

I am the President of Self Directed Advocacy Network (SDAN)—an all-volunteer advocacy organization, and the proud mother of a son with autism who is in his 5th year of Self-Direction.

If you haven't already, please watch the 7 minute video SDAN sent, and read the stories from our members in the written testimony. In combination with what you hear today, you will truly understand why we need your support for HB441.

It is important for you to know:

The Federal Centers for Medicare and Medicaid Services (CMS) defines Self-Directed Services (SDS) as allowing *“participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process. Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided.... participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services.”* (<https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>)

The CMS allows states wide latitude in how they implement these programs, and Maryland's DDA is moving away from allowing the participants to control how and by whom they receive supports. Self-direction has been severely curtailed here in the last six years. Nothing in this bill jeopardizes federal dollars. Our bill seeks a restoration of previous levels of choice and control where, incidentally, all federal matching funds were available, contrary to MDH's contention.

An option that was once individualized, person-centered, and efficient is morphing into one that is ever more *standardized, state centered, and costly*. Policy and procedure changes have included the following:

- Restrictions on who is eligible to self-direct
- Restrictions on the participant team's choice to hire family members, even when it is Participant's preference
- Restrictions on the amount and scope of assistance of a support broker — the only professional on the team with a fiduciary duty strictly to the person. Support Broker roles have been shifted to overburdened and under trained Coordinators of Community Service (CCS).
- Elimination of individualized transportation arrangements so people have funding to get to their community activities
- Severe restrictions on funding for activities and therapies (e.g. music, art and riding)
- Future elimination of choice and competition for essential fiscal management services – when choice increases quality and decreases cost
- The 4% COLA that you all voted to give to all DDA Participants as of July 2020 has not been given to most of SD Participants—even though 6 months have passed. At a minimum, 59% of our members do not have it. The mere 14% of participants who have received the COLA expressed that they had to really fight to get it, citing repeated requests and conversations with their CCSs and DDA directly.
- Created dysfunctional methodologies and procedures that are hurting participants by causing confusion and delays
- Elimination of overnight support as a self-directed option – what is now offered is an option to hire an agency and lose control of who is hired to provide supports in your home.

One young man in the SD program, Desi, wants his required overnight supports in his home, with staff of his choosing. DDA is forcing him to have his supports provided by an agency. Staff who may be strangers to Desi. Desi is losing choice and control over 128 hours of the 168 hours there are in a week.

This inferior service will cost the State of Maryland an additional \$40K every year. Desi is not alone. Figuring that a mere 10% of those in DDA's SD programs need overnight support, the **additional cost per year multiplies to 5.2 million**.

- In conclusion and most importantly, NONE of these restrictions/eliminations are due to The CMS rules. They are Maryland DDA Choices – none of the aspects of SB441 put federal money in jeopardy.

-SDAN has spent thousands of hours of time

-We've attended every meeting and work group that DDA has invited us to – every time

-Responded in writing with public and private comments, feedback and recommendations

-Written emails of concern in numbers too high to count

For 4 years

-SDAN has met with Secretary Beatty and Deputy Secretary Simons quarterly, now monthly and will continue to do so

- SDAN joined 7 other disability advocacy groups in regular meetings with the then Secretary of Maryland Department of Health Robert Neall to try and right the wrongs

*Although mandated to seek input, **DDA has heard much from us, but they rarely listened.**

So here we are with a **less flexible, less person-centered program that has left its Participants with less choice and control and some in jeopardy of their health and safety**

That is why along with us - other advocacy groups are SUPPORTING this bill – ARC, DD Council, DRM, People On The Go, Pathfinders For Autism, to name a few.

And we are asking for your support too.

Next you will hear testimony from Ginger Houston-Ludlam, SDAN Board Member.