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Advocacy in Action: Empowering Families and Individuals with Disabilities Transcript



**TOGETHER
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**Celebrating Abilities, Advocating
for Support, and Securing Futures.**

PLAN | NJ Podcast Series

Episode 1

Ellen: My name is Ellen Nalven. I am the Executive Director of Planned Lifetime Assistance Network of New Jersey. It is my pleasure to introduce this conversation with Paul Aronsohn on the topic of how to advocate for your loved one with a disability. I'm also delighted to introduce my co-host for this episode, Hazeline Pilgrim.

Hazeline is a member of the PLAN New Jersey Board of Directors. She's the Executive Director of the Family Support Organization of Essex County And serves on many boards, guiding and advising advocacy and service organizations. Hazeline has lived experience as a parent of a person with a disability, which informs her work.

Welcome Paul.

Paul: Thank you. It's good to be here.

Ellen: Thank you. Welcome, Hazeline.

Hazeline: Thank you, Ellen. It's my pleasure to be here today.

Ellen: Let's start by just telling you a little bit more about Paul. Paul Aronsohn is New Jersey's Ombudsman for Individuals with Intellectual or Developmental Disabilities And Their Families.

As such, he serves as the administration's leading advocate and ally for New Jersey residents in need of critical services and supports ranging from early childhood through adulthood. Paul was also appointed by President Biden to serve on the President's Committee for People with Intellectual Disabilities, which serves as a federal advisor to the President and to the U.S. Secretary of Health and Human Services. Paul was also the recipient of the Exceptional Public Service Representative Award at PLAN New Jersey's Celebration of Abilities in 2022. Paul, we greatly appreciate your taking the time to join us to talk about advocacy for people with intellectual or developmental disabilities and their families in New Jersey.

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Many people know that you are more than just a public advocate. You are a sibling of a person with disabilities who unfortunately has passed away. We support many siblings and family members at PLAN New Jersey, and we would imagine that your experience in this role has informed your work in important ways.

My co-host Hazeline is also, as we mentioned, a person with lived experience, and I think for both of you, your advocacy work continues to be informed by this. So, Hazeline, would you start our conversation?

Hazeline: Sure. Paul, first, as a family member, I always want to acknowledge the tremendous impact that our loved ones continue to have on our work and to extend my condolences on the loss of your sister. Would you say a little bit about how your experience, your family experience, influences your advocacy and how it influenced your advocacy for your sister?

Paul: Sure, no, I appreciate the question. I'm actually the youngest of four and all three of my siblings have had a mix of disabilities and healthcare challenges.

But it was my oldest sister Patty who had developmental disabilities and as a child, that meant some learning disabilities, some cognitive challenges, behavioral challenges. Physically though, she was very active, very independent. She liked to dance; we used to play baseball together.

I learned a lot about Patty being her younger brother, and about disability, being Patty's younger brother. As she got older, her disabilities started to express themselves physically. She started to have trouble walking in her twenties. She needed a cane, then she needed crutches, a walker, and then eventually needed a wheelchair.

She became quadriplegic, required a feeding tube. She effectively lost the ability to speak much, although she had some choice words she would keep for her younger brother! And so I, through her, not only when we were children, but more actually as adults, I learned a lot about disability, and I learned what it is to be a family member and to learn so much from my sister, who was my number one teacher.

I also learned a lot through my mom as her caregiver. Again, not as much when I was a child, but as an adult, as Patty lost her independence. My mom stepped in, in a very big way. They became quite a team. And I learned so much about what families do to try to navigate the system, to deal with the challenges, the fears, the setbacks and trying to find their way forward. So they were definitely my best teachers and the reason I've become so impassioned about disability. It's really through their example and even through their passing. They died three days apart. My mom in 2017; she died on June 20th. Three days later, Patty passed.

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My brother and I would joke at the time that my sister took a look at the two of us and said, nah...it was shocking and it was heartbreaking, but it was also beautiful, in the sense that these are two people that really journeyed through life and past life together.

And it really underscored, for me, the connection between parent and child. Again, my sister Patty was quadriplegic. She really didn't have the ability to do much for herself. She was able to let go of life when she chose, it seems, and so it was pretty, pretty amazing. So even through that experience, that passing, I learned a lot of what families who we work with now go through.

Ellen: Yeah, that's a remarkable connection they had.

Paul: Yes, it really was.

Hazeline: Were there some specific challenges that you encountered or that you recall when dealing with systems and service providers?

