



State of Connecticut
Department of Developmental Services

DDS

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**DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY
BEFORE THE PUBLIC HEALTH COMMITTEE**

March 2, 2016

Good morning Senator Gerratana, Representative Ritter, Senator Markley, Representative Srinivasan and members of the Public Health Committee. I am Morna Murray, Commissioner of the Department of Developmental Services (DDS) and I appreciate the opportunity to comment on **S.B. No. 294 AN ACT CONCERNING SERVICES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY.**

Section 1 of the bill focuses on concerns that have been expressed by some families regarding communication from DDS on status for funding and services by requiring DDS to share detailed information regularly in writing and in some cases, via certified mail.

First and foremost, I do appreciate the frustration of families regarding a perceived lack of information. The DDS system of supports is large and multi-layered, but the department works extremely hard to do as much as we can for as many individuals and their families as possible within available resources. At the outset, and with great appreciation for families' concerns, we must be cautious about legislation that may inadvertently create unforeseen and unnecessary administrative burdens which could interfere with our staff's ability to focus on services and supports for as many individuals as possible. We must also be cautious about sharing protected health information concerning individuals supported by DDS with those not legally entitled to this information.

I would like to explain the information that DDS does share with individuals and families. There are many processes currently in place that directly address a great number of the issues raised by the proposed legislation. Below please find brief summaries of how this information is distributed for both individuals who receive annualized funding for services and supports, and for those who do not receive annualized funding for services and supports. In addition, please find attached the following forms and notices, referenced throughout this document:

- **Attachment A:** [Sample DDS Level of Need \(LON\) assessment and LON summary](#)
- **Attachment B:** [Sample DDS person-centered Individual Plan \(IP\)](#)
- **Attachment C:** [Sample DDS Priority Status Notification](#)
- **Attachment D:** [Sample DDS Termination of Funding Letters \(First, Second and Final\)](#)

For individuals receiving annualized funding for services, individuals and families receive information on an annual basis. A LON assessment is done annually prior to an IP being written for each individual. An IP is done for:

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1. All individuals who receive services or supports through a DDS Home and Community Based Services (HCBS) Waiver,
2. all children in the Behavioral Services Program,
3. all individuals who receive any DDS funded residential supports, including individualized home supports, and
4. individuals who pay directly for residential habilitative services.

There is an annual planning process, in which the individual's planning and support team reviews the individual's LON and IP. The LON reflects the individual's strengths and needs. The LON also includes a record of the individual's annualized funding amount. The IP contains the goals, supports, and services for the individual for the year. The IP also includes a record of the individual's priority status.

Thirty days before the annual meeting, the case manager sends the individual's existing LON to the team. The team then reviews and updates the existing LON. Any changes are communicated to the case manager, who makes said changes and brings an updated LON assessment and LON summary for distribution at the annual meeting. This updated LON is the basis for discussion about the individual's IP at the annual meeting. At this meeting, the individual's team reviews each section of the IP and recommends changes, with a particular focus on any changes in the LON. At the end of the IP meeting, the case manager documents the participants in the planning process and obtains their signatures on a signature sheet. The form states that the individual, parent, guardian or advocate should contact the individual's case manager in writing if they do not agree with the plan as written. The case manager then has 30 days following the meeting to update the IP and send to the individual's team.

For individuals who do not receive annualized funding for services, individuals and families can receive information through the DDS Regional Helpline. Helpline staff are case managers who can provide information on how to apply for limited DDS Family Support Services, or to refer them to appropriate community resources and services. If they make a request for a service and are granted the service, they are assigned a case manager and follow the annual process outlined above. If the individual is denied a service, notification of priority status occurs at that time. These individuals would not have an IP and may have a LON if they have asked for priority status or for the purposes of planning.

I will now address each specific section of the proposed bill. To begin, the definitions in the raised bill are problematic in that they do not directly mirror current definitions in agency policies and procedures. It would be confusing at best to introduce a new version of definitions for some of these common terms within the DDS system. For example, the waiting list that individuals are most familiar with is a residential waiting list. To add in day supports to this conversation would cause unnecessary confusion. DDS does maintain a separate day services waiting list.

As to the requirements proposed in the bill, section 1(b) requires that a copy of the LON assessment be provided to multiple parties including the individual's parent, conservator, guardian or other legal representative. As described above, this information is shared with the individual or the legal guardian on an annual basis for individuals receiving annualized funding for supports and services. Confidentiality of protected health information is a requirement for DDS, as it is for many human service agencies. While many individuals supported by DDS have a legal guardian, not all do. The legislation seems to require that information be shared with multiple persons without addressing whether or not the persons listed are legally entitled to the information. Any requirements that DDS share the type of information outlined in the bill would have to be carefully analyzed so that such requirement would not violate any HIPAA restrictions on the sharing of protected health information.

Section 1 (c) (1) and (2) would require notification of an individual's priority status and the amount of funding budgeted for each service provided by DDS. These provisions are currently in practice at DDS. If an individual has an IP their priority status is listed therein. If there is a change to their priority status, they are also notified in writing, although not by certified mail. Of note, there would be a cost associated with requiring documents to be sent by certified mail which according to the USPS Certified Mail Rates, appears to be \$4.69 per 1-ounce letter. The confidentiality issues noted previously are also applicable to this section.

