



# Autism and Severe Challenging Behavior

Policy Recommendations  
for the State of New Jersey



Dear Friends,

Autism New Jersey is acutely aware that children and adults with autism and severe challenging behavior have few, if any, ways to access treatment. We recognize that any advocacy efforts to increase public and private capacity must be mindful of the complexities involved in state laws and regulations, funding, treatment, and long-term service provision. Thus, we are analyzing state policy, best practices, and the experiences of families and clinicians, all in an effort to better articulate families' experiences, quantify the scope and depth of the problem, and make comprehensive recommendations to improve state policies.



Governor Murphy's proposed FY 2020 state budget includes \$9.5 million to address the needs of individuals with developmental disabilities and other mental and behavioral health challenges and is a welcome investment for this underserved group.

In this document, we summarize who's affected, shed light on families' experiences, and define the scope of the problem. We also discuss effective treatment and offer recommendations to best leverage the Governor's proposed budget allocation.

For too long, families have told us harrowing stories of pain and injury and the revolving door of ineffective services. Essentially, they have nowhere to turn. With thoughtful and systematic implementation of our recommendations, the State of New Jersey can be more responsive and increase access to desperately needed treatment.

**Suzanne Buchanan, Psy.D., BCBA-D**  
Executive Director  
sbuchanan@autismnj.org

**Eric Eberman, M.S.Ed.**  
Public Policy Director  
eeberman@autismnj.org

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# Nowhere to Turn

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It's hard to believe in New Jersey in 2019, parents and professionals are struggling to properly care and find treatment for an estimated 14,000 children and adults who engage in severe challenging behavior. Yet, this is their reality. They call our 800.4.AUTISM helpline with stories of unequipped systems, such as emergency rooms, psychiatric hospitals, and mental health agencies. Families are left to their own devices as insufficient and ineffective suggestions are offered. Compounding the problem, funding sources typically attempt to address the challenges only when a situation has reached a full-blown crisis, and in many cases, years after the child began engaging in severe challenging behavior.

Families' stories convey the aching physical and emotional pain of doing everything they can to keep their child and themselves free from injury and having nowhere to turn for help. Here is a small sample:

- A dad holds his teenage son close to keep him from hurting himself. The son abruptly headbutts his father, which has caused concussions for both.
- A mom who didn't want to attend a family celebration because she couldn't bear for them to see and talk about the bruises her daughter unintentionally caused when she hit her in the face.
- A young man who hit himself in the eyes and head so many times that he detached his retinas.
- Parents who drove their adult son to the emergency room after he banged his head on surfaces all over the house only to be told, "We're sending you home. There's nothing we can do for you."

**This needs to change. We must help these families, and we can.**

# Who's Affected

## Dual Diagnosis

Those with autism and other developmental disabilities who are also diagnosed with a mental health disorder such as anxiety, depression, bipolar disorder, obsessive compulsive disorder, attention deficit hyperactivity disorder, psychosis, etc.

## Severe Challenging Behavior

Those with autism and other developmental disabilities who do not have another mental health disorder and who exhibit behavior such as aggression, self-injury, and other behaviors that inflict pain, injury or pose a risk to the health and safety of themselves and others.

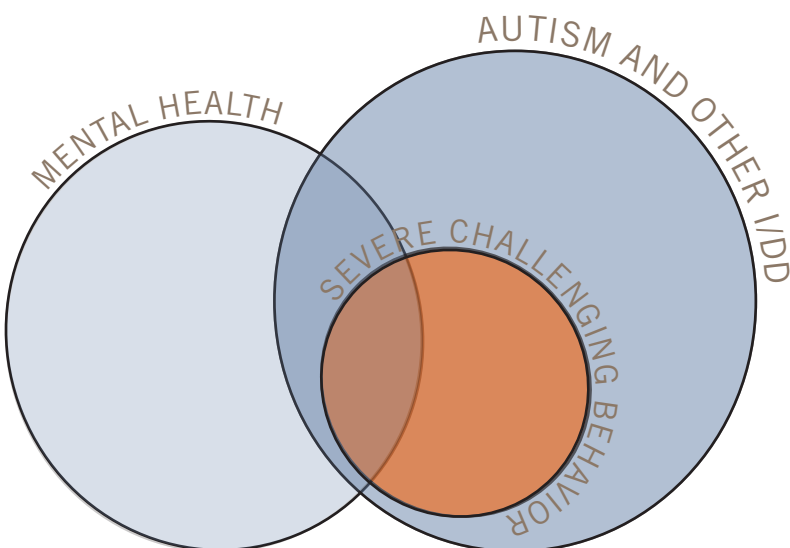
## Distinguishing between Dual Diagnosis and Severe Challenging Behavior

The term “Dual Diagnosis” is shorthand for individuals with “co-occurring developmental disabilities and mental health needs.” This umbrella term actually describes two unique and sometimes overlapping clinical presentations representing an underserved portion of the I/DD community.

