



Good afternoon. My name is Robyn Freedner-Maguire and I'm a parent of 3 amazing children, all of whom were adopted from Vermont's Department for Children and Families Their ages are 13 and twins who will be 10 in January next year.

I'm here representing our family experience which is reflective of and shared by so many families the Vermont Family Network supports, therefore the following comments have been reviewed by and represent Vermont Family Networks views as well. VFN is the state's designated Family Voices and Parent to Parent organization, and empowers and supports all Vermont families, esp. those with disabilities or special health needs, including mental health concerns.

I want to thank the committee for its focus on this issue. As an active parent in these conversations, it's recognized there are many dedicated people working together to solve this problem at both formal and informal tables, including many of those individuals who have testified this morning.

I've been asked to give an update on the status of families' experiences in the ED and what solutions are most critical to addressing gaps in the system for children. I've been asked to do so within minutes, which is unfortunate because I think if families were given the amount of time allowed for the Hospital Association, the Department of Mental Health and others, this committee would benefit greatly in achieving a broader understanding that would lead to real, family-driven solutions.

For context, my daughter has been to the UVMHC ER and then to Brattleboro Retreat three times in the past 2 months. So, our family has recent relevant experience concerning this issue and nearly 10 years of experience navigating Vermont's decimated mental health system.

I can say with confidence that if there were the right home and community-based services available when needed to support her healthy development, these stays in the ER and at Brattleboro Retreat could have been avoided.

With this in mind, my hope is that this committee focuses on prevention defined as timely, clinically and developmentally appropriate interventions. There are three main points I want to leave with this committee today:

1. There is a disturbing difference of opinions and facts between what is expressed by families and what the system of care says it is offering as treatment and support.
2. Parent and family rights and input must be respected and valued at all levels of decision making concerning the mental health care of their children and systems development.
3. The mental health system is eroding, and the pandemic pressures have accelerated its decline. It needs a transformational overhaul that calls for aspirational goals and a mental health scorecard that asks, "Are our children well and happy?" verses "Are we keeping our children from killing themselves?" We must aim higher.

To begin, our family has what people in the system of care referred to as “wrap around services” meaning that we are supposed to have a full complement of the right services or treatment options to help our daughter. But, what is articulated in her ACT 264 Coordinated Services plan has not been effectively implemented for years because the system is decimated, and services do not exist. So, we continue to cycle between the ED and the Retreat, and my daughter continues to struggle mightily, as does our family. And she is a fighter and we’re a strong family, she is not getting better because we can’t access prevention treatment and supports.

Examples of this include:

- We searched for a family therapist for over a year, however, nobody is available and we have not received any calls after being on several waitlists for over a year.
- The specialized services agency, NFI, does not provide DBT-C services to children under the age of 12. It is difficult to understand how DBT-C, an evidence-based approach to therapy, is exclusive to older children when we know it has the best impact during the early years. And, searching outside of the system of care, I called over 15 people. Only 4 or 5 called me back to say they’re not taking new clients, one said maybe and then I never heard from her again despite follow-up calls.
- We’ve been on the waitlist for a therapeutic foster home for respite care for my daughter for 3 years. NFI is unable to recruit Vermonters for this program. Why is this even considered by the state or NFI as an actual resource? Perhaps those funds should be reallocated to hire respite staffing and develop day programs or unlocked residential treatment programs.

On the second point, the system's lack of respect for parents as both the experts about our children and having the ability to participate in the decision making around our children’s care is pervasive. The most egregious is the Case Review Committee created by the State Interagency Team.

As parents, we have made the very difficult, but right decision, that our daughter needs residential treatment. The local team we work with agrees. However, we must go through the humiliating and arduous process of completing an application that goes to the CRC where a group of people whose names we don’t even know, despite our multiple requests for transparency, talk about my daughter, her needs and my family. My wife and I are relegated to sitting on the sidelines while a “parent representative” speaks on behalf of our family. This is a person who doesn’t know us - at all. And the only active participation in this process - which takes more than the promised 2 weeks - is to accept or appeal the final decision. Parents should have the right to be in that room and to speak for themselves and their children. Parents should have the right to know who will participate in the decision and why they’re involved. Parents should have the right to readily access all materials, notes and information. We need to take a good look at how LIT, SIT and CRC are engaging parents, and whether their decisions are helping to create better outcomes for children, families, and the overall system of care. We need to look again at what Act 264 was meant to accomplish.

