

Testimony with House Human Services Committee, originally scheduled for Tuesday February 8, 2022, 1:15 pm

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Thank you for this opportunity to testify. My name is Connie Woodberry. I live in East Dummerston. My 42 year old son Nathan has an intellectual/developmental disability, with very limited ability to communicate. He has seizures, anxiety, needs assistance with some basic hygiene, and has a few medical issues. The support of DAIL and the Division of Developmental Disability Services of Vermont have worked very well for him. Nathan is a gentle man with an infectious smile who needs 24/7 eyes on him. He loves being around people, animals, waterfalls, and listening to music. He wants very much to be helpful and to be included. I am grateful for the support that family, friends, and the Brattleboro, Dummerston, and Putney communities have given Nathan and our family. Since he has starting receiving adult services, Nathan has been supported by three different Agencies, Upper Valley Services, HCRS, and presently Families First.

22 years ago I co-founded, with parents of children with developmental disabilities, Black Mountain Assisted Family Living, a non-profit organization based in Brattleboro with a mission to provide high quality, permanent housing for individuals with developmental disabilities. Shared Living Providers live in Black Mountain Assisted Family Living homes. Nathan and many other individuals have thrived there. The consistency of both place and Shared Living Provider for the past 22 years has had a noticeably positive effect emotionally and physically on Nathan and the other residents.

I have been an active member of the Developmental Disability Services State Program Standing Committee for 23 years, attending monthly meetings in Waterbury and now on zoom. I appreciate what the state of Vermont has done to support Nathan, his education and now, his employment and housing, but I am DEEPLY concerned for Nathan's future and the future of the Vermont Developmental Disability Services system. It is at a breaking point.

The design of Vermont's Developmental Disabilities Services system is very good. The values it expresses are excellent. As stated in the System of Care Plan "the mission of the Department of Disabilities, Aging and Independent Living is to make Vermont the best state in which to grow old or to live with a disability; with dignity, respect and independence. " The core principles of the Disability System honor the rights of people with a wide range of disabilities, needs, and interests. These principles, as stated in the System of Care Plan include the following:

- Person-Centered

The individual will be at the core of all plans and services.

- Respect

Individuals, families, providers and staff are treated with respect.

- Independence

The individual's personal and economic independence will be promoted.

- Choice

Individuals will have options for services and supports.

- Self-Determination

Individuals will direct their own lives.

- Living Well

The individual's services and supports will promote health and well-being.

- Contributing to the Community

Individuals are able to work, volunteer, and participate in local communities.

- Flexibility

Individual needs will guide our actions.

1. Effective and Efficient

Individuals' needs will be met in a timely and cost effective way.

- Collaboration

Individuals will benefit from our partnerships with families, communities, providers, and other federal, state and local organizations.

Nathan and our family have been lucky enough, for the most part, to have the values and the flexibility of this system well-implemented by the Agencies who have supported him. The point is the system works very well when it works. Nathan has had an exceptionally good and stable Shared Living Provider and home situation at Black Mountain Assisted Family Living for the past 22 years. He has an excellent Community/Employment Support person now who assists him as needed, supports him in his work, encourages him to be as independent as he can be, and engages him in making daily choices and being part of the community. Nathan works part-time 4 days a week at The Putney School where he has worked for 16 years, he volunteers once a week at Loaves and Fishes (a community volunteer-run kitchen that serves over 200 meals to people in the Brattleboro area). Nathan participates in the peer activities that Families First organizes as well as Theatre, basketball, and weekly church attendance. Every weekend he comes to stay with me or with his father. He goes on our family vacations. Nathan's life feels full, connected and meaningful. We have team meetings at least every other month with his team which consists of Nathan, his Shared Living provider, his parents, his Community/Employment support person, and his Case Manager. The system provides wrap around support, so this team is aware of Nathan's well-being, his home life, his employment situation, his medical situation, and what he's interested in. When Nathan was in the education system I felt isolated, alone, and, except for my friends, without much of a support network. I don't feel that way now, there is a team of people who know what is going on with Nathan, who he is, what his issues are, what he is capable of, and what he needs support with. I still feel that I am his advocate, the person who takes initiative on most things, but Nathan's Shared Living Provider and Community/Employment support person will also make suggestions and ask questions which give me new perspectives, ideas, and make us all feel that we are part of a team wrapped around Nathan. No question there have been bumps along the way, Nathan has changed agencies, and changed direct service providers. We did engage Disability Law services to help appeal an issue, but the DS system always gave us a place to go to talk things out, to figure out the next best steps, to question, and appeal. When there were problems, there were choices, ways to question, disagree, discuss, and make things better.

