# RDAC_SB583_approved.pdf

Uploaded by: Ada Hamosh

Position: FAV

# Maryland Department of Health
# Rare Disease Advisory Council

***Wes Moore, Governor · Aruna Miller, Lt. Governor · Meena Seshamani, M.D., Ph.D., Secretary***

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*Jeneva Stone, PhD, MFA*

*Delegate Jamila Woods*

***Council Coordinator***

*Lauren Whiteman, MPH,*

The Honorable Pamela Beidle, Chair
The Honorable Antonio Hayes, Vice Chair
Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, Maryland 21401

February 19, 2026

Re:SB583
Favorable

Dear Senator Beidle and Finance Committee members,

I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) in support of SB583 which requires the Deputy Secretary for Developmental Disabilities to provide notice to the public before making changes to the Self–Directed Services Manual and allows for public comment. The RDAC is a legislated Governor's Advisory Council tasked with improving access to care and outcomes for people in Maryland living with Rare Disease.

Hearing from the public and especially those who use these services about the implications of proposed changes is essential to open government and meeting the needs of people living in Maryland. Many individuals living with rare diseases are medically complex and also have developmental disabilities. Hearing from their caretakers is important to prevent any unintended harmful consequences of proposed changes.

Please don't hesitate to reach out to me if you have any questions about this bill or about rare disease.

Sincerely,

Ada Hamosh

Ada Hamosh, MD, MPH,
Chair

## SB583testimonyAJohnson.pdf

Uploaded by: Ashley Johnson

Position: FAV

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

Ashley Johnson, M.Ed, BCBA, LBA

Mother of Jeremiah, a self directed participant.

# SB0583_Developmental_Disabilities_Administration_S

Uploaded by: Cecilia Plante

Position: FAV

MARYLAND
LEGISLATIVE
COALITION

# TESTIMONY FOR SB0583
## Developmental Disabilities Administration – Self-Directed Services Manual – Public Comment

**Bill Sponsor:** Senator Jennings
**Committee:** Finance
**Organization Submitting:** Maryland Legislative Coalition
**Person Submitting:** Cecilia Plante, co-chair
**Position: FAVORABLE**

I am submitting this testimony in favor of SB0583 on behalf of the Maryland Legislative Coalition. The Maryland Legislative Coalition is an association of activists - individuals and grassroots groups in every district in the state. We are unpaid citizen lobbyists, and our Coalition supports well over 30,000 members.

Members of the self-directed services community rely heavily on the Self-Directed Services Manual to determine how support is administered. Changes to that manual without their input, and without transparency cause immediate disruption to a Marylanders who need our care and concern.

This bill would –

- **Require notice** from the Deputy Secretary for Developmental Disabilities before any changes are made to the Self-Directed Services Manual.
- **Mandate a public comment period of at least 90 days** after notice is provided, during which the Deputy Secretary must receive and consider public feedback.
- **Prohibit adoption of proposed changes** until the public comment period has ended.

Almost every government publication has notice and comments requirements. This one should too.

We strongly support this bill and recommend a **FAVORABLE** report in committee.

# SB0583_Support_Milobsky.pdf

Uploaded by: David Milobsky

Position: FAV

February 20, 2026

To Whom It May Concern:

I wish to convey my strong support for SB583—a bill that requires the Deputy Secretary for Developmental Disabilities to provide notice to the public and consider comment on proposed changes before making changes to the Self-Directed Services Manual.

Our family uses Self-Directed Services (SDS) to provide supports for my son Jason. Jason is 24 and has an autism diagnosis. SDS provides invaluable staff and services to help Jason have a meaningful, engaging life experience. However, even under the best of circumstances, this "safety net" is fragile. Staff members come and go; day programs frequently cancel services and Jason's physical and mental condition can change without warning.

It's a delicate balance, but a productive one. Despite these challenges, Jason is thriving with SDS, and we are deeply grateful for its support. However, when DDA unexpectedly changes provisions in the service manual, this balance is broken and our family is thrown into a tailspin. In the recent past, DDA has reduced the acceptable wage rates for staff without any warning. Our family learned of the change by word-of-mouth. Then we had to wade through DDA's impenetrable website to identify the new pay scale. In the meantime, we scrambled to contact Jason's staff, inform them of the wage reduction and urge them to stay.

At the beginning of the budget year, Jason had allocated the bulk of his budget to staff wages. Now a large portion of this allocation was unusable. Technically, Jason was eligible to apply for a budget modification, but developing the budget mod request takes time, and once completed, is subject to DDA approval, which can take a LONG time. This situation caused untold stress and anxiety for our family.

In essence, DDA's unexpected wage action generated a pile of "dead money" in Jason's budget—funds locked in an allocation we could no longer use. Funds that we might have been able to put to some use had we received more notice. But, more importantly, it increased the anxiety level in our household tremendously. One staff member has already left Jason. The others are hanging in there, for now. But our family remains in a precarious position. SB583 would have given our family the notice and opportunity to plan that we desperately needed.

Thank you for considering my thoughts on this important piece of legislation. If you wish to discuss them further, please feel free to contact me.

Sincerely,

David Milobsky
902 Hurley Avenue
Rockville, MD 20850
240-271-5904

## Cohen - Written Testimony regarding the DDA Self-d

Uploaded by: Jamey Cohen

Position: FAV

Bill: SB0583 DDA Self-Directed Services Manual – Public Comment (Finance Committee)

Hearing date: Tuesday February 24th at 1pm

Name: Jamey and Stacy Cohen, parents of self-direction participant Caden Cohen (Caden is a 25 year old young man who is profoundly autistic, completely non-verbal, and he also suffers from epilepsy)

We fully support this bill that Senator Jennings has brought forward. The DDA has made far too many changes over the past few years without input from the community that it serves. Many of these changes have had a very negative impact on the developmentally disabled community. This may only be a first step in improving the ways in which the DDA serves the community, but it is at the minimum an excellent start.

Thank you, and I hope everyone in the committee supports the bill.

v/r

Jamey and Stacey Cohen

# DDA Senate Bill 0583.pdf

Uploaded by: Jane Moncure

Position: FAV

Thank you for letting me testify. My name is Jane Moncure and I have an 33 year old adult daughter with cerebral palsy. She was initially denied DDA services because she received a high school diploma in 2011, even though she cannot cut her own meat or carry a cafeteria tray. In 2024 she finally began to receive DDA services, including personal supports, community development services and employment development. In 2025 her agency decided to exit personal supports due to financial difficulty. As a result, we began self-directed services last October.

Since entering self-directed services, we have experienced changing, nonsensical and confusing policies. We requested funding for therapeutic programs, equipment, and administrative services but these were eliminated due to policy changes with no warning. I spend hours a week doing administrative work on my daughter's services to make sure our providers are correctly and timely paid. They cannot afford to miss a paycheck or take a cut in pay. These are not natural support activities. I do not make appointments, monitor budgets, coordinate staff and program schedules, read policies, review vendor invoices, or oversee payrolls for my other adult children.

We hired staff with the promise they would be paid certain hours at a certain rate and would receive certain benefits, but streams of red tape have made this difficult. We have paid out of pocket to make up shortfalls to keep our staff whole. We included health insurance benefits as part of our plan, only to find out that almost every type of health insurance is excluded from payment, including group plans, even though our employee incurs cost for her coverage as a dependent.

Employees cannot bill mileage for transportation to medical appointments, even when those appointments for physical or behavioral therapy health take place in the middle of their shift. For years we were told staff could not bill during these sessions. As of last week I read they can bill, but they have missed many past sessions.

I am an educated tech savvy woman, and I cannot find clear concise communications on key topics on the DDA website. Our providers have not billed respite services they provided at their homes because we cannot find a clear policy. What we have found makes little sense – respite can only be provided in our home or the provider's home, or at camp ( a remote location), but not at some other remote location. My daughter would like to attend the disability walk in DC and stay overnight to attend sessions the next day, but her staff hours would be limited.

I urge support for Senate Bill 0583 to require a 90 day waiting time before implementation of new DDA policies, and to require periods of public input for policy changes. I spent several years as the senior financial officer of the Baltimore County Public Schools, and public input was instrumental to the development of the school system budgets. Public comment periods are a step to open communications between institutions and their constituencies. I support this direction for DDA.

## Copy of Support Bill SB 0583.pdf

Uploaded by: Jimara Kocik

Position: FAV

Good Morning,

I am Jimara Kocik, mom of three sons, and one of my sons, age 12, has profound autism.
I am asking the committee to vote yes and advance the bill SB 0583, this important legislation.

I believe the Development Disability Administration should notify the public of changes to policies, procedures, and guidance.
I hear and experience very often that there have been changes to documents over the past year at expedited times that families, providers, and people with disabilities have not had the opportunity to express how those changes affect their lives, as well as the staff supporting them. And providers, sometimes with short staff, find it difficult to work and process their services because of the short time to implement those new changes.
I believe people with disabilities, families, and providers should be given the respect and time to process change because it is a fair way to have them at the table making decisions affecting them directly. Their voice matters, and it is important to always consider their point of view.

They have the right to decide how they want to work with, live with, and vote with, and have all the freedom to do so, as well as to have a voice in the community.

Please, approve the SB 0583 Bill.
Thank you for your time and services and for your continued commitment to our community.

Jimara kocik
Community Advocate.

# Testimony SB0583-combined.pdf

Uploaded by: Kaylee Cooper

Position: FAV

# Testimony on the Importance of an Adequate Public Comment Window for Changes to DDA Policies and Manuals (SB0583)

An adequate public comment window for changes to Developmental Disabilities Administration (DDA) policies and manuals is not a procedural formality, it is a necessary safeguard to ensure that policies are effective, equitable, and aligned with the real-world needs of the people they affect.