Section 1(d) focuses on DDS waiting lists, however, as written, it appears the intent of this section is the residential waiting list. Section 1(d)(1) requires an update of the waiting list at least every three years. DDS maintains a [Management Information Report \(MIR\)](#) which contains information about the residential needs of individuals, is updated quarterly and is available on the DDS website.

Section 1(d)(2) states that an individual cannot be removed from the waiting list without permission from the individual or other legal representative. This restriction would be unnecessary. If funding is allocated and the individual's needs are met, the individual is considered "placed" in the Planning and Resource Allocation Team (PRAT) database, once services begin. An individual can become activated on the Other Residential Needs List (ORN) at any time the individual has a new unmet need.

Section 1(d)(3) requires a written request to the Commissioner in order to remove an individual's name from the waiting list. The request must include a clear acknowledgement of the consequences of removing the individual's name. Removal from the residential waiting list occurs only if (1) an individual's residential needs are fully met, or (2) if an individual's residential needs are partially met through an allocation of more than \$20,000 at which time they are moved to the ORN List. Individuals on the ORN list still have a prioritization as Emergency or Priority 1 for the additional supports that they need. In FY15, DDS successfully met the needs of 134 individuals (33 Emergency and 101 Priority 1) who were on the ORN list.

DDS understands that the current waiting list definitions may be confusing. In an effort to address this, DDS initiated a project to review current residential waiting list and planning list definitions in order to ensure that the criteria and data is clear to all stakeholders. The Arc-CT and a family representative have been invited to participate with DDS on this project. The current residential needs data as of December 31, 2015 is as follows:

Residential Waiting List: 18 Emergency and 645 Priority 1 for a total of 663

Other Residential Needs List: 14 Emergency and 254 Priority 1 for a total of 268

Residential Planning List: 883 Priority 2 and 265 Priority 3 for a total of 1148

In FY 2015, 163 individuals came off the residential waiting list including 83 with funding from the waiting list initiative for individuals with elderly caregivers and 80 who did not receive funding from this initiative. To date, 117 individuals have begun residential supports and five additional individuals have plans to start this fiscal year (FY16), with funding from the waiting list initiative for individuals with elderly caregivers.

Section 1(e) of the bill requires that whenever funding for services is offered, it must be done in writing with notice of an explicit deadline for acceptance or rejection of said funding, and an explanation of the consequences of accepting or rejecting such offer including the individual's right to receive additional services or maintain his or her place on the waiting list. DDS has concerns about the administration of this provision and its potential unintended consequences for families. Establishing hard deadlines would likely limit flexibility and creativity of individuals, families, and providers in developing supports within

the person-centered system of planning that DDS utilizes. DDS looks at how to best meet the individualized needs as part of person-centered planning. There are multiple choices available to individuals including the choice of residential services, choice of provider, timing of services, etc. All these decisions affect what funding may be required for these individualized services and when the funding is needed. DDS believes that creating appropriate services and supports for individuals within this highly individualized and person-centered model requires fluidity and flexibility to maintain the focus on what is best for each individual.

As stated previously, DDS is a complex and multi-layered system. But ultimately, we are all working toward the same goals as individuals, family members, guardians, providers, advocates and other stakeholders, to ensure that the best supports and services are provided to as many individuals with intellectual disability as possible. We truly value the important role that all stakeholders have in each aspect of service delivery and DDS will continue to work on improving consistency in the various avenues of communication available to us. We caution legislators not to impose unrealistic or unnecessary administrative burdens on the department that could unintentionally hinder the important work that we are all trying to accomplish.

Section 2 of the bill would replace language from Section 23 of Public Act 15-1 of the December Special Session, and requires outreach to stakeholders for the report on a plan to implement the closure of facilities operated by DDS. This provision is not necessary since the Office of Policy and Management intends to consult with stakeholders.

The purpose of section 3 is unclear as written. Section 17a-218(g) of the Connecticut General Statutes already requires “any person who is in or is seeking a placement through the Department of Developmental Services or is receiving any support or service that is included within or covered by any federal program being administered and operated by the Department of Social Services and the Department of Developmental Services, and who meets the eligibility criteria for the federal program, shall enroll in such program in order to continue in the existing placement or to remain eligible for a placement or continue to receive such support or service.” DDS works closely with Department of Social Services (DSS) staff regarding Medicaid eligibility and redeterminations. Three DSS staff are located within DDS’s central office and are specifically dedicated to assisting DDS staff, individuals and providers with initial eligibility, waiver enrollment, redeterminations, and special projects. These DSS staff act as liaisons with DDS central and regional offices to resolve specific Medicaid issues or any problems that DDS consumers may have.

Specific notices (see **Attachment D: [Sample DDS Termination of Funding Letters](#)** (First, Second and Final)) are given to individuals and families who are not compliant with section 17a-218(g) CGS. Failure to comply with the request to contact the case manager and complete the waiver enrollment process results in a case review which may lead to termination of DDS funding for supports and services. Non-compliance with waiver requirements on the part of some individuals is not fair to the number of people waiting for funding for services. With the final notice indicating that termination of supports will occur, individuals are notified of the right to appeal the decision through the Fair Hearing Process at DSS. Finally, it would not be appropriate for DDS to assist in the identification and securing of private funding for care or services for someone who has not complied with Section 17a-218(g) CGS.

Thank you again for the opportunity to testify on **[S.B. No. 294](#)**. I would be happy to answer any questions you have at this time. You may also contact Christine Pollio Cooney, DDS Director of Legislative and Executive Affairs at (860) 418-6066 with additional questions.