



DDHI FAMILY STORIES: A PHOTO ESSAY

We are a group of over 125 parents of adults with Developmental Disabilities with moderate to high support needs living here in communities across Vermont.

Our adult children do not have housing options outside of adult foster care (which does not typically meet their complex needs) or remaining with us, their parents, until we cannot provide care for them any longer. We formed a grassroots group of parents willing to advocate for the necessary changes - the Developmental Disabilities Housing Initiative (DDHI).

With the hard work and support of many of your esteemed colleagues, Act 186 was passed. One of the things Act 186 accomplished was the commissioning of the 2023 research brief which indicates there is an immediate need for over 600 housing beds for this population. There is a desperate need for stable, service-supported peer residence options.

Act 186 also provided limited funding towards pilot planning grants to begin the process of planning housing for this particularly vulnerable population.

In this legislative session, we will be asking for additional funding to move these projects forward, and hope the attachment illustrate the 'why' behind our ask.

Please take a few moments to peruse the attached stories.

Thank you for your attention,

Developmental Disabilities Housing Initiative (DDHI) Co-Leaders
Karen Price, Katie Tormey, Collins Twing, Jenn Townley,
Marla McQuiston and Laurie Mumley



Contact Information

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My son **Joey** is 21 years old. He loves music, singing, swimming, adaptive snowboarding and biking. Most of all, he loves being a part of things. He has an infectious laugh and sense of humor.



He was diagnosed with autism at age 2. He struggles 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 about 390lbs. He is also functionally nonverbal and requires assistance with all activities of daily living. He requires 24/7 supervision.

I provided that 24/7 supervision and care as a single, aging parent for over 7 years by myself. It was beyond exhausting. It impacted my ability to work and to care for his younger sister, as well as having a serious impact on my health.

In February 2022, he began an out of state residential school because Vermont was unable to provide him with an education. He is absolutely thriving there—he has friends, he is repeatedly referred to as “a staff favorite”, a “role model”, and “a joy to have in the classroom”. These words had never been used to describe my boy before. He was even named Student of the Month in April. Clearly, he is getting what he needs there.

When he comes home for weekend visits (every 4-6 weeks), he is anxious to return to his friends back at what he calls “Easterseals College”. He checks the calendar repeatedly to reassure himself that he is going back (since I list all activities as part of his visual schedule). He will even sometimes say “Back to Easterseals!” during our weekly lunch dates.

He will age out of that program in May, 2024. I’m extremely worried about what will happen then, since Vermont still has no appropriate living situations to meet his fairly intense needs. If he has to return home to nothing, he will regress and lose skills. He will likely become depressed and angry. His counselor is also concerned about the impact that would have on him.

Vermont’s adult foster care system, Shared Living Providers, cannot provide him with what he needs. He needs a safe, stable, supervised, consistent HOME with peers and plenty of activities in the community. He cannot be an afterthought, living as a guest in some random stranger’s house, until he’s moved to some other house. He thrives on routine and stability. We owe our most vulnerable citizens that much. Vermont CAN do better. ~**Laurie Mumley**



I have a 27-year-old son, **Tiernan**, with Koolen-de Vries Syndrome. He was diagnosed with autism as a young child, and it wasn't until 2021 that we received a genetic diagnosis for his disability. He has intellectual, motor, and speech deficits, as well as epilepsy and other medical complications. He requires daily medication, 24/7 supervision and help with all activities of daily living. He cannot be relied upon to communicate discomfort or pain.



Tiernan is a gentle and sweet soul who wouldn't hurt a fly. He loves music, dancing, and different adaptive sports. He graduated from high school in 2019 and left behind a life of inclusion, activity, and peer interactions. As with many human services positions, direct service professionals have been slow to return to work, and Tiernan spends much of his life with us, his aging parents. Our ability to provide the 24/7 care that he needs erodes with each passing year.

Tiernan needs a housing situation which is safe and stable; he needs to know where his clothing is and how to operate the faucet in the bathroom. Living in a series of houses under the shared living provider model will only confuse him. He needs a home. We ALL value stability of place; we all need to feel safe. How can we deny that same need for our most vulnerable adult children? ~**Karen Price**



Our son Duncan is 23 years old. He loves all animals, especially his two dogs and two cats. He loves caring for farm animals. For 10 years, Duncan thrived living in an intentional community where he attended a fully accredited special needs school and transition program in PA that met his needs. The consistent rhythm and routine of the community fostered independence and confidence. Even when the support people around him changed from time to time, Duncan had a consistent place to call home. He flourished living a meaningful and productive life in a safe community where he was surrounded by friendship, love, and respect.

Duncan has an intellectual disability, autism, OCD, and since age 17, epilepsy. He is nonverbal, although he has some limited vocabulary (requests) using his 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, full support for activities of daily living, and needs constant prompting for doing most things.

Since Duncan's 22nd birthday when he aged out of educational services, he has been home in Vermont. We have been struggling to find options in Vermont that meet his needs and provide a safe, consistent place to call home. We have begun the process of creating a stable, long term, sustainable and meaningful option for Duncan to live his best life in Vermont - a safe place that is full of meaning, purpose, love, and community.

~Amy & Jim Caffry



My son **Jesse** is 25 and has Down Syndrome and Down Syndrome Regression Disorder. Jess exudes a warm and aware sensibility, has never heard a Broadway song he didn't love, and never, ever, forgets anyone who sincerely tries to engage with him. Despite his charm, he has extremely limited verbal capacity and would not be able to articulate if he was being exploited, manipulated, or mistreated in any way. And because so much of the world is incomprehensible to him, he thrives on stability.



Given Jesse's foundational need for stability and consistency of place, the thought of Jess spending his adult years as a guest in the homes of a series of strangers—as he would in Shared Living—is almost unbearable. Jess longs for community and mourns the loss of high school, where he had typical friends as well as friends with special needs who helped him feel less lonely in a world of mostly “abled” people. For these reasons and more, I hope Vermont sees its way to offering Jesse and others who share his high support needs a stable and communal housing option where he feels safe and secure, alongside lifelong friends. ~**Elizabeth Campbell**



“What will become of me when you die?” is a question my son spelled out to me a few years ago, using his eye-gaze board. I asked him if he meant who will take care of him, and he smiled a “yes” answer.

