

Thank you for the opportunity to testify on this bill, Raised Bill No. 294 An Act Concerning Individuals with Intellectual Disability, which I **support** with suggestions respectfully added for amendments and additions.

Thank you, Senator Gerratana and Representative Ritter and members of the Public Health Committee for this Bill.

Why this Bill matters to me ...

I am the single (adoptive) mother, 65, of 4 adult sons eligible for DDS services. I am also their Legal Guardian.

1. Edward, 52, severely autistic with ID, lived at the New Haven Regional Center prior to his adoption. More recently, he had to live at the Northwest Regional Center while awaiting placement in his current group home of 5 men with round-the-clock staffing in Waterbury. He attends a day program in Cheshire.

2. Jamie, 42, severely autistic with ID and severe behavioral challenges, lived in a hospital prior to this adoption, where he faced eventual transfer to Bellevue. As an adult, he lived at the Northwest Regional Center while waiting for years for his current placement in a community living arrangement of 3 men with round-the-clock staffing in Wolcott. He attends a day program in Waterbury with a 1-to-1 staff due to his behavioral challenges.

3. Adam, 32, quadriplegic due to cerebral palsy, blind, profoundly ID, fed by G-tube, wheelchair, lived in a hospital prior to his adoption. For the past 10 years he has lived in his ICF group home in Winsted with round-the-clock nursing and attends a nearby day program.

4. Patrick, 34, quadriplegic due to cerebral palsy, blind, ID, epilepsy, G-tube, J-tube, central IV port, trach, oxygen, requires round-the-clock nursing. He was adopted when he faced institutionalization at age 2. His recent situation is well known to many legislators. When I lost all but 14 hours a week of homecare nursing in October with no available replacement, requiring me to personally cover 150 hours a week of his care (there are only 164 hours in a week), the DDS PRAT team would incredibly not reclassify Patrick from P1 to an Emergency for residential placement funds. Yet his medical needs were considered of such a magnitude that a skilled nursing facility with a respiratory unit stated that it would not be able to adequately provide for Patrick's care, and his needs were also urgent enough that Hospital for Special Care admitted him in November to a hospital room in their Respiratory Step Down Unit, providing round the clock nursing and respiratory therapists. This is only an interim placement, however, and not meeting Patrick's other non-medical needs. He is still on the DDS residential waiting list, P1, in need of a residential placement in the community with round the clock nursing. He has been on the residential wait list for about 15 years.

A note about Language in the Bill -

Please note that while most adult individuals with ID (and all of my 4 sons) have a legal representative (parent, guardian, conservator), not every one does. There are some adult individuals with ID, functioning much higher than my sons, who act on their own

behalf and give consent on their own behalf. This must be included in language throughout this document, i.e. "individuals with ID or their parent, guardian, conservator or other legal representative."

Please make amendments to other language in the Bill-

Section 1.

(2) "Commissioner" means the Commissioner of Developmental Services;

AMEND: Commissioner means the Commissioner of Developmental Services or the Commissioner's designated DDS representative

(3) "Waiting list" means a list maintained by the commissioner that includes the names of individuals with intellectual disability who (A) have requested residential or day support services from the department, and (B) the commissioner has determined to be in urgent need for the services requested.

Amended definition of Waiting List-

Waiting List means a list maintained by DDS including the names of all eligible individuals who have requested, or whose parent, guardian, conservator or other legal representative has requested on their behalf, any DDS supports/services and are determined by DDS to have a current or future need for said support/services. These individuals have not received said supports/services or have received only partial, insufficient, interim or temporary supports/services.

DDS shall maintain separate waiting lists for Residential supports/placements, Day supports, in-home supports, respite services, and any other DDS services.

Note:

It is crucial that the word URGENT be removed.

DDS currently categorizes those on the waiting lists as Emergency, Priority 1 (P1), Priority 2 (P2) and Priority 3 (P3), not as "urgent." Only an extremely small minority of those on DDS waiting lists are currently considered Emergency by DDS, yet many on the P1 lists have urgent needs by any reasonable standard (like my son Patrick). Everyone else on the waiting lists who is not Urgent (i.e. Emergency) would be dropped !

