

February 20, 2026

To Whom It May Concern:

My name is Ashley Johnson. I am a Maryland mother of a 19 year old adult son with complex medical and behavioral needs. I hold two master's degrees in education and behavioral analysis. I left my professional career to become my son's primary caregiver under Maryland's self-directed services model after he failed to receive the support he needed under the traditional agency model in 2023. Jeremiah has a team of 4 individuals that provide support to him on a daily basis; I am the only family member who is paid to do so.

I want to note, we are not affluent. We are not profiting. We don't have powerful connections and unlimited resources. I am just a single, Black mother, who moved from the Midwest to the Maryland area looking for better opportunities for my son because I grew up in a neighborhood where children of people who look like me were not given many chances to thrive. I didn't want that same outcome for my son. I took a substantial pay cut from a master's-level clinical salary to become my son's caregiver because the alternative was unsafe and unstable. There was a point where the instability prior to self-direction placed us at risk of homelessness until we got emergency support the day before we were headed to a shelter. That is not hyperbole. When services fail and parents must step in without structural support, income collapses.

We initially chose the traditional agency model because we believed it would be simpler. We did not want to manage payroll, compliance, or employment regulations, or be responsible for learning policy and law. We pursued the services structured and allegedly preferred by the State of Maryland, hoping to focus on parenting and supporting a young adult with complex medical needs while continuing my clinical career.

Many days under the traditional model, I was forced to call off work because of late arrivals and no-shows. I was even asked to assist with interviewing and recruiting staff for my son's services by the agency and to train staff on protocols, even though his medical doctors were willing to collaborate with them directly. This was not always due to lack of effort by individual workers; it is a workforce issue. Highly qualified professionals cannot sustain employment at \$21 per hour for this level of responsibility. Even with my involvement, positions remained unfilled, staff frequently failed to show up, complained about his medical needs, and lacked the training and skills required to safely support him. Because of these repeated gaps and unprepared staff, I lost my clinical position. The current system assumes that "natural supports" will always be the backup plan.

My son has KIF1A, a rare neurogenetic condition that causes atrophy of many organs in the body including the brain, muscles, and vision systems. It also comes with a reduced life expectancy and requires specialized medical and behavioral support. He is the only known person with his variant of the disorder, and to my knowledge one of three Maryland families with the condition. There were multiple incidents where he faced risk during his time with agency

staff despite clear protocols, and I was often forced to leave my clinical job to intervene or take him to emergency care visits to ensure his safety.

I also reported serious staff misconduct, including theft and inappropriate behavior, through proper channels to the state of Maryland's MDH/DDA and Office of Healthcare Quality. No meaningful follow-up or corrective action was ever communicated to me, demonstrating systemic oversight failure rather than isolated incidents. Self-direction was not a preference; it was a necessity created by workforce instability and lack of accountability in the traditional model. I want my son to be safe and at home with me where I can provide some of his needs, and not be forced to send him to a home or hospital which would cost the state substantially more.

When considering the proposed bill, abrupt changes to policies or service guidance without adequate notice jeopardize family stability, the safety of medically complex individuals, and the ability to plan for care. SB583 is critical because it would require public notice and opportunity for comment before changes are implemented, giving families time to prepare, secure trained staff, and develop safety plans. It also gives time to give actual thought and consideration to the long term impact of changes in care. I am more than happy to continue to volunteer my time to help my son, but I need realistic options to adjust. I am even proud of the fact that even though we are "taking a handout" because we have the ability to self-direct, we are using less resources for his care than we did under the traditional model. But, we need stable services. I feel like the past two years have been a roller coaster of changes with no consideration to the individuals being harmed in the process.

Self-direction is not a loophole. It is a lifeline for individuals whose complex needs cannot safely be met through traditional agency care. Protecting the stability, safeguards, and accountability measures within Maryland's self-directed services ensures both safety and sustainability for families and reduces long-term costs to the state.

I urge the committee to support SB583 to ensure families have the time and tools needed to maintain safe, high-quality care for their loved ones. To quote John F. Kennedy, "We are confronted primarily with a moral issue. It is as old as the scriptures and is as clear as the American Constitution."

Thank you for reading/listening,

Ashley Johnson

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Mother of Jeremiah, a self directed participant.