



State of New Jersey

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**Testimony of Paul Aronsohn,
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New Jersey Assembly Health Committee
Wednesday, October 21, 2020**

Good morning, Chairman Conaway and Members of the Committee.

Thank you for convening today's hearing and for providing this important opportunity for a conversation about the challenges faced by individuals with intellectual and developmental disabilities and co-occurring medical complexities. I am especially grateful that you have invited several families to share their personal, first-hand experiences and insights.

Since becoming the state's Ombudsman, I have had the opportunity to work with these and other families, who know the challenges all too well.

- They know the anxiety of not being able to provide their loved ones with the right level of staffing, particularly with respect to nursing care.
- They know the difficulties of trying to find an appropriate residential setting that can meet the complex needs of their loved ones.
- They know the frustration of working with insurance companies and providers and government officials who too often say "no" rather than express a determination to get to "yes."
- They know the disappointment of working within a system of care that too often feels uncaring and unkind.
- They know what it's like to live lives full of constant fear, stress and uncertainty about their children's safety and well-being.
- And each in their own way, they have come to know what it's like to be an advocate –for their own families as well as for others.

In my recent annual report to the Governor and Legislature, I spoke to some of these challenges and offered some suggestions, including the need for higher salaries for private duty nurses, more flexibility with respect to the use of individual budgets and more residential options that provide the right level of supports. I also questioned the appropriateness of the several hundred New Jerseyans with intellectual or developmental disabilities reportedly living in nursing homes.

Clearly, there are big policy questions that need to be addressed, and today's hearing provides an important opportunity to begin exploring and discussing them.

To frame this discussion, we will hear from 8 different families, who will share their compelling stories with you. Some of their challenges are unique. Some are common with others. But all of the challenges are real, and all of the challenges have taken an unnecessary toll on them and their loved ones.

Again, I really appreciate you holding this hearing and for providing a platform for these families. And I look forward to working alongside you as we search for ways to mitigate, if not eliminate, these challenges.

Thank you.