

Human Services Testimony  
February 15, 2024  
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Moretown, Vt

Good afternoon. 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 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 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 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.

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

Chris is 26. 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 a few weeks ago; "Mom, 26-year-old boys don't live at home with their mother and father, they live with their friends"

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 friends 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 and built.

We found a wonderful young 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 owners lawyer helping them buy the house 6 years ago. They had outgrown the house 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 spent his first few nights there starting last Wednesday. He is there 4 nights/week and with us 3 nights/ week. The transition has been hard, he is clingy when with me, and does not sleep well. It is a lot for him to process.

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 us through our aging years to ensure our children have the opportunity to live independent lives. We need housing options that fit the desire of how our children want to live, and where they can age in place.

I am so thankful to Teresa Woods for sponsoring Act 186 last legislative session that funds the grants to research and develop housing models in Vermont for individuals with I/DD disabilities. We have 3 planning grants with initial models being developed.

Importantly however, these models can go no further than development without the funding to build. **We need the State to fund the building of these projects, and to create a funding pipeline for the many future models that will need to be built.**

Of note: In the 2023 research brief submitted to the State, it stated “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”. The spectrum of needs and supports is wide and a model that works for some will not work for all.

I want 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 sponsor a bill to create funding for the building of the models currently in development, and create a pipeline that will fund all future needed housing so we parents can be comforted in our old age knowing our children will be able to live and age in place in the housing model that they desire, and that provides the best possible life for them.

