Testimony for Vermont House Human Service Committee
Developmental Disabilities Housing Initiative

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Thank you for the opportunity to appear today. My name is Jim Caffry. For the last 25 years, I have lived in Waitsfield with my wife Amy. We have three children, ages 21, 20, and 17. Just before his second birthday in 2002, our son Duncan was diagnosed with Autism. He also has diagnoses of obsessive compulsive disorder ("OCD") and epilepsy. He is non-verbal, although he has some limited communication skills using his iPod communication device. Duncan has a very high pain threshold, and he does not communicate if, or how, he is hurt or feeling sick. He has no sense of danger. He requires 24/7 oversight, and he needs constant prompting for doing most things. Duncan is in his final semester at the Camphill (Waldorf) School in Pennsylvania. He will begin receiving adult developmental services back in Vermont in June 2022.

I have been a lawyer in Vermont since 1995, and for the last 15 years, my law practice in Waterbury has been focused almost exclusively on special needs estate planning for Vermont families like mine. I have worked with families and individuals affected by all manner of disabilities in all 14 counties of Vermont, and who have received services from all 10 Designated Agencies ("DAs") and all 5 Specialized Service Agencies ("SSAs"). I was a member of the Vermont Autism Task Force (2007-2010), Vermont Developmental Disabilities Council (2009-2014), the 2013 Act 50 Legislative Developmental Services Summer Study Committee, Champlain Community Services Board of Directors (2014-2018), and the DS Payment Reform Advisory Committee (2018 – present). My wife has been on the Board of Directors of Washington County Mental Health since 2013.

I have attended many, many Developmental Services State Program Standing Committee meetings, starting in 2008. In August of this year, I became involved in the parent-led group, that has evolved into the Developmental Disabilities Housing Initiative ("DDHI").

<u>Current State of Affairs</u>

It is evident from prior testimony that there are so many things that need to be done in order to preserve the Vermont developmental services system – to appropriately support both service recipients ***and*** service providers. I want to focus my time on housing – and the current lack of options for adults with moderate to high support needs.

For the parents who have been part of the DDHI group, the overarching objective of the group is for the Vermont Developmental Services system to provide real housing choice, and to finally meet the goals espoused when the Brandon Training School was closed, and when the Developmental Disabilities ("DD") Act was enacted. Among those key principles of service in the Vermont DD Act are: Full Information, Individualized Support, Family Support, and Meaningful Choices. 18 V.S.A. § 8724(3), (4), (5) and (6): (https://legislature.vermont.gov/statutes/section/18/204A/08724)

In particular, there is great room for improvement when it comes to "Full Information" and "Meaningful Choices". These principles are stated in the DD Act, and repeated in both the 2017-2020 DD System of Care Plan and the FY 20 DD Annual Report:

Full Information: In order to make good decisions, people with developmental disabilities and their families need complete information about the availability and choice of services, the cost, how the decision-making process works, and how to participate in that process.

Meaningful Choices: People with developmental disabilities and their families cannot make good decisions unless they have meaningful choices about how they live and the kinds of services they receive. Effective services are 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.

In terms of housing options for those individuals who need 24/7 support, what many DDHI families want, and what is now generally unavailable for most, is:

1. **Consistency of place; and**
2. **Choices, including the opportunity to live with peers.**

There should be a range of choices, to meet a range of needs and a range of desired living arrangements.

Many families are told that the only residential option available for their adult child is a Shared Living Provider home. The information that is publicly available, bears that out. The FY 2020 DD Annual Report (*the FY 21 Annual Report is not yet available*) provides the following:

Individuals served – Living with 24-hour paid home supports (June 30, 2020)
▪ 1,396 – Shared Living (1,245 homes)
▪ 57 – Staffed Living (53 homes)
▪ 86 – Group Living (20 homes)
▪ 6 – ICF/DD14 (1 home)
▪ 1,545 – Total

The FY 2020 Annual Report describes the Home Support options as:

▪ **Shared Living**: Supports provided to one or two people in the home of a shared living provider. Shared living providers are home providers contracted by DA/SSAs. The home is owned or rented by the shared living provider.
▪ **Staffed Living**: Supports provided in a home setting for one or two people that is staffed on a full-time basis by providers. The home is typically owned or rented by the service provider.
▪ **Group Living**: Supports provided in a licensed home setting for three to six people that is staffed full-time by providers. The home is typically owned or rented by the service provider.
▪ **Supervised Living**: Regularly scheduled or intermittent hourly supports provided to an individual who lives in his or her own home. Supports are provided on a less than full-time schedule (not 24 hours/7 days a week). The home is typically owned or rented by the individual.

