



Dannel P. Malloy  
Governor

State of Connecticut  
Department of Developmental Services

**DDS**

Morna A. Murray, J.D.  
Commissioner

Jordan A. Scheff  
Deputy Commissioner

To: Senator Terry Gerratana, Co-Chair, Public Health Committee  
Representative Matthew Ritter, Co-Chair, Public Health Committee  
Members of the Public Health Committee  
Members of the Autism Spectrum Disorder Advisory Council

From: Morna A. Murray, J.D., Commissioner

A handwritten signature in blue ink that reads "Morna A. Murray".

Date: February 1, 2016

Re: **2016 Department of Developmental Services' Division of Autism Spectrum Disorder Services Report to the Connecticut General Assembly's Public Health Committee.**

The following report from the Department of Developmental Services' Division of Autism Spectrum Disorder Services is submitted to the Connecticut General Assembly's Public Health Committee pursuant to section 5 of [Public Act No. 15-209](#).

Section 5 of [Public Act No. 15-209](#) requires the Division of Autism Spectrum Disorder Services to report on the following:

- (1) The number and ages of persons with autism spectrum disorder who are served by the Department of Developmental Services' Division of Autism Spectrum Disorder Services and, when practicable to report, the number and ages of such persons who are served by other state agencies;
- (2) the number and ages of persons with autism spectrum disorder on said division's waiting list for Medicaid waiver services;
- (3) the type of Medicaid waiver services currently provided by the department to persons with autism spectrum disorder;
- (4) a description of the unmet needs of persons with autism spectrum disorder on said division's waiting list;
- (5) the projected estimates for a five-year period of the costs to the state due to such unmet needs;

(6) measurable outcome data for persons with autism spectrum disorder who are eligible to receive services from said division, including, but not limited to, (A) the number of such persons who are enrolled in postsecondary education, (B) the employment status of such persons, and (C) a description of such persons' living arrangements; and

(7) a description of new initiatives and proposals for new initiatives that are under consideration.

### **Overview of the Division of Autism Spectrum Disorder Services**

The Department of Developmental Services' Division of Autism Spectrum Disorder Services currently has a staff of 10 employees (some full time and some with shared responsibilities) who provide statewide services to individuals with a diagnosis of autism spectrum disorder (ASD) who do not have a co-occurring diagnosis of intellectual disability. The Division's staff includes five case managers, who work directly with individuals and families on a daily basis. There are two resource specialists who provide outreach, education and resources to individuals who are on the Division's waiting list and their families. In addition, the resource specialists provide information to schools, state and municipal agencies, and community programs statewide. The Division also has one program manager, one case manager supervisor and one administrative assistant.

### **Individuals Served by the Division of Autism Spectrum Disorder Services**

During the 2015 annual reporting period, January 1, 2015 through December 31, 2015, the Division served a total of 144 individuals through the two DDS Home and Community Based Services (HCBS) waivers for individuals with ASD. Thirty-nine children, ages 3 and 4, were served through the Early Childhood Autism (ECA) waiver and 105 individuals both children and adults, were served through the Home and Community Supports waiver for Persons with Autism (Lifespan waiver).

Of the 105 individuals on the Lifespan waiver, 33 were children under the age of twenty-one. Seventy-two of the 105 individuals on the Lifespan Autism waiver were 21 years of age or over. All children on the ASD waivers live with their families.

As of September 1, 2015, individuals receiving waiver services through the ASD Division:

- 39 individuals, aged 21 and over, were competitively employed;
- 25 individuals participated in volunteer activities; and
- 9 individuals were enrolled in a higher education program.

As of September 1, 2015, of all individuals receiving waiver services through the ASD Division aged 21 and over:

- 83 lived with their family; and
- 21 lived independently in either their own apartment or home.

### **Medicaid Services Provided by DDS through the Early Childhood and Lifespan Autism Waivers**

The Medicaid services provided to individuals in either the ECA or the Lifespan Autism waiver include:

1. Clinical Behavioral Support (ECA waiver and Lifespan waiver)
2. Life Skills Coaching (ECA and Lifespan)

3. Community Mentors (Lifespan only)
4. Job Coach (Lifespan)
5. Assistive Technology (Lifespan)
6. Respite (Lifespan)
7. Social Skills Groups (Lifespan)
8. Specialized Driving Assessment (Lifespan)
9. Non-Medical Transportation (Lifespan)
10. Personal Emergency Response System (Lifespan)
11. Individual Goods and Services (Lifespan)
12. Interpreter Services (Lifespan)

