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April 1, 2025

Testimony of Rep. Sally Cluchey introducing
**LD 977, Resolve, Requiring the Maine Health Data Organization to Develop a
Plan for Measuring Gaps in Home and Community-based Services**
Before the Joint Standing Committee on Health and Human Services

Senator Ingwersen, Representative Meyer, and distinguished members of the Health and Human Services Committee, my name is Sally Cluchey, and I represent House District 52, which includes Bowdoinham, Richmond, and part of Bowdoin. I am here today to introduce LD 977, a resolve that takes a crucial first step in addressing Maine's home and community-based care crisis.

Maine is facing a critical shortage of caregivers—both in home care and residential facilities. This means that many Mainers who are authorized for services are not receiving the care they need, whether it's for daily activities like eating, bathing, and dressing or more intensive support. The result? Families scrambling to fill the gaps, vulnerable people left without adequate care, and an overburdened workforce stretched to the breaking point.

We all know the workforce shortage is a problem. The state has taken steps to address it, but we're missing a fundamental piece: data. Right now, we don't have a clear picture of just how many caregivers we need to close the gap or where those caregivers are most urgently needed. Without this information, any policy solutions we pursue are like trying to navigate in the dark.

During my time caring for my mother, I saw these gaps firsthand. She underwent a Medicaid functional needs assessment, which determined she required 68 hours of weekly care. But despite qualifying for those hours, she never actually received them all. Staffing shortages meant that even though the need was documented, it wasn't met. My family was left to fill the gap ourselves.

And my mother's case is far from unique. A 2024 report from the Maine Center for Economic Policy estimates that over 23,500 hours of approved home care for older adults go undelivered each week. That is a staggering number, and it represents real people—our neighbors, our parents, our friends—who are going without essential care.

LD 977 takes a straightforward approach: it directs the Maine Health Data Organization (MHDO) to develop a plan for measuring Maine's home and community-based care gap. This plan will:

- Establish a system for annual measurement of unmet needs
- Track the difference between authorized and actual services delivered
- Ensure compliance with federal reporting standards
- Use existing data sources, avoiding unnecessary bureaucracy

This is not just a good idea—it's necessary. We cannot fix what we do not measure. If we fail to establish a baseline, we will continue making decisions in the absence of crucial information. And that is a disservice to the very people we are here to support.

LD 977 builds upon a previous bill (LD 1238) from the 131st Legislature, incorporating feedback from this very committee. In fact, I have to give credit where it's due—this committee helped me come up with the solution.

Last year, I introduced a similar bill, and you all, in a show of bipartisan unity, promptly and unanimously killed it. But before you sent me on my way, the committee chair told me: "If you want to try again, you need to figure out what third party is going to collect the data and do the analysis because it can't be DHHS."

I took that to heart. Moments later, I walked out of the HHS committee room and straight into the HCIFS committee room, where Karynlee Harrington from MHDO was presenting. A light bulb went off—MHDO was exactly the right entity for this work. They already have access to claims data and regularly produce reports for the state. So, here I am, back again, with the exact solution you asked for. And let's not wait another two years to get this done—this bill is just the first step.

The risk in not acting is clear: people who need care and who are authorized for that care will simply disappear from the system. We cannot authorize services and then just assume people will be able to get them. That would be negligent. And in the absence of real data, we will continue to struggle to develop policies that actually fix the problem.

LD 977 is a practical, necessary step toward ensuring that our policies are informed by real numbers, not guesswork. It is the foundation we need to build lasting solutions.

I urge you to support this bill, because we owe it to the thousands of Mainers who are waiting for the care they have already been promised.

Thank you for your time and attention. I would be happy to answer any questions you may have.

Office of Aging and Disability Services

DHHS → [Office of Aging and Disability Services](#) → [About Us](#) → [Data & Reports](#) → HCBS Access Measures

HCBS Access Measures

This page is updated quarterly and reflects data as of December 31, 2024. Please contact oads@maine.gov (<mailto:oads@maine.gov>) regarding any questions about this data.