Paul: With my sister, I was sort of on the margins of it as we were growing up. As we got older I was going to school, then I went to work down in Washington, D.C. and my mom and sister moved down to northern Virginia. So we were working there and trying to get services and supports for my sister as she was just starting to lose her independence, and as her disabilities were progressing. They eventually moved down to Florida because they both liked the warm weather.

Even though I think the systems and supports are even less in Florida. So, it became even more of a challenge hiring the direct support professionals for my sister and getting the other services and supports. It was a lot and my mom was sort of leading the effort. My brother and I and my other sister would chip in to the extent possible

So I learned a little bit in that respect, but moving forward a little bit into 2015 when it was clear that my other siblings were having their own challenges. My brother particularly had a late onset of disability and he became paraplegic. Toward the later years, it became clear that I was going to be Patty's caregiver.

And so at that point, I started to look at the New Jersey system, because I was going to bring Patty back home at some point. I started to explore the system of services and supports here in New Jersey. I had been working with families prior to that when I was mayor of my town, and I'd work with families and I'd hear these stories about how complex it was, and then I started to see firsthand how complex the system of care was, here in New Jersey a state that has a lot of resources. The complexity was a real eye-opener for me at the time.

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A lot of families talk about considering moving out of New Jersey, but when they look at the social service system in other states, they realize that in some cases, New Jersey is more rich in resources than other states.

Hazeline: We've heard that as well.

Ellen: Yeah. Absolutely.

Hazeline: Would you say a little bit about your role as the Ombudsman for People with Intellectual or Developmental Disabilities and Their Families? How did your office come to be? Say a little bit about some of your goals, please?

Paul: Sure, I appreciate that. The office was created in December of 2017 by the state legislature. It was signed into law by Governor Christie in January of 2018. And I was appointed New Jersey's first Ombudsman in April of 2018. I tell folks, one of the first things I did when I was appointed was to look up the word "Ombudsman". And then I had to spend the next few months trying to learn how to pronounce it.

For me, it was a blessing. What an opportunity. The year prior, my mom and sister had passed and disability had always been part of who I was personally and professionally. Here was this great opportunity. It was born out of the recognition that again, here in New Jersey, there are a lot of services and supports, a lot of resources for children as well as adults with intellectual and developmental disabilities. But it's a very complex system. And that complexity can be just overwhelming, if not a complete barrier for a lot of individuals and families. And so they established this office to be a resource. To be a resource to help, and connect people, to make sure they get the services and supports they not only need but that they deserve.

So that's why the office was created. We've put it into three buckets if you will. One is, again, just trying to work to make sure that individuals, children, adults, and families get those services and supports that they need and deserve. And that means I spend about 80 percent of my time really just troubleshooting with families, trying to connect them to the right office, giving them the right link to the right webpage, trying to help them advocate. They come to us if they got a decision they don't like, or they got rejected from a program, or they are having trouble with social security or any number of issues, and we just try to help.

The second thing we do is work with individuals and families and try to help improve the system to make it more accessible, more user-friendly, more person-centered. We do that because our office is uniquely positioned in that we're like a nexus between those making decisions and those impacted by the decisions. So we take what we learned from the families, the good, the bad, and otherwise, and we try to convey that with our colleagues in the Governor's office, in the different departments, trying to use that as an opportunity to fix something that might be broken.

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Then the third thing we do is more generally to help make sure that the voices of individuals and the voices of families are heard and that they're heard in a meaningful way. And not only on the issues that are important to them, but in that larger policy discussion that takes place in Trenton and elsewhere.

We really think it's important that our office provides a platform, so we not only advocate alongside families, we try to give them the tools to advocate. Sometimes I'll help them write a letter if they're sending one to the assistant commissioner or somebody because their voice is the most important.

Too often it's not part of the discussion, and so we do everything we can to make it part of the discussion. We use our annual report for that purpose. We use our day-to-day conversations in our work. The last thing I'll say is, since the beginning and as a family member, I was trying to figure it out. This was new, and whenever you try to start something new, it's both a challenge and opportunity, right?

Because it never existed before, but it's a real opportunity to create something that you think needs to be created. We've taken a very personal approach to our work, from the beginning. We have direct, daily conversations, whether it's phone conversations, email conversations, now through video, and whenever possible, in person with individuals and families.

I spend a lot of time in folks' homes, in their living rooms, in their kitchens. It not only makes it easier for them to have those conversations, but they also don't have to come to Trenton, and it's better than a phone call, if you will. But it also allows us to understand what they're going through better and we meet other family members and we see the homes that they're living in or the schools or their workplaces.