DDA policies directly shape the lives of individuals with developmental disabilities, their families, and the professionals who support them. Changes to these policies can impact eligibility, service access, provider operations, health and safety outcomes, and individual rights. Because of this, policy and manual development must be informed by those with lived experience and operational knowledge. A meaningful comment period is the primary mechanism through which this input can be gathered.

Adequate time for review is essential due to the complexity of DDA policies and manuals. These documents are often lengthy, technical, and interconnected. Stakeholders—including individuals with disabilities, families, advocates, providers, and case managers—need sufficient time to understand proposed changes, assess their implications, consult with others, and provide thoughtful, accurate feedback. Short or rushed comment windows limit participation to only those with significant resources and capacity, effectively excluding many of the people most impacted by the changes.

A robust comment period also improves policy quality. Stakeholders routinely identify unintended consequences, implementation barriers, conflicts with existing regulations, and clarity issues that may not be apparent during internal drafting. Incorporating this feedback before policies are finalized reduces the need for later corrections, emergency guidance, or costly revisions. In this way, public comment is not an obstacle to efficiency, it is a tool for getting policies right the first time.

Transparency and trust are additional critical considerations. When stakeholders are given adequate notice and time to comment, it signals that DDA values collaboration and accountability. Conversely, abbreviated or perfunctory comment periods can erode trust and create the perception that decisions have already been made without meaningful input. Trust is especially important in systems serving vulnerable populations, where confidence in the fairness and responsiveness of the agency directly affects engagement and compliance.

In Colorado, HCPF sends policy changes to all stakeholders via email. They explain each policy and provide stakeholders a spot to be able to provide their response after each policy (see attached). Recently, DDA updated a 200+ page policy manual, provided no comment window, and gave us only 3 weeks to adjust to all of the upcoming changes (see attached). The amount of money wasted by DDA on the confusion they created must be astronomical.

Finally, an adequate comment window supports equity. Individuals with disabilities and their families often face barriers related to communication access, health needs, caregiving responsibilities, and limited resources. Sufficient time allows for accommodations, plain-language explanations, and community discussion, ensuring that participation is not limited to a narrow subset of stakeholders.

For these reasons, providing an adequate and consistent public comment window on DDA policy and manual changes is essential. It strengthens policy outcomes, protects the interests of those served, promotes transparency, and upholds the integrity of the DDA system. Meaningful engagement requires meaningful time, and DDA policies deserve nothing less.

Thank you,

Kaylee Cooper: Mother to DDA Participant and Hayden Cooper: DDA Participant

# Medicaid Innovation and Sustainability Opportunities: Policy Options Feedback Request

From Colorado Dept. of Health Care Policy and Financing
<hcpf_stakeholders@coloradodepartmentofhealthcarepolicyandfinancing.ccsend.com>

To unity.ed@proton.me

Date Thursday, February 5th, 2026 at 12:01 PM

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HCPF
COLORADO
Department of Health Care
Policy & Financing

**Your input will help us shape short and long-term policy decisions!**

**Provide feedback by Feb. 9 on the ideas shared on our recent webinar.**

Thank you for your continued interest in the Medicaid Innovation and Sustainability Opportunities (MISO) project. **Please complete the feedback form by 5 p.m. on Monday, Feb. 9.**

This feedback opportunity is a follow-up to the MISO webinar on Jan. 27, 2026, which covered policy actions developed by Manatt Health Strategies and the Colorado Department of Health Care Policy and Financing (HCPF). Manatt recently conducted an analysis of Colorado's Medicaid and Child Health Plan Plus (CHP+) program cost drivers and compared these trends to several states. Following the analysis, Manatt analyzed options for potential short and long-term policy changes to improve the affordability and sustainability of the Medicaid and CHP+ programs.

If you weren't able to join us, recordings of the January webinar in English, Spanish, and American Sign Language (ASL) are posted to the HCPF Sustainability webpage, where you can also find recordings from the December MISO webinar.

Please contact HCPF_stakeholders@state.co.us with any questions or concerns.

Colorado Department of Health Care Policy and Financing | 303 E. 17th Avenue, Suite 1100 | Denver, CO 80203 US

**Developmental Disabilities Administration**

# Self-Directed Services Manual

201 West Preston Street, 4th Floor

Baltimore, Maryland 21201

Issue Date: October 24, 2024

[redacted] Revised Date: September 24, 2025

[redacted] Effective Date: October 6, 2025, unless otherwise noted in the Manual

## Dear Finance Committee Members.pdf

Uploaded by: Lara Wynne

Position: FAV

Dear Finance Committee Members,

I am in favor of SB0583. Starting in October 2024, my daughter, Emma Wynne, has been receiving Medicaid Waiver Services from the DDA through the Self-Directed Services model. In that short time, the Self-Directed Manual has been changed twice, with very little time for meaningful input from stakeholders. Often times the changes contradict the Self-Direction Act of 2022. Every time the DDA "proposes" changes, their intent already seems etched in stone, without genuinely regarding the consequences on Marylanders with disabilities or thinking through how the changes will affect the community and those who support them. Changes are rushed, without proper time for Self-Directed participants and the agencies who provide services to prepare and learn about the amendments before they go into effect.

The Coordinators Community of Services (CCS), the Fiscal Management providers, Nursing Services, and Behavioral Support Providers do not receive proper training on the changes. Nor do the service providers have ample time to adjust to the new requirements. When the DDA is not transparent or accountable about decisions made, decisions that directly affect participants and families, health and safety are compromised. Here is an excerpt from an statement we received from Emma's Behavioral Support Services provider,

"As of **October 6, 2025**, DDA implemented major revisions to provider requirements, enrollment, and ongoing compliance under the updated *Self-Directed Services Manual* and *2025 Waiver Changes*. These updates require all individual Behavioral Support Services practitioners—including Board Certified Behavior Analysts—to complete **DDA certification and ePREP Medicaid enrollment** as individual providers by the established deadlines. The changes also introduce expanded documentation, quarterly training attestations, and programmatic compliance standards that significantly affect independent clinical capacity.

In order to remain in compliance and continue providing high-quality, meaningful services within these new parameters, I must **reduce my caseload** to a more sustainable level. Unfortunately, this means I will **no longer be able to provide Behavioral Support Services for Emma."**

While the new systems and requirements will hopefully strengthen service delivery for individuals under DDA, rushing and mandating without preparation is irresponsible.

Emma has now been without Behavior Supports Services since November 4, 2025. We have found a new provider, but in order for them to start services, Emma's Person Centered Plan and Budget needed to be revised and approved. This always takes **so much** longer than it should. We are still awaiting plan approval and Emma remains in limbo without behavior services.

Please support SB0583 to ensure Marylanders with disabilities using the Self-Directed Model are not put in harm's way due to DDA's lack of transparency, accountability and willingness to listen to the community it serves.

Thank you,
Lara Wynne

# SB0583 and HB1593 FAV  Feb  20  FINAL PDF.pdf

Uploaded by: Martha Gabler

Position: FAV

# SB0583/HB1953 FAV

## Developmental Disabilities Administration - Self-Directed Services Manual - Public Comment

Martha Gabler, District 20
10125 Markham St., Silver Spring, MD, 20901
February 20, 2026

Dear Respected Members of the Senate Finance Committee:

I am FAVORABLE in regard to this bill and respectfully request your support.

My family is directly affected by the concerns raised in this bill. My name is Martha Gabler. I am the Mother and Legal Guardian of Douglas Gabler, a profoundly nonverbal 29-year-old man with severe autism. Douglas has participated in Self-Directed Services under the DDA Community Pathways Waiver since 2017.

We appreciate Douglas's opportunity to participate in Self-Direction because he is thriving with this personalized approach. He has an excellent daytime Direct Support Professional who has been supporting him for 5.5 years! As a result, Douglas has the opportunity to participate in community activities and volunteer work that truly bring joy and accomplishment to his life and to others.

Self-Direction is a complex program for Participants and families to navigate. Many of the rules are excellent, because they set out the rights and responsibilities of the many parties involved in each Participant's plan. We welcome rules and procedures that support accountability and reporting requirements, and we take pains to comply with them.

However, we do not welcome sudden, unexplained policy changes that are imposed with no notice, no reason or explanation, and no opportunity to collaborate. These constant changes have made the system feel oppressive, and result in constant chaos as we jump through hoop after hoop trying to comply with confusing requirements. Alas, this has been the pattern for the last two years.

The first big example of this was the surprise release of the Self-Directed Policy Manual in 2024. On Thursday, October 24, 2024, the Self-Directed community was surprised to learn that the DDA had issued a new 23 page Self-Directed Services Comprehensive Policy and a new 115 page Self-Directed Services Manual. The DDA announced that this manual would take effect on Thursday, November 7, 2024, just 13 days later! This time period exactly straddled the Presidential election on November 5, 2024, thus creating a massive disruption just when our entire nation was intensely focused on our quintessential American passion: voting.

As you may recall, the Maryland General Assembly was inundated with calls and emails from constituents during this important time period, and finally a conference call was organized for November 4, 2024, just one day before the election!

It also turned out that the DDA had included an erroneous provision in the Policy Manual that attempted to tap into Participants' ABLE accounts and Special Needs Trusts. This attempt was a violation of law, and the Maryland ABLE people contacted them within a day to tell them that this was illegal, hence that provision was removed. There should have been a 90-day comment period for these documents.

This is a sad track record that shows disrespect not only for the Participants, but for the other important partners in Self-Direction such as the Support Brokers, Coordinators of Community Services, Financial Management and Counseling Services (FMCSs), vendors, and even for the Maryland General Assembly.

For these reasons, please support this bill. The DDA should be required to provide advance notice of proposed changes and offer a 90-day comment period. Further changes should not be implemented until this procedure has been completed.

