

SDAN Member Meeting

Thursday, January 15th
12:00 PM - 1:30 PM



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



Self-Directed Advocacy Network of Maryland, Inc.

01

The current advocacy landscape

02

Advocacy pathways - Systemic and Individual

03

Key Issues

04

Introducing - My Life, My Choice and new initiatives

05

Q&A and Discussion

SDAN IS:



Self-Directed Advocacy Network of Maryland, Inc.

- A statewide independent advocacy organization focused on Self-Directed Services - all volunteer board
- Centered on your voices - lived experiences of participants, families and team members
- SDAN was formed in 2016 to protect participants choice and control over services including the right to hire family as staff during the waiver renewal

SDAN: A Growing Community

As SDS Grows, So Does SDAN

Celebrating 10 years of advocacy protecting participant choice and control of services.

Thank you to all the original members who followed their heart to organize people and formed the first advocacy organization focused on self-direction.

Meet our Board

Seasoned Board Members

- Alicia Wopat- President
- Patti Saylor- Vice President
- Athena Elliott - Secretary
- Sunny Cefaratti
- Beth Munro
- Stephanie Watkins
- Lynne Gummo

Staff: Rachel Sullivan, administrative and technical support and Kevin Keane, communications

New Board Members

- Kimberlie Manns
- Peter Mattes - Treasurer
- Eldon Windyboy
- Samantha Ferraro
- Jessica Gallatin



Self-Direction Today



Self-Directed Advocacy Network of Maryland, Inc.

**Continued growth in
self-directed services -
National trends**

Learn more here: <https://www.selfdirectioncenter.org/the-news>

**Increased complexity, higher
administrative burden and
increased monitoring**

**Higher visibility, more scrutiny and
perpetuation of a negative narrative about
family as staff and Self Direction in general**

Maryland's Fiscal & Policy Reality



Self-Directed Advocacy Network of Maryland, Inc.

The Current Fiscal & Policy Environment

- Reports are that Maryland has a \$1.4b budget deficit
- Medicaid programs everywhere are under increased review
- We have heard from the Governor's Office that more information about MDH/DDA agency budgets will be revealed soon.
- We anticipate cost containment strategies across all DDA services

Advocacy Pathways:

Individual & Systemic

Many Forms, One Purpose



Both pathways have **legislative**, **collaborative**, and **legal** strategies

Systems Advocacy Collaboration

- Rate Review Advisory Group (RRAG)
- Maryland Intellectual/Developmental Disabilities Sustainability and Equity Committee (MIDSEC)
- Waiver Advisory Council (WAC) and Subcommittee
- MDH Secretary Roundtable
- Coordination with Developmental Disability Coalition and other advocacy groups
- Governmental Affairs Committee - The ARC Maryland
- Meetings with DDA leadership
- Governors Office staff meeting



Systemic Legislative & Legal Advocacy

- Continued call for MDH/DDA to adhere to the Self-Directed Act of 2022
- Staying in touch with key legislators to highlight your issues/Monitoring of legislative bills and issues
- Participating in DD Day in Annapolis (Save the date 2/18/26)
- Continuing consultation with Disability Rights MD (SD Act)
- Meetings with private attorneys



[Self-Directed Advocacy Network of Maryland, Inc.](http://www.sd-an.org)

DD Day Registration Link can be found here:
<https://events.humanitix.com/dd-day-26>

Individual Advocacy Pathway & Strategies

Collaborative

- YOUR story is the MOST powerful tool
- Attend meetings, hearing & rallies
- Personal Testimony

Legislative/Legal

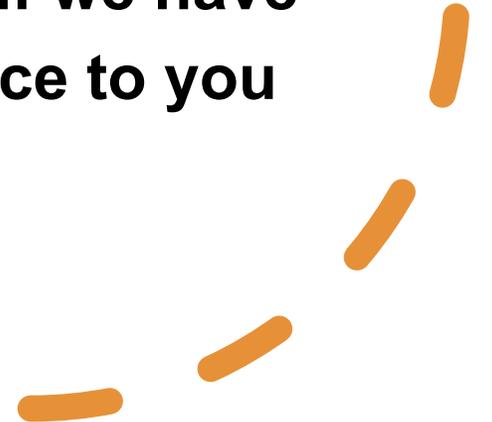
- Build a relationship with your legislators (Delegates and Senator)-Share your story!
- Pay attention to bills that affect you
- Individual legal consultation and exercise your appeal rights



Key Issues Impacting Self-Direction



- **The following slides are current issues that form our collaborative advocacy**
- **They are based on your ongoing feedback to us**
- **We ask that you let us know if we have missed anything of importance to you**



Fundamental Shift

Prior to Fall of 2025

Our vision: The DDA *envisions* people with intellectual and developmental disabilities living full, active lives in the communities of their choice.

