

# House Committee on Human Services

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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 we are being backed by Greg Mairs DD Operations Director of Counseling Services of Addison County, our Designated Agency partner.

As part of our testimony today, I will share with you our family's personal story. We will share with you how we created Yellow House Community and a bit about our organizational, operational, and funding structure.

Lastly, we believe our model is easily scaled, replicable, and adaptable to a variety of locations and to suit a wide range of individual needs across the state. We would like to offer and suggest that Yellow House be considered a Pilot Program by the State, so we may learn collectively from our experience and help other families, DAAIL, DDS, Designated Agencies, and communities help meet the needs of Vermonters with DD.

## **OUR STORY**

Our son Pierce is 21. He has autism, epilepsy, low muscle tone, and significant anxiety. Pierce is incredibly friendly and will talk to anyone and everyone he encounters, he loves Sesame Street, trains, the Teletubbies, and he is an artist who loves to paint and draw. Pierce is the only 21-year-old we know of who tells everyone who is kind to him how much he loves them. We graduated Pierce from Middlebury Union High School in 2020 because the pandemic environment of special education at home was crushing his spirit and significantly challenging our family.

I am 52. I am an architect and business owner and work full time. I also work tirelessly for Yellow House Community. In 2018, I shed my second job teaching at Middlebury College to spend more time focusing on a meaningful transition for Pierce to his adult life.

In 2019, tragedy struck. My husband and co-caregiver to Pierce suffered a brain aneurism. It was a horrible and rude awakening. Miraculously he survived, yet he is still recovering three years later. At that time our 12-year-old neurotypical son and my aging parents were our only additional support.

As primary income generator for our family and primary caregiver for Pierce and our other son, I realized we needed to push full throttle ahead with Yellow House.

## **HOW DID YELLOW HOUSE COME ABOUT?**

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. I should note that the Browns round our founding partnership very nicely: one an educator, the other a business owner and also entrepreneur.

Our vision for Yellow House is a 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. 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.

I want to note that my husband and I have committed our life savings to this endeavor. And, as founders we will all go to work every day, as long as we have to, to help cover the funding for this effort. When you have a neurotypical child, you expect to teach them the ways of the world and send them off with the tools and skills they need to support themselves long after you are gone. When you have a child with a significant disability, you sometimes wonder if they would be better off not outliving you. Because of this worry, we had to create a stable, safe, stimulating, and sustainable living situation for our children.

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. We believe that replication could happen more quickly.

## **THE RIGHT & THE NEED**

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 for adults with DD in Vermont. This seems to infringe on a basic human right and the tenet of CHOICE that our state has deemed critical, I cite the DD Act of 1996 - Principles of Service, which reads: “Services provided to people with developmental disabilities and their families shall foster and adhere to the following principles:

(6) Meaningful choices. People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values, and needs and assure that each recipient is directly involved in decisions that affect that person's life.

(7) Community participation. When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.

Parents, guardians, advocates, and DA 's are all seeking housing alternatives for adults with DD. While the SLP model has been successful, especially for individuals in crisis, it is not suitable for many.

It can be isolating for the individual, the care giver, and case worker and most critically it is not stable. Adults placed in SLP homes are often re-placed when the SLP is no longer able to provide service. There are not enough SLP's to meet the demand for housing even if the SLP model worked for everyone.

In addition, for individuals such as our son, if we had not created Yellow House Community, the SLP would have been his only option/choice. And, only after he had failed in one or more SLP homes, would he be considered for a group home, if there were a room available. If there is only one option from which to choose, or failure is required to access other options, that is not "meaningful choice."

Currently in an SLP, a maximum of 2 unrelated individuals with DD may reside together. For a TCR, the cap is 4 in one dwelling unit. In a group home, of which there are only 20 in Vermont, the cap is 6 residents. It is our understanding also that the state has a moratorium on creating new group homes.

At Yellow House Community our friends thrive because they are together. They have genuine friendships, and they support and care for each other. We call this interdependence, and we celebrate it! Inclusion is about belonging and being accepted for who you are.

Beyond protecting the health and safety of individuals with DD, aren't these things that the state strives to provide for all Vermonters? We need to try harder for our friends with DD.

### **SOUL-UTIONS**

In listening to testimony on this issue, we have heard you ask for solutions and ideas for how to address this need. This is a pivotal moment. This is an opportunity to re-think how we do things, not just how to do what we've always done a little better.