However, I would like to request that more information be required of the DDA prior to the 90 day comment period:

The DDA should provide information about whatever "problem" it has uncovered and why their "change" is the "solution" to the "problem". This would include:

- A specific description of the "problem"
- A detailed description of a consultation process to include all interested parties in addressing the "problem"
- Serious collaboration with all interested parties to continue until all facts relating to the issue are available, including:
    - Data describing the extent and frequency of the "problem"
    - A description and explanation of the "solution" the DDA wishes to implement
    - Consideration of "solutions" developed by other parties
    - Data describing whether this "problem" has occurred in other states, to what extent, and how well this "solution" addressed the problem in other states
    - A cost-benefit analysis of the costs, in both time and money for all parties, involved to implement this "solution"
    - Description of a trial period to see if the "solution" actually solves the "problem"

- Full and complete consideration of all these points should be completed and published before any changes are implemented.
- The implementation process should be carefully designed and monitored to ensure the “solution” actually does resolve the “problem.”

Furthermore, the DDA should focus on stabilizing the rules and regulations so Participants and families can plan for the future. The DDA regulations are hundreds of pages long. The Policy Manual is 100+ pages long. There should be no more specious changes. Participants need the rules to be stable because we families are trying very hard to figure out long term care for our Adult Children. Families have many important decisions to make that may involve huge sums of money, such as whether to move, whether to buy a different type of property, whether to buy a certain type of vehicle, etc.

If the rules and regulations change constantly, we cannot make decisions, and we cannot take action. If we risk taking an action based on one set of rules, we might find our innocent Participants in big trouble after yet another unannounced rule change. This is untenable and cruel.

Families want to provide for their Adult Children to the extent possible, or at least be able to start the planning process. At the present time, this is impossible.

In conclusion, please support this bill. Please support the goals of Participants and their families to have stability and transparency for their programs in the short term, and the ability to plan for the long term.

Thank you for your consideration.

Sincerely,

*Martha Gabler*

Martha Gabler, District 20
Mother and Legal Guardian of Douglas Gabler
10125 Markham St.
Silver Spring, MD 20901
Cell: 301-641-1943
Email: martha.gabler@gmail.com

# Written Testimony Supporting SB583 .pdf

Uploaded by: Mi Lee

Position: FAV

# Written Testimony in Support of SB 0583

Chair and Members of the Committee,

My name is Mi Lee. I am the mother of an adult son with developmental disabilities, and I am writing in strong support of SB 0583. I also submit this testimony on behalf of 33 Korean families in Maryland who rely on Developmental Disabilities Administration (DDA) Self-Directed Services and are closely following this legislation.

For our families, Self-Directed Services are essential. They allow individuals with developmental disabilities to live safely in their communities while giving families the ability to coordinate and oversee services responsibly. However, the effectiveness of this model depends on transparency, accountability, and consistent oversight.

SB 0583 strengthens these protections. It promotes responsible management of public funds and reinforces safeguards that ensure services are delivered appropriately and sustainably. Clear structure and oversight are not barriers to care — they are what protect participants and preserve trust in the system.

Families already shoulder significant responsibility in managing services, coordinating staff, and maintaining compliance. When systems lack clarity or consistent standards, the burden increases and stability is compromised. Strengthening accountability helps ensure that resources are used as intended and that services remain available for those who depend on them.

On behalf of my son and the 33 Korean families I represent in Maryland, I respectfully urge the Committee to issue a favorable report on SB 0583.

Thank you for your consideration.

Respectfully submitted,

Mi Lee

Maryland

## SENATE BILL 583 testimony oral.pdf

Uploaded by: Michele Gregory
Position: FAV

# SB583 Favorable Testimony (Oral)

Chair, Vice Chair, and members of the Committee,

My name is Michele Gregory. I am a Maryland resident, a caregiver, and a local elected official. I'm here today in support of Senate Bill 583.

This bill requires the Deputy Secretary for Developmental Disabilities to provide public notice before making changes to the Self-Directed Services Manual, to allow at least 90 days for public comment, and to refrain from adopting changes until that comment period has ended.

At its core, this bill is about transparency.

The Self-Directed Services Manual governs how families hire caregivers, manage budgets, and access the supports that allow individuals with developmental disabilities to live safely in their communities.

I want to briefly share why that matters.

As a caregiver to an adult child with complex medical needs, our family depends on the predictability of the self-directed system. We use it to hire trusted caregivers, coordinate medical appointments, and maintain stability in a life that already involves constant medical uncertainty. When guidance shifts without warning, it is not just an administrative inconvenience. It can mean scrambling to adjust pay structures, questioning whether essential travel will be reimbursed, or worrying whether care coverage will remain intact.

In families like mine, small policy shifts can have very real consequences.

Maryland law defines self-directed services as empowering individuals to exercise employer authority and budget authority over their services. But empowerment only works when there is transparency. When rules change without notice or structured public input, families are left reacting instead of planning.

For rural families especially, where provider shortages and long travel distances are already part of daily life, instability in policy can compound existing barriers.

Senate Bill 583 does not prevent improvement. It simply requires notice, a defined 90-day comment period, and consideration of public input before changes are finalized.

That is not bureaucracy. That is responsible governance.

Families who self-direct are not asking for special treatment. We are asking for predictability, transparency, and a seat at the table before the rules that govern our care are altered.

I respectfully urge a favorable report on Senate Bill 583.

Thank you.

**Councilmember Michele Gregory**
**709 Parkway Ave.**
**Salisbury, MD 21804**

## SENATE BILL 583 written testimony.pdf

Uploaded by: Michele Gregory
Position: FAV

# SB583 Favorable Testimony

Chair, Vice Chair, and Members of the Committee:

My name is Michele Gregory. I am a Maryland resident, a caregiver, and a local elected official. I am submitting this testimony in support of Senate Bill 583.

Senate Bill 583 requires the Deputy Secretary for Developmental Disabilities to provide public notice before making changes to the Self-Directed Services Manual, to allow for at least 90 days of public comment, and to refrain from adopting changes until that public comment period has concluded.

This bill is fundamentally about transparency and accountability in a system that directly affects the daily lives of Marylanders with developmental disabilities and the families who support them.

The Self-Directed Services Manual is not a minor administrative document. It governs how individuals and families hire caregivers, manage approved budgets, and access critical supports that allow them to live in their homes and communities. For many of us, it determines whether medically fragile individuals remain stable, whether caregivers can continue providing care, and whether individuals can maintain independence and quality of life.

State law defines self-directed services as empowering individuals to exercise employer and budgetary authority over their services. That empowerment loses meaning if the policies governing those services can be changed without meaningful notice or opportunity for public input.

Families who self-direct are not passive recipients of services. They are employers. They are care coordinators. They are compliance managers. They are often filling gaps in a healthcare system that is already strained. When changes to the Manual are implemented without structured public engagement, the consequences can be immediate and destabilizing.

This is particularly true for rural families, who often face limited provider availability and must travel long distances for medical and therapeutic services. Policy changes can disproportionately affect those who already operate with the least margin for disruption.

Senate Bill 583 does not prevent the Administration from updating or improving the Manual. It simply requires notice, a defined 90-day comment period, and consideration of stakeholder input before changes are finalized. That is not an unreasonable burden. It is a standard of good governance.

Transparent processes produce stronger policy. When stakeholders have the opportunity to provide feedback, unintended consequences can be identified before implementation. This reduces confusion, prevents hardship, and ultimately supports more stable outcomes for individuals and families.

Marylanders with developmental disabilities deserve systems that are predictable, transparent, and accountable. Families who self-direct deserve to be heard before rules governing their care are altered.

For these reasons, I respectfully urge a favorable report on Senate Bill 583.

Thank you for your consideration.

**Councilmember Michele Gregory**
**709 Parkway Ave.**
**Salisbury, MD 21804**

## Testimony 2.24.26.pdf

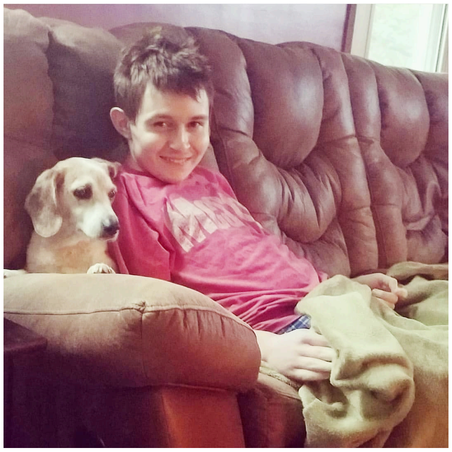
Uploaded by: Michele Gregory
Position: FAV

# NICK'S WORLD IS SELF-DIRECTED

In Nick’s world, he has the power to choose—when to wake up, when to watch TV, and how to engage with his community. He experiences the everyday freedoms that so many take for granted.

**This could all change if the Maryland General Assembly votes to approve the proposed cuts to the DDA.**

## SAVE OUR SERVICES! RESTORE THE FUNDING!



Nick Gregory is 31 years old and diagnosed with LGS, a form of epilepsy that comes with developmental delays.

February 26, 2025
*Appropriations Committee*
**House of Delegates**
Testimony: HB350 Budget Bill (FY26)

120 Taylor House Office Building
121 Taylor House Office Building
Annapolis, Maryland 21401

**Councilmember Michele Gregory**
**(443) 669 3483**
**mgregory@salisbury.md**
**709 Parkway Ave.**
**Salisbury, MD 21804**

Honorable Delegates,

It is 6:00 AM as I write this. I’ve rewritten this piece countless times, each version growing too long, too in-depth, likely losing readers along the way. So I scrap it and start again—throwing it at the wall until something sticks.

That’s what it feels like the state and Governor Wes Moore’s administration have done with these budget cuts. But before we get into that, let me tell you how my family ended up here.

