

Feb. 16, 2023 Public Hearing, Montpelier, VT

To: Members of The Senate Committee on Economic Development, Housing, and General Affairs and the House Committee on General and Housing

It has been brought to my attention, and I am so grateful, that your committees are seeking testimony from Vermonters who have been affected by Vermont's extremely limited housing options.

I would like to tell my family's story and share my deep concerns on behalf of my son.

I am Donna Savage, a lifelong Vermonter, and my husband, Patrick, daughter, Shea and son, Jack have been Williston residents for the past 19 years.

Our son Jack, soon to be 22 years old, has significant and intensive life-long disabilities which require 24/7 support and care. He is profoundly deaf with a cochlear implant, has cortical visual impairment, developmentally delayed, cognitively impaired, and non-verbal with limited other language skills. Due to his combined vision and hearing loss (deafblindness), he is on the Deaf-Blind census in the state of VT.

On an everyday basis our son needs help with all activities of daily living (ADL) inclusive of diapering - he is incontinent, food preparation and feeding, communication, transportation, and medication administration. He is currently in his last year at CVU in Hinesburg and has 2 intensive needs paraeducators at school who share their time with him.

Despite Jack's disabilities one thing we know **for sure**: Jack knows his people and his places. In fact consistency of people, places, and routine is crucial to his well-being.

As Jack's aging parents, we've begun to ready ourselves for his post-public school education days and to think about what his future living situation will look like once we can no longer care for him in our home. It is no understatement to say we are very concerned with what we have learned. Since 1992, when Brandon Training School (and other similar institutions) were closed, VT has developed only one model for this population of Vermonters with high support needs: the "Shared Living Provider," model which is, essentially, VT's adult foster care system.

While this might work well for some, for our sons and daughters with intensive special health needs, this model has proven to not work well at all! There is no "contract" that says people need to commit to being an SLP forever. Further, if it does not work out with one SLP or it is simply not a good match, off the disabled person goes to another home, and then perhaps *another*. This is scary. It would also be a dramatically destabilizing living arrangement for our son (a person *completely* dependent upon structure and routine).

But as of right now our families are faced with no choice. High Support Developmentally Disabled Adults in the state of VT have been left out of the equation for real housing choices and VT needs to urgently fix this.

On behalf of all the families who make up the VT parent-run advocacy group “Developmental Disabilities Housing Initiative (DDHI)” of which we are a part, I implore you to please prioritize the service-supported housing needs for our most vulnerable Vermont citizens.

Jack does not have a voice, but I want to stress **for him** that a stable environment which has a staff of skilled and dedicated support people, that is inclusive of friends he has known throughout his life, and that provides social engagement, community, and - perhaps most importantly - ***permanance*** - is what the focus for his next home should be.

A safe home – a “home for life.”

Thank you for making that a reality for him and others so deserving like him, right here in their home state of Vermont.

Sincerely,

The Family of Jack D. Savage:

Donna, Patrick (parents),

and Shea (sister)