It helps us not only to help them, but it really helps us to inform that larger discussion that's taking place in Trenton.

Hazeline: That's really wonderful. I really appreciate how you elevate the importance of the individual and family voice, and getting to see them in their natural environments to understand what a family or an individual is dealing with on a day-to-day basis. That certainly gives you a much broader perspective and a richer perspective than just responding over the phone.

Paul: Right. There's nothing like that in-person communication and context to really help you gain the understanding. I really appreciate that.

Hazeline: Yes, I agree. We meet with a lot of families, and people really know who you are.

Paul: And that is really important; you make yourself accessible.

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Ellen: I was interested in your description in terms of the buckets, and the issues you find that you're trying to influence policymakers. Can you give us an idea of what some of those issues are? What are you trying to address?

Paul: Yes. People come to us with every issue imaginable and that's great. We encourage that. We talk about in our office how a day doesn't go by when either we learn something new or a new question is brought to our attention, and fortunately we're in a position to have that answered.

We work very closely with our colleagues in all the departments and we work with families on a whole range of issues, but there are some that come to us more often than not, and by the nature of our office, people often come to us often when they're in crisis.

We deal with a lot of abuse and neglect concerns, usually in the congregate settings, both for children as well as adults. We deal with folks that have what they call severe autism or autism and severe challenging behaviors. We deal with folks that have medical complexities.

These are the folks who aren't being as well served in our system. People come to us with staffing issues all the time, which is also related to some of the other abuse and neglect and some of the issues. We deal with those issues on a daily basis. I will tell you though, that severe autism, when I took this job, was relatively new to me. I had grown up with disability. My sister didn't have autism. I've worked for families, and I've been in different disability organizations. But when I took this job almost from the get-go, autism with severe challenging behaviors became something that was front and center on a daily basis.

I was struck then looking back five and a half years ago, and I'm still struck today, not only about the prevalence of folks with severe challenging behaviors, but the seeming lack of supports and services for children as well as adults and families. It's something we've written about. We try to highlight it in our annual reports. We try to generate conversations on it. We've been really encouraging our colleagues in the administration to take a holistic approach to this.

We all want to have everybody sit at the table because it affects so many of us - my colleagues, whether in the Department of Health in the early intervention years, or overseeing hospitals, the Department of Children and Families, the Department of Education, the Department of Human Services.

The housing issue is important and it's also criminal justice. We work very closely with the attorney general's office on some criminal justice issues and trying to bring law enforcement and the disability communities together. I can't overstate how much we deal with that set of issues and the individuals at the center of them and families that are really in crisis.

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So that's some of what we deal with, but again, we deal with every issue imaginable. We deal with employment issues, housing issues, health care, and education, but those are the ones that on a daily basis, are the families who are in crisis who come to us. That's what most of our focus is on.

Ellen: Yeah, it's a huge issue, and it affects so many people that the numbers of people who are diagnosed with autism every day has dramatically increased over the years.

Ellen: Yes. I'm interested in your approach, bringing all the different organizations and departments together because it is cross-community, cross-systems. What kind of progress do you feel like is being made?

Paul: I don't know. It's never enough. I always try to contextualize my thoughts because I do think, as I write in our annual reports, that ours is a tale of two systems, one good, but one not good enough. I think there's a lot of good work being done in this space on autism, on a whole range of issues that we deal with, but from our perspective, for what we see or hear on a daily basis, we're just not doing enough.

I really think - not only bringing together folks throughout the administration who serve in different departments together, but we've got so many experts throughout the community, throughout the state, in our universities at Rutgers and Rowan – we need to bring everybody together. Again, while what we're doing might be good, it's just not good enough for everybody, and until we get there, I think we just have to keep pushing ahead and keep trying to do more.

Ellen: I like that - the idea of bringing people together. There are a lot of experts, a lot of people with really good ideas. The more we can collaborate, the more we have the potential of really influencing and improving the system, and maybe reducing some of the confusion and complexity.

Ellen: Getting back to one of your other buckets of getting input from family members and helping to have their voices heard, I know that we hear a lot about concerns related to the New Jersey comprehensive assessment test, the NJCAT, and I know that there is a survey that has recently been distributed to families and professionals to try to get some input. I thought that was encouraging that at least there is a survey and so family input and professional input is being solicited. What do you think we can learn from the feedback on that? And do you think that that's going to have an influence?

Paul: I think it will. And I'm grateful that the Department of Human Services is doing that survey and really looking for input. We work with a lot of families when they're taking their NJCAT or after they've gotten their results and they want to appeal it and take it again. We work with them. We go through it in detail. In my time here, we've looked at both the process and the substance of the NJCAT.