Our eldest son, Nick, is profoundly disabled. His condition was so rare that we didn’t receive a real diagnosis until he was 18. He always had global developmental delays—he's non-verbal with a skills range equivalent to 6-36 months—but it wasn’t until he suffered a breakthrough tonic-clonic seizure at school that we got answers. He was admitted to the hospital with a diagnosis of encephalopathy with global developmental delays and discharged with one for Lennox-Gastaut Syndrome—a complicated, treatment-resistant form of epilepsy that will forever shape his daily life.

At the time, he still had a few years of school left, and we were blessed with a wonderful teacher. But when the dreaded “transition” period arrived, it terrified us. We had little trust in the system or others to care for him properly. In fact, for the first year after high school, he stayed home with me while I worked 11-hour days running a childcare business. It was stressful, but the hardest times were when he got sick and had to be hospitalized. His dad had to take time off work because I, and my clients, couldn’t afford for the daycare to close four or five times a year, sometimes for weeks. He burned through his sick leave, flex time, and vacation days within the first six months of each year. We hoped and prayed we wouldn’t end up without paid leave when we needed it. Vacations? Nonexistent. Every day off was spent on Nick’s care.

Eventually, we tried enrolling him in a day program. His schedule ran from 7:00 AM to 2:30 PM, four days a week. Transportation was provided by a staff-driven car. But we quickly realized this setup wasn’t healthy for him. Waking up unnaturally early triggered more seizures, leading to aspiration pneumonia, then hospital stays. The cycle repeated.

We also discovered that his dedicated staff was frequently reassigned, meaning they were still paid from his budget while caring for other clients—or, as the system cynically calls them, “consumers.” It frustrated us endlessly, but we were powerless in the face of limited options.

In 2017, we finally took a vacation. For the first time, Nick lived on his own schedule—and the results were stunning. Two weeks, seizure-free. It felt like a miracle.

A few months later, at his annual health department review, we had yet another new coordinator—so new that his supervisor attended our meeting to train him. I mentioned how much better Nick did on his own schedule but explained that I had no choice but to work.

The next day, the supervisor called with news of a program that would allow us to do just that. We immediately applied. The wait was long—much longer than promised—but eventually, we got in, and I became Nick’s paid caregiver.

The impact was almost immediate. His seizure frequency dropped dramatically, from several dozen per day to about a dozen. That meant fewer hospital visits—down from every few months to just once or twice a year—saving the state tens of thousands of Medicaid dollars annually. And for the low cost of 40 hours of weekly pay, he received 24/7 care from his own mother.

As Nick has grown older, his needs have become more complex. New medications have further reduced his seizures, but every injury he sustains sets him back. Skills are lost, and his needs increase. We applied for his father to become a caregiver as well. After years of rejections, we finally got approval. His dad left his career as a cable technician to help with Nick’s daily care. Now, Nick has two caregivers working a combined 80 hours a week—still far less than the 168 hours of care he requires. This setup has worked for years. It’s not always easy, but it’s undoubtedly the best for Nick. His health has improved, and he receives the best care possible, in the comfort of his home. It’s Nick’s world—we just live in it and facilitate it.

Nick loves Mickey Mouse and Bluey. He’s an avid Ravens fan, though he’ll watch any football game just for an excuse to shake his fist at the TV. He’s a familiar face at community events like Third Friday downtown. He loves the loaded fries at Roadie Joe’s Bar, and thanks to our caregiver salaries, he just got a brand-new accessible van to cruise around town in search of the best milkshakes.

Which brings me to my final point: The budget that pays our salaries does far more than just compensate his caregivers. It pays for the roof over his head, the car that allows him to be part of the community, the ramp that lets him leave the house, and the wheelchair without which he would never experience the world outside our home. Every one of these things has been paid for out of our pockets—at no additional cost to taxpayers. And let’s not forget the unpaid labor we provide: being on call 24/7, every single day, without breaks. The alternative—placing him in full-time institutional care—would cost the state hundreds of thousands more per year and greatly reduce the quality of that care in the process.

As a member of the Salisbury City Council, I know firsthand how tough budget decisions can be—especially now. But these cuts won't just fail to save money; they will create even greater costs down the line. And worse, they won't just cost dollars—they will cost lives. Lives that are every bit as vibrant and full as anyone else's, all thanks to a program that could vanish for thousands if the current budget moves forward with your vote.

As an elected official and a visible advocate in the developmental disability community, I hear from families who are terrified for their loved ones' futures. I receive constant messages and calls—pleas for guidance, cries for hope. But for every voice you hear today, hundreds more remain unheard, their desperation and fear echoing again and again.

I urge every legislator to reject these cuts for the 2026 fiscal year. Find another way. This isn't trimming fat—it's cutting families like mine to the bone.

Sincerely,

Councilmember Michele Gregory
709 Parkway Ave.
Salisbury, MD 21804
443-669-3483
mgregory@salisbury.md

**Jennings - SB0583 .pdf**
Uploaded by: Michele Steward
Position: FAV

Dear Senator Jennings,

I did not expect to have to write in support of this bill. However, recent circumstances have made it clear why SB0583 is necessary.

My son, Zachary Steward, entered Self-Directed Services in 2023. Since that time, our family has worked with three different FMS providers. Policies shift rapidly. Guidance changes without clear written authority. And reimbursements that were previously approved — and paid — are suddenly being denied without citation to COMAR or waiver language.

One current denial directly conflicts with COMAR reimbursement standards. COMAR 10.22.17 requires Fiscal Management Services to operate in accordance with Medicaid and DDA regulations — not internal policies that impose more restrictive criteria. That matter is now being escalated accordingly.

Another involves Medicare Part B premiums for my husband, Guy Steward, who retired early at age 63 to help stabilize Zach during significant behavioral challenges. The Medicare premium replaced employer insurance costs. Reimbursement was previously approved, written into the budget, and outlined in the employee manual.

Now, outside prior approval and despite prior reimbursement, payment has stopped — without formal written denial or regulatory citation.

There is a much larger issue underlying all of this — **instability.**

Families are left trying to interpret shifting administrative standards that may or may not align with governing regulation. We are expected to comply fully, yet when we ask for the authority behind a denial, transparency can feel difficult to obtain — and at times families fear pushback simply for asking questions.

That is not how a person-centered system should function. The emotional toll this takes on families is real. We are managing care, workforce stability, compliance, and crisis prevention — all while trying to keep pace with policy changes that are humanly impossible to track.

I also recognize the weight legislators carry, returning each session to inboxes filled with stories like mine. That volume alone signals that something in the system needs recalibration.

SB0583 is a step toward restoring clarity, transparency, and regulatory alignment within Self-Direction.

I appreciate you taking the time to hear directly from families living this reality every day.

Respectfully,
Michele Steward

**JB Jennings 3.pdf**
Uploaded by: Shana Farlow
Position: FAV

Good afternoon,

My name is Shana. I am the sister and legal guardian of my two brothers, Andrew, 43, and Nathan, 34. We live in rural Stockton, Maryland, where services are already limited.

Andrew and Nathan have leukodystrophy, a degenerative brain disease. They have been quadriplegic since birth and require total care for every aspect of daily life.

I am here today fighting two things.

First, the cuts to DDA staff hours and wages specifically impacting clients who receive REM services. These reductions are happening now.

Second, this is before the proposed $150 million decrease to the DDA budget that the Governor has put forward.

Families like mine are being hit twice.

Reducing hourly rates for DDA staff — particularly for those serving clients connected with REM — is discrimination against some of the most fragile and medically complex individuals in our state. These are individuals who require the highest level of care. Yet their caregivers are being told their work is worth less.

In a rural area like ours, recruiting qualified caregivers is already challenging. Cutting wages now will make it nearly impossible to retain the experienced, compassionate staff my brothers depend on every single day.

A budget number on paper means nothing if the people providing hands-on care cannot afford to stay in these jobs.

I have dedicated my life to ensuring my brothers live in a stable, safe, and healthy home. Despite being medically complex, they have no skin breakdown, no neglect, no instability — because they are cared for properly. Our mother, a registered nurse, devoted her life to them. I am also a nurse. We understand what quality care requires.

Years ago, we tried respite care. My brothers were supposed to stay for two weeks. I brought them home after three days. One hundred and fifty of Andrew's prescribed pain pills were stolen. There was an investigation, but nothing could be proven. That experience broke my trust.

So when group homes are suggested as an alternative, I have to ask: how can I entrust my brothers' lives to a system where oversight can fail?

Andrew and Nathan want to remain in their home — where they are safe, loved, and thriving.

And this issue reaches beyond my family.

The staff who support families like mine are Maryland residents. They are parents, students, and members of our communities. These programs are not just support systems — they are job creators.

Through self-directed services alone, my brothers' care provides employment for eight people. Eight Maryland jobs from one household.

Now consider the more than 4,000 Marylanders who use self-directed services. What happens to their caregivers if wages are cut now — and then the DDA faces a $150 million decrease on top of that? What happens to those families who rely on that income? What happens to rural communities where these jobs sustain local economies?

If I cannot retain quality staff because wages are reduced, I will be forced to consider alternatives. And institutional placements will cost the state far more than supporting families who are already successfully providing care at home.

These programs are not broken. Families like mine have made them work for years.

This is not just about my brothers.

This is about dignity.

This is about safety.

This is about fairness.

Cutting wages now — before even deeper reductions are considered — destabilizes an already fragile system. It disproportionately harms individuals who are medically complex and those who serve them.

My brothers deserve to remain healthy and happy in their own home. The people who care for them deserve fair wages. And Maryland deserves a system that protects its most vulnerable citizens — not one that weakens it from within.

Thank you

# 2026 Maryland SB0583 Favorable Steven Bress.pdf

Uploaded by: Steve Bress

Position: FAV

My name is Steven Bress. I have been a Maryland resident for much more than 50 years. I urge you to vote YES on SB583. It is in the best interest of Participants in DDA's Self Directed Services Program.

