

Testimony of Shelagh McClure, Chair
Connecticut Council on Developmental Disabilities
Before the Public Health Committee
On Raised Bill 294
March 3, 2016
Submitted to: phtestimony@cga.ct.gov

Senator Gerrantana, Representative Ritter, members of the committee.
Thank you for the opportunity to present testimony in support of **Raised Bill 294, AAC Services for Individuals with Intellectual Disability.**

I am Chair of the Connecticut Council on Developmental Disabilities, a public agency whose mission is to promote independence and full inclusion of individuals with developmental disabilities in their communities, and to foster capacity building and system change. I am also the parent of a 25-year old son with an intellectual disability who lives at home with my husband and me.

First and foremost, the Council thanks you for this bill. It contains a number of important proposals affecting the Department of Developmental Services (DDS) that we support:

Section 1: We support the proposals in section 1 that would positively affect DDS proceedings: ensuring that individuals with I/DD and their families are apprised of basic information about their status with DDS; ensuring that the individual's status on the waiting list will be subject to clear rules that are communicated to individuals and their families; and that the notice of any funding decision will be in writing and will include such information so that individuals and their families know the full consequence of acceptance or rejection of funding.

Each of these proposals is important and comes from real life examples, told to advocates and legislators, by families—who made a decision to accept interim support while they awaited a full solution to their residential services request, and later found out that they had been moved off the waiting list; or who hesitated in making a decision only to find out when they called their case worker that they were “too late” and the promised funding was no longer available. The proposals would ensure that families would not be blindsided in the future about their status on the waiting list or the consequences of their decisions.

Although we are supportive, the Council believes that section 1 of the bill could be strengthened if the following changes are made. First, we believe that the proposed definition of “waiting list” in section 1(a)(3) is too narrow, especially in its limitation in subsection 1(a)(3)(B) to those “in urgent need for the services requested.” By adopting the proposed definition, it would dramatically understate the waiting list problem, as demonstrated by the following figures from the DDS December Management Information Report (December MIR).

http://www.ct.gov/dds/lib/dds/mir/master_december_2015.pdf.

According to the December MIR, the DDS waiting list (including the other residential needs list) includes individuals with the following designations: (1) Emergency—individuals who need services immediately because their own life or health, or the life or health of their current caretaker, is threatened or the caretaker becomes unavailable due to illness or death; and (2) Priority 1 –those who need services within 1 year. In the December MIR, there were 32 individuals with the Emergency designation, and 899 individuals were on the Priority 1 list—931 in all. DDS also maintains what it calls a “planning list” which includes individuals who have requested assistance with residential services, but do not need services in the next year. In December, there were 1148 people on the DDS planning list. To be clear, when advocates refer to the “waiting list”, they generally are referring to all 2047 individuals on the DDS waiting and planning lists.

If the proposed “waiting list” definition from RB 294 were adopted, the waiting list would precipitously drop in number to just those on the current Emergency list—32 people. What public policy is served by defining the waiting list to this small number, when we know that so many people are currently and critically waiting for residential services? Many of those that have come to the Capitol and testified on family hearing days of their desperate need for help are not on the DDS Emergency list, but rather are family members of individuals who have been, for many years, on the Priority 1 waiting list. No definition of waiting list for residential services should exclude those now designated as Priority 1.

The Council also notes that DDS is not currently reporting on the waiting list for day and employment services, or on any other waiting list DDS currently maintains—for example for respite services. We do not believe it would be a hardship for DDS to maintain and report on the waiting list for such services. It would allow the General Assembly to have a greater understanding of whether the service needs of those with I/DD in this state are being met.

The Council proposes the following as an alternative definition for “waiting list” to include all waiting lists maintained by the department:

(3) "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.

The Council also believes that the definition of "priority status" in section 1(a)(5) could be improved by clarifying that the purpose of the assignment of priority status is for the purpose of any waiting list maintained by the department:

(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 for purposes of any waiting list maintained by the department.

Section 1(c) provides for a one-time notification to families of the priority status and funding budget of their family member served by DDS not later than September 30, 2016. We agree that this is needed, but believe that this notification should occur annually, and should include the individual's Level of Need scores. We respectfully suggest that section 1(c) would be improved if it were amended to require annual notices.

Section 1(d) would require the Commissioner to update the waiting list once every three years. Currently, waiting list information is included in the Commissioner's Management Information Report (MIR), which is a quarterly report, so the list is updated 4 times a year. The Council is concerned that the new provision is a step backward from current practice. Accordingly, if the legislature decides set a statutory minimum for updating the waiting list that does not reflect current practice, the Council believes that it should be no less frequently than once a year.

Section 2: In section 2 of the bill, the DD Council thanks the Committee for naming the Council as a stakeholder in the process, passed in the 2015 December special session, for developing a plan to implement the closure of the State operated facilities, including Southbury Training School and the regional centers. The Council has committed significant resources to the 2020 Campaign to close state operated institutions, and has research and expertise that we look forward to sharing with the Secretary of the Office of Policy and Management.

The Council has one suggested amendment for section 2 of the bill: the list of stakeholders should be amended to include "individuals and family

members of individuals on the DDS residential waiting list.” Individuals who are denied residential services due to DDS’ lack of resources must be allowed to present their views on institutional closure—they have as much, if not more, at stake as any other stakeholder listed in the bill in the outcome of the plan and the savings that should accrue from the closure of the state operated facilities.

Section 3:

The Council has attempted to learn what the purpose of section 3 is, and we have not been successful. We are not aware of what circumstance are covered by this provision, and are asking the committee for clarification in the language of the bill.

Thank you for the opportunity to present this testimony.