



State of New Jersey

OFFICE OF THE OMBUDSMAN FOR INDIVIDUALS WITH INTELLECTUAL
OR DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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**Testimony of Paul Aronsohn,
Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families
New Jersey Assembly Committee on Women and Children
Wednesday, June 16, 2021**

Good morning, Vice Chairwoman Swain and Members of the Committee. Thank you for holding this very important hearing and for including myself and Commissioner Beyer as well as several family members and advocates.

My name is Paul Aronsohn, and for the past 3 plus years, I have had the opportunity to serve as New Jersey's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families.

- That means for the past 3 plus years I have had the opportunity to work with some outstanding professionals – in and out of government -- who have dedicated themselves to serving others.
- And that means I have also had the opportunity to work for some really extraordinary people – children, adults and family members all living challenging, yet inspiring lives.

There are two of us in the Ombudsman office – myself and my Associate Director, Christine Bakter. We are both family members with a personal connection to disability, and we are both passionate about our work. In fact, it was important to Governor Murphy that our office be staffed with people who have “lived” experience with disability – people who can speak the same language as individuals or families and genuinely understand and respond to their challenges.

Due to its scope and purpose, our office is most often contacted by people seeking assistance. Sometimes they need advice or direction. Sometimes they need an advocate. Often they are in crisis and in need of immediate relief.

Our focus therefore is most often on the many challenges faced by individuals and families – their frustrations as well as their unmet needs – rather than on the system's many success stories.

In fact, almost daily, our office is contacted by those who are falling through the cracks in our system of care.

- Some feel that their child's education is less than appropriate.
- Some feel that they are unable to access much needed supports and services.
- Many feel that they are on their own – that despite pleas for help and despite promises made to them, meaningful assistance is beyond their reach.
- Many literally call us in tears.

With respect to children with intellectual or developmental disabilities, our work with families spans across a full range of issues -- from the need for intensive in-home behavioral supports or private duty nurses ... to the need for additional respite hours or medically necessary home modifications, such as safety fencing or accessible ramps. We also work with many families in desperate need of an out-of-home residential placement for their child – without question, one of the most painful, most difficult decisions a family could ever have to make.

Needless to say, our conversations with families are often emotional. The situations are often complex. Yet, together, we try to find our way through issues important to them and to others.

But there is absolutely no question – many New Jersey children with disabilities and their families are in need of real relief.

- They need a system of care that is responsive to them and shares their sense of urgency.
- They need a system of care that understands them and their lifelong disabilities – that does not dismiss their concerns, that does not disregard their preferences and that does not require them to prove their disability year after year after painful year.
- Simply stated, there are many New Jersey children with disabilities and their families who need and deserve a system of care that genuinely cares.

And I can assure you that Governor Murphy fully understands that and has charged all of us – myself, Commissioner Beyer and our colleagues throughout the Administration – to do what needs to be done to transform our system into one that is more responsive, more sensitive, more effective, and yes, more caring.

So, it is in that spirit that I express my sincere appreciation to all of you for holding today's hearing and for giving families this important opportunity to be heard – an opportunity to share their personal, compelling stories and an opportunity to advocate for their children.

Make no mistake about it: What you are doing here today is important, very important, and I thank you for it.

Thank you.