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Testimony of Rep. Michelle Boyer

LD 1606, 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 *Before the Joint Standing Committee on Health and Human Service*

Senator Ingwersen, Representative Meyer and members of the Health and Human Services Committee, my name is Michelle Boyer, and I represent House District 123, which includes the town of Cape Elizabeth. I am pleased to present today **LD 1606, 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.**

I want to start by sharing with you all how this bill came to be. Some months ago, I was privileged enough to be invited into the home of a constituent who had convened a group of parents to share in some banana bread, tea and heartbreaking, personal stories with me. I have the distinct memory of one parent who cried for almost the entirety of our meeting. The people who will testify today are parents who rely on the current program and need the lifespan waiver to help care for their children.

This Committee recently passed, with unanimous consent, a bill sponsored by Rep. Cluchey, LD 977, which has a small amount of overlap with this bill. This bill before you focuses solely on data collection for the lifespan waiver, once the lifespan waiver is in operation, and includes additional data points that Rep Cluchey's bill does not. Specifically, under data collection, items C and D are not covered by LD 977. Items A and B are generally covered by Rep. Cluchey's bill.

I did talk with the Department and understand that they will likely not support this bill. I reviewed and thoughtfully considered their concerns but feel the bill's intent is still important and relevant.

This bill requires that the rules adopted for the lifespan waiver be substantive.

Additionally, this bill requires four data collection points to be collected annually. I'll provide a summary of the four points.

1. The percentage of individuals who are unable to access services identified in their personal plans.
2. The percentage of individuals who do not receive all of the hours or units of services identified in their personal plans.
3. The number of individuals who are receiving services while living with a service provider.
4. The number of individuals who experience residential transitions each year.

As the state continues to develop the lifespan waiver, there will inevitably be challenges and changes that need to be made. This bill intends to make sure that the state always has pertinent data, which can be viewed by families, to ensure we are making the waiver the best it can possibly be for those which the waiver will serve.

I believe this bill will strengthen the lifespan waiver. Transparency is important, and more transparency is a step in the right direction. This information will help legislators, parents and interested parties make informed decisions.

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

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

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

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

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

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

§5003-B. Services across lifespan

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

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

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

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

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

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

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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.