

RE: SB0362/HB0352

Testimony from Margaret Carter

Please remove from this bill any reference to ARTICLE-HEALTH-GENERAL SECTION 7-101 and SECTION 7-409. Leave all the provisions of the Self Direction Act of 2022 (The Act) intact.

My daughter Lucy Carter receives DDA Waiver services under the self-directed service model. Along with many other advocates for people who self-direct, I worked to pass the Self-Direction Act *less than two years ago*. Almost everyone on this committee also voted for the Act—which passed the legislature unanimously. As it is now written, the BRFA violates three key elements of the Self-Direction Act.

1. The BRFA specifically allows DDA to place an artificial cap on IFDGS (Individual and Family Directed Goods and Services.)
2. By capping IFDGS the BRFA effectively eliminates another key feature of the Act: the position of a day-to-day administrator dedicated to helping participants continue to self-direct when family members are no longer available to help.(That position is only funded through IFDGS).
3. The BRFA is an attack on Parity, another key feature of the Act. Parity means that people who self-direct must be allocated the same funding they would receive IF they were accessing services from Traditional Providers. By prohibiting participants to allocate their **existing** funding according to the needs outlined in their Person-Centered Plans, it actually places much of their allocated funding out of their reach.

My daughter Lucy has severe epilepsy and significant developmental delays. She suffers multiple seizures every day. She also has osteopenia and has suffered six foot and ankle fractures in the last six years. But thanks to self-direction, she is also living her best life. She has employees who love her. She sees friends and does activities in the community each day. She shops, rides, works out, socializes, and even climbs walls when she is well enough. We dedicate “savings” from her budget to the IFDGS category which enables us to pay for riding lessons, gym

memberships, fitness coaching and climbing lessons. Those activities all contribute to her physical and mental health. They engage her mind and make it possible for her to perform essential life tasks, such as being strong enough to get out of the bath tub; and more importantly, to avoid falls through improved strength and balance.

Lucy spends approximately \$8,000 a year on IFDGS activities. A cap would likely leave her about \$3,000 short.

.However, I am even more concerned about the cap's effect on the day-to-day administrator position which will cease to exist without the ability to dedicate funds toward it.. For the last 15 years I have been providing at least 66 hours of gratuitous supports each week. I have also been gratuitously assisting Lucy to self-direct her plan—which I am happy to do. I help with recruiting, supervising, scheduling and evaluating employees. I make sure her prescriptions are filled promptly, and that she has everything she needs from clothing to food to toilet paper so she can live safely and comfortably at home. I schedule and attend all kinds of appointments—from meetings with her DDA appointed Coordinator of Community Services to a dizzying assortment of medical appointments. In short I make sure that Lucy has the best life possible.

I turn 68 in April. And I know that someday I won't be there to support Lucy; s self-direction program. Since the passage of the Act I have been making plans so that Lucy can continue to self-direct when I am no longer available. The position of a day-to-day administrator is intended to do just that. Other parents like me have been making the same plans. Without that essential support it will be difficult, if not impossible, for Lucy and people like her to continue to self-direct when family members are no longer there to provide supports. I find it stunning that the State could so quickly pull the rug out from under people like Lucy.

Please retain the promise of the Self-Direction Act by preserving the participant's ability to dedicate their ALREADY allocated funding towards the IFDGS category.