Lastly, Vermont’s mental health system is decimated and needs a transformational overhaul that takes family experiences into account, not just financial and workforce considerations. I don’t say that lightly. I’ve spoken with dozens of families and it’s clear that many of us are experiencing a cycle of crisis. The virtual non-existence of home and

community-based services - which are prevention services - combined with a lack of clear understanding of the real experiences of families trying to help their children has yielded the moment we are living today. And let me underscore that it's been hugely impacted by the pandemic, but this tragic situation has been years in the making.

In closing, because the focus on this hearing is on the long waits in the emergency room department and we have had several recent stays at UVMMC's ER recently, I've attached a brief description of our experience to provide this committee with more insight. Importantly, when my daughter was five, she had to go to UVMMC's ER for the first time. It was terrifying for her and our family as the climate and physical environment was unwelcoming, certainly was not trauma informed and there seemed to be little to no support for patients with mental health needs, especially children. The constant threat of chemical sedation was ever present when at the same time, there was zero - zero - supports for children. I am really relieved to share that we have seen a difference in the UVMMC's ER that from my best estimation, is thanks to the leadership of the ER staff.

I know from our time there and from having the ability to participate in a few meetings with some of the team as a result that there is a dedicated group of physicians, nurses and social workers and others who are diligently working for better integration of trauma-informed care and supports for mental health needs. To name a few specifically, I applaud Dr. Anthony Pulcini who testified earlier today, Dr. Mark Bisanzo, and Dr. Haley McGowen for their leadership, commitment and above all else - care of patients.

I fear however, that there is not enough wind in their sails by the leadership of UVMMC. Admittedly, it's a sensitive that I have out of frustration, frustration that is shared by so many families that UVMMC has not made a real and concrete commitment to supporting children right here, in our state, who have mental health challenges. Two examples of this are the lack of consideration for the mental health needs of young children in the development of a pediatric emergency room and the inability of patients to access CVHP. I raise this because it's significant.

UVMMC's features their pediatric ER and I have no idea what they're talking about. My daughter has been in the same ER as any patient entering that building and when she was moved to a private room in her final 2 days of her last stay, I suspect it was designed for patients who have mental health issues. It was a bed, a chair and four walls. No space for physical movement. No TV. Nothing that would indicate that it was geared toward children.

Regarding CVHP, I urge this committee to gain a more comprehensive understanding of its use as a resource for families. Of the number of children under the age of 12 who enter the ER and are referred to CVHP, how many are accepted? And please dig deeper. It's held up as a resource and I suspect that it's in name only.

Neither of those examples lay at the feet of Dr. Pulcini, Bisanzo or McGowen. It's from the top.

For more detail about our family's experience, please refer to the written document of concise bullet points.

I think you for your time.

Experience at UVMHC's ER during the months of October-November

1. Upon crisis, our family called First Call for support. They would not send anyone to our home.
2. We called Burlington Police Department in the hopes for support in transportation, they wouldn't come to our home as well.
3. We had zero support getting her to the ER safely.
4. Our daughter stayed in the ER for a total of 23 days.
 - a. 1st – 12 days
 - b. 2nd – 4 days
 - c. 3rd – 7 days
5. While in the ER on her first visit, she was provided with a care package from Child Life, which helped to regulate her and eased her stress. Having left home in a rush, we were grateful. She didn't receive these her next two stays.
6. Her door was staff by a mental health tech. All were very kind to her and our family.
7. She was offered the opportunity to shower every day.
8. As parents, we were able to sleep there thanks to a recliner.
9. She was unable to access the new "lounge" until the final hour of her stay there on her last visit. This means she was unable able to access any physical activity for 551 hours of her total stay there.
10. The "lounge" was inaccessible due primarily to staffing issues.
11. Because of HIPPA, families are unable to go to the "lounge" as a rule, however, I was able to go with her for the 1 hour she was there because no other patient was accessing it at the same time.
12. At one point she was unable to access the "lounge" because of her "behavior." This was on day 5 of her 3rd stay. NOBODY could tell me what her behavior was and the fact that she had been in a small room for 5 days on good behavior was not a consideration nor did the doctor indicate when she would be able to access.
13. I was informed that although they didn't chemically satiate her when she was acting up, they thought it may have been necessary. This – after she has been in a bed for 5 days, holding it together.
14. She was unable to access CVPH and the rationales provided where things like, "It's more complicated because it's across stateliness. Referring to the different laws of NY and VT.