

**HB0520: State Personnel - Job Sharing Arrangements and Tri-Position Identification Number System**  
(Maryland Workforce Retention, Recruitment, and Reentry Act)

**Hearing Date:** 2/4/25; Appropriations Committee

**Written Testimony of Jeneva Stone** (Family Caregiver, Disability & Rare Disease Advocate)

**FAVORABLE**

Thank you to Chair Barnes, Vice Chair Chang, and Delegate Wolek, this bill's sponsor, for allowing me to provide remarks in favor of HB0520. As many of you know, my son Rob and I advocate at both state and federal levels for health care, disability rights, and rare disease. Also, as a long-term family caregiver (27 years now), I am more than familiar with the workplace inequities facing caregivers, our disabled loved ones, and the rare disease community. Del. Wolek is our D-16 representative; however, even if she weren't, I would still say this is a tremendously great idea. Job-sharing will benefit all of the communities Rob and I represent:

- In my travels in Maryland's developmental disabilities community, I've seen capable folks struggle to find & retain jobs. **Our family is friends with a number of people with IDD who do not, in fact, qualify for DDA supports & services at all.** These awesome people have work skills, great personalities & a critical need to support themselves. Yet, some job openings are closed to them entirely because they have skills that match only part of a job description—but they'd be excellent at those parts. Those who have DDA services, including job coaching, often find the workforce unforgiving & inflexible, yet could benefit as well from job-sharing.
- **People with disabling conditions who do not have IDD, including those with rare diseases,** find it difficult to support themselves. Job accommodations are challenging, and many in this population have high fatigue levels or other impairments that make holding a full-time job very challenging. Job shares could be a miracle solution for many.
- **Family caregivers can also benefit.** Maryland's limited support for children with disabilities, complex needs and/or rare disease means family caregivers contribute unpaid labor to the state valued at hundreds of thousands of dollars per year. Holding full-time work is a struggle for any caregiver, which has ripple effects through our economy: lost tax revenue, reduced spending, inadequate retirement saving, and, therefore, greater dependence on state services as we age.

My own example: I have a PhD & 3 master's degrees, but I haven't been able to hold a full-time job since the summer of 1998, when Rob's rare disease manifested itself suddenly & completely disabled him. My conservative estimate of my lost income is \$1.3 to \$1.5 million dollars. Because of the multiple failures of MDH's adult disability services for Rob (lack of access to traditional providers, unwillingness to coordinate Medicaid programs), Rob's staffing is profoundly inconsistent, which does not allow me to guarantee any employer that I can show up and do the job for which they might hire me. This means that, at the age of 60, having a resume full of holes & scattered skills, I find myself in a situation in which the most steady work I can manage is actually working for Rob in self-directed services. The point of SDS is to enable Rob to become independent of his parents, but, yet, here we are.

I urge you to pass HB0520! I don't want others to suffer the same economic problems I have faced.