The FY 2020 Annual Report states that 76% percent of adults with DD receiving "Home Supports" do so through the Shared Living Provider ("SLP") model (page 11). That is a little misleading because that 76% includes the 246 individuals served under "Supervised Living" – i.e., those individuals have the requisite skills and independence that they do not require 24/7 support. If you look at the 1,545 adults with DD that require 24/7 home supports, the Shared Living percentage jumps to 90.35%.

Furthermore, individuals served in Staffed Living and Group Living are generally individuals with significant behavioral (aggression or sexually inappropriate) or medical challenges. Anecdotally, individuals have ended up being served in the Staffed and Group Living only after multiple failed attempts at Shared Living. Information about the existing Group Living homes is not readily available to the public. The only detailed information I have obtained about those Group Living homes was the attached chart that I received back in 2010 after I filed a records request result under the Vermont Public Records Act.

Taking that into account, Shared Living is the *only* option for the vast majority of individuals in need of 24/7 home supports. People in Supervised Living have the skills to live with some independence. People requiring 24/7 supports only have 3 options – Shared, Group, and Staffed – the latter two being the option for those who could not remain in Shared Living for behavioral or medical reasons.

It is certainly necessary and appropriate for there to be those Group Living (and Staffed Living) home supports to meet the needs of those persons with DD who have the highest behavioral and medical needs. However, it is hard to accept the direct correlation that because these remaining, important Group Living homes are "not the requested service by many people" should mean either: (A) the State should not be working to provide "meaningful choices" when it come to housing options, or (B) that there is not a real desire for intentional community living opportunities for adults with DD to live meaningful lives, in the shared company of some peers.

There have been discussions in prior hearings about the length of stay in a typical Shared Living Provider home. The answers have varied, and there did not appear to be any clear data. There were several estimates that over 50% of people lived in the same SLP home for more than 5 years.

The FY 2020 Annual Report states that 56% of the 2019 DDS National Core Indicators Survey respondents said that they have lived in the same residence for more than 5 years. However, if one looks at the actual Survey, it states that 31% of those 338 individuals surveyed in 2019 lived in a parent's or relative's home (https://www.nationalcoreindicators.org/upload/core-indicators/VT_IPS_state_508.pdf). If 31% of the service recipients included in the Survey are still at home with their parents, of course that is going to skew the percentage of people who have lived in their "current residence" for more than 5 years.

I am certainly aware of many instances of incredibly successful Shared Living situations that have continued for 10 years, and many more. Several of them have been in homes that were owned by the family of the adult being supported rather than a home owned by the SLP. I am also aware of individuals and families who have had multiple unsuccessful Shared Living placements within a matter of a few years. Some of those individuals are back at home with their aging parents. Although there is apparently no public data available about the Shared Living Model, given the huge range of durations anecdotally known, any data collection done as part of providing the public with full information should include not just the ***average*** of SLP placements, but also the data on the ***mode*** – the most common number in the data set. For example, if five SLP placements have durations of 1, 1, 1, 1, and 30 years, then the ***average*** is 6.8 years, but the ***mode*** of only 1 year paints a very different picture of the stability of the SLP model in general.

Real data on how SLP homes do is difficult to come by. The DD Annual Reports, to my knowledge, have never provided data on duration of placements. The DD Annual Reports from 2006, 2007, 2008 and 2009 contained data stating that only 21% to 29% of Shared Living homes were inspected annually between FY 2005 and FY 2008. During those four years, 17%, 18%, 26% and 8% of those limited number of Shared Living Provider homes inspected remained out of compliance with the home safety requirements. Additionally, each of those DS Annual Reports states that the inspected Shared Living homes "were or became in compliance" meaning that some homes were out of compliance when inspected, but those SLPs took corrective action by the end of the fiscal year. The FY 2010 Annual Report deleted the paragraph that provided the inspection and compliance statistics. Those informative statistics have been absent ever since.