A few important things we have learned:

- **SYSTEM OF CARE:** The Vermont System of Care creates an atmosphere of crisis for those seeking or in need of housing. In order to qualify for Home and Community Based Services 24-hour housing and home supports, an individual must meet a designated funding priority. For most, the priority is:

"Health and Safety: Ongoing, direct supports and/or supervision are needed to prevent imminent risk to the individual's personal health or safety."

To do this, basically, a parent or guardian has to prepare a convincing argument as to why we can no longer care for our child and if he stays at home, his health and safety will be at risk.

Put another way, families basically have to do a "head fake," that their loved one is going to be homeless unless something is done immediately. This is twisted and horrible. This shouldn't be the way. Anytime action must occur in the midst of a crisis, it is much more expensive to whomever must be fiscally responsible. In addition, because one must demonstrate imminent danger, funding cannot be requested or anticipated until moments before a move is planned.

I am glad the System of Care plan is being reviewed and is being discussed in your committee this week.

- MULTIPLE SOLUTIONS ARE NEEDED. The needs of our DD population are diverse. We will need more than the SLP model to address the range of need. We believe the organizational and operational structures of Yellow House Community are replicable and adaptable to serve a variety of individuals with DD in a variety of settings. Our model is flexible and diverse now and for the future.
- PRIVATELY OWNED<BUT WE NEED STATE SUPPORT - Not being state- or DA- owned could be important. But we need to be State- and DA- supported. We need housing subsidy, and we need the Medicaid budgets need to be based on our model, not the SLP model.
- RESOURCES -We know that DD law has always included the caveat that DAIL's obligation to provide services is subject to being, "within the limits of available resources." The problem is that since the closing of the Brandon Training School 29 years ago, the Legislature has never made adequate resources available.
- CRISIS IS EXPENSIVE. Crisis is expensive. We know this. When there aren't enough SLPs, adults with DD end up in hotels. The SLP can also be expensive for DA s to monitor and support 24/7 as SLPs are spread out and most of the time there is only one resident per SLP. Community living situations may help free some of those dollars with economies of scale, place, and the on-site staff who are trained to manage challenging situations.

At Yellow House Community we are doing the out-of-box thinking, and we have spent a lot of time and money to realize a very carefully controlled experiment.

There is much to learn from what we are doing, and we want to share and be a resource to others.

I will pass this to Elise now who will provide some more details.

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Thank you. My name is Elise Haydon and I have served as the Executive Director of the Yellow House Community since its inception in 2019. I began my career in Special Education in 2006, starting as a substitute paraprofessional, then fulltime paraprofessional, personal care and respite provider, and eventually High School Special Educator. Not only am I passionate about supporting and advocating for individuals with Intellectual and Developmental Disabilities, I am someone who has worn many different employment hats within the field of developmental services. I have a unique understanding of the needs of the individual, of their parents and guardians, and of the staff members who support them; this understanding has helped guide me in the development of systems to serve the Yellow House Community. Andrea shared the heart of our story. I will spend my testimony covering the nuts and bolts of our alternative model.

## **PILOT PROGRAM OPPORTUNITY**

Before I get into what makes YHC tick, I am eager to lead with the recommendation that the Yellow House Community be considered as a Pilot Program for supportive housing for adults with DD. The Developmental Disabilities Services Division (DDSD) of DAIL is committed to exploring new residential options for adults with DD. YHC is poised and ready to act as a pilot program with DAIL & DDSD support and collaboration.

As a pilot program, YHC will...

- Help our state develop a sustainable model for supportive housing that can be replicated.
- Inform a review and hopefully legislation that considers an integrated, possibly multi-agency, funding solution (Medicaid, SSI, AND HOUSING)
- Move away from the Crisis response – there will always be instances of crisis, but with more intentional communities for which families and DA s can plan the future for individuals, we can lift many of these situations out of crisis and decrease costs.
- Contribute to workforce development – hands-on staff want to work for YHC because of the team-based model and collaborative atmosphere. We can learn from this and help build a stronger, more reliable and retained workforce.
- Help re-consider the System of Care funding requirements (again pre-empt the crisis situation) to make it easier for those in need to find solutions and find CHOICE.
- Create a Toolkit and provide consulting to other family groups, DA s, others who want to develop residential options.

