

My name is Ellen Riley, I live in Moretown, I am 68 years old and recently retired from the University of Vt Medical Center after 45 years in the Cytopatholgy Department. At this point in my life when I should be enjoying retirement, I am providing for and managing the life of my 25 year old son with Down Syndrome who lives at home with my husband and me.

Since the day he was born, I have worried about what would happen to him when he became an adult. Would I always have to manage his life and care for him? What will happen if I get sick, lose my mental status, or die? I have worked tirelessly to provide him an active and inclusive life so he has the same opportunities as his neurotypical peers. However, I have always had to rely on and utilize support from agencies and programs provided within the school system and state. He cannot navigate his life independently. Some of you may have children without disability and have raised them to be independent adults, my child will never have that life.

I need the support of direct service providers to transport him to work and to community activities, to support him at work and while involved in activities, to engage with him and create a robust and fulfilling life, to keep him safe, to mentor him, to continue to help him develop the skills he needs to navigate social situations and life skills.

Since June 2019, over the course of 3 and half years, my son has had FIVE different Direct Support Personnel (DSP). Some have lasted a few months, some a year. Some were moved to split their time between my son and other another client in need of support. Those who left, did so to take a better paying job with benefits. Now, just a week ago, I was informed his newest direct support person who has only been with him 5 months is leaving to take a better paying job with benefits.

With each change, my son has experienced a disruption of routine, anxiety and uncertainty, and the challenge of learning to interact and connect with the “new” person. This cumulative stress has resulted in episodes of depression and anger that can be spurred by even the slightest deviation in his daily routine. He normally is an incredibly happy and loving individual, who though stubborn at times, could always navigate change and be flexible. His change in temperament was so unsettling that I engaged a psychotherapist to work with him. The person who is leaving in just two weeks had finally been able to develop stability and confidence in my son. There is no one in place to replace her, so his job and activities are in jeopardy, and I fear he will experience a major setback.

My son is just one of hundreds of individuals with developmental disabilities who needs support and either have constant turn over, partial support, and NO support at all. I belong to the Developmental Disabilities Housing Initiative (DDHI) and through that I have met soooo many parents my age and older who have children older than my son still living at home, and with no direct support personnel or sevicees. There is an immediate staffing crisis for Developmental Services that is directly impacting our adult children and their families because of staffing shortages, families are left carrying the load.

Here are some sobering facts from the Vermont Care Partners (VCP), a statewide network of 16 nonprofit community-based agencies that provide mental health, substance abuse help and developmental disabilities services to over 30, 000 Vermonters!!!

- 1) Demand has never been higher; children are struggling in school after prolonged COVID social isolation, suicide rates in Vermont exceed the national average by 30% and is rising, our alcohol/opioid/drug use exceeds the national average, use of emergency services has risen from just over 7,000 in FY19 to over 9,000 in FY22, children and adults are stuck for days in hospital emergency rooms, and over 1,000...that's over 1,000 Vermonters are waiting for Vermont Care Partners agency services!!!
- 2) There is a catastrophic workforce crisis; in FY22 over 33% of staff at VCP network agencies left their jobs, staff who love their jobs left to take jobs with higher pay and benefits, vacancy rates as of January 1st this year were over 16% for mental health and nearly 20% for developmental services, and some programs have vacancy rates as high as 30%! On January 1, 2023 of the 6,280 staff positions...1,000 were vacant!

The system of care the Vermont Care Partners (VCP) agencies provide is almost entirely funded through state and federal Medicaid funding. They are unable to employ and retain staffing to deliver the services needed by over 30,000 Vermonters. Right now, most of those with Developmental/Intellectual Disabilities in need of services are living in their aging parent's home and not on the streets causing problems, but that could be the disastrous result as we die or can longer care for our children.

Improved funding is critically needed!

The Developmental Disabilities Housing Initiative (DDHI) requested a 10% Medicaid rate increase for Developmental Services to reduce the staffing crisis, along with an annualized rate review for Home and Community Based Services to stay competitive with other healthcare sectors. This request was minimal funded in the House Budget.

Since 2006, Medicaid rates for network agencies have lagged 15% behind inflation. While there was a 8% rate increase in FY23 (after several years of NO increase), inflation rate was 9% ! Staff are still leaving for pay raises of 10K, 20K and 30K dollars. The vacancy rate is beyond imaginable for the Developmentally and Intellectually Disabled population in Vermont.

I respectfully ask you to do what is needed to ensure my son and all Vermonters with developmental disabilities are supported, are able to live inclusive and fulfilling lives, and not spending their days at home with aging parents. Please ensure all the Vermonters with developmental disabilities have qualified, trained staff that are retainable. Please, do the right thing and support a 10% Medicaid rate increase.

Thank you for listening to this very personal, real, and emergent need.