

Ensuring Transparency and Stability in Self-Directed Services Policy Changes

Written Testimony in Support of House Bill 1593

Lisa Green

My name is Lisa Green, and I am the mother of a young adult who receives Self-Directed Services through Maryland's Developmental Disabilities Administration.

Self-Direction is built on an important principle: that individuals with disabilities can have meaningful control over their lives, including the ability to hire and manage their own staff and supports. My son is learning these skills every day. He is learning responsibility, how to communicate with his team, and how to participate in decisions that affect his life.

Self-Directed Services exist through federal Medicaid Home and Community-Based Services waiver authority and Maryland's commitment to community-based supports for individuals with developmental disabilities. The Self-Directed Services Manual serves as the guide that participants and families rely on to understand how to operate within that framework.

But for Self-Direction to truly work, the rules that guide it must be clear, stable, and accessible.

Over the past several years, families and participants have experienced frequent updates and amendments to the Self-Directed Services Manual. Often, these changes occur before participants are even aware they have happened.

At the same time, individuals are being encouraged to become more independent—to understand the manual, follow the rules, and in many cases act as employers.

Many participants genuinely want to understand the expectations placed upon them and remain in compliance with the policies that govern their services. However, frequent changes and short notice updates over the past several years have made that increasingly difficult.

This becomes even more challenging when the manual itself is written in complex language, when sections sometimes contradict one another, and when guidance can change before participants have had the opportunity to learn the previous version. For a program built on self-direction, the guidance documents should also be accessible and understandable to the individuals expected to follow them.

In addition, participants are often expected to monitor communications and policy updates on their own in order to stay informed of changes. Many individuals receiving services are focused on managing their daily lives, employment, health needs, and community participation. They and their staff cannot realistically spend time every day monitoring email or agency websites to determine whether policies have changed.

These sudden changes can create significant turmoil and stress for participants and for the staff and vendors they hire. One moment services may be operating smoothly, and the next a policy change can prevent a vendor from being paid, which can interrupt services entirely. When vendors or staff experience payment interruptions due to sudden policy shifts, it can contribute to workforce instability and make it harder for participants to retain the supports they rely on.

Interruptions in services can have serious consequences. For many individuals, consistency and routine are essential for stability in their daily lives. When services are disrupted, it can affect not only staffing, but also

therapies, supports, and activities that help individuals participate in their communities. These interruptions can create instability and inconsistency in a person's routine and day-to-day life.

Each policy change also requires participants and their teams to relearn procedures and expectations, which takes time and resources that are often not accounted for.

When individuals are approved for services, those approvals are based on the Self-Directed Services Manual as it exists at that time. Families build their supports, hire staff, and establish services according to those rules. However, when the manual changes without sufficient notice or opportunity for feedback, those same services can suddenly be altered or no longer permitted under new interpretations of the rules.

At the same time, participants are expected to remain fully compliant with the manual. If an individual is found to be out of compliance, they may be at risk of losing the very services they rely on. This places participants and families in the difficult position of trying to follow rules that may change without adequate notice or clarity.

In addition, some changes do not appear clearly aligned with existing policies and are often made without meaningful feedback from the individuals and families most affected by them.

We understand that these programs operate under Medicaid waiver requirements and must follow federal rules. However, when policies are changed with little notice—sometimes with less than 30 days before implementation, or even effective immediately upon posting—families and participants are left trying to adjust in real time.

Providing time for notice and public comment would allow participants, families, providers, and policymakers to review proposed changes to ensure they are workable and aligned with existing law and Medicaid requirements before they take effect.

In addition, consideration could be given to establishing predictable update periods for the Self-Directed Services Manual, such as annual updates or updates limited to circumstances where federal Medicaid requirements necessitate change. Limiting how frequently policies shift would provide the stability participants need in order to remain compliant and maintain consistent services.

Stable and effective self-directed services also support Maryland's obligations under the Supreme Court's **Olmstead v. L.C.** decision, which affirmed the right of individuals with disabilities to receive services in the most integrated community setting appropriate.

House Bill 1593 would provide that transparency by ensuring that proposed changes to the Self-Directed Services Manual are publicly noticed and open for comment before they are implemented.

Participants and families are not seeking to resist policy; they are seeking the clarity and stability necessary to understand the rules, remain in compliance, and make Self-Directed Services work as intended.

I respectfully request a favorable report on House Bill 1593.

Thank you for your time and consideration.