My 36-year-old son **Christopher** is a wonderful young man who is socially engaging, has a great spirit and a good sense of humor. He also has choreoathetoid cerebral palsy (CP) with severe dystonia, a full spinal fusion, dysphagia, a g-tube, and a permanently dislocated shoulder. Every single muscle in his body is fully impacted by the CP; therefore he needs total assistance for access to anything in life. He is totally dependent upon another person for any communication needs, for being fed, dressed, toileted, showered, turning on his computer, etc etc etc. Basically, someone else needs to be his body for him.

Chris does not speak verbally, but spells words letter by letter using an eye-gaze board held by and interpreted by an assistant. (This is time-consuming for someone who loves to talk like the rest of us!) He does have an AAC device, but his only successful access to that is through an interface on his wheelchair joystick. His current joystick is dismal & primitive because it is the only one that can withstand the force he exerts on it, so he doesn't use his AAC device much.

Because he is totally dependent for every need, he is also incredibly vulnerable.

He grew up with 3 other siblings and has always been fully included in our family and the community we lived in, until I, as a single parent, was no longer able to provide all his care for him at home. He has had several shared living providers, who lived with him in his apartment, but we had HORRIFIC experiences.

We had one who was investigated by Adult Protective Services (APS) due to neglect, financial exploitation and emotional abuse. Chris lost 23 pounds within 6 months because he wasn't being fed adequately. (“He didn't ask to be fed.”) That SLP also used Chris's personal money for his own use. All of this occurred under the ‘watch’ of a program manager at HCS, despite my advocating that things were not right. He was pulled out of that apartment and returned home to live when a new program manager was appointed, and she observed the neglect and lack of care.



The next APS investigation was of a shared living provider who was terminated due to gross neglect—he was left alone from early in the morning until a nurse arrived at 2:30 pm to find him lying on his bed. Chris was unable to do anything except lie there, screech for help, and “wonder what the hell was going on.” Another shared living provider was emotionally & mentally unable to care for Chris.

It is clear the SLP model does not work for someone like Chris; I lived through every parents' nightmare. Because of his need to rely on others for everything in life, including expressive speech, he is one of our most vulnerable citizens. Shared living providers do not have the training nor can they, even with extra support staff, provide the intensive care my son needs in order to exist. There are also no shared living providers with training and expertise lined up out there waiting to step into the job. This has been a problem for years—well before the pandemic and current crisis.

Chris is currently “staffed” 24/7 in his own apartment, with all of his support workers taking shifts to assist him and sleeping overnight there. This is a situation his program manager at HCS has had to fight hard for. We hope to find a more sustainable living situation for him, but the State of Vermont provides almost no options for someone like him. He's fortunate to have some outstanding people in his life, but it is never a steady supply and training new staff takes weeks, if not months, because his care is so complex. It's not like anyone can come in and jump right into working with him.

All I want is for my son to be safe, well-cared-for, intellectually stimulated and have as an enriching life as he had when he lived with me. Christopher is just as deserving as the rest of us of a good quality life. It is our civic and social duty to provide this to our weakest and most vulnerable Vermonters. ~**Nancy Osborne**



Our daughter **Annie's** story represents the exception for adults with disabilities in Vermont. She leads an active, healthy and purposeful life in a thriving intentional community, Heartbeat Lifesharing, in Hardwick, where she has made her home for 14 years. I am sharing her story to send a strong message about what is possible for Vermonters with disabilities—and the message that every Vermonter with a disability deserves the choices that Annie has had.



In the summer of 2008, our daughter Annie's life was in crisis. Born in 1981 with Down Syndrome, Annie grew up as an active, friendly, healthy and outgoing girl with a boundless appetite for life. By 2008, that vibrant young woman had become almost unrecognizable. At age 26, she rarely left her apartment. At five feet tall, she weighed 230 pounds. She was profoundly depressed and took eight different daily medications. Her teeth were abscessed. Her weight made even walking difficult. Her few relationships were exploitive and unhealthy. Ultimately, her physician told us she could no longer take responsibility for Annie's medical care if she remained in her current situation.

The program that placed Annie in her own apartment had seemed like a good option for our daughter. After two years of on-campus education in independent living skills, participants transitioned to their own private apartments with staff support every couple of days. Annie could walk to the grocery store; the bus line ran past her door; the YMCA was a few blocks away; and there was a theater around the corner. We wanted Annie to have as much independence as possible, and to be part of the larger community. *It closely resembled the living situation of many Vermonters with disabilities today.* It should have worked.

In fact, it was killing her. Our family began an intensive search for alternatives.

A relative told us about Heartbeat Lifesharing, an “intentional community” on a farmstead in northern Vermont. Initially, we rejected it as too remote and too isolated. Nevertheless, one hot August afternoon we paid a visit. Before we left, we knew Heartbeat was the right place for Annie.

One of only two intentional communities for adults with disabilities in Vermont, Heartbeat sits on a hillside in Hardwick. It provides lives of dignity and opportunity in an iconic farmstead community that includes people with and without developmental disabilities who live, work and share life together. Residential settings offer relationship-rich environments that emphasize interdependence and shared responsibility. Vocational programs develop practical and professional skills. Community members experience a rich artistic and cultural life and contribute to neighboring communities and to the world at large.



I hope you will have an opportunity to meet my daughter Annie at Heartbeat—although she's busy, and you might need an appointment. Since her move to Heartbeat Lifesharing, she's reclaimed her health, happiness, energy and dignity. She weighs 125 pounds and takes one medication. Her teeth are in great shape, and she looks beautiful. She's a ball of energy and walks, hikes or snowshoes through the Vermont countryside. She's learning to snowboard and to speak French. She works part time at a local artisanal cheesemaker, and takes personal pride whenever they win a gold medal. She votes at Town Meeting. She and her partner have frequent dinner dates in local restaurants. She is a talented fiber artist and a frequent public speaker. She's a member of the Culinary Arts crew and serves as a member of the Heartbeat Board of Trustees.

