



Vermont Developmental Disabilities Council

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TO: Senate Health and Welfare Committee
RE: Comments on S. 89
FROM: Susan Aranoff, J.D., Senior Planner and Policy Analyst
DATE: March 28, 2023

My name is Susan Aranoff. I am the senior planner and policy analyst for the Vermont Developmental Disabilities Council. It is a pleasure to see you here today. Thank you for the opportunity to testify about S. 89 and the development of a new forensic facility in Vermont.

The Vermont Developmental Disabilities Council

The Vermont Developmental Disabilities Council (hereafter “VTDDC”) is a statewide board created by the federal Developmental Disabilities Assistance and Bill of Rights (hereafter “the DD Act”), first adopted by Congress in 1970. Our constituents are health care users who have an important stake in the cost, quality, and availability of both traditional healthcare and disability long term services and supports. An estimated 86,000 Vermonters experience a developmental disability as defined by the DD Act, with approximately 5,100 receiving some type of community-based support through Medicaid.

VTDDC is charged under federal law with engaging at the state level in “advocacy, capacity building and systems change activities that... contribute to the coordinated, consumer-and-family-centered, consumer-and-family directed, comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.”

Although the Council is housed in the Agency of Human Services, we operate under a

federal statute and a memorandum of understanding with AHS guaranteeing our independence. I am free therefore to advocate on behalf of Vermonters with disabilities and their family members, regardless of any official agency positions on this bill or these issues.

Fund Oversight and Housing Now

Vermont's home and community-based service system is in crisis. Robust state oversight must be funded. There must be checks and balances in the systems that deliver community-based services. Last year, the House passed version of Act 186 required increased oversight of developmental disability services. The Senate Appropriations Committee removed the enhanced oversight requirements because the positions were not funded.

Instead of funding actual oversight, Act 186 ordered DAIL to issue 2 reports regarding oversight. Despite well-documented quality issues, the Department did not recommend any changes or increases in oversight. Rather the Department "recommends that changes in quality management and oversight of Vermont's HCBS programs, including increases in DAIL staff to manage these changes, not be designed or implemented until after the State of Vermont receives adequate clarity and direction from CMS."¹

It should be noted that Vermont is operating under one HCBS Corrective Action Plan and there are probably 2 more in the wings.

Increasing the oversight of the home and community-based services system for people with developmental disabilities was a good idea last year and it is an even better idea today.

Since you left last May a lot has happened.

In August, criminal charges were filed against 4 Medicaid-funded shared living providers in Franklin County. The allegations of abuse and neglect are horrifying – one of the victims is alleged to have nearly starved to death – normally weighing up to 130 pounds, his weight was reportedly 68 pounds when authorities intervened. [Digger Article](#), [DD Council letter in response to abuse allegations in Franklin County](#).

¹ https://legislature.vermont.gov/assets/Legislative-Reports/Act-186-legislative-report-2.010923-revised_FINAL-1-13-22.pdf

In December, we learned about more criminal charges against a Medicaid funded provider serving a people with developmental disabilities. This time someone died. [Digger Article.](#)

On January 18, 2023, [an article in Digger](#) laid bare a system in crisis. While detailing the plight of one young man, the article captures the harsh reality on the ground today. Perhaps the overall situation was summed up best by my boss, Kirsten Murphy, Executive Director of the Vermont Developmental Disabilities Council, who said [T]here's just so many different problems," said Kirsten Murphy, the executive director of the Vermont Developmental Disabilities Council. "And it's not anyone's fault, or bad actors. It's just that it's been an under-resourced system for a very long time. It doesn't have the quality oversight mechanisms it should. It doesn't have enough checks and balances."

The House Human Services Committee recommended the House Appropriations add 9 quality oversight positions for the developmental disabilities services system and add \$500,000 general fund (one million gross) to the budget to fund those positions.

We hope this committee will make a similar recommendation.

Support Housing

In addition to oversight, there is a severe need for housing. There are over 100 people receiving state funded services for a developmental disability who are waiting for a shared living provider. Our shared living providers need to be supported now to come into compliance with new Medicaid rules that took effect on March 17, 2023.

Act 186 also required a Housing Study². It has been emailed to you. As the report documents, Vermont needs service supported housing for 600 individuals with disabilities.

Finally, I want to mention that approximately 50% of the roughly 3,500 people who receive developmental services live with their families. Typically, someone does not meet a funding priority for residential support until their parents are no longer able to support them. In Vermont, there are many people with developmental disabilities who are in their 40s, 50s, and 60s living with their elderly parents.

² Housing report attached

This is a housing issue that needs to be addressed. New service-supported housing is a greater priority for people with disabilities than is a new forensic facility.

Thirty Years ago, Vermont was the second state in the country to close its institution for people with developmental disabilities, Brandon Training School. In 1993, Vermont was a leader in providing individualized community-based services for people with developmental disabilities.

The mission of DAİL is to make Vermont the best state in which to grow old or live with a disability. For that to happen, Vermonters with disabilities must have permanent supportive housing in our communities.

In closing, I want to share the promise made by Governor Howard Dean when Brandon Training School closed in 1993. Governor Dean said, "I'm proud to maintain the commitment of the state to the very kind of services that we still owe to the population that was once at Brandon and is now in the community. We will continue to assure that individuals receive support and services; We will continue to assure that those services meet acceptable levels of quality; We will continue to assure that persons receiving the services are free from abuse and neglect or mistreatment; To assure that the folks taking care of the people needing these services have adequate training and support. So, our commitment does not end with the closing of this institution. Our commitment continues."