

I am unable to present testimony in person on Wednesday and ask you to consider my comments and suggestions regarding SB 294:

1. Section 1 (3)

The waiting lists for residential, day, and anything else should not be combined, but should be maintained separately. As drafted, there will be only one, unified list; and the use of the word "urgent" is both confusing and too limited. Currently, the department uses a Waiting List definition that includes people who need services immediately and within 1 year (Es and P1s)—even though people often do not get services within 1 year.

DDS and everyone else uses the term "emergency." If "urgent" and "emergency" are the same thing, then there is no point in changing the term. It just creates confusion.

Limiting the List to either the proposed "urgent" definition (or emergency) will reduce the Waiting List to Es only. This will dramatically understate the Waiting List problem and the Waiting List virtually disappears if it is only Es.

Please consider the following wording:

"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."

2. Section 1 (5) Definition of "priority status": I am not sure what the purpose of this definition is, unless it relates to priority status on the waiting list. I think it should be amended to clarify that point.

I recommend an amended definition of "priority status" 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."

3. Section 1 (5) (c) (1): The notice in this section should be provided annually, not just one time. Families should be informed of their status annually.

Please consider an amended section as follows:

"Section 1 (5) (c)(1) 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."

4. Section 1 (5) (d): I believe this subsection, calling for the waiting list to be updated once every three years, would be a step backward, and should be eliminated.

5. I have heard repeatedly that DDS hearings are secretive proceedings. Families receive decisions with no rationale, and when they seek documentation of the decision, they can't get then, not even documents related solely to their own family member. I am aware that The Arc CT submitted language to address this which did not find its way into the bill. I think it should be in there, in a new section:

(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.

6. Section 2: The list of Stakeholders should be amended to include "individuals and families of individuals on the DDS residential waiting list".

7. Section 3: I am not sure what section 3 is about or how it helps families. I am confused as to why it includes DMHAS. DDS does give notice and they include appeal rights.

Thank you for considering my concerns and suggestions for changes.

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