

Support with amendments SB0959

Good afternoon, I am Edward Willard an advocate for the rights of Citizens with disabilities. This afternoon I will be representing myself as a citizen of Maryland. I have worked on Self-Directed Services from its conception in 2004. My history includes working at the Developmental Disabilities Administration on and off for ten years as a contractual Employee. My final position at DDA was as the Director of Advocacy Supports, where due to significant health issues I had to retire in 2017. Therefore, my testimony speaks to how Self-Directed Services were intended to be and the gross dilution and failed promises DDA has made over an eleven-year span.

In 2005 when The Center of Medicare and Medicaid Services, CMS, awarded Maryland the New Directions Waiver, they made one point crystal clear: They wanted people with disabilities to craft a life that made sense for them. And Maryland's DDA did just that. Here is one example. An incredible program developed by one participant paid for pottery classes at a community college and that person ended up opening a small business, displaying and selling their beautiful work. A key element in making this successful was that they needed minor support in class, so included in their plan was paying for their tuition and for a classmate willing to support the person, even their textbooks, and mileage. CMS said, "We regularly do not pay for things such as these, but come to us and talk about the justification for these items to be reimbursed, and likely we will grant the usage of the funds." Citizens with Developmental Disabilities made lives custom tailored for themselves. It was truly person-centered and **FLEXIBLE**.

The leadership of DDA at the time established a mindset throughout its Administration for the success of Self-Directed Services. It made the promised changes to the new service delivery system. At the same time, those administrators understood the responsibility for being good stewards of federal and state funds. **Self-directed plans cost no more than, and often are significantly less than, traditional services—often with more powerful results.** Having worked with three previous DDA deputy secretaries, I know firsthand about their passion and commitment to self-direction and self-determination.

However, I saw a significant change beginning in 2009, which accelerated when the New Directions Waiver was merged into the Community Pathways waiver in 2014 and continues through today. Self-Directed Services has been diluted and bureaucratized. There no longer seems to be understanding or compassion. It is not person-centered. It is state-centered. There is no commitment to the intent of people controlling their lives and becoming as independent as possible. Individuals no longer have the flexibility to craft supports that make sense for them and allow them to achieve their goals. No one is asking, like CMS did in 2004, "What do you want to do and we will work with you?" And no one at DDA is listening to the direct stakeholders, their families and their advocates. People with disabilities have been unnecessarily negatively impacted. I hope the establishment of the Advisory Council will allow Maryland to recapture and re-implement the principles of self-direction. Empowering individuals with disabilities to live truly self-directed lives will ultimately benefit all of us.

Self-Directed vs. Non-Self Directed Services Budget Year 2018-19

