

Testimony: Feb. 15, 2022, 1:15 PM, House Human Services Committee

First, I want to apologize for your inconvenience when my internet crashed last week just as I was about to testify. I'd like to think it was destined, as today is a more auspicious day: the 48th birthday of my son Andreas, and International Angelman Syndrome Day.

I have three things I want to talk to you about today: First, I'll show you Andreas' quality of life. You have heard concerns about Shared Living, but my son's life is genuinely good. Second, I'll describe briefly how we designed the DS system after Brandon Training School closed. Finally, I will share grave concerns about the current Payment Reform Process driven by DVHA. I believe it could dangerously damage the system of support for Vermonters with developmental disabilities.

Andreas was born in Taiwan, and raised in Hong Kong until he was 10, attending Chinese schools. He has Angelman Syndrome, a rare genetic disorder similar to autism, but is very social. He requires 24-7 supervision, sleeps with difficulty, and requires support for daily living. He doesn't speak but has close to normal comprehension in English, Cantonese, and Mandarin. When he was 15 we discovered he could read and type his thoughts. He was fully included from 8th grade onward and graduated with a regular diploma. He loves to come to the Statehouse, and votes regularly. Andreas receives services from Upper Valley Services in Moretown.

(Show slides). Jason, Andreas' Shared Living Provider, is a year older than Andreas. Jason had no training in this field, but was determined to give Dre a rich, typical bachelor life. For the last 16 years, this included camping, Red Sox games, concerts and rock festivals, and a trip to Florida at Easter Break. An example of Jason's ingenuity took place when they attended 3 nights of Pearl Jam concerts in Philadelphia. On the third night, Dre indicated he had to go to the bathroom. When he says that, you hustle! At the door of the restroom stood an old man, guarding the door. "You can't bring him in here. He's drunk!" Jason said, "No, he has a disability." The old man wouldn't move. I asked Jason, "What did you do?" knowing the urgency. "I'm a bit ashamed to tell you, but I picked up the old man and set him aside, and took Dre in."

When Jason got married, he asked Andreas to be his best man. Dre refused to give up the ring!

Jason built a house in the country where Andreas has his bedroom next to the game room. In 2013, Jason and Andreas received a national award for the best supportive relationship in the US. He typed an acceptance speech, "If help for this life of mine means totally giving up your individual life then didn't Jason do the right thing forming a relationship with me? There hasn't ever been someone else into giving that like he has. Sitting here typing this makes memories we have together. This is why I work so hard to say things in their special way to honor our connection with living together. Thank you." When they received the award in Chicago, he made Bill Ashe, the agency director, come up on stage with them.

A last bit of additional context: I am legitimately an aging parent; his father in Taiwan is 88; his oldest sister lives in London and the other in Hong Kong. When I am gone, he needs the supports we have built to continue. I have faith in Upper Valley Services and in the Shared Living model.

How did we get a DS system that could do this? When Brandon Training School closed, we needed to draft the Developmental Disabilities Act of 1996, which prescribed how services would be delivered in the community and the values and principles that shaped those services.

It was an honest process. The design task force represented a three-legged stool—state, provider agencies, and people served and their families. It wasn't all love and flowers. We fought about everything—but we knew that we had to listen to each other and come to consensus. We took the time necessary to do that, as we built in counter-balances .

We maintained the Designated Agency system. Each Designated Agency was responsible for serving eligible people from their catchment area, with "zero-reject". However, people could choose another provider agency or self-management after the initial intake. We required the boards of the agencies to have a majority of people with disabilities or their families. The state was a willing participant in letting the design emerge, and for many years was a strong voice along with the people served (especially under the guidance of Theresa Wood as Director of Developmental Services).

For 25 years now, the system redesign has held. Agencies go through redesignation regularly, responding to quality recommendations of the state. Current stresses on the system are real, and stem from limitations in funding to drastic workforce shortages and stress from COVID.

Now we are experiencing a shift, driven by DVHA under the guise of Payment Reform. It is important to sort out what is and is not required. For example, people are being told that the assessment tool SIS-A (from AAIDD) is required by Medicaid. (AAIDD is a good organization. I am honored to be a Fellow of AAIDD). But it is not true that Medicaid requires it. (After open-heart surgery, I had way too much time lying around and actually read the Medicaid rules. They state specifically that a standardized tool is **not** required.) This tool, while broadly used, is too general to address the context of each person's life, which is important in determining funding level. What do I mean by context? Well, for example, the fact that we, as parents, are aging. The fact that Andreas' community connections are limited now because he can't tolerate wearing a mask. The fact that people in rural areas have little to no public transport—all the details of the differences in the lives of real individual Vermonters versus a hypothesized standardized Vermonter!

Although stakeholders have been included in Payment Reform, this has been cosmetic rather than purposeful and accessible. After more than 3 years in the process, it is clear that the state had all along decided to use the Supports Intensity Scale. Funding will flow from the results of that assessment, likely into 4 buckets or tiers of service. We know this, but the state maintains that nothing has been decided about how funding would be determined. We will know when we are told. This is the antithesis of the participatory, equal system of design that shaped our system.

Those of us who have participated in good faith recognize clearly the potential negative impact of this Payment Reform on Vermonters with Developmental Disabilities and their families. There is also potential negative impact on the second "leg" of the stool—the agencies that deliver the services. Will the funding be sufficient to serve people with quality of life? Will it be necessary to group people to be able to serve them within the funding? Will the reporting devolve into 15 minute intervals for every service rather than the holistic, individual lives of the people served? Think back to what I showed you of Andreas' life with Jason. 15-minute intervals?

It is time to call out this sham of a participatory process and recognize it for what it is—a top-down effort to contain costs at the expense not only of quality but also equality of voice.