So – why am I here today if I think the Developmental Disability Services system is well designed and if Nathan is thriving? As I mention before the DS system is at a breaking point. But it also is a time of opportunity, with ARPA funding, with new leadership, and with the legislature taking a close look at what is happening within the Division of Developmental Disability Services. As a member of the Developmental Disability Services State Program Standing Committee over the past 23 years I have watched as priorities have changed, basic values and principles dismissed, and parents and advocates ignored. This is most blatantly reflected in the Developmental Disabilities Services budget. There were budget cuts in 2009, 2011 and 2012 even while the DS system increased the number of people it served. Other years since then, the increases in the budget were not enough to cover inflation, including the rising costs of health benefits. I believe to the extent possible the Division of Developmental Disability Services and the Agencies, with the best of intentions, tried not to cut direct services, and to somehow find the money to cover increasing operating costs. However, these budget cuts, along with the failure to keep pace with inflation has been crushing both at the state level and for the designated agencies! The salary to direct service providers at this point keeps them at the poverty level. Before the pandemic the system was beginning to fail but now the system is in crisis. You have heard testimony about the workforce vacancies. The work of direct service providers is critically important and very hard. It's a disgrace that Vermont does not give them a living wage. My **FIRST REQUEST** of this committee is that you increase the budget so that direct service providers can have at least a \$20/hour salary.

I am a member of the group of parents advocating for more options in housing people with developmental and intellectual disabilities. I hear daily from parents of adult children with a wide range of developmental disabilities around Vermont. We parents, in our 60s, 70s, and 80s, are petrified about what the future will be for our children, without us. Nathan is presently living in Black Mountain Assisted Family Living housing. As I mention above he has had an excellent Shared Living Provider for 22 years. They will not be there forever. The services in Vermont, particularly the options for meeting the housing and staffing needs for our children when we are gone, are limited. I am terrified that Nathan will have to change one shared living provider after another, one direct service provider after another. We are scared that our vulnerable children will be abused, and ignored, that they will not receive the support they need to communicate, to work, to be fed, to stay healthy and clean, and to participate in whatever way they can in the community.

There is no one housing model that meets the needs of the wide range of people with developmental and intellectual disabilities. With 90 shared living provider vacancies now and parents not able to see a housing model in Vermont that will provide the assistance and support their children need my **SECOND REQUEST** is that Vermont take the opportunity now of using the federal ARPA funds and some of the funds that have been saved as a result of all the staff vacancies over the past two years to create within DAIL a position, either temporary (at least 3 years) or permanent, but NOT a consultant, to take responsibility specifically for housing, perhaps a Residential Placement Director. Decades ago there was such a position within DAIL. Due to all the budget cuts mentioned above the number of DAIL staff is limited

now and overwhelmed. This job is not something that can be added on to a present position. Housing is a priority. Some of the responsibilities of this position would include, but not be limited to the following:

- talking with individuals with developmental disabilities to understand their housing needs and wishes,
- collaborating closely with the parent group that is already exploring nationwide and identifying housing options that meet their children's needs,
- helping agencies support appropriate stable housing,
- securing funding for housing and setting up a few pilot projects around Vermont,
- developing a system which regularly supports, trains, and monitors housing staff,
- ensuring that every housing model conform with the regulations in the DD Act; and
- identifying ways Shared Living Providers can be better supported.

It is EXTREMELY important that DAIL hold the moral compass and provide both oversight and assistance to ensure stability, safety, and consistency.

My **THIRD REQUEST** is that, with all the changes that are taking place in the lives of people with developmental disabilities, there be people trained and supported in Trauma Informed Care throughout Vermont to assist our vulnerable adult children. Repeated changes in housing, shared living providers, and direct service providers along with the many regular life changes are upheavals which have a traumatic impact. Whether pastors, school counsellors, social workers, agency staff, therapists or psychiatrists, people skilled in trauma informed care available to work with our children will make a huge difference. Let me reiterate these people don't have to be therapists and psychiatrists, just need training and support in trauma informed care.

To summarize, my requests, my hopes are that 1). the legislature will approve funding for a \$20/hour salary for direct service providers and in the future at least tie salary increases to inflation. 2). The legislature will approve funding for a Residential Director Position in DAIL, support some pilot projects around the state of different housing models, and make housing support and oversight a priority in the Developmental Disability Services Division, and finally 3). The Developmental Disability Services Division train and support people in trauma informed care to assist people with developmental disabilities as they face upheavals and changes in their lives. These three things will go a long way to help diminish my fears for Nathan's future.

Finally, a quote from Mahatma Gandhi - 'the true measure of any society can be found in how it treats its most vulnerable members'