

TESTIMONY IN OPPOSITION TO SB0362/HB0352

To: Senate Budget and Taxation Committee
From: Lisa Dornell
Date: February 28, 2024
Re: Written Testimony in Opposition to **SB0362/HB0352**:

Our son John, who was born with *severe and multiple disabilities*, receives DDA Waiver services under the self-directed service model.

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 our son's community inclusion, health and safety. IFDGS Day-today administrative supports aim to help sustain peoples' ability to self-direct.**

We are in opposition to DDA's efforts to cap IFDGS funding because of the significant impact this will have on the ability of people like John to pay for an Administrator after we (his parents) die. Legislation *specifically provided* for this important position so that individuals like John, who self-direct their services, will have a designated staff person to fill the administrative role that we, as parents now fill. Capping funding for this position will *effectively eliminate* the possibility of funding this important position.

My husband is elderly and I have had serious health issues which do not bode well for long-term longevity. I say this not to ask for sympathy, but to ask for your understanding and action to protect John's ability to live a healthy, safe and meaningful life after we die.

IFDGS is part of John's approved plan and budget based on his many, assessed support needs to address his diagnoses of spastic quadriplegia, severe intellectual disability, a cortical visual impairment which renders him legally blind and, a seizure disorder. To meet his many needs, John's plan provides for direct services such as, Personal Supports, Community Integration and, more. The rates for these services were set by DDA and the budget generated for his many needs must be available to him as this is the whole point of person-centered plans implemented through self-directed services.

It is so important to note that IFDGS spending does not add additional funds: it merely allows access to the approved funds within the budget.

Since the changes to waiver resulting from the Act became effective July 1, 2023, our son 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.

We have seen the charts and data prepared by the DDA as that agency seeks to erode the benefits that have been provided based on the individual needs of self-directed services participants. **We ask you to please not lose sight of the real people behind the pie charts!** People like our son John, who is now 26 years old, who is confined to a wheelchair, who cannot take himself to the toilet, bathe himself, prepare his own meals, who is totally reliant on others to meet all of his most basic human needs and who will never be able to live independently.

Self-direction is his salvation: The agencies we have approached **won't take him** because they are either unwilling or unable to meet his many needs.

As his parents through DDA's self-direction program, we play a critical role as a part of his team. While the self-directed services program has enabled us to hire staff to provide for many of his needs, as John's parents, we help to coordinate John's community development schedules to ensure that he can experience being a part of his community, take care of human resources for the staff to include work schedules, supervision and, training. We coordinate with Fiscal Management Services to approve staffs' stated hours and to ensure that John's staff gets paid in a timely fashion. We ensure that John is appropriately scheduled for his medical appointments and ensure that he is properly transported to all of those appointments.

As long-time Maryland residents and taxpayers, we certainly understand the need for fiscal responsibility particularly during these fraught times. However, as the parents of a person behind the pie charts, we implore you to resist all efforts to balance budgets on the backs of some of the most vulnerable people in our State.

I therefore urge an UNFAVORABLE report on **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.**

