MOOM Unfavorable Written Testimony.pdf

Uploaded by: Beth Gude

Position: FWA

Testimony to
MOOM Senate Health and Human Services Subcommittee- Budget and Taxation Committee
Department of Health- Developmental Disabilities Administration
UNFAVORABLE
February 20, 2025

Submitted by
Beth Gude

I am writing today on behalf of my daughter, Caroline Munro, who lives in an apartment in Rockville with the assistance of a Housing Choice Voucher. Caroline is 31 years old; she self-directs her DDA services with the assistance of a team identified during her annual budget and plan development process. Caroline 's primary disability is spastic quadriplegia cerebral palsy; her disability impacts, mobility, communication, cognition, and vision. She was included in general education during her school years, loves people, being active in her community and having a small business selling crafts at community fairs and festivals.

Caroline has a great life! She loves having her own apartment and, using her communication device, she can be heard expressing "I'm the boss"! Her staff, well-trained in "Caroline", have been supporting her for as much as 5 or 10 years. I, her mom, provide both paid and unpaid supports. **Caroline is budgeted for 7 staff – but currently she is short 3 staff. With the proposed budget cuts, and policy changes effected November 2024, we do not dare to hire this needed staff as it is impossible to know the full impact of the proposed budget cuts on her individual budget.** Currently, I am filling in all the gaps - at 75 years old, this is not sustainable, but I fear it may have to be if the budget cuts are approved. I guess we are saving DDA a lot of money right now.

Should these budget cuts be approved, Caroline's future is very uncertain. Her siblings live out of state (Florida and New York). She does not have other family able to take on my role. The 2022 SD Act put in place the option of hiring a **Day-to-Day Administrator.** This fall, prior to the release of the new DDA policies, I had identified an individual uniquely qualified to take on many of the tasks I either complete or assist Caroline with. This was a real solution to the ever-present question – what happens when I am gone? That option, with the proposed **IFDGS** cap of $5000.00 seems like nothing more than wishful thinking. Caroline has not previously been accepted by community providers due to her complex support needs – cuts in funding that will impact providers will certainly make that an even less viable option. Are we left with a State Residential Center? Maybe so.

The most disturbing thing in all of this is the absolute mayhem at MDH/DDA. First there was the transition to EVV, LTSS and new Fiscal Management Services which has resulted in payroll issues, vendor payment issues and completely dysfunctional accounting/budget reports making it impossible to track spending. Then significant policy changes were made in November impacting many processes, including hiring. Then the proposed budget cuts with potentially devastating impacts. In the meantime, DDA is denying any request – requests previously approved through the annual plan. This is not a system I feel my daughter can rely on to consistently support her when I am no longer able. If all this can happen now, with no action, it can happen anytime. What then?

Removal of the **Geographic Differential for Rates**, re-setting of **Reasonable and Customary Wages**, along with many DDA policy changes will mean that Caroline will lose current staff and potentially have difficulty hiring replacements. In the past, Caroline has been able to attract staff that have not previously considered direct care work, in part due to an attractive living wage. She is not able to offer a traditional benefit package so the higher wages help to compensate for a lack of benefits.

The proposed budget cuts will be catastrophic for Caroline and thousands of others whether they self-direct or rely on community providers. There is also the ripple effect on caregivers, supporters, agency staff, nurses, support brokers, etc. – how can this be a good choice for Maryland's economy?

OUR ASKS

1. Restore the DDA Budget without the proposed cuts.
2. Complete a Legislative Audit for compliance with the 2022 SD Act.
3. Rescind the November 2024 DDA policy changes and support **HB 1244 Maryland Developmental Disabilities Administration Waiver Advisory Council – Establishment** enabling all stakeholders a true voice in policy decisions.

Beth Gude
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Written Testimony for HB0352 BRFA.pdf

Uploaded by: David Noppenberger

Position: FWA

Written Testimony for HB0352 BRFA

My name is Dave Noppenberger. I am writing as the parent of two special needs children who receive DDA waiver services. We are asking that you remove the language which would cap Individual and Family-Directed Goods and Services (IFDGS) for self-directed participants at an arbitrary $5000 per year.

IFDGS provide true enrichment to my children's lives, funding:

- Adaptive horseback riding which promotes core strength (my daughter has cerebral palsy), balance, and bilateral coordination
- Membership to the League for People with Disabilities which has a workout facility and a heated pool/hot tub. These are invaluable to helping my children burn energy and reduce behaviors
- Adaptive bowling membership which promotes socialization and integration into the community
- Nutritional supplements which help promote health
- Dental items like retainers, electric toothbrushes etc. which help with health and hygiene

These items are critical to my children's lives, and capping the benefit at $5000 would force them to make difficult choices (for instance the horseback riding alone costs $4800 a year, which means all other IFDGS items would have to be eliminated).

In addition, the critical service of Day to Day Administrator is funded through IFDGS. This position was created to provide a "house manager" for self-directed individuals (similar to someone who might run a group home in a traditional setting). The Day to Day Admin has been very helpful already to my children, and will become essential as they age, and we become less able to manage their households for them. If Day to Day Admin needs to fall within the $5000 cap it will become impossible to staff, since $5000 comes out to less than $100 a week (hardly enough to get someone in a for a few hours a week).

DDA's cap of $5000 is arbitrary and spiteful. It removes choice for what is supposed to be a person-centered process. The IFDGS funding comes from cost-savings, and does not allow the participant to spend more than their total DDA-approved budget. DDA will tell you it is an unfunded mandate, but this is patently false – DDA themselves approve the IFDGS budget, and also painstakingly audit each IFDGS purchase to make sure it falls within the waiver guidelines. So there are many checks and balances in the system to ensure the spending is appropriate and reimbursed correctly.

Please remove this arbitrary and mean-spirited cap of $5000 on IFDGS items for self-directed participants in the BRFA!

K Bowers Save IFDGS HB0352.pdf

Uploaded by: Karen Bowers
Position: FWA

House Appropriations
HB0352 BRFA Bill Hearing
Health DDA
Karen Bowers LCSW-C
Friday February 28, 2025

Good afternoon, thank you for allowing me to share my concerns. My name is Karen Bowers. I live in Hagerstown Md. My daughter Jennifer is 34 and has been self-directing for the past 12 years.