Heartbeat Lifesharing saved Annie's life and changed the world for her and for our family. ~ **Judith Jackson**



Hi! I'm **Owen**. I have Sturge-Weber Syndrome, Epilepsy, am 20 years old, and developmentally young. I need help with most daily tasks, and I live with my Mom and Dad in Georgia VT. I have had seizures since I was 2 years old. I had brain surgery twice which has helped bring my epilepsy more under control. I have a short seizure about once a day now. When I was younger, I had a team that helped me navigate elementary school. I enjoyed being there with friends. High school was tough because I did not know any of the kids. I enjoy being silly, playing board games, having books read to me and visiting with family and neighbors. Doing things outside my home now is scary. I am learning to be brave and trust others with the support of my family and designated agency. Being with people I trust is super critical to make me feel safe. When I don't feel safe my most common behavior is to run away and hide. I don't move from my hiding space until I am found. This can be very stressful for those who love me. If people understand me, explain things to me, and give me choices, I do well. Patience is required as I process information and speak slowly. I also have rituals/routines that help me feel safe. If people don't understand, they may find these quite

annoying. Patience is required. Mom, Dad and those supporting us are trying to help me access my community, be a bit less bored, and make some friends. Thank you for your help! ~**Owen, Juliane and Dan Foley**



My daughter **Ella** is 18 and has autism. She is partially verbal and uses a speech generating device or “talker.” Although that has been a wonderful tool for Ella, she is still not capable of communicating her emotions and needs. She wouldn’t be able to tell anyone if she was being physically or sexually abused. She lives a life of eternal vulnerability. She loves a hug but doesn’t understand that you shouldn’t be hugging strangers in Hannaford’s.

Ella is currently attending a special needs residential school in PA. She is surrounded by people who see her as a true human being. She is safe, loved and thriving. Once Ella falls off the education “services cliff” and has to come back to Vermont her choices of where to live keep me up most nights. When I hear stories from parents telling me where an agency wants to

place their child I want to be sick. She is not a high functioning person like many who advocate for “independent living.” Autism is a spectrum. So many people forget that. She is a member of an under-represented population.

Ella is a young woman who needs 24/7 care. If she lived in a town or city she would face huge safety issues. Ella is an amazing artist. She loves music and horses. She needs a safe space. The SLP model does not fit her needs and I cannot care for her at home anymore. I want her to live in a place that is truly her home and not as a visitor who is regarded as income. Vermont is supposed to be a state of innovation and forward thinking. Let's work together to create true choice. Help give our children a life of happiness and dignity. ~**Laura MacDonald**



Our daughter **Kate** is 28 years old. She is Deaf and has cerebral palsy with spastic quadriplegia. She is nonverbal and uses an iPad to express herself. She is bright and social, but has serious developmental delays, and is a graduate of the American School for the Deaf. She needs total assistance with all activities of daily living. She thrives in a Deaf environment and needs to live with other Deaf people. We have been trying for three years to recruit a Deaf homecare provider without success because Vermont abandoned its Deaf community when Austine closed. Since her graduation from high school in 2015, she has lived with homecare providers who were either A) not Deaf and who did not include her fully in family life, or B) Deaf, but unable to provide a clean, happy, functional home. The oversight home provider B

received from Kate's designated agency seemed not to register that her home was filthy, and that she was rapidly losing weight because one of her homecare providers was not feeding her adequately.

Kate would ideally live in a small community or group home (4-6 clients) of Deaf clients and Deaf support staff, within wheelchair distance to retail, library, and cultural resources.

This system does not work for people who cannot advocate for themselves. There are not adequate safeguards in place to make sure these homes are healthy. Neglect can and does happen quite frequently, and did with our daughter. The State of Vermont is trying to avoid our worst fears of institutionalizing these vulnerable Vermonters, but fostering them out individually to live in strangers' homes is not the answer for all these folks. We can and must do better. ~**Ellen McKay Jewett and David M. McKay**



Pictures are always so telling. Here is my son **Travis** golfing, bowling, swimming and independently engaged in all hygiene just three months ago, solo, with me.

Due to the complexity in processing language I provide visuals to map out our several hours of activities which includes conversing with recreational facility and Stoweflake Resort managers. My son shines when with trusted and qualified supporters. Upon returning to his confinement site my son has a totally different presentation: self-fulfilling prophecy. My hope is our united efforts produce change so devoted moms like me are not the only formula to success. Sustainability in housing and supports in a system free of conflict of interest is necessary for ALL to move forward. ~**Linda Luxenberg**

My daughter **Nicole** is 31 years old. She has severe autism and does not like change. If she was put into shared living and something happened to one of the homeowners and they weren't able to continue providing housing, my daughter is the one that would have to be uprooted and moved. This would cause great stress on her and her family. ~**Ruth Banghart**





Maybe you've seen me around town scootering on the bike path, singing loudly or running to our van. My name is **Nicholas** and I am 26 years old.

I have to be with two people in the community. I am autistic. I may have seizures and sometimes gastrointestinal issues. Last summer my parents thought I had a small stroke as I stopped walking and couldn't move. Then within a few minutes I came to and was able to walk but it was another bizarre episode in my life. There is a lot of guessing on my medical state.

I can talk but I don't talk like you. I can type but I don't type like you. I am engaging when I feel well but I also have gone through some unprecedented ice pick headaches. It is devastating and changes my mood in a minute. I can be frightening in that state and you will have a lot of sorrow knowing I have such pain without a medical solution. But my mom

and Dad are working on it diligently.

I really like engaging people who don't talk at me but with me. I especially like accents. My personal care needs are 24/7 and I want to keep learning whether it's drums, games or even signing (I know a lot of it receptively). My parents can't continue to take care of me alone. It is a huge job! They don't complain but everyone sees how much it is.

They want to live forever to take care of me but they can't. I know I will thrive having a home community in my city with an educated, respected workforce that will help me grow to be helpful to not only myself but others. I have a lot of potential and need healthy stimulating activities. I also need people to know me, be consistent in my life.

