

I am Barbara Lee and I live in Dummerston with my husband and our 33 yo daughter who has an intellectual and developmental disability. Thank you for the opportunity today to give testimony to this committee in support of offering our adult sons and daughters with disabilities greater choice in not only where they live, but also with whom they live. This is a basic right for all Vermonters.

Last summer, a grass roots, parent-driven housing initiative took off in our brave little state, and it continues to grow. Most of the involved families have adult sons or daughters with high support needs. What does this mean? It means that not only do they have an intellectual disability, but also other challenges such as limitations in speech and/or hearing, or decreased mobility due to conditions like cerebral palsy, or epilepsy. Most require 24/7 support, often on a 1:1 basis, for a range of daily, individualized needs. As their parents, we have had to learn, from Day one, to advocate for them. Many in the disabled community can speak up for themselves, and we applaud their self-advocacy and self-determination. Our sons and daughters also possess wonderful gifts, and they teach us, all the time, how to be better, more compassionate human beings.... but, they would not be able to speak, to testify here today. So here I am, representing not only my family, but also families from across the state.

Over 25 years ago, the Developmental Disabilities Act was enacted. It states that the Dept. of Disabilities, Aging, and Independent Living is to ensure that:

each citizen with a developmental disability shall have the following opportunities:

- (1) To live in a safe environment with respect and dignity.
- (2) To live with family or in a home of his or her choice.
- (3) To make choices which affect his or her life.

The Department of Disabilities, Aging, and Independent Living is charged to:

develop, maintain, and monitor ... a statewide system of community-based services that reflect the choices and needs of people with developmental disabilities and their families;

In addition, the Dept. is to:

promote and facilitate participation by people with developmental disabilities and their families in activities and choices that affect their lives, and in designing services that reflect their unique needs, strengths, and cultural values;

Today, the vast majority of adults with I/DD, who are served in the Medicaid Waiver program, either live with their family or in a “Shared Living” arrangement. This is referred to as “adult foster care”. It means that a person or couple opens their home to an adult with a disability. Once this home provider can no longer support this disabled adult, he or she must move on to another home provider. This model works well for some people, but not for all, and especially those with higher support needs. These vulnerable people can only thrive in stable, consistent environments coupled with well-trained, compassionate folks who serve to support them with many facets of their daily life. Safety is paramount, and these most vulnerable adults cannot always express clearly their needs and wants, and thus are at high risk for abuse and exploitation. As parents, many of us are well into our “senior” years, and we know, with fear in our hearts, that all too soon, our sons and daughters will lose their faithful parental anchor.

It is time, now, that we, together, move forward and make the intent of this Developmental Disability Act a reality, by offering more choice in housing arrangements, which would exist within the living, breathing fabric of our local communities. Choice based upon individual needs and desires, just like you and me, here today, have choice.

I would like to share with you a picture of my daughter.

(screen share: photo)

Here she is (in the pink t-shirt), doing what she loves: contra dancing with a bunch of fellow enthusiasts. See that infectious smile, that happiness in the moment, with her hands on the shoulders of the person in front of her, and the hands of the person in back of her, on her shoulders, ...all linked together in spirited, joyful community.

Diversity means being asked to the party....inclusion is being asked to dance... but even greater is the embrace coming from the sense of belonging. All of us, no matter who we are, thrive when we feel a sense of belonging.

Our adult sons and daughters have a right to choose where they live and with whom they live. They have a right to authentic friendships. They have a right to feel that they belong.

We ask that you, with your gifts and talents, as our elected representatives, help to make meaningful CHOICE truly happen ...especially for our more vulnerable Vermonters. Yes, it will take funding...yes, it will take some creative thinking....but let's be brave...we can do it.

In closing, may I offer this thought from Henri Nouwen:

“This gift of the handicapped...for them what really counts is true relationship, a real friendship, a faithful presence ...they often reveal to us our own hypocrisies and invite us, always, to greater sincerity and purer love...”

Thank you. You are welcome to ask me any questions.