SDAN Member Meeting

Thursday, May 14, 2026
12 PM and & 7 PM

SDAN

Self-Directed Advocacy Network of Maryland, Inc.

Please Mute.

Submit comments & questions and download slide deck through CHAT.

Recording will be available on our website and YouTube channel.

Closed captioning available.

Today's Agenda

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01 Guest Speakers and National Scene

02 Maryland is following the federal trends and we are not alone.

03 Proposed Waiver Amendment #4

04 How to submit Waiver Amendment comments

05 Q&A and Discussion

Welcome to our guest speakers:

Molly Morris - Co- Founder of The Self Direction Center

Dedicated to strengthening self-direction through community building, education, and research nationwide.
https://www.selfdirectioncenter.org/

Heather Sachs - National Down Syndrome Congress

Policy and Advocacy Co-Director for the National Down Syndrome Congress
Heather@ndsccenter.org

Federal Update on Medicaid

Heather Sachs, J.D.

NDSC Policy & Advocacy Co-Director

Medicaid = State/Federal Partnership

- Medicaid is funded by both the federal gov't (50-75%) and states
- States run their own Medicaid programs within federal rules
- States can request "waivers" from certain Medicaid rules
- States decide:
  - Who delivers services
  - Optional benefits offered
  - Payment rates and program structure
  - Mandatory vs. Optional services
- Medicaid waivers must be BUDGET NEUTRAL
- (waiver will cost the fed gov't no more than cost without the waiver)

Center for Medicare & Medicaid Services (CMS)

- Oversees Medicaid at federal level CMS
- Responsibilities
  - Approves state Medicaid plans and waivers
  - Issues regulations and guidance
  - Monitors compliance with federal law
  - Conducts audits and program integrity reviews
- CMS can:
  - Require corrective action plans
  - Delay or deny waiver approvals
  - Withhold federal funding
- CMS is being extremely aggressive under this Administration

H.R. 1 - Where Things Stand

OBBBA/HR 1:

- Signed July 4, 2025; now in implementation phase
- Not just cuts—structural changes to how Medicaid works

Key Provisions:

- Work / “Community Engagement” requirement - starts Jan. 1, 2027 NE - early mover, started 5/1/26 6-month eligibility renewals (vs. 12 months) - increases churn risk Changes to eligibility for some noncitizens
- New limits on state financing mechanisms

H.R. 1 - Where Things Stand

CMS guidance issued, but major rule still pending:

- Interim Final Rule expected by June 1, 2026

Overall financial impact on Medicaid:

- HR 1 is expected to reduce federal Medicaid spending by **$911 billion** over ten years, and the work requirement provision alone is estimated by CBO to reduce federal Medicaid spending by $326 billion and increase the number of uninsured people by 5.3 million.

What States Are Doing Now

Rapid implementation prep underway

- IT system overhauls, staffing, eligibility workflows
- $200M federal grants from CMS + vendor support

Budget impacts already showing up

- States allocating millions for new admin systems
  - Utah $16.5 million, Colorado over $50 million, Kentucky $35.6 million, and Wyoming $7.4 million just for the law's redetermination changes.
- States are concerned about the short timeline, lack of staff capacity, system changes, and enrollee outreach costs.
- States already making budget cuts from HCBS

Recent HCBS Impacts

NC: Elimination of entire HCBS programs, reduced provider rates NE: Reduced provider rates, more restrictive eligibility

CA: new or reduced total program spending caps VT: limits on hours or visits

CO: New or reduced total program spending caps MA: limits on hours or visits

IN: new or reduced per-participant spending caps, limits on hours or visits, reduced provider rates

ID: reduced provider rates, limits on hours or visits

GA: State legislature funded 900 new waiver slots (8000 on waiting list), but Gov. Kemp vetoed funding for 800 of them

More and more states are making cuts, with more to come...

Medicaid HCBS Fraud Claims & Real World Impact

Reality:

- Some fraud exists (especially in personal care/HCBS), but it is being amplified and politicized in 2026

Federal Response:

- Treating fraud as a system-wide problem, not targeted to bad actors
- Increased audits, enforcement, new restrictive rules, Congressional hearings and high-profile state actions (MN, CA, NY)

Why is this harmful?

