

Promoting Diversity in the Courts: Antonella Barbieri on “neurodiversity”

John Caher: Welcome to Amici, news and insight from the New York Court System. I'm John Caher.

For today's Diversity Dialogue segment, I'd like to introduce you to my colleague, Antonella Barbieri, a senior management analyst who's worked her way up in the court system since joining the Unified Court System back in 2004.

Antonella was recently promoted and is now a manager in our Division of E-Filing. She was previously a court clerk training specialist and has trained judges and attorneys and clerks and agencies, and the general public.

She also served as liaison between the highest volume courts in the state and the New York State Courts Electronic Filing System. Her efforts are greatly appreciated, as evidenced by the fact that she has been honored with multiple awards, including the New York County Lawyers' Association Unsung Hero Award.

It's a tough job and it's an important job.

But she has another job that's even tougher and even more important—and that's being mom to two young children, including one with autism. Today, we hope to view autism from the perspective of a mother and her child.

Antonella, thank you for your willingness to share your story. I'm hoping that the unique insight you have will clear up some misconceptions and help us all appreciate the family dynamics with an autistic child.

Let's dive right in. So, you have a little boy who was diagnosed as autistic when he's two and a half years old. What led to that diagnosis and was it a surprise for you?

Antonella Barbieri: Oh, it was certainly a surprise! But what led us to the diagnosis was when we were at the doctor's office for my daughter's well visit. She was three months old, and I was asking the doctor, just in passing, “When's my son going to talk more?” The doctor was like, “Well, what do you mean?” And I was like, “Well, he counts one to 10. He does it really well. But he's not really saying anything else.” And my doctor said, “Well, what are you waiting for? Get him evaluated. They get services in the house until

they're three years old." I said, "Oh, well maybe he can get some speech therapy."

So I called an agency that assigned us a service coordinator, and she explained to us the process, scheduled an evaluation of our son and there was a speech evaluation, an occupational type of evaluation and a psychological evaluation.

After the psychological evaluation, the person who did the evaluation just said, "I'm going to diagnose your son with autism at this time, I'm sorry," and hung up the phone. It was a virtual appointment and the phone hung up and I'm looking at my son, who was still playing with some of the toys they had me put in front of him, and I was stunned to say the least. It was definitely stunning and shocking hearing that, especially when you thought you were just going to get some speech therapy. So that was the concern and that's what led us to the diagnosis.

John Caher: How did you react?

Antonella Barbieri: I cried. I cried a lot. We were stunned and shocked. There was a lot of crying, a lot of not understanding, even anger. But we couldn't be there long because there was a call to action. We had to schedule over 20 hours of services for him, so it became something real and changed our lives immediately. So life really hasn't been the same since. And life before the diagnosis, it's not clear to me anymore what life was like before this, because we just know life now, living with someone who is neurodiverse.

John Caher: Let's take a big step back and start where I probably should have started in the first place and define what it is we're talking about. So, what is autism?

Antonella Barbieri: Autism is a spectrum disorder. It can impact people in different ways, but essentially it's a developmental disorder that impairs someone's ability to communicate or interact in society. And there could be a range of symptoms. It can manifest in different ways and that's why they call it a "spectrum."

John Caher: So the first sign to you was that your son was late in speaking? Was there anything else, in retrospect?

Antonella Barbieri: Looking back on it, some of the behavior that I thought was just typical child behavior, the psychologist was pointing out as "sensory seeking behavior." My son would hold a toy and he would spin in a circle and I

would sit there and say, "Man, look at the way he loves that toy. It's like a love story, him and that toy, the way he's spinning with it," thinking that that's what it was, that he was just in love with his toy. Clapping his hands or flapping his hands when he's excited or tiptoeing over to something when he's excited. I mean, I tiptoe over to the dessert table sometimes! So I took that behavior and interpreted it as something else, but actually it was brought to my attention by the psychologist that it was "sensory seeking behavior," and that's behavior that is typical of someone who is autistic.

John Caher: So at the time that the diagnosis was made, your daughter was a newborn, very, very young, and she's grown up with a special needs child in the house. What is her outlook on this? How does it affect her?