My son Michael is a Participant in DDA's Self Directed Services (SDS) program. He has been in the SDS program for two and a half years. The SDS program is his only choice due to behavior issues. He has been asked to leave every other type of program that he has been in. Basically, Traditional Model Providers do not exist for a Participant with behaviors. His behavior has also affected his ability to retain staff in the SDS program.

Over the last couple of years, DDA has made major changes to the SDS program. These changes have impacted a wide range of topics from employee wages to training requirements for the staff members. They have also taken services such as IFDGS, which allowed a small portion of his funding to be used for such health related items as supplements and dental visits, that are not covered by any other program. Last year they put so many restrictions on his ability to have help with the SDS program, in the form of a Day to Day Administrator, that such services are effectively not available.

All of these changes were put into effect with little warning and no effective communication, including participant feedback, as of the effective date of the announcement. The program supports such as the Coordinator of Community Services and the Support Brokers, are not trained in advance and cannot help navigate the new rules on the day that they are effective, even if compliance with the new rules were possible to be accomplished in a day.

I urge you to vote in favor of SB 0583 as it can help prevent interruptions and essentially mandatory non-compliance with rules for this very important DDA program.

Thank you for your consideration.

Steven Bress
Germantown, MD

## SENATE BILL 583.pdf

Uploaded by: Alicia Wopat
Position: FWA

**SENATE BILL 0583**
Developmental Disabilities Administration – Self–Directed Services Manual – Public Comment
**POSITION:** Favorable with Amendments
**COMMITTEE:** Senate Finance Committee
**SUBMITTED BY:** Alicia Wopat
**DATE:** February 24, 2026

Chair and Members of the Senate Finance Committee:

SB583 represents an important and practical step toward restoring transparency and accountability in how policies are developed and implemented within Maryland's developmental disabilities service delivery system. Participants, their families and teams deserve to be truly heard and their needs taken into consideration.

For many years, the Maryland Developmental Disabilities Administration (DDA) followed a workable and effective process when considering policy changes that affected self-direction. Draft policies were vetted with self-direction advocates and stakeholders prior to release, and then opened for a 30-day public comment period to allow input from the broader community. This approach was feasible, collaborative, and helped identify operational concerns before implementation—preventing unintended consequences and dysfunction within an otherwise efficient and effective service delivery model.

SB583 will assist to return to that proven framework. With amendments extending these protections to all policy guidance used by the Administration and for all users of the 1915c Waiver the bill can ensure:

- Transparency in how policies are drafted and revised
- Consistency and fairness
- Meaningful public participation before policies take effect
- Greater accountability for decisions that directly impact participants,

Policy changes in a system as complex as Maryland's developmental disabilities network must be thoughtful, predictable, and informed by those who rely on the services every day. SB583 provides a reasonable and necessary structure to achieve that goal while protecting the integrity of self-direction and the broader service system.

This is a feasible bill. It restores a process that has worked before and helps safeguard against unintended harm—strengthening both the Administration and the community it serves.

For these reasons, I urge the Committee to issue a Favorable Report with Amendments on SB583.

Respectfully submitted,
Alicia Wopat for Team Al

**MDOD_SB0583_FWA_FIN_2026.02.20.pdf**

Uploaded by: Anne Blackfield

Position: FWA

**Carol A. Beatty,** Secretary
**Anne Blackfield,** Deputy Secretary

**Wes Moore,** Governor
**Aruna Miller,** Lt. Governor

Maryland
DEPARTMENT OF DISABILITIES

**BILL: SB 583**
**POSITION: FWA – Favorable with Amendments**
COMMITTEE: Finance
DATE: February 20, 2026

SUBMITTED BY: Maryland Department of Disabilities
217 East Redwood Street, Suite 1300, Baltimore, MD 21202

Dear Chair Beidle and Committee Members:

The Maryland Department of Disabilities (MDOD) respectfully submits this letter of support with amendments for **SB 583, Developmental Disabilities Administration - Self-Directed Services Manual - Public Comment.**

MDOD is in support of the bill contingent on the amendment that the Maryland Department of Health (MDH) has submitted, which would require MDH to adopt regulations for the Community Pathways Waiver program. DDA's regulations should be updated to reflect the changes that have taken place in the waiver over the last 13 years.

Like MDH, MDOD believes these amendments will accomplish the intent of the legislation by providing significant stakeholder and advocate input in the Department's procedures through the State's existing regulatory process, governed by the Administrative Procedures Act in State Government Article, Title 10, Subtitle 1.

MDOD believes that the proposed regulatory process would be a more meaningful opportunity for stakeholder and advocate input.

MDOD supports the amendment as follows:

On page 3, strike in their entirety lines 2 through 12, inclusive, and substitute:

"THE SECRETARY SHALL ADOPT REGULATIONS FOR THE COMMUNITY PATHWAYS WAIVER, INCLUDING REGULATIONS PERTAINING TO THE DELIVERY OF SELF-DIRECTED SERVICES."

*Rationale:* MDOD suggests adopting the amendment submitted by the Maryland Department of Health, included here for reference. This amendment would ensure that MDH undertakes a process to update and modernize DDA's regulations, which would include opportunities for meaningful public and stakeholder input through the State's existing regulatory process, governed by the Administrative Procedures Act in State Government Article, Title 10, Subtitle 1.

For these reasons, MDOD respectfully supports SB 583 as amended.

Sincerely,

Carol A. Beatty

Carol A. Beatty

Secretary, Department of Disabilities

## Testimony Bill SB583.pdf

Uploaded by: Anne Smith

Position: FWA

# Testimony For Bill SB583

Dear Senator Jennings and other members of the committee,

Thank you for taking the time to listen to me today.

I am Anne Hollenshade Smith.

I live in Towson, Maryland.

My child is Patrick. He suffers from Autism and mental retardation, along with other needs.

I want to let you know I support your Bill.

But It does not go far enough. DDA has recently notified us of changes by email on February 3rd, 2026, in over 20 different categories. Some of which effected my son directly. Assistive technology and Behavior therapy to name a few. We waited over a year and half to receive start Behavior therapy. It has been very beneficial to Patrick and the family.

We are excited to see the benefits of assistive technology as it takes off. It takes time to get the right app and get it set up.

I am asking you to expand from just the manual to any CHANGES made by DDA. IT must include a 90-day notice be given and community input be necessary. If you exam this email sent on Febuary 3rd alone, you can see how detailed it is. While you are taking care of your loved one, reading all these detailed emails and manuals takes time!

Again, Senator Jennings, Thank you for your Support for Self-Directed Services and for my Son!

# Testimony in Support of SB 583(with Amendments) (2

Uploaded by: Carin Smith

Position: FWA

# Testimony in Support of SB 583(with Adaptations)

Carin Smith
Middle River, Maryland

Thank you for the opportunity to speak today. My name is Carin Smith, and I live in Middle River, Maryland. My daughter, Ellie, is 28 years old and has significant developmental disabilities. She lives in a home in her community(Parkville) and self-directs her services with assistance.

Senator Jennings, thank you for sponsoring Senate Bill 583 I strongly support this bill with amendments and respectfully ask that it be expanded to include all Developmental Disabilities Administration (DDA) policies and all individuals served under the waiver.

Over the past year and a half, families like ours have experienced ongoing chaos due to constant changes within DDA. Policies have been altered or dropped with little to no notice. These abrupt changes have created instability in my daughter's program and for the staff who support her every day.

Recent changes to healthcare reimbursement policies for direct support staff and the severe reduction in Day-to-Day Administration services have resulted in the loss of critical services and valued staff members. This instability not only impacts Ellie's quality of life and well-being but also affects the professionals who are dedicated to supporting her. DDA has made it a habit of making changes that impact people's lives without even talking to the people whose lives they impact. We're asking for your help in fixing the problem because we have repeatedly begged DDA to not do this and have been unsuccessful.

In addition, these sudden policy shifts have created confusion and significantly increased the number of hours worked by her Coordinator of Community Services, her Support Broker, and her Fiscal Management company. This inefficiency ultimately results in taxpayer dollars being spent ineffectively — the very opposite of what we all want.

I respectfully ask each of you to hear our community's plea and support SB 583 , with the necessary adaptations to protect all individuals served by DDA. Please help stop policies that unintentionally harm Maryland's most vulnerable citizens and instead ensure stability, transparency, and accountability moving forward.

Thank you for your time and consideration.

**SB583.pdf**
Uploaded by: Ellen Jennings
Position: FWA

SB583
February 24, 2026
Ellen Jennings
Support with Amendments

I strongly support this bill with the following amendments: that it cover all DDA participants (not just Self-Directed) and apply to all DDA Policy, not just the Self-Directed Services Manual.

# Is This A Partnership?

## Maryland Participants in Self-Direction and Their Teams Deserve Notice. Stability. Respect.

Maryland's Developmental Disabilities Administration (DDA) describes its relationship with participants, families and teams as a partnership. But partnership requires effective communication, transparency, and collaborative action.

### Major DDA Policy Changes — Minimal Notice

- Self-Directed Services Manual – 14 days' notice (Oct 24, 2024 - Nov 7, 2024)
- Self-Directed Services Manual – 14 days' notice (Oct 24, 2024 - Nov 7, 2024)
- Revised Manual – About 2 weeks' notice (April 2025 - May 9, 2025)
- Waiver Amendment – 30-day public comment (June 9, 2025)
- New Manual – 16 days' notice (Sept 21, 2025 - Oct 7, 2025)
- New Policy – Effective BEFORE public notice (Feb 4, 2026 announcement)

### This Is Not Sustainable

- Rebuilding services in days
- Adjusting staffing and budgets overnight
- Responding to complex policy shifts without input
- Maintaining stability while rules repeatedly change

### SB583/HB1593: A Step Toward Transparency

- Requires public notice before changes to the Self-Directed Services Manual
- Provides at least 90 days for public comment
- Prohibits adoption of changes until the comment period ends

### Legislators: Support SB583/HB1593

It is time for the Developmental Disabilities Administration to provide meaningful public notice and opportunity for comment whenever there are changes—or proposes to change—the terms and conditions under which individuals receive services, or alters the scope, duration, or delivery of those services, whether through regulation, policy, practice, or procedure.

