

LD 659 – An Act to Promote Seamless and Flexible Home and Community Supports Across the Lifespan for Individuals with Intellectual and Developmental Disabilities or Autism

Summary:

We strongly recommend that LD 659 be amended to be Major Substantive, not Routine Technical, to ensure the Lifespan Waiver leads to a better quality of life for Maine citizens with I/DD.

The Lifespan Waiver is a new program that will replace the Section 21 and Section 29 Waivers. Implementation of the Lifespan Waiver and dissolution of the Section 21 and 29 Waivers will bring significant life changes to thousands of adolescents and adults who rely on these waivers for long-term support services that include: housing, skill building, socialization, transportation, and assistance with basic daily needs. The complete transformation of the system of care for individuals with I/DD holds great promise as well as great risk.

The Lifespan Waiver holds the promise of a seamless transition from HS to adult services for adolescents with special needs and a new Self-Directed option that would allow individuals and families to manage their own services. At the same time, the Lifespan Waiver risks reducing services for those with the greatest support needs and irreparably damaging their quality of life.

Due to the tremendous impact of the broad systemic changes in the design and delivery of long-term support services, more time and thoughtful planning are needed to permit proper legislative oversight. The creation of this new waiver is precisely the type of action that is meant to trigger a Major Substantive designation. Replacing the two waivers for adults with IDD with an entirely new system of care is a policy decision, and the Legislature, not an administrative agency, is the body responsible for making policy decisions. Every one of the thousands of Mainers impacted by these rules is represented by the Legislature whose role it is to oversee the drafting of this life-altering policy.

We suffer from a lack of data that exacerbates the difficulties addressing the needs of a diverse population when that population is so poorly understood. It would be negligent to approve the new Waiver as merely Routine Technical instead of vetting it as Major Substantive change. Below is a sample of the questions that remain unanswered about the new Lifespan Waiver. The only way to ensure that these issues will be appropriately addressed in the rulemaking process is if this bill is amended to be Major Substantive.

Questions Regarding Cost Neutrality

OADS has stated that the Lifespan Waiver is cost neutral, not a cost-cutting change in funding the waivers.

- How will the Lifespan Waiver remain cost neutral while enrolling hundreds of new consumers ages 14-21, continuing to serve consumers whose needs are best met by the current Section 21 and 29 Waivers, the 2,000 waitlisted individuals, and those individuals who have Waiver Services yet are underserved?

- How does the Lifespan Waiver maintain availability of housing choice? 75 group homes have closed (with 20 more scheduled to close in the next six months). Individuals with higher needs will continue to require the supports available in the group home model. Their needs cannot be met by tiered shared living/foster care.

Questions regarding Community Support Programs

OADS made changes to the community support/day programs by introducing a model offering individuals 1:1 support in the community. This is particularly beneficial for people for whom a day program is not an appropriate setting. But for many people with IDD, group activities provide critical socialization opportunities and exposure to a broad range of community activities and volunteer work experiences. The 1:1 model, while guided by the principle of consumer choice, is an isolating option for those who need support to build and maintain relationships.

- Under the Lifespan waiver, will there continue to be a choice between group activities offered by the current day program model and/or receiving 1:1 support in the community? We have concerns about the sustainability of community support programs if the 1:1 support model is prioritized by DHHS. Several programs have already closed.
- As agencies are experiencing significant staffing shortages for group activities, how is there also funding for the more costly 1:1 support option?

Questions and concerns regarding the Supports Intensity Scale (SIS)

The Supports Intensity Scale (SIS) will be used to determine the needs of individuals who want to access the Lifespan Waiver. The term “resource allocation” is not used, however stakeholders are concerned that is how OADS plans to use the SIS.

Medicaid regulations require that Section 21 and Section 29 Waiver Services be based on individualized Person-Centered Planning. 42 C.F.R. SS 441.715,441.720. The Lifespan Waiver should meet the same requirement.

At present the Person-Centered Planning process has been compromised. It will be important to develop and implement stricter standards to ensure the regulations are adhered to for all the waivers. The SIS can be useful when used as a single data point, but the final decision about services should be determined by a team of people on the Person-Centered Planning team. An appeal process should also be put into place.

- How will SIS scores be determined when the scoring rubric does not reflect an individual’s more complex needs such as severe communication challenges and/or episodic mental health crises?
- How will the SIS be scored when questions cannot be answered within a given timeframe?

- What will be the mechanism to appeal an assessment that appears inappropriate or inaccurate?

Questions regarding the Self-directed Option described under the Lifespan Waiver

The Self-Directed option will apply to certain services for each enrollment group (e.g HS students, adults living in different housing models). In this option, individuals and families should be able to hire their own service providers. However, many essential aspects of Self-directed services have yet to be determined.

- Will there be a choice of fiscal management services in Maine? Currently there is only one, and it is unresponsive to clients.
- Will employment services be included in self-direction?
- Will clients have access to enhanced support broker services? These are people who advocate on a client's behalf and take over the role that parents typically fill in hiring support staff, when there is no parent or family member available.
- Is Maine planning to establish a citizen advisory council to review vendor contracts, as is done in Colorado, New Jersey, and Ohio?

Questions regarding Support Coordinators

OADS is exploring the use of "Support Coordinators" to replace the current Case Management system. At present, Case Managers can adjust their time based on a consumer's needs. When a person faces a major life event (e.g. change in health status, death of a parent, loss of housing), a Case Manager can increase their hours to provide additional support to find needed services.

Questions:

- Under the Lifespan Waiver, would Support Coordinators have the flexibility to adjust their hours as needed, or will their hours be capped?
- Can this service be funded outside the Lifespan Waiver?
- What does a support coordinator do?