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The process has evolved, and I give the DHS and the DDD credit for the way it's administered and when it's administered. They've looked at ways to fine-tune that. I think they've done a good job. But the substance really needs to be addressed, because it is a very black and white tool and we live in a world of gray. It's not necessarily yes or no, it's maybe sometimes, and there are certain areas, particularly on the NJCAT, that need to be improved, because it's not capturing everybody with the medical complexities or severe challenging behaviors.

I always look at it as it's like the SAT or something, you know what I mean? It's a useful tool. But it shouldn't be a stand-alone. There needs to be more context, there needs to be more that's factored into determining somebody's budget level, somebody's tier level, and so hopefully we're going to get there. I'm hopeful that the DDD is getting a lot of good feedback through this process. Because that really has a direct impact on what kinds of services someone can receive; the budget is determined as a result of that assessment.

Ellen: So, I gather you hear from a lot of families out of concern.

Paul: Yes, we hear from concern. We work with a lot of families, and we try to advise them on how to look at it. Particularly parents want to be aspirational when they're thinking of their child and you've got to be realistic, but again, there's some frustration because parents will come to us and say it's not yes or no.

I'm hoping they're going to get there and again, it should be one tool. And I know it's hard to have different tools to be used, but it shouldn't be the one and only thing that determines a person's budget and therefore their services.

Hazeline: Yes Yes. It's hard to narrow down who a person is and what their needs are with just one tool.

Hazeline: I'd agree with that. I think there are some other tools that are being used with families now that can be particularly useful in helping families to think about what life realistically can look like and what their needs would be, and to see how those tools, like Charting the Life Course, for example, might be utilized to bring a richer picture of what the family realistically needs as a budget.

Ellen: Yes, those Charting the Life Course tools that are available for free, to be downloaded. Those are wonderful ways of helping to understand a person, what their skills and abilities are and also what their needs are.

Ellen: That's a good point. On another topic that I know you're familiar with, there was a white paper developed by the Health and Safety Commission of the New Jersey Regional Family Support Planning Council that offered some recommendations to the Division of Developmental

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Disabilities related to increasing the health and safety of residents in residential services. I believe that you're in favor of that. Can you talk about that document, why you think it's important?

Paul: Yes, it was spearheaded or initiated by a parent who lost their adult child, who had real first-hand experience, and the people that were behind the white paper were people who know. It's from their own real-life experiences and it's a set of common sense, not unrealistic recommendations about what should be done in terms of preventable causes of injury or illness, the fatal five, and engaging parents more and giving them more of a role in the process.

To me, it seems like common sense. You know, I wish DDD would say thank you. We're going to implement it, because it makes a lot of sense. And again, to me, it speaks to that larger point we were talking about earlier: no one knows this world. No one knows these individuals. No one knows the needs better than the individuals and the families, period end stop.

And so to the extent we can take opportunities like this and incorporate them into what we do, the better for everyone.

Ellen: What do you think might be the barriers to adopting those recommendations?

I don't know. Again, they seem like very, very reasonable, common sense recommendations. There was nothing extraordinary that I recall. We need to do more in terms of training staff. We need to do more, frankly, in terms of paying staff. I know there are efforts underway to look at core competencies of group home staff, of direct support professionals, and looking at standards and trainings. And that's all good and really important. But we also need to look at the compensation issue. Because until we pay these direct support professionals like professionals, you're going to have folks that need to have two jobs. You're going to have understaffing. You're going to have a lot of rotations.

That doesn't serve anyone's purpose. And so we really need to look at the way we compensate staff, and that's true not just with direct support professionals in congregate settings, that's also true with respect to self-directed employees in private homes and in family homes.

We need to be realistic. None of this is easy. However, some of this is really common sense, to pay people a living wage so they can raise their families and stay in these jobs and train them appropriately.

One of my issues, I'm going to go off on a tangent for a second, is with respect to the administration of medication. It was something we put in our report this year. You know, we administer medicines to children as well as adults in congregate settings without any nursing being involved, any medical professional necessarily being involved. I understand in New York and other states they have nurses who either can delegate it or are involved somehow. They

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don't have to be the ones that necessarily administer, but maybe they're looking over the records on a monthly basis. We don't have that. And so we have problems. We get that all the time. Children, as well as adults, not being properly medicated, not being given the right medication.

We had an example not too long ago of a young man in one of the children's group homes who was given two doses of his nighttime medicine and had to be rushed to the hospital. Because these folks aren't necessarily trained properly, and we need to do a better job doing that.

