

## **Testimony in Support of HB 1020 (SB 868)**

House Health and Government Operations Committee

March 9, 2022

My name is Kathy Cooper and I am here virtually today with my husband, Jim and our daughter, Melanie who is 36. Melanie was one of the very first to enter the Self-Directed Waiver at 21, back in 2006. Melanie has experienced a life of seizures. Her syndrome is degenerative, but Self Direction allows her to continue to live her best life inspiring others with her courage. In her 17 years self-directing her program, she has impacted hundreds of support staff who have gone on to careers in service to others.

In many ways, Melanie is blessed more than most. I was privileged to be able to afford to leave a teaching career to raise our 4 children and to then coordinate Melanie's Self-Directed life. Her Dad is retired from McCormick, and we are both 67. Melanie has 3 siblings and 6 nieces and nephews. She is well loved and has a good life, so some may ask 'why are you here?'

Ninety-nine percent of the individuals in Self Directed Services and their families do not have the privilege of time to testify even virtually, much less in person. I feel fortunate to speak on their behalf.

I have concerns about the present waiver and HOPE this bill will address them. **We are thrilled to hear as of Friday, March 4<sup>th</sup>, that DDA has reinstated Overnight Supports.**

- 1. Participants should have the right to choose Family to Work as Staff. (Recent Waiver changes threaten this choice. )**

Paying **family members** who are already invested and knowledgeable about Melanie makes the team stronger and more person centered. Melanie's days with her family and 6 direct support professionals (DSP) in her apartment and out in the community is a Person Centered Solution that works for her.

- 2. Self-Directed Overnight Supports are NEEDED (Overnight supports were removed in 2018) No need to mention this since DDA reinstated this service.** After waiting 7 years for a housing voucher, Melanie has now lived in her own apartment for 8 years and has thrived. She loves her space and her independence. She requires 24/7 support for her health and safety and without overnight supports, she is at risk of losing her apartment. We ask that overnight supports be returned to the waiver.

- 3. Remove Competency Requirements in Favor of Team Support**

We ask DDA to recognize the ability of men and women like Melanie, who communicate their needs, not with their words, but with their level of contentment/health, to self-direct their lives using the voice of a team of caring individuals. Melanie is the captain of the team whose members are her Service Coordinator, her Support Broker, her mother, her father and her sister.

DDA's forethought to implement this waiver in 2005 has given families like mine the courage and the resources to live good lives. **It is important for participants to continue to have Choice and Control over services and that these services be person centered and flexible.**

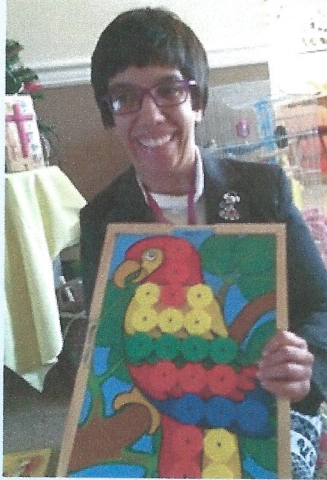
# I support HB 1020/SB 868

# Self Directed Advocacy Network

March 2022

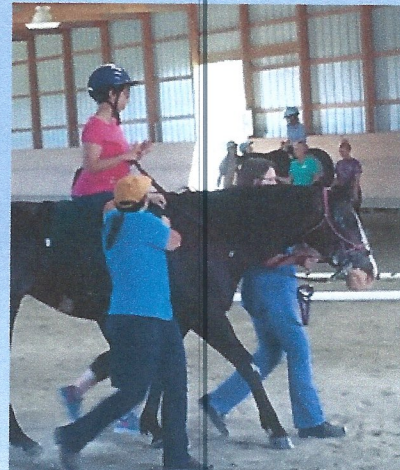
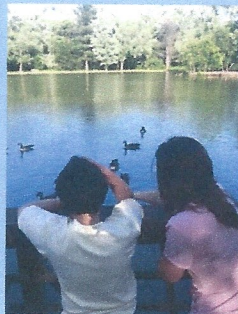
**My name is Melanie Cooper.** I am 36 years old. For 17 years I have enjoyed Self Direction through the Medicaid Waiver. I have lived in my very own apartment for the last 8 years. I have a rare seizure disorder (LGS), autism and IDD. I need 24/7 assistance that staff and my family provide. I love to swim and walk the Ma & Pa Trail. I like to deliver lunch to my elderly neighbors and help keep my apartment clean. I enjoy going out to eat and singing. I love being *Aunt Melanie*.

## *Self Direction Gives me Self Worth through Independence*



Self Direction is Important to me because...

- **(Safety)** I hire and train my own staff who always walk beside me to keep me safe as I experience daily drop seizures.
- **(Choice)** I choose how I wish to spend my days
- **(Independence)** I can come and go as my energy level and changing moods allow.
- **(Support)** I have a team that works together for my best life.
- **(Health)** I have not been hospitalized in 11 years.



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Self-Directed Advocacy Network of Maryland, Inc.

## THE SELF-DIRECTED SERVICES ACT OF 2022 (HB1020/SB868)

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**Self-direction allows an individual with Intellectual/Developmental Disabilities to have choice and control of their Medicaid waiver services, including choosing the staff that supports them (employer authority) and how their budget is spent (budget authority) so they can tailor their daily activities to meet their own needs and interests.**

**History: Maryland was a trailblazer with its Self-Direction (SD) Waiver in 2005**

- 2013/2014 – it was combined with the provider-centered Waiver which meant less choice, control and flexibility for SD
- 2016 – further DDA changes took away many participant choices and control
- Grassroots efforts since then culminating in this Act

**Goals:**

- To achieve greater equity by ensuring that people in disadvantaged communities, those with language barriers and those who lack robust family supports can also access SD
- To restore and maintain flexibility and access to SD while retaining cost-savings
- To ensure that anyone be deemed capable of self-directing with the needed supports

**The bill stipulates:**

1. Case managers (CCSes) will be better trained in self-direction and will fully orient new and current participants about self-direction annually (PCP).
2. Reinstate Support Broker roles and increase hours available where needed.
3. Reinstate Self-Directed Overnight Supports (this waiver service removed in 2018)
4. No Prohibition to Having Family as Staff per CMS rules
5. Transparency in Person Centered Planning (PCP) – ability to track
6. Mileage Reimbursement for Specialized Vehicles
7. Remove Competency Requirements in Favor of Team Support
8. Parity in Budgets/Services – SD doesn't have all needed services
9. Individual Family Directed Goods & Services (IFDGS) to be more flexible per needs
10. Progress Report to Legislature Annually – 3 years

**Takeaway:**

- **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.