

March 1, 2016

Testimony of Michelle Rivelli, M.D., F.A.A.P. to the Committee on Public Health

I am writing IN FAVOR (WITH RECOMMENDED IMPORTANT CHANGES DISCUSSED BELOW) of Raised Senate Bill 294--AN ACT CONCERNING SERVICES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY

As the parent of a 21 year old daughter with autism and intellectual disability, and as a pediatrician caring for many young adults with disabilities, this bill is a much needed step to ensure that families can clearly navigate the too often convoluted, unclear, and vague protocols of the Department of Developmental Services. This bill requires that the DDS decision making process (which currently does not allow family input for major funding decisions about their loved ones) be more accountable and consistent.

In my own daughter's case, we have no idea if and when she will receive day program funding after she graduates from the educational system in June. We will not even be given this information by DDS until late in June. This is truly cruel and tragic, as all of the work that has gone into her transition and all of the money spent on her current services in the educational system are at risk if she loses skills and develops behavioral problems due to a lack of consistency and predictability in her life.

I do have several concerns about the text of SB 294 which I will explain below:

SECTION 1 (3) THE DEFINITION OF "WAITING LIST": It is important that the waiting lists are not combined. The list should not be limited to "urgent/emergency" only as this understates the "true need" and is not helpful for public policy and planning. I would suggest redefinition 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 of each service."*

SECTION 1 (5) DEFINITION OF "PRIORITY STATUS": This section needs to clarify that "priority status" is *"for purposes of any waiting list maintained by the department"*.

SECTION 1 (5) (c) (1) This notice needs to be done not once but annually. Add to not later than Sept 30, 2016, *"and annually thereafter"....and then include "Beginning Sept 30, 2017, the annual notification shall include the individual's up-to-date level of need assessment"*.

SECTION 1 (5) (d) The waiting list needs to continue to be updated quarterly not once every 3 years as this section states.

SUGGESTED NEW SECTION 1 (5) (f) Families are not currently able to participate in nor receive accurate information from the PRAT process (which decides in a closed process if and what funds the individual will receive) I would like a section added that the department is *"required to provide copies of documents used for the decision process"*

SECTION 2 The list of stakeholders needs to be amended to include *"individuals and families of individuals enrolled in DDS"*

I hope this committee and the entire state legislature understand the importance of this bill and the changes noted above. Unless you are an individual with a disability or the guardian of an individual with a disability in the state of Connecticut, you would have no idea of the incredible difficulty families have getting information about needed services from the Department of Developmental Services. I applaud you for raising this bill and encourage you to see it to its passage. Our developmentally disabled citizens and their caregivers deserve no less.

Sincerely,
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