Why is This Harmful?

- HCBS framed as a “fraud problem” - easier to justify cuts (HCBS are optional and often cut first)
- Providers exit or downsize due to burden
  - Worsens workforce shortages, less choice, longer waitlists
- Access restricted before proof of wrongdoing
  - Enrollment pauses, service caps, increased reviews
  - People lose or delay services even without fraud
- Burden shifts to individuals
  - More paperwork, verification, timesheets
  - Self-directed HCBS especially at risk

The Bottom Line

- All states (not just MD) are under enormous Medicaid pressure
  - Rising Medicaid costs w less funding
  - Workforce shortages & waitlists
  - HCBS waitlists & provider instability
  - New HR 1 implementation requirements
  - Increased fraud investigations and oversight
- State response
  - Tightening eligibility & reassessments
  - Increasing audits & paperwork
  - Slowing HCBS or limiting spending

How did we get here?

The state of Maryland (DDA) has made a fundamental shift in its mission from focusing on a "*flexible, person-centered, family-oriented system of supports" to* "providing a high-quality and sustainable *healthcare system"*

Despite tremendous advocacy efforts this legislative session from participants, families, advocacy groups, and individuals across both models, we were not successful at stopping significant changes in service, wage and rate cuts.

As you heard many of these significant changes are being seen across the country.

The changes are reflected in the final budget language (SB 282). Some of these changes require an amendment to Community Pathways Waiver (CPW). DDA is proposing CPW waiver amendment #4.

What's next?

- **Understanding the proposed waiver amendment impacts and formulating comments**

SDAN is:

- **seeking clarifications from the DDA**
- **continuing conversation with Disability Rights Maryland**
- **supporting advocacy efforts looking into the cost neutrality concerns**
- ***Developing comments to the proposed amendment***
- ***Encouraging stakeholders to submit public comments detailing the impacts of changes***
- **Encouraging participants and families to build positive relationships with legislators, help them understand participant needs and impacts of these severe changes**

Key Self- Directed Changes in the Waiver Amendment Proposal 4

- **60/40 Limits**
- **Self-Directed Funding Methodology**
- **Change from Vendors to Individual Providers (elimination of unlicensed providers)**
- **Changes in FMCS payments**
- **Lack of Day-to-Day Administration Changes as per the SB 282**

Reference Document:

Plain Language Summary

60/40 Staffing Limits

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Proposed Change:

If a relative, guardian, or legally responsible person is paid to support one or more participants:

● They can work up to 40 hours per week total (per participant). This went into effect last year.

● They can work up to 60 hours per week total (across all people they support).

● Each participant can receive a total of up to 60 hours per week from all relative/guardian/legally responsible providers combined.

Why This Matters:

- Deviates from person-centeredness
- Erodes employer authority, choice, control, and flexibility
- Destabilizes the current workforce

Things to think about in formulating waiver comments:

- How does this impact, erode, and impinge you or your participant's budget/employer authority?
- The 60/40 rules must contain exception for Respite by non primary caregiving family members.
- The 60/40 rules must contain exception for short term emergencies situations that will arise.

Self-Directed Funding Methodology

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Proposed Change

DDA is proposing to create specific Self-Direction rates based on Bureau of Labor Statistics with the cost components of wages, Employer-related expenses (ERE) payroll taxes, and costs like training and transportation.

Why This Matters:

- This has reduced rate and wage ranges by an average of 20-30%(with some ranges being as high as 50%)
- This creates a high risk situation for sudden shifts in service coverage
- The BLS code that is being used is not representative of the job; While there is advocacy on a federal level for this to change, it is a timely process
- There have been no rate studies on the costs of self-direction to substantiate the proposed rate cuts

Things to think about when making waiver comments:

- Does this move towards separate rate standards between the two models?
- Is the BLS code that DDA chose appropriate for all service levels (and if not, is there a better one-link in reference slides)
- Will this change impact the entire brick methodology that is currently used in LTSS?
- Recruitment of staff with the necessary qualifications, experience, etc. is greatly hampered by these reductions
- Could there have been a transition period to allow for these changes to be made reducing harming/jeopardizing?

