



Government Administration & Elections Committee
Public Hearing: March 16, 2007

***PLEASE SUPPORT HOUSE BILL 7144 –
AN ACT ESTABLISHING A BOARD OF EDUCATION AND SERVICES FOR
CITIZENS WITH AUTISM SPECTRUM DISORDERS***

My name is Robert Shea and I am an attorney/lobbyist at the State Capitol. My 11-year-old son Jeremiah has a severe autism spectrum disorder. House Bill 7144 is a great proposal that will help Jeremiah and the thousands of other Connecticut citizens who have autism. **Thank you very much for raising and considering this bill!**

This proposal is very closely modeled after the Connecticut Statutes that authorize and govern the Board of Education and Services for the Blind (BESB). The BESB model works very well for Connecticut's blind and sight-impaired citizens, and we believe that a similar "seamless lifetime service" model should be implemented for the rapidly growing number of citizens who have the extremely complex and perplexing disability of autism. The sad truth is, everyone in Connecticut now has a family member or a friend with autism, and the problem appears to be getting worse, not better. The U.S. Center for Disease Control now estimates that 1 of every 150 children born will have autism. Under this estimate, in Connecticut where we have 3.5 million citizens, there could be as many as 23,000 citizens with an autism spectrum disorder.

WHY AUTISM? Many reasonable people will ask: Why establish a new separate Board for citizens with Autism? What about the citizens with other disabilities? This is a very good question, and the right answer of course is that it would be a great idea to have specialized boards for all specialized disabilities -- this would be ideal. But autism may be considered a distinct and unique disability for some of the following reasons:

- Autism is an extremely fast-growing disability, with no end in sight; and there is no real answer to how autism is caused or how autism can be prevented. Often times, autism spectrum disorders are very hard to detect and diagnose. Many children aren't correctly diagnosed and don't receive appropriate intervention services when they are young children. It should be our common goal to have improved diagnosis and early intervention services, because if a young child can work with trained and experienced professionals to obtain important life skills at an early age, then that child hopefully will not require expensive services for the remainder of his/her life. The goal of everyone who loves and cares about a person with Autism is to have that person become independent and to have that person live a happy, productive and fulfilling life.

- Many citizens with Autism require one or more full-time professionals to be with them at all times during the school day or the workday for safety and other life needs. Self-reliance and independence is something that must be repetitively taught through thousands of hours of hard work.
- Everyone now understands that it is very, very hard to work with people with autism, and professionals who work with people with autism should have extensive education, training and ideally, apprenticeship experience. These professionals also must have enormous hearts and tons of patience (thank goodness that there are professionals who are willing to work with citizens with autism – it is extremely difficult work!). Unfortunately at this time, the Birth-to-Three/Early Intervention Program does not have enough staff to meet the growing demand for autism services; most towns don't have enough trained and experienced staff in the public schools to work with the growing number of students with autism (kids in some towns have to be shipped to very expensive, specialized autism schools an hour or more away from their homes); and the current programs for adults with autism are very limited if not nonexistent.
- The current turnover rate for professionals who work with children and adults with autism is alarmingly high in many public schools and community programs. Professionals get burned out very quickly, because many of the citizens with autism have severe emotional and behavioral problems, many do not have verbal or physical skills, and many do not have the self-reliance skills that come naturally to typical people. The turnover rate is especially high because many professionals receive poor wages and benefits, and they do not receive appropriate training and support resources. A statewide board will certainly help provide more resources to the dedicated professionals across our state who are only trying to do their best to help children and adults with autism.
- Autism is certainly not any more important than any other physical or cognitive disability; it's just very, very hard to figure out how to work with citizens with autism. I respectfully suggest that it's a very good idea to have as many trained and experienced professionals as possible working together in a Statewide Board to develop, coordinate and offer the best possible services throughout the state. Ultimately, many towns could save money by using and relying upon the Statewide Board's services and professionals – instead of having to spend \$50,000 or more per year to send a child far away from their homes to attend one of the few specialized autism school programs in this state. The State could also save money in the long run if more citizens with autism can live independent and productive lives.

SECTION-BY-SECTION ANALYSIS OF HOUSE BILL 7144:

SECTION 1. Creates a Board that is housed within the Department of Mental Retardation (soon to be the Department of Developmental Disabilities). There are 12

members of the board – and importantly, three of the board members will be parents or legal representatives of citizens with autism spectrum disorders.

SECTION 2. Describes the position of the executive director of the Board –who shall be a person with background, training or education related to providing services to citizens with autism spectrum disorders.

SECTION 3. States that *All citizens of this state, regardless of age, who because of an autism spectrum disorder, require specialized educational, medical or therapeutic programs, goods or services shall be entitled to receive such instruction, programs, treatment, goods and services.* The board is also authorized to hire professionals and offer services to school districts and to citizens with autism spectrum disorders.

SECTION 4. States that the executive director of the Board may aid in securing employment for citizens with autism spectrum disorders in industrial and mercantile establishments and in other positions that offer financial returns.

SECTION 5. Requires the Board's annual reporting to the Governor.

SECTION 6. Requires that each physician and psychologist shall file a report with the Board of Education and Services for Autism Spectrum Disorders not later than thirty days after any person comes under such physician's or psychologist's private or institutional care and such person presents with an autism spectrum disorder. Section 6 also states that the Board may maintain a vocational rehabilitation program, as authorized under state or federal law, for the purpose of providing and coordinating the full scope of necessary services to assist citizens who have autism spectrum disorders and who are recipients of services from the board to prepare for, enter into and maintain employment consistent with the purposes of the applicable law.

SECTION 7. Authorizes the Board to receive federal funds for vocational and rehabilitation services.

SECTION 8. Authorizes the Board to develop vocational and rehabilitation services.

SECTION 9. Requires the Board to file an annual balance sheet with the State Comptroller's Office.

SECTION 10. Requires the Board to maintain strict confidentiality of information and records of citizens with autism spectrum disorders who are receiving services from the Board.

THANK YOU FOR YOUR CONSIDERATION OF HOUSE BILL 7144!