



2023 Autism Resources Fair

Transcript of Keynote Speaker Paul Aronsohn, NJ Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families

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Paul

Thank you, everybody. Great to be here. I appreciate the opportunity to talk about our work, talk about our office, particularly because a lot of people don't know about our office because we're relatively new. So I always welcome this opportunity. I'll tell you a little bit about us and then I'd love to take any questions you might have. So again, my name's Paul Aronsohn and I do have the longest title in state government. I am New Jersey's Ombudsman for individuals with intellectual or developmental disabilities and their families

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Paul

You should see the fine print on my business card, it's really small. But it's it's a position in your office that was born out of a recognition that while there are a lot of resources in New Jersey for children as well as adults, there are a lot of families that fall through gaps because the system is very complex and it can be overwhelming.

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Paul

But we're talking about lifelong disabilities. And so today you might get this challenge, tomorrow you might help with this challenge. And so folks in the legislature, as well as some of our family advocates, put together some legislation and it was adopted by the New Jersey legislature in December 2017. Governor Christie signed it into law in January 2018, and I was appointed by Governor Murphy.

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Paul

I was actually appointed by Governor Murphy, I think five years ago tomorrow, so tomorrow's our 5th anniversary. And this is really been an experiment. I was telling Wendy earlier I don't think a position like this really exists in other states. There's a couple of similar things, but nothing quite like this. The

enabling legislation that created our office, sort of with some responsibilities, that we've sort of thrown into three buckets.

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Paul

First and foremost, our job is to help make sure individuals, children, adults, families get the services or supports that they need and that they deserve. That means we spend about 80% of our time troubleshooting families. They email us or call us sometimes connecting to the program, but some families we've been working with all five years because again, the challenges don't go away.

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Paul

And so we work on big issues, large issues, and just help families navigate the system, which can again be very overwhelming, very complex, ever changing. We talk about the complexity of the system. There are more offices, as you probably know, and more acronyms and more requirements and paperwork and stuff like that. It's just it's nonstop. So we try to help families sort of find their way through all that.

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Paul

The second thing we do is because we work so closely with individuals and families, we try to sort of use that experience that we learn from them to sort of inform the larger policy discussions. What I mean by that is we work very closely. One on one. So my colleague CJ just came in here, I'll tell you about him in a minute.

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Paul

But what we try to do is we work very closely with individuals and families and we try to sort of serve as a nexus, if you will, between the decision makers and those impacted by decisions. Because we work very closely with our colleagues in government, in various government offices. So we try to bridge the gap. And what we try to do is use their experiences that we've learned from families to

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Paul

to not only help them, but we try to use it again to inform larger policy discussions and that brings us to a third sort of set of responsibilities, which is very overarching. And that is we work really hard to help make sure that the voice of individuals and the voice of families is heard and that it's heard in a meaningful way.

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Paul

Again, not just on issues or directly impact you as a family member, but again, making sure that that point of view is being represented in Trenton and policies are being made for to help make sure that

families have the table. And we we do that to make it a better system, make it more accessible, to make it more user friendly.

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Paul

Because, again, there's no better sort of experts, if you will, than the individuals and families who are moving through the system to sort of help us make it a better system. We have an office in Trenton. Originally, they put us in the Department of Community Affairs. I think that was a random decision because they had some free office space. But we've recently moved and there's four of us in the office.

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Paul

I rarely spend time in the office and I made a decision early on when I first took this job that what we needed was more of a personal touch. And I come from a family and I'll talk about that a little bit. And so we try to spend as much time as we can working one on one with individuals and families.

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Paul

That means we're always on the phone with individuals and families right now on video, because you all like to use Zoom and other, other platforms. But whenever possible, we make it a point. Going to family's home, to sitting with the family, to meeting other family members, to seeing the house, to seeing the challenges, the opportunities. We visit schools, we visit workplaces. And again, doing so not only allows us to help the individual, help the family better, and inform a policy discussion.

