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DEPARTMENT OF DEVELOPMENTAL SERVICES
TESTIMONY BEFORE THE LEGISLATIVE PROGRAM REVIEW AND
INVESTIGATIONS COMMITTEE RE: TRANSITIONAL SERVICES FOR YOUTH AND
YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER
September 24, 2014

Good afternoon. Senator Kissel, Representative Mushinsky and members of the Legislative Program Review and Investigations Committee (LPRIC). I am Terrence W. Macy, Ph.D., Commissioner of the Department of Developmental Services (DDS). Thank you for the opportunity to comment on your study regarding transitional services for youth and young adults with autism spectrum disorder (ASD). I understand that the scope of this study is to identify the needs of individuals with ASD and services that are available with a focus on the transition from secondary school completion to young adulthood up to age 25. LPRIC staff has met with DDS staff on multiple occasions regarding this important issue. As always, I appreciate their thorough analysis on an issue of such importance to so many of the families supported by DDS.

Connecticut has made significant progress in the past eight years developing 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 individuals with autism who do not also have intellectual disability. In March 2014, the Centers for Disease Control (CDC) reported a prevalence of one in every 68 children with ASD, further highlighting the great need for services in the community. A federal Medicaid Home and Community Based Services (HCBS) waiver was approved in January 2013 for individuals with ASD who do not also have intellectual disability. Services under the waiver include life skills and job coaching, social skills groups and community mentoring. As of June 30, 2014, the DDS Autism Division supported 103 individuals on this "Lifespan" waiver which includes 35 children from the Department of Children and Families' (DCF) Voluntary Services Program (VSP). Of the 35 children who have transitioned from DCF to DDS's autism division as of July 1, 2014, 13 are between the ages of 15-25. Services are determined by the individual's team with input from the annual Level of Need assessment. Over five years, the capacity of the waiver will increase to 136 individuals. Additionally, a new Early Childhood Autism waiver was approved February 1, 2014 to serve three and four-year-old children with significant needs. This waiver provides intensive home-based behavioral intervention for 10 hours per week and the goal of this waiver is to fill the gap between the Birth to Three Program and Kindergarten.

With the growing success of the ASD waiver program has come an increase in the number of individuals requesting services. As of September 18, 2014, the DDS Autism Division had a waiting list of 400 individuals. Of the 400 individuals on the waiting list, 188 are between the ages of 15-25. In

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December 2013, two Autism Support and Resource Specialists were hired. The focus of the Resource Specialists is to work with individuals and their families waiting for services. They have been busy with outreach activities at resource fairs, schools and transition events as well as conducting home visits and assisting individuals on the autism division waiting list. In the past two years the Autism Division has grown from having two case managers to six. Additionally, DDS has added a full time Division Director, a Case Management Supervisor, the two Autism Support and Resource Specialists mentioned previously, and an administrative assistant.

The work of the Autism Spectrum Disorder Advisory Council and its five subcommittees continues. The majority of the Council's subcommittees have developed and submitted high quality proposals designed to meet their subcommittee goals. The subcommittees include: credentialing, training, creating a resource guide, social/recreation pilot programs and in-home behavioral support pilot programs. We look forward to implementing these activities in FY15 to positively affect individuals with ASD and their families.

The activities described above are a glimpse at what the DDS Autism Division has done over the past few years for individuals with ASD, including transitioning youth, who do not have intellectual disability. We share the concerns of the broader community about how to better serve these individuals with limited resources.

DDS also provides supports and services that are more broadly focused on individuals with intellectual and developmental disabilities which could include individuals who also have ASD. As of June 30, 2014, there were 2959 individuals with intellectual disability between the ages of 15 and 25 who were eligible for DDS. Of that number, 1121 had a level of need assessment that indicated a diagnosis of autism. DDS continues to work closely with the Department of Rehabilitative Services (DORS) and the Connecticut State Department of Education (CSDE) to improve employment outcomes for students graduating from high school. Staff from all three agencies collaborate on a variety of state teams and group projects that are focused on producing better employment outcomes for people with disabilities. DDS and DORS also have a Memorandum of Agreement which requires that the two agencies meet periodically to review ways to enhance employment supports for individuals that are served by both agencies.

