

AUTISM AND THE LAW SERIES

Part 3: Why NJ Must Increase Social Awareness of the Need for Early Diagnosis

By Lawrence R. Jones

This article is the third installment of a four-part special series in honor and recognition of National Autism Awareness Month.

On April 26, 2018, the United States Center for Disease Control (CDC) issued a periodic report of updated findings by the Autism and Developmental Disabilities Monitoring (ADDM) Network. The results were noteworthy and must be viewed as relevant by lawmakers throughout the state and nation.

The data contained in the report reflected that the estimated percentage of children identified with Autism Spectrum Disorder (ASD) was higher than in previous reports. Approximately one in 59 children were identified with ASD, based on tracking within 11 communities in the United States. (2018 Report, page 2.) Moreover, the percentage of children identified with ASD was significantly higher in areas of New Jersey than in other specified parts of the country. In New Jersey, the incidence was one in every 34 children—the highest rate of any state included in the study.

The reasons for regional differences in statistics are unknown, and may have been partly attributable to the diagnosis

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process. Both on a state and national level, however, it is clear that the rate of autism is prevalent and recurring enough to warrant increasing public concern and focus. For this reason, the ADDM report itself expressly urges policymakers and community leaders to use the information in its report of findings to: (a) promote social awareness of autism spectrum disorder and bring the community together to address the growing needs of families living with ASD; (b) develop policies and promote early identification and equity in access to services and supports so that all children get the help they need; and (c) serve as the basis for the creation of a task force or commission, focused on

the coordination of ASD activities in local communities.

The ADDM report further notes that service providers, such as healthcare organizations and school systems, can use the findings in the report to: (a) promote early identification efforts in order to lower the age when children are first evaluated for developmental concerns, diagnosed with ASD, and enrolled in community based support systems; (b) plan for resource and service needs; and (c) target outreach to under-identified groups of children.

Moreover, the study reflects that most children (85%) identified with ASD actually had concerns about their development noted in their records by three

years of age. Specifically, parents or caregivers may have noticed concerns through ongoing tracking of a child's development (developmental monitoring) and/or developmental screening. Parental concern regarding development is a reason to have a comprehensive developmental evaluation. In turn, such evaluation is often a key step in getting access to services, including through an applicable school system. Yet, while the majority of children with ASD had concerns about their development documented in their records by three years of age, there was frequently a lag between first concern and first developmental evaluation. Accordingly, despite the fact that developmental concerns were noted in many of children's records by three years of age, fewer than half of children with ASD received a comprehensive developmental evaluation by this same age. Further, while ASD can be diagnosed as early as two years of age, about half of children were not diagnosed with ASD by a community provider until after four years of age. Such a lag can negatively impact when children with autism may begin to actually obtain the services they need. It is well-established that obtaining services as early as possible can make a very positive and meaningful difference in the development of a child with autism. Unfortunately, however, the CDC study found that fewer than half (42%) of children with ASD received a developmental evaluation by three years of age. Yet, the percentage of children with ASD increased in New Jersey, from about 2.5% in 2012 to about 3%, in 2014.

Future efforts may therefore need to emphasize the importance of screening young children with standard tools and connecting families to needed services before three years of age. The importance of early diagnosis and intervention cannot be overstated. As noted in the undersigned's judicial opinion in unreported New Jersey case of *Rooney v. Wall* (2015):

There is no known "cure" for autism. It is well-documented

and critical to note, however, that young children who receive an early diagnosis, followed by intense behavioral intervention often make very significant improvement to the point that they can effectively mainstream with non-autistic children, both in school and otherwise. In the realm of intervention and behavioral therapy for autistic children, perhaps the most recognized form of behavioral intervention is known as Applied Behavioral Analysis (ABA), with a sub-category known as discrete trial techniques (DTT). This type of therapy is based on a 1987 study conducted at UCLA known as the "Lovaas" study, which supports intense behavioral interventions of 25-40 hours a week or more.

Generally, the earlier the diagnosis and start of intense therapeutic intervention, the greater the chance for possible success in improving the autistic child's functional abilities. Some professionals refer to the age bracket of two-to-five as the greatest "window of opportunity to improve an autistic child's functionality, since the brain is still forming (i.e., the age of "plasticity of the brain") Thus, failure to provide a young autistic child with intense behavioral intervention during his or her early years of life may have significant negative consequences on the child's progress and future (*Citing Dr. Sandra Harris in "Right from the Start: Behavioral Intervention for Young Children with Autism 2d edition (2007).*).

This benefit of early diagnosis and intense early intervention, was documented in a 1987 study by Dr. Ivar Lovaas of UCLA, who was considered one of the major pioneers is the treatment and education of children with autism.

According to the CDC, there are possible "red flags" that a child might

possibly have autism. For example, a child with ASD might:

- Not respond to their name by 12 months of age
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap hands, rock his/her body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

A child may possibly have autism even without demonstrating any or all of these traits. If a parent or guardian believes that his or her child might possibly have autism, it is logical for such parent or guardian to schedule an appointment with the child's physician as soon as possible. If the child does in fact have autism, an early diagnosis and the start of intense early intervention may potentially make a world of difference in the child's future progress.

Based upon the findings of the report from the ADDM and CDC, there is arguably a clear and compelling social need to focus upon increasing public education and awareness of the need for early diagnosis of childhood autism. Accordingly, in view of these statistics, the New Jersey governor and legislature may consider reviewing the status of the state's prior public awareness efforts and strategies, and thereafter launching an increased public awareness campaign through the Department of Health and/or Human Services of the critical importance of early diagnosis and intervention of children with autism. ■