(4) "Level of need assessment" means the department's method, using any standardized assessment or screening tool, to (A) determine the level of services from the department that an individual with intellectual disability requires for the management of the individual's behavior, health condition and to complete activities of daily living, as

defined in section 19a-693 of the general statutes, (B) determine an individual's priority status, and (C) assign an individual an estimated funding amount for services.

My Question:

If an individual doesn't need services until say 5 years from now, is the estimated funding amount for services going to be in "today's" dollars, or an estimate of what it will cost 5 years from now when the service is actually needed?

Also, there shouldn't be one lump sum estimate for a person's services. If they need more than one service, then each service should be line itemed. For example, there should be a separate amount for day services and for residential services.

(5) "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.

It used to mean that P1 should be placed in a year, P2 in 2 years, P3 in 3 years, but this is no longer the case. What, in fact, do these status designations actually mean???

Individuals and their parents/guardians/conservators/legal representatives have a right to be told, in writing, exactly what their designation MEANS. What exactly does it mean to be a P1, P2 or a P3???

(c) (1) Not later than September 30, 2016, 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.

Initial notification to each served AND UNSERVED person should be not later than Sept.30, 2016, AND THEN ANNUALLY THEREAFTER.

Additional written notice shall be given whenever there is a change in the individual's service(s) or budgeted amount.

If an individual is on a wait list, the service should still be listed with a budgeted amount of \$0, with an estimated start date.

For an individual who receives, or requested to receive, more than one service, each must be line- itemed separately.

(d) (1) On and after July 1, 2017, the commissioner shall update the waiting list not less than once every three years.

The residential waiting list is currently updated quarterly in the Commissioner's Management Information Report (MIR). This should be continued. Changing this to updating every 3 years would be counterproductive in planning and in keeping individuals and their representatives apprised of their situation, and a big step backward.

(2) The commissioner or any other department employee shall not remove, from the waiting list, the name of any individual with intellectual disability who is receiving services from a private entity or a state agency for the individual's intellectual disability without the written consent of the individual's parent, conservator, guardian or other legal representative.

ADD:

Individuals with ID whose names were removed from the residential wait list due to the acceptance of in-home supports shall be added back onto the residential wait list until such time as the individual with ID or the individual's parent, guardian, conservator or other legal representative requests or agrees to removal, in writing.

Sec. 2. Section 23 of public act 15-1 :

The list of Stakeholders should be amended to ALSO include:

-individuals and parents/guardians of individuals on the DDS residential waiting list who are emergency and/or P1 status,

(since they have a higher stake in this than those with P2 or P3)

-representation from CT DDS Families First , and

-private provider agencies providing DDS-funded residential services

Regarding the residential wait list -

It is essential for an up-to-date wait list to be kept. For it to be meaningful, it must be totally re-assessed, re-built from scratch. Currently, there are persons on the residential wait list whose needs or desires or whose caregiver's situations have changed. It would be impossible for DDS or legislators to plan for persons on the residential wait list without knowing what services are desired or when.

Each individual on any residential wait list or on the "other" "served" residential wait list (where DDS placed names of some persons who accepted in-home supports, usually without their knowledge) , or his/her parent, guardian, conservator or legal representative must be contacted by DDS by Sept. 30, 2015 and asked exactly what kind of residential support or placement is desired, and when. This information must be put in writing and signed by the individual or individual's representative.

Survey Information for each individual with ID, less names or other identifying information, shall be listed in a written report and made available to the legislature for planning purposes.

Why keep someone a P1 status who isn't even interested in placement for another 10 years?

Some persons need only minimal support to live almost independently in an apartment, while others require round the clock care including nursing.

Some persons would like to live in an apartment, alone or with a room mate. Others would like to live in a community living arrangement of 2 or 3 persons with staff. Others would like to live in a family situation. Still others in a group home.

Does DDS even know what each individual wants and needs? How can planning (whether long term or short term) be done without this information?

These are substantially different in cost for DDS or the legislature which must construct budgets. An estimated amount required for services, as mentioned in Section 1 (4) of this Bill, could not be obtained without obtaining the information discussed here.

