



State of Connecticut
Department of Developmental Services

DDS

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**DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY
BEFORE THE PUBLIC HEALTH COMMITTEE**

March 19, 2014

Senator Gerratana, Representative Johnson, and members of the Public Health Committee. I am Terrence W. Macy, Ph.D., Commissioner of the Department of Developmental Services (DDS). Thank you for the opportunity to submit testimony regarding **H.B. No. 5558 - An Act Concerning Services for Persons with Autism Spectrum Disorder.**

Section 1 (j) of the bill seeks either Medicaid coverage or a waiver amendment to provide or expand physical activity programs to persons with autism spectrum disorder (ASD) and to provide transportation for such persons to and from such programs. While it is difficult to know exactly what sort of physical activity this language is referring to, DDS agrees that weight gain that is associated with a lack of physical activity for individuals with ASD is a serious problem. In fact, new research from the U.S. Centers for Disease Control and Prevention indicates that adolescents with developmental disabilities are significantly more likely than others of a similar age to struggle with weight and that those with ASD are at greatest risk. The Division of Autism Spectrum Services currently operates a Home and Community Based Services (HCBS) waiver that addresses the issue of sedentary lifestyle in a number of ways. Community Mentoring is one example of a waiver service that benefits many of the waiver participants. Community Mentors can be considered 'social coaches' for individuals with ASD. These mentors support individuals so they can access community activities such as hiking, cycling, swimming or attending a gym. Another waiver service, Life Skills Coaching allows life skills coaches to work with individuals with ASD to build adaptive skills, such as shopping for healthy foods and learning to cook a balanced meal. Transportation is another HCBS waiver service that is available for those individuals who demonstrate a need for this service.

Although it is not clear, we assume that Section 1 (k) of the bill attempts to provide services to individuals currently on the DDS Autism Division HCBS waiver waiting list. It is important to distinguish that the Autism Waiting List is not a residential waiting list like the more traditional DDS waiting list for persons with intellectual disability. Connecticut has made significant progress in the past seven years in providing services for individuals diagnosed with autism spectrum disorder. What started as a small pilot program in 2006 has grown into a division within DDS serving 114 individuals with autism who do not also have intellectual disability. A federal Medicaid waiver was approved in January 2013 allowing Connecticut to receive fifty percent reimbursement for services that were previously fully paid for with state funding.

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With the growing success of the waiver program has come an increase in the number of individuals requesting services. As of the end of February 2014, there were 231 people on the Autism Division waiver waiting list ranging in age from 3 years old to 66 years old. Based on an average of \$42,000 per year for the 91 children and \$30,000 per year for the 140 adults the annualized cost to address these 231 individuals would be approximately \$8 million. (Fifty percent of the cost of the waiver services would be reimbursed by the federal government.) This funding would not guarantee that another waiting list would not start to grow as new individuals continue to apply and become eligible for the division's services. At the request of Senator Maynard and Representative Abercrombie, DDS has provided cost information to them on various methods to address the Autism Division waiver waiting list. We would be happy to share that information with the Public Health Committee as well if the members are interested. As would be expected, all of the options have a fiscal impact that is currently not budgeted.

Section 2 of [H.B. No. 5558](#) establishes a pilot program for individuals diagnosed with developmental disability and ASD who require a high level of clinical services, have behavioral needs, are on DDS's residential waiting list, and have an Emergency priority designation or have been served in a hospital setting or out-of-state facility. It is unclear from the bill whether or not the intent is to serve individuals who have both "developmental disability", which is broader definition than "intellectual disability" which is what DDS's eligibility is based on, and ASD or if just one diagnosis would qualify a pilot participant. Regardless, based on the individuals having a high level of need (LON) as the bill states, we estimate the average annual cost of residential services to be approximately \$152,000 per person (based on a LON level of 8). For 24 pilot participants the residential cost would be approximately \$3.6 million annually, not including several hundred thousand dollars in room and board costs that are paid by the Department of Social Services. These costs are not included in the Governor's proposed budget.

The DDS Autism Division currently serves 114 individuals with ASD without intellectual disability. Included in this number are 31 children previously served by the Department of Children and Families (DCF) Voluntary Services Program (VSP). Of the DCF children served, more than half of them fit the description of the target population identified in section 2. Some of the children were previously served out-of-state and many have spent time in hospitals. These children present with significant behavioral needs and require high intensity services. All of these children receive in-home behavioral supports which utilize an approach consistent with Applied Behavioral Analysis (ABA).

While this bill attempts to address the needs of individuals with developmental or intellectual disability and ASD, I would request that department staff be part of any conversations that attempt to move any parts of this bill forward so as to ensure that duplicate efforts are not occurring and that there are appropriate resources for any new initiative.

Thank you again for the opportunity to submit testimony on **H.B. No. 5558**. Please contact Christine Pollio Cooney, DDS Director of Legislative and Executive Affairs at (860) 418-6066, if you have any questions.