

Economic Housing and General Affairs Testimony

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Ellen Riley

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My name is Ellen Riley, I am the parent of a 26-year-old son with Down Syndrome, Christopher. I am also a member of the Vermont I/DD Housing Initiative, and a member of the Central Vermont group that received one of the Act 186 Grants for the development of 2 service supported housing models.

Christopher is joyful, loving, a master of puns (some not so good), a Disney encyclopedia, a great alpine skier, loves dances and loves being with his friends. He is relatively high functioning, has no physical challenges, and has many of the essential life skills needed to live independent of us, BUT, he is vulnerable and cognitively not able to manage his life: he cannot manage his required doctor or dentist appointments, cannot pay bills or manage money, cannot find and apply for jobs, cannot manage a household keeping food and household needs supplied, cannot plan meals and cook without supervision, cannot plan his social life, keep himself informed about the opportunities that are available with Vermont Adaptive, Special Olympics, or in the community. He cannot transport himself or arrange for transportation. He can do laundry, fold and put away cloths, take showers, shave, start a dishwasher, put dishes away, set a table, brush his teeth, put himself to bed, set an alarm to wake, and be ready when his DSP arrives. HOWEVER, he has to be prompted to do all these daily tasks. He will always need someone to support him and manage his daily life, someone to ensure he has a full, active and meaningful life.

He is a young adult male who has seen his younger sister leave for college and then set up her own life in Bethesda, Maryland. He has seen his neurotypical peers, respite providers, Direct Support Personnel, and cousins living separate from their parents, living with friends, with girlfriends/boyfriends, and getting married. They don't have mothers reminding them of 'this or that' and managing every aspect of their lives. He has made the connection that, as he said to me ; "Mom, 26-year-old boys don't live at home with their mother and father, they live with their friends"

I am 69 years of age and still a full-time parent for my son who lived at home, and was managing all aspects of his life until recently.

Last April, it became clear to us that Chris wanted to "launch" and live separate from us. He wanted to live with friends and had shown us that he could "rise to the occasion" of getting to bed, getting up, eat breakfast and being ready when his DSP arrived. HOWEVER, the option of living with his peers is not allowed in the State of Vermont unless he were to live in a licensed therapeutic residential community.

Something had to be done to move forward and get him living independent of us. Living with friends was not an option, so we felt getting him in an apartment with a Shared Living provider would be a good stepping stone until the Service Supported Peer Residence Model could be approved in Vermont, and built!

We found a wonderful “30 something man” who Chris knew from Zeno Mountain Farm who agreed to live with Chris “for one year” if/when we found an apartment (if you are not familiar with Zeno, google them! They are a fabulous non-profit in Lincoln Vt). Then the flood hit and everything was halted.

In October, we learned of a small, renovated, two-bedroom carriage house in Montpelier that would be for sale. John (my husband) had been the lawyer helping the current owners buy the house 6 years ago. They had outgrown the house, were buying a new home, and were going to be putting it on the market. We jumped on it; it was a block from downtown, 2 blocks from his dad’s office, and tucked away behind the house that fronted the street. Chris now spends 4 days/week there and 3 at home while he transitions to living there full time. The transition has been hard, he is clingy when home with me, and does not sleep well. While this is what he desired, the reality and separation is a lot for him to process.

The financial implications to us in purchasing this home are not inconsequential. In order to buy the house, we had to mortgage our home and cash in part of our retirement.

Parents should not have to compromise financial stability that will see them through their aging years to ensure their children have the opportunity to live independent lives. We need housing options provided by the state that fit the desire of how our children want to live, and where they can age in place.

I am so thankful to Rep. Theresa Woods and the House Committee on Human Services for sponsoring Act 186 last legislative session that funded grants to research and develop housing models in Vermont for individuals with I/DD. There are currently 3 planning grants with initial models being developed. Importantly however, these models can go no further than development without the funding to build.

We don’t want to lose the gains made in H. 829. Please add the policy breakthroughs from H. 829 to H. 639. The House bill included new pipelines- please support adding them to H.639 or elsewhere.

Our I/DD community desperately needs the development of affordable housing options that address the range of needs and provides choices, in permanent service-supported housing. My son would like to live with peers in a residence, like others his age, in the area that he grew up, near friends and well-known neighbors - the “village” that has supported him

I need to see my son settled and happy living with his peers in a Service Supported Peer Residence while I am still alive and able to help with the transition. Support personnel may change over the years, but he will have the companionship and support of his friends to weather those changes. In the model he is living now, he will lose his SLP in a year and have to readjust to whoever we next find. Potentially this could happen year after year. Can you imagine you or your parent going through that?

Please support the pathway language changes as proposed
(see separate page)

Respectfully submitted
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Of NOTE:

9% of individuals who have ID/DD are either homeless, or at risk of homelessness, (Vermont Care Partners).

The State of Vermont needs to create 602 new units of supportive housing to meet the needs of adults with I/DD who receive HCBS. (VTDDC 2023 Housing Research Brief)

The State of Vermont failed to meet their obligations under Federal Medicaid Rules, and now have 2 Corrective Action Plans to demonstrate that HCBS recipients have true choice, including choices in housing. The three Act 186 Pilot Planning Grants are contained in the latest Corrective Action Plan.

Since closing Brandon in 1993, there has been little to no money invested by the State of Vermont in appropriate service supported housing for adults with developmental disabilities and moderate to high support needs, in spite of promises made by Governor Dean. People with Developmental Disabilities have been unfunded for over 30 years, it is time to include them.

1999 Olmstead Act directed states to develop a fiscal plan to include housing for people with developmental disabilities in their state budgets, however there are no targets in the VT Olmstead plan.

Our family members have HCBS funding provided by Medicaid for services, and access to entitlement benefits (SSA benefits) for ongoing housing costs.



Pathway Language H639 or other bill

Language to add people with Medicaid funded Home and Community Based Services to the priorities for the Vermont Housing and Conservation Board and VHIP.

Vermont Housing and Conservation Board existing priorities:

To provide support and enhance capacity for the production and preservation of affordable rental housing and homeownership units, including support for manufactured home communities, permanent homes for those experiencing homelessness, recovery residences, and housing available to farm workers, or refugees.

NEW LANGUAGE:

or individuals with disabilities who are eligible to receive Medicaid-funded home and community based services;

V.H.I.P. Language

10 V.S.A. § 699 is amended to read:

§ 699. VERMONT RENTAL HOUSING IMPROVEMENT PROGRAM⁵

(1) A landlord shall coordinate with nonprofit housing partners and local coordinated entry organizations to identify potential tenants.

(2)(A) Except as provided in subdivision (2)(B) of this subsection (e), a landlord shall lease the unit to a household that is:

(i) exiting homelessness, including any individual under 25 years of age who secures housing through a master lease held by a youth service provider on behalf of individuals under 25 years of age; or

(ii) actively working with an immigrant or refugee resettlement program.; or

(iii) composed of at least one individual with a disability who is eligible to receive Medicaid-funded home and community based services.