Mental Health Advocacy Day

Testimony to the Senate Health & Welfare Committee – January 30, 2019

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Thank you for this opportunity! My name is Kelly Deforge. I live in Essex Junction with my husband and 2 sons. My youngest son was diagnosed with Mental Illness when he was 6 years old. Through the years thanks to many supports most of which are through Howard Center he has made much progress. In mid-2017 new symptoms appeared. At this point he was 16. Over the years he has spent time in crisis stabilization either at Jarrett House that is run by Howard Center or at the Brattleboro Retreat. He is currently going into his 6th month in a residential program run by NFI in Williston after spending 6 months at another residential program in Brattleboro.

When you have experienced a mental health crisis with your child that may be at your home, at the grocery store, at school or in your car. Its not a meltdown, its not a misbehaving child. It's a child who later says… I don't remember what happened. All I saw was a tunnel. I could hear you, but I couldn't respond. These are the words I have heard far too many times. So, we reach for help. In my house that meant many phones at once calling clinicians, first call and even the local police. A visit follows from first call if they can get there fast enough and or the police arrive and do their best not to overwhelm while trying to help get things under control. All that is easy to say but when someone is struggling in a mental health crisis there is no bandage that can be put on. Once he is safe enough to transport, he is brought to the Emergency Room @ UVMMC. Then the wait begins. He may have to sit in the waiting room, the hallway, a shared room or a tiny little secluded room (as my husband calls it… the jail cell with no bars). You have a "sitter" assigned to you they watch to make sure everyone is safe. While also highlighting for anyone in the ER that you are a "mental health patient" My family and I are asked to put our belongings in a locker before we join him, and also sign a form agreeing to visit conditions. STIGMA! Then you wait. The ER technician comments that since you are waiting for psychiatry you will be here a while. As they tell you any other department when paged comes right down. We get a visit from first call for the once over. They are great but can only do so much. We wait… Then you may have a person come in with a white coat turn on the lights, shut the door and start talking to realize they are in the wrong room and not from Psychiatry…Any idea what this means for a child that has a sensory disorder? Finally… Psychiatry shows up we talk then they talk to first call and a plan is made. If that plan is for crisis stabilization we wait again. Is there a bed? Where is it? How will we get him there? This part could take days or weeks. So, when you look at the numbers of wait times in the ER they are real. However, I will tell you the "wait time" for children is not accurate. We have many times felt we didn't have a choice but to take our kiddo home and wait for a bed. Of course, we didn't realize by doing this he steps down in the cue. So now we wait. Once there is a destination selected and a bed open, we coordinate transportation. Its not safe at this point for us to transport him so we send him off strapped to a gurney for a 3-hour drive looking out the back window. Not allowed to move from the bed.

Now what about residential care? Well you can take the story above multiply it by 3 and fast forward 10 days. With many trips back and forth already… we drive to Brattleboro to pick him up on a snowy day because his time is up, and they don't have enough to keep him. So, we bring him home and our house is on "lock down" literally we all sleep with our doors locked! One week later we are in an Act 264 meeting, decision is made he needs a residential placement for 90 day assessment. DMH signs off, etc. A place is chosen… where? Linden Street across from Brattleboro Retreat. Why there? Why not closer? Well with his current mental health struggles they want him to be near a hospital. Gee wouldn't that be nice in BURLINGTON. Oh, and we have to wait another month for a bed at that residential program… Here we are 12 months, many miles, many tears, many family therapy sessions on the phone, many planned visits that we would arrive to find out something happened, and he can't join us. So, we visit for a few minutes and get back in the car to go home. This is just one year of the past 12 years of this precious child's life!

Mental illness is a disease. There are so many diseases but this one isn't treated like any other. That sounds like STIGMA to me. I have spent years telling my son that what he has is an illness like a friend that suffers from a medically defined illness. He has a disease! Now we enter the adult mental health world with him. I will always remember these times and do my best to see that other parents, care givers and family members don't have to experience the same thing.

Please put children's beds in Central Vermont at the very minimum! I will also continue to fight to see children's beds at UVMMC and more residential programs in Chittenden County and greater funding overall for Mental Health. We are fortunate to have some amazing MH workers in our presence but they can’t survive on what they are paid now!