

Chairman Baldacci, Chairwoman Myers, and Distinguished Members of the Joint Standing Committee on Health and Human Services,

My name is Kathy Rickards and I am the parent of a 42 year old man with medical, intellectual, and mental health diagnoses that significantly impact his life. In Section 1 of LD 659, it states that the Department of Health and Human Services shall adopt routine technical rules pursuant to the Maine Revised Statutes, Title 5, Chapter 375, Subchapter 2-A establishing a Maine Care Home and Community based Lifespan program for individuals with intellectual and developmental disabilities, autism, or other related conditions, referred to in the Act as “the lifespan program.” My purpose in testifying is to ask that the designation “routine technical” be amended to “major substantive” because simply put, it is a huge departure from all previous Waiver Services and may have life altering effects for people with more severe disabilities.

The Lifespan Waiver is purported to be a flexible, seamless, and fair allocation of services. I appreciate that the Department of Health and Human Services has begun this major rules change well ahead of implementation, and that a stakeholder advisory committee was initiated, however I am in hopes that this committee will work to be more responsive to individuals served and their families, as I understand this is not the case currently.

Maine has long been a leader in person centered planning for adults with disabilities. Planning for services was done by invested stakeholders who knew the individual and the services that would be required to support quality of life in their chosen communities. The Lifespan Waiver negates all the knowledge and care of a person’s team, and instead, relies on a one-time assessment by an unknown evaluator. This will never capture the needs of people with intellectual, communication and/or behavioral challenges. This one-time assessment will assign each person a funding level tied to a budget. The ramifications of this one-time assessment became clear when this disastrous policy of using the SIS (Supports Intensity Scale) was begun in 2015, and then discontinued due to the harm done to the disability community. I have seen no research that the implementation of the SIS has led to improved quality of life for people with disabilities. In fact, I believe the majority of individuals lost significant funding and services. In no other segment of the population is a one-time test done to determine every aspect of their lives.

Section 21 has long been the funding mechanism for housing and community services. It is my understanding that Section 21 will die from attrition as the Lifespan Waiver is put into effect, so this very stable foundation of people’s lives will be gone. This is in no way “routine technical” for people with disabilities, their families, and the agencies that support them. Please amend the language of this bill to major substantive in the interest of meeting the needs of individuals with disabilities who have seen the collapse of care for many in their community.