

# Lifespan Concept Paper Update

The Plain Language Concept Paper published on June 28<sup>th</sup>, 2023 below, is not current, and does not include changes resulting from feedback received during the comment period.

Please review the FAQ document (insert Link) on the Lifespan website for updated content.

The next published summary of the waiver will be the CMS Waiver application, which will have a comment period. The announcement for this will be provided through DHHS' GovConnect messaging. Sign up on the [OADS' webpage](#).

# *The Lifespan Waiver*

## **Concept Paper: Plain Language Executive Summary for Stakeholder Review and Input**

### **June 28, 2023**

The Maine Department of Health and Human Services (DHHS) is developing a new Lifespan Waiver program. It will serve people with Intellectual Disabilities (ID), including Autism Spectrum Disorder (ASD). It will also serve people with other related conditions. The primary goal is to better meet the needs of people across their lifespans. The waiver would include people beginning at age 14. Once a person is enrolled, they would not need to change waivers during their life. This would make life transitions smoother for people as their needs change with their age.

This is a concept paper for Mainers to read and share their comments with DHHS. This paper talks about key parts of the proposed Lifespan Waiver. This is just one of the opportunities there will be to provide feedback to DHHS. The Offices of MaineCare Services (OMS), Aging and Disability Services (OADS) and Child and Family Services (OCFS) are working together on this waiver. They will host two virtual public forums. The first is on July 6th from 12:30PM to 2PM. The second is on July 20th from 10:30AM to 12PM. These meetings will present the most important information in this concept paper to people. We will also take comments. Details about these meetings may be found at: <https://www.maine.gov/dhhs/oads/about-us/initiatives/hcbs-lifespan-project>.

Comments about this Concept Paper may also be sent to DHHS through July 28<sup>th</sup> at 5PM by:

- Going online at: <https://forms.office.com/g/SV9ewiLjeg>  
OR
- By email to: [OADS.LifespanProject@maine.gov](mailto:OADS.LifespanProject@maine.gov)  
OR
- By mailing comments to:  
**Attn: Lifespan Project**  
**Office of Aging & Disability Services**  
11 State House Station  
41 Anthony Avenue  
Augusta, ME 04333

OMS, OADS and OCFS will carefully consider all comments on this concept paper. The next step will be for DHHS to send the application(s) for the Lifespan Waiver to the federal Centers for Medicare and Medicaid Services (CMS) for approval. These application(s) will also be posted for public comment before being sent to CMS. People can comment on the application(s) when they are posted.

# *The Lifespan Waiver: A Concept Paper for Stakeholder Review and Input June 28, 2023*

## Executive Summary

This is a proposal for a new waiver in Maine called the Lifespan Waiver. This “Executive Summary” tells how the State of Maine could provide Medicaid Waiver Home and Community-Based Services (HCBS). These services would be for:

- People with Intellectual Disabilities (ID)
- People with Autism Spectrum Disorder (ASD)
- People with other related conditions (ORC)

The Lifespan Waiver will help those who need these services once the legislature has approved the rule for this waiver in 2025. The goal is for people with ID/ASD to be eligible in 2025 and for people with ORC to be eligible in 2026. More detail in a longer document can be found [here](#):

This concept paper is based on statewide input received from stakeholders through:

- A paper called “The Developmental Services Lifelong Continuum of Care.” This was proposed by stakeholders through the Maine Coalition for Housing and Quality Services.
- The Disability Services Reform Innovation Workgroups. These were sponsored by the DHHS' OADS.
- Three stakeholder efforts that were just to talk about a Lifespan Waiver:
  - Seven (7) listening sessions held in the fall of 2022.
  - A Lifespan Waiver stakeholder workgroup run by OADS between January and June 2023. This group met 11 times to talk about a Lifespan Waiver.
  - A survey of people with ID and ASD currently on a waiver waiting list for HCBS. This survey was conducted in early spring of 2023.

417 individuals with ID or ASD, family members, advocates, providers and other stakeholders provided feedback and comments to help with developing the Lifespan Waiver. The comments were similar to comments made in past years. The comments supported the reasons DHHS wants to create a Lifespan Waiver. The proposed goals of the Lifespan Waiver are:

- 1. A waiver that’s flexible across a person’s whole life.** A waiver that offers services that fit a person’s age. As people move through life and get older, their goals and their needs change. Family members who provide support to a person will also have needs that change over time. By having one waiver for a person’s whole life, the person avoids having to change waivers when their needs changes.
- 2. Easier, smoother transitions.** Everyone has transitions during their life. Transitions happen when we get older and when things in our life may change for other reasons. A Lifespan Waiver can help with better planning and support for these transitions. The Lifespan Waiver can offer different types and levels of services within a single waiver. The services can change with the person as the person goes through life. There will also be less confusion for people if there is only one waiver throughout a person’s life.

