

Good afternoon. My name is Janet Hamel. I am testifying in strong support of LD 659, the bill to create the Lifespan Waiver for Individuals with Intellectual and Developmental Disabilities, or IDD.

My qualifications? I'm Marty's mom. Marty has IDD. For 40+ years I've been an active partner in helping Marty learn and grow, first throughout school and now in her adult life. An incidental qualification is my PhD in leadership.

When Marty returned to Maine in December 2018 after living out of state for 3 years, she was put on a waiting list for MaineCare waiver services. It took 4 years, and simultaneous medical crises in our family, for her to regain Section 21 waiver services. Marty and I are familiar with Maine's waiting lists.

Lives are put on hold—often devastated—when people with IDD do not receive the services they need. When adults with IDD do receive needed services, they grow in independence, contribute to their communities as workers and volunteers, and enjoy activities and relationships with others. They can lead safe, happy, and purposeful lives.

By 2018 Maine DHHS and OADS had been decimated by underfunding, understaffing, political agendas, and low morale. Families like mine dealt with a broken waiver system with limited funding and few residential options. Maine was also dangerously behind the rest of the nation in complying with Federal requirements for meeting the new Final Settings rule for Home and Community Based Services. If Maine failed to comply on time, the Federal match that pays 66% of the cost of Mainer's IDD support services would be lost.

Just in time, new leadership arrived in OADS. In March 2019, Paul Saucier was appointed Director. Paul's career has been in public service, with extensive aging and disability experience. He started his tenure as Director of OADS by holding listening sessions and meeting with groups of stakeholders throughout the state. I attended a few sessions. He didn't hear good things. And weary stakeholders were wary.

Six months later Paul selected Betsy Hopkins to serve as Associate Director, Developmental Disabilities and Brain Injury Services. Betsy's knowledge, experience, and commitment are only surpassed by her honesty and kind heart. Like Paul, her career has been a public service path developing both leadership and disability service system expertise.

Their vision? A support service system providing a seamless transition for youth with IDD from school into adult services that adjusted as needed for changes through the lifespan. In that system, individuals' support needs would be determined by a set of assessments and input included in a comprehensive person-centered planning process. OADS is committed to establishing a more equitable system for determining Home and Community Based Support needs, and a responsive route for adjusting supports as people's needs change throughout their lifetimes.

Another team member of OADS' Lifespan Waiver change initiative is Dr. Lisa Mills, who in over 30 years of leadership in disability policy, has helped 20 other states design and implement innovative public programs and waiver systems.

Committed to work with stakeholders throughout the process, Paul and Betsy added system change expert Craig Donnan to the team, as project manager. In a recent letter, Craig summarized his perspective as “focus[ing] on policies that work and a world where we are all welcome at the table, working together to create a better world.”

This exciting, still evolving, massive shift in “how things are done” at OADS and in Maine is a process with numerous stakeholders engaged—bringing passion, perspectives, and direct experience with the nuances, the broken pieces, and the possibilities when redesigning a support system so that Mainers with IDD will have better lives.

Please join us in supporting the Lifespan Waiver system change initiative.

Janet Hamel  
Bar Harbor  
LD 659

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