

To: Representative Houghton, Chair, State of Vermont House Health Care and Members of House Health

Re: Written Testimony on Behalf of Vermont Family Network on Youth In-Patient Facility

I write this testimonial letter on behalf of Vermont Family Network (VFN), whose mission is to empower and support all Vermont children, youth, and families, especially those with disabilities or special health needs. We support hundreds and hundreds of families per year multiple times in areas such as Education, Mental Health, and Health Complications. We know what Vermont families go through regardless of their zip code and have a deep understanding of their needs. VFN is the federally designated Parent Training and Information (PTI) Center in Vermont. PTIs are required by the Individuals with Disabilities Education Act (IDEA) and exist in every state. We have been supporting families of children with disabilities for more than 30 years! Our Family Support program operates a helpline where we respond to families who call us when they have concerns and questions about their child, from early learning through transition to adulthood.

It is also important to note that I am a mother of four adult children with disabilities, one of whom was diagnosed with major depressive and generalized anxiety disorder at the age of 7, who eventually had involuntary admission to a state facility for treatment after an attempted suicide and needed to be placed nearly two hours away, which was brutal. I was working two jobs, serving on the local school board, and had two autistic eighth graders when I had to take that daily round trip drive to see my child in the treatment facility. The drive was difficult, tensions were high in the family, and we had not planned for four weeks of gas - but I had to go. I was her life force through that intense treatment experience after her suicide attempt. I made nearly every visitor hour so I could be there for her, my beautiful child, ghost-like in her baggy clothing devoid of laces and drawstrings so she would not be a danger to herself. My beloved daughter who should be preparing her salutatorian graduation speech instead of playing Go Fish with me during the 5:00-7:00 visiting hours. One minute we are in a local hospital waiting to hear if her liver would come back from the poison she ingested, and the next, we are in a far-off world, trying to navigate the surreal experience of the psychiatric facility, volumes of complex paperwork, and keeping our family together during a scary, confusing, nebulous time. Of course, you choose your child above all else. But I recognize I had the resources - I could find a way to pay for the gas. I had a reliable vehicle. So many others do not and have to face and make difficult decisions. Like so many of the families we serve at VFN, I can identify with the fear, stress, isolation, and anxiety, and heart ache that can come from not being able to provide your child relief in their time of intense need; I recall the moments of panic over seeing my child's door closed, not knowing what I was going to find on the other side. It is critical to ensure equitable access to mental health resources. Regardless of your zip code, no family member or caregiver should have to endure the stress of supporting their loved one with significant mental health challenges because of inequitable access.

Given our statewide reach as an organization, and on behalf of myself and those VFN staff members who have raised a child with mental health needs, we are qualified to share our prospective on the action being proposed.



Facts on Emotional Disturbance/MH and from VFN Helpline:

We are at a moment when more children and youth than ever are in need - kids with significant mental health needs are waiting weeks and months, sometimes in emergency rooms until a bed opens when they are not stable at home. May 2020 Fast Facts data from the Office of Special Ed Programs show that Vermont students have the highest rate of emotional disturbance in the nation - this includes conditions such as depression, anxiety, bipolar, obsessive-compulsive disorder, etc. The Center for Disease Control and Prevention, from April to October 2020, tracked and reported the proportion of mental health-related visits for children ages 5 to 11 increased 24% across the country, compared to the same time in 2019. Those visits increased 31% for adolescents and teens 12 to 17 years old. According to a recent Vermont Suicide Prevention report, Vermont has the 18th highest rate of suicide in the nation.

From our VFN Helpline: Children who have a diagnosis of emotional disturbance (ED) have represented over 40% of calls to our helpline. Calls in the last two years reflect escalating behavioral challenges in schools. We have seen an alarming increase in truancy, school avoidance, bullying and behavior issues. Shortages in service personnel are failing to meet the needs of these children and their families.

