

URGENCY OF NOW

PROTECT PEOPLE WITH IDD

People with intellectual and developmental disabilities often do not report Abuse and Neglect, because they may not understand what Abuse and Neglect is. Communication problems can serve as a major obstacle for the individual, in terms of verbalizing occurrences of Abuse and Neglect. Staff members are concerned about retaliation and have concerns about losing their jobs. Even when individuals or their staff do report incidences of Abuse and Neglect, these allegations are not given the same level of criminal or legal justice as neurotypical people are afforded. Individuals with complex severe behavioral health conditions are at greater risk of being abused, because of the acute nature of the challenges they experience. These are just a few of the many reasons why we need to be extra vigilant and provide specific training and supervision when it comes to overseeing all aspects of an individual's care and staff support.

Despite these obstacles, Paul Aronsohn, the NJ Ombudsman for Individuals with Intellectual and Developmental Disabilities and Their Families, in his 2023 Annual Report, discussed the “the fierce urgency of now” when referring to the Abuse and Neglect that occurs in state-licensed provider residential/day programs, and state-operated developmental centers, Psychiatric Hospitals and DCF. He shared some of the tragic calls and emails his office has received from families and others, highlighting a system that lacks accountability and transparency.

<https://www.nj.gov/treasury/njombudsman/documents/2023-Annual-Report.pdf>

Families agree, the time for action is now. Major changes are required to ensure the safety of this vulnerable group of citizens. This will entail a multi-faceted approach, so that preventative measures are comprehensive in scope, producing effective and sustainable outcomes. When these often, life-threatening issues are eliminated we can focus on restoring the dignity and quality of life for all individuals with IDD as valued and respected members of the community.

THE STRATEGIC VISION

VISION:

New Jersey recognizes all individuals with intellectual and developmental disabilities as cherished human beings, worthy of the assurances of equal protection of rights for all state citizens.

MISSION:

To eradicate the abuse and neglect of individuals with intellectual and developmental disabilities, who are depending on a just and benevolent society to do so.

GOAL:

To create an effective protective system of care that includes accountability and consequences for abuse and neglect incidences against all individuals with intellectual and developmental disabilities.

OBJECTIVES:

1. Create a new reporting and investigation structure for incidences of Abuse and Neglect led by the NJ Office of the Attorney General in partnership with an investigative program modeled after the NY State Justice Center,
2. Appoint a third-party, privately managed entity to efficiently monitor the performance of state-licensed residential service providers, state-operated developmental centers, and State Developmental Centers, reporting Abuse and Neglect incidences directly to the NJ Office of the Attorney General.
3. Institute state policy reforms requiring that the NJ Office of the Attorney General inform families/legal guardians when they discover reportable incidents of Abuse and Neglect, afford families/legal guardians the right to provide input, and guaranteed access to investigative reports.
4. Enact a state law administering financial penalties and potential rev with greater independence and influence, utilizing the independent advocate framework of NJ Office of the Long-Term Care Ombudsman as a model.
5. Mandate the training and monitoring of Management, Direct Support Professionals, and Nursing and Clinical personnel, in compliance with an individual's service and behavior management plans, healthcare protocols at state-licensed provider residential and day programs, and state-operated developmental centers and Psychiatric Hospitals.
6. Restructure the NJ Office of the Ombudsman for Individuals with IDD and their Families to function with greater independence and influence, utilizing the independent advocate framework of NJ Office of the Long-Term Care Ombudsman as a model.

Requirements To Ensure Safety

Regardless of positive intentions, organizations cannot investigate themselves and expect direct and honest answers. Community service provider employees need the safety and anonymity that only an independent investigator can provide. This lack of efficacy is particularly dangerous when considering the handling of alleged cases of Abuse and Neglect against individuals with intellectual and developmental disabilities. Current investigative arms of the DHS and DCF would be incorporated into a third-party, privately managed entity, reporting to the NJ Office of the Attorney General.

