

April 21, 2021

### Testimony:

- **FOR LD 499, “An Act To Eliminate Waiting List for Older and Disabled Residents Who Are Eligible To Receive Home-based Care”**
- **FOR LD 962, “An Act To Appropriate Funds To Eliminate Waiting Lists for Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions”**
- **FOR LD 1360, “An Act To Provide Services to Maine’s Most Vulnerable Citizens by Eliminating the Waiting Lists for Certain MaineCare Services”**

Chairman Claxton, Chairwoman Meyer, Distinguished Members of the Joint Standing Committee on Health and Human Services:

My name is Alan Cobo-Lewis. I live in Orono. I have two 20-year-old sons, one of whom has a significant disability. That son is currently receiving children’s services and is undergoing transition to adult services.

I am testifying for all three wait list appropriations bills (LD 499 for wait lists on state-funded services and LD 962 and 1360 on MaineCare-funded services), though the data I share pertain to the MaineCare-funded services, with which I have more direct experience.

Yesterday you heard testimony on several bills addressing workforce issues. It is critical that you pass them, because otherwise people have unmet needs when they are approved to receive needed services and supports but can’t staff the programming. But when people are stranded on wait lists, they can’t even get that far, because they’re ineligible to even seek out the staffing while they’re stuck on those wait lists.

### First-Come First Serve Wait List for Section 29 “Supports Waiver”

The Section 29 “supports waiver” has a cap on annual per-person expenditures and has a first-come-first-served wait list. Section 29 does meet the needs of many recipients. But for others, it serves as a last resort for people who may wait years upon years for comprehensive services and supports on Section 21. That’s why Maine eliminated the Section 29 wait list in mid-2015 as one of two crucial elements in settling the *Aldrich* class action lawsuit, as you can see in the first graph in my testimony. But 3½ years later it was back, climbing by 1 person per day until decelerating and then topping off at 391 people (near the level that had triggered the lawsuit). You appropriated money in last year’s supplemental budget to partially address that wait list but not to eliminate it, so as of 02/10/2021 it stood at 234 people. LD 221 would also partially address it. But the Section 29 wait list should be zero—Section 29 is the critical “backup plan” for too many people! It is unconscionable for there to be any wait list for Section 29. Its immediate elimination should be the starting point for any discussion.

### Prioritized Wait List for Section 21 “Comprehensive Waiver”

The Section 21 “comprehensive waiver” has a prioritized wait list. Thanks to the other element of the *Aldrich* settlement, there is no longer anyone in the Priority 1 portion of the Section 21 wait list (adult protective status without waiver services), but about one-third of the people on the Section 21 wait list are in Priority 2 (at risk of adult protective status without waiver services), with the balance in Priority 3. People can be stranded on the Section 21 wait list for many years, and, to my knowledge, no one in Priority 3 has ever received a Section 21 waiver offer. As of 02/10/2021, the wait list for the Section 21 “comprehensive waiver” stood at an all-time high of 1,874 people and will keep growing, as last month’s biennial budget and LD 221 do not address the Section 21 wait list. Section 21 is important for people whose needs exceed what Section 29 covers. For example, for people whose needs are typically met in a group home, **Section 29 has an annual per-person expenditure cap**

**that does not meet that need**, so Section 21 needs funding. Other services included in Section 21 but not Section 29 are counseling, consultation services, crisis assessment, crisis intervention services, non-traditional communication assessments, non-traditional communication consultation, occupational therapy maintenance, physical therapy maintenance, specialized medical equipment and supplies, and speech therapy maintenance. (Oddly enough, Section 29 even excludes consultation by a Board Certified Behavior Analyst—a potentially critical service for a person with challenging behaviors—even though the Legislature directed the incorporation of that service into Section 29 a dozen years ago—see [Resolve 2009 chapter 33](#).)

## Wait Lists for Section 18 Brain Injury and Section 20 “Other Related Conditions” Waivers and for State-Funded Services

Also expected to keep growing are the wait lists for the Section 18 brain injury waiver and the Section 20 waiver (as of New Year’s also at an all-time high, of 98 people) for adults with other related conditions such as spina bifida or cerebral palsy, as last month’s biennial budget and LD 221 do not address those wait lists either. These three other wait lists must also be addressed, not ignored. It is also critical to address the wait lists for the state-funded services in LD 499.

