

April 23, 2025

My name is Lorie Dorrance, my husband and I are the parents and guardians of a 31 year old son who is receiving benefits through a Section 29 Community Based Waiver. He lives at home with us. At age 70, when my husband retired, he became his Shared Living Provider. We do not have a plan in place for when we are too old to keep him at home.

Our son has a rare genetic syndrome, he is kind, gentle, funny and well liked by his peers and caregivers. He cannot read or write. He does not understand danger, he has not mastered any of the activities of daily living; cooking, bathing, shaving, tooth brushing or food preparation. He cannot be left alone in our home, at 65 and 70 we are still hiring babysitters for a night out. We are fortunate to be able to care for him.

I attended the DHHS workshop for parents of children with developmental disabilities. It was difficult for me to envision the promises the Lifespan Waiver would achieve. Our lived experience has been one of Case Management turnover, direct-care workforce crisis, long waits for promised assessments, and limited funding. I understand that the wait list for services will be eliminated, stretching the existing programs thin. Without ongoing oversight by the legislature, for all the rosy promises, I believe the waiver could end up doing more damage than good.

I urge you to approve LD 1606, requiring the waiver to be major substantive, indefinitely ensuring there is adequate oversight as the new program is rolled out and adjusted.

Thank you.