



132nd MAINE LEGISLATURE

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Legislative Document

No. 1606

H.P. 1060

House of Representatives, April 15, 2025

**An Act to Require Data Collection and Major Substantive
Rulemaking for the Lifespan Waiver Providing Home and
Community-based Services for Individuals with Intellectual and
Developmental Disabilities, Autism Spectrum Disorder or Other
Related Conditions**

(EMERGENCY)

Received by the Clerk of the House on April 11, 2025. Referred to the Committee on Health and Human Services pursuant to Joint Rule 308.2 and ordered printed pursuant to Joint Rule 401.

A handwritten signature in cursive script, reading "R B. Hunt".

ROBERT B. HUNT
Clerk

Presented by Representative BOYER of Cape Elizabeth.
Cosponsored by Senator CARNEY of Cumberland and
Representatives: ARFORD of Brunswick, CLUCHEY of Bowdoinham, HEPLER of
Woolwich, SALISBURY of Westbrook, Senators: MOORE of Washington, TEPLER of
Sagadahoc.

1 **Emergency preamble.** Whereas, acts and resolves of the Legislature do not
2 become effective until 90 days after adjournment unless enacted as emergencies; and

3 **Whereas,** the Department of Health and Human Services is currently engaged in
4 developing the lifespan waiver with the federal Department of Health and Human Services,
5 Centers for Medicare and Medicaid Services; and

6 **Whereas,** the Department of Health and Human Services will be undertaking
7 rulemaking and the Legislature determines that the rulemaking should be major substantive
8 with legislative involvement; and

9 **Whereas,** in the judgment of the Legislature, these facts create an emergency within
10 the meaning of the Constitution of Maine and require the following legislation as
11 immediately necessary for the preservation of the public peace, health and safety; now,
12 therefore,

13 **Be it enacted by the People of the State of Maine as follows:**

14 **Sec. 1. 34-B MRSA §5003-B,** as enacted by PL 2023, c. 412, Pt. LLLLL, §1, is
15 repealed and the following enacted in its place:

16 **§5003-B. Services across lifespan**

17 **1. Lifespan waiver development.** The department shall facilitate the development of
18 a home and community-based waiver from the United States Department of Health and
19 Human Services, Centers for Medicare and Medicaid Services that provides services for
20 individuals with intellectual and developmental disabilities, autism spectrum disorder or
21 other related conditions across the lifespan, including smooth transitions from childhood
22 to adulthood. Upon federal approval, the department shall adopt rules to implement this
23 section. Rules adopted pursuant to this section are major substantive rules as defined in
24 Title 5, chapter 375, subchapter 2-A.

25 **2. Data collection.** For each year the lifespan waiver is operational, the department
26 shall collect data related to service provisions and unmet needs for care for individuals
27 receiving services or individuals approved for receipt of services under the lifespan waiver
28 under subsection 1. The data to be collected must include, but is not limited to, the
29 following:

30 A. The number of individuals who are unable to access services identified in their
31 personal plans required by sections 5003-A and 5470-B, sorted by category of service;

32 B. The number of individuals who do not receive all of the hours or units of service
33 identified in their personal plans required by sections 5003-A and 5470-B, sorted by
34 category of service;

35 C. The number of individuals who are receiving services while living with a service
36 provider, also known as a shared living provider, in a family-style environment and a
37 categorization of the providers as family or nonfamily, as well as the ages of the
38 providers; and

39 D. The number of individuals who experience residential transitions within each year,
40 including, but not limited to, transitions between group homes, shared living providers
41 or self-directed services, sorted by the type of residential arrangements that individuals
42 are transitioning to and from.

3. Report. The department shall publish an annual report with the data collected pursuant to subsection 2. The report must be published on the department's publicly accessible website and submitted to the joint standing committee of the Legislature having jurisdiction over health and human services matters no later than February 28th of each year.

Emergency clause. In view of the emergency cited in the preamble, this legislation takes effect when approved.

SUMMARY

This bill requires the rulemaking for the lifespan waiver to be major substantive. Current law requires only the initial rulemaking to be major substantive. The bill also requires the Department of Health and Human Services to collect data related to unmet needs identified in individuals' personal plans and related to residential transitions between group homes, shared living and self-directed residential arrangements. The department is required to publish an annual report with the data on its publicly accessible website and submit the report to the joint standing committee of the Legislature having jurisdiction over health and human services matters.