**Partnership means listening. Planning together. Time to prepare.**

Please visit **CCSDSMD.org**
or contact us at **ccsdsmd@gmail.com.**

Concerned Citizens of
Self-Direction Maryland
Community. Choice. Accountability.

## SB583-Written Testimony.pdf

Uploaded by: Jessica Gallatin
Position: FWA

# SENATE BILL 583

Developmental Disabilities Administration – Self–Directed Services Manual – Public Comment

**POSITION:** Favorable with Amendments
**COMMITTEE:** Senate Finance Committee
**ORGANIZATION:** Self-Directed Advocacy Network of Maryland (SDAN)
**SUBMITTED BY:** Jessica Gallatin, Representative of SDAN
**DATE:** February 24, 2026

## TESTIMONY

Chair and Members of the Senate Finance Committee:

The Self-Directed Advocacy Network of Maryland (SDAN) respectfully submits this testimony in support of Senate Bill 583 (SB583) with amendments.

SDAN is a statewide advocacy organization committed to protecting and advancing participant choice, control, flexibility, and the long-term sustainability of self-directed services and supports in Maryland. Our work centers the experiences and rights of people who rely on Maryland's developmental disabilities service system and the teams that support them.

SB583 takes an important step toward transparency by requiring public notice and a minimum 90-day public comment period before changes are made to the Self-Directed Services Manual. SDAN strongly supports this intent.

### Why SDAN Supports SB583

Policies contained in the Self-Directed Services Manual are not merely operational guidance; they influence real-world access to services, participant autonomy, and the consistency of service delivery. Changes to definitions, requirements, or interpretations can have wide-reaching impacts on individuals and families who depend on stable, predictable rules.

### Why Amendments Are Necessary

SDAN urges amendments because transparency protections should not depend on where policy language is housed.

Maryland's developmental disabilities service system operates through two parallel service delivery models (traditional and self-directed) that are intended to provide comparable services and supports. Yet, policy guidance for these models is not consistently handled:

- The Self-Directed Services Manual was described as a consolidation effort, bringing policy into one accessible reference point, yet its implementation has, at times, contributed to major disruption when policies were not aligned, clear, or workable in practice.
- The Self-Directed Services Manual has also become a place where implementation can be more prescribed, limiting the flexibility that is otherwise preserved in the traditional model, where

provider organizations are typically permitted to determine implementation design within policy parameters.

- Most importantly, recent updates to PolicyStat and other guidance sources have occurred with little or no public visibility (sometimes seemingly “overnight”) despite the fact that such changes can redefine terms, shift access thresholds, and move expectations for services already in operation.

When rules and definitions change without notice and stakeholder engagement, it undermines trust, disrupts planning, and can function as a “moving goal post” for participants and their teams. Changes of this significance must be balanced, transparent, and public; not quietly implemented through whichever platform is used at the time.

## SDAN’s Requested Amendments

SDAN requests amendments to ensure the transparency and public comment requirements apply to all policy vehicles that govern services under the Developmental Disabilities Administration, including but not limited to:

1. PolicyStat (the statewide archive for DDA-related policies), and
2. Any other formal policy guidance used by the Administration that affects eligibility, access, definitions, service parameters, or implementation requirements.

SDAN also recommends amendments to require:

- Public posting and broad dissemination of proposed changes;
- Accessible notice (plain language and accessible formats);
- Publication of a summary of public comments received and how they were considered; and
- Clear standards to distinguish “substantive” policy changes from administrative or technical edits.

## Conclusion

SB583 is a strong step toward rebuilding transparency and accountability in how policies are changed within Maryland’s developmental disabilities service system. With amendments extending these protections to PolicyStat and all formal policy guidance used by the Administration, SB583 can ensure consistency, fairness across service models, and meaningful public participation.

For these reasons, SDAN respectfully urges the Committee to issue a Favorable Report with Amendments on SB583.

Respectfully submitted,

Jessica Gallatin
Board Member, Self-Directed Advocacy Network of Maryland (SDAN)
selfdirectedadvocacynetworkmd@gmail.com

SDAN
Self-Directed Advocacy Network of Maryland, Inc.

## Written Testimony in Support of Senate Bill 583.pd

Uploaded by: Krista Ennis

Position: FWA

**Written Testimony in Support of Senate Bill 583**
**Developmental Disabilities Administration – Self-Directed Services Manual – Public Comment**
**Senate Finance Committee**
**February 24, 2026**

Dear Chair and Members of the Senate Finance Committee,

My name is Krista Ennis. I am a CPA specializing in taxation, and I am the mother of my 24-year-old son, who participates in Maryland's Self-Directed Services program through the Developmental Disabilities Administration (DDA). I am writing in strong support of Senate Bill 583 because the current process for implementing policy changes is causing real harm to families like mine.

As a CPA, I was trained in one of the most volatile professional environments in modern history. During COVID-19, my profession faced constant upheaval—moving tax deadlines, new federal relief programs like the Employee Retention Credit and Payroll Protection Program, and nonstop regulatory changes. My job was to absorb complex new rules immediately and help others navigate uncertainty. I know how to pivot. I have done it professionally, successfully, and under pressure.

But nothing in my professional experience prepared me for the instability created by repeated, abrupt changes to my son's Self-Directed Services.

When my son entered the program three years ago, I worked tirelessly to build a stable support system. I recruited, hired, and trained his staff. I coordinated with vendors and the Fiscal Management Agency. I built a team of people who understand him, who keep him safe, and who allow him to live with dignity in his community. That stability is not a luxury—it is essential to his health, safety, and quality of life.

Yet over the past 15 months, that stability has been repeatedly undermined.

- On **October 24, 2024**, the DDA released a new manual with just **14 days' notice** before implementation.
- In **late April 2025**, another manual was issued, effective **May 9, 2025**, reducing wages and threatening our ability to retain qualified staff.
- On **June 9, 2025**, a Waiver Amendment was proposed. Families submitted public comments in good faith, but those voices were not meaningfully reflected in the outcome.
- On **September 21, 2025**, another manual was released, effective **October 7, 2025**, eliminating Day-to-Day Administration—supports that the legislature itself had recognized as necessary.
- Most recently, on **February 4, 2026**, the DDA sent an email stating, "Partnership is at the heart of this work," while quietly linking policy changes that had already taken effect **the day before families were notified.**

Five major changes in 15 months. Some with two weeks' notice. One with no notice at all.

This is not partnership. This is not transparency. This is not stability.

Each time this happens, families like mine are forced into crisis mode. We must immediately reassess budgets, reassure staff, prevent resignations, and protect continuity of care. We must absorb the administrative and emotional burden while shielding our loved ones from disruption and fear.

I am fortunate to have professional skills, financial literacy, and schedule flexibility. Even so, I am struggling to keep up. I am exhausted by the constant uncertainty and the fear that the carefully built support system my son depends on could unravel at any moment.

Many families do not have my resources. They cannot simply “pivot.” They may lose staff. Their loved ones may lose stability. And when stability is lost, individuals with developmental disabilities can experience regression, behavioral crises, hospitalization, or worse.

These are not abstract policy changes. These are decisions that affect whether real people are safe, supported, and able to live meaningful lives.

Senate Bill 583 offers a simple, reasonable solution: transparency, notice, and the opportunity for meaningful public comment before changes are implemented. Ninety days is not an obstacle—it is a basic safeguard. It allows families to prepare. It allows stakeholders to provide informed feedback. It allows the DDA to benefit from the real-world expertise of those living this system every day.

Most importantly, it restores the principle that families and individuals are partners—not afterthoughts—in decisions that shape their lives.

Self-direction cannot exist without stability. It cannot exist without trust. And it cannot exist without a voice.

I urge you, on behalf of my son and thousands of Maryland families like mine, to issue favorable support on Senate Bill 583.

Respectfully,
Krista Ennis
Parent

# final testimony in support of SB 583 support with

Uploaded by: Mat Rice

Position: FWA

# People On the Go Maryland

In the Senate - Hearing 2/24 at 1:00 p.m.

## TESTIMONY ON SENATE BILL 583

Sponsored by Senators Jennings, Bailey, Salling, Gallion, Carozza, and Ready

Developmental Disabilities Administration - Service Manuals - Public Comment

## POSITION: FAVORABLE WITH AMENDMENT

Testimony Written by Mat Rice on Behalf of People on the Go Maryland

To the Honorable Members of the Senate Finance Committee:

People on the Go Maryland respectfully submits this testimony regarding Senate Bill 583, sponsored by Senators Jennings, Bailey, Salling, Gallion, Carozza, and Ready. We recommend a FAVORABLE WITH AMENDMENT recommendation to strengthen this bill's positive impact on the developmental disability’s community.

### About People on the Go Maryland:

Our mission is to promote advocacy and civil rights throughout the state. We are a self-advocacy organization made up entirely of people with developmental disabilities. We believe strongly in the principle of 'Nothing About Us Without Us' - meaning that people with disabilities must be meaningfully included in all decisions that affect our lives, our services, and our communities.

### Statement of Support:

People on the Go Maryland supports Senate Bill 583 and believes it represents an important step forward in promoting transparency, accessibility, and meaningful participation for people with developmental disabilities in the policymaking process. Public comment opportunities are essential because they ensure that decisions affecting our lives are informed by those who experience their impact firsthand.