I am afraid for my daughter's future as a self-directed participant.
The proposed cap for Individual and Family Directed Goods and Services of $5,000 will impact Jennifer's current supports which are being provided in this service.

Jennifer's Behavior Plan calls for multiple community interventions to address her aggression, anxiety and communication issues. IFDGS allows us to provide these interventions, and they are making a difference. Without these interventions Jennifer's ability to participate in her community will be negatively impacted. The cap would prevent Jennifer from receiving services in her plan and recommended by the Behavior Support Team.

Even more important is to remember IFDGS also provides for hiring a Day-to-Day Administrator which we have done. The $5,000 cap will absolutely wipe out this important employee role. This service has been a godsend for older parents like me by offering a path toward sustainable self-direction for Jennifer after I am gone. Without this support Jennifer will be unable to live in her own home with the support she needs to access the community. **She will become a nursing home candidate.**

What does the Day-to-Day Administrative Employee do on our team?
This individual person manages Jens' 7 employees by doing scheduling, tracking benefits, monitoring employee skills, coordination of education and training for our employees who are CMT certified, household management, scheduling with vendors, and other medical providers.

The Self Direction Act of 2022 does not impose a cap on funds which can be used other than the actual budget amount as determined by the DDA. In addition, the law provides for the addition of the Day-to-Day Administrator to support sustainability of the Self Direction Model after parents are unable to fill this role. **The Self Direction Manual issued in October 2024 should be abandoned. All Self Direction policies should adhere to those in the Self Direction Act of 2022.**

I'm asking for the $5,000 cap in IFDGS to be removed in BRFA HB0352 so Jennifer can continue to receive the services and supports she depends on to participate in her community.

I am also asking the DDA to consider amending the waiver to add Day-to-Day Administrator as a regular Waiver service and remove it from IFDGS so it can be a permanent option in the Waiver to protect access to Self-Direction for years to come.

Thank you.

Karen Bowers /Jennifer Bowers
20242 Huntington Ct.
Hagerstown, MD 21742

MDAC - 2025 - BRFA - HB352 - FWA.pdf

Uploaded by: Liz Zogby

Position: FWA

T21 MDAC

MARYLAND DOWN SYNDROME
ADVOCACY COALITION

HB 352 Budget Reconciliation and Financing Act of 2025

House Appropriations Committee and House Ways & Means Committee
February 27, 2025
Position: Favorable with Amendments

The Maryland Down Syndrome Advocacy Coalition (MDAC) provides this testimony regarding several provisions of this year's Budget Reconciliation and Financing Act that impact services and programs for individuals with disabilities, specifically programs at the Developmental Disabilities Administration (DDA) and behavioral health supports in public schools. MDAC is a coalition of the five Down syndrome organizations in Maryland as well as individuals with Down syndrome and their family members who have come together to advocate for improved quality of life for all individuals with Down syndrome throughout the state of Maryland.

First, with respect to DDA services, MDAC is deeply concerned by the proposals to eliminate the Low-Intensity Support Services program (LISS) and to limit Individual- and Family-Directed Goods and Services (IFDGS) in self-directed Medicaid waiver programs. As with the draconian "cost containment" measures in the larger DDA budget proposal, the weight of these cuts will fall on families, who will attempt to fill the breach left by our state in retreat from the promises made to disabled Marylanders and their families.

The LISS Program, which provides $2000 grants to families selected by lottery who are not otherwise served by the DDA, allows families to stay out of crisis. LISS is literally a lifeline for families. Some important context about the need for this program to consider:

- Many families with minor children with Down syndrome are not yet receiving any services from DDA despite having kids with lifelong disabilities; many do not qualify for Medicaid.
- Families with children with Down syndrome face significant expenses for therapy, medical needs, adaptive equipment, child care—that can greatly exceed what families without disabled children in their communities face.
- When our children with Down syndrome are young, our families often need flexibility at work or, when possible, one parent may stop working or move to part-time employment, because of the intensive therapy, medical needs, and the very real challenges of finding (and keeping) child care for disabled kids.

MDAC collected stories from our Maryland Down syndrome community about the ways families have used LISS funding and its impact. Our families report using LISS funds for respite services, reimbursement of medical co-pays, adaptive equipment, assistive technology to support communication, promoting safety and well-being of children (e.g., fence construction, door alarms, swim lessons), and encouraging community integration and skill development (e.g., summer camp).

Here are a few excerpts from the stories collected from MDAC families:

- "LISS funds allowed us to train and hire a consistent person to care for our son so we could take a break from caregiving ... Caregiving is exhausting both mentally and physically ... Families often have to cut back hours or quit work altogether to care for their child. Out of pocket expenses are higher than that of families raising typically developing children ... While this funding is not guaranteed**, it is funding, that when received, feels like the weight of $2,000 worth of pennies is suddenly lifted from our shoulders**."

- "There are limited camps in this area that are exclusively adapted for kids with disabilities. My son thrives at Camp A ... but it is **more expensive than a traditional camp due to the need for increased staffing ratios to meet the needs of all campers**. **While we tried traditional camps, they were unable to meet the needs of my son** ... LISS makes being able to work and ensure our son is in a safe, structured environment during the summer break possible."

- "We rely on LISS funding to help us offset the cost of my daughter's therapies, particularly during the summer, when we lose access to school-based PT, OT, and speech. **It is also very difficult to find care for children over 3 who are not fully independent with toileting—most summer programs are fully closed to us** ... Losing access to this funding will directly affect my daughter's ability to stay on track with her peer group. It will also affect my family's ability to continue working full time during summers."

We also heard from families who have used LISS funds for needs as diverse as:

- a scoliosis brace
- glasses
- orthotics
- AAC device apps for communication
- incontinence supplies
- tutoring
- respite care
- speech therapy
- adaptive car seat
- home security cameras for safety
- swim lessons
- medical co-pays
- medical supplies
- backyard fence to support safe play
- home security system to prevent elopement

Second, with respect to IFDGS, the proposal to allow DDA to set a limit is antithetical to rate parity—the dollar amount per hour for personal support services is equal in both provider-based and self-directed services. The limit for every individual is their budget, which is based on a Person-Centered Plan, approved by DDA, and may include only expenses authorized by the Centers for Medicare and Medicaid Services (CMS). IFDGS allow a person to exercise control over the design of their life and build meaningful activities into their lives as defined by their Person-Centered Plan.

