Support of SB868
The Self Direction Act of 2022

My heartfelt thanks to you for your attention to this bill.
My name is Alicia Wopat. I am a member of the work group, on the SDAN board and proud parent of a self-direction participant.

This bill seeks a return to the flexible and person-centered Self Direction program envisioned when MD created it in 2005. It seeks to provide equity by codifying policies and allowing additional CMS approved services. It will allow families to set up a program for when they are unable to provide gratis services for their adult children.

DDA tells us that an approved budget for a participant using the DDA formula is earmarked for that individual for the fiscal year.

BUT some of these dollars cannot be accessed due to arbitrary caps or a choice to exclude needed CMS waiver services. This bill seeks to allow ACCESSS NOT MORE MONEY.

There is nothing new in this bill. Nothing that advocates and stakeholders haven't told the administration time after time and for years.

MDH had a seat at the table during the House Summer Study. The chair expressed her desire to resolve the issues. At the conclusion, MDH expressed appreciation of the opportunity to continue to work together. No resolutions. It is interesting to note that there were no MDH objections to the recommendations of the summer study which formed the basis of this bill.

You may hear from MDH that they have agreed to some of the items the bill seeks. That isn't wrong and we are grateful. These concessions have come after years of advocacy and many policies we appeared to win came back in the following year or with a new policy clarification. This bill codifies important policies and services important to the people who self-direct and protects them through future administrations because we have seen what has been given can be taken away. In other words, we had it, we lost it and we need it back.
Highlight of two items in the bill:

Missing Services Right now, many parents and siblings of self-direction participants assume an unpaid role of manager, i.e., making sure staff are scheduled and hiring substitutes when needed, or being the substitute themselves.

They also have responsibility for the home where the individual lives. For example, ensuring bills are paid, that the home has the needed supplies, that medical and other necessary appointments are made and kept, etc.

When families are no longer able to provide these supports gratis; this bill ensures the ability of the individual to hire staff to provide these supports out of the program funding that is earmarked for them. Again, access not additional cost.

I am not alone in having a recurring nightmare that my son, who needs 24/7 care won't be truly cared for. Perhaps it is hard for everyone to relate to having a child with intellectual and/or developmental disabilities but we all have parents and can imagine what would happen to them in their most frail moments…what would they do without someone to ensure their needs are met?

This same provision/service would also allow the funds to pay for administrative supports, such as office equipment or the internet, so the individual can communicate with his CCS and/or support broker and maintain online connections to their community.

Transparency
Close to 10% of the plans and budgets haven't yet been approved for the fiscal year.
We hear from our membership that one of the reasons for these delays is that the participant is left out of the process after signing the plan.

Participants have no mechanism to see if the plan was submitted or received by DDA, They cannot see if there were questions, or if those questions were answered in a timely and correct manner. In other words, the person at the center of plan is left in the dark not knowing the source the delay.

This bill stipulates transparency through access to the tracking system the administration uses and fits into Governor Hogan's commitment to transparency.

I humbly ask for your favorable vote.

Alicia M. Wopat
SDAN Board Member
Proud parent of an adult in the self-direction program