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Paul

But it gives us a perspective that a lot of our colleagues don't get. Frankly, because of their jobs, they're stuck behind desks, stuck in meetings. We make it a point of really connecting with families one on one. And so I drive all over the state, we go wherever we can, including here, to the Ocean County Library. Because we really want to keep it as personal, because we feel that that's the best way we can serve you and we can serve again.

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Paul

The larger community. There's four of us in our office now. Three of us. A fourth one just started two weeks ago, we're really excited about her. three of us had brought to the job both a mix of both professional experience with disability and personal experience with disability. Myself, professionally, I've been when I was mayor, I've heard on different committees of different, worked with different organizations.

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Paul

But most of my experience, most of my knowledge, all of my passion for disability has come from my family experience. I'm a sibling. I had an older sister, Patty, who had developmental disabilities, not autism, but she had some cognitive learning disabilities as a child, behavioral issues. Physically, she was a dynamo, she loved to dance and she was very athletic, we used to play softball and baseball together as she graduated high school, she went to a program at NYU that had a program for special needs students who wanted to work with children.

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Paul

My sister loved babysitting. She loved children, so she wanted to become a teacher's aide. So at these programs, she became a teacher's aide at the United Nations Daycare Center of all places. And it was great. But in her twenties, she started, her disability, started to express itself physically, and she started having trouble walking. She needed a cane, she needed crutches, she needed a walker and eventually she needed a wheelchair.

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Paul

And my sister eventually became quadriplegic with a feeding tube, a trach, effectively she lost ability to speak, except she always kept some choice words for her younger brother. And so through her life as a child, as an adult, I learned so much about disability and through my mom as her caregiver when we were children, but even more we were adults.

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Paul

As Patty lost her independence. I learned what a parent goes through the struggles, the fears, the concerns, the stress just and it's nonstop. Wanting to advocate for your child, but not wanting to go too far as to sort of, you know, make somebody mad on the other end of the phone or, you know, potentially lose those services and supports. So I watch and I learned and I became very passionate and it informed my understanding, you know, like our deputy, Christine Bakter, also professional and personal experience.

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Paul

She worked with Autism Speaks. She worked for NAMI Mercer. She's an autism mom. She has a young son, a young adult. I think he's 24 years old with autism and C.J, who joined our staff last year, he's got both professional and personal experience with disabilities. Professionally, he worked with different organizations, including one of the Centers for Independent Living in New Jersey, which are one of the best kept secrets of New Jersey.

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Paul

And CJ has spina bifida. And so that is really important, particularly for such a small office, because we want to be able to connect with people and speak the same language. And in fact, one of the main

reasons that the governor appointed me in the first place was because of the family experience, because I can connect and can speak to families in a language that we can all understand.

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Paul

So our work, as you can imagine, covering the whole state, three now four of us, children as well as adults. It's a lot sometimes it's seven days, but for us it's a labor of love because of our professional, our personal connections with disability. Interestingly you know, as our our office was created to help families, you know, sort of navigate the system and find their way and make sure they get certain supports that they need and deserve.

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Paul

As it evolved over the last five years, our place has become an office where people turn to more often than not when they're in crisis or when there's a time sensitive issue of some sort, when the system's just not working, when it's failing them. And so we deal with a lot of families who are in distress, not in a good way, really needing help and needing it now.

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Paul

And one of the things we do is we have to do in our office is an annual report they're on our website if you're ever interested, and we've tried to since beginning use our annual report, not just to be like a normal annual report that organizations use to tout the accomplishments in the previous year really use it to try to tell the story, the story of folks with disabilities and their families, what they're struggling with, what the challenges are.

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Paul

Again, by its very nature, people come to us when something's not right. They can't find something, something's wrong. So we don't get all the success stories. We don't get. And there are plenty of lot of folks that are doing really well in the system. But we deal with the folks that are not always and we try to reflect that and we try to do it that way without finger pointing or blaming anybody.

