



August 13, 2021

Secretary Mike Smith
Agency of Human Services
280 State Drive - Center Building
Waterbury, VT 05676

Dear Secretary Smith,

On behalf of the thousands of families the Vermont Family Network has served throughout the state over many years, we would like to thank you for your interest in learning about what families need to support their children and youth living with disabilities, special health needs or mental health challenges. The significant, one-time investment of \$162M toward Home and Community Based Services (HCBS) provides us with a unique opportunity to take bold action.

As Vermont's federally designated Family to Family Health Information Center and Parent Training and Information Center, as well as the state's national affiliate for Family Voices and Parent to Parent, an important aspect of our work is to understand the priority needs of families with children who have disabilities and to educate decision makers about these priorities. Concerning this historic opportunity to invest \$162M in HCBS, we have engaged with families across the state, several of whom participated in the public hearing on July 22, 2021. In this letter, we would like to highlight what we have learned.

Notably, a consistent theme that we heard from families is that they want the state to take bold actions to help solve problems placed on families through no fault of their own. Although there is a sense of optimism that this funding can accelerate progress toward a system that comprehensively supports families, there is real concern that family voices will not be reflected in the resulting spending plan.

Understanding the complex nature of shepherding family-centered systems, I want to make it clear that VFN is here to partner with the state to ensure that the voices of families and individuals with disabilities are heard and reflected in the design, implementation, and evaluation of Vermont's HCBS spending plan. Our expert staff are people with lived experience who are ready to contribute as well as lift other family voices in making certain that Vermont's proposed investments make a real and lasting positive impact.

These are the issues we urge the state to take bold and immediate actions on:

- **Housing** - For decades, families have advocated for a full continuum of housing options for their adult children with disabilities that meet their loved ones' needs for independence, community connections, safety, affordability, and accessibility. Vermont and our neighboring state of New Hampshire have strong group-living housing models that solve the problems with the current approach of shared living, which often creates more housing insecurity, adding undue stress and safety issues. Examples include The Yellow House in Middlebury and Black Mountain Assisted Family Living in Brattleboro. We encourage the use of HCBS funds to shift our system toward more equitable and stable housing options.
- **Parents as paid caregivers:** During the COVID pandemic, the Vermont Department of Health and the Department of Disabilities, Aging, and Independent Living created flexibility in our system to allow for payments to be made to family caregivers who were expertly supporting children and adults with disabilities and medical health needs at home when personal care and nursing supports could not. This shed light on the essential role that family caregiving plays in a system of care that cannot adequately recruit, train, and sustain a skilled essential workforce for people with disabilities or special medical needs. We believe that Vermont should reinforce what we created during the COVID emergency. These payments demonstrate the warranted respect for parents that are helping the state solve a workforce problem. These payments also begin to address the very real challenge that many families experience of being unemployed or under-employed because of the significant---and unmet---care needs of their loved ones. We know from our recent experience in Vermont, and the success of other states, including Maine, in creating options for payment to family caregivers, that this could make a significant difference.
- **Respite and Flexible Family Funding:** We strongly encourage more investment in these two essential family supports. We know from years of experience that these resources can truly make a difference in a family's stability, health, and well-being. Respite is the only source of funding that allows caregivers to regenerate, restore energy levels, and build resilience. While there are many barriers to finding respite - including lack of available providers, inadequate training, narrow definitions of respite, and restrictions on eligibility - clearly lack of overall funding is the most challenging obstacle. Without respite, caregivers are becoming tired, sick, and less able to fill the roles that the system needs them to fill. They also begin to require other support, such as increased mental health services and increased reliance on public assistance programs as their ability to work decreases. Flexible funding has long been a priority in the Vermont System of Care plan, and is under resourced, especially in these challenging times.

- **Vehicle Modification and Down Payment Fund** - The cost to modify or purchase vehicles for accessibility is exorbitant, costing tens of thousands of dollars. We urge the state to develop a fund that would provide families with a one-time grant to modify vehicles and/or to provide a down payment on new vehicles.
- **Workforce** - Families rely on skilled workers to support their family members with disabilities and special medical needs; however, it is difficult to find supports because of an underdeveloped and under-supported workforce. Families need the state to drive a focused workforce development strategy so that home and community-based services are robust. Families need a significant increase to their budgets. Current salaries for Personal Care Attendants (PCAs) in Vermont are \$28,200 with a benefit package of \$15,161 for a total compensation of \$43,482. Given the few benefits offered to ARIS employees, PCAs providing care under waiver budgets, would need to be paid an average hourly salary of \$19.60 to be competitive. For LNAs and LPNs, the rates are even higher.
- **Peer Navigation/Family to Family Support**- We would like to see funding provided to a family-led organization like VFN to bring back the evidence-based Peer Navigator model to support families in the Person-Centered Planning Process. This type of family-to-family support is cost effective and ensures that families have full information on the options available for services for their children with disabilities. Additionally, it safeguards against conflict of interest in case management and has a proven track-record of success in Vermont, especially with parents who have developmental or intellectual disabilities.

In the more than 30 years of VFN's existence as a family-driven organization that works diligently to help improve outcomes for families with children who have disabilities or special health needs, we have never observed such a significant opportunity for bold choices. We are encouraged by the collective hope for impactful change and look forward to learning more about the state's spending plan following the comment period.

Sincerely,



Pam McCarthy
President/CEO

CC: Monica White, DAIL Commissioner
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