Ellen: Yes. So it sounds like it's a combination of oversight and availability of the appropriate experts to make sure we're not doing people harm.

Right. And, again, paying people a living wage, there's no way around that. There really isn't. And you know, I don't think I've ever advocated necessarily for more money being put into the system because I think we do put a lot of money into the system. I know this administration, the Murphy administration, has put in over a billion dollars more into the adult system in the last several years.

Holding provider agencies accountable and making sure they spend the money appropriately, making sure the money they're being paid is going largely to direct care staff – I think we need to put those kind of controls in place.

Ellen: Yes. Do you think that also might have to do with the distribution of the funds? In New Jersey, we still have a number of institutional settings where the costs are perhaps a lot higher than they might be in the community.

We've actually done an analysis on that. I was part of this; they call it DDAN. I forget exactly what it stands for at the New Jersey Council on Developmental Disabilities. We looked at an analysis. We looked at the developmental centers versus DDD's community care program, and we matched it up from 2018 to 2022 in terms of the number of staff, in terms of the cost per person, and the money wasn't that big of a difference.

Again, there's been a lot of money put into the community care program in particular in DDD. So that's not to weigh into the conversation about developmental centers, but in terms of the money, the money is there. It's in the system. We just don't have any staffing ratios that are implemented in group homes.

We don't have any requirements in terms of how much you pay your staff, except that they have to be paid more than minimum wage. I think we need to revisit that. I think these provider agencies do really good, important work, but there have to be some requirements in there on how they spend their money.

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Again, if you're somebody in DDD who has what they call an EA tier level, you come with a \$500,000-a-year budget that's going to that provider agency. There should be some guardrails in place to make sure that the overwhelming bulk of that money gets paid to the staff to take care of that individual because that's why that budget was assigned to them. That's what it's for, and that doesn't exist right now.

Hazeline: Yes. I think those safeguards are absolutely critical for families and for the protection of people in the system, actually, the idea of staffing. Appropriate compensation is such a big issue. Do you have any thoughts about how one might resolve some of the workforce development issues? We see a lot of turnover. By the time a person is really competent and effective in the role, they may have to move on because of the compensation. Do you have any thoughts about how to address that?

Paul: Yes, I think there should be a requirement to put in place that some percentage of a provider agency's revenues should be dedicated towards direct care staff, and that there should be bare minimums that folks should be paid. Again, the money's there, I believe. We just need to make sure that it's being spent appropriately. So that's in the congregate setting. In the self-directed world, if you will, there's been what I would say is a somewhat arbitrary cap of \$25 per hour for families to pay their self-directed employees.

Now they've created a little wiggle room if your employee has certain certifications or a Ph. D. or I don't remember exactly what. We need to give families who are doing self-direction not only budget authority so they can spend their budgets as they see fit with guardrails in place but what they call employer authority.

So not only can they determine who's going to be working with their son or daughter or loved one, but how much that individual gets paid. That kind of budget authority and employer authority exists in other states because maybe \$20 an hour makes sense for one situation, but maybe \$35 an hour is needed for another situation with more significant needs - behavioral, medical, whatever.

We talk about person-centeredness. We need to really take that to heart and realize no one knows better than the individual or the family member, period. I'll keep saying that, but it's true. And again, I realize there have to be guardrails in place, and the families I work with in self-direction, none of them are asking for bigger budgets. They're just saying, let us spend the budget as we see fit. And I think we need to. That's where we need to go.

Ellen: There are some other issues in relation to self-direction that I know you've been involved with, and you have some suggestions about how we might address those. There's an issue of succession planning, because families are extremely involved, and that is their task in a self-directed program, but what happens when the family is not able to continue being the manager of that program? What are your thoughts about how we can continue this?

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Yes, it's a big set of issues and for our purposes, it was brought to our attention by one parent who came to us and said that, "like a lot of folks, we don't think beyond tomorrow sometimes."

It's true, what happens next? What happens when the parents, the guardians, the caregivers are no longer in the picture for self-directing families who have chosen to live outside of a congregate setting, in a personal home, a family home? How do they maintain that when they're gone?

