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RE: Testimony regarding H402 authorizing Achieving a Better Live Experience (ABLE) savings program within the Office of the Treasurer

To the Representatives on the House Committee on Commerce and Economic Development,

Thank you for providing me the opportunity to offer testimony on authorizing the ABLE Act in Vermont. My name is Joanne Wechsler and I live in Jericho Vermont, with my husband David, and my two sons Adam (18) and Jacob (16). I work at Vermont Family Network, as a Family Support Consultant, working closely with families who have children with special needs. I listen, problem solve, offer support and assist parents, and sometimes professionals, understand the systems and services that will help them help their children. I came to Vermont Family Network almost 12 years ago, after moving to Vermont with my family. They assisted me with understanding resources, as my own son Adam has Duchenne Muscular Dystrophy, a progressive life-limiting neuromuscular disease. Diagnosed in 1999 at the age of 3, we have watched his muscles slowly fail him; eventually his heart and lungs will also succumb. It is 100% fatal. I'm here today to speak to the fairness related to saving money, as an individual with a disability, without fear of losing benefits, that are truly a lifeline.

Adam will be 19 years old next month. He is attending the University of Vermont, Honors College, studying electrical engineering, following his dreams to be productive in society, to be a part of change in the world, to work in the renewable energy field and to live independently. He is an eagle scout, an ardent student, a musician, and a loving son, brother and a friend to many. He is also a wheelchair user, and medically fragile; a simple cold could easily derail his pulmonary system. As a freshman this year, he is attending to a full course load, and living in the dorms on his own, with the assistance of personal care aides. The PCA's stay overnight and assist Adam with all of his physical needs, including dressing, bathing, getting to bed and up in the morning, housekeeping, charging equipment and so much more. His only mobility consists of the use of his hands, and the very strong will embodied in his creative and optimistic outlook on life.

We rely on Medicaid and SSI for his basic needs. Medicaid not only pays for necessary medical support and equipment, but is the only avenue to pay for personal care services. SSI assists with his basic needs related to housing and meals and qualifies him to remain on Medicaid. As his parents, we guide him in understanding the complicated rules that exist related to keeping his services, which are a lifeline to our family. We help him monitor his bank account, and other assets, allowing him to

keep his benefits. These programs require the recipient to have fewer than \$2,000 in cash and assets. An ABLE account would allow Adam (and his family) to save money, to help with his education, his housing, equipment, assistive technology, and dare I say, funeral expenses. My other son Jacob will enjoy saving money, buying a home and a car, and being independent, without any penalty. We are only asking for fairness for my son with a disability.

The only other avenue for savings now available to families is to create a Special Needs Trust, which is not only cost prohibitive to many families, including my own, but requires a certain savvy and puts families in an uncomfortable position of needing to do one more “special” thing, only because their child has a disability. Although my husband and I are hard-working community contributors, we often struggle with the additional financial burdens unfamiliar to the general population. Not only are we under-employed, allowing us to meet the needs of our son, but we have many additional costs, including accessibility of our home and vehicle. For example, the Toyota mini-van with a ramp and tie downs was close to \$60,000, double the cost of a traditional vehicle. Hiring an attorney to create a trust, was never in the budget. Moreover facing disability as though it were a death sentence is a place we try to avoid. We pay as we go, and hope and trust that tragedy doesn’t hit. Creating an ABLE account would be a simple and desirable solution, to the issue of saving for my son’s future needs. Our expectations for both of our children are high, knowing they will rise to the bar. Unfortunately the reality of many with disability is a future of anticipated poverty, with poor health outcomes, as the rules set forth require one never to save. Not for housing, not for equipment, not even for one’s own funeral expenses. I can’t even have my son listed as a beneficiary of my own life insurance, as it would risk him losing his benefits. Setting up an ABLE account will provide many, including my own son, with an opportunity to work productively, to be independent, to make his own choices, and to not have to choose a life of poverty, simply to keep his necessary benefits.

I’m happy to answer any questions or to provide any additional information you may find helpful, as you work to pass this important legislation, allowing ABLE accounts in Vermont. Thank you.