The Self-Direction Act of 2022, unanimously approved by the Maryland General Assembly, allowed for IFDGS to include "Day-to-Day Administrative Services." The intent was to acknowledge the hours of indirect services required to provide the "glue" for managing the administrative/life details for someone self-directing their services. While unpaid family members may have played this role for some in the past, this is inequitable; and those with aging parents or without close family need to be able to pay someone for these services. Without this provision, many will be unable to self-direct their services—and their lives. The 2024 Joint Chairman's *Report on Self-Directed Services* *and IFDGS Spending* acknowledges that "expansion of IFDGS is not the most significant fiscal impact," yet the DDA proposes to limit it anyway. At this point, many participants report that IFDGS are being routinely denied by DDA; they have little confidence that with a cap in place, DDA will actually allow participants to access money allocated to individuals in approved budgets. The breakdown of communication and trust appears to be at the heart of this issue, not inappropriate expenditures within the IFDGS line.

Finally, MDAC is concerned about the proposed 70% cut to funding for behavioral health services through the Consortium of Coordinated Community Supports—from $110 million to $40 million in FY25 and from $130 million to $40 in FY26 and every year thereafter. From March to October 2024, more than 58,000 Maryland students were provided with behavioral health services in more than 80% of Maryland schools through this fund. Unaddressed behavioral health concerns have severe negative impacts on students, leading to poor student achievement, attendance problems, and exclusionary discipline (e.g., suspension). For students with disabilities these concerns are even more pronounced. Finally, access to behavioral health supports can be extremely difficult for students and families. Slashing this essential program provided for by the Blueprint for Maryland's Future appears short-sighted and, given the availability of Blueprint Funds for FY26 and FY27, unnecessary at this time.

MDAC urges the following changes to the BRFA of 2025:

- Strike lines 6-19 on page 22 which substantially cut the funding for Coordinated Community Supports [Article–Education, 7–447.1]
- Strike lines 7-20 on page 45 which would allow DDA the set a limit on IFDGS [Article–Health–General, 7–409]
- Strike lines 25-26 on page 128 which would eliminate the LISS program [Article–Health–General, 7–717]

Thank you for considering these concerns and suggested amendments.

Respectfully submitted,

Liz Zogby
Maryland Down Syndrome Advocacy Coalition
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443-691-1755

HB352.BRFA.SWA.pdf

Uploaded by: Rachel London

Position: FWA

Maryland Developmental Disabilities Council
CREATING CHANGE • IMPROVING LIVES

DRM Disability Rights Maryland

House Appropriations Committee
February 27, 2025
HB 352: Budget Reconciliation and Financing Act of 2025
Position: Oppose elimination of LISS program; Support change in nonpublic special education funding formula; Support the change to the Waiting List Equity Fund

The Maryland Developmental Disabilities Council creates change to make it possible for people with developmental disabilities to live the lives they want with the support they need. Disability Rights Maryland (DRM) is federally mandated to advance the civil rights of people with disabilities.

Low Intensity Support Services program

The BRFA, in Section 8 on page 128, proposes to eliminate Health General §7-717 which established the Low Intensity Support Services (LISS) program. **The Council and DRM oppose the elimination of the LISS program.**

➔ WHAT is LISS?

According to the Developmental Disabilities (DDA) website, the LISS program serves children living at home with their family and adults living in their own home in the community who are not receiving any services from the DDA. It provides up to $2,000 to help children and adults with developmental disabilities to purchase eligible services or items to address their needs, enhance or improve their quality of life, and promote independence and community integration.

➔ WHY is LISS critical?

LISS serves between 2,000 and 2,500 children and adults with developmental disabilities a year. Recipients can only access funds if they do not receive other Medicaid waiver services. LISS is the only DDA service these Marylanders receive. It helps with purchases like respite, home modifications, adaptive equipment, and summer camps.

We understand that the leaders in the budget committees in the General Assembly have worked with Governor Moore to remove this language from the BRFA, and appreciate the acknowledgement that the statute only requires LISS services to be delivered *IF FUNDS ARE AVAILABLE.*

Waiting List Equity Fund

The BRFA, on page 45 eliminates a section of Health-General §7-205(e)(2) to increase the way the Waiting List Equity Fund (WLEF) can be used to provide services. **The Council and DRM support this change to offset some of the proposed budget cuts to DDA's FY 2025 budget.**

Nonpublic Special Education funding formula

The BRFA on pages 23-24 changes the nonpublic special education schools formula set in Education §8-415 from the 70%-30% ratio to a 60%-40% ration in FY 2026 and a 50%-50% ratio in FY 2027 after the local school systems the initial 200% **The Council and DRM support a change in the**

funding formula because it decreases the incentive for local school systems to send students with disabilities to nonpublic special education schools.

- **WHY should the funding formula change?**

Maryland is one of the most segregated states in the nation for students with disabilities. According to 2022-2023 data among the 50 states and DC, Maryland has the ***6th highest rate of placing students with disabilities in separate (public and nonpublic) schools.***[i]

> 5.92% (6,081) of students with disabilities in Maryland are educated in separate schools. The total cost is 14% of the entire special education budget.

It is cost-effective. Data show that the total per pupil spending tends to be *higher* for students educated in more restrictive environments. As compared to regular class: 13.8% higher for a resource placement, 33.3% higher for special class placements, 111.1 percent higher for special school placements.[ii]

> Based on 2022-2023 expenditures, Maryland spends $48,398 per student with a disability in nonpublic schools compared to $21,494 per student with a disability in public schools.[iii]

Research shows that students with and without disabilities experience positive outcomes when all students learn together.[iv] The research identified these benefits for all students with disabilities, including who are most frequently placed in more restrictive educational environments (e.g., students with the most significant cognitive disabilities[v] with emotional disability/conduct disorders[vi]).

Contact: Rachel London, Executive Director; RLondon@md-council.org

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[i] US Department of Education, EDFacts Fata Warehouse: “IDEA Part B Child Count and Educational Environments Collection,” 2022-23.

[ii] Chambers, Perez, and Socias (May 2004).

[iii] Selected Financial Data Maryland Public Schools SY2021-2022, Part 2 Expenditures. Table 5A Expenditures for Special Education: Maryland Public Schools, 2021-2022.

