

DDHI testimony, February 2024

My name is Ellen McKay Jewett. I live in Middlebury. I am part of the Developmental Disabilities Housing Initiative, a group of over 100 Vermont families, who like me, have an adult child with an intellectual/developmental disability who need safe, caring, stable homes when their parents can no longer care for them.

My 31 year-old daughter Kate has cerebral palsy, spastic quadriplegia, intellectual disability, and is non-verbal and deaf. She will never be able to live independently due to her physical and intellectual disabilities. She requires help in all activities of daily living. She can't get herself out of her wheelchair, feed herself, pull up her covers, or open a door.

She is an unbelievably positive and endlessly hopeful human being.



Kate currently lives in a shared living arrangement with a homecare provider. That arrangement is unpredictable and may fall apart any day. Her father and I are both aging, with health problems, and within a few years will no longer be able to care for her.

Familial guardians and advocates – Kate's natural protectors – will eventually be no longer able to care for her if her housing situation falls apart, leaving her care precarious.

It is critical that we put a better system in place for Kate and her peers.

In Vermont, Shared Living – which is essentially fostering out these most vulnerable Vermonters to literally anyone who will take them (as long as they don't have a criminal record) – is the only housing option. To get a sense of what this feels like, imagine sending your aging parent with mild dementia off alone to live in a series of unknown strangers' homes. It is hard for me to imagine that any of us would choose that option.

Please support DDHI's request for \$10.82 million for the implementation of three pilot planning projects under Act 186, and the continued annual development of service-supported housing for adults with intellectual/developmental disabilities so that there can be sufficient housing and care.

Thank you for your consideration. These are our most vulnerable citizens. Please help us create some better living options for them.

