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Re: Testimony in favor of LD 1606, Data Collection and Major Substantive Rulemaking for the Lifespan Waiver

Dear Senator Ingwersen, Representative Meyer, and Members of the Joint Standing Committee on Health and Human Services:

I am writing to express my support of LD 1606. I believe that Legislative oversight should be expanded and preserved as the Lifespan waiver is implemented. I also believe that there are serious deficiencies in the way information about unmet needs and a person's transition to adult services is communicated to the HHS committee and to the general public. LD 1606 seeks to redress these shortcomings.

I am writing in my capacity solely as a single member of the Maine Developmental Services Oversight and Advisory Board. I am not speaking for anyone but myself.

As 34-B MRS §5003-A is now written regulations pertaining to the Lifespan Waiver start out as major substantive but then become routine technical for any amendments. The Lifespan Waiver will be a major overhaul of the way that services are delivered, potentially to the five thousand or more current recipients of the Section 21 and Section 29 waivers and certainly for new people wishing to obtain waiver services. As I currently understand the Lifespan proposal, people now receiving Section 21 and Section 29 services may opt into the Lifespan Waiver. Any regulations governing the Lifespan Waiver are certain to be lengthy. Given that the current Ch. II and Ch. III regulations for Section 21 and Section 29 both exceed seventy pages, the Lifespan Waiver regulations can be expected to be at least the same length. Amendments, at least in the way the public understands the words "major substantive" as opposed to "routine technical" are likely *not* to be routine or technical.

The prior administration attempted to use the Supports Intensity Scale ("SIS") as a resource allocation tool. That attempt, and the way the SIS was implemented, sparked a petition for review under the Maine Administrative Procedures Act. That review in turn resulted in the HHS committee holding a contentious hearing with many participants, which then led to the Department abandoning the SIS as a resource allocation tool. Waivers are so comprehensive in terms of their impact upon so many facets of a recipient's life, as well as the lives of the families who are caregivers and guardians, that invariably the rules governing a waiver are very complex. It would be far better to acknowledge that complexity at the outset, which the current law does, but instead of having new amendments be the trigger for routine technical review, I recommend at least a few years operation of the Lifespan to find out if later amendments may really be deemed "routine technical."

Many of the people interested in Waiver services now and who in the future will be receiving the Lifespan Waiver are fervent in their desire to protect themselves and their loved ones. Most have experienced the challenges of managing their way through the special education system. Both recipients themselves and their loved ones tend not to be shy about regulatory changes that may affect the quality of their life or the quality of a loved one's life. In order to avoid future petitions to ask the HHS committee to review the Lifespan regulation I hope that LD 1606 will become law and thus legally enable the possibility review of amendments by the Committee.

Regarding paragraph two, the data collection portion of LD 1606, unfortunately the Department of Health and Human Services and the Department of Education do not have a good track record of complying with laws pertaining to the collection and transmission of data to the Legislature and to the public. In my testimony pertaining to LD 1634 I have addressed the fact that the DOE and the DHHS have **never** submitted the report on transition to adult services required by 20-A MRS §7258(1-B). I attached a copy of 20-A §7258 to my testimony in favor of LD 1634. As I explained in that testimony, there is strong, specific statutory language that requires the DHHS to work with the DOE to keep the Legislature informed about the transitions to adult services for persons who are waitlisted. Transition appears to be one of the primary motivators for DHHS to pursue the Lifespan Waiver. That desire is laudable, but the track record of never having filed the report required by §7258 justifies skepticism. I mentioned in my LD 1634 testimony that it would be particularly helpful for Legislators to have information about unmet needs identified in each yearly report under 34-B MRS §5003-A(6) of the persons who are waitlisted and who are in both the Priority Two waitlist category (thus having been determined by DHHS to be at risk of abuse, exploitation or neglect in the absence of provision of residential waiver services) and who are counted as persons identified in quarterly HCBS Access Measures reports as persons "without other coverage". Obviously, persons who are eligible for the waiver are an especially vulnerable population. That subset of people who are not receiving other services *and* who have been identified as "at risk" for the need for adult protective services in the absence of the waiver are a subset of a subset and hence even more vulnerable. They deserve special attention so that their unmet needs can be met.

State statute sets out requirements for personal planning at 34-B MRS § 5470-B, §§1-9. Personal planning is often referred to as "person centered planning". The concept is not difficult to understand. The plan, which must at least be done on an annual basis, must identify "all of the needs and desires of the person without regard to whether those desires are reasonably achievable or the needs are currently capable of being addressed". (§2(G)) For every unmet need there has to be an **action plan** that describes the services to be provided. "In cases where resources are required to address identified needs or desires are not available, the action plan must identify **interim measures** based on available resources as nearly as possible and identify steps toward meeting the person's actual identified needs. Unmet needs must be documented continually, **collated annually**, **and used for appropriate development activities** on a regional and statewide basis." (§3) Then "the department shall develop and record information about a person's needs, identify anticipated needs without regard to service availability" and "recommend optimal courses of action and include plans for the **active and continued exploration** of suitable program or service options based upon the person's needs." (§5) The department shall assist persons with needs identified "insofar as resources permit." (§6) Then "The department shall maintain adequate written and electronic records… to permit monitoring and accountability." (§7) (emphasis added throughout the paragraph)

The PCP statute establishes a system that identifies individual needs and then records and collates those needs. The clear intent is to use that information to guide development and resource allocation. Those unmet needs are what must be transmitted to the HHS committee in the annual report that is required by 34-B MRS §5003-A(6)(B)(1). The Department is granted wide discretion as to exactly how it wants to collate the needs, but given the ten categories of information that are listed in 5003-A(6)(B) ("unmet needs, reportable events, adult protective services, etc.) it is obvious that the goal is to present information that is sufficiently organized so that the HHS committee, with input from interested members of the public, will be enabled to make important policy and resource recommendations and decisions based upon data that, though deidentified, was generated from the wellspring of personal planning.

The 5003-A(6) report is required to "be posted on the department's publicly accessible website and must be easily available to persons served by the department, families, guardians, advocates, Legislators, and the provider community." (*See* 34-B MRS 5003-A(C)). The most recent report on the OADS web site is under the tab "about us" which then brings up "Data and Reports". It is the report from 2022. If there is a later 5003-A(6) report somewhere else on the DHHS website I could not find it after a diligent search.

On pages 25-27 of the 2022 report is a section entitled "Measuring Unmet Need". Nowhere is there any collation of or reporting on unmet needs for "housing, employment or other meaningful occupation, medical and other professional therapeutic services, recreational and vocational opportunities, and educational services", all of which are listed in the personal planning statute at 34-B MRS §5470-B(6), which governs the implementation of a personal plan.

The Department is not in compliance with state law because the report is at least two years out of date; it is not easily accessible on the Department's website; and the report does not collate and report individual unmet needs.

It is this failure to comply with the letter and spirit of the law on reporting unmet needs to the Legislature that the Data Collection portion of LD 1606 seeks to address. The data collection that will be required by LD 1606 will be an important indicator of the quality of the services delivered and an accurate barometer of the degree to which there are crucial areas of unmet need.

Thank you.

Sincerely,

Richard A. Estabrook

Cc: Cullen Ryan, Chair, Maine Developmental Services Oversight and Advisory Board