Hello, and thank you all for allowing my testimony.

My name is Laurie Mumley. I live in Shelburne, Vermont and am a single parent of two children. My son **Joey** will be 21 years old next month; I am here today on his behalf- and ALSO on the behalf of the hundred or so parents that are part of the Developmental Disabilities Housing Initiative (DDHI) AND on behalf of the hundreds of parents of adults with developmental disabilities who are not able to join in our advocacy work.

I've often thought that, in many respects, our families are the invisible ones. You don't often see us at little league games, or community garage sales, 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.

My son Joey loves music, singing, adaptive snowboarding and biking, Disney movies, 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 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.

I had been providing that 24/7 supervision and care as a single, aging parent, and am overwhelmed not only from his needs but also from navigating Vermont's fragmented System of Care. I retired from the Agency of Human Services about 4 years ago. I had planned to seek employment but have been unable to do so given the needs of my children.

Vermont schools were unable to provide the level of care that Joey needs. We tried a variety of alternative placements. In February of 2022, he began 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. He comes home for visits every 4-6 weeks, and I drive 6 hours each week to take him out for lunch. His grandparents (in their mid-eighties) also make the trip to see him regularly. This puts a strain on our finances, our vehicles, and my availability for his younger sister.

However, Joey is surrounded by people that "get" him. He is enjoying the very age-appropriate experience of living with his peers and feeling independent. He is thriving there. He is being called a "role model" and "a joy in the classroom". He is happy and feels good about himself. He asks to go back to school when he comes home for a visit. He will age out of this program next year, when he turns 22. I don't know what will happen then, other than his active and engaged lifestyle will end. There are currently no options for him in Vermont.

Right now in Vermont, adults with Developmental Disabilities and significant 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 or
2. Shared Living (which is not an appropriate level of care for my son).

There are a few scattered group homes in the state. The few that exist serve specific populations, primarily those that have lower support needs. ***None*** serve developmentally delayed adults like my son (with significant support needs). Medicaid covers the cost of their services. The Department of Aging and Independent Living (DAIL) cannot provide 'bricks and mortar' but this bill can provide this for society's most vulnerable population. We don't even need to develop the "models" for appropriate housing-they have long existed in other states. The DDHI Parent group that I am part of has compiled a report on appropriate housing models-ANY of which could work for my son. Last month's report (The 2023 Developmental Disabilities Housing Research Brief) by the Vermont Developmental Disabilities Council also lists a number of potential housing models. This report further 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 (**thirty years later**) and the growing Developmental Disabilities community has been ignored and underfunded these past few decades. We are frighteningly behind.

As his parent, guardian and sole caregiver, I have been exhausted and overwhelmed for years caring for my son, and advocating for his needs. I would like to slow down….. and yet our children have no voice but ours. And so, I advocate for him and for the other adults like him.

Act 186 (An Act Relating to the System of Care for Individuals with Developmental Disabilities) was implemented last year, which is an important first step. I am asking that, as you explore the housing needs across Vermont, please remember that adults with developmental disabilities and significant support needs also need housing. When other projects and populations are being considered, **include specific housing set aside for our adult sons and daughters**. Housing choice is actually mandated by federal Medicaid (CMS) rules; Medicaid also has training available to support partnerships between our local designated agencies and our local housing organizations.

The final issue I'd like to mention is the worker shortages. The burden of this crisis has fallen onto families. Just because no paid caregiver is available, does **not** mean that adults with developmental disabilities don't still need to eat, or use the bathroom, or shower etc. The parents are continuously forced to step in and "fill the gaps".

As a single parent with zero assistance from my childrens' father-I cannot work , or grocery shop, or care for my other child if I do not hire caregivers for my son when he is home. If I do not have help, it is me alone caring for my son 24 hours a day. I have been paying caregivers well above the going rate for many years. I was paying nearly double the "going rate" out of my sons budget long before the pandemic. It was the only way to attract and maintain reliable workers, given the intensity of the demands on them and the fact that they do not receive any other benefits. It is critical that we maintain and encourage this workforce to help care for our most vulnerable population. I would ask that you support a 10% medicaid rate increase for developmental services and that you support an annualized rate review for Home and Community Based Services (HCBS).

I am more than happy to answer any questions you might have. Thank you for your time and attention.

Thank you,
Laurie Mumley