Kim Tardie, Community Member Testimony for House Health Care Mental Health Advocacy Day "Caring for Vermonters - Invest in Mental Health" January 31, 2017

Hello, my name is Kim Tardie. My husband and I adopted our grandson Isaiah a little over three years ago. Isaiah came to live with us full time when he was two years old and now he is eight years old. He was exposed to drugs, alcohol, and tobacco use when he was in utero. Isaiah was born sixteen weeks early weighing one pound and twelve ounces. He spent the first four months of his life at Dartmouth Hitchcock Hospital and defied the odds. Several times the doctors gave us little hope, but Isaiah was a fighter. He endured thirteen surgical procedures while at Dartmouth. His nervous system was highly compromised and he has PTSD and has a VP Shunt. At one time a psychiatric nurse practitioner reviewed my son's medical history and stated, "this child is at risk for every potential mental health illness out there". While 1 in 5 children ages 13-18 have, or will have, a serious mental illness Isaiah's journey began at birth and has clear symptoms at a much younger age.

My daughter suffered from mental illness and was not able to take care of herself much less the needs of a newborn child with the level of care that Isaiah required. As a result, Isaiah did not have a predictable schedule of when he would be fed or cared for. He developed Reactive Attachment Disorder and Developmental Trauma as a result. When Isaiah was four years old he was diagnosed as being on the Autism Spectrum and later diagnosed with ADHD. I guess it is best to say that his special needs come in layers.

Isaiah has huge challenges with self-regulation and his brain is very disorganized. He can become physically aggressive. My encounters with my local mental health services in Vermont leave a lot to be desired. I was advised that when the safety of Isaiah or others is in jeopardy I need to call the local Crisis Line. On one occasion we were told that they do not tend to seven year olds that are having temper tantrums. On another occasion I was reported to DCF as self-medicating my child. I was able to show DCF that I was doing exactly as the doctors ordered, but they were not making note of medication changes in their discharge summaries. DCF decided to open a case and stated that they found that we did nothing wrong, they just wanted to be a support to help us bring cohesiveness to Isaiah's team.

I had a case manager assigned by Washington County Mental Health, but she was just out of college and I had to train her. We were approved for services to come into our home in the form of trained Washington County Mental Health employees, but they did not have the staff to provide the services. We were also approved for Intensive Family Based Services and they sent in a gentleman that only had experience working with men on the FSU program with ankle braces. He did not know the firswst thing about how to be a support to our family. As a matter of fact, Isaiah became aggressive on one of his visits and in the middle of the crises the

gentleman left. I will say that Washington County Mental Health did provide an in home trainer for some parenting skills for six weeks and we found that beneficial..

Isaiah was seven years old when he experienced his first inpatient stay at the Jarrett House in Burlington. The challenge was that we had to wait over six weeks to get him admitted due to a waiting list. Meanwhile, he was very unsafe at home. I tried to get support from Washington County Mental Health Crisis Line at that time, but only ended up with a report to DCF, as I have previously stated.

We did not find any value in the Jarrett House stay whatsoever as they took him off of all medications and sent him home. I had requested access to him each day due to his extreme attachment to me, but neither the doctor nor the facility would accommodate that need. As a result, when Isaiah was released he was very angry with me for abandoning him.

Several weeks later as we were driving down Highway 89 Isaiah attacked my husband in the head with a snow scraper. My husband was the driver. I got the snow scraper from Isaiah, he then unlatched his seatbelt and came over the top of my seat and attacked my head. We had to pull over to the side of the highway in very dangerous conditions.

Subsequently, Isaiah was admitted to Brattleboro Retreat. Less than 24 hours of admission they realized that Isaiah could not be with the general population as he could not tolerate the high level of activity with the other patients. He was placed in a separate unit that has two beds for children that need low stimulation. However, there is a room for kids to go to seclusion when they become unmanageable. One door opened directly into the area where Isaiah was present. Kids would go in that room and scream about killing themselves and all sorts of other profanities. I am glad that I was present so I could immediately remove Isaiah from the area, however, I could not ensure that he would not be exposed to such actions without me being present.

Medicaid did approve to pay for me to stay in a local hotel and my meals so I could visit with Isaiah daily. The staff at Brattleboro told me that I was the first person in eleven years that Medicaid approved. I replied by telling them that more parents need to be afforded this opportunity because the kids need their parents. Some kids were jealous that Isaiah got to see his mother every day and told him how lucky he was.

Then there was the time when Isaiah was in the ER at our local hospital and became unsafe. The police officer came into the room and manhandled Isaiah. He yelled at him and told him that he did not have time to deal with a seven year old brat. Then the officer went back in the hallway and resumed standing at his post doing nothing for the next few hours. This was not an appropriate way to treat a seven year old child with such trauma history. There is a big need for law enforcement training as it relates to children's mental health.

