

# Senate Committee on Health and Welfare

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Testimony by:

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Thank you so much for inviting us to testify.

My name is Andrea Murray, and I am one of the founders of the Yellow House Community in Middlebury and mother of a young man with intellectual and developmental disabilities (I will refer to this as DD throughout my testimony). I am joined today by Elise Haydon, Executive Director of Yellow House Community, and she will share specifics about YHC in a moment.

I would like to share a bit about my role as a mother of a young adult with DD, the desperation with which my husband and I pursued the creation of the Yellow House Community, and my thoughts on H.720.

My son Pierce is 21. He has intellectual, developmental, and physical disabilities. He has autism, epilepsy, low muscle tone, and a significant anxiety disorder. Pierce is a friendly and loveable person who needs 24-hour care 7 days per week to lead a safe, healthy, and meaningful life. He needs assistance with communication, mobility, getting dressed, eating, bathing, toileting, taking medication, and more. He also needs to be supervised constantly because he has a grand mal seizure disorder. We graduated Pierce from Middlebury Union High School in 2020 because the pandemic kept him home and received hardly any services. It was crushing his spirit and significantly challenging our family.

In pre-pandemic environments, Pierce always had a one-on-one assistant, and his days were well-programmed with meaningful learning and interactions. When a young adult like Pierce who needs 24-hour care leaves the school system, there really is no meaningful programming or living situation for him to transition to that compares in any way to what he would receive in the school system. In addition, at a time when neurotypical young adults are graduating from college, fleeing their family nests, and beginning their own adult lives, we wanted Pierce to have his own meaningful transition to his adulthood.

I am 52. I am an architect and business owner and work more than full time. I also work tirelessly for Yellow House Community. I have another younger child in addition to Pierce for whom I am also responsible. My husband has had some very serious health issues in the last few years, making it difficult for him to share the caregiving responsibility for our children, especially Pierce. My other caregiver support has been challenged recently as Pierce's grandfather died in November, and his grandmother is aging and no longer able to do the

physical work necessary to support Pierce. I tell you this because our situation is not unique. The large group of parents and extended families advocating for the bill before you, H.720, are experiencing very similar circumstances.

What will happen to our kids with special needs when we are no longer here to advocate for them? Most parents hope their children outlive them. Parents with adult children who have disabilities similar to Pierce are terrified about what will happen to their children once they are gone. And, when you've investigated the options for Vermonters extensively as I have, it is discouraging. In creating the Yellow House Community, we are being proactive by addressing the need now, as opposed to when it is a crisis or emergency. Doing so now makes for an easier transition, is more cost-effective, and leads to a better quality of life for our children now and in the future.

In 2018, my husband and I formed a partnership with the Brown Family of Cornwall who were also planning for the future of their daughter with DD. Not knowing really what we were getting ourselves into, we purchased a property in the walkable downtown of Middlebury. In 2019 we formed the Yellow House Community.

Our vision for Yellow House is a stable and supported living situation/community within a community where our children are our neighbors and can make meaningful contributions to our broader Middlebury community.

Neither of our children are well-suited for a shared-living provider (SLP) living situation, often referred to as adult foster care. Recent high school graduates, they both depend on a robust schedule and a great deal of socialization and integration. They also rely on and require constant attention and supervision from their caregivers.

From a seed of an idea to residency, we brought Yellow House Community on line in 2 ½ years. We formed our family partnership in 2018, purchased property in 2019, renovated our first dwelling and became a licensed Therapeutic Community Residence (TCR) in 2020, and welcomed our first four residents with DD in 2021. And, we did much of this amidst a global pandemic. We hope to welcome another four residents to our second dwelling unit in 2022 – for a total of eight individuals with DD.

Having gone through the process as a parent of creating a housing alternative to shared-living, I was asked to share my thoughts on the H.720. I strongly support this bill and hope you will too, He's why:

1. AWARENESS – For some time, the population of adults with DD who need 24-hour care and assistance have not been on the radar of legislators. That is no longer the case. This bill creates awareness of the need; awareness that there are very limited options for housing for adults with DD; awareness that the systems in place need to change to make it easier for independent organizations like ours to create the kind of living environment our children need.