Shared Living is not going away – it is too financially attractive, and for some people it works very, very well.

However, when it is the only choice for everyone needing 24/7 home, excluding only those with the highest behavioral and medical needs, ***that is not a meaningful choice***.

What Should Be Considered?

In short – anything and everything.

Shared Living is inexpensive because if the income tax-free payments under Internal Revenue Code Section 131(https://www.law.cornell.edu/uscode/text/26/131). Since about 1986, federal law permits tax exempt payments for up to 5 adult individuals. My understanding is that it has always been Vermont policy to limit the number to 2 adults with DD in a single Shared Living Provider home since the SLP program started, and then the "no more than two" limit was codified in 2007 at 33 V.S.A. § 502(1) (https://legislature.vermont.gov/statutes/fullchapter/33/005).

There are obvious sound public policy reasons for the limitation to 2 people, but as part of considering what's possible for increasing meaningful choices, nothing should be off the table from consideration. The health and safety considerations that presumably led Vermont to reduce the federally allowed number from 5 down to 2 could perhaps be addressed through additional requirements for training and staffing in addition to the SLP. I am aware, though not in any detail, that other states have programs that utilize the cost effectiveness of the income-tax free payments under IRC 131 to the full extent, but in a more structured manner, and with greater oversight.

There are already SLP situations where a Sharded Living Provider moves into a home owned by a family (or trust) rather than the person with DD moving into the SLP owned home.* There could be opportunities for like-minded individuals and families to come together to create that "consistency of place" in a cost-effective manner. This could facilitate additional models that are similar to Connie Woodberry's Black Mountain Assisted Family Living in Brattleboro.

** Note: different DAs and SSAs have very different levels of enthusiasm for working with families to find SLPs to move into a family-owned property.*

Any study by DAIL/DDSD of alternative models should include intentional living communities, including Camphill communities (such as Heartbeet in Hardwick), and the L'Arche communities that Barbara Lee spoke of in her testimony on February 1st.

Analysis by DAIL/DDSD should include a review of Section 119 of the Internal Revenue Code (https://www.law.cornell.edu/uscode/text/26/119), whereunder the inclusion of meals and lodging as part of employment are exempted from imputed income taxation.

On February 3rd, Beth Sightler from Champlain Community Services ("CCS") spoke of consideration of provision of student loan assistance as a possible incentive to attract and retain direct support providers (*which, of course, is secondary to paying direct support workers a livable wage*).

Camphill communities, such as my son's school, include long-term householders, many of whom have been there for decades, as well as younger direct support providers that stay for shorter one to two year commitments – some are through the AmeriCorps program, while others are come from all over the world through J-1 visas (which are an increasingly common way for Vermont ski resorts to have enough seasonal mountain staff).

Any DDSD analysis should also include the licensing requirements for any residential setting of more than 3 people under 33 V.S.A., Chapter 71 (https://legislature.vermont.gov/statutes/chapter/33/071).

All of the existing 19 Group Living homes that are owned and operated by 7 of the DAs are licensed by DAIL's Division of Licensing and Protection as either Residential Care Homes or Therapeutic Community Residences ("TCR"). Additionally, the intentional living communities of Heartbeet and Yellow House are also licensed as TCRs. Again, there are obvious sound public policy reasons for licensing requirements to ensure the health and safety of people receiving services under one roof. However, the question arises whether there are ways in which the health and safety goals of the licensing system can be achieved but made less burdensome and costly so that alternative living models are easier to establish.

As Vice Chair Wood noted in a prior hearing, the Vermont zoning statutes provide that a home providing support to *up 8 persons* with a disability (of any kind) are considered a residential use by right under 24 V.S.A. § 4412(1)(G)(https://legislature.vermont.gov/statutes/section/24/117/04412). Being a use by right under the zoning regulations does not mean that there could not be improvements in the home licensing regulations that would make alternative housing options easier to create.

As Vice Chair Wood also noted, Vermont used to be looked upon as the best developmental services system in the country, but that is no longer the case. Additionally, Beth Sightler made abundantly clear that currently the System of Care is a "System of Crisis". As part of the Covid-delayed readoption of the System of Care Plan, the DDSD should go back and take a look at how the current "System of Crisis" came about.