[iv] Cole, S.M., Murphy, H.R., Frisby, M.B., & Robinson, J. (2022). The relationship between special education placement and high school outcomes. The Journal of Special Education.

[v] Kleinart, H. Towles-Reeves, E., Quenemon, R., Thurlow, M., Fluegge, L., Weseman, L, & Kerbel, A. (2015).
Where students with the most significant cognitive disabilities are taught: Implications for general curriculum access. Exceptional Children, 81, 3, pp. 312-28. Kleinart, H., & Kearns, J. (2022). Reconsidering LRE: Students with the most significant cognitive disabilities and the persistence of separate schools. TIES Center.

[vi] Powers CJ, Bierman KL, Coffman DL. Restrictive educational placements increase adolescent risks for
students with early-starting conduct

HB352.BRFA.SWA.pdf

Uploaded by: Rachel London

Position: FWA

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[vi] Powers CJ, Bierman KL, Coffman DL. Restrictive educational placements increase adolescent risks for students with early-starting conduct

Committee Testimony 02252025.pdf

Uploaded by: David Milobsky

Position: UNF

I ask that you require the DDA to abandon its November 2024 policy changes to Self-Directed Services (SDS) and adhere to the policies established in the Self-Direction Act of 2022.

Unless the DDA is required to adhere to the policies established by the Self-Direction Act of 2022, developmentally disabled individuals who utilize SDS will not have equitable access to DDA funds. Their personal support staff wages will be cut (putting them in danger of losing staff), and their IFDGS (Individual and Family Directed Goods & Services) budgets will be capped at $5000, making it impossible for them to pay for the important position of Day to Day Administrator (which is oddly categorized under IFDGS).

The position of Day to Day Administrator is an essential staff position for individuals who utilize Self-Directed Services, as many parents are aging out of our ability to perform the vast array of administrative functions we've always performed for our children. In order to make Self-Direction sustainable for individuals and families, the position of Day to Day Administrator is key.

We are asking that you:

- Require the DDA to abandon its Nov 2024 policy changes to Self-Directed Services (as these do not align with the Self-Direction Act of 2022) and adhere to the policies established by the Self-Direction Act of 2022.
- Work with SDS participants and families to develop any new reforms.
- Protect DDA funding in the upcoming Maryland FY26 budget, ensuring the continuation of the successful Self-Directed Services model.

Jeneva Stone_HB0352 testimony_MGA2025.pdf

Uploaded by: Jeneva Stone

Position: UNF

SB0362: BRFA re: Health - DDA, 2/27/25
Jeneva Stone, Parent Caregiver
UNFAVORABLE

I'm Jeneva Stone. My son Rob and I testified in favor of the Self-Directed Services Act of 2022, which helped level the playing field between those in self-direction and traditional providers. Lifting the $5K cap on Individual Family Goods and Services has been key to Rob's amazing life: he can pay for the classes and other activities that are written into his person-centered plan. He can also pay for a day to day administrator—managing Rob's care takes, on average, 20 hours per week of my time.

Please keep in mind that **children and adults with disabilities and complex medical needs—like Rob—are a group that state policy consistently underserves from birth through adulthood**. Our families face intense pressure to place our loved ones in facilities or other institutional settings, which are far more expensive—and far less safe—than community services. And, as many of you know, Rob cannot enroll with any of the traditional providers because the DDA intentionally wrote the waiver programs to exclude him and others.

Community inclusion is a civil right for disabled people, and I've stood up for Rob's rights. As a result, I have lost income, friends, my career, and much more because the patchwork nature of Maryland's support for people like Rob means that my husband and I are always filling in—often gratuitously—for gaps in care the state declines to fill.

We understand that the legislature faces difficult budgetary decisions, especially given uncertainties at the federal level with Medicaid funding. **But please keep in mind that disabled Marylanders with complex needs and their families—whether these are medical, behavioral, or communication-related—have faced excruciating financial pressure for decades already**. During the pandemic, many of us became dependent on income from family-as-staff due to our need to protect a loved one who was especially vulnerable to Covid.

If you must cap IFDGS, I respectfully request that you consider the following two issues:

1. **The original $5K annual cap left our family to cover roughly $7,000 of expenses** written into Rob's person-centered plan. Rob's SSI for the year is roughly $7,500, which leaves him nothing for clothes, entertainment, gas, and other expenses.

2. **Establish the Day to Day Administrator as a budget line item separate from IFDGS**. Our CCS and REM coordinator can manage only a fraction of Rob's care needs*—and there's no one to coordinate the two programs at all.

Thank you for listening to us.

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*List of administrative duties I perform for Rob as a Day to Day Administrator:

- schedule medical appointments
- communicate with physicians (10), nurses, staff, medical supply companies (2), the DDA, the MDH, and more
- gather paperwork for DME and other services that require documentation
- manage 10+ prescription drugs & medical supplements
- comply with DDA requirements
- attend medical appointments as the repository of Rob’s medical history
- comply with paperwork for the home nursing agency
- repair/adjust Rob’s wheelchair and/or work with DME vendor to do so
- order medical supplies from two vendors
- organize medical supplies (about 45 different items)
- provide guidance to staff
- update medical care sheets
- keep a log of changes to care protocols
- answer Rob’s email
- respond to a plethora of email from 5 or 6 different agencies
- order other OTC supplies
- assist with organizing Rob’s room and medical equipment
- troubleshoot a variety of problems with staff, equipment, physicians, etc.
- program Rob’s communicator
- work with Seating Clinic and Assistive Technology per Rob’s needs
- manage Rob’s schedule & calendar
- and much more!

Written Testimony Senate Hearing 2_20_25 - Google

Uploaded by: Jessica Gallatin
Position: UNF

Senate Briefing 2/20/25

DDA Budget Briefing- Testimony Jessica Gallatin

Overview

- **SDS as a Last Resort:** For families like mine, SDS is not a choice but a necessity due to the lack of other available resources. There are no other options available for some families as most facilities are already at capacity.
- **Impact of Budget Cuts:** The proposed budget cuts threaten the lives of self-directing participants like my sister, Jennifer, who relies on this program for essential care. SDS provides the only alternative to institutional/facility care and for the medically complex and severely impaired individuals could reasonably be considered a death sentence.
- **Systemic Issues:** The healthcare industry faces staffing shortages, high vacancy rates, and inadequate services. The COVID-19 pandemic further exposed these weaknesses. Although cost effective methods (SDS) have been sought and proven, it is threatening the sustainability of community providers that have monopolized this population. Because of this, there is an undescribed effort to create barriers to the Self Directing Model of care. There is, what feels like, an attack and concentrated focus and annoyance with family members.
- **Lack of Transparency:** Programs and administration are not transparent. DDA refuses to

comment to the legislators on their lack of communication with SDS stakeholders, lack of oversight with their FMCS contracted providers(distinctly specific to SDS billing), lack of SDS data inclusion in any rate setting data collection, and lack of adequate training on the SDS model to CCS agencies leading to costly errors and mistakes.

