

My name is Marla McQuiston, I'm here to ask for two things, the funding needed for the last of the three pilot projects from Act 186, and the funding needed to support a Medicaid rate increase, to increase the pay for Direct Service Professionals. The Champlain Housing Trust project in Burlington still needs \$2.8 M to move to construction.

I am part of the Developmental Disabilities Housing Initiative. I have 3 sons and a daughter. My youngest son has Down syndrome. He's 27 and we're hoping to make sure that he'll have a place to live before we are gone. He has friends and is well known in Williston, and would be happiest if he could live there with some peers. He works at UVM in the Grounds Dept and can take the bus there and back, so he has some skills to be independent.

But he will always need Direct Support Professionals to help him with cooking, keeping on his schedule and all money management. He doesn't want to live in a different town where he doesn't know people, or move around every few years. The state has relied almost exclusively on Shared Living Providers, called adult foster care, for those with highest needs. One of his friends was moved to a different shared Living provider 5 times in 2 years. My son would not be able to do that and retain the skills he has to be independent.

We want him to have a stable place to live and be involved in his community. Like everyone else, he needs a place he can call home long term.

Housing for individuals with IDD is long overdue

In 1993 when Brandon institution closed, the state promised to support people with IDD in their communities, but very little has been done in 30 years.

The state has relied almost exclusively on Shared Living Providers, called adult foster care, for those with highest needs. Would you want to have your elderly parent with dementia and mobility issues placed in a stranger's home?

Shared Living Providers, often don't work well for those with highest support needs, because of the burden placed on one person to care for someone with high support needs. And while some have extra help during the day, that is not always available.

There are some heartbreaking stories of awful abuse of individuals with Intellectual and Developmental Disabilities who were placed in housing with inadequate care providers, there are a few in our Family Stories Essay.

A recent survey by 5 agencies, found 25% of Shared Living Providers are planning to leave in the next 5 years. Because of the staffing crisis, the state is now relying on aging parents for housing. Many of the parents in our group have left work to care for their young adults. There is an immediate need for 602 units. This number is from the DDC housing brief done in 2023.

<https://ddc.vermont.gov/news/housing-report>

IDD housing is different

The CHT project and all of our DDHI work is aimed at individuals with moderate to high support needs. These are not people who can live on their own with periodic check-ins. They have a range of needs, some are nonverbal and need diapering, some are able to work 15 hrs week, but can't drive, manage their schedule to get to work, and can't manage their money, like my son.

The ADA standards are not enough

The cost of creating IDD housing is higher. Some people need a lift system to use the bathroom, toilet and shower, which means a bathroom big enough for the person and 2 people to assist. They need food prepared for them and they want to be able to eat with their peers, who also need help, in a large kitchen. These extra spaces cost more than a typical affordable housing unit.

Even if we are able to include apartments in large affordable projects, the apartments will need extra space. We expect that as these projects are built we will learn efficiencies within the design and operation, **but we need to start now.** You can't evaluate results to create efficiencies until you have the data from actual practice.

The Champlain Housing Trust project in Burlington still needs \$2.8 M to move to construction.

We understand that there is a huge need for housing for many marginalized people, and that people who

are homeless are dying because of lack of housing.

Many of those with severe DD are not out on the streets because they would not survive 24 hrs, so they are housed - inappropriately - 23 yrs olds in a nursing home, some with high medical needs in the hospital emergency department for weeks, or some in the motel programs.

These people also need permanent housing.

We need to provide housing and staff to support Vermonters with IDD who want to live permanently and be involved in their communities.