

HB0352: BRFA, Article-Health-General Section 7-101 & Section 7-409, 2/28/24
Jeneva Stone, Parent Caregiver, Self-Directed Services
UNFAVORABLE

I'm Jeneva Stone. My son Rob and I testified in favor of the Self-Directed Services Act of 2022. The ability of self-directed participants to access their full budget allocations, that is, go above the \$5,000 Individual- and Family-Directed Goods and Services limit, was a key reform of the SDS Act that passed the General Assembly by a unanimous vote. My son received a standing ovation for his hearing testimony.

I'm concerned that the governor has been misled by MDH into requesting a change that would work against his vision for an inclusive Maryland. Children and adults with disabilities and complex medical needs—like my son Rob—are, in Maryland, a group that the state consistently leaves behind. Many people with rare disease, like Rob, are also in our community.

Our families are clustered in self-direction in part because MDH and the DDA have deliberately chosen to exclude us from full access to the federal Medicaid Home and Community-Based Services waivers that were designed to ensure their civil rights, including their right to live in their communities. The leadership of the DDA believes my son belongs in institutional care, which is horrifying.

Lifting the IFDGS cap was supposed to level the playing field for Rob, allowing him access to his own budget so that he, too, could afford enrichment activities and classes that let him socialize with his disabled peers, just as he did in school—and so that he, too, could have his administrative needs met, just like his peers in traditional services. Don't let the DDA discriminate against Rob.