

*Ronald O. Langner, Ph.D.
80 Barstow Lane
Tolland, CT*

**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**. I live in Tolland with my wife and adult son, who is a client of the Department of Developmental Services (DDS). Shortly after my Son turned 21 he expressed a desire to move into his own apartment like his older brother and sister had (he is now 29 and still living at home). We were told at that time that monies for residential support were not available and that he would be placed on a waiting list for residential services. After a while, my wife and I realized that we really did not know the full meaning of what it meant to be placed on the “waiting list”. In order to gain some understanding we committed to attending several meetings and seminars given by agencies other than DDS. This was a time consuming process and is something I could not have done were I not retired. This is something families should not have to do in order to understand what and when services are available from DDS.

SB 294 is important bill since it will clarify the status of their family member’s eligibility for funding, in writing, and in a timely manner. However, there are some sections of this bill that should be considered for revision. The following suggested revisions would help bill SB294 to accomplish it’s purpose of informing families.

- **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".

