, she'll never have children, she'll never go to college, she'll never do all these things?

And my response to them at the time -- surprisingly, it was my response, is that: How do you know? How do you know? I don't know what the future holds for Jeanine. So you can't just assume that that would not happen. And I think that's an important thing, that I always wanted to focus on Jeanine's abilities -- once I came to the realization that Jeanine had this diagnosis, and she will always be in special education, and she will always have needs and et cetera, was to focus on her abilities, and not on her disabilities.

I'll tell you, the I have another daughter, Kristen, who Jeanine and she are 10 years apart. And I remember the teacher at the school at the time -- because Jeanine was verbal. She started with words and all. But sometimes not appropriate. It took her a while. She had

receptive and expressive language delay. So it would take her a while to be able to express what she wanted to say. And the teacher said to me, after Kristen was born, she said that was the best thing that ever happened for Jeanine, because Jeanine just keeps saying “baby, baby, baby.” So it was just wonderful to hear, that she was starting to communicate, but also tried to initiate communication.

>> BERGREN: Fantastic. So I know that you spoke about when the diagnosis happened, and early intervention, and school, and the process of getting the supports, or creating the supports you needed at the time, and asking for the supports you needed at the time. But going from parent to advocate takes a lot of time and growth. When did you realize that you had crossed over from seeking help to giving support to others?

>> LONG: I don't even know if I ever realized it. It just seemed to be just this natural transition or progression. I think what happened was that Jeanine was my barometer, and I would think, well, she needs to do this, and she needs to have this service. And if she needs it, then others need it as well. I think that's how my advocacy progressed in the fact that if Jeanine needed it, there were other children out there who needed it also, and that was a big thing.

And also, that other parents would need the -- especially when you first get the diagnosis, as we discussed with the mourning period, helping parents get through that, because that's very hard. And by that time, there were more services available, and more recognition of autism and developmental disabilities as well. And I realized that in order to attain some independence for Jeanine and others like her, that it was important to ensure that people knew

what options were out there, and what services were out there, and how their child can benefit from them.

>> BERGREN: Now, you've lobbied in Albany, the city council, community boards, local legislators, on behalf of individuals with IDD and autism. What motivated you to extend your advocacy beyond the immediate needs of Jeanine? And tell us a little bit about your professional journey.

>> LONG: My professional journey started as a job coach, believe it or not, a job recruiter; and that was going into businesses and trying to find a fit for individuals with developmental disabilities to get a job in the community -- those who had the ability to do so, so it was supportive employment. And to have them have that opportunity.

To be honest, it was extraordinarily difficult for me, and that's where the parent part overtook the advocate part. Because I would go into some businesses and talk about the attributes of the individuals, and the benefits of hiring an individual who had a developmental disability, and sometimes hearing back: Oh, we don't want those kind of people here, or we don't need that, and we can't baby sit -- just not very kind words.

I would be very polite, surprisingly, and go in my car and just cry. Because I thought, you're talking about my daughter, you know? So it was not easy. So that was my initial start of it, and I think because at the time, the agency had reached out to me, and they thought because I was a parent, and because I started to involve myself in so many things with the advocacy part, that it would be a good fit.

And I did it for a while, and then from that point, I progressed to being the community liaison for the agency; like a development person at the agency. And that's how I really started with the legislators, because I would meet with them, and talk about the agency and the services, et cetera, et cetera. And it kind of put me in a different position. I started getting very comfortable with that. And hence, many trips to Albany, and locally -- I mean, at the time, Elizabeth Conley was our assemblywoman and she was a beacon of light for the developmentally disabled. She was such a supporter, such an advocate, and helped so many of us. I certainly consider her a mentor. And we were very fortunate to have her at the time in Albany, advocating for the services.

So we would go as groups, and meet with the different legislators, and talk about the needs and the services, and try to get funding, et cetera, to not only sustain programs, but more importantly, to expand programs, because more and more individuals were being diagnosed. And it was very important that there were services out there that would accommodate the needs of the individuals.

And the reason I would go to community boards at that time was because there was tremendous resistance to community residences coming into neighborhoods. And honestly, the very first one I went to -- I won't say which community board meeting it was -- but I went to a community board meeting, and I listened to these horrific things being said about putting a community residence in this neighborhood. And when I went home, the next day, I packed Jeanine up, and I went out to my sister's house in Long Island, and I stayed there for three

weeks, because I didn't want anything to do with Staten Island -- because I felt if they can't embrace my daughter and individuals like her, I don't want to be here.

And obviously, that changed. I did come back, and thought, now it's time to really hit the pavement and really get out there and let people know, again -- once again, getting back to the ability part, focusing on the ability and not the disability -- and that our children are entitled to everything that every other child is entitled to. And we need to ensure that they lead a quality of life. It's very important.

>> BERGREN: How has the autism advocacy movement developed and matured over the years? Do you see big differences between what you were doing in the '80s and '90s compared to what we're doing today?

>> LONG: I think today, because there's more awareness about autism and intellectual developmental disabilities, that more people are involved with advocacy. And the more we have, the better it is, because as we all know -- and I hate saying this, because I say it so many times that people are probably sick of me saying it -- but there's strength in numbers. And we need to continue with that.