### The Need for Amendment:

While we strongly support the intent of this bill, we respectfully recommend an amendment to ensure that ALL people with developmental disabilities benefit equally from its provisions, regardless of how they receive their services.

Currently, Senate Bill 583 only requires public comment for changes to the Self-Directed Services Manual. According to the Maryland Developmental Disabilities Administration, there are two primary service delivery models:

- Self-Directed Services - where individuals have employer and budget authority over their services
- Agency-Directed (
- Provider supported) Services - where provider agencies coordinate and deliver services on behalf of individuals

Additionally, many people receive supports through specialized waivers and programs including residential habilitation, day habilitation, supported employment, and community living options. All individuals deserve equal opportunity to participate in shaping the policies that govern their services.

**PROPOSED AMENDMENT TO SENATE BILL 583:**

On page 3, line 2, strike 'SELF-DIRECTED SERVICES MANUAL' and substitute 'SERVICE MANUALS, POLICIES, PROCEDURES, AND WAIVER AMENDMENTS OF THE DEVELOPMENTAL DISABILITIES Administration.'

On page 3, line 3, after 'ADMINISTRATION' insert ', INCLUDING BUT NOT LIMITED TO ALL MANUALS, POLICIES, PROCEDURES, AND GUIDANCE DOCUMENTS RELATED TO BOTH SELF-DIRECTED AND PROVIDER-DIRECTED SERVICES.'

On page 3, line 6, strike 'THE SELF-DIRECTED SERVICES MANUAL' and substitute 'ANY SERVICE MANUAL, POLICY, PROCEDURE, OR GUIDANCE DOCUMENT.'

**ADDITIONAL CLARIFYING LANGUAGE:**

*After the amended subsection, add the following:*

'For purposes of this section, policies, procedures, manuals, and waiver amendments includes any written guidance, operational instructions, rate-setting methodologies, eligibility criteria, and procedural requirements that directly impact the delivery of services to individuals with developmental disabilities, regardless of the service delivery model utilized.'

**PROPOSED PLAIN LANGUAGE ACCESSIBILITY AMENDMENT:**

People on the Go Maryland further recommends the following additional language to ensure that all documents are fully accessible to the individuals they are intended to serve:

'(1) PLAIN LANGUAGE REQUIREMENT. The Developmental Disabilities Administration shall provide plain language versions of all policies, procedures, manuals, and waiver amendments alongside the original technical/legal versions to ensure meaningful participation in the public comment process by individuals with developmental disabilities.'

'(2) DEFINITION OF PLAIN LANGUAGE. For purposes of this section, plain language means communication that is designed so that readers can:

- (A) Find the information they need;
- (B) Understand what they find the first time they read or hear it; and
- (C) Use the information to understand their rights, make decisions, and take action regarding their services.'

Plain language shall include: short sentences using common, everyday words; active voice; clear organization with headings; visual supports such as bullet points, numbered lists, and examples; and explanations of technical terms.

'(3) USE OF ACRONYMS AND ABBREVIATIONS. Plain language does not require the complete elimination of acronyms. Documents shall ensure:

- (A) All acronyms are defined in full upon first use, with the acronym in parentheses;
- (B) A glossary of acronyms and key terms is included with all policies and guidance documents; and
- (C) Commonly recognized acronyms (e.g., DDA, CCS, SDS) may be used after initial definition.'

**Research-Based Justification for Plain Language and Acronym Provisions:**

These provisions are grounded in federal law and supported by peer-reviewed research. The Plain Writing Act of 2010 mandates that federal agencies use 'clear government communication that the public can understand and use.' Research published by RTI International demonstrates that creating effective materials for adults with disabilities requires language at approximately a sixth-grade reading level with relevant, concrete examples that connect to real-life situations.

Regarding the strategic use of acronyms, research published in the Global Journal of Intellectual & Developmental Disabilities shows that acronyms serve as effective mnemonic devices for people with intellectual and developmental disabilities. Studies demonstrate that properly introduced acronyms can improve information recall by up to 200%. Familiar acronyms like 'DDA' become valuable reference points that reduce cognitive load while maintaining technical precision.

**What This Amendment Means in Plain Language:**

Right now, the bill only lets people comment on changes to the self-directed services manual. Our expanded amendment would mean:

- People who get help from agencies would have the same rights as people who self-direct
- People in group homes and day programs would get to comment on policy changes
- People receiving employment services, respite care, or other DDA support would be heard
- Changes to waiver programs would require public input before implementation
- ALL policies affecting people's services would go through public comment
- DDA would write easy-to understand versions of all important documents

**Everyone deserves a voice, no matter how they receive their supports.**

**A Note About Acronyms:**

When we say documents should be in 'plain language,' we do NOT mean getting rid of all acronyms. Some acronyms actually help people understand and remember information better. For example, acronyms like 'HOMES' help people remember the Great Lakes (Huron, Ontario, Michigan, Erie, Superior). Similarly, 'DDA' is much easier to say and remember than 'Developmental Disabilities Administration.' Research shows that when acronyms are clearly taught and explained, they can help people remember important information better. What matters is that acronyms are always explained the first time they appear, and that a complete glossary of acronyms is included in every document.

**Why This Expanded Amendment Is Essential:**

Policies, procedures, and waiver amendments can have just as much impact on people's lives as service manuals. Furthermore, requiring plain language versions of all documents ensures that the public comment process is truly accessible to all individuals with developmental disabilities, not just those with strong reading skill s or professional advocates.

**IMPORTANT:**

It is the position of People on the Go that even if the amendment is not adopted, the bill should pass as originally drafted. SB 583, with or without our proposed amendment, represents meaningful progress toward greater transparency and public participation in the policymaking process.

People on the Go Maryland hopes for the Senate Finance Committee to adopt this amendment and issue a favorable report on Senate Bill 583.

Respectfully submitted,

**Mat Rice**
On Behalf of People on the Go Maryland

**For More Information, Contact:**

EXECUTIVE DIRECTOR: Mat Rice

| PHONE: 4109255706

| EMAIL: mat@pogmd.org

# SB 583 - FIN - MDH- LOSWA (2).pdf

Uploaded by: Meghan Lynch

Position: FWA

Maryland
DEPARTMENT OF HEALTH

*Wes Moore, Governor · Aruna Miller, Lt. Governor · Meena Seshamani, M.D., Ph.D., Secretary*

February 24, 2026

The Honorable Pamela Beidle
Chair, Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, MD 21401-1991

**RE: SB 583 – Developmental Disabilities Administration - Self-Directed Services Manual - Public Comment – Letter of Support with Amendments**

Dear Chair Beidle and Committee Members:

The Maryland Department of Health (the Department) respectfully submits this letter of support with amendments for Senate Bill (SB) 583 – Developmental Disabilities Administration - Self-Directed Services Manual - Public Comment. SB 583 establishes a new requirement that the Developmental Disabilities Administration (DDA) provide at least 90 days of public comment before making any changes to the Self-Directed Services (SDS) Manual.

The Department respectfully presents amendments that would instead require the Department to adopt regulations for the Community Pathways Waiver program. Existing regulations for DDA services are a part of Medicaid regulations under COMAR 10.09.26 and have not been updated since 2013. Since then, the Community Pathways Waiver has been renewed twice (2018 and 2023) and amended 14 times with the Centers for Medicare and Medicaid Services (CMS), including the most recent amendment implemented beginning in October 2025. As such, DDA's regulations should be updated to reflect the changes that have taken place in the waiver over the last 13 years.

The Department has been planning comprehensive regulatory updates for DDA regulations, including creating a new subtitle specifically for DDA Waiver Services. The planned regulatory revisions will also include an entire chapter focused on Self-Directed Services. The Department believes these amendments will accomplish the intent of the legislation by providing significant stakeholder and advocate input in the Department's procedures through the State's existing regulatory process, governed by the Administrative Procedures Act in State Government Article, Title 10, Subtitle 1.

The SDS Manual is an operational guidance document for DDA's SDS delivery model. It is intended as a resource to help people involved with SDS—including participants, families, Coordinators of Community Services, and DDA regional staff—understand the ways participants can receive services and DDA's guidance and standards related to those services. It does not establish law or regulation.[1] For these reasons, the Department believes that the proposed regulatory process would be a more meaningful opportunity for stakeholder and advocate input.

As part of the proposal, the Department is committed to a thorough, transparent regulatory process with significant stakeholder engagement. Prior to submitting any regulations to the Joint Committee on Administrative, Executive, and Legislative Review, the Department will share draft regulatory text with stakeholders, advocates, and other interested individuals through a new dedicated webpage and targeted stakeholder meetings of existing DDA workgroups. Following submission to AELR and publication in the Maryland Register, these regulations would have a 30-day formal comment period in accordance with State Government Article, §10–111(a)(3), Annotated Code of Maryland.

For these reasons, the Maryland Department of Health respectfully supports SB 583 as amended. If you would like to discuss this further, please do not hesitate to contact Meghan Lynch, Director of Governmental Affairs at Meghan.Lynch@maryland.gov.

Sincerely,

Meena Seshamani, M.D., Ph.D
Secretary of Health

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[1] More information can be found in DDA's October 2025 report describing the history and impact of the SDS Manual. *See,* Maryland Department of Health, Developmental Disabilities Administration. (2025, Oct.). *Self-Directed Services Manual - Impact*. https://mlsd.ent.sirsi.net/client/en_US/default/search/detailnonmodal/ent:$002f$002fSD_ILS$002f0$002fSD_ILS:56857/one.