- **Harm from Cost Containment:** Current cost containment actions have already harmed and jeopardized the safety of participants. There have been widespread denials and reductions for services already rigorously and clinically proven to be necessary with little to no correspondence or rationale.
- **Issues with DDA:** The Developmental Disabilities Administration (DDA) has denied my sister's entire plan and services, leading to an appeals process. The vast reach and tone of DDA has shifted. Participants, particularly the most complex, have been treated and spoken to like a nuisance to the state. The DDA directors and administrators, privately and publicly, have threatened many families and individuals. This behavior has been massively inappropriate and yet easily overlooked in the current state of affairs.
- **System Overwhelm:** Backlogs in hearings, intakes, and increased complaints indicate a system in crisis. The increase in reductions and denials of services has overwhelmed the legal advocates and Office of Administrative Hearings (OAH) leading to serious processing delays and vulnerable participants at risk of serious harm.
- **Fear of Retribution:** Many are afraid to speak out due to fear of retribution. *Days after my sister and I were interviewed by a news reporter in November, her entire plan and all services were denied.* In public formats DDA administrators inappropriately ask for detailed information and the names of each participant raising specific concerns, particularly concerns that question the integrity of programs and administration.
- **Accountability and Oversight:** There's a need for accountability in contracts for targeted case management and Financial Management Consulting Services (FMCS) providers. The poorly managed contracts have led to complete loss of trust in the integrity of all billing practices deterring many and much needed providers (example- delegating nurses).
- **Need for Thoughtful Solutions:** Rushed and careless approaches to budget cuts are harmful. Decisions should be made with careful consideration and empathy. Participant health and safety should be prioritized. Stakeholder input should be and could be immensely helpful! Only recently has DDA attempted to engage with stakeholders and efforts have been minimal at best. Questions and concerns are always screened and most public communication is scripted and rarely relevant to participant concerns.
- **Personal Impact:** I have never been so overwhelmed and outraged by the lack of competency or sophistication of an administration in my life. I have dedicated more effort in advocating and caregiving to my sister, whom I am not in any way legally responsible for, than all 3 of my kids combined. I try my best to shield my sister from any real impact caused by this chaos but the struggle has been significant! The physical and emotional strain has caused massive stress to my parenting, functioning, and sanity. This has impacted all of my children, causing them to sacrifice many important things (sports, activities, attention, help with homework, family dinners, etc.) The financial strain is by far the most significant impact and has left me depleted of any savings or safety net I spent years trying to acquire.

Key findings

A. Staffing shortages: The healthcare industry as a whole is experiencing a lack of available staff.

B. High vacancy rates: There are many unfilled positions within the system; at the state level and at the program level. Recruitment efforts in both models prove challenging

C. Inadequate services: The existing services are not meeting the needs of the population they serve. Service design has been effective but only when quantity of hours and acuity levels are being met and approved. Service reductions are detrimental to the vitality of the service

D. Lack of transparency: The programs and their administration are not open or clear in their dealings. Intentional silence from DDA regarding issues raised by SDS participants is causing more harm than the issues themselves, leaving many families frustrated with no options.

E. Issues with DDA: The Developmental Disabilities Administration (DDA) has issues, as evidenced by their denial of services and the resulting appeals process. Blatant withholding of critical information that could lead to the formulation of viable solutions has caused widespread distrust threatening the integrity of the administration, the Department of Health, and state government as a whole.

F. System overwhelm: The system is overloaded, leading to backlogs in hearings and intakes, as well as an increase in complaints.

G. Lack of accountability and oversight: There is insufficient accountability in contracts for targeted case management and Financial Management Consulting Services (FMCS) providers. There is little to no apparent oversight on the Administration to adhere to state law, federal regulations, CMS policies and procedures, and governing statutes.

Solutions

A. Thoughtful and Empathetic Decision-Making: Decisions should be made with careful consideration and empathy, rather than rushed or careless approaches to budget cuts. This suggests a solution of improved decision-making processes within the administration.

B. Transparency and Accountability: Transparency in programs and administration and accountability in contracts for Targeted Case Management (CCS providers) and Financial Management and Counseling Services (FMCS) providers. Proper oversight would resolve many budgetary discrepancies at individual participant program levels and wholly provide more reliable information for the SDS model.

C. Adequate Funding for SDS: Self Directed Services Model DOES provide current and future opportunities for cost reductions to the state. The DDA and the Dept. of Health have made policy decisions to shift from a prospective payment system to a fee-for-services system. The fee-for-service system can be projected to be more costly but provides better outcomes and quality of care for participants accessing services. It also provides for greater transparency and accountability in billing practices compared to a prospective payment system. As traditional community providers become accustomed to this transition, costs can be predicted to rise exponentially as all services are now viewed and approved on an individually needed basis. Traditional providers have slowly but fully transitioned to this new system with many struggling with how to redesign billing practices and continue to generate and justify the same revenue streams. As traditional providers become accustomed to fee-for-service billing practices, costs can be predicted to rise year over year. Comparatively to SDS, traditional community providers bill at the fully loaded rates.

D. Address Staffing Shortages: Easier said than done, however, considerations for retention efforts in this sector are not unique. Like any other area, recruitment and retention efforts are done with careful consideration to wage and benefit incentives. SDS model provides for the flexibility to provide wage incentives that have proven to provide higher retention. Comparatively, traditional community providers have the ability to provide greater benefits packages should they choose to make those investments. The state funded positions for comparable service staff have even greater all around employment packages with respectable wages and robust benefits packages. **Careful consideration should always be given to adjustments in state minimum wage and Cost of Living Adjustments. Most health occupations but particularly direct care roles in home and community based settings are directly competing with workforces that can be easily swayed to traditionally minimum wage workforces like retail, or food and beverage. Additionally, careful consideration should be given to various other trends and more specifically federal mandates for healthcare workers and settings, so as not to create vast discrepancies in pay across similar sectors or lengthy gaps in meeting standards. Lastly, careful consideration should be given to policy decisions regarding the use of CPI vs. medical CPI when adjusting the rate system.