Points/Concerns :

In July of 2022, Southwestern Vermont Medical Center (SVMC) in Bennington, Vermont was the sole bidder for the INPATIENT PSYCHIATRIC UNIT(S) FOR CHILDREN AND ADOLESCENTS Request for Proposal by the State of Vermont. In the proposal, SVMC expressed a plan to develop a 10-12 inpatient mental health unit for adolescents ages 12-17. SVMC included cost estimates to launch and ramp up at \$10.5 million over 2 years, which included renovation and recruiting expenses. Gov. Scott's administration recently requested approval to reallocate \$9.25 million from this year's budget to support the rapid development of an inpatient youth psychiatric unit at Southwestern Vermont Medical Center. VFN had a member of the House reach out to us and recommend we provide testimony of our concerns regarding this allocation proposal, or if VFN would like to raise concerns on behalf of the families it serves. We see Vermont needs, and we also consider needs in other States, where there are significant challenges for families when pediatric inpatient psychiatric facilities experience chronic underfunding or are unable to get adequate staffing, which hurts and does not help the children and youth; further, the mental health workforce crisis is leading to high employee turnover and serious understaffing, which certainly does not help our kids receive the timely, targeted interventions they need. These concerns include how existing programs are restricted in capacity right now because of staff shortages. We cannot emphasize enough that resources be directed toward recruitment and retention of qualified professionals to do this critical work. Are these elements being considered and discussed by lawmakers as decisions are made with fiscal resources that may not lead to a faster pace or a more efficiently placed treatments facility?

Family concerns need to be heard. The governor's supplemental budget adjustment act for this year proposes \$9 million to expedite building a children's inpatient psych unit at SWMC in Bennington, but this provides very little time for public input to the legislature regarding approval. Since this funding is in the budget adjustment, it will likely move much more



quickly that a regular budget, which is a good step moving forward if it is a good initiative, which we can have more confidence in when it has adequate vetting and input from families, where their perspectives are considered as decisions are being made.

We understand the need for more facilities that are regionally located - it would be regrettable to invest in expanding inpatient beds in southern Vermont and continuing to leave families in central and northern Vermont with long distance travels to support their kids. We understand the need for inpatient beds. However, this plan is for Bennington County, and inpatient services support the entire state. The only current existing option, the Brattleboro Retreat, is also located in the southern part of the state. For families in the northern part of the state this creates significant challenges with engaging in a child's treatment. And imagine how painful it must be for a child in crisis not being able to see their family for prolonged periods of time. A virtual visit is not the same as an in-person hug or in-person words of support and reassurance from their loved ones. We don't want to advocate for any limitations on resources for Vermont children. At the same time, we need an option that is more accessible to Vermont families in the northern part of the state. It often comes up in discussion that UVMMC has a unit across the lake in New York for children. But this is not a resource if it is inaccessible to children and families. There are children with complex challenges who may be deemed inappropriate for their milieu and there are also, times when a youth's mental health challenges are so impactful that there may be a need for an involuntary admission. Involuntary admission can only happen at an instate facility. A child on involuntary status cannot be treated at a hospital across state lines.

We appreciate the recognition that there must be resources where there can be integration of acute mental health and health care resources. This is necessary for youth who have co-occurring complex medical needs who need access to medical urgent and non-urgent care. It is also important to make you aware that youth with co-occurring developmental needs who need hospitalization may be sent to out of state hospitals. This is a longstanding accessibility issue for children with developmental disabilities who are also entitled to mental health treatment under EPSDT (Early and Periodic Screening, Diagnosis, and Treatment). For these children, admission to out of state hospitals can be delayed due to additional administrative requirements. All children need timely access to appropriate mental health treatment. We also assert there should be ample and adequate resources for children under the age of 12 years, particularly given Vermont's rates of children identified with an emotional disturbance in upper elementary and early middle school grades.

Concluding Remarks:

It took years for my beautiful child to recover from her mental health emergency and she required another hospitalization in her early adulthood. She experienced years of symptoms and failed treatments before her eventual hospitalization. She was just 17. But she survived. She lived. She chose life thanks to her treatment, counseling, and a family who rallied around her. She found relief and peace. And this April, she will bring me my first grand-daughter, and I have the privilege of watching her become a mother. We need solutions. We must invest in our systems of care and support, so all families have access to the medical care they need.



Children with disabilities have been disproportionately affected by the pandemic. More than ever, our children need services and supports in the areas of mental health and behavior. They have endured three years of disrupted schooling. Please consider the needs of ALL Vermont children through the length and breadth of the state and make a decision that is equitable geographically. When you are making tough decisions about resource allocation, please think of the families, even if you have never encountered a situation so dire. Lift family voices. Ensure that Vermont families thrive! Reflect on if this is the right decision for all Vermonters. We also hope that families will consider Vermont Family Network as a resource they can access at no cost, especially given our staff has experienced this journey and are here to wraparound families with support. Thank you for your time and attention.

Respectfully,

Jacqueline Kelleher, MA, Ph.D. Executive Director