

## **2/14/2025 Senate Health and Welfare Committee Testimony**

**My name is Laurie Mumley. I live in Shelburne, and am an aging single parent to two children. I retired 5 years ago. I had planned to resume working but am unable to do so due to the needs of my son. My daughter is a senior in high school. My son Joey -who is here with me today- turns 23 this coming May. He loves music, singing, Disney movies, the Rocky Horror Picture Show, swimming, and being a part of things. He is very social, and enjoys spending time with his peers. He can be absolutely charming, funny, has an infectious laugh, a beautiful singing voice, and a fantastic sense of humor.**

Joey was diagnosed with autism at age 2 1/2. He continues to struggle with compulsive behaviors, multiple sensory challenges, a complete lack of safety awareness, and numerous behavioral challenges (heightened by the fact that he is 6'3" and nearly 400 pounds). He is also minimally verbal and requires assistance with all activities of daily living. He requires 24/7 supervision and needs a high level of structure and predictability.

Vermont schools were unable to provide the level of care that he needs. We tried a variety of alternative placements. Finally, in February of 2022, he began Easterseals, an out of state residential educational program in Manchester, New Hampshire. I did not want my son to have to leave the state to get the care that he needs. However, from the very first day he arrived, he LOVED it. He lived in a hall with 15 other boys who were just like him. He shared a room

for the first time in his life. He was surrounded by people that “get” him. He had a routine and activities for 12 hours a day. Being active and engaged for so many hours a day improved his sleep issues. He lost over 40 pounds, and was working his way to a healthier weight. He enjoyed the very age-appropriate experience of living with his peers and feeling independent. He absolutely thrived there. His teacher called him a “role model” and “a joy in the classroom”. He was happy and felt good about himself.

He gained so many skills during his two and a half years there, and was so proud of himself.

During that time, we had numerous meetings with school staff and our designated agency. Vermont does not have housing to meet his needs so we began exploring out of state placements. Most other states have a variety of options to meet the needs of adults like my son. Unfortunately, last May, Joey aged out of Easterseals to.....nothing. He still will ask about what he calls “Easterseals College”. He has started to regress and lose some of the gains he made in New Hampshire.

Right now in Vermont, adults with Developmental Disabilities and moderate to high support needs have basically two housing options-

1. Remaining with their aging parents until their parents die or are physically no longer able to provide even minimal care

This is not ideal for adults like my son. He craves time with his peers and constantly being engaged. or safe for my son. No matter WHO those 1 or 2 people are, they CANNOT provide him the level of care he needs. My physical health is suffering. My house is constantly needing repair. When he doesn't sleep, he is very loud and sometimes engages in unsafe or destructive behaviors. His little sister has expressed exhaustion and an inability to concentrate on her schoolwork. If I suffer a medical emergency or need surgery, he would become homeless. When I die, he will become homeless. He struggles with transitions in the best of times. Living through one of those scenarios and THEN being moved would compound his trauma and make his next placement that much more difficult.

2. The second option is Adult Foster Care, also called Shared Living (SLP model)

While this can be a good option for those with lower support needs, there is no way that Joey's needs and behaviors could be managed by 1-2 people. No matter WHO those 1 or 2 people are, they CANNOT provide him the level of care he needs. In addition, being hidden away in someone's home with very limited communication and little to no oversight would put him at high risk for abuse and/or neglect. Finally, it is not a “permanent” situation. When shared living providers quit, retire, or are fired, it is the person needing care that has to move.

There are a few scattered peer residences in the state. The few that exist serve specific populations, primarily those that have lower support needs or have specific programming needs (such as sex offenders). *None* serve developmentally delayed adults that have significant support needs.

I'm part of the Developmental Disabilities Housing Initiative (DDHI), an all-volunteer group of over 125 Vermont parents of adults with Developmental Disabilities, who receive the Home and Community Based Waiver (HCBS) and have moderate to high support needs. We formed a few years ago to advocate for housing choices for our adult children. We've researched housing models, conducted housing surveys, and advocated for systemic changes to remove barriers to developing appropriate housing for this population.

I've often thought that, in many respects, our families are the invisible ones. You don't often see us at sports events, or concerts, or farmers markets, or other community events. Those types of events are difficult, if not impossible, for most of us to attend. You might think that there aren't families “like us” in your community. You would be wrong. We are here, in every community across this state, but we are exhausted and need your help. The 2023 Developmental Disabilities Housing Research Brief by the Vermont Developmental Disabilities Council indicates an immediate need for at least 602 beds for this population and suggests that this is likely an extremely conservative number.

Joey WANTS to live with a community of his peers. He also NEEDS stable, service supported housing with sufficient 24/7 supports to safely meet his needs. This, sadly, does not yet exist in Vermont.

The fact is, when the Brandon Training School shut down in 1993, promises were made by the State and have not been kept. The community programs (day programs, work programs, and HOUSING) STILL do not broadly exist (over thirty years later!) and the growing Developmental Disabilities community has been ignored and underfunded these past few decades. We are frighteningly behind other states, and dependent on rapidly aging parents to provide care.

Act 186 (An Act Relating to the System of Care for Individuals with Developmental Disabilities) was implemented in 2022, which was an important first step. This included seed money for three Pilot Planning Grants across the state. These have been awarded to groups in Chittenden, Washington and Addison counties. The first opened last fall- Riverflow in Monkton. The first four beds are full, and the last time I checked, the waiting list had over 60 applicants. They hope to break ground on Phase 2 by late summer, but this will be contingent on funding. The Washington County project is funded and moving forward.

The Chittenden County project needs 2.8 million for the Champlain Housing Trust. That allocation is currently in the Budget Adjustment Act (which passed from the House to the Senate this week). This would bring Vermont a little bit closer to meeting the needs of this population. I am asking that you support this.

I am well aware that housing in Vermont is at a crisis point. Many many different groups (the homeless, New Americans, substance abusers, etc) get money year after year to create housing options. People with developmental disabilities and moderate to high support needs are the MOST vulnerable people in our community and yet year after year, they have been ignored. It is long past time to designate money to house this population.