In both the FY 2005-2007 and FY 2008-2010 System of Care Plans, there were 12 Funding Priorities for Developmental Services. In the 2018-2020 (extended to 2022) System of Care Plan, there are only 6 Funding Priorities.

Conversely, trending in the opposite, but also wrong direction, the FY 2005-2007 System of Care Plan contained only 7 "Limitations for Funding", and by the 2018-2020 (extended to 2022) System of Care Plan, the "Limitations for Funding" had exploded up to 20.

It would appear to be a safe bet that funding priorities going south and funding limitations going north over the last 25 years is how Vermont arrived at the current "System of Crisis".

Among the limitations that warrant revisiting is the prohibition on family management of 24-hour home supports, which had been allowed from the late 1990s until 2005. That prohibition on 24-hour family management of Home Supports was adopted into the March 2011 DD Regulations of the *unanimous objection* of every public comment filed on the proposed change (I know that from a public records request that I filed in 2010 on the proposed rulemaking). Currently only 3 percent of service recipients utilize family manage. Reauthorizing the ability for families to manage 24-hour home supports that was originally permissible, would likely result in an uptick in the utilization of the Self & Family Management program.

Finally, the intentional living communities of Heartbeet and Yellow House have come into existence in Vermont under the current Vermont system, *where families and DD service recipients not under guardianship have exercised their rights to choose a different service provider* under Section 4.10 of the DD Regulations, and then Heartbeet and Yellow House have, as non-designated providers, entered contracts with Designated Agencies under Section 10.6 of the DD Regulations. The DDSD should be looking at ways to support new residential communities can come into existence in Vermont at a quicker pace than one every twenty years.

What's Next and What This Isn't

It was very encouraging to hear during the DDSD presentation on February 10th that DDSD is moving forward with the overdue System of Care Plan and DD Regulations updates, and as part of that, including consideration of: (1) payment of parents*, (2) increasing autism supports, and (3) "increased housing models for adults with developmental disabilities beyond those currently available".

* *Note: parents of adults* ***can*** *be paid with Medicaid funds – many states already do that, and Vermont allows payment of parents under the Choices for Care program.*

I encourage the members of the Committee to watch the video from the closing ceremonies of the Brandon Training School in December 1993: (https://player.vimeo.com/video/87974538). In the final minutes of the video, the narrator states:

> In the years ahead, we must be careful not to settle into a particular way of providing services. We must continue to change, to give people what they want, and what they tell us they need.

None of the parents involved in the DDHI are asking to go 'back to Brandon'. It is kind of ludicrous that such a thing even needs to be said. Advocating for housing options that will making easier for high support needs individuals to live with a few peers, in permanent housing that does not require them to move when their support people change is progress – not a regression. Being able to live with people with similar interests (and perhaps quirks), or similar means of communication, within the broader community is exactly what anyone else is free to do. Individuals with intellectual and developmental disabilities should have those same opportunities.

Increasing house options that provide long term stability for higher needs individuals is not a threat to the rights of self-determination for self-advocates. Absent serious health and safety concerns, no one receiving DD services should be forced to live where they do not want to. That is clear from both the 1992 Developmental Disabilities Act and also the 2014 Home and Community Based Services ("HCBS") regulations from the Centers for Medicare and Medicaid Services ("CMS").

Additionally, none of the housing options desired by anyone from the DDHI parent group is in conflict with the "settings" provisions of those 2014 HCBS regulations from CMS. https://www.medicaid.gov/sites/default/files/2019-12/hcbs-setting-fact-sheet.pdf

It is my fervent hope, and the hope of many others like me, that the Committee will move forward with a legislative proposal that will:

- Require the creation of stable housing options for individuals with developmental disabilities.
- Set aside sufficient sums of the ARPA money to facilitate the development of several new stable housing communities.
- Require DAIL/DDSD to provide, by July 1, 2022, a comprehensive proposal for all statutes, regulations, and policy documents (System of Care Plan) that need to be amended to facilitate the implementation of new stable housing models.
- Create a full-time position within the Developmental Disabilities Services Division to oversee the implementation of new stable housing models for adults with developmental disabilities.

Thank you.