~Anne Barbano & Mike George



My son **Jake** is turning 22 this July. He has profound autism, cystic fibrosis (CF), and epilepsy. He is mostly nonverbal and cannot tell us he's hurt or feeling sick. He has disabling grand mal seizures every 4-6 weeks.

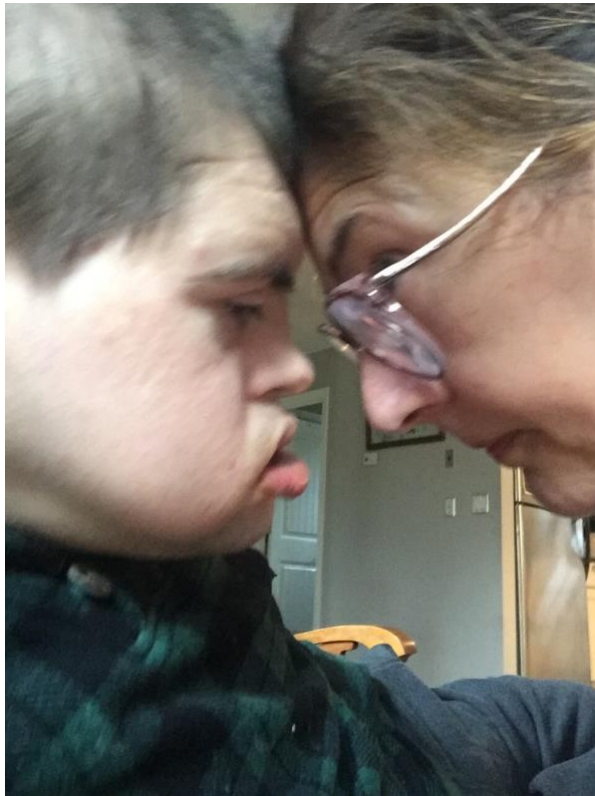
For the past 4+ years he has attended a residential program in PA, The Camphill School, a farm-based intentional community with intensive supports for his high needs. He has thrived here with peers, and support staff around him 24/7 who care about him and meet his needs within the framework of predictable routines and rhythms.

Jake is a happy-go-lucky, sweet, silly young man despite the challenges he faces every day. He requires help with everything from getting dressed to doing his CF lung treatments to taking the 70+ pills he must take daily. He is in excellent health only due to very careful and diligent management of his CF and epilepsy.



He will enter adult services in 6 months, and he faces an uncertain future. I am a single parent with a disability myself and cannot care for him safely at my home alone, at all. If we can even find a Shared Living Provider, that person or couple will need additional 24/7 staff. They will also need training and ongoing support to learn how to care for him and meet his needs. The existing system doesn't have these elements. I am afraid he will fall apart without the structure he needs.

Come July, we need what he has now: a team of trained, compassionate, energetic staff who love what they do and treat him like a family member; who are paid well, supported well by experienced supervisors, and who have adequate respite time to recharge from giving such demanding care. Ideally, in a community of his peers with a rich and full social life. ~**Lauren Arcuri**



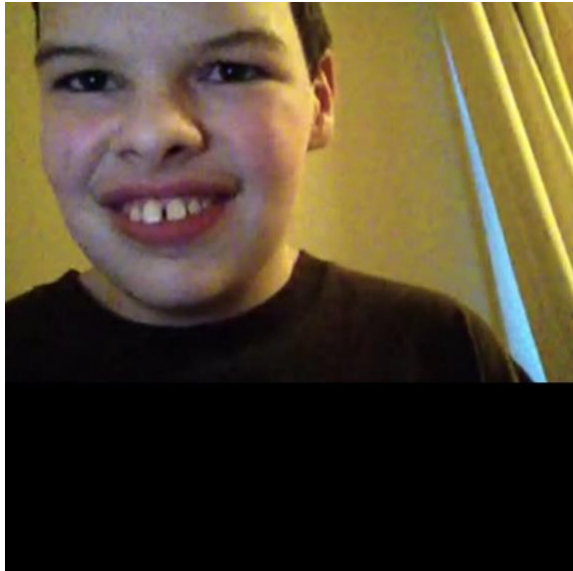
My son **Joseph** is a 38-year-old young man with Down Syndrome and Lennox-Gastaut Syndrome, a seizure disorder. These two diagnoses have led to the need for 100% personal care, combined with his inability to communicate with any method we've tried over the years. He is always in an extremely vulnerable state.

At age 19 he entered the world of Shared Living when I became a single parent and could no longer care for him by myself. In the last 19 years he has been in and out of 7 shared living situations as well as time periods when he returned to my home due to lack of housing options. Joseph was removed from 3 of the 7 shared living homes due to neglect and abuse (broken bones, burns, unexplained weight loss, frostbite, cuts and bruises). Another 3 placements ended with caregiver burnout due to his 24/7 care needs. He is currently in his only successful placement, but will be

moving again later this year due to his caregivers entering a well-deserved retirement. For many months, his care team has been searching for a new placement with no success.

His medical needs have increased as he has aged. The damage done by years of uncontrolled seizures have added to this. Also, people with Down Syndrome age at an accelerated rate with Alzheimer's sometimes developing at an early age. Sadly, I'm also aging and find that I can no longer physically care for him. At this point in his life, a housing option that offers stability and a team of caregivers who share his 24/7 needs would be such a pleasant and necessary change.

Unfortunately Joseph has a very limited life but on the bright side, doesn't realize it. He seems most happy when being well cared for and is surrounded by others who know him and connect with his gentle spirit. ~**Patricia Waite**



Our son is a compassionate, fun loving 20-year-old young man who resides in a shared living home in Chittenden County. He has autism and has endured two open heart surgeries, seizures, clots, a broken knee and ankle, and has a valve replacement on the horizon. Our son is a non-speaker who uses a multimodal communication support to communicate.

We worked together early and hard with our educators to develop supports and opportunities for inclusion. We are still at it—we have strong school and community teams, but I am concerned about his future when his education ends at age 22.

As our son moved forward to adolescence, he experienced significant aggression and violent behavior, needing to be institutionalized out of state for over a year. There were no options, for there was no system of care in Vermont to support his level of need. It was an incredibly devastating experience, to know that our son had to be placed out of state. Additionally, when he was discharged, there was no step down aftercare program and it was a scramble to find staff.