Our mission: The DDA's mission is to create a *flexible, person-centered, family-oriented system of supports* for individuals with intellectual and developmental disabilities

Fall 2025

Our vision: *To connect* Marylanders with intellectual and developmental disabilities to services that help empower them so they can live the lives they want to live in communities they choose.

Our mission: To provide a high-quality and sustainable *healthcare system* that is equitable and accessible to all.

The Core of Self Direction

Person-Centeredness, Flexibility & Authority

SDAN VISION

We envision people with intellectual and developmental disabilities living self-directed, fulfilling lives with access to all the long-term services and supports they need.

SDAN MISSION STATEMENT

SDAN-Maryland's mission is to advocate for participant choice, control, flexibility, and the sustainability of self-directed services and supports. We do this through education, training, legislative advocacy, maintaining partnerships with state agencies and divisions, and collaborating with organizations committed to supporting people with intellectual and developmental disabilities.

SDAN remains committed to core beliefs:

- *Self-Direction must remain person-centered*
- *Budget and Employer Authority are foundational*
- *Policies and communication must be accessible, flexible and functional and person centered*
- *Anyone can self direct with the right supports*

Participant's Choice In Hiring

Employer Authority

Issue: Continued scrutiny and policy changes have impinged on a participant's choice to hire family for a variety of services.

Position:

- Participants have the right to choose who they hire to provide approved services.
- This includes the Participant's choice to hire family as staff (FAS) should they choose to.
- Utilize existing safeguards to address any real or perceived conflict of interest

FMCS - Reimbursements and Payments

Issue:

Members are reporting an increase in difficulty obtaining payments and reimbursements that are in approved PCP budgets.

Position:

Participants need count on their FMCS for timely to ensure they have continued access to their approved services.

DDA should be accountable to ensure that participants have a functional and responsive FMCS.

Day To Day Admin (D2D)

Issue:

The recent waiver and policy changes mean that participants' previously assessed need for administrative support is no longer being met, which violates both the intent and the law of the SD Act.

Position:

Participants with the assessed need should have the option of hiring a day-to-day administrator, where authorized by the SD Act. For many participants reasonable hours and duties are essential for sustainability for participants who self-direct.

Advocacy is focused on this issue!

Individual and Family Directed Goods & Services (IFDGS)

Access to PCP approved budgets

Issue:

The recent waiver and policy changes are restrictive and prohibitive and limit or block access to the \$5,000 cap for goods/services as outlined in the SD Act.

Position:

Participants should have access to their full annually approved budgets of up to \$5,000. Policies should not be overly restrictive and block access. Participants should receive approval for the full range of IFDGS activities and programs as allowed by SD Act and CMS.

Decision-Making & Substituted Judgement

Issue:

CMS/DDA may require substituted judgement (SJ) when an individual is not fully capable of making their own decisions.

Position:

- Adults who make their own decisions, legal guardians and legally responsible persons are recognized decision makers therefore not requiring a process for SJ.
- Adults who are not able to make their own decisions or have the legal authority to do so, and don't have a legally appointed person would require a Team process/Team attestation for SJ - building on the current form(s) e.g. Participant Agreement

REM/Skilled Nursing

Supporting People with Complex Needs

Issue:

Participants/members report that they are being denied DDA services and other services from MDH if they have skilled nursing from the REM program.

Position:

The participant with complex medical needs who require skilled nursing services have a statutory right to live in the community with the services and supports necessary to achieve that goal.

Due Process & Case Resolution Conferences (CRC)

Due Process & Resolving Disagreements

Issue: The recent waiver and policy changes eliminates the opportunity for CRC for service denials.

Position:

Bring back the CRC option.

