

Health and Government Operations Committee

HB 1020- Developmental Disabilities Administration – Self-Directed Services (Self-Direction Act of 2022)



Position: Favorable

My husband Mark, my daughter Carmen and I would like to register our support for HB1020/SB868.

Meet Carmen Houston-Ludlam, a 24 year-old young lady with Down Syndrome. Carmen has been self-directing her services since she transitioned from school-based services to adult services in 2019.

Carmen is a swimmer, a cheerleader, a ballroom dancer, a snowboarder, a fashionista, a ventriloquist and a ukulele player. She has a job at MOD Pizza in Dunkirk, MD which she loves. And they love her. She is able to live her full, fabulous life because she is able to tailor her services to her individual needs and desires through the self-direction option for HCBS services in Maryland. The same kind of flexible and tailor-made life that YOU are able to choose for yourselves.

What's more, self-direction is cost effective. Carmen only uses about 65% of her allocated budget- the amount that a provider would charge to provide more rigid, one-size-fits-all services to her.

Unfortunately, the DDA has been systematically reducing flexibility in self-directed services since 2016. The Self-Direction Act of 2022 codifies and protects certain freedoms and flexibilities that should be there- freedoms and flexibilities that are completely consistent with CMS rules and which provide excellent services to people with I/DD while maintaining cost savings to the State of Maryland. There are three provisions in the bill that are especially important to Carmen and her family.

- 1. *The removal of competency Requirements in Favor of Team Support.*** We are believers in a trusted team surrounding Carmen to make sure that she is able to live her best life. This approach is really how we all live- we all have accountants, lawyers, tax preparers, investment advisors, etc. to help us make decisions. Why should someone with an intellectual disability be forced to give up all their decisionmaking ability because they can't independently do all those things? And this approach is also more sustainable, given that so many caregivers for people with I/DD are aging and won't be around forever. We need to jettison the entire concept of "competency" from DDA policies and instead be consistent with current thinking regarding disability rights, which is allowing the individual with I/DD make decisions about their life with the support of a trusted team.
- 2. *No Prohibition to Having Family as Staff.*** If we have learned anything from the COVID-19 pandemic, it is that the lives of people with I/DD are particularly susceptible to upset when things go south. When Carmen's staff person was not able to come into our house to support Carmen, guess who stepped up to the plate? Her family. This happened in households all over the State. Some people had to quit their jobs to support their loved ones with I/DD. Having a permanent understanding of the important roles that Family plays in supporting people with I/DD is critical. We are always the staff of last resort- let's celebrate that instead of trying to stamp it out!! This has been a constant fight with the DDA for years.
- 3. *Reinstate Support Broker Roles and increase hours where needed.*** I have already expressed how important having Family available to support Carmen is, but what happens when we are no

longer around to advocate for/with her? We need to be able to access people who understand the rules and regulations surrounding Self-directed Medicaid Waiver Services, and that person is the Support Broker. Right now, because mama-bear is around, we don't even use the 4 hours of Support Broker services that we have allocated in her plan. Once family support isn't around, she will need more than 4 hours to make sure all the paperwork is done, and done properly. Some people with intense needs have been flatly denied any more than 4 hours. This service needs to be allocated on an as-needed basis, not an artificial cap of 4 hours. And once family support is not there, we can't have people with I/DD having to fight the DDA to get what they legitimately need. Please raise the cap of "argument-free" hours to cover what is needed by so many people.

Here is the bottom line:

- **NOTHING in this bill causes the state to lose federal matching dollars.**
- **EVERYTHING in this bill complies with CMS rules/regulations ensuring federal match.**
- **Policy changes can be addressed with current allocations - no increase in cost.**
- **SD services are generally less expensive than traditional provider managed services.**

Our family has watched in frustration as the past two attempts to codify these freedoms into law were torpedoed by ridiculous fiscal notes provided by Maryland Department of Health. Please don't let the MDH fool you- they are using big, frightening, UNSUPPORTED numbers to avoid legislative oversight. They have succeeded twice. Don't let them get away with it!!

Please vote to recommend passage of this bill out of committee. Let Carmen and those like her live her best life- a life of her choosing- while saving the State of Maryland money.

Genevieve Houston-Ludlam, Ph.D.