3. **Give people access to a waiver earlier in life. Get rid of the waiting list.** Allow people to enroll when they reach age 14, rather than having to wait until age 18. This will help better support the transition from childhood-to-adulthood. This includes better support for the process of leaving high school. The plan is also to take five years, from 2025 to 2030, to end the waiting lists for people with ID and ASD (Section 21 and Section 29 waiting lists) and other related conditions (Section 20 waiting list).
4. **Planning for independence and inclusion for all people.** Offer services that help people live their best lives. Examples would be: supports at home; independent living skills training; supports for being part of the local community; supports for employment and supports for relationships. Services will meet the needs that people have and build on people's strengths, gifts and abilities. Services will also build on the strengths of families and keep families strong. The Lifespan Waiver will help people get the most out of being part of their communities, and help people give back to their communities.
5. **Making sure all a person's supports and services are working together for the person's benefit.** Move beyond case management as we know it today. Go beyond just case management of waiver services to someone who pays attention to all the different services and supports a person may have. This includes supports from family, friends, employers and coworkers. It would also include services from other programs like vocational rehabilitation, school and mental health services. Additionally, this would include housing programs, transportation programs and services from community places.
6. **Use new ideas that are working.** Use new ideas that are being tested or working somewhere else. Some of these ideas are having different levels of support in Shared Living. Some ideas include: using the Supports Intensity Scale (SIS) as a tool to understand each person's support needs better: having different support levels and funding levels for people who have higher medical and mental health needs: having more opportunities for self-direction of services: having a service that helps a person and their family explore employment as an option, and finally, using remote support technology and other technology to help people and families, especially given the shortage of direct support staff that we have in Maine.
7. **Better payment methods for service providers.** Consider better ways to pay providers for services. This includes paying in ways that encourage providers to provide quality services. This should also ensure that providers can provide the right type of service in the right amount when a person needs it. This helps people reach their goals and have lives they want to live. It also helps more people get the services they need with the funding DHHS has for services.

Until now, Maine DHHS has operated three separate HCBS waivers for people with ID, ASD and other related conditions. As of April 2023:

- The Section 21 Waiver is a comprehensive waiver for people with ID and ASD ages 18 and older. It currently has 3,553 people enrolled. It has a waiting list of 282 people who are receiving no waiver services. There are also 1,703 people on the waiting list for Section 21 who are already on another waiver. Most are on Section 29.

- The Section 29 Waiver is a supports waiver for people with ID and ASD ages 18 and older. It currently has 2,804 people enrolled. It has a waiting list of 186 people who are receiving no waiver services.
- The Section 20 Waiver is a comprehensive waiver for people with other related conditions like Cerebral Palsy, Muscular Dystrophy and Spina Bifida. It serves people ages 21 and older. It currently has 44 participants enrolled and a waiting list of 21 people with no waiver services.

The state currently manages separate waiting lists for each of these waivers. People may put their name on multiple waiting lists. Some people are putting their name on the waiting lists as part of planning for the future. Also, people may get services under one waiver and may also be on a waiting list for a different waiver. For example, in 2022 three quarters ( $\frac{3}{4}$ ) of the people on the Section 21 waitlist were already getting other waiver services. This creates confusion for people and their families. The proposed Lifespan Waiver design intends to address this. It would create one doorway to HCBS waiver services by creating a waiver for life.

Within the Lifespan Waiver, there would be different enrollment groups based on age and a person's needed living arrangement:

- Enrollment Group #1: For individuals ages 14-21
- Enrollment Group #2: For individuals ages 22-64
- Enrollment Group #3: For individuals ages 65+
- Enrollment Group #4: For individuals ages 18+ who need placement in group home or Shared Living with an unrelated provider.

At the end of this paper there is a table that says more about the enrollment groups. The services for each enrollment group are proposed based on the unique needs of the enrollment group. The table at the end of this paper lists the services proposed for each enrollment group.

Each enrollment group will have an annual budget set for each person in the group. There will be a higher budget available if a person has a lot more needs than everyone else in the group. People will have their annual budget to pay for the services in their person-centered plan. These annual budget amounts will be set by an actuary (a person specially trained to do this kind of budget setting work). Over time, the actuary will review the annual budget amounts and make changes to these amounts if needed. An increase for cost of living would be one reason for a change to be made.

By creating the Lifespan Waiver, DHHS plans to eliminate waiting lists for people with ID, ASD and other related conditions. Once the waiting lists are gone, this means no wait for anyone who is eligible. People can be enrolled as soon as they apply. This will better ensure that crises can be prevented. It will also better support transitions throughout a person's life.

