

New Jersey Department of Children and Families
Children's System of Care Contracted System Administrator Listening Session
Written Testimony | June 24, 2024

Good afternoon. We appreciate the opportunity to provide input on the future scope of work for the CSA. I am Dr. Suzanne Buchanan, Executive Director of Autism New Jersey, and over the last ten years, we have had a collegial and productive relationship with many PerformCare employees. Our suggestions today are specific to the needs of the families who call our 800.4.AUTISM Helpline, especially those families of profoundly autistic children who exhibit severe challenging behavior.

I am a licensed psychologist and a doctoral-level Board Certified Behavior Analyst and have been with Autism New Jersey for 23 years. Our mission is to ensure the health, safety, and happiness for individuals with autism and their families. Simply stated, children with profound autism require a lifetime of 24/7 supervision and care. Many of them also exhibit frequent and severe challenging behavior; behavior that places themselves, their families and the professionals who work with them at risk of injury, in some cases on a daily basis.

Over the last year at Autism New Jersey, we have spoken with more than 2,000 families, 89 of whom are in chronic crisis punctuated by episodes of acute danger, meeting our helpline's criteria for "unmet safety and treatment needs." Although these families make up only about 4% of our call volume, they are our most complex, involve helpline and clinical staff, and are rarely resolved. They are stories of daily struggle, fear, and helplessness.

In just the last week, we received calls from two families with the following stories:

- A mother of an eight-year-old boy with increasingly aggressive behaviors - This mother says she has exhausted all her options with CSOC and PerformCare. She has also reached out to her insurance carrier and has been assigned a Health Advocate, but they have not been able to help her. At this point, she says that she is taking things into her own hands to find services as his behaviors are worsening.
- The mother of an eighteen-year-old man who is increasingly agitated in public and damages property - This mother is facing eviction because of her son's aggressive behavior. At this time, she is looking for any way to make her home safe and has had to consult legal counsel to avoid eviction.

These stories are only two examples of the calls we receive regularly on our helpline.

Fortunately, the Children's System of Care has some infrastructure to meet those needs, and here's the opportunity. We don't yet see that infrastructure meeting the safety and treatment needs of this portion of children with profound autism and severe challenging behavior. Consensus from multiple sources (e.g., calls to our helpline, news stories in the popular press, the IDD Ombudsman's five (soon to be six) annual reports) makes it clear that we have much work to do to build capacity for these acutely vulnerable children and families.

The CSA plays a critical role in this capacity-building, and we're here to ask that the Scope of Work include objectives that will explicitly and meaningfully address these safety and treatment needs.

The Scope of Work could be expanded in three (3) areas: personnel, DD services, and outcomes reporting.

- **Section 3.3.1 Personnel** could include a leadership-level staff member or designated team who would:
 - Review, analyze, and report on both quantitative metrics and qualitative stories to identify trends that will inform current capacity efficiencies and barriers as well as short- and long-term planning
 - Participate in a workgroup that includes external professionals with expertise in the assessment and treatment of severe challenging behavior
- **Section 3.9 Developmental Disability Services** could include a new section (3.9.2) to capture the safety and acute treatment needs
- **Section 3.17 Quality and Outcomes Management and System Measurement Program** could include a new section (3.17.C.10) to report on the met and unmet safety and treatment needs

As we have been since 2012, Autism New Jersey is a resource to the Children's System of Care and looks forward to the work ahead to increase safety and access to treatment for children with profound autism.

Thank you,

A handwritten signature in blue ink that reads "Suzanne Buchanan". The signature is written in a cursive, flowing style.

Suzanne Buchanan, Psy.D., BCBA-D
Executive Director