

**Testimony to the House Human Services Committee  
Susan Yuan, Jericho, February 19, 2013**

**The Design, Development, and Evolution of  
VT's Developmental Service System**

In 1993, Vermont became one of the first states in the country to close its institution for people with intellectual disabilities—Brandon Training School. This was both enlightened and fiscally wise, as we couldn't maintain a dual system—institutional and community-based. The 7 or 8 years that followed benefitted from an administration which supported the concept of community and the right of everyone to a life with dignity and connections to that community. Most of you will remember, though, that the Dean administration was also fiscally responsible.

Key Concepts

- **Individualization**
  - There were to be **no more congregate settings**. This has resulted in the closing of sheltered workshops and the development of individualized employment in the community. It has also meant that 98% of people served with residential services live with less than 3 people served together. *In recent years, there have been new congregate day programs in several agencies.*
  - **Each person has an individual budget** based on an individual needs assessment, as well as accountability for staying within that budget.
  - **Each person has an Individual Service Agreement**, a “contract,” saying what will be done with the funding.
  
- **Transparency**
  - A hard fought effort resulted in **transparency in the individual budget**—how much is in the budget, and how it will be spent. This has resulted in greater accountability with the funds, as individuals and families know what is in there, and what is intended.
  - **Transparency in the system** has also resulted in the possibility for greater accountability. Everyone knows what is supposed to be done and how much it costs.
  
- **Choice/self-determination**
  - The person served has the **choice of agency** that provides services (or the choice for self or family-management). This has given the opportunity to find the right match between the agency and the person and family.
  - The person served has the **right to choose (or reject) their case manager**. Although limited numbers of service coordinators can

make this complicated, no one has to work with a case manager they don't like.

- The person served has the **right to choose their direct support provider**. This worker may assist in the most intimate activities of the person's life. Many hours will be spent with this worker; the level of comfort and compatibility of interests is the most important element in a quality experience. No one has to spend time with someone they don't like and trust.
- Each person has the **right to choose their activities, friends, and companions**. No more compulsory bowling.

- **Frugality balanced by flexibility**

- People and their families or guardians know the budget and decide themselves how it will be used. **Flexible Family Funding** has been a highly appreciated, though limited, support. *This has now been reduced from \$1122 a year to \$1000 a year. Based on adjusted figures, the current amount should be \$1900 in today's dollars.*
- Budgets in comprehensive waivers used to contain a **flexible "goods line"**, that could be used for things to improve the life of the individual. In my son's case, it was used to buy a bed with a good mattress, a low-cost health club membership, tickets for a weekly movie, therapeutic horseback riding. *The "goods line" was eliminated from the budgets at the same time that Flexible Family Funding was reduced. There is no longer any flexibility in the budget.*

- **Quality Assurance**

- Especially in the majority of situations where the person lives in the home of a support provider or family, in many fairly isolated rural situations, **it is important that there be "eyes on" to ensure quality**. *Each person used to be "reviewed" by the state every 3 years; now there may be up to two decades or more between reviews. When I said that this would be all right as long as my son still had family to keep an eye on things, I was told that it was the same situation for people who had no family.*
- Vermont Developmental Services has always emphasized **measurable outcomes**, long before "RBA". VT was one of the first states to participate in the National Core Indicators Project. *Even as emphasis grew on measurable results, VT dropped out of the Core Indicators Project. The reason—DS had to absorb cuts, and rather than cut the personnel for quality assurance even more, they gave up the cost of participating in the Core Indicators, and now have **less** measurable data to use.*

- **Governance**

- “Governance Bill” puts those receiving services in a key role; a **majority on boards for Developmental Services must be people receiving services or their families**
  - State and local Standing Committees were established, with majority governance.
  - System of Care Plan and process was established, with the requirement for a “comprehensive needs assessment” at both the local and state level, every 3 years, with recommendations for priorities for the System of Care. *The System of Care Plan process has been used more for meeting budgetary targets and cuts than planning to meet identified needs. While estimates of high school graduates are still made, data is not gathered on aging families and their health. The number of refugees who needed services came as a complete surprise to the system. We need better demographic data, collected systematically and regularly.*
- **Family Support**
    - Families are the largest provider of care, long past the age when sons or daughters without disabilities move out and form their own households. They need encouragement, recognition, and concrete support at the same time that they help their son or daughter prepare for a more independent life in the future. The priority should still be on getting a life for the adult with a disability, but in the meantime, families are just hanging in there with limited help.

For a personal example of how it works when everyone pulls together, my son has a care provider who is supposed to work 24 hours a day, 365 days a year. He has a respite budget, but we have always provided additional respite so he wouldn't burn out. When the first round of cuts came, the “goods line” disappeared, which meant that the activities that enrich my son's life were diminished. When the next round of cuts came, we chose to cut more out of the respite line in the budget, and instead, we provided more respite for free.—approximately 40% of my son's care. When the next round of cuts came, we didn't cut any more, because there was nowhere left to cut. The payment to the care provider couldn't be cut because this outstanding relationship has lasted for 8 years with almost no additional pay; the respite line couldn't be cut more, because at some point, we will need to rebuild it. I am 70 and Andreas' stepfather is 76. We have all made it work—but we can't keep doing this much forever. It is time to look again at the System of Care Planning Process and to have more oversight from the legislature.