We made a bold move as a family to relocate to Chittenden County in an effort to get more services. The Shared Living option was the only one offered to us. Luckily, we finally found the right family through the Howard Center and I am so grateful to them for their help and support.

In terms of the future, we need to allow our adults to lead self-directed lives and participate in their own decision making. It is our hope that our son will continue to thrive. Personally, I find the Yellow House and the Heartbeat program viable options for inclusive living and have always felt a residential advisor situation in an apartment setting may also be another gateway to independence for many of our adults.

For this to work, we need integrated medical and community commitments that invite our sons and daughters to the table, see them as contributing members and support them in developing a future that is worthy of their caliber. ~**Jeanne Bradley**



Our daughter **Jordan** has an ASD diagnosis (and more recently a diagnosis of Pheland-McDermid Syndrome). She has lived in the Shared Living model for ten years with a single provider. When we were considering housing, Shared Living was characterized as supported living, and was the only offering. Here is what we've learned:



- Shared Living combines the housing and care into a single model or pricing structure. SLPs are contracted by the DA (designated agency) or SSA (Specialized Service Agency) as independent contractors
- SLPs do not access any of the employee benefits that DAs/SSAs offer—they get a tax-free stipend for care + a respite budget to hire additional care providers when they need “breaks” (respite is considered a “break” for primary caregivers, as opposed to needed coverage for the wellbeing and safety of the person receiving care)
- Our daughter (the client) pays room and board monthly to the SLP via her SSI benefit. She retains a small monthly amount for personal spending
- If staffing is not available from the DA/SSA (for those that have community access budgets), the SLP is expected to cover those shifts—themselves or by using the respite budget
- There is no additional pay for the SLP while covering for agency staff; they essentially work more for less money
- The SLP is expected to identify and hire additional staff to cover their “breaks” via the respite budget—vacation, weekends off, sick time

Given the well-known shortages for caregiver staff, the burden of care for a vulnerable adult often falls to a single person, the Shared Living Provider. In no other human service industry (healthcare, senior care homes) do we expect workers to work for extended periods without breaks. Nor do we expect them to sort out their vacation time, sick time, etc. on their own. Yet these are the conditions under which Shared Living Providers provide care to people with disabilities in this state.

Adults with disabilities deserve to be safe, well cared for, and have choices. They deserve options that address their varying support needs. We are asking our legislators to do something to address the limitations of the Shared Living Model, and to support the provision of additional housing models for our most vulnerable citizens.

~**Tammy Willey**



My daughter **Shea** will be 19 in a few months. Shea enjoys horse-back riding, singing, listening to music, baking, crafting (especially beaded jewelry), playing games, skiing with Vermont Adaptive Sports, and boating with her family. She loves connecting with people, especially her peers.

As a baby Shea struggled with sensory sensitivities, digestive troubles, difficulty sleeping, and frequent emotional dysregulation. At age 7, she was diagnosed with a genetic disorder and has a long list of diagnoses including Autism Spectrum Disorder, ADHD, Anxiety, and speech and language challenges. Shea is 4 foot 8 inches and this will be her maximum height. She is fun and sweet and also quite vulnerable as she becomes easily confused in social situations. Shea needs prompting to get things done or be anywhere on time, needs assistance with anything relating to money, and needs 24/7 support in order to stay safe. She will not be able to live independently.



Shea recently experienced many of her friends going off to college. Her question for me was, “what about me? Where do I get to go and live with my friends?” Shea sometimes expresses to me that she feels like an “outcast” and wishes she wasn’t so different.

One of the greatest challenges in caring for Shea is that she talks pretty much non-stop and her anxiety rules much of the conversation. Her relational enthusiasm has its charming moments but for the sake of all involved, she needs a living situation that allows her to interact with a number of different people.

Shea has had the good fortune to spend some of her summers at Camp Thorpe in Goshen, VT. Shea thrives in community, working with others toward a common goal. She enjoys helping out and being part of a team. She is lonely living at home and struggles with anxiety and depression when she doesn’t spend enough time connecting with friends or feeling purposeful. It has been an intense parenting journey and I can no longer meet all of her needs. She is ready for a bigger world and needs safe, stable housing where she can be actively engaged with peers and the community. I need to know she will be cared for and have a good quality of life when I am no longer here.

~Josette Blais



Gabriel Roberts-Peres is a 25-year-old autistic man who moved to Burlington, Vermont, with his mother Donna Roberts and Stepfather Chip Hoffman in August 2019. Gabe enjoys music, reading, travel, history, all kinds of transportation - especially trains - going to the movies, cooking, swimming, and learning about pretty much anything! He has a dream to have his own food truck, and to be in a marching band. He played percussion with his high school band in Pittsburgh, Pennsylvania.

With three passports, Gabe is a citizen of his birth country Canada, the U.S, his mom's birthplace, and Brazil, where his father was born and where he lived for three years during middle school. Yes, Gabe can speak Portuguese!

Gabe volunteers and works at the Salvation Army; you can see him bell-ringing during the holiday season. He wants more work and prefers that it be related to any of his keen interests. But in Vermont, there is not much in the way of supported employment tailored to individuals' strengths and needs; his mom spends a lot of time advocating with other parents in a community of practice trying to get Customized Employment in place in Vermont with the help of Vermont Developmental Disability Council.

Gabriel has a lot of anxiety, OCD tendencies, and intellectual disability, along with sensory integration issues. Along with autism, this can all lead to cognitive overload, lack of impulse control, and agitation...unless the environment is just right.

Like most people, Gabe wants to live a full life in his own apartment or forever community, with a partner, maybe a wife. He wants to be as independent as possible, spend time with friends, and basically enjoy most activities that others do. However, at least for now, Gabe needs 24-hour support, which can also be shared with others. In Vermont, this is currently not available to Gabe, unlike in many other states, like Pennsylvania, where Gabe had a consolidated waiver which would guarantee him a space in a supported group home community - one of the hundreds that exist throughout Pennsylvania. But we moved to Vermont for clean air and quality of life. How ironic.

