

Testimony to Senate Health and Welfare

Good morning and thank you for the opportunity to testify. My name is Susan Yuan, and I live in Jericho. I have a 48-year-old son served by Upper Valley Services, and I have been involved in policy work with Developmental Services extending back to the closure of Brandon Training School. I urge you to adopt the language in H720, as it reflects input from many stakeholders.

In the 38 years I have lived in Vermont, I can't remember a time when more families have expressed concern about Developmental Services, and about their voice in influencing changes. My testimony today is bolstered by ideas from an active group of families in southern and central Vermont, including people who self-manage their services.

Families of young adults with intensive needs are worried about living options. The Shared Living model, while cost-effective and successful for some, is not the answer many families are seeking. They want, at least, a range of options, and H720 offers pilots for different models, a responsible way to move forward. It also includes a position for a Residential Program Developer to expand options available.

I rejoice at the promise of more quality service reviews. While I believe that most agencies are working very hard to provide quality lives for the people they serve, for many years we have had to accept this largely on faith. The requirement that there be annual quality services reviews of agencies is absolutely essential to doing our best to ensure the health and safety of the people served. The Department provided information that 5 positions would be required in order to accomplish this. As a vulnerable population, individuals with DD and their families have the right to expect at least annual site visits.

Confidence in Developmental Services has been eroded both by persistent shortages in the direct support workforce and by the payment reform initiative of DAIL, which has demonstrated a lack of real commitment to stakeholder participation. On the first issue—workforce—this was something that a hard look at the demographics of Vermont should have foreseen. More than 20 years ago, I served on a short-lived workgroup that predicted inadequate numbers both for direct support workers as well as caregivers for people who are aging. The problem was identified, and then the effort ended. This, rather than payment reform, is where the energy of DAIL should be focused.

I have served for four years on the Steering Committee for the Payment Reform, and I still can't figure out why we are doing it. Yes, an auditor's report in 2014 identified that accountability within Developmental Service agencies was too loose. Procedures needed to be tightened to establish whether people were actually receiving the services for which they were budgeted. That is fair, but not that hard to fix. Rumors of inequity among service recipients circulated but seem to be based

on anecdotes rather than data. Appeals processes have been available all along. So why are we spending all this energy? What problem are we solving?

Stakeholder involvement in the Payment Reform process has been abysmal. The true stakeholders—people with developmental disabilities—have not had plain language materials to understand what is going on. As a result, for the most part, even when they are listed on committees, they have not participated. They have better sense than to participate when their voice is not valued. Some of the rest of us have participated on committees in good faith, only to come to the conclusion that the decisions had already been made. We give our input, and are informed about the decision, with no attempt to build consensus. For example, on the Assessment Workgroup, two of us have our doctorates, with solid understanding of assessment, and others are well-informed participants, including at least one teacher. I am a Fellow of AAIDD. We argued strongly that the use of AAIDD's Supports Intensity Scale (SIS-A) was incomplete for assessing the needs of Vermonters with IDD, regardless of the fact that it was "standardized". There also needs to be a context assessment, which would consider the environment in which people with disabilities live and operate, and the appropriate supports for functioning successfully within that environment. The decision "was made" to move forward with the SIS-A. A 5-year contract was entered into to conduct the assessments, and because of that contract, our efforts to slow the process down and make sure we are on the right track have been disregarded.

As a result, grassroots initiatives have sprung up among people with real investment in Developmental Services—family members, agency directors (past and present), people who have served on the State Standing Committee of DS for a cumulative number of easily more than 100 years, people with knowledge and experience of payment reform in other states. We are taking the things that have already been decided and building an alternative process plan that meets the CMS requirements, satisfies our standard of keeping the individual receiving services as the focus of the process and which assures equity and fairness without the use of mechanical algorithms.

We do not trust the payment reform process without the oversight of the legislature. The reason for such oversight is consistent with what occurred when Brandon was closed, and this new system change process is every bit as large as Brandon. DAIL has not involved stakeholders in a meaningful way thus far, and legislative oversight is necessary for this practice to be improved. Every member of the legislature will have constituents who are affected by these changes. It is reasonable to expect elected leaders to be the decision makers over this type of fundamental change in the way people with I/DD will be served and treated in the future.