- Install the N.J. Office of the Attorney General in the principal role of investigating allegations of Abuse and Neglect for all individuals with IDD, supported by state-licensed residential provider agencies, and state-operated developmental centers. The Divisions of Civil Rights (DCR) and Criminal Justice (DCJ) under the Attorney General's authority, would adhere to the following duties. DCR would be responsible for enforcing the "N.J. Law Against Discrimination", which includes housing. DCJ would be responsible for investigating and prosecuting violations of N.J. criminal laws. As is current practice, DCJ would be involved in high-impact cases that require significant or highly specialized investigative resources.
- Develop legislation modeled after New York State's 2013 "Protection of People with Special Needs Act," which established the "NYS Justice Center (JC) to restore public trust in the institutions and individuals charged with caring for vulnerable populations by protecting the health, safety, and dignity of all people with special needs." The agency operates a toll-free hotline 24/7 for receiving reports of allegations of abuse and neglect. The JC "is authorized to investigate these reports and pursue administrative sanctions against staff found responsible for misconduct." The JC's "Special Prosecutor/Inspector General works with local District Attorneys who prosecute criminal offense allegations," as well as "issuing recommendations for corrective actions." <https://www.justicecenter.ny.gov>
- Install the N.J. Office of the Attorney General in the principal role of investigating allegations of Abuse and Neglect for all individuals with IDD, supported by state-licensed residential provider agencies, and state-operated developmental centers. The Divisions of Civil Rights (DCR) and Criminal Justice (DCJ) under the Attorney General's authority, would adhere to the following duties. DCR would be responsible for enforcing the "N.J. Law Against Discrimination", which includes housing. DCJ would be responsible for investigating and prosecuting violations of N.J. criminal laws. As is current practice, DCJ would be involved in high-impact cases that require significant or highly specialized investigative resources.
- Appointment of a third-party, privately managed entity to establish an efficient monitoring system to oversee the performance of state-licensed residential provider agencies, for people with IDD, including state operated developmental centers and Psychiatric Hospitals. This independent monitor would be required to report its findings involving the Abuse and Neglect of individuals with IDD directly to the Office of the Attorney General, as well as DHS/DDD and DCF/CSOC
- Designate the NJ Office of the Long-Term Care Ombudsman (NJLTCO) as a model to restructure the NJ Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families to function with greater independence and influence. NJLTCO is an independent advocate, which is part of a national resident-focused, person-centered advocacy program. NJLTCO representatives work with individual residents to help them address challenges they face, as well as seeking opportunities to bring about change on local, state, and federal levels by advocating for policy and legislative initiatives. NJLTCO's core mission is to advance the rights, the dignity, and the self-determination of individuals in long-term care. As is the responsibility of NJLTCO, it is essential that the NJ Ombudsman's Office serving children and adults with IDD, be equally responsible for securing, preserving, and promoting the health, safety, and welfare for all those they are charged to serve through investigations of abuse, neglect and exploitation; legislative and regulatory advocacy, policy work; and education and outreach.
- Ensure transparency by instituting guaranteed access to investigative reports (CIMU, OPRA, the Registry, DRNJ) concerning allegations of Abuse and Neglect to individuals, families, and the public, to improve treatment and support practices, and to hold provider agencies accountable. In addition, the Office of the Attorney General should be required to immediately contact family members/legal guardians when they discover any reportable incidents of Abuse and Neglect. Family members/legal guardians should be afforded the right to inform The Office of the Attorney General of any health and safety concerns, and request that these potential problems be promptly and thoroughly investigated. Presently, the Office of Attorney General defers all investigations to the Department of Human Services, as do all other investigative entities, yielding consistent unsubstantiated findings from DHS and DCF, resulting in almost all cases lack of justice for the disabled victims and families.

- Mandate specific training and monitoring of state-licensed residential, school and day program provider Program Managers, DSPs, Nursing/Clinical Staff, as well as at state-operated developmental centers, and Psychiatric Hospitals regarding medication administration, and an individual's health specific protocols. A person's Medical Administration Records (MAR) must be made available to families/legal guardians, to confirm accurate medication administration, and related health care protocols.
- Mandate the training of all management and staff members at state-licensed provider and state-operated developmental centers, in compliance with the individual's established behavioral management plan, healthcare protocols, Individual Service Plan (ISP/21 y/o+) and Care Management Plan (up to 21 y/o), according to the principles of person-centered planning. Where necessary, all those responsible for providing care and support should be trained on the person's Behavioral Health and Healthcare Protocol Emergency Plan developed in collaboration with the individual's physicians, clinical team (behavioral health and medical), Program Managers, DSPs, and Family Members/Legal guardians.
- Mandate the development of a Trauma-Informed Service System for individuals with IDD, where all those involved in the care and support of the person (family members, caregivers, service providers, state agencies, etc.) recognize and respond to the impact of traumatic stress. For example, routine screening for trauma exposure and related symptoms. The use of evidence-based, culturally responsive assessment and treatment for traumatic stress and associated mental health symptoms. Making appropriate resources available. Work on strengthening the resilience and protection of individuals and families impacted by and vulnerable to trauma. Create and maintain an environment of care for families, caregivers, DSP staff, which addresses, minimizes, and treats secondary traumatic stress, and increases wellness.
- The Centers for Medicare and Medicaid Services'(CMS) recently released finalized regulations entitled, "Ensuring Access to Medicaid Services Rule" (Access Rule). These new regulations were established to strengthen Home and Community-Based Services (HCBS), and they include requirements related to the direct care workforce, access to home and community-based services (HCBS), health and safety protections, quality measures, etc., and should be enforced for persons with IDD served by CSOC and DDD, with oversight from the Office of the Attorney General.

This mandate represents a major systemic change.

With everything that connects our unwavering support of the IDD community, it will require the collaboration of all stakeholders, including self-advocates, families, advocacy groups, state-leadership, human service departments and divisions, service providers, outreach organizations, law enforcement, The Ombudsman's office and the community at large.

PLEASE JOIN US IN THIS IMPORTANT WORK!

Urgency of Now Founding Families

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