It is more cost-effective for the state budget and for the person seeking an agreement or resolution. Disallowing the CRC impacts people without the time and funding to file an appeal and go to administrative hearing.

“Unless otherwise specifically approved by the DDA”

Issue: The recent waiver amendment removed the phrase “Unless Otherwise Specifically Approved by the DDA”. This eliminates the ability of the State to respond to the unique needs of the participant and further reduces person-centeredness.

Position: Restore this language to the waiver so that DDA has discretion to approve services based on the unique needs of the individual.

Additional Key Issues

Issues:

- Benefit and mileage restrictions
 - limiting mileage to 200 miles per day
 - limiting “health” reimbursements
- Criteria for enhanced rate subjective
- EPrep for BSS and NSS vendors
- Training issues:
 - inconsistencies in CCS knowledge of systems; FMCS staff knowledge and application of policies
 - Staff eligible for overtime can no longer work for more than 40 work hours if hours are for training

What key issues are we missing?



Self-Directed Advocacy Network of Maryland, Inc.

selfdirectedadvocacynetworkmd@gmail.com

Feedback Form: <https://forms.gle/8Xvzqe2P7SxpTghn6>

Please share issues you believe should be included in advocacy work.

Two New Initiatives - Exciting Opportunities



Self-Directed Advocacy Network of Maryland, Inc.

- Promoting best practices in self direction through educational offerings.
- Engaging participants with disabilities using self direction.





Education Initiative:

Ongoing Education Series - Starting soon

Exciting opportunity to be a part of creating and sharing clear, practical resources and best practices to help participants and their teams.

We invite you to join us as attendees or to help plan!

Participant Engagement Initiative :

Nothing about us, without us.

The SDAN Participant Engagement - Monthly Discussions
is focused on creating meaningful ways for participants with disabilities to share their experiences and be connected.

Participants can openly discuss issues impacting self-direction in a supportive, facilitated environment.

WHEN: First Monday of every month - Beginning February 2nd

TIME: 6:00 PM via ZOOM

Open forum discussion of issues impacting self-direction facilitated by SDAN

New SDAN Campaign: My Life, My Choice

Self-Directed Services are shaped by real lives, not just policies.

My Life, My Choice is a new SDAN campaign designed to center participant experiences across the full spectrum of self-direction:

- the value and affordability
- the good and the challenging
- the complicated
- the profound

These stories help ensure advocacy reflects lived reality systemically and Individually..

My Life My Choice

JONAH

A Turning Point Through Self-Direction

Because of self-direction, Jonah is supported to safely explore his community, build independence, and enjoy life alongside people who know and care for him.



SDAN

My Life My Choice

KEVIN & THEA

Building a Life Together

Through self-direction, Kevin and Thea gained the flexibility to shape supports around their shared life, allowing them to live more independently and thrive together.



SDAN

My Life My Choice

SUNNY

Shining a Path Through Self-Direction

Sunny uses her musical talent to bring joy to others wherever she goes. Self-direction allows her to share her gifts, set her own goals, and stay active in her community.



SDAN

My Life My Choice

MAURA

Surrounded by Care, Rooted in Love

Self-direction has helped create a stable, supportive life for Maura, built around trusted relationships and meaningful community experiences.



SDAN

New SDAN Campaign: My Life, My Choice

How it works

We're excited to strengthen how we share stories about Marylanders who are self-directing! SDAN is collecting photos, videos, and stories that highlight members' experiences, accomplishments, and day-to-day life in self-direction.

Interested in participating?

Submit your content here:

[SDAN Story & Content Submission](#)

OR Email:

kevinkeanesdan@gmail.com



Upcoming Events

Mark Your Calendars

January 14, 2026- Maryland Legislative Session begins and lasts for 90 days

Sign up for the ARC MD Annapolis Insider

Look for emails regarding Legislative FAQ's from SDAN

Let us know or contact Kevin Keane directly to write your story!

DD Day in Annapolis- February 18, 2026

*******We NEED project volunteers to prepare for this day!*******



Apply to
the waiver
advisory
council!



Thanks for attending!

Like us on
Facebook!

Join our Facebook group at:
[SDS Participants in Maryland](#)

[SDAN Website](#)

**WE'RE NOW ON
INSTAGRAM!**

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@sdanmaryland

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