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**Testimony to the Public Health Committee on Raised SB 294 - AN ACT CONCERNING
SERVICES FOR INDIVIDUALS WITH INTELLECTURAL DISABILITY
March 2, 2016**

I would like to thank you, Senator Gerrantana, Representative Ritter and members of the Public Health Committee for Raising SB 294, and I would like to thank the Co-Chairs the opportunity to speak **in favor of Raised SB 294 – An Act Concerning Services For Individuals with Intellectual Disability**. My husband and I live in Tolland with our 29 year old son, Scott, who receives employment services from the Department of Developmental Services (DDS). Our family was one of the fortunate Wait List Initiative families that qualified for residential funding in April 2014. However, more than 2,000 families are languishing on the DDS Waiting List for Residential Services and now there are more than 100 individuals on a Waiting List for Day/Employment Services.

SB 294 is critically important for all families requesting and waiting for any type of service from DDS because it will clarify their family member's status for funding, in writing, and in a timely manner. However, there are some sections of this bill that should be revised for clarification and completeness.

- **Section 1 (3) Definition of "Waiting List":**

This definition should be amended as follows:

"Waiting List means a list maintained by the department that includes the names of individuals with intellectual disability who have requested residential, day support, or any other services from the department, and have either not received or received insufficient services. The department shall maintain separate lists for each service."

- **Section 1 (5) Definition of "Priority Status":**

This definition should be amended as follows:

"Priority status" means the code assigned to an individual with intellectual disability for whom services from the department have been requested that identifies the level of urgency of the individual's need for services for purposes of any waiting list maintained by the department."

- **Section 1 (5) (c) (1)** This section concerns notification from DDS to individuals and their families about priority status and funding.

This section should be amended as follows:

“Not later than September 30, 2016, and annually thereafter, the commissioner shall notify, in writing, each individual with intellectual disability who is receiving services from the department, and the individual's parent, conservator, guardian or other legal representative of the individual's priority status and the amount of funding budgeted for each service provided by the department. Beginning September 30, 2017, the annual notification shall include the individual's up-to-date level of need assessment.”

- **Section 1 (5) (d) (1)** This section concerns the frequency with which waiting lists should be updated. The residential waiting list is currently updated quarterly in the Commissioner's Management Information Report (MIR).

This subsection, calling for the waiting list to be updated once every three years, would be a step backward, and should be eliminated.

- **Addition of Section 1 (5) (f)** DDS hearings are secretive proceedings. Families receive decisions with no rationale, and when they seek documentation of the decision, they cannot get them - even documents related solely to their own family member. Rationale for decisions by DDS should be required.

(add new) Section 1 (5) (f) “Upon the request of any individual that has requested services or supports from the department, the department shall provide copies of any document used by the department that in whole or in part formed the basis for the department's decision. Documents shall be provided in accordance with HIPAA, but HIPAA shall not be used to deny access to the individual's own records.”

- **Section 2**

Recommendation: The list of Stakeholders should be amended to include "individuals and families of individuals on the DDS residential waiting list".