

State of New Jersey

OFFICE OF THE OMBUDSMAN FOR INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES P. O. BOX 205

TRENTON, NEW JERSEY 08625-0221

PAUL S. ARONSOHN Ombudsman

PHILIP D. MURPHY Governor

SHEILA Y. OLIVER Lt. Governor

Testimony of Paul Aronsohn, Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families New Jersey Assembly Committee on Women and Children Thursday, August 20, 2020

Good morning, Chairwoman Mosquera, Vice Chairwoman Swain and Members of the Committee.

Thank you for holding today's hearing and for including my office in this important conversation. This is my first time appearing before your committee, and I genuinely appreciate the opportunity.

As you know, my office was established by the State Legislature in December 2017 and signed into law by Governor Christie in January 2018. The Office was then made operational when Governor Murphy appointed me a few months later.

We work with children as well as adults, and our responsibilities can be grouped into 3 categories:

- (1) Assisting individuals and families to navigate New Jersey's system of care to get the services and supports they need and deserve;
- (2) Working with individuals and families to identify opportunities for improving the system; and
- (3) Helping to ensure that the voice of individuals and families is heard in a meaningful way in decisions that directly affect them as well as in larger policy discussions.

During this pandemic, we have been operating on all 3 of these cylinders – staying in daily contact with the people we serve through emails, phone calls and video meetings and working daily with our colleagues in the various departments, the Governor's office and the Legislature. And when I say "daily" I mean literally 7 days a week.

Due to its scope and purpose, our office is most often contacted by people who don't know where else to turn or who feel that the system is not serving them or their loved one. They may have a question. They may have a concern. They reach out to us, because they want assistance.

And so that means our focus is largely on the challenges faced by individuals and families – their frustrations as well as their unmet needs – instead of the many success stories.

And so with that understanding, let me just underscore a point that becomes increasingly clear day after painful day: this pandemic has been hard – very hard -- on children with intellectual or development disabilities and families.

- Hard in that many of our children are being significantly impacted by the loss of routine.
- Hard in that many of our children are being significantly impacted by the loss of in-person education.
- Hard in that many of our children are being significantly impacted by the loss of in-person therapies.

For many of our folks, virtual learning and virtual therapy just doesn't work. And the result is not just a lack of progress; in many cases, it is actual regression. Parents tells us the most heartbreaking stories about children falling behind in essential skills, while engaging increasingly in self-injurious and other dangerous behaviors.

Back in mid-March, our office began compiling a list of questions, concerns and suggestions from families and others, and we have been sharing that list regularly – sometimes daily – with our colleagues in different departments, including the Department of Children and Families and the Department of Education as well as the Governor's office.

- We have done this so our colleagues know in unedited fashion what families are telling us.
- We have done this so they hear the voices and know the perspectives of parents, who are trying desperately to keep their families safe and healthy during this unprecedented time.

In closing, let me underscore a key takeaway with respect to our special needs children.

Without question, we – as a State and as a Nation -- are living through an extraordinary moment in human history – one that has challenged all of us – individually and collectively – in ways never before imagined. From the loss of family and friends to the loss of jobs and businesses to the loss of so many other things important to us – including an overall piece of mind --- this pandemic has and continues to take a damaging toll on each and every one of us in ways we don't even fully understand yet.

And what parents remind us daily is that for many children with intellectual or developmental disabilities, the impact has been especially difficult, especially challenging, especially damaging.

I am therefore deeply grateful that you are holding today's hearing and that you are helping to lead this important conversation.

Thank you.