We're working with some families and provider agencies and advocates trying to figure our way forward. How do we do that? How do we maintain that, particularly when there's not a sibling or another family member who's going to be that successor, not just even a guardian, but someone who's going to be there to pay the bills, or call the other staff person when someone calls in sick, or, help with day to day issues. I'll never forget when I was volunteering on Phil Murphy's (before he was Governor Murphy) gubernatorial campaign in 2017, and one of the things I did was advise a campaign on disability issues and serve as a surrogate. But one of the last things I did in that role was I set up a meeting for Mrs. Murphy, for Tammy Murphy, to meet with about 14 parents, and it was just a couple weeks before the election, it was clear that, you know, Phil Murphy was going to become Governor Murphy and Tammy would become First Lady, and so we thought it was a good opportunity for her just to get a little sense of what families are going through. We went around the table and one by one, the family members shared just a few minutes of their story.

They went around, and it got to one parent, and he said the difference between us and other parents is that we want to outlive our children. And it's such an incredible statement, audacious. I looked around the table, of course, all the family members were just nodding quietly because all the family members knew exactly what that father was talking about.

I was trying to wonder what Tammy and the other folks that were in the room were thinking about that because that's so counterintuitive. I mean, no parent wants to outlive their children. Special needs parents are concerned about what's next, who's going to be there to love their child.

That's why PLAN|NJ does what they do. It's a haunting fear that families have. And in the self-directing world it's even more so, because they've created these lives and they're established, you know what I mean? We have independence of choice, of personal preference, a real person-centeredness, and they're afraid it's all going to go away once they're no longer in the picture. So that's the work we're doing with folks like you and others, both of you actually, and that work needs to continue. We need to speed that up because we're dealing with the first generation of parents who are now aging out, and we need to be prepared.

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Ellen: Yes, exactly. One of the things we are working together on is this issue, and one of the things that really struck me is that I did a little national research on this, and no states really have any significant answers, so we're moving the needle by creating more person-centered services and more individualized and self-directed services, but we haven't thought about what's next and how do we handle the future. It's a very important conversation to have.

Ellen: Getting back to your very appropriate focus on families knowing what's best for their children, I wanted to turn the conversation to Hazeline for a minute because Hazeline, that's been your work at the Family Support Organization of Essex County, and you actually employ families to do the work of your organization. So can you talk a little bit about that and why you employ families?

Hazeline: First, I have to say that the model that was developed by the Children's System of Care over 20 years ago requires the hiring of parents with lived experience, either in mental health, developmental disabilities, or substance use to act as peer support to parents who are going through similar life experiences. So by the very nature of the system it's a conscious decision. Personally, and ethically, it's just the right thing to do. Who can better guide you through a system, or understand your experiences, than someone who's had a similar life journey?

So that's primarily who we hire. Eighty percent of our board of trustees and the overwhelming majority of our staff are parents with lived experience. Even in positions that do not require that, we find that people are drawn to the mission and want to give to others that which they themselves had wanted.

So that's the model for family support organizations. I would also like to point out that we're not unique. This is a movement, not only here in New Jersey, but across the country of family-led, family-run organizations that elevate the voices of individuals with lived experiences and their families. So I truly appreciated Paul's comments earlier.

In my current role as Executive Director of the FSO, we really are focusing on some of those workforce issues that you mentioned and getting the appropriate compensation for frontline employees who go into the homes, meet with families, listen to their journeys, help them strategize, whether it's related to the Children's System of Care and the care plans they would be responsible for participating in the design of, or whether it's in a school setting or in the community. And that's why we hire folks that have actually utilized some of these services or been involved with these different systems and have that expertise. Thank you.

Ellen: And you're training your family employees, family partners, partnering with the family. Perfect. Are there certain philosophies or perspectives that you're trying to communicate? What are some of these? What kind of concepts are you trying to teach?

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Hazeline: There are a number of values and principles that we rely on. Obviously, family voice and choice is huge. We also believe in collaboration. We don't think that it's beneficial to families to function inside or in silos. Our lives are not compartmentalized that way, and we have to be able to look at the different systems that our family members are involved in and figure out how to partner with them effectively. We do a lot of work around the values and principles of wraparound, which include team-based plans, team-based collaboration, community-based so that they're sustainable after formal services have ended and people are accessing supports and services in their local communities. So that they're included in the community in such a way that they're not only the recipients of services, but they're actually giving back to the community by their very presence and their involvement.

Another concept is around outcomes. We want to see, as a result of families being involved with us and individuals being recipients of our services in the local Children's system, that there are discernible outcomes that are achieved: a reduction of parental stress, increased resilience, increased optimism, and the feeling that we can do this. We're looking for those kinds of outcomes when we engage with individuals and families.

Another critical piece for us is making sure that we are fostering resilience and hope. And that begins with the team members themselves and how we care for each other in the office and how we do this work as a community of practice. We really want to focus on caring for ourselves as we care for others so we can be of the best service.