## The Economy Does Not Explain Wait List Growth

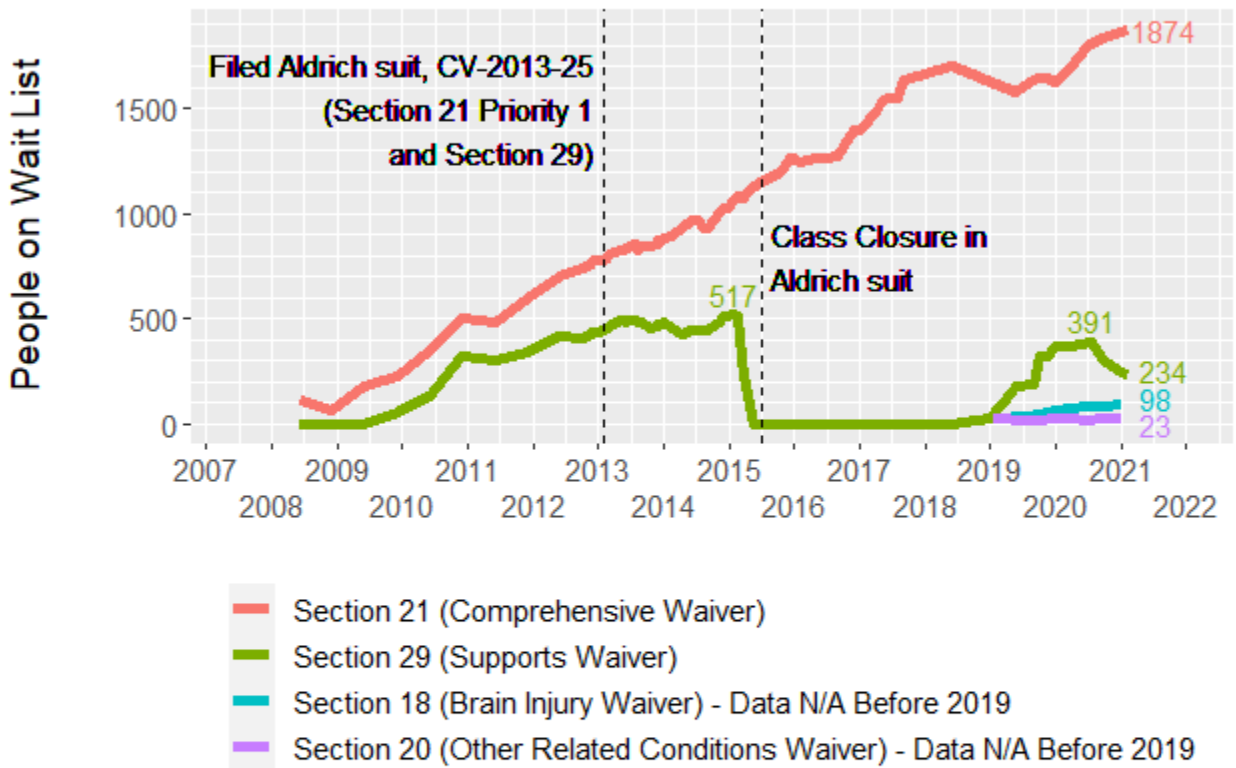
Long-term failure to address wait lists is not explained by the economy. Please compare the wait list trends in the top graph of my testimony to the unemployment trend in the bottom graph. You will find no correlation: when unemployment was high, wait lists grew; when unemployment was low, wait lists also grew. With the exception of the significant action taken to settle the class action *Aldrich* suit and occasional other smaller-scale action (including the appropriation in last year’s supplemental budget that *partially* addressed the Section 29 wait list), the state has let the wait lists fester and grow, regardless of the state of the economy or the state of the budget. This must end.

## Conclusion

There are roughly 2000 people on one or more of the Section 21/29/20/18 HCBS wait lists, and about 600 of them are receiving no other services. There are additional people in the wait lists for state-funded support. This is completely unacceptable, but you have the opportunity to change it. Please recall from my testimony yesterday that [Section 9817 of the federal American Rescue Plan Act of 2021](#) (ARP, Public Law 117-2) includes a 10% increase to the Federal Medicaid Assistance Percentage (FMAP) specifically targeted at HCBS provided during the 12-month period that began April 1, 2021, with this money available provided that the state “implement[s], or supplement[s] the implementation of, one or more activities to enhance, expand, or strengthen home and community-based services” [see [ARP Sec 9817\(b\)\(2\)](#)]. I urge you to take advantage of that opportunity.

# History of Wait Lists for Adult Developmental Services in Maine

Source of Data (Heavy Solid Lines): Maine DHHS



# History of Unemployment in Maine

Source of Data: Bureau of Labor Statistics, US Dept of Labor