Waitlist Data (#WaitlistData)

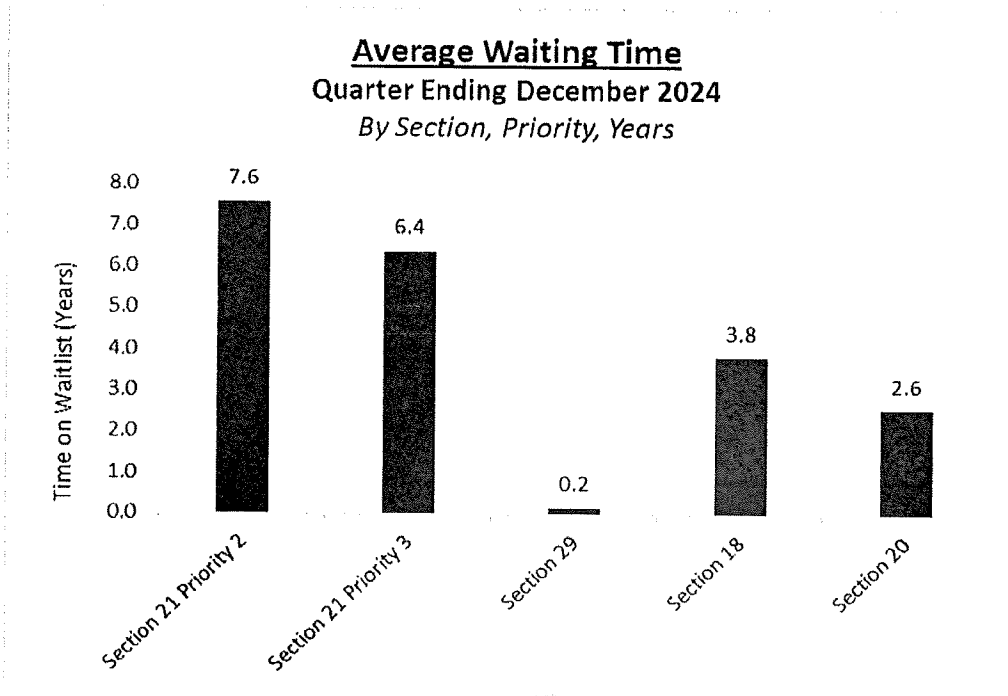
Developmental Disabilities and Brain Injury Program Participants and Waitlists

WAIVER PROGRAM	PARTICIPANTS	WAITLIST [^]	WITH OTHER COVERAGE ^{**}	WITHOUT OTHER COVERAGE ^{**}	PERCENT OF CURRENT PARTICIPANTS WITHOUT OTHER COVERAGE
Brain Injury (Section 18)	215	200	103	97	45%
Other related Conditions (Section 20)	42	31	18	13	30%
Comprehensive Services for IDD/ASD (Section 21)	3,022	2,222	1,736	486	16%
Support Services for IDD/ASD (Section 29)	2,713	59	19	40	1%
Unduplicated Member* Totals	5,991	2,487	1,780	707	11%

*Other Coverage includes coverage under sections of policy as described in Table 2

^Members can be on multiple waitlists simultaneously.

Developmental Disabilities Lengths of Wait Time



Notes:

Wait time is reported regardless of other coverage Members who meet Section 21 Priority 1 criteria receive an immediate offer More information regarding Section 21 priority level determination can be found in the MaineCare Benefits Manual Ch. II Section 21 (<https://www.maine.gov/sos/cec/rules/10/ch101.htm>)

Medicaid and State Funded Services for Older and Disabled Adults Participants and Waitlists

Data from October 2024 - December 2024

PROGRAM	PARTICIPANTS	WAITLIST
Home and Community Benefits for Older and Disabled Adults (Section 19)	3,005	0
Private Duty Nursing and Personal Care Services (Section 96)	2,892	*
Consumer Directed Attendant Services (Section 12)	321	0

PROGRAM	PARTICIPANTS	WAITLIST
State Funded Home Based Care (Section 63) (includes former Chapter 11)	1,074	969
State Funded Independent Support Services (aka Homemaker) (Section 69)	1,197	1,393
Totals	8,489	2,362

*Due to limited care coordination capacity, a referral management process was in place for Section 96 during this reporting period.

Service Data (#ServiceData)

Archived Data (#ArchivedData)

Credit

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