

Dear Chairperson and Members of the Committee,

RE: **SB0362/HB0352**

**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.**

**Institute a workgroup to study the utilization of funds in self-direction model as compared to provider-manager/traditional model.**

I am a parent/caregiver of **Jonathan Bamberger**, who receives DDA Waiver services under the self-directed service model. I am also a proud advocate for my son!

The changes proposed in the above referenced bill reverses a major provision of the Self Direction Act of 2022. This would allow the DDA to establish an arbitrary limit on Individual and Family Directed Goods and Services (IFDGS).

**This cap will have a detrimental effect on Jonathan's independence, community inclusion and health and safety.**

IFDGS is part of Jonathan's approved plan and budget based on Jonathan's assessed support needs--direct services such as, Personal Supports, Community Integration, and more. The rates for these services were set by DDA and the budget generated for Jonathan's needs should be available to him.

**Please Note: IFDGS spending does not add additional funds it merely allows access to the approved funds within the budget.**

*IFDGS funding helps people stay healthy, active, and productively engaged in their communities. IFDGS supports peoples' independence and helps keep them safe. IFDGS Day-to-day administrative supports aim to help sustain peoples' ability to self-direct, even when their parents or siblings are not able to help*

Since the changes to waiver resulting from the Act became effective July 1, 2023, Jonathan has been able to access the funds from his DDA approved budget in order to reach the outcomes and goals in his person-centered plan.

*John Bamberger (Proud Parent, Caregiver and Advocate for Jonathan Bamberger)*

## **Don't leave Jonathan and others fighting for a higher quality of life and integration into society behind!**

My son, Jonathan, is a participant in the Community Pathways program. He has cerebral palsy and is confined to a wheelchair, living with various physical and mental challenges and limitations. Before joining this program, Jonathan aged out of school and had limited opportunities to engage with friends and integrate into the community. This program allows him to participate in social and educational activities that enhance his quality of life and allows his skilled caregivers to assist with his complex medical needs. Jonathan is mentally challenged and is unable to manage his own care. The Day-to-Day Administrator services allow his parents and caregivers to coordinate his care, so he gets the proper care he needs. Limiting these services to \$5000 is not a data-based solution when considering an individual's complex needs. I can speak to this as a parent of a child with such needs.

Below are a few points I would like to highlight:

1. Leaving the \$5000 limit as proposed in the BFRA will have a **negative** impact our ability to access funding already allocated to Jonathan by DDA, based on his level of need and as allowed by CMS.
2. The Day-to-Day Administrator position has been key to the sustainability of self-direction for Jonathan. He is not able to coordinate the complexity of his care without a lot of support. Examples of assistance provided by the Day-to-Day Administrator include hiring qualified caregivers, arranging opportunities for engagement and integration in the community, coordinating medical appointments and interactions with insurance carriers, ensuring caregivers are paid properly, etc. Unfortunately, I would suggest many people with disabilities in this program have similar needs that will go unmet if funding is limited.
3. Finally, artificially limiting access to these "program" cost components in Jonathan's budget restricts his access to his community, affects his health and safety, and curtails the sustainability of his program when his family can no longer provide aid.