E. Improvements within DDA: Shifts in attitude and tone could go a long way. Transparency and accountability at the administrative level is needed. Focus on contract integrity is needed. Swift and adequate software functioning is needed. LTSS software systems need to be reviewed consistently and robustly to avoid systemic delays and processing. Communication should be consistent, open, non aggressive, considerate, and helpful!

** In the interest of my sister's privacy, we chose to provide a detailed perspective of information we thought was important to share with you. She and I are happy to discuss details regarding her disability, medical issues, limitations, and personal experiences in greater depth, privately anytime. Please reach out to us with any questions or concerns!**

We truly appreciate your time and effort!

Thank You!

Jessica and Jennifer Gallatin

HB0352_Karl_Soper.pdf

Uploaded by: Karl Soper
Position: UNF

Dear Delegates:

My sister and brother-in-law have worked for years to take care of my niece Jennifer, who has developmental disabilities and can never care for herself.

At the ages of 69 and 74, they have a fairly smooth running Self-Direction program under the guidance and with the financial support of MDH's Developmental Disabilities Administration.

They are getting to the point where they never know how much longer they can care for Jennifer. But the Self-Direction program alleviated that worry.

Now, apparently due to Maryland's fiscal straits, Self-Direction has come under attack and could fall victim to indiscriminate cuts.

Self-Direction is not a large item in Maryland's 2026 budget. There are surely less critical expenditures than this.

Audits of Self-Direction have proven it to be highly cost effective when compared to Traditional services. It also provides better outcomes for citizens like Jennifer. And greater peace of mind for parents like my sister and brother-in-law.

Much of the attack on Self-Direction has come in the form of calls to cut wages severely.

I say fairly paid staff is what makes Self-Direction effective. Reasonable pay makes staff want to stay and dedicate themselves to helping care for Jennifer. And it makes for good jobs in our state, in our counties.

No reductions in pay should be implemented before an impact study is conducted.

MDH and DDA should fully implement the Self-Direction Act of 2022.

Recently, advocates, participants, and families have been shut out of the process. They deserve a seat at the table.

I ask you to vote against anything that threatens Self-Direction and tries to solve our state's budget woes by sacrificing the care of citizens unable to care for themselves.

Sincerely,

Karl Soper
1110 High Meadow Court
Mount Airy, MD 21771
301-802-3513

Gabler Family Testimony HB0352 Budget Reconciliat

Uploaded by: Martha Gabler

Position: UNF

TESTIMONY

HB0352 Budget & Reconciliation Act of 2025 (BRFA)
Gabler Family Position, February 25, 2025
UNFAVORABLE

PLEASE SAVE IFDGS

(Individual and Family Directed Goods and Services)

Our names are Eric and Martha Gabler. We are the parents and Legal Guardians of Douglas Gabler, a profoundly nonverbal 28-year-old man with severe autism. Douglas has participated in Self-Directed Services under the DDA Community Pathways Waiver since 2017. He is lucky to have a skilled and caring staff person to maintain his health and well-being. With the help of this excellent Direct Support Professional, he participates joyfully in a Community Development volunteer work activity at the Cura Personalis Project, located at the Wheaton Park Stables in Wheaton, MD. This activity is the keystone activity of his life, occupying the greater part of his daily routine out of the house. His invoice for participation in the Cura Personalis Project has been approved by the DDA in his Person-Centered Plan and annual budgets since 2017 and, until recently, has been covered under the Community Development budget category. The current invoice is $1,000 per month for an annual total of $12,000.

Last year, for reasons that were never explained (there was no written notification), the monthly invoice for Douglas's participation in the Cura Personalis Project was transferred from the Community Development budget category to IFDGS. We are concerned and confused about the proposed IFDGS changes, especially the proposed $5,000 spending cap. We were told originally that there would be no problem with paying the Cura Personalis Project invoice from the IFDGS budget category. However, the current discussion about capping IFDGS spending at $5,000 will not cover the annual charge at Cura Personalis. We don't understand why this change was made. Can the invoice be transferred back to the Community Development spending category, where it legitimately belongs?

We are grateful that the funding was restored to the DDA Budget for FY25 and respectfully urge you to fully fund the DDA Budget for FY26. Please also take action to ensure that Douglas can continue to be fully funded for the activity that is the highlight of his life.

Thank you for this opportunity to submit written testimony.

Eric and Martha Gabler (District 20)
10125 Markham St.
Silver Spring, MD 20901
Home: 301-681-2716
Cell: 301-641-1943
Email: martha.gabler@gmail.com

Bill 925991 Save IFDGS revised.pdf

Uploaded by: MARY GRELLI

Position: UNF

My name is Mary Grelli, and I OPPOSE bill **925991**

I have been involved in the disability community since my son, Francis was born and was diagnosed with multiple developmental disabilities. He went to the MD School for the blind and upon receiving his graduation certificate, started his journey in the adult services world.

Francis was enrolled in the traditional service model waiver in 2012 and for one year attended the United Cerebral Palsy Day Center program. Our family quickly realized ***the inadequacies*** of the program, especially when it came to the health and safety of someone vulnerable like Francis due to multiple disabilities including quadriplegia. We had heard about DDA Community Pathways Self-Direction Waiver and found that this program was the best fit for Francis.

Under self-direction, Francis thrived. His Direct Support Professionals (DSPs) were dedicated staff who attended to his daily health and welfare. He was able to enjoy a tailor-made plan that addressed his specific needs. Over the span of nine years Francis was able to obtain funding from DDA's self-direction, **IFDGS** budget line item to install a lift in his van so that he could attend community activities like music therapy (also funded under **IFDGS**) physical therapy, and special needs bingo at a local church. He enjoyed swimming activities with the help of his DSPs. He took walks outside and staff helped him access adaptive devices (funded under self-direction's **IFDGS**) for his computer and other equipment. **IFDGS** also funded a walkway in Francis' yard so that he could access his wheelchair swing.

