

**TO: Human Services - Senators/Reps**  
**FROM: Cristy Jones – 554 Wagon Trail, Orange, CT (203-882-0212)**  
**DATE: March 13, 2007**  
**SUBJECT: BILL 7280 – MEDICAID WAIVER FOR ASD ADULTS**

**BILL DESCRIPTION: To require the Commissioner of Social Services to take all necessary action to secure Medicaid funding for home and community-based individualized support services for adults who have autism spectrum disorders, but who are not mentally retarded.**

Good afternoon ladies and gentlemen. My name is Cristy Jones and I live in Orange Connecticut with my husband, my 9 year old daughter and my 15 year old son.

This story is about my son Ryan. Ryan has had severe social and emotional disabilities since he was an infant. For several years he was misdiagnosed, misunderstood and mis-handled in the private daycare and in the public school systems. Although in 2<sup>nd</sup> grade his IQ was tested to be 127, which is in the superior range, his behavior and the lack of appropriate social and emotional supports resulted in a child that was suspended twice, spent most of his time in “the office”, had no friends, was being brutally bullied and became suicidal by 3<sup>rd</sup> grade.

When Ryan was 4 years old, it became clear that I had to quit my career to be his champion and advocate. However, it wasn't until his outbursts from frustration became extremely aggressive in 3<sup>rd</sup> grade that he finally was placed in Special Education. After 2 years of failure on the part of the public school system, Ryan was transferred to an appropriate private therapeutic program outside of the school district. By 5<sup>th</sup> grade he was finally was getting the services he desperately needed, but the damage had been done. His self-esteem was terrifyingly low!

Eventually my son Ryan received the diagnosis of Pervasive Development Disorder – Not Otherwise Specified, usually referred to as PDD-NOS, an Autism Spectrum Disorder. He is now getting the social and emotional supports he needs to make it through a day and by going one day at a time he is making slow but steady progress and is able to interact appropriately in a very few, very limited, very controlled situations. But - at 15, he doesn't go to dances, the mall, sports games or even a movie. He rarely leaves the house because he lives in fear of losing his own self-control if he encounters something or someone that he doesn't know how to respond to appropriately. Frustration still causes anger, fear and paralyzing anxiety.

People affected with Autism have as many differences as they do similarities. However, what is common among people with Autism is that they perceive and interact with their environment differently than a “typical” person does. People with Autism have a neurological impairment that causes their brains to process stimuli differently. Basic responses to smells, touch, sound and physiological needs like hunger are often acute and often trigger unpredictable extreme anxiety and discomfort.

Things a “typical” person learns intuitively, by trial and error, or by watching others, people with Autism need to be taught regardless of their IQ! Not only do they need to be taught basic social skills, but they need constant repetitive re-teaching of the same concepts over and over and over for it to become a “natural” response for them (again, regardless of their IQ).

Ryan is now in his 6<sup>th</sup> year of outplacement and continues to work daily on re-establishing his feelings of self worth and value in our world.

*Clearly* Ryan does not experience or understand the world he lives in the same way most of us do.

*Obviously* he is many, many years behind his peers in social skill development.

*Probably*, he will never catch up to his peers in his abilities to consistently apply appropriate behaviors and be successful in the many choices and challenges our society requires.

*Definitely*, Ryan will need social and emotional supports throughout his life to become independent and a contributing member of society.

At 21, only 6 years from now, Ryan will no longer get services from our school district. At 21, Ryan does not qualify for any state or federal support services because he is not mentally retarded (intellectually disabled). At 21, Ryan will not be able to be self sufficient, self reliant or independent and financially responsible. He will need social and emotional supports to attend any further education after High School. He will need social and emotional supports to obtain and sustain employment. He will need social and emotional supports for him to develop and maintain any type of social life.

Please approve bill 7280 to provide services for adults with Autism Spectrum Disorders (ASD). Please provide my son and hundreds of other ASD adults who live in Connecticut, with an opportunity to obtain a productive and interactive adult life. We want what any parent wants for their child – an opportunity to succeed!