Ellen: That makes a lot of sense. In relation to what Paul talked about in terms of families often feeling that they're not necessarily listened to, or that they're not given the full opportunity to provide the input that they believe is best for their child, what are your thoughts about that? What are your thoughts about the ways we can encourage families to perhaps improve the relationship and the communication between families and provider organizations?

Hazeline: Well, I'd have to say that I think it's incumbent upon provider organizations to look at how they engage families and look at the time of day and the locations, the agenda, and the whole way we have been socialized to think about family engagement. It shouldn't be a one-off kind of thing where we invite you to a meeting periodically. We have to look at how we begin to create caring networks that include families when the table is being built, as one of my Board member says, not just after we've built it, and say come and tell us what you think while it's being designed. That's where family voice can be so powerful, whether we're talking about mobile response and stabilization services, crisis services, support, whatever it is, the point where an agency, a provider agency, is thinking about a change, a service, how it can be delivered, how it can be improved. Before those decisions are made, reach out to the families, not just one, but many, and get their input on what works, could work better. What are some ideas that you might have?

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As Paul said, who better to give that kind of input but families with lived experience? I think consulting families often and early, involving them in authentic conversations, not just here it is, tell us what you think; do you like it? But rather, actually, listen to the feedback.

On the family side, I think many families, especially the ones that I work with, are so stressed and overwhelmed with just the business of living, particularly if you have a child with complex needs. If you're the head of household, or even in a dual parent family, the stressors are so incredible. People come to us afraid of losing their job, they're trying to keep the other children in the family in a safe space and secure, and going to school and doing all the right things.

So, to say that families should be more involved - yes, but we have to make it convenient for them. We have to give them multiple options in terms of how to participate. And we also have to educate them about how to sit at the table, take in the information, and give feedback. I think there are powerful organizations in the state that are doing great work around parent training and education.

New Jersey is fortunate to have some people here that are also nationally recognized leaders in that area. And more of that kind of education and training for parents, beginning in the earliest stages. The moment you know that your child has a diagnosis or may have an intellectual or developmental disability, that's a great space for the schools to collaborate with health care and for the special child health services folks to know about how to access that kind of training to elevate families' voices. Because the more parents know, the better the outcome for the child.

Ellen: That's a great expression: before the table is built. Get the input from the ground floor. Yes. Paul, what are your thoughts about how do we bring families in?

Paul: First of all, I agree with everything you just said, and the way you said it, it's spot on. In one of our annual reports we took a deep dive on this because I was struck as a family member, one of the things that I find most disheartening in this job over the years, has been the way families are too often treated.

They are disregarded, disrespected, they're not always part of the conversation. And again, that's not always the case, but more often than not in the families we deal with, their voice is not being heard, and if there is outreach to them, it's more of an obligation as opposed to seeing them as a resource. There's so much more to be gained by including them.

We talk about having something we called the Disability Family Bill of Rights. There should be certain things every provider agency should have; an advisory board, meaningful conversations with families. Families should have access to records - this was one of the recommendations I think of the Health and Safety Committee - being able to have access to this information so they could spot something and maybe share their thoughts on something or see if something's wrong. So we need to really see families as a resource because that's what they are. But to

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your point, they're often overwhelmed and they can't necessarily come to Trenton for a meeting, so we need to go to them. We're always trying to encourage our colleagues to go to the family's home, go to them. There's so much we can learn if we stop talking and just listen a little bit.

When you were talking, I was thinking of this example from when I was mayor of Ridgewood, Bergen County. We were trying to make our town pool, which is a man made lake, accessible. And we got some grant money to make it accessible. We wanted to put in a ramp. And there was a small group of folks, including a couple members of the council, who were just constantly pushing back on it. I won't drag you through the whole conversation, but that went on for three years until we finally got it built.

But one of the things I kept being asked about was why I was making such a big deal about this, because no one was coming to the council meetings to ask for this. And I said, you don't understand disability families. They don't have the luxury of going to council meetings at 7:30 at night. They've got more important things to do, frankly.

They've got to take care of their family. They've got to take care of themselves. And so we really need to go out and meet families where they live, where they are. But, really do it, not just out of an obligation, but out of an opportunity to tap into what's working and not working, and you're absolutely right, before the table is built. So often the table is presented and people are only then asked what do you think?

No, go to them early. You know, it's amazing what we'll learn. I feel blessed just being in this job. I mean, I am family member so I have this personal connection, but I learn so much from listening to these families so I couldn't agree more.

