

February 26, 2024

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.

My daughter Faith Guilbault is a participant who 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 Faith Guilbault's independence, community inclusion, health and safety.

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

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, Faith Guilbault has been able to access the funds from her DDA approved budget in order to reach the outcomes and goals in her person centered plan.

A little bit about me and why the funding is important to me:

I have cerebral palsy, postural orthostatic tachycardia (POTS), cortical vision impairment and I am considered legally blind. I currently use my IFDGS funding towards my gym membership and personal training. Due to my cerebral palsy and POTS, it is critical for me to continue to exercise and keep moving or I will regress causing me to require needing more assistance, possible surgeries, and more therapies which in the long run would cost more in healthcare. I also use my funding towards supplements that insurance does not cover which are important due to my health conditions. I plan to hire someone for my day-to-day administration and if this funding is capped it will not allow me to hire someone on. I will also need additional items to help assist in the long run that may include a front-loading washer or dryer for easy access due to my cerebral palsy, adaptable kitchen items to help me be more independent, etc. I also use this for activities out in the community. When I have staff with me it is not fair for them to

have to pay entry fees when they are working for me. What we get in SSI does not scratch the surface when it comes to rent, utilities, food, doctors, etc. and then we would be expected to pay for these things out of our pockets which we don't have. This will put us at risk for isolation and social regression as well. I also use special software for my visual impairments and there is a software fee each year. I believe if we have unallocated funds, we should not have a cap on them. If I was on the traditional model, there wouldn't be a cap so I believe we should not either. I am a human being with needs. It is hard enough to have to find and hire good staff and to have staff show up and to have staff as back-up. We need to be able to pay them a wage with benefits so they can make a living as well. Most families have a hard time finding staff so we are grateful that we can hire our parents and family members. Afterall, they know us, our routine and are best qualified for the job. If they ever took that option for us to hire on family that would be detrimental to our physical, mental, and emotional health. Many families are in debt due to our disabilities already, some requiring two working parents or maybe a single parent and then who will pay the bills when they must care for us and are unable to go to a paying job. Bills get unpaid, stress builds up and things fall apart.



Faith Guilbault and Karen and Jesse Guilbault

Don't leave me behind!

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