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# **Vermont Developmental Disabilities Council**

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TO: House and Senate Appropriations Committees

RE: Comments on the Governor's 2024 Budget Recommendation

FROM: Susan Aranoff, J.D., Senior Planner and Policy Analyst

DATE: February 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.

### 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."

The VTDDC is concerned about state spending that impacts the quality of life for people with disabilities, especially Medicaid's support for Home and Community Based Services

(HCBS). Although the Council is housed in the Agency of Human Services, we have 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 what is in the Governor's budget recommendation.

### **Fund Oversight Now**

Vermont's HCBS 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 a bill requiring increased oversight of developmental services. The Senate Appropriations Committee removed the enhanced oversight requirements because the necessary state positions were not funded.

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. It is not a stretch to say lives depend on it.

Since you left in May a lot has happened.

In August, criminal charges were filed against four 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. <a href="Digger Article">Digger Article</a>, DD Council letter in response to abuse allegations in Franklin County.

In December, we learned about more criminal charges against a Medicaid-funded provider serving a person 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. 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."

Fund the developmental disabilities system now. It is under one CMS plan of correction now, and there are 2 more in the wings. There are over 100 people waiting for shared

living providers. Our shared living providers need to be supported now to come into compliance with new Medicaid rules that take effect on March 17, 2023.

## **Conclusion**

Please invest the peoples' money in the people who need it the most. Please fund the quality oversight requirements the House passed last year now. Please support people with disabilities, their families, and their direct support providers, including the critical workforce of Vermont's designated and specialized services agencies.

Thank you for listening and thank for your service.