Antonella Barbieri: Well, I would say my daughter, who's now three years old, has a front row seat in living with and loving someone who is neurodiverse. At the young age of three—she started 3-K back in September, and in that first month, she actually won the Respect Award that recognized children that accepted the diversity in others. And I said, "Wow. At three years old, she's already doing that!" And at parent-teacher they said, "Yes, Stella advocates and speaks up for some of the children that are having trouble communicating in the class." It was remarkable to find that out. They said, "Well, what are you doing with her at home?" And I said, "Well, her brother is autistic, so maybe she's picking up on that." And they said, "Oh wow, then you're doing an excellent job."

I wasn't looking for accolades. I was just so glad to hear that my daughter was well-behaved. It was just such a breath of fresh air to know that at three-years-old that she would be conscious of advocacy and people having needs and people that have needs can be helped and addressed by people that have that capability, like her at three-years-old. It's phenomenal.

John Caher: There seems to be a natural empathy with her.

Antonella Barbieri: Yeah, certainly. But it doesn't mean I don't have concerns. I certainly have concerns. I worry as a parent sometimes, will she perceive me being tough on her, more tough on her than to her brother? But we're being equally tough on them and we're still challenging them both, but they're being challenged based on the needs and the abilities that they have. So the challenges that our daughter has are greatly different than the challenges our son has, and I would just hope that she doesn't see it as favoritism or just being easier on her brother.

John Caher: I think just the fact that you're conscious of that kind of mitigates the possibility that that will happen.

Antonella Barbieri: I hope so.

John Caher: How does the world look from the eyes of an autistic child?

Antonella Barbieri: I don't know. I wonder myself sometimes when it's late at night and it's quiet and my son's lying in bed and the only thing you hear is him hysterically laughing at something. I don't know what he's laughing about. I ask him what he's laughing about and he doesn't answer. So I'm sure it's got to be way more amazing than the world that we perceive the world as.

I can imagine the world at times may be difficult or tricky for him to navigate, depending on his sensitivities at the time. Perhaps a scenario can be scary, like getting a haircut. Maybe he will be able to tolerate it better at some times than other times, and then there are those times where he's not able to tolerate it and it could be scary that he's getting a haircut. Sometimes the feeling of water on his skin hurts and he says, "Ow!" So that could be scary as a child, or as a parent. You're just trying to give your kid a bath, not realizing at that moment maybe just he's a little sensitive and the feeling of water on him actually hurts. The world can be unstable, I think, for a child with autism or a person with autism, and we have to be more mindful and sensitive to that.

John Caher: That's interesting. You had told me offline that "the world will never know of the struggles he has." And it sounds from what you're saying that to a large extent, neither will you.

Antonella Barbieri: Right, right, certainly. The uphill battle that society faces is that there's a huge implicit bias that comes with autistic people, autistic children, people with neurodiversity. I've been told by people at times, "But he doesn't *look* autistic." And it's real innocent when they say that. They really believe it. But what they're really trying to say is that there's no physical indication that my son has neurodiversity or any type of developmental delay in any sort of way.

You look at him and you say, "Wow, he's such a cute little boy. Look at the energy and look at that smile and, wow, look how fast he goes and doesn't that hurt and how does he pick that up," and all of that. And that's what people see. But they don't see that maybe he's doing that because it feels good to push a couch into the middle of the room. Maybe it feels good to walk on all fours or when he asks to be swung

upside down. It feels good for him. But the world won't understand why he's asking for those things.

When people see it as an adult, there's an implicit bias that my child is misbehaving, that my child is naughty, that the parents let the child do whatever the child wants to do because the parent is lazy. There's a lot that the world doesn't understand about that and I think it comes from an implicit bias. If you see a child in a wheelchair, you would have an implicit bias that they couldn't do something, but in fact they can and they wouldn't want you to think that. And the same thing goes for a child that may look like they have no barriers, no boundaries, or something that a typical child would be able to easily navigate and the parents don't see it. I know, especially with my son, we've seen that people probably think he's just a misbehaved child when he's in the world looking for input, but he's not.

John Caher: Or that you are a bad parent.

Antonella Barbieri: Or that I'm a bad parent.

John Caher: I started this discussion by quoting you as saying, "The world will never know of the struggles he has." I'm going to change that: "The world will never really know of the struggles that *you* have."

Antonella Barbieri: Or any other parent or person, John, navigating as a human being in this world. You know when some people say, "Well, I'm not a math person." You kind of take that as, "Maybe they're just not good at math." No, there are some people that are just not math people, that math just doesn't make sense to them, and it's very hard to learn math. So it's that type of implicit bias that we have to strip away and we have to get rid of. If we really want an inclusive world for everybody to function in, then we have to get rid of these types of implicit biases.

