

Welcome Thank You Agenda

The logo for SDAN (Self-Directed Advocacy Network of Maryland, Inc.) features the letters 'SDAN' in a large, bold, sans-serif font. Each letter is filled with a pattern of red, yellow, and black, resembling the Maryland state flag. The letters are set against a white rectangular background.

Self-Directed Advocacy Network of Maryland, Inc.

WELCOME!

DD Day
Advocacy

Advocacy
Prep

Sign up for
1:1 Sessions

SDAN Meeting - January 17, 2025

Telling Your Story

Please Mute.

Use Chat Box for questions. Please keep side conversations to a minimum.

We will be recording.

Close captioning available.



MEETING AGENDA

- SDAN Advocacy Committee update on DD Day (February 13th)
 - Sign up for DD Day
 - <https://www.eventbrite.com/e/developmental-disabilities-day-at-the-legislature-2025-registration-1144615940089?aff=oddtcreator>
 - Sign up for a meeting with your legislators (allow lots of time to get through security on DD Day!)
 - <https://mgaleg.maryland.gov/mgawebsite/members>
 - Write your “1 pager”
 - Sign up for 1:1 sessions with SDAN (put your name, email address and preferred meeting time in chat and we will respond)
 - Sample 1 pagers
 - SDAN support on DD Day



Building Relationships – Why?

- You are the constituent
- Your legislators work for YOU
- They are real people with (mostly) good intentions
- They want to put faces to issues and get to know you - it is their job!
- They often turn to their well-informed constituents for advice and guidance.

Building Relationships – When?

- NOW, and year round
- Do not wait until session begins
- Your child is never too young!
- Make contact when things are going well, not only when you have a complaint
- Keep in touch

Building Relationships – with Whom?

- In MD: State Delegates and State Senator
- Their STAFF
- People who work in the Governor's office or a key Cabinet in MD (e.g., Aging, Disabilities, Health, Budget)
- Also good to build relationships with federal elected officials, local officials (city council, school board, etc)
- Thank them publicly when they do something good – social media (X, TikTok) – tag them on your post (conversely – do not publicly slam or shame them when you disagree!)



MD Legislature Leadership

- Are your reps in leadership in their party or on key committees? Are they members on key committees?
 - Find your state legislators - <https://mgaleg.maryland.gov/mgawebsite/members>
- Key Committees for Disability Issues
 - Senate – Budget & Tax; Energy, Finance
 - House – Appropriations; Health & Gov't Operations (HGO), Ways & Means

<https://mgaleg.maryland.gov/mgawebsite/Committees/Index/senate>

<https://mgaleg.maryland.gov/mgawebsite/Committees/Index/house>



Thoughts for preparing your Story

2025 Pivoting Strategy

Developmental Disability Day at the Legislature- Save the Date- Feb 13

- One day event sponsored by the Developmental Disability Coalition
 - Held at the Graduate Hotel on West Street in Annapolis
- Opportunity to be part of 600+ people-
 - Really makes a statement to legislators!!
 - Wonderful networking opportunity
- Hear from your legislators and other advocacy organizations
 - <https://www.md-council.org/policy/public-policy-priorities/dd-day-at-the-legislature/>
 - When the registration link is published, we will send an email to our membership
- Schedule appointments with your legislators NOW
 - SDAN will have a booth in the lobby of the Graduate Hotel to gather and meet up
 - We will have some materials to guide people wanting to talk to their legislators
 - Some SDAN volunteers are coordinating group meetings with delegations.
 - This is often a more effective way to get an appointment,
 - being respectful of our delegate's time.
 - If you would like to coordinate in your district - put it in the chat

Developmental Disability Day at the Legislature- Save the Date- Feb 13 (con't)

- If you want to schedule a meeting with you delegate(s) (on your own)
 - Let them know you live in their district (e.g., I am a resident of Kensington)
 - That you would like to schedule 10-15 minutes on the afternoon of 2/13 during DD day to meet
 - Tell them what you would to discuss
- You have to arrange for parking
 - [Garages and Lots | City of Annapolis, Maryland \(MD\) Parking Guide](#)

SDAN Meeting- Writing your 1-pager January 17, 2025 12:00-1:00pm

The most effective advocacy tool is your personal story and your relationship with your legislator

Identifying your most compelling issues

Expressing those issues in a concise way (“Elevator Speech”)

Avoiding jargon and the “weeds”

Instructions for making an appointment with your legislators



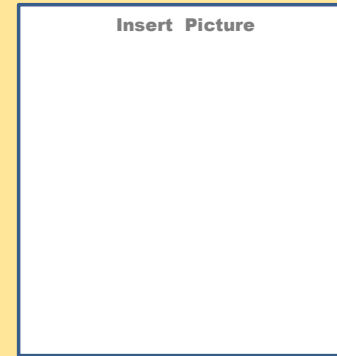
Preparing for DD Day- NOW!!

