

Genevieve Houston-Ludlam, Ph.D. testimony in favor of SB-441

Hi, my name is Dr. Genevieve Houston-Ludlam. I am a volunteer board member of the Self-Direction Advocacy Network. I am also the mother of Carmen, my charming adult daughter with Down syndrome, who self-directs her DDA Medicaid waiver services. I am here to present you with the data supporting SDAN's concerns.

Self-Direction is a steadily growing slice of the DDA waiver-services pie, having grown from 218 participants in 2012 to over 13 hundred, or 8% of about 16 thousand people receiving DDA Medicaid waiver services in Maryland in 2020. That is about a 500% increase in 8 years. As a growing percent of Medicaid waiver services in Maryland, we think it is critical to intervene in the reduction of the choice and control of self-directed services due to the choices that DDA is making. The more people discover the flexibility of self-direction, the more your constituents will choose this option. Please help us fix this now.

Self-directed services, along with being a more person-centered way of delivering services, is also more cost effective. We received anonymized budget data from the DDA through freedom of information in December 2020, making this a very current snapshot of currently active Medicaid waiver service budgets.

The average budget for people self-directing their Medicaid waiver services is about \$65K, compared to an average budget of about \$89K for people receiving traditional provider-managed services. On average, the self-directed model delivers a 27% cost savings to the State of Maryland, while providing tailored services to the individuals out there living their best lives the way THEY want to live it. WIN-WIN. Self-direction also shows excellent health outcomes, especially during this COVID health crisis.

Finally, you have heard about problems we are having with the DDA, including timeliness of budgets, lack of communication and non-responsiveness. SDAN conducted a survey of their membership on these issues in December of 2020.

60% of our survey respondents said that they were having issues with plan approval or updates. As of mid-January, 26% of Self-directed plans have not yet been approved by the DDA. In the comments, most of the respondents cited delays and lack of responsiveness from DDA as their main issues.

Let me conclude with briefly sharing my own personal experience with these issues. My daughter Carmen transitioned from school-based services in July of 2019. For 6 months, she was left without her waiver services because DDA did not get her budget approved, and I had to stop working as a result. In fact, the only reason it did get approved is that I contacted the Governor's office and the Maryland Department of Health. The next July, her new budget was supposed to begin. It was not approved until September, and only after I threatened to go to the governor's office again.

We are not asking for more money- we are asking to streamline to make our lives easier, and it also saves the state money. WIN WIN.

Thank you.