

March 20, 2023

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

My name is Alan Cobo-Lewis. I live in Orono. I am the parent and guardian of a 22-year-old with significant disabilities who receives Section 21 support. I am testifying **NEITHER FOR NOR AGAINST LD 659** to establish a Home and Community Based Services (HCBS) Lifespan Waiver.

I am generally in support of the concept of the lifespan waiver. But details are crucial to successful implementation, and I would like to suggest a few amendments to LD 659 to ensure that the implementation is successful.

1 Major Substantive Rule: “Nothing About Us Without Us”

Sec. 1. of the bill directs the Department to adopt routine technical rules. But the lifespan waiver is too important for these rules to be routine technical. The Department has done a good job of involving stakeholders, including people with disabilities receiving HCBS services, in providing advice on the design of the lifespan waiver. But when it comes to rule-writing, LD 659 proposes to cut the Legislature out from review of the rules that the Department finally adopts. It is a fundamental principle of the disability rights movement that there be “Nothing About Us Without Us”. Just as the Legislature has recognized the critical importance of making special education rule major substantive (see [20-A MRS §7005](#)), it should recognize the critical importance of the lifespan waiver by making its rules major substantive as well. A public hearing in front of the Legislature will give people with disabilities a louder voice.

2 Sharing Wait List Data with Stakeholders, the Public and the Legislature

Existing statute requires that the Department [report on its publicly facing web site](#) about wait lists for the existing HCBS waivers (Sections 21, 29, 20, and 18 being those with wait lists, which currently total 2,267 people, 20% of whom have no other coverage). Please ensure that existing statute about reporting at [34-B MRS §5003-A\(1\)\(H\)](#) applies to the new lifespan waiver as to the waivers it replaces.

3 Sharing Unmet Need Data with Stakeholders, the Public and the Legislature

Existing statute at [34-B MRS §5003-A\(6\)\(B\)](#) requires reporting about unmet needs and other critical performance metrics in an annual report to the Legislature. But it does not require reporting on the Department’s publicly facing web site. Please amend LD 659 to make the following changes:

- Require the metrics at [34-B MRS §5003-A\(6\)\(B\)](#) to be publicly accessible on the Department’s web site in the same manner as the wait list reporting required under [34-B MRS §5003-A\(1\)\(H\)](#), and

- In order to ensure data quality in unmet need reporting at [34-B MRS §5003-A\(6\)\(B\)\(1\)](#), mandate that the rules promulgated by the Department require Person Centered Planning teams to quantify needs for support regardless of whether those needs are met and to input unmet data into the Department’s information system in a manner facilitating quantitative analysis (i.e., not just in a free-text narrative).

4 Informed Consent

Sec. 2 of the bill at lines 39-43 allows members enrolled under Section 21 or 29 to have the option of continuing in their current program or applying for enrollment in the lifespan program during phase 2. But how will members know what services they would receive in advance of making such a decision? The lifespan waiver will include high-stakes standardized assessment of needs. Please amend the bill to require that such assessments be conducted—and results shared with a member—before the member makes a decision about whether to transition to the lifespan waiver. Otherwise the member will be in the position of being asked to buy a pig in a poke. Respect the members. As President Reagan once said, “Trust but verify.”

5 Require Availability of Behavioral Support

A decade and a half ago, the Legislature required that the Section 21 and 29 waivers, among other MaineCare services, cover services by Board Certified Behavior Analysts ([Resolve 2009 chapter 33](#)). While the Department implemented this for Section 21 (though not until 5 years later¹), it has never implemented this legal requirement that Section 29 cover this service. In addition, at 16.5 hours per year, the amount of behavioral consultation coverage in Section 21 is well below the standard of care for behavioral programming, and the compensation rate is so far below market rates that the service is rarely accessed in any event. Accordingly, please amend LD 659 to require that the lifespan waiver cover behavioral consultation at a benefit level and compensation rate competitive with private health insurance.

¹ Contrast the rule at <https://web.archive.org/web/20130702094555/http://maine.gov/sos/cec/rules/10/144/ch101/c3s021.doc> (which still lacked behavior consultation) with the rule at <https://web.archive.org/web/20140928102406/http://maine.gov/sos/cec/rules/10/144/ch101/c3s021.docx> (which finally covered behavior consultation)