Written Testimony for the Feb 16<sup>th</sup> Public Hearing on Housing

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

Vermont is a wonderful place to live but if you, like me, are the parent of an adult child with a significant intellectual disability, Vermont can be a scary place to call home. Not because Vermonters aren't kind to my son, who has a particularly disabling form of Down Syndrome and so will need lifelong supervision. It's scary because once I am no longer able to care for Jesse, he'll likely end up in Vermont's adult foster care system, called "Shared Living". The prospect of my open-hearted, vulnerable son spending his adult years as a guest in the homes of a series of strangers is deeply disturbing.

The Shared Living program, while a well-intended step up from the Brandon Training School, is particularly unsuitable for adults whose developmental disabilities significantly limit their ability to express, protect and care for themselves, and who thrive on stability and in the company of their peers.

Once my husband and I realized that adult foster care would likely be Jesse's fate when we were gone, we began advocating for Vermont to consider developing the kind of stable housing communities for adults with intellectual disabilities that exist in many other states. We were busy parents and did our best, but nothing seemed to change. And when my husband was diagnosed with a terminal brain tumor, our hardest conversations were about what would happen to our son.

And so, a few months after my husband's death, I reached out to other aging parents of adults with significant developmental disabilities and together we formed the Developmental Disabilities Housing Initiative (DDHI). We were the driving force behind Act 186 and will continue to relentlessly advocate until we get the support we need to develop stable housing for our adult sons and daughters. I have no doubt that none of you would want your elderly parent – perhaps with some dementia – to be placed in adult foster care. So I ask you to please put yourself in our shoes and help us do the right thing by our adult children – the most vulnerable adult Vermonters.

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