



Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Major Systems Change or Add on to What is Working

Reflections on the “Urgency of Now” White Paper

We thank the Urgency of Now Founding Families for their commitment and thoughtful ideas intended to help ensure the safety of our citizenry with intellectual and developmental disabilities. As a partner in this regard, we submit our reflections on their recent paper.

Retaliation

With respect to the reporting of abuse, neglect, and exploitation (ANE), the paper states that “Staff members are concerned about retaliation.” Though this is disheartening to read, ABCD member agencies continue to maintain that it is the agency’s responsibility and in their best interest for individuals, families and/or guardians to feel comfortable to report concerns to the agency so that they can be investigated and addressed. To help prevent retaliation, agencies must inform staff that retaliation is prohibited, to respond to questions, concerns, and complaints promptly and effectively, ensure that managers and supervisors understand their responsibility to stop, address and prevent retaliation, and to hold staff accountable for complying with and enforcing rules and policies.¹²

Uniform Justice

We have been unable to identify the levels referenced by the statement “...allegations are not given the same level of criminal or legal justice as neurotypical people are afforded,” and, therefore, are not able to provide a response at this time.

Multitasking

“When these often, life-threatening issues are eliminated we can focus on restoring dignity and quality for all individuals with IDD as valued and respected members of the community.” We understand the logic, but frankly, it’s a lot harder than that. We believe it is our duty and moral obligation to do both at the same time.

¹ Based on the Conscientious Employees Protection Act, NJSA 34.19-1 and the US EEOC, “What is Retaliation and How Can I Prevent It?” <https://www.eeoc.gov/employers/small-business/8-what-retaliation-and-how-can-i-prevent-it>

² Response to NJRFSPC White Paper on Health and Safety. January 10, 2022. <https://www.abcdnj.org/advocacy>

Investigations

Why is the assumption that “...organizations cannot investigate themselves and expect direct and honest answers?” We disagree. ABCD members internal oversight helps to ensure accountability, quality, adherence to laws and regulation, effectiveness of programs and services, and control unfair treatment, corruption or unethical behavior. Combine this with external oversight and investigations by the Division of Developmental Disabilities (DDD) regional offices and the Department of Human Services (DHS) Critical Incident Management Unit (CIMU) and the Office of Program Integrity and Accountability (OPIA), and we have a structure which a long-time professional disability advocate recently described as “DDD’s robust system of oversight.” The bones are there, and we imagine that the state would accept additional resources for this purpose.

Disability Rights New Jersey (DRNJ)

We remain confused by the paper’s failure to recognize DRNJ and its role to ensure the health and safety of individuals with intellectual and developmental disabilities (IDD). Specifically with respect to the suggestions to appoint a third party, privately managed entity to effectively monitor DDD service providers and for the restructuring of the IDD Ombudsman utilizing the framework of the LTC Ombudsman as a model.

DRNJ is New Jersey’s federally mandated Protection and Advocacy (P & A) system provider of legally based advocacy services for people with disabilities. It is an independent non-profit organization which has 24/7 access to all state-run facilities such as developmental centers, psychiatric hospitals and all Home and Community Based Service settings which includes group homes, day programs, and sheltered workshops.

Except for DRNJ’s legal component, New Jersey’s federally mandated Long-Term Care Ombudsman has similar responsibilities to advance the civil and human rights of individuals in LTC through advocacy, systems change, outreach and education.

DRNJ is a third party, privately managed entity with powers that supersede that of the Long-Term Care Ombudsman. What is the value of creating redundancy in the system? If anything, give DRNJ more resources to do their job.

Financial Penalties, Trauma Informed Care, Improved Trainings

These are valuable suggestion some of which are currently under consideration and development by DHS and the Legislature

“This Mandate Represents a Major Systemic Change”³ versus Adding on to What is Working

Here is what we know:

- The office of the NJ Ombudsman for Individuals with Intellectual and Developmental Disabilities and their Families reports to DHS all allegations of abuse, neglect, and exploitation that they are made aware of. We presume the vast majority of these cases are currently or have been under investigation. Those that were not previously reported are immediately reviewed by DHS. We imagine that some calls are from families who are not satisfied with the outcome of an investigation. The point is fewer cases are falling through the gaps.
- ABCD is unaware of any significant rise in OPIA investigations. In fact, incident reports have reduced over the last 2 years.⁴
- In 2023 DHS’s Field Services and Safety Unit (FSSU) conducted 4125 visits to 2225 licensed sites which resulted in 16,515 assessments for 8,931 individuals. In 2024, FSSU has conducted 2583 visits to 2060 licensed sites which resulted in 9739 assessments for 7907 individuals. At the outset FSSU staff assumed that they would find numerous episodes of abuse, neglect and exploitation (ANE) during visits but instead starting in 2022, 1% of visits identified as ANE, in 2023, a little over 1%, and in 2024, 1%. The majority of ANE found during this period were judged by the state to be, “neglect with no injury.”⁵
- Based on information provided in the *NJDHS DDD COVID-19 Dashboard* and data on the number of people served in NJ’s congregate settings, ABCD calculated that while the fatality rate for individuals with developmental disabilities was not less than 8.8% in nursing facilities and specialized hospitals⁶ and was 4% in NJ’s developmental centers, it never rose above 1.69% in DDD licensed group homes and supervised apartments
- In addition to state laws and regulations, agencies must comply with CMS regulations through Section 6032 of the Federal Deficit Reduction Act of 2005. This requires agencies to take steps aligned with prevention of fraud, waste and abuse of Medicaid funding. Embedded in that is the obligation to provide services that are promoting health and safety for individuals with IDD.

We are very supportive of DHS’s ongoing efforts to improve transparency in the reporting system. In addition to additional information, this will help build trust.

We don’t agree that our system is broken to require the level of change outlined in the white paper. We believe it prudent and wise to add on to what’s working. When it comes to abuse, neglect, and exploitation, unending vigilance, upgrades and refinements are essential.

ABCD member agencies will remain extra vigilant in our efforts to provide individuals with intellectual and developmental disabilities the safety and security they require and the dignity and independence they rightly deserve.

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³ *Urgency of Now. Protect People with IDD*. September 2024. info@Urgencyofnow.blog

⁴ ABCD notes from DDD Leadership monthly meeting, September 2024.

⁵ Ibid.

⁶ Data from nursing homes and specialized hospitals on IDD fatalities due to COVID-19 was voluntarily reported.