



State of Connecticut  
Department of Developmental Services

DDS

Ned Lamont  
Governor

Jordan A. Scheff  
Commissioner

Peter Mason  
Deputy Commissioner

**DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY  
BEFORE THE HUMAN SERVICES COMMITTEE  
February 19, 2019**

Senators Moore and Logan, Representatives Abercrombie and Case and members of the Human Services Committee. I am Jordan A. Scheff, Commissioner of the Department of Developmental Services (DDS). Thank you for the opportunity to submit testimony on **S.B. No. 834 AN ACT CONCERNING SERVICES FOR PERSONS WITH SMITH-MAGENIS SYNDROME.**

This bill would require DDS, in consultation with our sister agencies, to study whether children with Smith-Magenis Syndrome are receiving adequate services through the state and then develop recommendations on how to improve such services.

DDS recognizes Smith-Magenis Syndrome as a rare congenital disorder that has a multisystemic effect on an individual that also may include mild to moderate intellectual disability. As the syndrome relates to a chromosome 17 depletion, it is our understanding that genetic testing would be required to properly identify the condition.

For anyone interested in receiving supports or services from DDS, including a child under the age of 21, a formalized review process to determine eligibility must be completed. Specifically, an individual must complete an application, provide documentation and meet the requirements set forth by the department as detailed; (1) be a resident of the State of Connecticut; and (2) have an intellectual disability, as defined in section 1-1g of the Connecticut General Statutes or have a medical diagnosis of Prader-Willi Syndrome, which is a neurobehavioral genetic disorder that must be diagnosed by a physician.

To show that an individual has an intellectual disability, an applicant is required to submit a copy of all intelligence/cognitive tests and tests of adaptive functioning completed prior to the age of 18, in addition to full scale IQ scores on intelligence/cognitive tests showing more than two standard deviations below the mean as measured by tests of general intellectual functioning that are individualized, standardized and clinically and culturally appropriate to the individual. Significant limitations in intelligence and adaptive skills also must be present at the same time and have existed before the individual was 18 years of age.

If an individual is determined eligible then the department works with the individual and their family to assess what funding and services are appropriate. In many cases, this process begins with a DDS case manager evaluating the individual's level of need (LON). This assessment is done through a standardized tool called the CT Level of Need Assessment and Screening Tool. This tool assesses areas of need including, but not limited to: health and medical, personal care and daily living activities, behavior, safety, comprehension and communication. Once an individual's LON is measured, the department is able to better

Phone: 860 418-6000 ♦ TDD 860 418-6079 ♦ Fax: 860 418-6001  
460 Capitol Avenue ♦ Hartford, Connecticut 06106  
[www.ct.gov/dds](http://www.ct.gov/dds) ♦ e-mail: [ddsct.co@ct.gov](mailto:ddsct.co@ct.gov)  
*An Affirmative Action/Equal Opportunity Employer*

match the appropriate supports and services to that individual's needs. In addition to the LON, individuals receiving DDS services also are provided an individualized plan of support. This collaborative effort engages the DDS case manager, the individual's family, the appropriate clinicians and the individual directly, to determine a course of action that details how services will be provided. Each plan is person-centered and created specifically with input from the individual and their team.

For an individual diagnosed with Smith-Magenis Syndrome, the process for eligibility would be the same as anyone else who believes they or their family member has intellectual disability and wishes to receive DDS funding and services. As individuals with Smith-Magenis may have an intellectual disability, eligibility for supports and services through the department may be appropriate, but a formalized review of each application and support documentation would be required before a determination of eligibility could be made. As outlined above, once eligibility is determined, the process to measure the need for and offer supports is specific to the individual and their needs and not, necessarily, to their diagnosed medical condition.

In the context of services it is also important for the department to note that DDS services are not considered an entitlement and are therefore subject to available appropriations.

Thank you again for the opportunity to offer testimony regarding [S.B. No. 834 AN ACT CONCERNING SERVICES FOR PERSONS WITH SMITH-MAGENIS SYNDROME.](#) Please contact Krista Ostaszewski, DDS Director of Legislative Affairs at (860) 418-6066 with additional questions.