At this point in time the **IFDGS** budget line-item is being threatened by a severe **cap** and the need for ***excessive documentation.***

I am asking that the DDA Self-Directed IFDGS budget line-item will not bear any additional restrictions or cuts for this greatly needed service.

I need to add that Francis passed away 3 years ago and is no longer benefiting from these programs. But Francis' memory lives on because he has instilled in his family the commitment to continue to advocate for these vulnerable individuals.

Written Testimony HB0352 (2).pdf

Uploaded by: Christine Ader-Soto

Position: INFO

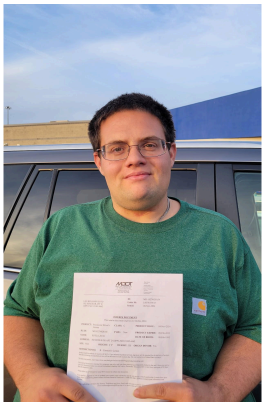
HB0352 Budget Reconciliation and Financing Act of 2025 (BRFA)
Hearing: Thursday, February 27, 2025 - 1:05 PM
Written Testimony provided by: Christine Ader Soto (mother of Leo Soto)

Leo is an amazing young man who continues to challenge the perceptions of those diagnosed with autism. Misdiagnosis and treatment 32 years ago led to one physician saying that Lee would need to live in a group home. Lee graduated from Kennedy Krieger, where for 13 years he received the services and support that helped him thrive and develop some amazing skills. After graduating Lee participated in the ARC program for a brief period where he was assigned to work at a large warehouse with a peer group. They were required to wear a common tee-shirt that identified their affiliation with the ARC. Lee was appalled and hated the experience. Thankfully we learned about Self-Directed Services. Today Lee lives independently in an apartment in Joppatowne/Harford County, works part-time in a grocery store, and has a small ebay business where he purchases old tools, refinishes them, and sells them. His Support Staff takes him to auctions, helps him post on-line, and manage his business. Lee independently handles photographing his products, determining the value through online research, packaging and mailing. Until recently Lee rode his bike to work which is more than a mile each way and in all kinds of weather. In fact, his supervisor used him as an example to other employees who would call out. Lee independently joined a local church where he is an active member. He regularly receives public thanks for his contribution of time and talent.

In January of last year, Lee decided that he wanted to drive and get a car so that he could be more independent and pursue other opportunities. With the assistance of DORS and his support team, Lee learned to drive. In November of this year, Lee got his license and a car. He continues to amaze us and defy the perceptions of individuals with autism.

We adamantly believe that Lee's success is directly tied to being in a Self-Directed program. He does not fit into a rigid, predetermined and planned program. Instead, he thrives on his independence; and is indeed a testament to the success of Maryland's Self-Directed program. He is like a bird that discovered it could fly. Lee is a contributor and leads a happy, full, and productive life.

On behalf of Lee, myself, and families just like us, I urge you to continue to fully fund Maryland's Self-Directed program administered through the DDA.



HB352.DD Coalition.LOI.pdf

Uploaded by: Gregory Snyder
Position: INFO

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

The Arc Maryland
8601 Robert Fulton Dr
Suite 140
Columbia, MD 21046

DRM Disability Rights Maryland
1500 Union Avenue
Suite 2000
Baltimore, MD 21211

MACS Maryland Association of Community Services
8835 Columbia 100 Pky
Suite P
Columbia, MD 21044

Maryland Developmental Disabilities Council
CREATING CHANGE · IMPROVING LIVES
217 E Redwood Street
Suite 1300
Baltimore, MD 21202

People On the Go Maryland
7000 Tudsbury Road
Windsor Mill, MD 21244

House Appropriations Committee
February 27, 2025
HB 352: Budget Reconciliation and Financing Act of 2025
Position: Letter of Information

The Maryland Developmental Disabilities Coalition (DD Coalition) is comprised of five statewide organizations that are committed to improving the opportunities and outcomes for people with intellectual and developmental disabilities (IDD) and their families. As such, **we oppose the elimination of the LISS program, support the change to the Wait List Equity Fund, and provide an opinion on IFDGS caps.**

Low Intensity Support Services program

The BRFA, in Section 8 on page 128, proposes to eliminate Health General §7-717 which established the Low Intensity Support Services (LISS) program. **The DD Coalition opposes the elimination of the LISS program.**

- ➔ **WHAT is LISS?**

According to the Developmental Disabilities (DDA) website, the LISS program serves children living at home with their family and adults living in their own home in the community who are not receiving any services from the DDA. It provides up to $2,000 to help children and adults with developmental disabilities to purchase eligible services or items to address their needs, enhance or improve their quality of life, and promote independence and community integration.

- ➔ **WHY is LISS critical?**

LISS serves between 2,000 and 2,500 children and adults with developmental disabilities a year. Recipients can only access funds if they do not receive other Medicaid waiver services. LISS is the only DDA service these Marylanders receive. It helps with purchases like respite, home modifications, adaptive equipment, and summer camps.

We understand that the leaders in the budget committees in the General Assembly have worked with Governor Moore to remove this language from the BRFA, and appreciate the acknowledgement that the statute only requires LISS services to be delivered *IF FUNDS ARE AVAILABLE.*

Waiting List Equity Fund

The BRFA, on page 45 eliminates a section of Health-General §7-205(e)(2) to increase the way the Waiting List Equity Fund (WLEF) can be used to provide services. **The DD Coalition supports this change to offset some of the proposed budget cuts to DDA's FY 2025 budget.**

Individual and Family Directed Goods and Services (IFDGS)

People who self direct use IFDGS funds for a variety of needed items and services as allowed by CMS and supported by their Person Centered Plans. If DDA reinstates caps on IFDGS, the caps must be reasonable and data-informed as not to disrupt the lives of people with IDD and their families.

For more information, contact any member of the DD Coalition.

