

Testimony on behalf of my daughter's peers, who are at risk of harm

Feb. 16, 2023 Public Hearing on Housing

To: Members of the Senate Committee on Economic Development, Housing, and General Affairs
and the House Committee on General and Housing:

I am a mother of a 23-year-old daughter who has autism. I am also a paid legal guardian. I have a conciliation agreement with the attorney general due to a public accommodation discrimination complaint that I filed on my daughter's behalf.

My daughter is now living in her own home under a shared living contract with the Howard Center, I only get paid if that contract is not staffed, as I am promoting her independence, as most parents would do, given the means to do so. What she and I had to go through to get to this point is unconscionable. VT's lack of compliance with Federal laws in home and community-based settings caused her harm. The Federal government does not have a "quality assurance plan" in the Home and Community-Based Settings Program. It is up to VT to figure that out, and VT doesn't respect parents and legal guardians in its systems of care in adulthood. As I shared my daughter's story with Representative Topper McFaun, he and I figured out that "federal quality assurance plan" that VT needs, and it is budget neutral. Please ask him about his bill.

What my daughter went through was not 'adequate' under State Managed Care Organization Regulations. Leaving her natural supports took the only safeguard she had that protected her ability to feel safe. Imagine being in 'fight for flight' and trying to thrive? Psychological harm looks like: Alarm-Resistance-Exhaustion. That's what people feel if they are institutionalized. They are scared, they may fight back and then they give in, forever psychologically harmed. Can the person deal with it, or can they try to run away? As you read the VT Digger articles of systemic failures causing death and abuse of my daughter's peers, please think of 'fight or flight' and put yourself in their shoes. How can VT have a system that promotes human rights violations? You've taken in hundreds of millions of federal funding. Where did it go?

My daughter's story can be read under Martha's Story on a nonprofit organization inspired by her www.marthasbarnvt.com She is now taking the skills she's learned and helping others, earning a small paid wage that will hopefully grow over time. Our mission statement is to do just that, put skills into action. Family-centered care is NOT existent in VT, and that was the intention and purpose of VT's DD Act of 1996. VT failed to create a system to support it, even after decades of federal funding to do so. My daughter was born 3 years after VT's DD Act. To say I assumed she had human and civil rights is an understatement. I am no longer naïve to think VT cares about the most vulnerable. The Conflicts of Interest in case management allow for due process violations. I see no systemic change in sight. VT only receives federal Medicaid because it uses 'shared living' as that 24/7 medical assistance, yet the state indemnifies themselves. Lack of transparency is how it's gone on for so long.

My mother started VT's first residential care home for my brother after he sustained a traumatic brain injury in 1979. The state's only infrastructure was a nursing home. This was before the Supreme Court's ADA Olmstead Act. She single-handedly saved hundreds of vulnerable Vermonters from institutionalization as owner of multiple residential care homes. I watched her and I learned. Our family now operates 5 VT licensed residential care facilities providing home and community-based care for individuals with traumatic brain injury. Growing up with a brother who had a TBI and having a daughter with autism gave me a lot of tools. One of those tools is the knowledge of the laws to protect the human rights of vulnerable people who I love. My late brother and my daughter have disabilities that are covered under the Americans with Disabilities Act.

See VT's Global Agreement with Centers for Medicaid Intergovernmental Agreement between Agency of Human Services and Office of VT Health Access September 30, 2005, Page 1-1.3 **COMPLIANCE with Americans with Disabilities Act.** VT 'can comply' with Title II of the ADA, an ADA reasonable accommodation under the Fair Housing Act, and pay a legal guardian. I am that legal precedent. As I sit on committees, I hear the engrained bias against parents and legal guardians in this state. It is abhorrent. The bias is so deep that parents and legal guardians are looked at as using our children as 'cash cows'. We are VT's greatest natural resource and currently doing the jobs of the designated agencies who are receiving federal funding to contract or provide comprehensive services. *But VT's single state agency did not give the Designated Agencies any authority to provide or contract a system that operates under federal ADA laws. The federal funds stay in the state off the backs of the poor and disabled, perpetuating a bias that parents/legal guardians are somehow harmful. What is/was VT's intention of receiving federal funding? I thought it was to provide healthcare, yet there are mothers in their late 60s and 70s who have no paid support.

All caregivers paid or otherwise must follow federal vulnerable adult abuse laws and legal guardians are being forced to consent to shared living providers, and the state indemnifies in that contract. The state causes harm to vulnerable adults, not the legal guardian. Can you imagine the position of a legal guardian, having to consent to potential abuse of their loved one when they can't report it? The 'dignity of risk' is taken by the responsibilities of the legal guardian under VT Probate court order. The most vulnerable don't have the dignity of risk, that the Green Mountain Self-Advocates speak of. VT's Single State Agency did not implement Title II ADA laws in policies to give a voice of those who can't speak. Had VT done so, our loved ones would have the opportunity to be supported in their own homes.

Governor Phil Scott proclaims that VT will take affirmative steps to protect the most vulnerable. I am happy to help him. My daughter's conciliation agreement under the Human Rights Commission and signed by the Attorney General are those affirmative steps.

VT's Olmstead Plan was written in 2006-this is a summary of issues that were never addressed-it is not a working plan. I am currently on the VT Center for Independent Living Committee working on Housing and Healthcare to turn Olmstead into a plan that stops institutionalization. This includes abilities to limit emergency room costs because there are no services to return to, stop sending vulnerable adults to out of state facilities and allow school districts to create innovative models like we created for my daughter, stop violating a family's right to be a legal

guardian instead of Office of Public guardian when there are willing and able family members. No parent/legal guardian should ever feel threatened and must give up their guardianship to receive the services they need, or have it taken from them without due process. VT froze the state funded waiver for those ADA protected individuals who don't qualify for Medicaid because they work. Why did VT take their opportunity to be a productive member of society away?

VT can do better. Supporting families can be budget neutral.

https://archive.ada.gov/olmstead/q&a_olmstead.htm

<https://disabilityrightsvt.org/wp-content/uploads/2020/06/DRVT-Olmstead.pdf>

Lenny Burke Farm, Inc. started in 1986, and it has taken the blood, sweat and tears of my family to keep it running today. If VT does not allow legal guardians to be paid caregivers, on a case-by-case basis under Topper's bill, you will continue the status quo of human and civil rights violations of the most vulnerable with developmental disabilities. VT knows how to create housing pilot models. They hired a Housing Director to do it 17 years ago, and now they just did it again. VT doesn't want to comply with necessary safeguards to protect the most vulnerable, and VT is risking losing federal funding if they do not. Legal guardians can come forward to ask for ADA reasonable accommodations under the Olmstead Integration Mandate. I see no other way, as the lack of transparency is impeding any infrastructure growth and our state prefers profiting off the backs of hard-working families, who protect their vulnerable loved ones at home without pay. Look at your leadership.

Representative Topper McFaun is the only state representative who has ever cared enough to fix the problem that the single state agency created and can't find a way out of. Please look forward to his bill.

With all due respect,

Kathleen Burke Kourebanas, Essex VT