2. HOUSING OPTIONS – You have no doubt been made aware that there is a large spectrum of need for individuals who qualify for housing and home supports. There are also different options for different needs; however, there are very limited or no CHOICES, for adults with DD who require 24/7 care and supervision other than the Shared-Living Provider model. This model does not work for everyone. It would not work for our son Pierce. The pilot program grants in this bill will allow families, DAs, and other groups to be creative and explore and imagine possible living situations and solutions to the needs. These grants are enough to prepare a feasibility study and prepare a strategic plan. They are not enough to fund a capital project, achieve a licensure, hire staff, etc. These are only planning grants and their outcomes will provide information to DAIL and DDSD about creating new housing options.
3. RESIDENTIAL PROGRAM DEVELOPER POSITION – This position is critical. The person who is hired needs to understand the needs of adults with DD and their families, and needs to advocate for creative, new solutions to the current problems. This person must be a visionary and an innovator. I am not convinced the funding allocated for this three-year position is adequate to hire a qualified, forward-thinking individual. Some of the things this person would do, I will highlight in a moment.

While I strongly support this bill, there are a few things that I encourage you and the Department to consider as it is implemented:

1. THE BEGINNING – This is only the beginning. We need commitment at the legislative level that the outcomes of the Pilot Planning Grants and the Housing Developer position will be acted upon. Why spend \$500k to investigate new options, if you are not going to follow through? Another way to look at it is: we can't do the pilot programs and investigative work and determine that the systems in place are the only viable option. We must collectively move forward knowing that this is the beginning of something much bigger than the house, the senate, DAs, DAIL, DDSD, housing agencies and funders, advocates, and families alone. We will act. We must act. We must find a solution to this problem.
2. ACCOUNTABILITY AND ANALYSIS – When the pilot programs are complete, the Housing Developer and DAIL/DDSD should be required to prepare and submit a report summarizing the findings of the pilot programs. In addition, the Housing Developer should be required to analyze and explain how all housing for adults with DD in Vermont is currently funded and to offer options for funding adjustments to existing programs and options for funding new facilities.
3. ELEPHANT IN THE ROOM – FUNDING - At YHC have been through this process, we know what the findings will be. We know the current state of funding in Vermont. SLP's are an inexpensive route, yet they are currently underfunded. Group living situations such as YHC are funded for only through the Medicaid waivers of our residents and SSI funds. We do not receive any funding for the indirect costs associated with our business.

Indirect costs include things such as: insurances, life safety facility upgrades, requirements of our TCR license such as a nurse affiliate.

4. INTEGRATED SOLUTION – While this is largely an issue of caring for/providing service and support to the most vulnerable among us, it is also a housing issue. We need an integrated solution, and DAIL/DDSD and the new Residential Program Developer should help make these conversations happen. We cannot burden DAIL and DDSD and our DAs that are already operating in crisis mode with the additional housing development and operational costs the housing agencies and partners need to understand that people with DD who need 24-hour support are impoverished and risk homelessness if appropriate housing solutions are not created.
5. LONG TERM PLAN – The housing pilots and the residential development director initiatives should culminate in a draft of a long-term plan for development of housing alternatives. This plan should describe the individuals served, the workforce development opportunities, and the financial strategies at a minimum for developing housing alternatives for adults with DD across the state. The plan should be prepared by DAIL and DDSD with input (and creativity) from parents and advocates who will ultimately be the ones making this happen.

There is a huge amount of momentum, wisdom, and ambition with parents who have adult children with DD to create alternative living situations and choices for living situations. Meaningful choice is a fundamental right for adults with DD as described in the DD Act of 1996. In our country, most people who share something in common, race, gender, age, sexual orientation, religion, even a simple hobby, etc., may choose where, how, and with whom they would like to live. This is not the case right now for adults with DD who need 24/7 support in Vermont.

I will tell you, as a parent, we are the ones who make change. We have to. We have no choice but to advocate for our children. Those of us who have some resources, who are retired, or who have specialized skills related to the development of such projects are better equipped and can do more. And, we want to do more than simply help our own children.

Yellow House Community has learned how to navigate the system in Vermont that is circuitous, exhausting, and falling apart. There is much improvement to be made, and this Bill H.720 is a great start, but it is only the beginning.

We are at a tipping point where you, our legislators, DAIL, DDSD, and our DAs can support and help us champion the rights of those in our communities who cannot advocate for themselves. Let's get started and help design the future we want ALL of our children and their peers to live and thrive in.