**Division of Autism Spectrum Disorder Services – Waiting List as of December 31, 2015**

As of December 31, 2015, there were 785 individuals on the DDS Division of Autism Spectrum Disorder Services waiting list. The Division’s waiting list was started in 2009. The age break-out for individuals on the Division’s Waiting List is as follows:

Age 60 and over	1
Age 40 to 60	11
Age 30 to 40	26
Age 21 to 30	200
Age 16 to 21	191
Age 10 to 16	125
Age 5 to 10	141
Age 3 to 5	90
Total	785

**Description of Unmet Needs of Individuals on the Division’s Waiting List**

In 2015, a survey was conducted by the DDS Division of Autism Spectrum Disorder Services of all adults and families of children on the Division’s Waiting List. The survey was sent to 230 families and individuals for whom the Division had e-mail addresses. Of the 230 surveys sent, 97 or 42 percent were completed and returned to DDS.

The results of the survey of adults on the Division’s waiting list indicated that 66% of respondents felt that employment was their most urgent need. Barriers that prevented them from obtaining employment included:

- transportation;
- communication skills;
- job supports; and
- personal anxiety.

Other needs identified by the adult survey respondents, in addition to employment, were:

- social and recreational activities, and
- social skills groups.

(Please see the information outlined later in this report detailing efforts to address social and recreational needs.)

The results of the survey of families with children on the Division's waiting list showed that 80% of respondents indicated their child would like to be involved in a support group with other individuals on the autism spectrum. These families identified their children's most important needs as:

- communication;
- social skills development;
- participation in social activities; and
- independent living skills.

Several of the families surveyed noted that supervision for their child while they were at work, especially during the summer, was a significant unmet need.

### **Projected Cost of Unmet Needs for Individuals on the Division's Waiting List**

There were 785 individuals on the Division of Autism Spectrum Disorder Services' waiting list as of December 31, 2015. The average budget for individuals on the Lifespan waiver is \$40,000 per year. The annual cost of adding 785 individuals at \$40,000 per individual would be \$31.4 million. This cost over 5 years would be \$157 million.

### **New Initiatives and Proposals under the Autism Spectrum Disorder Advisory Council (ASDAC)**

The Autism Spectrum Disorder Advisory Council (ASDAC) has 23 members representing state agencies, private providers, advocates, parents of adults and children with ASD, and individuals with ASD. The Council was established in 2013 with the charge to advise the Commissioner of Developmental Services on all matters relating to autism spectrum disorder.

During the past two years, the Council formed five workgroups to outline projects to address the various recommendations of the 2012 Autism Feasibility Study Workgroup report "[Autism Services in Connecticut](#)". To that end, five Autism Feasibility Study projects are underway (or have been completed):

1. A Comprehensive Autism Spectrum Disorder Resource Guide was completed and can be accessed on the Autism Services and Resources Connecticut (ARSC) website at: <http://autismconnecticut.org/professional-resources> or on the DDS website under Autism Spectrum Disorder Services "Latest News". This Resource Guide was completed in 2015. ASRC has suggested that an annual update should be considered.
2. Three specialized in-patient beds for care of persons who are Medicaid eligible with autism spectrum disorder were funded at the [Hospital for Special Care](#). This unit, consisting of 8 beds, the first of its kind in the country, officially opened its doors in December 2015. For further information, please see the following link: <http://www.courant.com/health/hc-ctm-autism-hospital-1007-20151006-story.html>

3. The “In-Home Behavioral Supports” project is being developed with local education agencies (LEAs) in Suffield and Regional School District #17 to provide a school-to-home behavioral support program for children with ASD between the ages of 13 and 21 who are at-risk of out-of-district placement. Participants and providers have been selected and the teams are formed and have begun working with families.
  
4. The “Psychiatric Residential Treatment Facilities (PRTF)” project is being developed with the Center for Children with Special Needs, LLC. The PRTF project’s goal is to create a specialized multidisciplinary team of licensed professionals with expertise in ASD to assist children and adolescents with ASD, who are having a psychiatric behavioral crisis. This project is designed to prevent in-patient hospitalization to support PRTFs as an alternative to in-patient stays. The Center for Children with Special Needs is also charged with developing a “train the trainer” model for PRTFs to provide sustainability in the treatment of children with ASD and psychiatric behavioral issues.
  
5. The “Social and Recreational Activities for Individuals with ASD across the Lifespan” project is in development with ASRC. This project supports individuals with autism spectrum disorder and their families by developing and expanding peer mentor programs and group recreational activities for individuals with ASD. Deliverables for this project include peer mentoring, short-term community mentor and adult social opportunities.

DDS looks forward to continued progress in addressing the needs of individuals with ASD and their families across the state. Please contact Debra Anderson at (860) 418-6031 with any follow up questions related to this report.