DDHI FAMILY STORIES: A PHOTO ESSAY

The Developmental Disabilities Housing Initiative (DDHI) is a Vermont grassroots parent advocacy group of over 150 families in support of developing stable, permanent, service-supported housing peer residences for our adult sons and daughters with Intellectual / Developmental Disabilities (I/DD).

Many DDHI families became involved because their adult sons and daughters have higher support needs meaning that not only do they have an I/DD, but also other challenges such as limitations in communication, behavioral challenges, decreased mobility or significant medical needs, and may require 24/7 support, often on a 1:1 basis.

Long term housing stability, coupled with well trained, compassionate support people are critical building blocks to provide stable, permanent, service supported housing options for our adult sons and daughters to live and call home, that fosters safety and wellness, independence, community, and dignity.

Please take a few moments to peruse the attached stories of some of our wonderful, amazing adult sons and daughters.

Thank you,
DDHI Families

Contact Information

For general questions about DDHI, please contact Karen Price at karen.price@vtfn.org.

For questions about DDHI's Legislative Advocacy, please contact Laurie Mumley at Mjustlaurie@aol.com.

I have a 27year-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

"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.

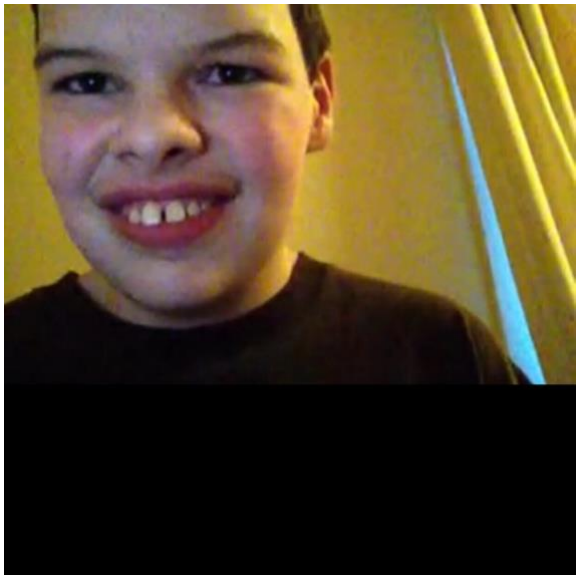
~Nancy Osborne

Our daughter **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



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 Heartbeet 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.

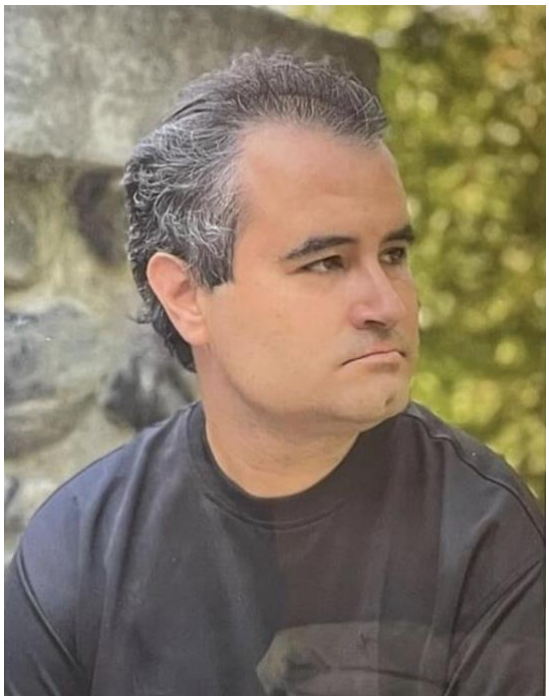
We had no idea upon moving here how dire the situation is for people like Gabriel, especially in terms of supported housing. Parents are expected to continue supporting their adult children for as long as they physically, psychologically, and emotionally can, without regard for anyone's true quality 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**

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**



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@vtfn.org.

The full family stories and other resources can be made available upon request.