

Dear Appropriations Committee Members,

To House Committee on Appropriations:

We are elderly (62 and 73 years old) parents of a young man (28 years old) with Koolen-deVries Syndrome. He is severely intellectually disabled, suffers from a seizure disorder and other medical issues, and requires supervision and support in every activity of daily living – eating, drinking, bathrooming, dressing, etc. He is functionally non-verbal and completely compliant, making him heartbreakingly vulnerable. He cannot be relied upon to communicate pain, discomfort or abuse. He is completely trusting, innocent, sweet and has not one mean bone in his body. He loves music and dancing, reading and watching videos.

His needs have exceeded our ability to care for him and we live day to day, trying to keep him with us for as long as we can. But time is working against us. We have our own health issues. We cannot bear to put him into adult foster care or “shared living,” the only “option” Vermont offers where he will be secluded with one or two individuals who may or may not care for him adequately. Even if he is cared for adequately, he will only be with a shared living provider for as long as they will have him. My son thrives on predictability and will be shattered and confused if shuttled from one “home” to another. And that is assuming there are enough shared living providers to be had.

When the Brandon Training School closed, Gov. Dean promised that this population and their families would have the support and resources needed for adults with intellectual and developmental disabilities to live safely and securely. But as the years passed, resources were reduced, and this most vulnerable population has been left behind, dependent on their elderly parents who hope to, but cannot, live forever to care for them. Vermont broke its promise.

I ask that you move forward to offer a range of supportive community services, including service-supported housing options to allow my son to live safely and with stability, and with the opportunity to live with his peers.

As a member of the Developmental Disabilities Housing Initiative – a group of aging parents advocating for our adult children who are eligible for services under the Home and Community Based Service waiver, I ask you to support these asks, which are part of the Act 69 report:

1. New permanent position at DAIL – Department of Disabilities, Aging, and Independent Living – to support housing development and housing process for participants in HCBS services (DS,CFC,BI).The position is included in S. 328 Senate Housing Committee bill, and recommended by the Act 69 Road Home Report;

2. New funding for Vermont Housing and Conservation Board to develop I/DD service supported housing – there is no money in the Governor’s recommended budget specifically for I/DD housing. The Senate Housing Bill includes \$3 Million – the Road Home Report recommends \$5-10 million per year for 5 years;
3. New funding for Bridge Rental Assistance – State funded rental assistance (Section 8 vouchers)for participants in DAIL’s HCBS programs- The Road Home report recommends \$1-2 million dollars per year.The Bridge Rental Assistance Program that would include DAIL/HCBS is in bill H. 494.

Please do not turn away from the most vulnerable Vermont citizens. Fulfil the promise made to adults with intellectual/development disabilities and their parents.

Thank you.

Robert and Karen Price
Essex, Vermont