We had no idea upon moving here how dire the situation is for people like Gabriel, especially in terms of supported housing. Parents are expected to continue supporting their adult children for as long as they physically, psychologically, and emotionally can, without regard for anyone's true quality of life, the limitations of aging parents, the injustice to our young people who want the rights that every other person has...to be able to thrive aside their peers yet in supportive communities. That's why his mom has been actively involved with the Developmental Disabilities Housing Initiative and is developing a documentary film about the plight of families like ours in Vermont...along with the joys of life with an extraordinarily creative, bright, deserving, and very entertaining young man. ~ **Donna Roberts**



My son **T.J.** is 30 years old and has autism. T.J. enjoys skiing, hiking, bowling, playing pool, bingo, doing puzzles, go-fish among other games!

He loves to have a football catch and watching sports on TV, yet he has no understanding of the rules of the game. He is well behaved most the time but his OCD does get in the way sometimes. He does need 24/7 care. He has limited language and cannot express his needs and wants all the time. He does have a high tolerance for pain and has trouble expressing that as well.



I have chosen not put my son in the SLP system because he requires a higher level of support than an SLP can provide, and he is at high risk for abuse and exploitation since he can't make his needs and wants known clearly all the time. ~**Janet Ottas**



Our son, **Jack**, who just turned 22 years old this past March ('23) has lifelong significant disabilities. While a genetic diagnosis still eludes us, we know his brain did not form normally in utero, he is profoundly deaf, visually impaired, globally developmentally delayed and non-verbal. He requires 24/7 care and oversight. As his family we nurture him and just celebrate him for who he is: a sweet, loving, cheerful young man who loves being with his family, friends, and caregivers. He also loves music, being read to, going to the park, playground, and the "Y", and doing his best at his job at Shaw's one morning a week. It is without

question that Jack will need a safe, structured, and stable home when we, his aging parents, are no longer able to provide 24/7 care for him. We *dream* that it can be in a staff-supported residential community with friends, in our beautiful home state of Vermont. ~**Donna & Patrick Savage**



Maitri is a bright, strong, creative and resilient young woman. She developed typically until age 5 when she began having symptoms of nightmares that morphed into epilepsy over a 10-month period. Since 6 she was diagnosed with intractable epilepsy having 40-60 seizures a day. Since 2010 we have been navigating the systems of care to help understand what is causing the seizures and to best support Maitri in her life. We are thankful for doctors and individuals along the way who have shown Maitri so much love and support.

This past April she fell during a seizure and developed a large clot in her brain. She regressed so much and is now healed and regaining strength and abilities that were lost. Grief is part of the lives that we face and it is real. I have held Maitri in my arms, and she has deeply sobbed, “Mama, what is happening to me!” And we are very thankful because through the grief and the loss we have created a beautiful life with the supports around us who are consistent and reliable.

To have a community of love who steps up for Maitri and me as her caregiver to help us through each day is the greatest blessing. Maitri has faced so many cycles of gain and loss for the past 13 years. Through it all she has kept a joyful heart and is independent in many ways. She also is extremely vulnerable; she can fall down in a seizure at any moment and needs complete care. She needs a stable loving home where she can learn and thrive and rest and recover. She loves her family and friends and they love her so much. She loves to come to church and give away her art to the children and “adults too!” as Maitri says. She has a strong sense of who she is, her likes and dislikes, her passion, and abilities. She will speak up when she can and say, “I need rest,” when she has had so many seizures she doesn’t want to get out of her bed. Maitri is a blessing and she brings so much joy to those she meets.

For her future, she wants to be home surrounded by family and loving friends supported by people who can be constant like a star shining light and providing her with the stability that comes with a loving home. When you meet Maitri it can take her time to respond verbally, she doesn’t say hello or goodbye or do fist bumps, as she says, “that’s not my thing”. She does smile a beautiful smile and will share with you all that she holds dear in her heart. Which, right now as a 19-year-old, is her love of the movie *Gnomeo and Juliet* and singing the amazing love songs that she says are “healing me from the seizures”. One service that she is receiving is her music therapist through Pediatric Palliative Care Program. The concern is when she no longer is eligible for this program how will her relationship with her teacher continue? What will we and the systems we create do to ensure that Maitri can keep singing with her teacher and growing into all who she is created to be? Helen Keller had Annie Sullivan as a teacher and friend for Annie’s entire lifetime. This is a simple and honorable model of constant love and support. I am praying for this for Maitri and all our families in need that throughout their lifetimes they will be surrounded by devoted teachers, by loving family and friends and have joyful hearts. ~ **Annie Galloway**



Our 19 year old daughter, Kennedy, came into our lives through adoption. We knew from the day we met her that she was a special child. She had such an intense stare and amazing fine motor skills. But as the months went on, I knew she was not developing as my other children had. At three years old, we began the journey (more like a gauntlet) of visiting specialists all over New England to determine why she was developmentally delayed. She was diagnosed with Autism at age 5, along with being Intellectually disabled and having mood disorders. As she went into puberty, those mood disorders grew into Bipolar with psychosis, and then we went further to schizoaffective disorder. She has sadly struggled with psychosis more as she is entering adulthood.



The complexity of our daughter's disabilities has made accessing services, including education and behavioral health support, nearly impossible. She shares her unique profile with very few other individuals, and recently, we learned through an advanced-level genetic test that she carries a mutation of the TRIO gene. This gene mutation seems to explain her Autism, schizoaffective disorder, and seizures. But it did not give us more solutions or services. My challenge with our daughter is that inclusive models do not work, nor do community-level resources. Because she has a co-morbid diagnosis, she requires a collective team approach to treatment, but sadly, our systems have not caught up yet to service individuals such as here. We have entered two local hospital inpatient programs in the past year only to be told that she was out of their scope. Kennedy is on the leading edge of the tidal wave of aging autistic individuals; her complexities are going to be seen more and more. It is time that Vermont not only looks at ongoing supportive housing models but also adjusts our systems so those with intellectual disabilities and autism can readily access mental health services, too, at equal quality as those who are neurotypical. We need specialized providers to provide diagnosis, behavior support, and medication management. Without these core supports and services, individuals like our daughter will remain in the revolving door of the ED. According to the Children's Hospital of Philadelphia, children with autism are 85% more likely to have a mental health diagnosis (2023), yet we do not have the mental health teams to treat those with Autism in Vermont. This is the missing piece to a puzzle that is extremely complicated.