The distinction between the two groups is important.

We assert that individuals with developmental disabilities and severe challenging behavior who do not have a secondary diagnosis are a unique and deserving segment of the intention to help those with the greatest clinical needs and should be included the FY 2020 budget initiative.

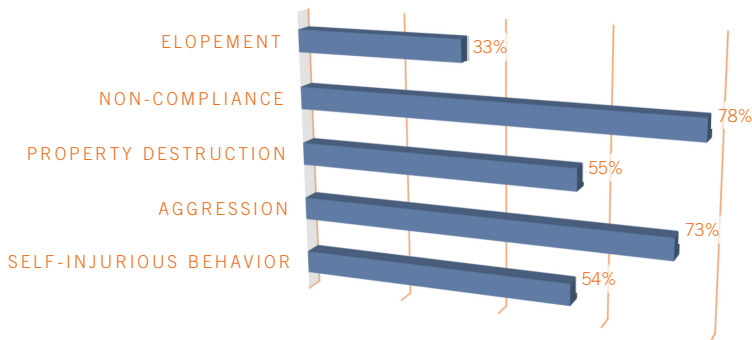
It is well documented in medical literature that many children and adults with autism frequently engage in severe challenging behaviors, such as aggression, self-injurious behavior (SIB), and property destruction. The severity of these severe challenging behaviors can range from skin-picking and slapping to head-banging, self-biting, punching, and kicking. Research suggests that anywhere from 30% to 70% of individuals with autism will engage in SIB at some point in their lives.<sup>1,2</sup> Possibly more troubling is that, left untreated, 84% of these individuals will continue to engage in SIB 20 years later with no significant change in the type or severity of the SIB.<sup>3</sup> Couple these statistics with the rising prevalence rate of autism in New Jersey – now 1 in 34 children (highest in the country), and it is easy to see that this is a growing problem.



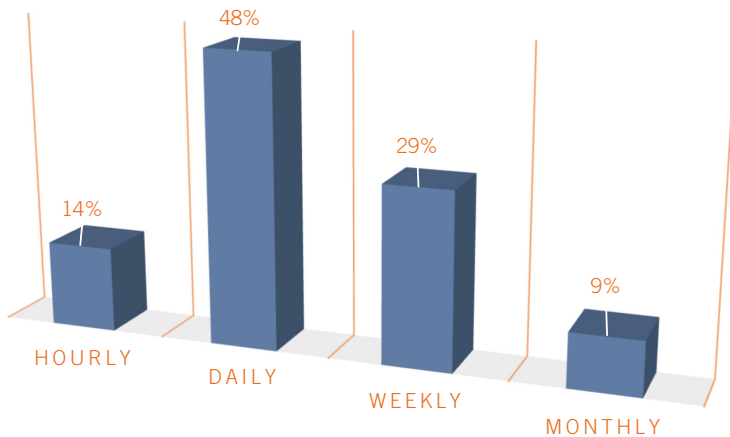
# Family Impact

## Severe Challenging Behavior Survey Results

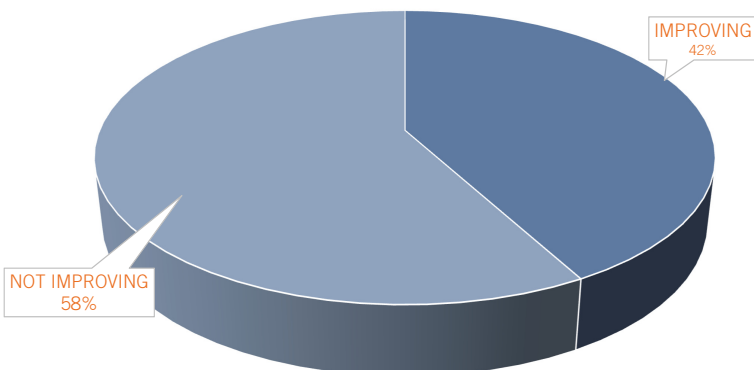
### TYPE



### FREQUENCY



### CURRENT STATUS



**6 out of 10 families endure severe challenging behavior every day.**

To better understand the experiences of families in our state, Autism New Jersey recently surveyed 200 families whose children engage in severe challenging behavior. What we found was alarming on many levels. On average, the individual with severe challenging behavior is a 16-year-old male who lives with his family; is aggressive, non-compliant, self-injurious and/or destructive; exhibits these behaviors daily; and is currently not improving. Due to these behaviors, the family's participation in social and other family events is very limited or nonexistent.