A larger issue that we talk about, and we do this in all of our annual reports, is we need to do two things. One is, we need to get more individuals and families at the table, if you will, on committees in offices and not just committees that deal with disability issues. But all issues, right? Because we have a lot to say about all this.

Also, we need to revisit the way we staff our disability-specific offices. We talk about diversity in the workplace and it's so important. We all know not only does it create better work environments, but also better work products when we have diversity of gender, ethnic, racial, socioeconomic backgrounds - you name it, the more diversity, the better. But too often disability is not sitting at that table. Why? Because maybe some folks with disabilities don't have the means to get to the table, or they're not invited to, and family members are overwhelmed. We need to make sure we're at these tables. But in these disability specific offices, we need to make sure that they're largely staffed, if not by, people with lived disability experience. Any other organization, any other office that deals with a specific population, I guarantee you is led and largely staffed by folks in that population. It's not true with us. This isn't to say somebody without lived disability experience doesn't have anything to contribute. They have a lot to contribute, but

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we need to make sure that, again, if not leading, although we should be leading, it's largely staffing a lot of these offices.

So that's a recommendation we put in all our reports because that's how we're going to get to where we're going to go. We know it's a different conversation when you talk to somebody with a lived disability experience or somebody who's been on the front line working with folks with disabilities and families. It's a different conversation.

Ellen: Great points.

Paul: Yes, it's how we really will be able to listen and hear what the true needs are.

Ellen: Before we close, I just want to hear a little bit about your experience on the national level, on the President's Committee. What kinds of issues are you dealing with and how do they compare to the issues that we're seeing in New Jersey?

Paul: I was appointed to the President's Committee for People with Intellectual Disabilities in 2022 and it was a great honor. It's great to be on with a great group of people. It's probably about 21 members of the public. I'm considered a member of the public. And then they have some ex officio folks that are tied to CMS and the Social Security agency and Health and Human Services.

Unfortunately, we've been just meeting virtually, so we haven't got that richness of that experience yet. I'm really looking forward to the day when we can actually meet in person and get to know each other a little better. But we've been really working on a report and hopefully it'll be coming out early next year.

After a couple of public meetings, and then many internal meetings, we decided to focus on home community based services and looking at different aspects of that. One is probably going to be staffing, and the committee actually put out a report back in 2017, which was an excellent report, to talk about the workforce crisis.

In part, what we're doing is revisiting that report to see what if anything has changed and what still needs to be done. Then there are other different components to looking at: employment and other community based services. I've been focused on co-chairing a subcommittee that is looking at the federal support programs like Medicaid, Supplemental Security Income. Not only in terms of the need to update them in terms of their asset and income levels, but also, very importantly, to eliminate what's known as a marriage penalty that's baked into these programs that really make it impossible for folks with disabilities to marry because they'll lose their services, they'll lose their supports. So many of these programs on the federal, state, and local levels have that embedded in there. We're trying to shine a light on that and hopefully we can start to eliminate that.

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Ellen: Yeah, that's an issue for a lot of people.

Paul: It's just such an unfair situation and I really think it's unintended. I think a lot of these programs were built not with our population necessarily in mind. They didn't really think of the long term implications of people with disabilities and how having discriminatory asset limits in Supplemental Security Income or Medicaid would impact people with disabilities. We now get to focus on it, we need to fix it, and again, we need to update these, because some of these asset income levels are just unrealistic.

Ellen: Hazeline, anything else you'd like to add before we close?

Hazeline: I just want to underscore that first, it's been a pleasure being here with you both, and that the voices of individuals with lived experiences and their families are probably the most powerful tools that we have to work with to move the system forward.

I also believe very strongly that we need to continue the efforts to build cross-system collaboration and break down the silos because our lives are not structured that way. When I listen to Paul talk about all the different agencies and sectors that our lives interface with, it's evident that we need to have more of those kinds of cross-system conversations to see how we can enrich the lives of people with disabilities in our communities and also enable them to live more successful, inclusive lives and contribute to the communities in which they live.

Ellen: Beautifully said. Great summary and wonderful thoughts for us too. Paul, anything you'd like to say before we end?

Paul: Thank you for this opportunity, and this conversation, but more generally, for what PLAN|NJ does and the good work you do. It's so important. I've referred many folks to your organization. I've said, even if not to use PLAN|NJ's services, start that conversation, because it's such an important conversation around what's next and what's the future. So thank you for that. And thanks for the partnership.

Ellen: It's a pleasure. Thank you so much.