It is worth noting that we will be requesting ARPA funding through the Agency of Human Services via DAIL and DDSD to support capital costs, programming, and day programming. With our wealth of knowledge, however, we feel a responsibility and a calling to share our model and support change at the state level. This is where the pilot program comes in. There has never been a better time for YHC to act as a pilot program for Vermont. We are not just dreaming of change and alternatives; we are really doing it! We are providing choice for adults with DD, and we have a solid strategic plan to support growth and expansion. We welcome your consideration as a pilot program and hope the following additional background will bolster your confidence in our program as a model to be replicated.

I will now share specifics about Yellow House, review our timeline and trajectory, address compliance with CMS HCBS settings, speak to our commitment to workforce development, shed light on the funding gap we face, and propose solutions.

## **A LITTLE MORE ABOUT YELLOW HOUSE**

Yellow House Community is a licensed Therapeutic Community Residence (or TCR) for adults with Intellectual and Developmental Disabilities. TCRs can be designed to serve a variety of different populations and needs around the state such as substance abuse disorder and mental health support. When creating an “outside of the box” residential community, the TCR was the only “box” in which we could fit. We’re grateful to Claire McFadden, former DDSD Director, who helped us navigate our early endeavors.

Our community currently supports four adult residents with DD in the Yellow House 24/7, and we aim to support an additional four adults with DD in our second dwelling, the Carriage Barn, starting in the fall of 2022. Our staff includes an Executive Director, a Program Director, a live-in Co-worker, Sidekicks (direct

support workers), interns, and our nurse affiliate. We subcontract with our local Designated Agency, CSAC, to provide Home and Community Supports to our residents. This allows us to accept Medicaid Waiver Funding for services. We are recognized by the IRS as a 501 C 3 non-profit. We offer robust programming to our residents, where we celebrate the concept of interdependent, emphasize life skill and employment skill development, socialize with friends and neighbors, access our local community daily, and have FUN!

### **TIMELINE AND TRAJECTORY**

As Andrea noted in her testimony, YHC has made great progress in two short years, all while navigating a global pandemic. During this time, YHC developed a family partnership, purchased and renovated the 29 Seminary St., achieved our TCR license, fully trained and staffed our operation, offered daytime transition programming, established contracts with two DAs, moved four residents into the Yellow House, and achieved our non-profit status. Moving forward, we have these goals in our sights:

This spring we will complete the carriage barn, review applications for residency, and hire our CB staff. In the summer we hope to offer day programming for current and prospective residents. We hope to identify and move four new residents into the CB in the fall. By the early 2023, we aim to expand day programming to support both residents and non-residents, alike, a great need in Addison County and around the state. As entrepreneurs, we are thinking ahead to 2023 and 2024 where we can scale and support the replication of our model. This may look like a third dwelling, YH industry, continued advocacy, and support for budding organizations.

As you can tell, we are an organization with a track record of setting lofty goals and achieving them.

### **COMMUNITY INTEGRATION AND COMPLIANCE WITH CMS HCBS SETTINGS**

One thing that sets YHC apart is our emphasis on and commitment to Community Integration. As you can see from this map, YHC is located in the walkable downtown where our residents, who cannot drive, can be fully integrated into their local community. This map shows all of the amenities and programming opportunities within a ½ mile of Yellow House that residents access regularly. Examples are the public library, post office, grocery stores, pharmacies, museums, athletic facilities, restaurants, and work settings. Last week, Beth Sightler, Executive Director, Champlain Community Services testified that Community Integration is something that Vermont wants to promote, but in reality, it's not happening much for the DD community. At Yellow House, we're living Community Integration every day, and we're helping our community neighbors to recognize, accept, and celebrate individuals with DD. We want to be clear that we have researched the Center for Medicare and Medicaid Service's federal HCBS settings rule and have been intentional in creating a residence that is in compliance with this rule and is not an isolated setting.

### **STAFFING/WORKFORCE DEVELOPMENT**

- YHC is also in a positive position to contribute to workforce development and retention within the field of DS. YHC Currently employs 14 individuals in a combination of full-time and part-time positions. We also employ additional 10+ subcontractors. With the addition of a second dwelling, YHC has the potential to employ up to 24 staff members. With the expansion of day programming and the possibility of a third dwelling, we have the opportunity to employ 32 individuals.

