

Dear Legislatures,

I am writing as a mother of a 27 year old daughter with multi disabilities, who is non verbal and cognitively between 3-5 years old. Ellie is completely dependent on others to care for her and needs full management of her life. Our family and Ellie work hard to provide her the ability to have a meaningful life.

I am writing to make you aware of a small section in House Bill 352 that will significantly affect Ellie and other individuals with developmental disabilities in a very negative way.

Beginning with line 9

“authorizing the Developmental Disabilities Administration to establish certain limits on certain goods and services provided to certain recipients;”

This section is VERY MISLEADING and will only hurt individuals with developmental disabilities that are in Self Direction services.

In Self Direction each individual receives a budget that they must stay within. Within this budget, there is a section where unallocated funds within an individual's budget can be used to support them with goods and services that are greatly needed for each individual.

This can range from Administrative personnel, much needed dietary supplements that will keep individuals alive, items not covered by Medicaid, therapeutic activities, etc..

Individuals that are on self-directed services do not receive any more money than individuals that are in group traditional services/ group homes. Self-directed services just allows the individual to choose how the money is spent as opposed to going to an agency to decide what will be purchased for an individual. Self-directed services enables individuals with disabilities to have both budget authority and employer authority so that they are cared for by the people they choose, and live where they choose. Striking these line items from the House Bill.352 will dramatically help individuals with disabilities and it will not hurt the budget as the individual is staying within their allotted DDA budget, and will use their unallocated funds that have been approved for the individual.

The lack of investigation committed to this is beyond frustrating as we (families on self direction) have advocated for years to be able to have equal treatment as traditional services. Traditional services are able to have program directors, house, managers, etc.

As you may not be aware, recipients of self-direction were always dependent on their families to manage their day to day care, however after years of advocacy, in July 2023 self-directed participants were finally granted the ability to use their allotted resources to assist with this management. Now only 7 months later self-directed participants are potentially being discriminated against by this bill revoking the ability to access the funds that have been allocated to them. By placing unreasonable and unnecessary limits on these allocated funds you will be doing a disservice to participants and their families and placing unnecessary stress which could have detrimental repercussions.

We are just trying to have equal rights and have our adult children with disabilities in a safe healthy environment with staff that treat them with respect and not allow them to get abused, emotionally, physically, or sexually.

We are not asking for any more money than what traditional services get and actually even less in many cases.

Beginning in 2023, thanks to the Self Direction Bill as it was written, our family after years of advocating, was finally able to hire someone to assist with all of the management of our daughter's around the clock care in the home that we purchased for her. Now all of this could be taken away in less than a year's time. As you can imagine, taking care of a multi disabled individual is a 24/7 responsibility and falls on the shoulders of family members. Many of you may have cared for your elderly parents or a loved one and understand the toll this takes on a person. But unlike elderly people, younger individuals often need this care for 40-50 years, long after their parents have passed away and their must be a life management plan in place.

I cannot thank you enough for taking the time to carefully review and look into this as the past four months DDA has been unresponsive and there is no accountability for their actions.

By striking lines 9 -12 from HBBill 352 you would allow those who qualify to stay with-in the allowed budget the state has awarded them the ability to continue accessing these much needed funds and to use them within COMAR guidelines to meet each individual's needs. The intent of self-direction is for the purpose of allowing participants and their families the ability to access and use allotted funds as they see fit (within COMAR guidelines). As I am sure you can understand, each individual's disability and circumstance is so unique and cannot fit into a box.

Again we are not asking for additional funds we are just simply asking that the funds which are allocated to each individual will continue to be accessible to the participant.

I ask that you please take a close look at this and help educate other legislators and PLEASE strike these lines from the bill.

I will continue to advocate on the behalf of Ellie and all those individuals in the state of Maryland that want to self direct.

Much appreciation,
Carin

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