

House Human Services Committee
February 9, 2017
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Thank you for this opportunity to share the family perspective of a Vermont citizen served by Developmental Services.

I have a son, Andreas Yuan, who will turn 43 years old next week. When we moved to Vermont, he was 10, and I was a newly single parent trying to make a new life for the two of us in a place I had chosen. Andreas has Angelman Syndrome, caused by the deletion of a little piece of the genetic code on the 15th chromosome. It is considered rare—about one in 20,000. I know of 3, possibly 4 people in Vermont with this syndrome. It results in a combination of characteristics that defies categorization. People with Angelman Syndrome don't use spoken language, which leads many to think they don't comprehend. You think that at your peril! Andreas understands not only English, but two dialects of Chinese—and most people with AS are now considered to have much greater comprehension than believed before.

As much as he understands, he still needs support in almost every area of his personal care, and can't be safe left alone. People with AS have many of the characteristics of autism, as AS is one of the identified causes of that syndrome. They are stubborn, independent, and self-determined. One of his previous classmates at Mt. Mansfield High School said to me, "I always admired Andreas, because if he didn't like the way a class was going, he would just stand up and walk out!" Some of you have seen him down in the legislature—he's quite comfortable in the Statehouse. In the clinical literature, people with AS have been described as having "excessive love and happiness." They also have serious sleep disorders and in childhood have seizures.

So what does Developmental Service look like for Andreas? I want to emphasize that it looks different for each individual in Vermont, which is the strength of the program.

It has changed over the years. At first it was just occasional respite so I could get a break—but it also covered the time between when he would be out of school and when I could get home from work. It provided for an aide to go with him to a summer camp when they threatened to send him home after the first sleepless night. Mostly we used teenagers who were only a little older than he was. Some of those respite workers ended up in human service careers as a result of their experience with Andreas.

As he got older, and as he got out of school, by then he had a Medicaid Waiver to pay for in-home supports, but it got harder and harder to find workers who were good with him and who would stay with the job. It got to the point that I often would be sending him off with someone we had just met—because there was so much turnover in the workforce. A couple of times, he categorically refused to go, and I

respected his instincts. I once sat down and tried to estimate the number of different people who have worked directly with him over his life—and stopped when the estimate easily topped 2000.

I am very happy to tell you that he has had his direct support provider/friend Jason now for over 11 years, and Jason says he will be with him for the rest of his life. One of the reasons that has happened is that the agency that serves Andreas, Upper Valley Services, considers the most important value to be building lasting relationships.

What does his support look like? Well, personal care will always be part of the job. Jason was able to desensitize his resistance to tooth-brushing far better than I could. Jason cuts his hair, his nails when he can, shaves him, and keeps him clean. But Jason also got Andreas a volunteer job at Higher Ground, posting flyers, and takes him to rock concerts often enough that the staff of Higher Ground have become his network of friends. He took him to Florida one year for Spring Break because Andreas had never done that when all the girls were down there. In 2008, one of Andreas' goals was to be able to vote, which he does by absentee ballot, The town clerk, who knew Andreas from his time in Jericho schools, now sends his absentee ballot for every major election without my even requesting it.

Communication has always been an important goal in Andreas' plan, and since he was 15, he has been able to type his thoughts on his iPad—when he will cooperate. I asked him to type something for me to share here, but he declined.

Jason comes with us to all Andreas' medical appointments, as much a support for me as for Andreas, especially when Andreas has to go under anesthesia for dental work. That is traumatic for us all, but Jason is there for us both.

Andreas was best man in Jason's wedding—and refused to give up the ring! He now is an uncle to Jason's baby.

None of this is conventional care. It is flexible, creative, and stable. It could not happen without a committed, funded, values-based system of support.