

Additional Information on LD 1490

Submitted by Alan Cobo-Lewis, PhD, 04/23/2021

Behavioral Add-On

In their [testimony](#), the Department shared a helpful report titled “[Study of Services for Persons with Intellectual Disabilities or Autism and Adequacy of MaineCare Reimbursement, in Relation to Challenging Behavior](#)”, pursuant to Public Law 2019 chapter 290. This report recommends Value Based Payment to address essentially the same problem that Sec 16 of LD 1490 seeks to address. While the report indicates that the Department has not taken any position on the content of the report, I do agree with the report’s recommendation that any response (whether it be behavioral add-on, Value Based Payment, or some other response) should not just incentivize increased staffing but rather incentivize increased quality. Perhaps the Committee could craft more permissive language than Sec 16 to require the Department to address the issue of people with significant challenges being denied access to community support by some date certain without specifying what the mechanism must be, provided that the Department be required to report back about specific strategies, the extent to which they were successful, and what additional strategies the Department was considering in longer-term reform.

Inclusion of Brain Injury and Other Related Conditions

Thank you to Attorney Lauren Willie of Disability Rights Maine, who suggested in [written testimony](#) that people with brain injury and other related conditions (Section 18 and 20 waivers) be included in LD 1490. I agree with the suggestion to thusly amend the bill.

Reporting Frequency

While current reporting about wait lists on DHHS website has never been quarterly, it has *approached* quarterly (mean of 3.3 reports per year before 08/21/2020). See Figure 1. No reports have been posted in 244 days (2.7 quarters), though the Department did report directly to HHS committee about wait lists on 03/04/2021 (170 days after the most recent report posted by DHHS) in response to a Committee request for information. The Legislature posted that report to <http://legislature.maine.gov/doc/6158>, though not everyone testifying was aware of that post’s existence.

During the rapidly moving pandemic, there was significant concern about how wait lists were developing, so more frequent reporting would have been helpful—though the pandemic obviously placed strains on resources.

Sec 5 of LD 1490 would require the reporting about number of people on wait lists to be monthly. Sec 5 would also add the requirement that the reports include number of people in priority 2 vs priority 3 of the Section 21 wait list. While the Department has not included this information in its posted reports,

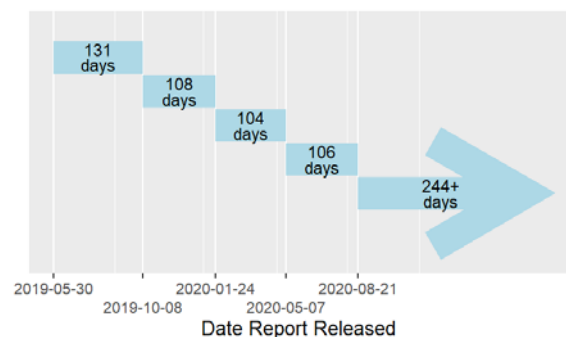


Figure 1. [Gantt chart](#) of timing of wait list reports posted to DHHS web site. For each report, a vertical line connects to the date the report was released, and a subsequent vertical line marks 90 days from that date. The arrow indicates an open-ended interval since the most recent report.

previous administrations have, and the information is useful to inform legislation such as found in Sen Keim's bill, LD 1360.

If the Department views monthly reports as burdensome, the Committee might consider revising it to quarterly.

Time on Wait List

Sec 6 of LD 1490 would require reporting to include information about median time on wait list. [Written testimony on LD 962](#) from Mr Randy Hillman and Mr Brandon Clukey indicated that Mr Clukey has been on the Section 18 Brain Injury waiver wait list for some period well over a year, as he was [already on the wait list](#) during LD 1984's public hearing 01/27/2020 15 months ago.

The Department has the data needed to calculate median time on each wait list. I would be happy to provide technical assistance to ensure that median time (and potentially other quantiles, as suggested by [Ms Nancy Cronin's testimony](#) for the Maine Developmental Disabilities Council) are calculated with a statistically valid methodology (one that applies the principles of [survival analysis](#) to ensure proper treatment of times until events that have not yet occurred). This calculation can be automated with few resources.

Given that roughly two-thirds of people on the Section 21 wait list are on Priority 3, and that it is not clear whether anyone in Priority 3 has ever received a Section 21 waiver offer while in Priority 3, it may be that the median time on the Section 21 wait list approaches the age of the wait list. But this is an empirical question that proper reporting could resolve.

Information Not Held by Department

[The Department's testimony](#) indicated that some information required by LD 1490 would impose a burden on community service providers (and presumably on the Department as well). I have asked the Department to clarify. While I have not yet received a response, I imagine that it might be the requirement in the last sentence of Sec 9 to report on how many people on prioritized wait lists would be in a higher priority if they weren't living with a parent. While I would hope that the Department has the data to address this, the Committee might consider deleting this requirement if they would need to seek it from community service providers. Alternatively, the Committee could defer this requirement for a set period of time (say 2 years) if the Department does not have such information, provided that the Department consider retaining such data as it makes prioritization decisions about new waiver applications.