John Caher: Well put. Now, your son, what's his name by the way?

Antonella Barbieri: It is Joseph. We call him Joey.

John Caher: Does Joey know he's different? Does it bother him?

Antonella Barbieri: I think Joey knows he's different to the extent that everyone is different and he's the same as everyone else; we're all different. I don't think it bothers him because he's constantly surrounded by people that accept him and love him. It's important during the beginning stages of early intervention with children with autism, teaching them self-acceptance,

for them to grow their self-esteem and for their neurodiversity to be celebrated because that will ensure that he is accepted and it won't bother him. The foundation of his happiness and whether this bothers him or not is on us as adults. It's our responsibility to make sure that it doesn't bother him. That's why I am sitting with you today, to make the world aware and to be more gentle when it comes to people who may struggle in unseen ways.

John Caher: Now, when you cited examples of implicit bias, you were mainly talking about adults. How do the other kids treat him? Has he endured bullying or anything like that?

Antonella Barbieri: Honestly, I have to say that I've never encountered my son being bullied, being made fun of or teased by another child. I think society, parents, schools, extracurricular activities and places where kids go, I think they're doing a great job at teaching inclusion and acceptance and diversity. I'm real proud of that.

Children will see my son if we're waiting in line for ice cream, if we're waiting in line for one of those kiddie rides at the park, and a kid sees my son wiggling and I'm rubbing him and I'm squeezing my son to stay still and just to wait a few more minutes. Kids let us go in front of them in line. Children who are waiting just the same amount of time as us. "Oh, you can go in front of me." John, it's so wonderful and it gives me hope for the future for our son.

Obviously, there's kids that bully. I just have never seen it. And I don't want to say it doesn't happen, maybe it does, but in my eyes and with my son, I have not witnessed it and I'm very thankful for that, and I'm hopeful for the future because of that.

John Caher: That is wonderful. It sounds like we as adults have an awful lot to learn from children.

Antonella Barbieri: Always, *a/ways*. We can look at them for that newness and that freshness that we lose somewhere along the way.

John Caher: How do the parents of other kids view him? Have you run into, "I don't want my child playing with yours, he's ... whatever." Have you ever run anything like that?

Antonella Barbieri: I have witnessed it with other parents, and it's actually fine because it's more reflective on other people and not us as a family. So I don't internalize that. In fairness, to try to play devil's advocate. I can

understand the parent maybe who doesn't want a child who might bite or push around their child. They might be scared that their child's going to get hurt. I understand because I wouldn't want to put my child in an imminent risk. But I wouldn't want parents to prevent their children from interacting with neurodiverse children, whether there's behavioral issues or anything that comes along with it, because there has to be an acceptance and there has to be a tolerance and a patience.

I find that when I'm sitting with another child and my son, I'm able to create a bridge that allows them to play with each other. Some parents don't want to be the bridge. They just want to let their kids play without parent interaction. We're not really afforded that. If my child is going to play with another child, I'm going to sit right there next to him and guide him and help him to socially interact with another child. So it's a big responsibility to play with a child that is neurodiverse and maybe has some behavioral issues that would be concerning to another parent.

John Caher: Someday, Joey's going to have to navigate the world as an adult. That must give you some concern.

Antonella Barbieri: I go back and forth on this one. There's times I could see my son, he'll go and fix himself a snack or he'll go and change his clothes or he'll go to the bathroom by himself. And I think, "Wow, what an independent kid." If he could only just be that independent when he gets older. But then I think about what type of education is he going to get? Can he sit for exams? Can he go to college? Does he need to go to college? Will he have a vocational job? What type of quality of life will he have? Can he live independently? Will he live in assisted living in an assisted living home? I'm not sure. I'm not sure. I do worry about these things and they're valid concerns, but they're not anything I really have to worry about now. He's only five and a half.

In the school that he's in now, it's a school that has other satellite schools. One of the schools is a vocational school and they do an excellent job teaching neurodiverse young adults how to clean, how to fold clothes, how to become a server. So I know that there are support services that'll help a young adult transition into adult living. For any parent to think about their child growing up, it's real sad. So I don't even want to think about them growing up right now. But I do know that when we get to that point that he'll be supported in the same ways that he's supported now as a child.

