

H.728 Testimony – 2.19.14

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Not so many years ago my son would be living a life dictated by others, sent here and there and told what he could and could not do, without choice. Saying that I appreciate the Vermont Developmental Disabilities Act is an obvious understatement – the well being and happiness of my son is dependent on the very principles upon which it was built; to allow every person access and choice to a life of dignity and respect with safety and supports in place to protect those rights.

Even in the 16 years I have been engaged in the system I have seen great changes, many of which seem to spell increased challenge and burden on the family. As families, our day to day life regularly incorporates things such as constant searches to find reliable care for our children, going to the store for bread and milk, complete with wheelchair, oxygen tank, and communication device, operating lifts throughout our house to assist children who are bigger than in tending their daily needs, and through it all making every attempt at as normal a life as possible. There are times this feels a bit neurotic. And now, in truth, it feels like we are being asked to be more attentive and watchful to what decisions are being made for us, affecting our lives directly, but not the lives of those making the decisions. And even then, we have little to no say in whether or not changes take place. There are no rules, guidelines, or boundaries. We are completely vulnerable.

I'm sure you have all heard the saying about "it taking a village" – We need our village. In Vermont our citizen legislature is our village. We vote people in and trust them to do their best to do the right thing. They follow a process, and work in groups to make decisions. This is a process our families are familiar with, often through Medicaid funded programs. They understand there are opportunities to be heard, and they value that. It is only fitting and right that the same process be followed for the DS System of Care.

Nationwide throughout Maternal Child Health, Aging and Disability Resource Centers, and statewide at the Department of Health, UVM Jeffords Center, and our very own Blueprint for health there is a focused push for family/person engagement in systemic decision making. Let's not allow our DS System to be left behind the strong logic and evidence towards the push in this direction.

Thank you.