Members already enrolled in Section 20, 21 or 29 waivers can remain on those waivers when the Lifespan Waiver opens. **These members will not be required to transition to the Lifespan Waiver. However, they can choose to transition to Lifespan if they want to.** It is proposed that members already enrolled in Section 21 or 29 can start moving to the Lifespan Waiver one year after it opens. Members already enrolled in Section 20 can start moving to the Lifespan Waiver

one year after Lifespan is open for people with other related conditions. Any member thinking about moving to Lifespan will be given counseling to make sure they are making an informed choice before deciding to move to Lifespan.

The plan for the Lifespan Waiver is to serve 540 people with ID and ASD in the first year. This would be done using new funding from the legislature. With stakeholder input, the priorities for enrollment will now be youth, ages 14-17, and adults on the waiting list who are not receiving any waiver services.

The plan for the Lifespan Waiver is to use as many best practices as possible. The plan is also to use ongoing stakeholder input. Some best practices will come from the “Innovation Pilot” projects that started in early 2023. These projects are funded by DHHS American Rescue Plan Act (ARPA) funding. DHHS will also consider best practices from other states.

Best practices will allow DHHS to serve people better. This means serving people without a wait or delay. This also means serving people in ways that use funding smartly so more people can get the services they need, and providers can be paid fairly for the services they provide. This will also help with the direct service staffing shortage. Better pay rates for service providers will mean better pay and benefits for direct service staff in the Lifespan Waiver. This will help get more direct service staff. The proposed Lifespan Waiver is expected to offer case managers and provider agencies more freedom to move beyond long-standing challenges they have faced.

Look below for a table that lists the proposed services for the Lifespan Waiver. The tables also show the four proposed enrollment groups within the Lifespan Waiver. You can see what proposed Lifespan services would be available to each enrollment group.

In the second table below, you can see a list of the Lifespan services that would be available for self-direction.

For additional detail, see the full Concept Paper at <https://www.maine.gov/dhhs/oads/about-us/initiatives/hcbs-lifespan-project>.

Table 1: Four (4) Proposed Enrollment Groups in the Lifespan Waiver

<b>Group #1</b>	Ages 14-21	<p>All youth ages 14-17 will be enrolled in Group #1. Also, a person who is age 18-21 will be enrolled in this group if, with Lifespan Waiver services for this group, the person is able to:</p> <ul style="list-style-type: none"> <li>• Live independently</li> <li>• Live with natural family</li> <li>• Live in supported living arrangement; and/or</li> <li>• Live in a Shared Living-Related setting with paid family supports.</li> </ul>
<b>Group #2</b>	Ages 22-64	<p>A person who is age 22 to 64 will be enrolled in this group if, with Lifespan Waiver services for this group, the person is able to:</p> <ul style="list-style-type: none"> <li>• Live independently</li> <li>• Live with natural family</li> <li>• Live in a Supported Living arrangement; and/or</li> <li>• Live in a Shared Living-Related setting with paid family supports.</li> </ul>
<b>Group #3</b>	Ages 65+	<p>A person who is age 65 or over will be enrolled in this group if, with Lifespan Waiver services for this group, the person is able to:</p> <ul style="list-style-type: none"> <li>• Live independently</li> <li>• Live with natural family</li> <li>• Live in a Supported Living arrangement; and/or;</li> <li>• Live in a Shared Living-Related setting with paid family supports.</li> </ul>
<b>Group #4</b>	Ages 18+	<p>A person who is age 18 or over will be enrolled in this group if, with Lifespan Waiver services for their age-appropriate enrollment group, the person is <b><u>not</u></b> able to:</p> <ul style="list-style-type: none"> <li>• Live independently</li> <li>• Live with natural family</li> <li>• Live in a Supported Living arrangement; and/or</li> <li>• Live in a Shared Living-Related setting with paid family supports</li> </ul> <p>and therefore, needs placement in a provider owned or controlled residential setting (i.e., Shared Living-Unrelated setting or Agency Group Home setting.)</p>

Table 2: List of Proposed Services for Each Enrollment Group:

For sample descriptions of the services that you can comment on, please refer to the Appendix A of the Lifespan Concept Paper on the OADS Lifespan Website. [HCBS Lifespan Project | Department of Health and Human Services \(maine.gov\)](#)