Sign up for one-on-one sessions with the SDAN DD Day Committee to help you write your story

Contact your legislators and legislators on key committees NOW to make appointments- can be another day to avoid the crowds

Your Story- the big message

- Picture- show them the beautiful face of the person who is being hurt by what's happening
- Contact information
- Short, concise statement (bullet points?) of what is hurting your loved one



Stop the Chaos!
Save Our Services

A solid red rectangular box with a thin white border. Inside, the text "Name", "Address", and "Contact Information" is centered in a small, white font, stacked vertically.

Insert Text and more pictures in any format within this box.

Example 1-pagers



Carmen Houston-Ludlam

address

Cell:

Email:



Stop the Chaos Save Our Services

Hi, my name is Carmen Houston-Ludlam

- I have self-directed my services for six years.
- I have worked at MOD Pizza for 5 ½ years. I love my job
- I practice my ventriloquism, and I hope to be on America's Got Talent some day.
- I am very active, and I swim, dance and cheer.
- I also like to make reels on Instagram with funny songs. I have almost 11,000 followers!
- I really like fashion, and I post pictures of myself wearing outfits similar to a British model named Holly Willoughby.

Self-Direction is important to me because...

- I like to decide what I am going to do with my time instead of having to do what someone else tells me.
- I have a lot of interests, and I like having someone close to my age to share them with and hang out with- like my aide Angel.
- I am proud that I can make my own decisions.

But I can't do that now.

- The DDA is refusing to approve the activities that get me out into the community.
- They won't respond to my CCS or my mom when they are refusing activities for incorrect reasons
- They didn't approve small pay raises for my DSP (within the reasonable and customary rates) for 6 months- after they LOST the first request we submitted

PLEASE MAKE THE DDA STOP HURTING PEOPLE WITH DISABILITIES! MAKE THEM FOLLOW THE LAW AND THE RULES!!!



Example 1-pagers



Stop the Chaos!
Save Our Services

RYAN GERHOLD, AGE 39

Leonardtown, MD

Debbie Hamann, Mom 301-717-2211

debbiehamannrf@gmail.com

My History: Meningitis at 9 months resulted in brain damage making it difficult for me to concentrate. I have severe anxiety, OCD, severe cognitive delays, hyperactivity and uncontrollable thoughts. I went to the Benedictine School on the Eastern Shore at age 10 where I lived until 21. Transitioned to a Group Home in St. Marys County where I felt unsafe and not secure. After being neglected and abused, I was able to come home with **SELF DIRECTION** services where I thrived and was once again **HAPPY!**

My Likes (made possible by Self Direction):

- Hanging out with my family, friends and girlfriend
- Having a Day Program where I can do volunteer work, which I enjoy
- Sleeping with my dog in my own home (where my **Personal Support Staff** help me)
- Having friends and family as my **Personal Support Staff** where I feel more safe and secure
- Vacuuming, taking out trash, setting the table and other household chores
- Staying active in my community – Church, shopping, going to the parks, movies, dances
- Going to Easter Seals **Camp Fairlee** where I get to have a vacation and make new friends
- Having a Support Broker who helps me to manage my program and gives me advice

My Dislikes (caused by policy changes by DDA 11/21/24)

- **Self Direction** is in jeopardy this year! Proposed cuts in our budget will impact my services even though we are cost-efficient.
- It is taking months to process **IFDGS** approval for my dental work (I had severe tooth decay because I needed sedation which isn't covered by my Medicaid Insurance or Dental Insurance. **IFDGS** uses unallocated funds from my budget to reimburse us so that I can have bi-yearly cleanings and checks. Since the new Policy took effect, this process took 3 months to approve, putting my health in jeopardy and actually cost the State more money because of the constant back and forth to process paperwork.
- My **Support Broker** can no longer speak with DDA or FMCS without me being present – I can't have conversations and I refuse to talk on the phone (my speech is limited and I can't sit still). She also can't check and approve my payroll anymore, as well as other things she used to help me with! (all because of the new Policy 11/21/24!)
- My **Yearly Plan** took months to approve (even though it was unchanged from previous years) preventing me from giving staff necessary raises and access to my yearly Budget

SDAN

Example 1-pagers



Stop the Chaos! Save Our Services

Caroline Munro
212 Deer Meadow Lane, Unit 1 Rockville 20850
cmunro@aol.com/301-461-3615

Mom: Beth Gude

1003 Brice Road Rockville 20852

My annual plan was approved and thank you!

But...

- **The new rules keep me from hiring staff and I need more staff.**
- **The new rules keep me from giving a raise to staff that have been with me and know me well – unless they have been with me for eight years!!!!**
- **My staff can't count on being paid on time or paid correctly – so how can I do staff evaluations. Am I really the boss?**
- **My Support Broker isn't allowed to help me in ways she did before and I need that help.**
- **My Nurse and other vendors have a very hard time getting paid and it's hard to keep vendors.**
- **I now have to submit so many more forms when I need to buy something approved in my plan. My mom spends many hours trying to get all this stuff done for me instead of just being with me. My CCS is the only one allowed to do a lot of stuff & she is really nice and works hard but doesn't know me as well. All these forms cost the state \$\$\$ in time spent by the CCS & DDA.**

I am really scared. I want to stay in my own apartment but without mom holding things together (she's 75) I might have to go to an institution. All this is just too much.