# AMENDMENTS TO SENATE BILL 583

(First Reading File Bill)

On page 3, strike in their entirety lines 2 through 12, inclusive, and substitute:

"**THE SECRETARY SHALL ADOPT REGULATIONS FOR THE COMMUNITY PATHWAYS WAIVER, INCLUDING REGULATIONS PERTAINING TO THE DELIVERY OF SELF-DIRECTED SERVICES.**"

*Rationale:* The Department suggests requiring the adoption of regulations for the Community Pathways Waiver program. This amendment would ensure that the Department undertakes a process to update and modernize DDA's regulations, which would include opportunities for meaningful public and stakeholder input through the State's existing regulatory process, governed by the Administrative Procedures Act in State Government Article, Title 10, Subtitle 1. Stakeholders would have the opportunity to provide input on changes across all DDA waiver services, including, but not limited to, those provided under the self-directed services delivery model.

# SB583.DD Coalition.SWA.pdf

Uploaded by: Rachel  London

Position: FWA

MARYLAND DEVELOPMENTAL DISABILITIES COALITION
Dedicated to the rights and quality of life for people with developmental disabilities in Maryland

**Senate Finance Committee**
**Februrary 24, 2026**
**SB 583: Developmental Disabilities Administration – Self-Directed Services Manual – Public Comment**
**Position: Support with Amendment**

The Maryland Developmental Disabilities Coalition (DD Coalition) is comprised of five statewide organizations that are committed to improving the opportunities and outcomes for Marylanders with intellectual and developmental disabilities (IDD). As such, the DD Coalition supports SB 583 with the following amendment to make sure all people with developmental disabilities, families, and advocates have the opportunity to comment on policies, procedures, and guidance that will affect their services.

- Move the requirement to Health-General §7-401 (C), and add language that **any policies, procedures, and guidance, including the Self-Directed Services Manual…**
- ADD: **(D) Any proposed changes to policy, procedure, and guidance, including the Self-Directed Services Manual shall be described in plain language.**

### WHAT does this legislation do?

- Requires the Developmental Disabilities Administration (DDA) to provide 90 day notice to the public before making changes to the Self-Directed Services Manual, and directs the Deputy Secretary not to adopt the changes until after the public comment period has concluded. **The amendment broadens it to include all DDA policies and procedures.**

### WHY is this legislation important?

- DDA does not currently have to provide notice to the public before makingchanges to policies, procedures, and guidance.
- There have been many changes to documents over the past few years. Often people with disabilities, families, providers, and staff do not have the opportunity to express how changes might impact services and supports, or enough time to adapt to changes.

### WHY are amendments needed?

- Notice and opportunity to comment should be available for all changes to policy, procedure, and guidance regardless of the model a person uses to receive their DDA services.
- Plain language benefits everyone. It makes the information easier to understand the first time someone reads it, and makes it easier to translate.
- Policies and guidance shape day-to-day services and supports, and meaningful public input leads to stronger, more workable policy.

Contact: Rachel London, Executive Director, Maryland Developmental Disabilities Council; Chair, DD Coalition: RLondon@md-council.org

The Arc Maryland
DRM Disability Rights Maryland
MACS Maryland Association of Community Services
Maryland Developmental Disabilities Council
CREATING CHANGE • IMPROVING LIVES
People On the Go Maryland

# SB583 Self Directed Services Manaul SUPPORT  final

Uploaded by: Rebecca Rienzi

Position: FWA

PFA PATHFINDERS FOR AUTISM

SENATE BILL 583 Developmental Disabilities Administration – Self–Directed Services Manual – Public Comment
POSITION: Favorable with Amendments
COMMITTEE: Senate Finance Committee
DATE: February 24, 2026

Pathfinders for Autism (PFA) is Maryland's largest autism organization dedicated to helping individuals, parents, and professionals find resources, support, and training while working to increase awareness of autism spectrum disorders. We accomplish this through a variety of programs and services with a focus on safety, community, and resources. We partner with many organizations to work collaboratively to serve not only the autism community, but the broader intellectual and developmental disabilities (IDD) community across the state.

SB583 represents an important and practical step toward restoring transparency and accountability in how policies are developed and implemented within Maryland's developmental disabilities service delivery system. Policies contained in the Self-Directed Services Manual influence access to services, participant autonomy, and the consistency of service delivery. Changes to definitions, requirements, or interpretations can have wide-reaching impacts on individuals and families who depend on stable and predictable rules.

For many years, the Maryland Developmental Disabilities Administration (DDA) followed an effective process when considering policy changes to Self-Directed Services. Draft policies were vetted with advocates and stakeholders prior to release and then opened for a 30-day public comment period to allow input from the broader community. This approach was collaborative and helped identify operational concerns before implementation, preventing unintended consequences and dysfunction within an otherwise efficient and effective service delivery model.

Recent updates to PolicyStat and other guidance sources have occurred with little or no transparency undermining trust and disrupting services. Changes of this significance must be balanced, transparent, and public; not quietly implemented. SB583 will assist in returning to a proven transparent framework.

PFA requests amendments to ensure the transparency and public comment requirements apply to all policy vehicles that govern services under the Developmental Disabilities Administration, including PolicyStat and any formal policy guidance used by the Administration that affects eligibility, access, definitions, service parameters, or implementation requirements. PFA also recommends amendments to require consistency, public participation before policies take effect and greater accountability for decisions that directly impact participants,

For these reasons, PFA respectfully urges the Committee to issue a Favorable report with Amendments to SB583.

Rebecca Rienzi, Executive Director, Pathfinders for Autism

# Written Testimony in Support of SB0583.pdf

Uploaded by: Robyn Michelle Shramek

Position: FWA

**Oral Testimony in Support of SB0583**

Good afternoon, Chair and members of the Committee.

My name is Michelle Shramek. I live in Forest Hill, Maryland, and my adult son, Matthew, depends on Self-Directed Services to live safely in his own home and community.

Senator Jennings, thank you for bringing forward SB0583. Your bill is needed, and I fully support its purpose. It recognizes something families have been experiencing for years — that major changes to Self-Directed Services should not happen without transparency and public input.

The way policy is repeatedly revised and communicated throughout the year — whether through multiple four-hundred-page manual revisions in a single calendar year or even through newsletters or emails that quietly “clarify” or “update” expectations – must stop. Every proposed change should be submitted for public input. For teams supporting participants, this peppering of “policy updates” as they are called creates constant instability.

Self-direction requires careful coordination between the participant, board certified behavior analysts, coordinators of community services, the support broker, fiscal management agencies, and direct support professionals. When rules are constantly shifting teams are left operating under a cloud of uncertainty. We are left wondering whether we are unknowingly out of compliance because we missed a buried update in an email sent or another revision of DDA’s manual without any formal notice. Uncertainty creates fear. It creates administrative chaos, and it makes it nearly impossible for teams to operate with confidence and consistency. Participants cannot meaningfully engage in a process that is fragmented at best and contradictory at worst.

As a trained educator, I am witnessing professionals struggle to track scattered updates across manuals, newsletters, and informal communications. Expecting families to function as compliance auditors just to keep their loved ones safe at home is unreasonable.

SB0583 is necessary. But to truly protect participants, it must require notice and public comment whenever DDA changes Self-Directed Services policy in any form — not only when the manual itself is amended.

Families deserve consistency. Teams deserve clarity and compliance should not feel like a moving target.

Thank you, Senator Jennings, for standing up for Marylanders with developmental disabilities. I respectfully ask that this bill be strengthened to ensure full transparency and accountability in all changes to Self-Directed Services.

Thank you, Michelle Shramek

**Bill 583.pdf**

Uploaded by: TRACIE Feron

Position: FWA

Dear Chair and Members of the Senate Finance Committee,

My name is Tracie Feron, and I am the mother of Connor, a young man on the autism spectrum who self-directs his services through the Developmental Disabilities Administration (DDA). I am writing in strong support of Senate Bill 583.

Self-direction is not a convenience for our family — it is a lifeline. It allows us to carefully recruit, train, and retain staff who understand Connor's communication style, sensory regulation needs, and behavioral supports. For individuals with significant support needs, consistency is directly tied to stability, health, and safety.

Last year the budget was almost fully restored to DDA. However, wage cuts and manual changes were still made by DDA. This had immediate and harmful consequences. As wages were reduced, we lost long-term, highly trained staff who had supported Connor for years. These were professionals who knew how to anticipate triggers, de-escalate behaviors, and maintain a safe environment. Their departure was not due to lack of commitment — it was due to unsustainable compensation.

As a direct result of losing experienced staff, Connor experienced an increase in behaviors. Disruptions in staffing do not simply cause inconvenience; they create instability that can jeopardize an individual's physical safety and emotional well-being. When unfamiliar or undertrained staff are placed in complex support roles, the risk of escalation increases. For medically and behaviorally vulnerable individuals, that risk is serious.

Since the wage cuts, we have struggled to recruit and retain qualified staff at the lower rates. The labor market does not support these wages, particularly for work that requires skill, patience, crisis management ability, and deep knowledge of disability supports. Chronic vacancies and turnover leave families scrambling to fill shifts, often working around the clock to prevent gaps in care. This is not sustainable.

Cuts to wages in self-direction are not abstract budget decisions — they have real-world consequences. They destabilize the workforce, undermine continuity of care, and place the health and safety of individuals with developmental disabilities at risk. When experienced staff leave and cannot be replaced, individuals lose critical safeguards that protect their well-being.

DDA often describes self-direction as a “partnership.” A true partnership prioritizes stability, transparency, and meaningful collaboration with families. Unilateral wage reductions and policy changes that weaken the workforce do not reflect partnership. They shift risk and burden onto families and, most concerning, onto the individuals who depend on these services for daily safety and support.

Senate Bill 583 is essential to restoring stability, protecting health and safety, and ensuring that self-direction remains a viable and responsible service model. Individuals with developmental disabilities deserve consistent, qualified support professionals. Families deserve a system that strengthens — not undermines — the very supports that keep their loved ones safe.

I respectfully urge a favorable report on Senate Bill 583.

Sincerely,
Tracie Feron