

# CHERI QUICKMIRE

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To: Senator Slossberg, Representative Caruso, Members of the Government  
Administration and Elections Committee  
From: Cheri Quickmire  
Re: SB 7144

Good Morning Senator Slossberg, Representative Caruso, Members of the GAE Committee. My name is Cheri Quickmire and I would like to thank you for the opportunity to testify in favor of Senate Bill 1744, AA Establishing a Board of Education and Services for Citizens with Autism Spectrum Disorders.

I am here today as Ian's mom. I am here today because my son is diagnosed with Pervasive Development Delays Not Otherwise Specified - or PDD NOS. This is a rather vague term about which there is much disagreement and confusion, and it used to describe many children with autism.

In data collected from its Autism and Developmental Disabilities Monitoring Network (ADDM), a population-based, multi-state surveillance network that surveyed 8 year olds in 2000 and 2002, the Centers for Disease Control found that the data confirm that Autism Spectrum Disorder (ASD) prevalence affects approximately an average of 1 child in every 150. The data represents 10 percent of the U.S. population of 8 year old children.

The CDC study includes children with behaviors consistent with autism, Asperger's and pervasive developmental delays not otherwise specified (PDD-NOS). The data came from 14 sites in five states (Arizona, Georgia, Maryland, New Jersey, South Carolina and West Virginia). The study also found higher prevalence in boys than girls (a range of 2.8-6, boys to girls, depending on the state) and no statistically significant difference among non-Hispanic whites and non-Hispanic black children.

Autism has become a raging controversy in this country. I hope this data can help end the debate about the prevalence of autism and will help us focus on getting the services and supports families need. We need to recognize that autism is a health crisis and deal swiftly.

But today I am here to tell you about being Ian's mom. Ian is 16 years old now and he's a wonderful kid. He was born at a time in Connecticut when autism was not being diagnosed as frequently as it is today. In fact, Ian wasn't diagnosed until he was nearly 8 years old partly because he was able to communicate and, in fact, had an extensive

vocabulary (although he was difficult to understand). He wasn't diagnosed partly because he didn't exhibit many of the stereotypical behaviors that some autistic children do. He did not receive services from Birth to Three (which I understand are quite helpful although very understaffed) but had extensive speech therapy that we requested from a clinic in our town. But by 8 he had fallen farther and farther behind his peers in school, was having great difficulties with social interactions, and had been suspended in the second grade for threatening his principal from under the desk where he was hiding out of frustration. Planning for frustration and outbursts was a constant when Ian was in elementary school. Anticipating disappointment was what we did every day. Going to a grocery store often meant leaving the cart in the aisle to go back to the car without food. Relationships with other children were nearly impossible because of the risk of injury to those children. Forgetting to do things in a certain order could create hours of chaos and serving something other than vanilla ice cream for dessert could incite a riot.

Surviving the PPT system in our local public school system and getting a referral to a school that could meet his educational needs without suing was a victory after years of frustration. Many families are not so successful and many children suffer without appropriate support and education. Ian spent three years in a wonderful public school in our town that was completely incapable of meeting his needs. Hours in the hallway with very nice women who had no training with children with special needs were basically wasted hours. This is not unique, in most communities the systems are not prepared for children with autism. And in most, the school systems are extremely difficult to navigate without support. We had no support. And I am painfully aware that after he can no longer attend school because he has aged out there are few on-going supports.

We have come a long way from there. My son has learned to read and do basic math. He has learned to love his older brother without physically harming him. He has friends and talks to them on the telephone. He speaks more slowly, cooks wonderful spicy garlic shrimp and he adores his new puppy. And I no longer blame myself for every bump or earthquake in the road. But it has been a struggle and there are no road maps. No professionals have been able to tell me what to expect at any point in his development and certainly none have been able to suggest how to plan for his future. No one was helpful as we tried to anticipate the next developmental challenge, the next barrier to friendships, or the next roadblock to a calm conversation.

I have another, wonderful older son, so I am not under the illusion that growing up is easy to chart. Kids are unpredictable, they don't come with instruction manuals and most parents feel that we are making it up as we go along. But with children with autism "making it up" is not an option. Life needs to be predictable and planful.

There is no cure for autism. There are treatment and education approaches that may reduce some of challenges but families need support to access them. There needs to be significant research into the causes of autism so we know what to expect and how to prepare for our children to have productive, happy lives. And we need research to be done to explain why we have this epidemic and how to prevent it.

But since that isn't the prevue of this committee, we need a system that will help families navigate these unknown waters with support. We need trained professionals prepared to provide appropriate educational and emotional supports for children and parents. We need appropriate services for families unable to pay for testing and tutoring and special therapy. We need early screening, diagnosis, intervention and services. We need a commitment to a lifetime of support to address this baffling mystery because this is about our children.

Thank you.