

**Testimony of Paul Aronsohn,  
Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families  
NJ Assembly Committee on Human Services  
Monday, September 17, 2018**

Good afternoon, Madam Chair and Members of the Committee.

Thank you for holding today's important hearing, and thank you for including all of us. My hope is that this will be the first of many such conversations concerning ways in which we can all work – together – to improve the services and supports available to those with developmental disabilities.

This is my first appearance before your committee as NJ's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, and I am genuinely grateful for this opportunity.

- I say that not only as a member of the Murphy Administration; I say that also as a long-time advocate and someone who came from a family with disability ... someone whose understanding of these issues was informed and whose passion was fueled by the experience of my sister Patti and my mother Margot, who always, always took such good care of her.

As you know, the Ombudsman office was created by the legislature just this past December; it was signed into law by Governor Christie in January; and I was appointed by Governor Murphy in April.

The responsibilities for the Ombudsman office effectively sit in 3 buckets:

- To help individuals and families navigate NJ's system of care, helping to make sure they get the services and supports they need and deserve:
- To work with individuals and families to improve the system, making it more accessible and more user-friendly.
- And to help make sure that the voice of individuals and families is heard in a meaningful way, particularly on decisions that directly affect them.

Since April, I have had the opportunity to meet and work with a host of good people doing good, important work. That includes --

- State government officials – throughout the Administration as well as throughout the legislature.
- County and municipal government officials.
- Provider agency leaders and staff.
- School officials.
- Hospital officials.
- Disability advocates.
- And of course, families – about 80 families thus far, with whom I have already worked on a range of issues and a range of challenges.

Weekdays. Weeknights. Weekends. I have spent the past 5 months traveling the state, visiting with families – often in their homes -- and meeting with the people who provide these families and their loved ones with needed services and supports.

And through it all, I have come to better appreciate both the strengths and the weaknesses of New Jersey's system of care.

To begin, we have some really good, really dedicated people, who come to work each day determined to make a positive difference in people's lives. Some work in our government. Some work in our non-profit community and in our schools, our hospitals, our provider agencies and our homes.

- They are the lifeblood of our system of care.
- They are the reason that so many New Jerseyans with disabilities live safe, fulfilling lives.

We also have many really good, really necessary programs and services. That's true for children as well as adults. Some are provided through our school districts. Some are provided through our Departments and Agencies at all levels of government.

Yet, there is no question that there is not only room for improvement; there is an imperative.

- NJ's system of care for people with developmental disabilities is good, but needs to be better -- much better ... a fact not only recognized by the Murphy Administration, but one that drives our work in so many important ways.

And so based on my experience over the past 5 months, here are some preliminary general observations:

- First of all, the system is too confusing -- way too confusing.
  - So many programs with so many names and so many acronyms offered by so many offices in so many departments in so many different ways with so many differences in timelines, requirements and eligibility criteria.
  - Even people who know the system don't completely know it.
  - This is why families often get a different answer depending on who they ask.
  - This is why families are often so frustrated and so underserved.
  - Now, although much of this stems from federal law and regulation, there is no question -- we need to simplify the system as much as we can at the state level. We need to make it more user-friendly and more accessible.
- Second, the system is not always as responsive as it should be.
  - Granted, state government serves many, many people, and there are a lot of good folks working very, very hard to serve them.
  - But still ... too many calls go unanswered. Too many emails go unreturned. And the system as a whole often seems cold, detached and uncaring.
  - This needs to change.

- We are in the people business working on very personal, critically important issues that require us to deliver the very best in customer service.
- We need to be compassionate, empathetic and responsive to the people we serve.
- We need to bring our humanity to work with us each day, every day.
- And the third of my general observations is that our government needs to improve its communication with families – in form as well as in substance. Too often, the information provided is incomplete, inconsistent and at times, incoherent. And the ability to engage in meaningful dialogue – two-way communication – is somewhat of a rarity.
- - We need to fix this.
  - We need to provide folks with clear, consistent information ... and we need to engage them in regular conversations.
  - This is why our Commissioner of Human Services has been revisiting the way her department communicates, including through her new quarterly bulletin, her work to improve the department’s online presence and her and her staff’s many meetings with families and other stakeholders.
  - This is why our Commissioner for Children and Families has been traveling the state doing a “listening tour” – meeting with families, advocates and officials.
  - And this is why I’m working with the Governor’s office to create an Ombudsman website, which can serve as a one-stop-shop for families with developmental disabilities.

Beyond these general observations, there are many specific issues that warrant our immediate attention.

- We need to address the serious lack of adequate housing for people with developmental disabilities – both in terms of quantity and quality.
- We need to acknowledge that while there are many employment and day program opportunities for people with developmental disabilities, we often lack the transportation needed to make it a reality for many people.
- We need to recognize that direct support professionals -- who play indispensable and difficult roles in the lives of our loved ones -- are often underpaid, undertrained and underappreciated – a reality that leads to a host of serious staffing challenges.
- We need to recognize that Support Coordinators -- who also play an invaluable role – need to be appropriately trained and compensated.
- We need to acknowledge that the so-called “cliff” for children ageing out of the school system is both very real and very scary for too many families ... and much more needs to be done to make the transition from childhood to adulthood seamless.
- We need to make our system of care more responsive to the needs of parents – those who need a few more respite hours to keep their families together as well as those faced with the excruciatingly difficult decision to place their child in an out-of-home residential setting.

- We need to address our state's lack of capacity to properly serve those with severe behaviors – including those with dual-diagnosis of intellectual and developmental disabilities as well as mental health challenges.
- And yes, we need to resolve the situation with respect to the Department of Human Services' current fiscal intermediary – a problem that was inherited, but that is, in fact, being addressed. I hope and expect more progress on this very soon.

Madam Chair, Members of the Committee – this is just a sample list of the issues that need to be addressed so that we can better, more effectively serve people with developmental disabilities and their families, and I'm sure my colleagues on the panel could add to it.

But my point is this: There is much good about NJ's system of care, but there is much that needs to be done to improve it – again, a fact well-recognized by Governor Murphy and administration officials and one that drives our work each day, every day.

And I know that we are not alone in this ... that there are many people who not only share this perspective and this determination, but who are also working to bring about needed change.

- People like all of you on this committee, my colleagues testifying alongside me today, others in this room and others throughout our state.

This is important, because we are all in this together.

- Officials and legislators at every level of government. Advocacy organizations. Providers. Schools. Anyone and everyone working on these issues.
- We are all stakeholders. We are all part of the larger disability community. And we must approach our work with a shared sense of mission, a shared sense of purpose and a shared sense of urgency – the same urgency felt by every parent of every special needs child.

Madam Chair, Members of the Committee --

The work of my office and the Murphy Administration more generally is premised on the understanding that while many of us have special needs, all of us – each and every single one of us – has special gifts and that we all deserve the opportunity to be safe, to be healthy and to reach our God-given potential.

It is in that spirit that I appear before you today, and it is in that spirit that I and others in the Administration look forward to working alongside you every day.

Thank you.