John Caher: That must give you great relief.

How has this experience affected the way you do your job or has it caused you to view your job differently?

Antonella Barbieri: I'm one of the managers here in the Division of E-filing where it is the vision of this office to create a virtual representation of a courthouse. For how many years did we think, well, there's only a courthouse, what other type of place do you go for justice? We always imagined filing your documents and interacting with the court as going into a courthouse. But as time progresses, and as technology has developed, we are able to now create an alternative court where people can file their documents electronically, they can view their documents electronically, and they can interact with the court electronically, in a virtual way, eliminating that social aspect. Perhaps during COVID we lost during the pandemic a lot of the social interaction. But for some people who struggle with social interaction, I think that maybe this was a good thing.

I continue with that vision of creating this alternate access to the courthouse. And I think about it with the motivation of my son in mind for people who may not walk into a courthouse because it may be too much of an overload for them emotionally, sensory wise, to go into a courthouse, to speak to someone, to accomplish a task that may be better off if they were just able to do it without social interaction. So I think about that.

John, I'm in the perfect place for that here at the Division of E-Filing, where we are aware of the people who need an alternate method of filing documents. We're constantly thinking about the underdogs, the people that need us the most.

John Caher: That's fascinating. I hadn't thought of E-filing in that context. I was thinking of E-filing more as an *efficiency* rather than an *accommodation*, and I think you're telling me it is very much both.

Antonella Barbieri: Absolutely. It's definitely both. And it's a living creature. The E-filing site, even though it's a website, is constantly evolving and constantly catering to the individual needs that are presented to us in New York State-- families, agencies, and the people that really need us the most.

John Caher: This might be a strange question, but do you think the experience of having an autistic child has made you a better professional, better employee?

Antonella Barbieri: I don't know about "better." Well, maybe my managers would say "better." I'm more patient. I would say I'm definitely more patient. I also

have less expectations and I have more acceptance. So how that translates into what we do here in the Division of E-filing, yeah, maybe it makes me a little better. I'm more patient, I'm more mindful of the needs of individuals. When people are calling, I don't expect them to have the same tools that I have to navigate.

John Caher: It sounds like maybe this experience is helping you to become the person that you are meant to become in a way.

Antonella Barbieri: Well, I absolutely feel that way, especially in becoming more accepting of the way things are rather than having expectations. That's helped me grow as a person, and it helps me to continue growing, being more accepting of where I am in my life and the role that we play in this world.

John Caher: What do you wish people better understood about the life of a parent with an autistic child?

Antonella Barbieri: I'd like to offer the following insight: The parent of an autistic child is not just simply a parent. The parent of an autistic child ends up wearing many hats. I would say for myself that I am an advocate. I'm an advocate for my child, so that he receives the services that he needs, that he's growing in the ways that he needs to grow. We do this for our children. If you're an active parent, you do this for your children, but there's an extra layer of advocacy that comes with being a parent of an autistic child where you're dealing with other agencies, city agencies, state agencies.

You're in this world of professionals you didn't think that you were going to have to deal with and interact with. So you almost become a professional parent of a special needs child, where you have to be on top of all these things.

Part of being a parent of an autistic child means that we have to go also into the world and protect other autistic children, and that we need to always keep other autistic people in mind. You're almost the parent to all autistic children, and you almost become the spokesperson for all autistic children and an advocate for all of them. It's a big job, being this parent, but I wouldn't trade it in for anything.

John Caher: Why do you say that?

Antonella Barbieri: Because I waited my whole life to become a parent. I think that I had an idea of what type of parent I was going to be, but I was so wrong because you don't know what type of parent you're going to be until you have that child in front of you and you say, "Oh, I got to be a parent to *that*

child." So I'm a parent to my son. I'm a parent to my daughter. And I'm a different parent when they're together. It's a wonderful journey, and that's why I say I would never trade it in, because it's something that I've always wanted.

John Caher: What can society and the courts do to better understand or accommodate those with special needs?

Antonella Barbieri: I think as a society, what we can do is always just be mindful of the people that are around us, to constantly be mindful of our diversity, even the diversity in the people that look exactly like you. That's what we can do as a society. To look for the differences, to look for the similarities, but always to keep in mind that we are all different, and that we are all the same.

John Caher: Well put. Thank you so much for your time and your insight.

Antonella Barbieri: Thank you, John. Thank you so much.