Please add language to this Bill about the RACs -

BACKGROUND INFORMATION:

An important addition to this bill should be a section regarding the DDS Regional Advisory and Planning Councils known as RACs .

According to the DDS website "The Regional Advisory and Planning Councils are responsible for consulting and advising the Regional Director on the needs of persons with intellectual disability within the region. The councils engage in education and advocacy and fosters communication between advisory groups, individuals, family members, local citizens and organizations. Members include parents, consumers, a practicing attorney and individuals designated by the local association for persons with intellectual disability."

RAC meetings are intended to give individuals with ID and their families the opportunity to present their needs, issues, questions, etc. Unfortunately only a very small minority of individuals with ID and their family members have ever even heard of the existence of the RACs and therefore have never attended or participated in a meeting, nor applied to become a member, even at a time when not all RACs have a filled slate of members or a quorum at all meetings. The RACs are not even well known among extremely involved parents who frequently advocate for their family members. Most who do hear about the RACS hear of it by word-of-mouth from other families, not from DDS.

Amendment Language to be added about the RACS -

An individual with ID or his/her parent/guardian/conservator/other legal representative shall be notified in writing about the RACs at least once yearly. This written information shall include a description of the RACs and their purpose, which one of the regions of the RAC the individual is located in, whom to contact for additional information about the RACs, and how the individual can obtain a schedule of RAC meetings.

Please add language to this Bill about PRAT-

BACKGROUND INFORMATION:

Another important addition to this bill should be a section regarding the DDS regional Planning and Resource Allocation Teams known as PRAT.

When an individual with ID and families/guardians/conservators/legal representatives request DDS supports/services such as a residential placement, day program, in-home supports, or a change in status on the wait list (ex: a request to be changed from P1 to Emergency), the DDS case worker and/or supervisor submits that requests to PRAT.

Individuals with ID and family members/guardians/conservators/legal representatives do not participate in writing the request, do not see the request, and do not sign the request to validate the information contained in it.

PRAT meetings are considered by families to be secretive. Individuals with ID and families/guardians/conservators/legal representatives are normally forbidden to attend. They are unable to contribute important information, answer questions, or hear discussions while their request for supports/services/change in status is being discussed. In fact, even the DDS case worker who is familiar with the case apparently isn't normally in attendance. So what we have is a system in which those least familiar with a case take as little as 15 minutes to decide the fate of an urgent request. Afterwards, individuals with ID and family members receive no verbal or written information regarding what transpired. It is difficult to even find out from a DDS case worker whether the request that went into the PRAT meeting was granted or denied. Eventually down the road, one learns whether it was granted or denied, in just a word (Yes or No) , with denials given no substantiating reasoning by anyone in DDS. Imagine schools having PPT meetings to decide the fate of students, without allowing the student (if able) or families to participate in the process, then eventually, in their own good time, letting them know in one word (Yes or No) whether or not they would receive services, with no written documentation.

Amendment language to be added about PRAT -

Individuals or their parent/guardian/conservator/or other legal representative should be given the following rights regarding regional Planning and Resource Allocation teams:

- 1. Individuals or their parent/guardian/conservator/ or other legal representatives will see all information being submitted to PRAT regarding their case, and will sign and indicate their agreement or disagreement with said information. They shall receive a copy of this information. Regardless of whether they sign that they agree or that they disagree, they may attach additional written information to be submitted to, and considered by PRAT.**
- 2. Individuals or their parent/guardian/conservator/ or other legal representatives shall be invited to their PRAT meetings to participate in discussion of their case, and may request that their DDS case worker be invited.**
- 3. Within one calendar week, PRAT shall send by registered mail a written summary of the proceedings to the individual or his/her parent/guardian/conservator or other legal representative. The summary shall include minutes of the meeting and a) whether the request was approved with detailed information about the service approved and any implications of acceptance, or b) whether the request was denied with detailed information about what this decision was based on including any supportive documentation. The PRAT mailing shall also include written instructions for requesting an appeal to the next level, and contact information if the individual or legal representative needs assistance requesting an appeal.**

Thank you very much for taking the time to review and consider my testimony.

Sincerely yours,
Sue Bastien