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Paul

So really sort of helping tell the story and just shining a light on some of the issues that need to be addressed and some possible ways for addressing them, you know, we could go into some of the some of the work we do. But I can tell you, you know, one of the things I learned when I took this job, when I first took this job and again, I come from a family of disability who worked on disability.

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Paul

I never knew autism until I took this job. And I say that in general. But autism and severe challenging behavior in particular. From the very beginning of my days in this office, it's been an issue. And, you know, a dynamic I've been dealing with meeting the families across the state who are struggling. Children, adults, really having just an amazingly difficult time and the thing that struck me then and it still strikes me now two things.

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Paul

One is the prevalence of autism in general and again, autism, or severe challenging behavior in particular, as well as what struck me is the lack of supports and services that don't exist. They just don't exist. And for me, you know, it was a real wakeup call because I wondered, you know, again, being involved in disability for so many years you know, professionally and personally, why didn't I know this, why didn't I know the problems with autism and severe challenging behavior.

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Paul

And it dawned on me early on, that probably one of the reasons is because these families are often in crisis. They don't go to restaurants, they don't go on family vacations. They're so focused on taking care of their own. And the rest of us don't see it. And so one of the things I've tried to do in this job, and we try to do in our office is really shine a light on this. One of the things we've done in the context of autism is we've been really trying to get the governor's office to set up an interagency committee, if you will, a whole government approach to autism.

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Paul

And severe challenging behavior because it's something that affects individuals or families throughout the span of their life, from early intervention, education. You're going to have to be part of the children's families, you know as they get older, housing, you know, adult services, transportation, public safety. You know, we a lot of what we look at very closely with the attorney general's office working with public safety, the intersection through law enforcement and special needs community in general, autism in particular.

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Paul

So we've been really we've been trying to sort of like really know, you know, making noise, blow the whistle, you know, sound the alarm, you know, trying to get folks to focus on this because it really is a crisis of proportion. The latest numbers we have, you know the CDC came out recently, one of 34. As we all know, New Jersey we've been, have one of the highest prevalence rates not just in the country but in the world, it's been 1 in 35, 1 in 32.

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Paul

It's been around that. But what that means is we work very closely with Autism New Jersey. It's really sort of our go to organization for us. But what that means is, is about 220,000 New Jerseyans with

autism. That includes 60,000 children. And it's estimated that about 30,000 New Jerseyans with autism engage in severe challenging behavior. And so I'm sure you all know that is self-injurious behavior.

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Paul

It's punching yourself in your head, hitting your head against the wall. It's rushing towards others. It's destruction of property. To me, you know, I mean, we see this again with children, we see this with adults. You know, the system's not working for these folks and their families. And this is what we've spent a lot of time on, which not at the expense of other working on other disabilities, because, you know, we help anybody who comes to us whether to get involved with it or not.

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Paul

But this is what we do is on a daily basis, these are the emails we get, these are the phone calls, these are the meetings we have. The other thing that we deal with a lot is abuse and neglect, particularly mostly in the adult system, but also in the children's system. It's something that, you know, we again, it's another issue that we're trying to sound the alarm on, get people to focus on. It's not something that's talked about much.

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Paul

So that's the kind of work we do. But again, we work with folks and not just on those issues. We work, you know, people, particularly young, you know during the pandemic, families would contact us for help. They were having trouble getting unemployment checks we would help them. You know, we would help we help families on any issue to possibly help them with it across the board.

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Paul

We have the ability to because of the reach of our office, one of the most important things we did was to create our office is, you know, we're technically housed within the state's Department of Treasury. The reason they do that, they want to put in the Department of Human Services or the Department of Children and Families because the issues that affect folks and families with disabilities, don't just reside in one department.

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Paul

Yes, it's children and families, it's education, it's health, transportation and public safety. So by putting us in transportation, it gives a system wide perspective, gives us some independence. So we can work and help and advocate for families and with families on a whole range of issues that impact their lives. Anyway, thank you very much for coming. We have a table. CJ will be there at the table in there.

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Paul

If you want more information, don't hesitate to reach out anytime. Thank you so much.