- At Yellow House, it has been relatively easy to recruit and retain staff. Over the past 2 ½ years, we have enjoyed a 93% employee retention rate. We believe this is for the following reason:
  - We are not operating in a constant climate of crisis.
  - We pay competitive, but not extraordinary, wages - they are in line with those being requested and suggested by DA s currently.
  - Our Staff are part of a collective team all of whom are supporting the same individuals. This provides opportunities for comradery, collaboration, learning from each other’s experiences, and the ability for a break and/or added support in a challenging situation.
- We believe the Yellow House staffing model can help address the burnout and employee turnover that agencies and organizations are experiencing. Collaborating in a group setting is more productive and builds redundancy and resilience while meeting the needs of the individuals we serve. It is also more satisfying professionally and a lot of fun!
- We look forward to the opportunity to contribute to workforce development in Addison County through our collaborative staffing model and expanding services. We also welcome the role we can play in providing services to individuals that DAs would historically need to serve (and currently can’t, due to staffing shortages). These services go beyond Housing and include Community Supports and Employment Supports.

**FUNDING GAP – THE REALITY**

We know that adults with DD in the State of Vermont want choice in where and with whom they live. Even if options did exist (such as Yellow House), the reality is that the Medicaid Waiver funding doesn’t recognize the costs of such an operation. I’ll explain why.

Yellow House has been privately funded in its start-up. It has been a heavy financial lift to get to a point where we could welcome our first resident(s). These upfront costs include:

- The cost for the property,
- Renovations and construction to meet our program’s needs,
- Facility life safety and accessibility upgrades as prescribed by the TCR license and our insurance companies.
- Lots of insurances!
- Hiring an ED
- Being fully staffed and trained prior to receipt of our licensure
- Hiring a Nurse Affiliate (licensure requirement)

Operationally, Medicaid Waiver funding and SSI help to cover direct costs associated with care and a small amount of room and board. Because resident funding is based on the SLP model (where typically a tax-free stipend is extended to a sole care provider), there is no funding for the indirect costs associated with our organizational model and the TCR. Examples include: insurances, administrative staff, nurse affiliate, facility upgrades (sprinklers, fire alarms).

In summary, the care is largely covered, but the housing is not. Right now, the residents of YH have budgets with home supports that range from \$22,000 to \$36,000 annually. In contrast, a resident of a Group Home may carry approximately \$67k - \$72k Home Support budget, since these homes are considered state resources and are funded to cover costs. As a result of being treated as an SLP for

budgeting purposes, our organization faces an approximately \$32K annual funding gap for each resident, even once we are at full capacity with 8 residents.

### **HOW TO COVER THE GAP – LET’S TALK ABOUT SOLUTIONS**

To solve the problem of choice, we need to solve that of the funding gap. We know how to do this collectively. Here are some options:

- As I mentioned above, Vermont already subsidizes group homes for indirect expenses equally on a per resident basis. See also nursing facilities and corrections facilities. The same consideration could be extended to licensed TCRs.
- Low-income housing subsidies and vouchers (we understand that Vermont has adjusted the Federal Section 8 accessibility so that only one residence/household ay receive a voucher, whereas we really need each individual served/or each room or bed provided to a person who meets poverty standards to receive the assistance)
- Assist organizations with capital expenditures, so their investment dollars can be used for an endowment, which will, in turn, generate supplemental income.
- Fundraising & Grants

Note: this is a complex problem that to be financially sustainable requires an integrated solution.

Up front, this may cost more, down the line, it should save money due to minimal turnover and replacement for individuals with DD and also for staff.

Crisis mode is always more expensive. SLP should be reserved for special cases and crises. Let’s try to create meaningful living and working situations that are bright and forward-thinking – that integrate our most needy with their community and in turn teach tolerance and break down the stigma of what it means to have a developmental disability.

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### **CLOSING**

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. We hope you will seriously consider our experiences, suggestions, and proposal to be a pilot program for our state.

Yellow House Community is on a crusade to make change. We are at a tipping point where you, our legislators, DAIL, DDS, and our DA s can support and help us champion the rights of those in our communities who cannot advocate for themselves. Let’s help design the future we want ALL of our children and their peers to live and thrive in.