Vendors to Individual Providers

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Proposed Change

- DDA is shifting from using the language of “vendors” to individual providers, but also limiting individual providers to only support brokers and nursing services vendors.

Policy Change

- DDA has released a new policy stating that all unlicensed vendors would need to go through the DDA provider application **and** be approved by 6/30 to continue services.

Why This Matters:

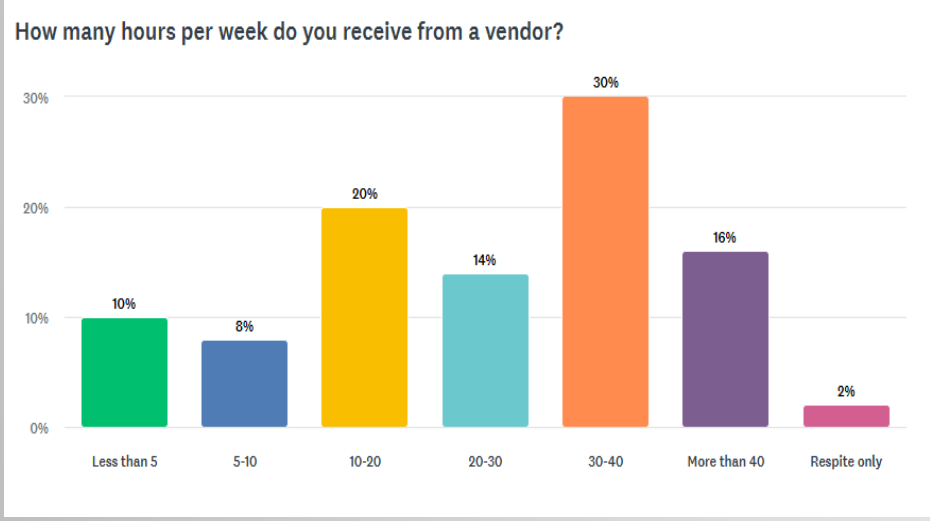
- As of 7/1, no unlicensed vendors will be able to provide services and be paid
- It is participant/team responsibility to ensure that their vendor is aware of this change and to develop a plan to move forward
- Many participants are going to face a sudden loss of services and relationships

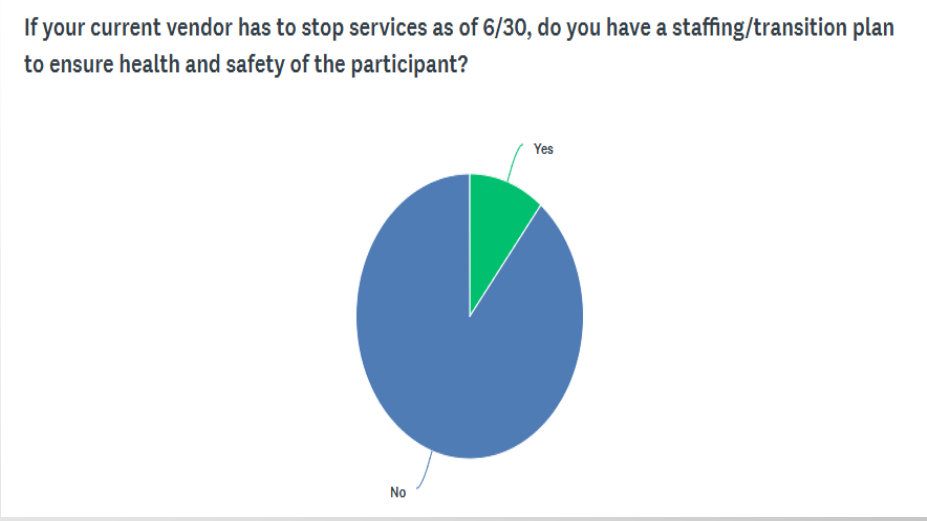
Things to think about when making waiver comments:

- DDA is citing this as a simple language change; however we all see the lack of transition and implications of this occurring even prior to the 9/1 updates
- Pathway options, expedited processing period, or extension of the requirement for RSA licensed providers, vendors who have already submitted applications, etc

Survey Responses

SDAN recently finalized a survey regarding the implications of payments to unlicensed vendors ending as of 6/30/26. We identified several key data points but most concerningly: Data shows that there will be a minimum of 2200 services hour **per week** unserved, and at the time of the survey, 90% of respondents had no transition plan in place on how to account for those hours.