DDS and CSDE have formed a joint workgroup to look at issues surrounding service delivery that would lead ultimately to a student's ability to work in a competitive work environment upon exiting high school. This workgroup, *Collaborating Across the Lifespan*, is comprised of representatives from both agencies who are working with students ages 3-21 as well as representatives who are working with adults, including aging services.

CSDE recently developed a "Transition Community of Practice" focused on secondary transition in general and competitive employment. DDS is represented on this state team which will focus on better ways to collaborate to improve post-school employment outcomes for all youth with disabilities. CSDE's "Transition Community of Practice" will be working on the following: 1) development and use of a statewide transition website; 2) development of a transition calendar of events and proposals for the development a statewide transition conference; 3) identification of existing transition training statewide and development of cross-agency training; and 4) development of a directory of transition resources including the web-based transition timeline.

Two years ago, DORS entered into a sustainability initiative with CSDE, the six Regional Educational Service Centers (RESCs), the State Education Resource Center (SERC) and the Connecticut Parent Advocacy Center (CPAC) to develop effective working partnerships between DORS and the local education agencies. Other state agencies, including DDS, that provide employment services to people with disabilities, were also invited to participate in this group's activities. Although the funding for this

effort has ended, the group continues to meet to identify ways that collaboration can be improved in order to better meet the transition needs of students with disabilities.

DDS staff recently participated in a DORS Interagency Strategic Planning retreat. At that retreat three priorities were identified: 1) support students and families in navigating the transition landscape; 2) promote meaningful collaboration across agencies and schools; and 3) build outreach and engagement across the state. DDS staff will continue to partner with DORS and other agencies to implement activities developed to achieve these priorities.

In addition to these interagency initiatives, DDS has been involved in several strategies around the issue of youth and transition. In 2011, DDS created an employment website to provide individuals and their families with extensive information on transition and employment. In 2014, DDS also created a family website which provides families with useful information across an individual's lifespan. In 2012, eighteen DDS employees were re-assigned to new transition advisor positions that are critical in helping to make sure that students with intellectual disability receive appropriate educational programs that focus on employment. DDS also created six employment/self-determination positions (two per region) to help enhance employment outcomes in the regions. Case managers are provided technical assistance by the employment/self-determination personnel to help individuals on their caseloads find and keep competitive employment. Technical assistance case studies have been written up in a training manual that has been made available to all case managers. Additional training continues to be provided through job developer networks and through joint training opportunities offered by DORS, the Association for Persons in Supported Employment (APSE) and DDS. This training is available for anyone interested in supporting and promoting employment for individuals with intellectual and developmental disabilities.

Over the past year, DDS's Employment Steering Committee continued to increase job opportunities for DDS consumers focusing on industry-based training programs. The successful partnership with Connecticut companies has created a growing case management referral base which has helped more individuals find work. Community Enterprises, a DDS provider, continued their participation on the committee and played a major role in sharing job opportunities from companies which were focused on hiring people with disabilities into their competitive job openings. The provider, a partner in the successful Walgreens Initiative in Connecticut, offered tours for families and case managers at Walgreens, HomeGoods and other companies. Work incentives created by DDS continue to be successful. The number of individuals in supported employment and the funding to providers who provide these services have both increased.

DDS continues to encourage individuals and their families to make use of the Benefits Counseling provided through DORS. Families continue to have a lot of questions about how employment impacts an individual's federal and state benefits. There continue to be myths about an individual's employment negatively impacting his or her benefits. Ongoing training on employment and benefits, especially during any period of transition, is needed for all DDS stakeholders.

DDS is very involved in activities to better support individuals as they transition from school to the adult service system, however, limited resources require us to continuously evaluate community resources and alternative solutions to help these individuals transition.

Again, thank you for the opportunity to comment on this important topic. We look forward to continuing to work with LPRIC staff as the study continues and recommendations are developed. I would be happy to answer any questions you may have at this time.