This is not a manageable situation for any family. It is also important to keep in mind that families with children who exhibit the highest frequency of severe challenging behavior barely have time in their day to shower and do other basic home chores, let alone find time to complete a survey. Siblings also suffer. Virtually all brothers and sisters love their siblings and want to help, yet they also may need to lock themselves in their rooms to avoid being aggressed upon and forego parental attention. All families want is to keep their child safe while they desperately try to find someone or some place that can effectively treat the severe challenging behavior.

Our survey results align with the findings of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families who documents similar systemic and individual issues in his annual report.<sup>4</sup>

# Treatment

## What doesn't work?

Individuals with a developmental disability, many times autism, who exhibit severe challenging behavior have acute clinical needs. Yet, their symptoms are typically not responsive to medication and are not responsive to talk therapy and other traditional mental health treatment models designed for populations with an average IQ, even when these methods are adapted for individuals with intellectual disabilities. Furthermore, they are most at risk for costly and inappropriate hospitalizations and out-of-home placements.

## What does work?

Individuals who exhibit severe challenging behavior often respond well to applied behavior analytic (ABA) treatments that are based on the results of a variety of ABA-based assessment methods (e.g., functional analyses, preference assessments, reinforcer assessments), designed and regularly evaluated by highly competent doctoral-level behavior analysts with extensive experience, and delivered by a direct care workforce that has been trained to and can successfully implement an individualized ABA treatment plan. The assessment, treatment, and generalization of treatment gains to home- and community-based settings often requires months of focused and specialized effort.

While too few have access, individuals with autism and severe challenging behavior often also benefit from access to specialized medical evaluations and treatments to address underlying medical conditions and injuries.



(Photo Credit: Neal Santos / The Atlantic)

# Applied Behavior Analysis

The most effective treatment for severe challenging behavior is ABA.



Currently, the most well-researched and effective treatment for severe challenging behavior is Applied Behavior Analysis (ABA).<sup>5,6</sup> Over the past four decades, the field of ABA has developed highly effective assessment and treatment procedures that can substantially reduce severe challenging behavior.

The common ABA assessment and treatment model typically begins with conducting a Functional Behavior Assessment (FBA). The purpose of the FBA is to determine the cause/function of the severe challenging behavior. There are different types of FBA procedures, and the choice of procedure is usually dependent on the setting in which it is being conducted along with the experience and clinical judgment of the Board Certified Behavior Analyst (BCBA).

Once the function(s) of the severe challenging behavior has been determined, the BCBA then develops a function-based treatment plan. The function-based treatment plan includes reinforcement and teaching strategies aimed at increasing adaptive behaviors that serve the same purpose as the severe challenging behavior. As the individual learns that the new adaptive behavior results in the same reinforcement as the existing severe challenging behavior, the frequency of the adaptive behavior increases while the severe challenging behavior decreases.

Please be aware that this is an extremely over-simplified description of the process and does not include the many nuanced modifications and changes that are typical in an ABA assessment and treatment model.

Even with an effective function-based treatment plan in place, there are several considerations to ensure ongoing success (e.g., parent/caregiver education and training, treatment plan integrity and consistency, generalization to other settings). Each of these considerations present real-world challenges to implementing highly specialized behavior plans.

For more information on applied behavior analysis and board certification in the profession, visit [www.bacb.com](http://www.bacb.com).

# Recommendations

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To create an effective and efficient service delivery system for the children and adults with developmental disabilities and severe challenging behavior, we recommend:

## 1. LEADERSHIP COUNCIL OF STATE OFFICIALS, EXPERTS, AND PARENTS

### Partnership

A robust partnership between state officials, experts, and parents represents the best hope for this population. Fortunately, we are off to a great start. When the New Jersey Council on Developmental Disabilities (NJCDD) convened a meeting to discuss the FY 2020 budget proposal, there was a palpable sense of urgency and commitment among everyone in the room. We recommend that we continue the conversation started by the NJCDD and use it to inform the spending of the monies allocated in the FY 2020 budget proposal. With a limited timeframe and specific mandate to develop a game plan for FY 2020, we believe that the NJCDD-convened group could move this conversation forward in innovative and meaningful ways.