Lifespan Waiver – Enrollment Groups		Enrollment Group #1 Ages 14-21	Enrollment Group #2 Ages 22-64	Enrollment Group #3 Ages 65+	Enrollment Group #4 Ages 18+
<b>PROPOSED SERVICES</b>					
<b>Community Resource Coordination (Case Management)</b>		X	X	X	X
<b>Employment Exploration</b>		X	X	X	X
<b>Career Planning</b>		X	X	X	X
<b>Must Use VR First if Available</b>	<b>Job Development Plan or Self-Employment Start-Up Plan</b>	X	X	X	X
	<b>Job Development or Self-Employment Start-Up</b>	X	X	X	X
	<b>Job Coaching</b>	X	X	X	X
	<b>Co-Worker Supports</b>	X	X	X	X
	<b>Career Advancement</b>		X	X	X
	<b>Integrated Employment Path Services</b>	X	X	X	X



<b>Lifespan Waiver – Enrollment Groups</b>	<b>Enrollment Group #1 Ages 14-21</b>	<b>Enrollment Group #2 Ages 22-64</b>	<b>Enrollment Group #3 Ages 65+</b>	<b>Enrollment Group #4 Ages 18+</b>
<b>Benefits and Work Incentives Counseling</b>	X	X	X	X
<b>Community Transportation (not medical)</b>	X	X	X	X (Employment only)
<b>Community Membership, Volunteering and Relationship Supports</b>	TBD	X	X	Part of residential service
<b>Personal Care/Assistance-Community Supports</b>		X	X	Part of residential service
<b>Consumer Education and Training (including supported decision-making)</b>		X	X	X
<b>Peer Specialist Services</b>	X	X	X	
<b>Family Empowerment &amp; Systems Navigation Counseling</b>	X	X	X (esp. healthcare system)	
<b>Unpaid Natural Family/Caregiver Education and Training</b>		X	X (esp. dementia, etc.)	
<b>Home-Based Independent Living Skills including Financial Literacy</b>	X	X	X	Part of residential service
<b>Personal Care/Assistance Home Support</b>	X	X	X	Part of residential service

<b>Lifespan Waiver – Enrollment Groups</b>	<b>Enrollment Group #1 Ages 14-21</b>	<b>Enrollment Group #2 Ages 22-64</b>	<b>Enrollment Group #3 Ages 65+</b>	<b>Enrollment Group #4 Ages 18+</b>
<b>Respite Breaks and Opportunities</b>	X	X	X	N/A
<b>Remote Supports Technology and Real-Time Response</b>	X	X	X	X
<b>Assistive Technology and Adaptive Aids (including disposable medical supplies)</b>	X	X	X	X
<b>Housing Counseling and Start-Up</b>	X	X	X	X (to leave residential)
<b>Housing Start-Up Assistance</b>	X	X	X	X (to leave residential)
<b>Supported Living Services</b>	X (18-21)	X	X	Part of residential service
<b>Minor Home Modifications</b>	X	X	X	Part of residential service
<b>Shared Living-Related Services</b>	X (18-21)	X	X	
<b>Shared Living-Unrelated Services</b>				X
<b>Agency Group Home Services (Ages 18+)</b>				X
<b>Positive Behavioral Supports</b>	X	X	X	X

Lifespan Waiver – Enrollment Groups	Enrollment Group #1 Ages 14-21	Enrollment Group #2 Ages 22-64	Enrollment Group #3 Ages 65+	Enrollment Group #4 Ages 18+
Physical Therapy	X (Age 18-21)	X	X	X
Occupational Therapy	X (Age 18-21)	X	X	X
Speech and Language Therapy	X (Age 18-21)	X	X	X
Skilled Nursing	X (Age 21)	X	X	Part of residential service
Individual-Directed Goods and Services (for users of self-direction)	X	X	X	X
Support Broker (for users of self-direction)	X	X	X	X

Table 3: List of Proposed Services for Self-Direction:

<b>Employment Exploration</b>	
<b>Career Planning</b>	
<b>Must Use VR First if Available</b>	<b>Job Development Plan or Self-Employment Start-Up Plan</b>
	<b>Job Development or Self-Employment Start-Up</b>
	<b>Job Coaching</b>

	<b>Career Advancement</b>
	<b>Integrated Employment Path Services</b>
<b>Community Transportation (not medical)</b>	
<b>Community Membership, Volunteering and Relationship Supports</b>	
<b>Personal Care/Assistance-Community Supports</b>	
<b>Consumer Education and Training (including supported decision-making)</b>	
<b>Home-Based Independent Living Skills including Financial Literacy</b>	
<b>Personal Care/Assistance Home Support</b>	
<b>Respite Breaks and Opportunities</b>	
<b>Supported Living Services</b>	
<b>Skilled Nursing</b>	
<b>Individual-Directed Goods and Services (for users of self-direction)</b>	
<b>Support Broker (for users of self-direction)</b>	