I have been my daughter's "everything" for 18 years; I am her biggest advocate, run her case management, search out services, and make it clear to all who come across my path that she is worthy of equal quality care. She did not choose this life; her genetics did. Her behaviors can be intense, and her daily need for care exceeds our funded budgets. Our family of 8 has been her support system since day one, and I am beyond proud of her siblings for all of the care and sacrifice they have given. I believe she was placed with us for a reason, and God had a purpose for us. As difficult as her care is, the life lessons she has taught us outweigh the struggles. Kennedy may not speak often (she has selective mutism), but if she could, I believe she would ask for a better understanding of her needs and better support in our beautiful state of Vermont.

~ **Mitzi Motley and family**



Our son, **Ari**, was born 3 1/2 months early at 24 weeks, weighing 1 1/2 pounds. The results of his extreme prematurity are that he has cerebral palsy and an auditory processing deficit that renders him unable to understand spoken language. He has developmental disabilities, walks with a walker, uses a wheelchair at home and uses sign language for communication. He is also extremely social, outgoing, funny and engaging. Ari is 33 and has been in shared living since he was 24, coming home to us every other weekend. He is presently in his fourth shared living situation.



When he was enrolled at Austine School (school for the deaf in Brattleboro), we spearheaded an initiative to develop a group living facility for deaf/developmentally delayed adults. At that time, before the recession, we were embraced by State officials, among other interested parties, and had a big team that met monthly including representatives from the DD Council, Vermont Center for the Deaf, Vermont Center for Independent Living, Dept. of Housing and others. We (the only client parents on the team) met for 7 years usually at State offices in Waterbury. We eventually reached the point where we'd identified a likely location and had architectural plans ready to go to build a "group living" facility in Burlington for 6 individuals. The next step was to make it a line item in the next State budget, which the legislature was considered likely to do because deaf/DD adults had too long been vastly underserved and a sense that our collaborative initiative was being positively received.

That is when the economic recession hit: all State budgets were suddenly on the chopping block; most of the State-employed members of our team lost their jobs and nearly all deaf services for the state were terminated. We were wished good luck and sent packing.

After Ari graduated from Austine School for the Deaf, he came home to live with us for 2 years as my husband and I tried navigating the barren landscape of supported living. Ari's first shared living arrangement came about as a result of Howard Center's inability to find staff to serve his deaf communication needs. Our inability to singlehandedly provide our son with a well-rounded life resulted in fast developing frustration behaviors and he had no deaf peers with whom to relate. Although an occasional signing staffer was found or people received rudimentary sign language training from me, there were no social situations available for him to interact with peers in Burlington.

However, in St. Albans NCSS was offering a newly developed program for deaf adults with developmental disabilities. We immediately enrolled Ari in NCSS' innovative day program for one day per week. Coincidentally, I met a single mother, "H", from Milton who had a son with autism and a typically developing teen-age daughter. She was



looking for stay-at-home job and was eager to learn sign language. “H” jumped at the opportunity to be Ari’s shared living provider. In many ways it was wonderful for Ari. The daughter learned ASL like magic and was very interactive with Ari. In addition, his involvement in the St. Albans deaf program finally created a community of peers for him.

Although Ari seemed well adjusted and happy, somewhere along the way, “H” informed me that she “hated being a shared living provider and that no one would do this job if they didn’t desperately need the money.” After 4 years, “H” eagerly started planning her “escape”. What ensued for us was a nervewracking, trial-and-error recruiting campaign for a new home provider.

The exercise of recruiting possible new home providers gave us another idea: purchasing an attractive, functional shared living home to attract potential shared living providers. No sooner did we buy a townhouse condominium than Ari’s case manager and her husband, “C and C,” both deaf, presented themselves to us for consideration. We jumped at the prospect and even partially furnished the house to ensure the comfort and safety of our son as well as a pleasant transition from his current living situation. But when it was time for Ari to transition to his new home, there was no transition. “H”, along with her daughter, brought Ari to his new home with no explanation to him of what was happening and essentially “fled” the scene never to see him again.

“C and C” had a hearing baby who was clearly the centerpiece of their existence. It quickly became clear to us that they regarded Ari as nothing more than a troublesome but necessary evil to be endured in exchange for their otherwise wonderful new home. The mother actively avoided any room that Ari was in and the dad was unable to appreciate Ari’s fun and playful interactions, often mistaking his innocent intellectual miscues as intentional attempts to make things more difficult. Ari was essentially being ignored and misunderstood. We were aware of his unhappiness living there. When they had friends come to visit, they wanted us to take Ari. The father told us that their family couldn’t understand why they would want to live with a disabled person. The family didn’t even want to see him.

On the occasion of “C and C’s” son’s first birthday, C and C asked us to take Ari home so that their family wouldn’t have to see him. We expressed disappointment that they weren’t going to include him in an event that he clearly would have enjoyed. I asked for them to have him stay. They told us they would have him stay, but instead, without telling us, they had him go to a deaf respite person’s house. When it came time for him to return to the deaf couple, Ari laid in a corner crying. The respite person, “T” (who we knew) got in touch with us and said she didn’t have the heart to return him to the shared living providers. In the end we told her not to return him. In a frantic 2 days during which time Ari stayed with “T”, we had Ari’s shared living provider changed to “T.” Ari had lived with the “Cs” for just 3 months.

“T” seemed ideal. She lived with her deaf partner, deaf daughter and another deaf shared living client, 2 dogs and a rabbit. All seemed good for the first year. Ari enjoyed



an extended deaf community through this active family, which included going to a deaf church on weekends and participating in deaf community activities.