We envision at least two outcomes from this process: (1) a detailed recommendation on how best to invest the funding in this budget proposal, and (2) the establishment of a first-of-its-kind, department-level partnership between state officials, experts in the field, and parents. Together, we could integrate best practices in treatment with federal and state funding and policies to accelerate the development of model services.

### Experts

Autism New Jersey staff and our ABA Advisory Committee have decades of experience in effectively treating children and adults with severe challenging behavior, designing innovative treatment and transition programs from inception, and supporting families throughout this difficult journey. At the request of the Department of Children and Families' Children's System of Care, our ABA Advisory Committee has collaboratively produced updated policies for behavioral programming and behavior support committees as well as reviewed treatment plans to improve the quality of care children with autism receive. These efforts could easily translate to the adult service delivery system administered by the Division of Developmental Disabilities (DDD). More broadly, the Department of Human Services is welcome to call upon this committee at any time - from conceptualization to implementation and evaluation of ABA services for individuals with autism under various funding streams.

### Parents

Parents have lived through such unique and harrowing experiences that only they truly understand their families' experiences. All efforts to serve this population should actively solicit and incorporate families' recommendations.



# Recommendations

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## 2. EARLY IDENTIFICATION

The earlier we can provide effective treatment, the more success we will have in slowing the growth of this escalating problem and keeping everyone safe. The FY 2020 budget proposal of \$44.5 million combined state and federal dollars to fund the treatment of autism for NJ FamilyCare beneficiaries is a tangible investment in this effort.

More specifically, we need a system to identify children with severe challenging behavior and provide them with access to ABA treatment as early as possible. This could be a function led by the Department of Health's Autism Registry in collaboration with school districts, the Children's System of Care, and others. Doing so will significantly reduce the costs associated with ineffective crisis services and inappropriate hospital placements as they become adolescents and adults.

## 3. INTEGRATION OF ABA SERVICES

As previously stated, ABA is the single most effective treatment for children and adults with developmental disabilities and severe challenging behavior. Despite this fact, few existing programs incorporate this powerful clinical technology. Going forward, each of the following service lines would be more effective if built upon a behavior analytic framework and seamlessly integrated with medical/psychiatric treatment and ancillary services:

- Mobile crisis services
- Out-patient clinics\*
- In-patient stabilization units\*
- Transitional residential services
- Long-term (day and residential) services

\*Consistent with best practices, out- and in-patient services should be conceptualized as a months-long effort to assess and treat; not short-term crisis beds. The best models are interdisciplinary in nature and feature behavior analysis as the core assessment and treatment methodology.

# Recommendations

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## 4. WORKFORCE DEVELOPMENT

With decades of scientific evidence demonstrating that severe challenging behavior can be successfully treated using ABA, it is time that we create systems that provide access to ABA treatment for those in need. We must find ways to strengthen existing programs and establish new programs that can effectively reduce severe challenging behavior and improve the long-term outcomes for these vulnerable children as well as adults.

As of this writing, there are approximately 1,700 Board Certified Behavior Analysts (BCBA) in New Jersey. While the profession has grown, the demand still far outweighs the supply, especially with only a small percentage of BCBAs possessing expertise to treat the clinical needs of this population.

### **Licensure (S3099/A4608)**

As a foundation, we need to ensure that behavior analysts are licensed and regulated. We can then build on this foundation to increase the number of behavior analysts who develop expertise to serve this population.

### **Higher education in behavior analysis**

There are currently nine (9) institutions of higher education in New Jersey that offer such coursework; some of which offer master's degrees and one of which offers a doctoral degree in behavior analysis. Attracting the most compassionate, intelligent, and dedicated talent to these programs is of the utmost importance.

### **Incentives**

Working with individuals with severe challenging behavior presents moment-to-moment risk that requires highly specialized and individualized programming. Providing criteria-based incentives for professionals to work with this population could increase the state's capacity to deliver these essential services; for example, loan-forgiveness programs for early career professionals who train in this area and commit to working with this population for a period of time.

### **Training**

Consistent reports from across the state suggest that the vast majority of providers do not have the current workforce expertise to ethically and effectively assess and treat severe challenging behavior. Given the well-documented limitations of lecture-style training models, hands-on and competency-based training models are needed to become proficient to deliver these specialized services. The ABA Advisory Committee could take a lead role in establishing an ABA training consortium to plan, pilot, implement, and evaluate these efforts.

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The Power of Connection

Autism New Jersey serves as a collective and influential voice for the community and systematically and compassionately improves the lives of individuals with autism every day through our four core service pillars.

Information Services | Education & Training | Public Policy | Awareness

**800.4.AUTISM**  
**[www.autismnj.org](http://www.autismnj.org)**