On the Friday before Labor Day weekend Isaiah attacked my husband at home to the point of drawing blood (while the Washington County Mental Health IFBS guy was at the house). I had been in conversation with the Boston Children's Hospital about my frustrations of the challenges with getting appropriate care for Isaiah in the state of Vermont. Boston Children's Hospital advised me that the next time that Isaiah became unstable that I should bring him to their hospital. We went through the usual protocol of cat scan to make sure his shunt was not malfunctioning and got clearance from the Neurosurgeons. Then he was evaluated by Mental Health providers and they could clearly see that he was not safe and since it was a holiday weekend they admitted him into the hospital. They assigned a security guard to watch Isaiah 24 hours a day. They reduced that to having a sitter watch him, but they quickly learned that would not work when Isaiah got aggressive and cleared the nurses station computer and various supplies off their desk.

The first course of action they took was to contact Vermont Medicaid to locate a facility for Isaiah to be admitted. Medicaid advised the Boston Children's Hospital staff that Isaiah would need to utilize any available facilities in the state of Vermont. Brattleboro Retreat advised Vermont Medicaid that they had beds available. I called the Retreat to see if they had beds available in the low stimulus area, but there were none. I asked to speak to a supervisor and requested that they advise Medicaid that there were no appropriate beds available that would meet Isaiah's medical needs. I asked them to look at the medical records from Isaiah's last hospital stay.. I was told that by law the Retreat had to tell Medicaid that a bed was available and that Isaiah would have to be seen in person and assessed to determine if he would need to be in any other place than the general population. The only way they would be able to assess him would be if the Boston hospital would transport Isaiah to the Retreat and he would have to go through admissions. Since I had already been advised that there were no beds available in the low stimulus area, I asked what would happen if they determined that Isaiah could not be with the general population. I was told that if that were the case they would not be able to provide care for Isaiah.

That night I called DCF to ask for support, since they opened a case to be a support to our family. They were of no use and did not even return my calls. So I called the Retreat back and asked to speak to a social worker in the children's unit. I was attempting to get the staff to review his past medical record, which was less than one year old. While I was speaking to her I could hear screaming in the background. She advised me that the unit was so acute at the moment that she did not recommend us bringing Isaiah to the Retreat since there were no beds available in the low stimulus area. In the middle of our conversation she had to abruptly end our conversation because of a crisis on the unit.

I shared this information with the social worker and Psychiatrist at Boston Children's. They told me that they made every attempt to advocate for Isaiah with Vermont Medicaid. However, Medicaid was not willing to bend because we had to use a facility in Vermont if beds were available and Medicaid had been advised that Brattleboro Retreat had beds available. The

hospital staff went on to tell me that in all of New England there really was not an appropriate placement for Isaiah. At that point I had two options:

- Have Isaiah transported to Brattleboro Retreat via ambulance and admit him into the general population where it was very acute and risk further de-stabilization. If they had determined that the general population was not an option based on his medical records of his previous stay and no beds were available we would be placed on the doorsteps of the Retreat and go home.
- Take Isaiah home in an unsafe condition.

We ended up choosing option two and kept our fingers crossed.

The challenge in Vermont is the lack of bed availability for kids in crisis and the lack of training for parents on how to handle a child in crisis while we wait for a bed. The time that it takes to get a child help puts the child and the family at high risk of injury. I have been advised that it may come to a point that Isaiah has to be at a facility if he cannot learn emotional regulation. I am working very hard to advocate for the best early intervention services out there for Isaiah. However, if we are faced with him having to leave our home in the future there is no place in Vermont for him to go. I was told the nearest is in Massachusetts.

Historically speaking, in the state of Vermont institutionalization of children with mental health challenges has been eliminated. I do agree that with the proper supports and training in the community a child can live a healthy fulfilling life. However, there are those times when a child is in crisis, and for their safety and the safety of others, the time to get them help needs to be shortened. Six weeks is way too long for a child to remain unstable at home. Having accessible care for children in crises along with education for parents on crisis prevention and management would provide much support for Vermont families.

Isaiah's story is just one, but I know of many parents that are highly discouraged by the lack of crisis care and parent education available for children with mental illnesses. It is also my desire to see the NAMI Basics class come to Vermont. It is a class for parents and other family caregivers of children and adolescents who have either been diagnosed with a mental health condition or who are experiencing symptoms but have not yet been diagnosed. Educating the advocates and care providers of children so they can provide the best possible advocacy and care for their children while they are young and having accessible care can save this state a lot of money. Thank you for taking the time to hear my testimony.