



500 Horizon Drive
Suite 530
Robbinsville, NJ 08691

800.4.AUTISM
609.588.8200
609.588.8858 (fax)

www.autismnj.org

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Margaret Rose
Division of Medical Assistance and Health Services
Office of Legal and Regulatory Affairs
P.O. Box 712
Trenton, NJ 08625-0712

RE: NJ FamilyCare Comprehensive Demonstration Renewal Comments

Dear Ms. Rose:

Consistent with the objectives of the Title XIX grants to states for medical assistance programs and the demonstration programs to furnish medical assistance to individuals with disabilities to drive better health and quality of life that ultimately reduces the volume of services consumed and allows states to maintain the long-term fiscal sustainability of their Medicaid programs and provide more medical services to more Medicaid beneficiaries, Autism New Jersey respectfully submits the following recommendations for the 2022-2027 NJ FamilyCare Comprehensive Demonstration renewal. Our recommendations fall into three (3) areas:

1. Medically Necessary Treatment for Severe Challenging Behavior
2. Medically Necessary Treatment for Autism
3. Provider Qualifications for Behavioral Treatment

1. Medically Necessary Treatment for Severe Challenging Behavior – The most acute problem facing the autism community is the lack of effective treatment for children and adults with autism who engage in severe challenging behavior. Autism New Jersey wholeheartedly supports the State's multi-year commitment to address these needs as evidenced by the current renewal's *Pilot Program for Adults with I/DD and Co-occurring Behavioral Health Needs* and the 2019 announcement of a fiscal appropriation for this population.

Severe challenging behavior is a clear and imminent danger to health and safety and can present in many forms. The most common and dangerous forms are self-injury, aggression, property destruction, and elopement. Families experience a seemingly endless cycle of physical harm, ineffective attempts at treatment, isolation, and despair. For most families, this goes on for years. Families' attention is continuously directed toward keeping their child and everyone else in the household safe and free from injury. When they seek professional help, the options are, at best, insufficient and ineffective, and, at worst, harmful and traumatic. Parents also understandably turn to

emergency hospital services, psychiatric units, and assistance from law enforcement, none of which have the specialized workforce or capacity to serve this population. This never-ending and extremely dangerous cycle occurs because we do not yet have the capacity to provide effective treatment for this highly acute population of children and adults.

In New Jersey, an estimated 14,000 children and adults with autism engage in severe challenging behavior. Yet, this estimate is a conservative one and may underestimate the full scope of the problem. Research suggests that as many as 70% of individuals with autism will engage in self-injury at some point in their lives. More troubling is that left untreated, 84% continue to engage in self-injury for more than 20 years.

Fortunately, there is hope. Over the past four decades, the field of Applied Behavior Analysis (ABA) has developed highly specialized assessment and treatment procedures and delivers the most well-researched and effective treatment for severe challenging behavior. Now, with licensure for this profession here in New Jersey and a large body of empirical evidence, we have two of the four fundamental components to create a viable path forward.

The remaining components are funding mechanisms for this specialized service and willing providers. Of course, the funding mechanism must come first, and as the State has stated, it is imperative that both provider qualifications and rates be set with this specific population in mind. This current renewal provides an opportunity to more fully conceptualize and design the funding models needed to establish programs to provide effective treatment.

Autism New Jersey requests that the Department of Human Services and the Department of Children and Families consider the following as they design potential demonstration projects for inclusion in the 1115 waiver renewal.

- **Early Identification of Severe Challenging Behavior** – the development of a system to identify children with severe challenging behavior and provide them with access to ABA treatment as early as possible to reduce both the financial and human costs of the trauma created by lack of access to treatment
- **Building State Capacity** – the development of high-quality and cost-effective treatment models for children and adults with severe challenging behavior to put an end to the cycle of inadequate programming and hospitalizations that do not meet their needs.
- **Integration of ABA** – the incorporation of ABA expertise and services within existing and new service lines developed for children and adults with autism to increase access to empirically-validated and effective treatment

In order to truly help the 14,000 children and adults with autism who engage in severe challenging behavior, we must invest in the right programs, that is, those based on

Applied Behavior Analysis in collaboration with multidisciplinary teams. It is these programs that have the greatest scientific support and offer the greatest hope for changing lives.

2. Medically Necessary Treatment for Autism – At the present time, 87% of children with autism have either publicly- or privately-funded insurance coverage for medically necessary behavioral treatment for autism. This is due in large part to the newly established EPSDT benefit and the state autism insurance mandate. The remaining 13% of children should continue to be afforded access to medically necessary behavioral treatment under a demonstration program or other appropriate funding source. Autism New Jersey strongly recommends that any such publicly-funded services that are intended to treat autism meet an evidentiary standard for effectiveness.

3. Provider Qualifications – We request that the State consider inclusion of the recently enacted P.L.2019, c.337., the Applied Behavior Analyst Licensing Act into all provider qualifications for behavioral services, including but not limited to the Supports Program, the Community Care Program, and the Children’s Support Services Program.

Autism New Jersey stands ready, willing, and able to partner with state officials and others to bring these recommendations to fruition. We welcome the opportunity to learn more about state and federal requirements and share our clinical expertise, connections with nationally-recognized leaders, and budget-friendly policy recommendations.

Thank you for your time and consideration of our recommendations on behalf of individuals with autism.

Sincerely,



Suzanne Buchanan, Psy.D., BCBA-D
Executive Director
Licensed Psychologist #4265