Money was always tight and “T” decided to take on an additional client. We worried that it was going to be too much for “T” because the client had much more extreme needs than Ari. As it turned out, the client’s needs caused a lot of arguing between “T” and her partner of 10 years. There was constant anger and tension in the house all the time. Finally, her partner moved out, leaving “T” with her daughter and 2 high needs clients, as well as 2 big dogs and a rabbit to take care of. “T” was never great at housekeeping and depended on her partner to do much of it. After he moved out, the house became dirty and unkempt. The big dogs slept on the furniture, but Ari used a wheelchair mainly in the house. Ari’s room was ok and we asked that she keep the door shut so the dogs wouldn’t sleep on his bed. We were convinced that he was being given a decent nutritious diet. “T” was nearly always angry and frequently felt sick. She found her other client extremely challenging.

Ari began exhibiting signs of unhappiness, frequently acting out negatively and sometimes biting himself out of frustration. We started meeting as a team regularly with an NCSS staff psychologist and psychiatrist. Nothing seemed to change with his behavior. We also had regular meetings to discuss “T’s” options and how she could be better supported. Nothing ever came of those meetings.

Finally, after two years on her own with the two clients, “T” decided to give up the other client. We moved “T” and Ari along with her two dogs and rabbit to a nice clean townhouse in St. Albans, helped her set it up and furnish it. Unfortunately, the dysfunction continued. “T” remained angry and sad. Her daughter was going to a deaf school out of state. She gave up one of her beloved dogs. While pet sitting a friend’s Doberman at her house, he attacked and killed her rabbit. She decided to submit her notice in August terminating her shared living arrangement with Ari as of November 1st, in order to move out of state to be closer to her daughter. In August, “T” packed all her things in boxes and put them in the living room. She took everything down from the walls and only left a space at the table for Ari to eat.

Around that time, Ari’s self-mutilating behavior had become regular. We were startled that his wrist was deeply scarred with bite marks. We had emergency meetings with his case manager and bought him a wrist guard to discourage the behavior.

On November 1, when we went to get his things from the St. Albans town house, the entire house, upstairs and down had dog hair and rabbit droppings all over the carpeted floor and stairs including Ari’s bedroom. Since the rabbit was killed in August, that meant that “T” hadn’t vacuumed for at least 3 months. Ari’s case manager was supposedly doing home visits every month. It was impossible not to notice how appallingly filthy the house was.

NCSS was slow to advertise for a new shared living provider for Ari. We had to keep reminding them that very little was out there by the way of ads. We did all that was



available to us as parents to advertise and research the best places to find new deaf shared living staff. All attempts amounted to nothing. Ari was placed alone in a remote respite house in Enosburg from November to February, staffed by one person at a time. Many icy winter days, no one could leave the respite house because the driveway wasn't plowed. Ari spent days alone in that house with one staff and on other contacts. No cooking was done for him. All the food were canned or frozen dinners. Ari isn't able to read or write. Email and phone conversations can't happen. We did have FaceTime conversations now and then, but conversation with Ari is limited. This 3-month period was extremely isolating. It was over 2 hours away from us, so, except for our having him at home every other weekend, we didn't see him.

In January, one person applied for the shared living position. Ari is presently living with a nice family with 2 children and lots of pets on Enosburg Mountain, over 2 1/2 hours away from our home in Charlotte.

Throughout Ari's shared living time, his father and I have taken him home with us two weekends a month. My husband and I are 71 and 75. We both have health issues. Having Ari home with us can be sweet and lovely, but also extremely physically and mentally demanding and getting harder with each passing year. He can't be left alone except for during sleep. He gets up during the night for bathroom visits and then again early in the morning. Often we don't get back to sleep. He wants our attention constantly. Having him with us for more than 2 days and nights is too difficult. During vacations together, we need respite support to accompany us with Ari.

To summarize, the reasons why shared living is not the best option for our son are:

1. Inconsistent oversight by designated agency. Bad things can be happening and living conditions can be inadequate/unhealthy/ traumatizing when shared living providers are left unaccountable. With nonverbal developmentally delayed adults, it is impossible to know exactly what goes on inside a private home. And if the client has signs of physical or mental abuse, case managers don't seem to notice unless they receive a report from the client's guardian.
2. The income reality for the majority of shared living providers is such that they are apt to overestimate their capacity to provide adequate care simply to chalk up an additional source of income.
3. Designated agencies provide little or no training for shared living providers. And when they do, the emphasis is often on the wrong things.
4. When a client is in need of a new shared living provider, the recruitment process can take months during which time the client may be warehoused in a less than optimal living situation or, as a default, end up with guardians who may be unable to provide adequate care. Effective advertising for new shared living providers costs money, making designated agencies reluctant to look beyond their existing staff and immediate community for candidates. ~**Deborah Lamden**



My son **Kristofor (Kris)** is 39 years old. As a single parent, our family moved to Vermont in 1984. At three years of age, he was diagnosed as having a Pervasive Developmental Disorder that was later confirmed as Autism. At that time, there were no resources or places to look for support.

When he was in the second grade, he was introduced to a new method of supported typing or facilitated communication. It was through this method that he found his voice. All of the thoughts, needs, and wants that were trapped inside his head came pouring out. Having this newly found sense of himself, his life changed.

Over the years, his trained support staff came and went due to poor wages, along with his ability to consistently be able to communicate his needs. His verbal ability today is still quite limited but with the support of a trained support

staff, he is able to engage in meaningful communication. However, when COVID hit, he lost both his Case Manager and his trained support staff.

The Shared Living Provider model would not meet my son's needs. The stories I have heard from other parents about the neglect, abuse, exploitation and a lack of oversight and accountability by the designated agency is unacceptable. Kris requires 1:1 support 24/7 due to his limited and inconsistent verbal abilities, difficulties performing daily living skills, and a lack of safety awareness. He has a high threshold for pain and will not admit to not feeling well. He also struggles with compulsive behaviors and anxiety.

Kris has only had one home and that is with me. I am 69 years old and have significant health issues. My dream is that before I leave this world, that my son will be living in a stable, consistent, and safe forever home with a few of his peers within his community supported by people who understand him and appreciate him for the wonderful man he has become. ~**Sharon Medina**



DDHI Contact Information

For questions, please contact Karen Price at karen.price@vtn.org.

The DDHI Housing Models Report and Needs Assessment can be made available upon request.