**PLEASE STOP THE CHAOS. FORM A WORK GROUP.
LET ME LIVE MY LIFE.**

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Self-Managed Support Network of Maryland, Inc.

SDAN Issues 1-pager

How do these new policies hurt you/your loved one?

- Non-payment of staff or vendors
- Loss of Support Broker and/or nurse
- Loss of overnights or 2:1 staff
 - health and safety
- Plans not approved
 - Threats?
- Hiring delays
- ??????
- They are coming for:
 - IFDGS
 - reimpose cap
 - wholesale denials
 - Intrusive policies to “prove” you can’t afford things
 - Wages
 - Overnights
 - 2:1 services
 - Enhanced Supports
- They are balancing their budget on the backs of self-directed participants!

Budget Savings – Loyal Staff

- I need 24/7 1:1 supports
- I live in my own home
- When I go to doctor's appointments, I need 2:1 supports because I try to leave.
- Last year, I received 99% of my approved hours for 90% of my approved budget.
- While my supports will always costs the state money, my being in self-direction saved the state money on my supports over any other service option.
- I have four staff members who have worked with me for 5-25 years.
- In order for them to not have to have more than one job, I pay them a living wage, include 1.5X holiday differential pay.
- Now, DDA says that my staff wages are too high, and I can't pay them holiday differential any more.
-
- I DON'T WANT TO LOSE MY STABLE STAFF!
- I need to retain my employer and budget authority as CMS allows and expects in self-direction.

Budget Savings – 95% Utilization of Hours for 71% of Funding!

- I need 24/7 one-to-one supports.
- I live with my mother. She works for me 40 hours a week.
- I have two other VERY PART-TIME staff that provide, on average, 20 hours a week in supports (10 hours each).
- My mom provides at least 108 hours of gratuitous supports EVERY WEEK!
- This has saved the state lots of money over the last 12 years that I have self-directed my supports. (A community provider refused to provide support to me 12 years ago even after the state offered to pay them for 2:1 supports for me).
- **When my Mom is no longer able to support me, I will require 24/7 intensive supports because I am a big boy and have behavior issues.**
- We are working to introduce more people into my life so that the transition away from my mom will be easier.

SDAN Bill 1-pager



THE SELF-DIRECTED SERVICES ACT OF 2022 (HB1020/SB868)

Self-direction allows an individual with Intellectual/Developmental Disabilities to have choice and control of their Medicaid waiver services, including choosing the staff that supports them (employer authority) and how their budget is spent (budget authority) so they can tailor their daily activities to meet their own needs and interests.

History: Maryland was a trailblazer with its Self-Direction (SD) Waiver in 2005

- 2013/2014 – it was combined with the provider-centered Waiver which meant less choice, control and flexibility for SD
- 2016 – further DDA changes took away many participant choices and control
- Grassroots efforts since then culminating in this Act

Goals:

- To achieve greater equity by ensuring that people in disadvantaged communities, those with language barriers and those who lack robust family supports can also access SD
- To restore and maintain flexibility and access to SD while retaining cost-savings
- To ensure that anyone be deemed capable of self-directing with the needed supports

The bill stipulates:

1. Case managers (CCSes) will be better trained in self-direction and will fully orient new and current participants about self-direction annually (PCP).
2. Reinstate Support Broker roles and increase hours available where needed.
3. Reinstate Self-Directed Overnight Supports (this waiver service removed in 2018)
4. No Prohibition to Having Family as Staff per CMS rules
5. Transparency in Person Centered Planning (PCP) – ability to track
6. Mileage Reimbursement for Specialized Vehicles
7. Remove Competency Requirements in Favor of Team Support
8. Parity in Budgets/Services – SD doesn't have all needed services
9. Individual Family Directed Goods & Services (IFDGS) to be more flexible per needs
10. Progress Report to Legislature Annually – 3 years

Takeaway:

- NOTHING in this bill causes the state to lose federal matching dollars.
- EVERYTHING in this bill complies with CMS rules/regulations ensuring federal match.
- Policy changes can be addressed with current allocations - no increase in cost.
- SD services are generally less expensive than traditional provider managed services.

SDAN table at DD Day

- We will have a table in the lobby of the Graduate Hotel on DD Day
 - 8am-noon
- We will help you assemble packets of information for your meetings
- We will practice with you
- We will be your cheerleaders!
- **BRING COPIES OF YOUR 1-PAGER**

QUESTIONS? THOUGHTS?

Put your questions in the chat box or if you are unable to do that, use the “raise your hand” function.

We will answer as many questions as possible!

Reminder: Please feel free to email any private/sensitive information to info@marylandsds.org



Thank you!



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info@Marylandsds.org

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