This past year, we have, through advocacy, really aligned with the statewide group, and that has been extraordinarily beneficial. And it enables us to focus on the priorities right now, but we're focusing and we're doing this as one voice across the state -- from Montauk to Buffalo. And that has helped tremendously. I mean, not that long ago, because of COVID, we've had Zoom meetings, and we had a virtual rally, and over a thousand people were on that. And that was followed by other town hall meetings, and we did a city-wide -- typically each borough

does their own legislative breakfast. But because we couldn't all be together, as we know, we opted to do a city-wide breakfast, and all five boroughs joined together with one message, and again, over -- close to a thousand people attended that as well.

So advocacy has become very, very, very important. And it's something that we really must, must do. We really have to impress upon younger parents who are just getting a diagnosis, and going through those stages that we discussed before, that the only way they're truly going to help their child is by advocating for the services; to ensure that the services are there. And that's very, very critical.

>> BERGREN: What are the hot button issues of the day? And in what way are they different or the same?

>> LONG: Right now, there's quite a few hot button issues. One that comes to my mind, because it's close to me, to what I'm looking for, and that's residential opportunities. There are not many residential opportunities, and there hasn't been many residential opportunities in quite some time. That is something we really need to focus on.

My daughter, as we said before, is 43 years old. She still lives at home. My husband and I are not getting any younger. And I want to be part of the process of what agency is going to provide a residential opportunity for my daughter? Who she will be living with? These were the things that years ago, when residences were being developed, that is how it worked. Where a family member, a parent, family member, would go to an agency, and request that they would like their child to be in a residence with that agency. And their development was quite good back then.

I opted, unfortunately -- can't say regretted, but I opted to turn down quite a few opportunities way back when, because A, I wasn't ready. I don't think a parent is ever ready. But then reality has to take charge. But I wasn't ready, and I felt maybe there was another individual out there who needed it more than Jeanine, so let me wait. That waiting has now put us in a position where there are very few residential opportunities. So that's one hot button issue.

The workforce is another hot button issue. Staffing for agencies is not doing very well right now. The CARES tool that OPWDD is going to be using for rate-setting is something that we really need to be mindful of. And all of these things are topics that families may want be aware of, that we really need to have them understand how this can impact their child's life. It's really very, very important.

What is different? Part of your question is that we used to have an ally with OPWDD, and we were a partner with OPWDD. But unfortunately, for quite a number of years now, that has not happened. There is a significant disconnect and a lack of transparency. And it's really vital -- it's really important that we restore what has been lost in services. And move forward with some one goal in mind, and that is to focus -- to ensure that the quality of life for our individuals with autism and intellectual disability, developmental disability, is at the forefront of any plans or decisions that are being made in the state. And that those decisions should be need-driven and not cost-driven.

And that's something that we are seeing more and more of, and that's very, very disconcerting.

>> BERGREN: Now that Jeanine is an adult, and you've reflected all of these amazing experiences, and what you wish her future to look like, what would you tell the new moms that are starting out on this journey with their children? How can they get involved in advocacy? How should they advocate for the future? What are some words of advice from a guru like yourself?

>> LONG: I'm not a guru, but I'm just a mom who had experiences. I would just emphasize getting involved. There are many, many ways of getting involved. We have the Staten Island Developmental Disabilities Council, which is a great, informative, and educational group of family members, parents, self-advocates, providers. And we meet monthly, and it's an opportunity to learn, to get information, to be your child's voice, if need be. Or if your child has the ability to be their self-advocate, to be part of it as well. That, to me, is very, very important, is getting involved. It's critical, it's critical.

>> BERGREN: Yeah, I think that in the beginning stages, when you started to speak about early intervention, I thought about what that was like for me, and how isolating that experience was. You were in it, and you had the therapists, but you were alone. There was no connection to find support or resources. I really admire you going out and asking for that support and resources. And I think that's so important, that parents and family members and caregivers know that they're not alone in this. And that they can make a difference.

>> LONG: They absolutely can make a difference. Because in most cases, families, parents and family members are listened more than a provider agency, because that could look a bit like it's

self-fulfilling. But the parents know the need, know what your child needs, know what is important and what's going to give your child the independence that is so important.

I remember -- I don't even remember how I heard about the council, but I remember going to the first meeting, and feeling -- I don't know, what did I get myself into? I don't know any of this stuff. I don't know what they're talking about. And going to the meetings monthly, and then getting involved, getting on a committee. Being part of the conversation. And it just grew from there. And that's what parents, family members, self-advocates need to do as well, is the resources are there now, and take advantage of them. Because it's beneficial all around. It's very, very important.

You know, recently, I think it was last month, that there was The Annual Willowbrook Lecture. And the participants were parents, as well as two of the doctors, and it was the parents whose children lived at Willowbrook, and they shared the horrific stories of what went on there, and how they became parent activists. And through their activism and being involved, that led to the closure of Willowbrook. And that's huge. That's how powerful parents are. That's how powerful your involvement can be. And these brave parents continue today to advocate. Many of them are up in age, but they're still advocating. What they accomplished was monumental.

And I think we and those that are behind us who are coming up and getting diagnoses, that's what we all must aspire to follow in their footsteps, and learn from them. We learned from them, but we have to continue to learn from what they've done. With one common vision, again, we're stronger together with one voice, and just to realize that we don't ever want to go

back to a Willowbrook. We have to remember the past to protect our future. And that's key.

Because we need to protect what we have and we need to move forward to ensure that what we have remains. And then make it better.

>> BERGREN: I couldn't have said it better myself. I agree 100%. Donna, it's been such a pleasure having you today. Thank you so much for coming and joining me on this topic.

Thank you so much for everyone who's listening. And tune in next time for another great conversation on "Disability, Inc."