

Thank you for letting me testify. My name is Jane Moncure and I have an 33 year old adult daughter with cerebral palsy. She was initially denied DDA services because she received a high school diploma in 2011, even though she cannot cut her own meat or carry a cafeteria tray. In 2024 she finally began to receive DDA services, including personal supports, community development services and employment development. In 2025 her agency decided to exit personal supports due to financial difficulty. As a result, we began self-directed services last October.

Since entering self-directed services, we have experienced changing, nonsensical and confusing policies. We requested funding for therapeutic programs, equipment, and administrative services but these were eliminated due to policy changes with no warning. I spend hours a week doing administrative work on my daughter's services to make sure our providers are correctly and timely paid. They cannot afford to miss a paycheck or take a cut in pay. These are not natural support activities. I do not make appointments, monitor budgets, coordinate staff and program schedules, read policies, review vendor invoices, or oversee payrolls for my other adult children.

We hired staff with the promise they would be paid certain hours at a certain rate and would receive certain benefits, but streams of red tape have made this difficult. We have paid out of pocket to make up shortfalls to keep our staff whole. We included health insurance benefits as part of our plan, only to find out that almost every type of health insurance is excluded from payment, including group plans, even though our employee incurs cost for her coverage as a dependent.

Employees cannot bill mileage for transportation to medical appointments, even when those appointments for physical or behavioral therapy health take place in the middle of their shift. For years we were told staff could not bill during these sessions. As of last week I read they can bill, but they have missed many past sessions.

I am an educated tech savvy woman, and I cannot find clear concise communications on key topics on the DDA website. Our providers have not billed respite services they provided at their homes because we cannot find a clear policy. What we have found makes little sense – respite can only be provided in our home or the provider's home, or at camp (a remote location), but not at some other remote location. My daughter would like to attend the disability walk in DC and stay overnight to attend sessions the next day, but her staff hours would be limited.

I urge support for Senate Bill 0583 to require a 90 day waiting time before implementation of new DDA policies, and to require periods of public input for policy changes. I spent several years as the senior financial officer of the Baltimore County Public Schools, and public input was instrumental to the development of the school system budgets. Public comment periods are a step to open communications between institutions and their constituencies. I support this direction for DDA.