

I'm Ellen Blackmer McKay Jewett, and I live in Ripton.

I'd like to describe what it feels like to be the parent of an inspiring young Deaf woman with intellectual and physical disabilities. Due to the unfortunate circumstance of her high-support needs, she has been left stranded and at significant risk in her home state of Vermont by a well-intentioned but indiscriminate system of support. This system offers her no reasonable and compassionate option for her housing other than a form of adult foster care, referred to as the Shared Living model.

Kate is a bright, happy and social 2015 graduate of the American School for the Deaf. She has cerebral palsy with spastic quadriplegia, is unable to speak and is profoundly deaf. She needs total support in all activities of daily living, such as dressing, getting out of bed, toileting, feeding herself – even pulling up her covers in bed.

She has a good understanding of written English and of American Sign Language, but she can't sign because of contractures in her arms and hands, so she expresses herself as best she can by writing on her iPad with her one good pointer finger.

She is ***inexplicably*** and endlessly positive and hopeful. She is 29 years old.



The only living options for Kate in Vermont are to live with her aging and exhausted parents, or – to be sent by the State to live

with literally almost anyone who is willing to take her as part of the Shared Living system.

I'd like to describe to you what's happened to Kate in the seven years since her high school graduation. The only designated agency providing developmental services in Vermont that has supports in place for deaf clients is Northwestern Counseling and Support Services in St. Albans. So when Kate aged out of the educational system at age 22, we knew she had to be up in the northwest corner of the state for her services.

We found a Deaf couple in that area who were willing to be her shared living providers but their home was not wheelchair accessible, so we managed on our own to purchase a house for all of them to live in together. This, of course, is not within the means of most Vermont families.

We didn't realize that this couple had severe relationship problems which led to their break-up about a year after Kate moved in. She was the unfortunate witness to domestic trauma, and suffered severe neglect both before and after the break-up.

Because of the turmoil, the house became filthy and chaotic, but her case manager (who was supposed to visit once a month) had literally no other living options for her, so Kate was forced to stay where she was.

Kate came home twice a month, but never expressed to us what was happening in her home. She was intensely loyal to the people she relied on to take care of her.

When that shared living provider moved on, we found after several months a single mother who was willing to be Kate's new care provider. She did a good job but she was not deaf, and so Kate inevitably felt isolated and left-out in the house, since no one in the house used sign language. Imagine how you would feel as a hearing person if you were placed in a household where no one ever spoke and the only communication was by signs you would never be able to understand. That's what it's like for a Deaf person to be placed in a hearing home.

When the pandemic hit, Kate came home to Middlebury and has been living with her dad ever since March 2020. Both of them are especially vulnerable to covid because of lung conditions, and they've stayed safe together for all that time. But her dad is 73, and is exhausted from two solid years of 24/7 care.

Now that Vermont's covid numbers are coming down, her dad can allow Kate to come to our house in Ripton on the weekends.

I spent the last year caring for my husband who had terminal cancer, and who died two months ago. Many of you knew and served with him here at the State House. Willem loved Kate and was horrified at the lack of housing choices she had. In the months before he died, Willem built ramps and an accessible first-floor bathroom in our home so Kate could comfortably visit.

Willem's death is tragic in so many ways, and it underscores a terrible but obvious truth: the natural guardians and advocates for our sons and daughters will die (sometimes way too early), leaving them unprotected. This is why we must put a better system in place for their care .

That does not yet exist, so we are looking frantically for a new shared living provider for Kate, now that the pandemic is becoming manageable. Despite advertising that runs continually throughout the northeast, we've had just one wildly inappropriate application in more than three years.

In Vermont, Shared Living – which is essentially fostering out these most vulnerable Vermonters to literally almost anyone who will take them – 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. None of us would do that.

Many families can't bring themselves to do this to their adult children and keep them at home. But what happens when those parents are no longer alive?

Currently, our sons and daughters would have no choice but to go live with strangers. Some of these placements are good and work for up to several years. But then our vulnerable adult children are homeless again when those caregivers are no longer able or interested in providing a home. And if their parents are gone at that point, where do they go? They go into another stranger's home.

This system is inherently unstable and temporary. For developmentally-disabled Vermonters like Kate, stability is crucial. They need a home that stays constant even though their caregivers change.

This reality is an ongoing source of anxiety for us as parents, as we watch our aging children move closer to a precarious future, with no real choice about where or with whom they live.

This is at its core a human rights issue. We all deserve choices in where and with whom we live.

When the Brandon Training School closed almost 30 years ago, promises were made about creating new ways to care for these citizens. The only system put in place was the Shared Living model. While it works for some, Shared Living isolates many others in unhappy and inappropriate living arrangements, far away from their peers. It also makes it more likely for neglect and terrible abuse to take place. [VT Digger reported on such a case on Nov. 8, 2019.](#)

The Developmental Disabilities Housing Initiative (DDHI) is a group of 75 aging parents who are advocating for some better options.

We envision small supported peer communities of perhaps 3-4 residents in walkable neighborhoods, with well-trained, well-paid staff who work in shifts. This model would allow residents to stay in their homes even when staff members change. It would allow residents the opportunity to make friendships with their peers living in the home, as well as increasing the potential for active participation in community social and cultural events. And it would allow staff to care for them in a sustainable way. We are talking about residents who need 24/7 support. Caring for them, as you can imagine, is a very challenging job. Individual care-givers burn-out at a high rate if they do it day-in and day-out. There are good

people who want to do this work, but they need colleagues doing it with them.

The Models Committee of our group has assembled information on a variety of successful supported housing models in nearby states. This isn't rocket science. Good models exist for Vermont to emulate.

Our Coalitions Committee is creating partnerships with housing trusts, developers and state agencies that manage the care of these citizens. These coalitions will be crucial in making these small, stable and stimulating residential communities a reality.

To close, I'd like to ask you to imagine that you are the parent or grandparent of a young woman like my daughter Kate; that the universe has given you a wonderful young woman who cannot speak or protect herself. What kind of living arrangement would you like her to have? Would you want her to be able to choose the people she lives with? Would you want her to have some good choices?

Thank you for taking the time to hear my testimony.

Ellen McKay Jewett