Testimony for Reconciliation BRFA SB0321 B0352 op

Uploaded by: Richard B Kolm

Position: INFO

Testimony on Reconciliation SB0321/HB0352

For: House Appropriations Committee (Senate Budget and Taxation Committee)

Position: Informational - opposing cuts to Self-Directed Services IFDGS for FY26

By: Richard B Kolm and Margaret L Kolm – parents of Katherine B. Kolm

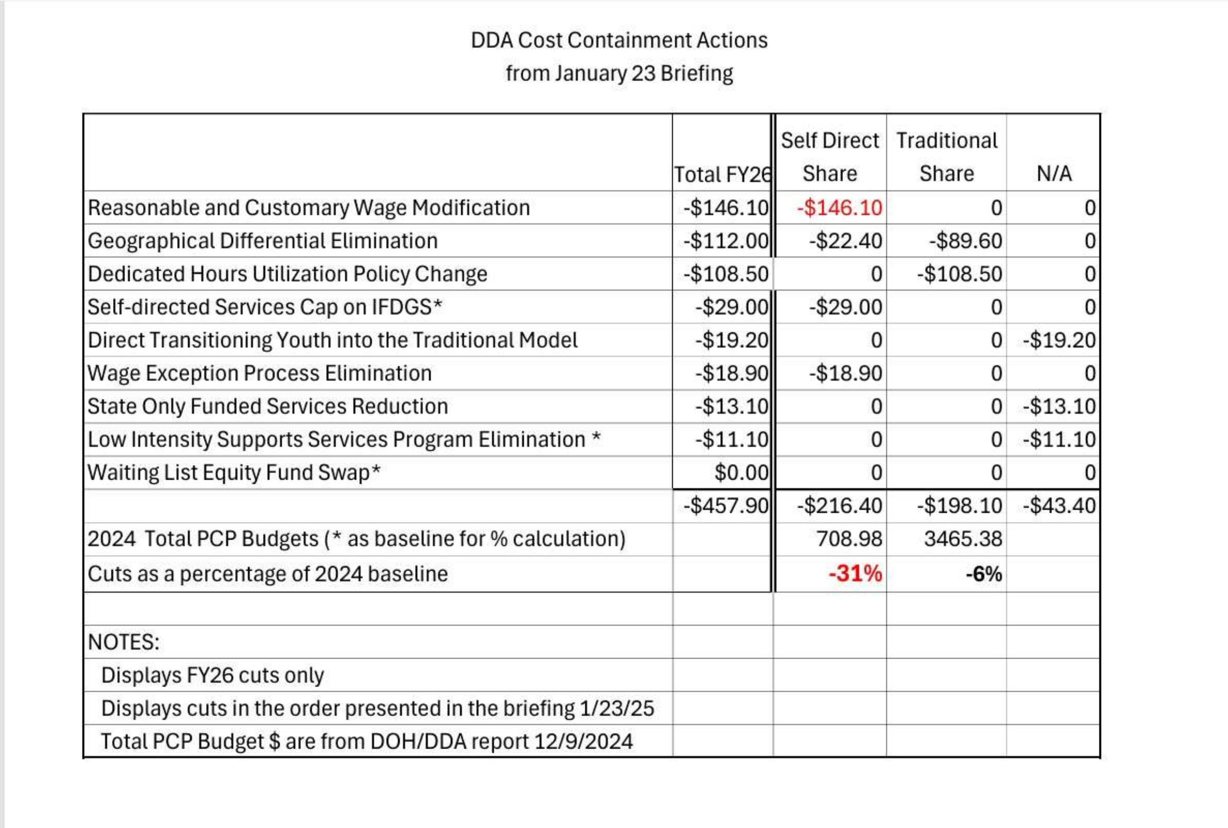
Good afternoon and thank you for this opportunity. My name is Rich Kolm, father of our adult daughter Kate who is Deaf and Blind. Kate gets DDA services under the CP Waiver Self-Directed or "SD" model. She was in the Traditional model for 2 years but had to switch to SD because of neglect related to staffing issues. Her day program in Traditional was a key area of neglect. Kate was supposed to be going out into the community but instead was often taken to a private meeting space with far too many other participants and far too few meaningful activities.

Under SD, Kate is in her home community in Charles County. She uses unallocated funds to budget Individual and Family Directed Goods and Services (IFDGS) which has allowed us to both fund truly adaptive activities and fund the Day-to-Day Administrator position to help schedule and manage. The Administrator position is also crucial to the long-term sustainability of her program. Together, these line items give Kate access to meaningful activities that keep her healthy and stress free. This is why we oppose the budget cuts through a cap on Individual and Family Directed Goods and Services (IFDGS).

The SD cuts for FY26 are harmful and disproportionate. They total a 30% reduction in Self-Direction versus only a 6% cut in Traditional. The IFDGS cap, which applies only to SD, comes to $29m and is 4.1% of total PCP budgets in SD.

The news on DDA budgets is not good, including news of a "staggering shortfall" of $350 Million, but that reflects problems in the $3.5 Billion Traditional model. We believe that the SD cuts in the FY26 budget are meant to deflect attention from this shortfall of $350 million in the $3.5 Billion Traditional program by implying that growth in the $708 million Self Directed budgets is a major contributor to DDA budget problems. This is a misrepresentation. DDA budget problem cannot be solved by cutting 30% ($200 million) from the smaller, lower cost program while cutting only 6% ($198 million) from the much larger, higher cost program. Please do not allow these harmful and disproportionate cuts.

Rich and Peg Kolm rbkolm@mindspring.com, mlkolm@mindspring.com



DDA Cost Containment Actions
from January 23 Briefing

	Total FY26	Self Direct Share	Traditional Share	N/A
Reasonable and Customary Wage Modification	-$146.10	-$146.10	0	0
Geographical Differential Elimination	-$112.00	-$22.40	-$89.60	0
Dedicated Hours Utilization Policy Change	-$108.50	0	-$108.50	0
Self-directed Services Cap on IFDGS*	-$29.00	-$29.00	0	0
Direct Transitioning Youth into the Traditional Model	-$19.20	0	0	-$19.20
Wage Exception Process Elimination	-$18.90	-$18.90	0	0
State Only Funded Services Reduction	-$13.10	0	0	-$13.10
Low Intensity Supports Services Program Elimination *	-$11.10	0	0	-$11.10
Waiting List Equity Fund Swap*	$0.00	0	0	0
	-$457.90	-$216.40	-$198.10	-$43.40
2024 Total PCP Budgets (* as baseline for % calculation)		708.98	3465.38	
Cuts as a percentage of 2024 baseline		**-31%**	**-6%**	
NOTES:				
Displays FY26 cuts only				
Displays cuts in the order presented in the briefing 1/23/25				
Total PCP Budget $ are from DOH/DDA report 12/9/2024				