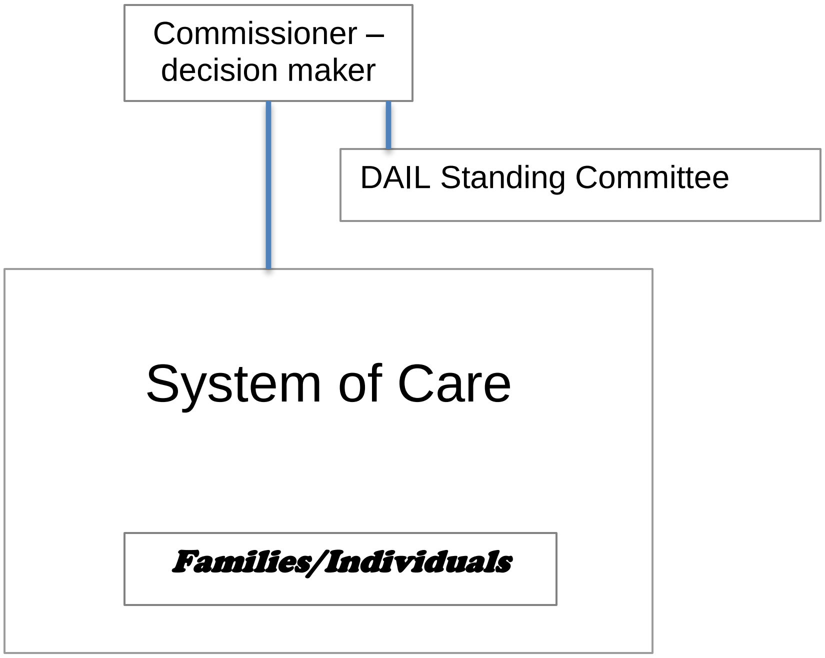

The Problem: People who are immersed in the System of Care and who are directly impacted by changes made to it have no formal connection to the decision making process.

As a parent, and as a professional working with families and individuals who live with disability on a daily basis and rely on the system of care – I worry about the barriers between families/individuals and the decision maker. I worry that the families can't reach the decision maker and I worry that the decision maker is isolated from the real human element of the process. It's a big burden and responsibility for one person, and one that impacts many. And the families and individuals are in a very vulnerable position.

I have great respect for a person in the role of commissioner, and all the responsibilities they handle. For example, the person in this role certainly has overwhelming budgetary pressure on them during these difficult times. It's important that we ensure that they maintain a connection to the human piece too though. Recently, in the Human Services testimony on this bill, I heard reference to "the elephant in the room" being money. I disagree. The real elephant is the human impact that these decisions have. The families and individuals whose lives are changes in a negative way, and who are left to figure it out on their own without even properly knowing how things changed.

At Vermont Family Network we hear from families about many things. We would much rather be helping families organize their voices, their stories, and their collective expertise to help inform and be a part of decision making than for us to try to regroup and refocus a collection of confused, angry, and hurt family members who have lost something critical to their already tenuous survival.

In short – we welcome an opportunity to help families speak and be heard as part of a decision making process, rather than trying to de-escalate a situation that was created by decisions made without them that negatively impacted their lives.

Our families' lives' today are far from perfect. But – if there is one thing I know it's that families who experience the pain and challenge of a child with special needs are resilient, and hopeful. They endure what comes their way, push forward with strength and optimism, and work very, very hard every single minute of every day. Their work is both mental and physical, and honestly, it is all in the name of love. There is nothing else to gain or to motivate them.

Some typical struggles our families see on a daily basis include:

- having to work a "second job" (without pay of course) practicing quality assurance to make sure their children have a life that is healthy, and safe (reductions in state level staff place burden on families);
- older parents call us worried about lack of supports and fear losing their children to the system (some have called and already have lost this battle), the older we get the harder it is to practice and endure the level of physical and mental work;
- respite is an ongoing problem – there are simply no supports to help maintain the mental and physical health of family members;
- employment challenges – without proper supports in place, families often cannot work outside the home, earning an income. Supports might include proper time off opportunity (for medical appointments etc. that arise with a childe with special needs), or ability to find suitable care for their child. Without proper supports and the ability to work, these families are at risk of draining the public system in other areas, and I know these families do not want this. I am one of them.

I will conclude with a personal story. I am a single mother – my daughter is 21 with a history of depression and anxiety, a recovering addict who is clean for almost 2 years now, and a mother of a 1 year old girl. She is doing very well today – but never received any support from the system to get there. My son is 16 and was born with a rare neurodevelopmental disability. His academic level is around 1st grade. Socially, and as a human being he is a genuinely positive soul and he has many friends and is a happy guy. He will require assistance his entire life in activities of daily living, and for community integration.

I worry:

- I am a cancer survivor, and reality is that I worry that something will happen to me and there will be nobody to watch dog every act in the state that might interfere with his potential success, even I miss many things. I don't trust the fairness of the current system processes.
- That my daughter will some day be burdened with the job of oversight for her brother's well being, and without proper supports and systemic oversight, she would relapse, and both of them would suffer the consequences, as would the system that failed them in the first place. The strength required is a lot to ask of anyone.
- That families like mine who already live with low expectations will give up completely, and accept a darker fate than their neighbors who happen to not have a child with special needs.

Please consider the human impact that systemic decisions have, thank you.