



# State of New Jersey

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OR DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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**Testimony of NJ's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families  
Before the NJ State Senate Committee of Health, Human Services and Senior Citizens  
Thursday, December 19, 2024**

Mr. Chairman, Members of the Committee – Thank you. Thank you for holding today's hearing. Thank you for introducing this important legislation. Thank you for caring and for taking these issues so seriously.

As New Jersey's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, I can speak to the importance of today's discussion. Since taking this position more than 6 and a half years ago, I have had the opportunity to work closely with and for people across our State – children and adults with lifespan disabilities and their families who are living lives that are often challenging even on a good day.

Our office is relatively new, and we have taken great care to develop it in a way that provides a "value added" to the work of our colleagues in other State government offices and to the lives of the people we serve. Sometimes as advisors. Sometimes as advocates. Always as partners and resources, often sharing information between those who staff our system of care and those who depend on it.

And realizing the importance of a personal touch - particularly with human service issues - we have spent as much time as possible working one-on-one with individuals and families, talking directly with them by phone, by video, and, whenever possible, visiting with them where they live, learn, work, and socialize.

Due to the nature of our office and the way we've developed it, people often come to us for assistance with challenging situations. Often, there is a time-sensitivity. Often, the individuals and families are in crisis.

Among the challenges most often brought to our attention are those that involve abuse and neglect in group homes for children as well as adults. Indeed, individuals and families approach us daily with heartbreaking stories and horrifying pictures. Physical abuse. Emotional abuse. Sexual abuse. Improper medicine administration. Improper food practices. Questionable visitation policies. Questionable house practices. Unexplained injuries. Unexplained deaths.

In each of our 6 annual reports, we have spoken to these disturbing realities.

Most recently, in our 2023 annual report, we framed our discussion in the context of the "fierce urgency of now" – a reference to the Rev. Dr. Martin Luther King's famous refrain about the need for immediate action, and we offered recommendations for mitigating, if not eliminating, abuse and neglect in group home settings – recommendations that are, to some extent, reflected in the legislation being considered by this committee.

In brief, here are a few of those recommendations:

- **Direct Care Staffing:** We know that abuse and neglect occur in group homes that are understaffed. We know that abuse and neglect occur in group homes where staff are underpaid and undertrained. We know that there is high turnover and high vacancy rates of direct care staff in group homes, because they are underpaid, undertrained, and overworked. As such, we recommend that direct care staff be paid a living wage and trained appropriately and that staff-to-resident ratios be established and enforced.
- **Investigations:** We know that abuse and neglect are under-reported. We know that many, if not most, investigations are conducted by the provider agencies themselves and that most allegations are – not surprisingly – unsubstantiated. We know that deaths in group homes are not automatically investigated, even when the death is unexpected and otherwise suspicious. We know none of this makes sense, and as such, we recommend a complete overhaul of the investigations process – one that would inject much needed rigor, transparency, and objectivity into the process. To this end, we recommend that we look to New York’s Justice Center for the Protection of People with Special Needs as a model for us to consider here in New Jersey.
- **Provider Agency Accountability:** We know there are good agencies led by good, mission-driven people and staffed by good, caring, hardworking professionals. But we also know the opposite is true, too – that there are some agencies that are not so good, agencies that have organizational cultures seemingly not aligned with the interests of the people they are charged to serve. We know that there are currently no financial penalties for agencies that violate State policies, understaff group homes, or allow abuse and neglect to happen. We know that there are minimal incentives to keep the bad actors from acting badly. As such, we recommend the NJ Department of Children and Families and the NJ Department of Human Services follow the lead of the NJ Department of Health, which long ago established a schedule of civil monetary penalties to punish hospitals, nursing homes, and assisted living residences for misconduct – to incentivize even the poorest performers to do the right thing and to do it in the right way.
- **Video Technology:** We know that many people living in group homes are among our State’s most vulnerable people. We know many have an intellectual disability. We know many have a communication disability, including many who cannot speak. We know many of them and their families fear retribution from provider agencies if they express a concern or if they question a policy or practice. We know that most, if not all, families want video cameras in the common areas of their loved ones’ group homes. We know that most, if not all, provider agencies that use video cameras swear by them as an invaluable tool for protecting residents, protecting staff, and educating all involved in particular situations. As such, we recommend that video cameras be more readily available in State-licensed settings.
- **Money:** We know there is a lot of taxpayer money given to provider agencies. In fact, we know many agencies receive between \$300,000 and \$500,000 per year per resident from the State and Federal governments - money intended to support the needs of individuals that usually have complex medical and behavioral needs. We know much of that money is spent on direct care and other important services. But we also know the opposite is true, too – that much of that money is used instead for executive compensation and other purposes that do not benefit the individuals in their care. We also know that many group home residents are required to effectively sign-over most, if not all, of their monthly social security checks to pay for rent, food and utilities without being given an itemization of how those monies are spent. We therefore recommend meaningful transparency measures that can shine a much-needed bright light on the way provider agencies are spending taxpayer money as well as spending individual, personal money.

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Mr. Chairman, Members of the Committee – In closing, allow me to read from our most recent annual report:

“As I have said in each of our previous annual reports, ours is a tale of two systems – one good, one not good enough....

On the one hand, our system of care for people with disabilities is strong, vibrant, and well-resourced. Lots of good people - in and out of government - doing lots of good, important work for the many thousands of New Jerseyans with disabilities. Educators. Providers. Advocates. Direct care professionals. Government officials at all levels and of all political affiliations.

This is a very important point that I fear sometimes gets lost in the conversation.

Indeed, New Jersey’s system of care benefits from the hard work, passion, and unwavering commitment of many, many people who have dedicated their professional lives to serving others. And it also benefits from the availability of significant resources – funding, supports, services and programs – that make it possible for people with disabilities to live safe, fulfilling lives.

However, this is not the case for everyone. Many people are not safe. Many people are not able to live their full lives. For them, the system is too complex, too rigid, and too inaccessible. For them, the system is not person-centered. In fact, for many of them, the system is broken.

This is also a very important point that I fear sometimes gets lost in the conversation.”

Mr. Chairman, Members of the Committee – I thank you for your leadership on these critically important issues. And I thank you for giving me and others an opportunity to speak today.

Without question, none of this is easy. Ensuring the safety and well-being of people with lifespan disabilities is often difficult and demanding. But let’s be clear - none of this is rocket science either. We know the answers. We know the importance of a well-paid, well-trained direct care workforce. We know the importance of robust, credible investigations. We know the importance of transparency and accountability. We know the importance of spending resources the right way.

Going forward, we certainly have a lot of work to do to make our system of care for people with disabilities better, stronger, and safer. But I am convinced that together, we can do this. We can fix what needs to be fixed. We can improve what needs to be improved.

As my mother would often remind me, “Where there’s a will, there’s a way.”

Thank you.

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