

Public Testimony to The Vermont House Committee on Appropriations and
Senate Committee on Appropriations re: Governor's Budget

We have a 25-year-old son, **Tiernan**, with Koolen-de Vries Syndrome. He was diagnosed with intellectual disability/autism as a young child. In 2021 we received a genetic diagnosis for his disability/autism. He has intellectual, motor, and speech deficits, and epilepsy. He requires 24/7 supervision and help with all activities of daily living. He cannot be relied upon to communicate discomfort or pain. Tiernan is a gentle and sweet soul and loves music, dancing, and different adaptive sports. He graduated from high school in 2019 and left behind a life of inclusion, activity, and peer interactions. Now, most of his life is spent at home with us, his aging parents, as direct service professionals through the supported services agency (SSA) have been virtually impossible to find. In the four years he has been eligible for services through the SSA, he has had five case managers and we are currently without a case manager once again. We ask you to support the Vermont Care Partners' request for a 10% increase in Medicaid funding and an annualized rate process for Home and Community Based (HCBS) services to stabilize the staffing situation. This is a crisis situation for families like ours.

We also ask for increased funding for the housing needs of adults with intellectual/developmental disabilities (I/DD) who qualify for the HCBS waiver. When we are no longer able to care for him, Tiernan will need a housing situation which is safe and stable. Vermont's Shared Living Provider (essentially adult foster care) offering for individuals with intellectual/developmental disabilities is the **ONLY** real option available to him. Living in a series of houses will only confuse him. He needs a home. In "Closing the Doors of the Institution, Opening the Hearts of our Communities" a booklet written upon and about the closing of the Brandon Training School, the conclusion states, "In the years ahead, we must be careful not to settle into a particular way of providing services. We must continue to change, to give people what they want and what they tell us they need...The state must affirm its commitment, both to people with disabilities and to the people who support them with services. We need to figure out ways of enabling individuals and their families to become involved in decisions about the services we offer.. We need to continue to prove to the community at large that making life better for those with the most intensive needs makes it better for all of us."

We ALL value stability of place; we all need to feel safe. How can we deny that same need for our most vulnerable adult children?

Robert and Karen Price