[See full survey results here]

Changes in FMCS payments

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Proposed Change

- The FMCS fees will no longer be allocated through the participant's budget, and instead will be considered an administrative cost covered by the state.

Why This Matters:

- This is reverting to how things were done previously; it didn't have negative implications in the past
- This could open up participant choice for those who are priced out of different FMCS' based on current unallocated funds

Things to think about:

- There may be unintended consequences; there has been limited information shared on how this could directly impact the participant.
- Could this impact my choice on FMCS options?

Day to Day Administration
(lack of change)

Background: Senate Bill 282(final budget language) provided an update day–to–day administrative supports shall include non-direct supports that assist the individual with household management and scheduling, appointment scheduling, and money management tasks such as reviewing and paying bills and assisting with the maintenance of benefits

Language from Current Waiver:

The CURRENT Waiver amendment(page 211) does not align with the Senate Bill 282, and therefore should have been updated via this waiver amendment.

It is clearly listed in the waiver that Day to Day **DOES NOT** include these actions:

- Making payments for household management care
- Budgeting and money management
- Developing staffing or cleaning schedules
- Managing money and property management

What Needs to Change:

Day-to-Day Administrative Supports include direct and non-direct support not available under another waiver service such as:
a) Household management and scheduling including assisting with staff scheduling and oversight.
b) Scheduling appointments, including medical visits; or
c) Personal money management such as reviewing and paying of bills and assisting with the maintenance of benefits.

Day-to-Day Administrative Supports may not include tasks such as:
a) Making decisions for the participant; or
b) Approving and signing timesheets or vendor payments.

Waiver Amendment Comment Period

Before the proposed amendment can be submitted for approval by the Centers for Medicare and Medicaid Services (CMS), there is a mandatory 30-day public comment period.

The DDA will accept public comment from **April 29, 2026-May 28, 2026**

Public comment can be submitted directly to wfb.dda@maryland.gov.

We encourage you to share your thoughts, suggestions, and concerns as a member of the self-directed community.

As SDAN formulates our organization's public comments, we would love to hear from you have further feedback or commentary on these focus areas. Please reach out to us at selfdirectedadvocacynetworkmd@gmail.com.

How to Write an Effective Comment

Public comments are compiled and not only reviewed by DDA, but compiled into the waiver amendment proposal for CMS to review.

The formula: **State the problem+why it matters to you+the ask**

A strong public comment will:

- **Identify the specific proposal or section you are commenting on**
- **Explain the real-world impact to the medicaid waiver participant**
- **Offer a concrete recommendation or change**

Example:

The restriction of the proposed 60/40 staffing limitations will impact me by….

Long Term Advocacy

As said in the beginning, despite tremendous advocacy efforts, advocates were not successful in fully stopping what is happening, but we are not stopping with our continued advocacy.

- SDAN was formed in 2016 when DDA initially wanted to dismantle family as staff; we have seen this cycle repeat itself through the years and we are prepared to continue this fight
- SDAN will continue to advocate for protection of critical wage rates, participants retaining choice and control over hiring (including family as staff), and maintaining strong self-direction principles within HCBS programs.

Questions From the Chat

???

Given time constraints, if we do not get to your question or if you have further feedback, please feel free to email us selfdirectedadvocacynetworkmd@gmail.com

Thanks for attending!

Like us on Facebook!

Join our Facebook group at:
SDS Participants in Maryland

SDAN Website

Support SDAN: Click the "Donate" button at the top right of our home page https://marylandsds.org/ Every contribution makes an impact..

Reference Links

DDA Waiver Amendment Homepage

DDA Youtube Channel(to re-watch any of the proposal videos)

DDA SDS Manual-May 2026 Updates

BLS Chart

Applied Self Direction

The Self-Direction Center

Disability Rights Maryland

The ARC US

National Down Syndrome Congress

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