



# The SDAN Advocate

October 2018

Self-Directed Advocacy Network of Maryland, Inc. (SDAN)

SDAN supports Marylanders with developmental disabilities in leading remarkable lives through self-direction. We uphold program integrity and participant choice and control of services. Please visit us at [www.marylandsds.org](http://www.marylandsds.org).

**Thank you to Governor Larry Hogan, Senator Addie Eckardt, and Delegate Kirill Reznik for taking action on behalf of Md.'s self-directing participants!**

## SDAN Headlines

**August 7:** The Request for Proposals for a single Fiscal Management Service (FMS RFP) was canceled. Had it been awarded as written, this costly contract would have restricted options for SD participants. SDAN will continue to work with state administrators to develop a new RFP that reflects stakeholder input.

**September 11:** SDAN representatives met with Governor Hogan's staff to describe our State's remarkable SD program and to convey specific concerns about its preservation. Deputy Chief of Staff Tiffany Robinson listened carefully to our concerns and acted on them.

**October 9:** SDAN representatives met with Secretary Carol Beatty of the State's Department of Disabilities. Mrs. Beatty, a member of the governor's cabinet, will continue to work with SDAN to ensure that stakeholder concerns are reflected in State programs.



*SDAN Board Members Alicia Wopat, Mat Rice, Carol Custer, Karen Bowers, and Meg Carter visit Governor Hogan's office.*

## **News You Need**

**Transportation Concerns:** On July 13, SDAN board members met with DDA staff regarding concerns about significant changes to crucial Transportation services as described in the Waiver renewal effective 7-1-18. A summary of that meeting is posted on the SDAN website: [marylandsds.org](http://marylandsds.org)

**EVV Update:** Congress passed a law to postpone the EVV (Electronic Visit Verification) mandate for all personal care services until January 2020. It was to go into effect in 2019. It is unclear how this delayed implementation date will affect Marylanders, as states have the option to proceed as planned. On November 7 the Center for Medicaid and Medicare Services will hold an EVV stakeholder forum from 1:00-3:00 p.m. SDAN has already submitted comments and will participate in the forum.

**Have you experienced the SIS—Supports Intensity Scale?** The SIS assessment will affect supports for everyone receiving DDA services. It is crucial that participants, advocates and family members learn about the SIS *and* participate in the required interview conducted by Telligen employees. SDAN will provide more information about the SIS as it becomes available. Meanwhile, visit the DDA website to find out more. <https://dda.health.maryland.gov/Pages/SIS.aspx>

**SDAN Meetings with DDA:** SDAN's 8-7-18 quarterly meeting with DDA was canceled. We look forward to our renewed dialogue on stakeholder concerns at our next meeting with DDA, scheduled for November 13.

**August 2 General Membership Meeting:** On August 2, about 30 participants and advocates attended the August SDAN general membership meeting in Odenton. Members volunteered to contact their legislators to support and preserve self-direction in Md.

Since that time, SDAN has received copies of over 20 letters sent to Governor Hogan by our members! THANK YOU to all who wrote. You made a difference!

**October 4 General Membership Meeting:** On October 4, about 40 participants and advocates attended the October SDAN general membership meeting in Savage. Individuals shared their experiences with self-direction and concerns related to the provision of services, especially Transportation.

## **SDAN Board Member Spotlight**

Get to Know Alicia Wopat, SDAN Board Member and Al Wopat, Self-Direction Participant

By Meg Carter

Alicia Merz Wopat never makes a commitment lightly. But once she does, she means it—whether that commitment involves raising a family or working to preserve and improve Maryland's self-direction program. Alicia is the mother of self-directing participant Albin Wopat and is the President of the SDAN Board. Since Al transitioned into self-direction she has worked every day to facilitate community integration and build self-advocacy skills. And since joining the Board in January 2018 she has worked to build consensus between SD advocates and state administrators. Her favorite question is, "What problem are we trying to solve here?" She firmly believes that if advocates were fully informed about the demands faced by administrators—and administrators understood the remarkable outcomes for SD participants as well as the tremendous challenges faced by participants and family advocates, we could work together to achieve better outcomes for everyone. Meanwhile, she has spoken up and spoken out for a self-direction program that is not only cost-effective and accountable but one that

remains true to its original promise of flexibility and person-centeredness.

Alicia's son Al, now 24, has autism and struggles with language. Alicia, her husband Dave and Al stumbled into self-direction in 2015 because the day program they selected was unable to meet his needs. They chose self-direction out of necessity and initially planned to transition into the traditional program as Al built skills. But self-direction was such a perfect fit that they have never looked back. Al's program exemplifies the principles of Supported Decision Making and centers on daily practice of self-advocacy skills. Al's team includes his parents, his private speech therapist, his private Board Certified Behavior Analyst (BCBA), his Coordinator of Community Services (CCS), his support broker, and staff members. With their support he has made remarkable progress. Alicia wants other participants to have the same opportunities that Al has. She firmly believes that the ability to hire highly qualified staff members has been key to Al's success. Both of Al's part-time employees are college graduates studying to be BCBA's. Al uses his self-directed budget to pay them well, and Alicia says it is well worth it.



“Because communication is such a challenge for individuals with autism, other people often underestimate them, so when I first learned about the concept of Supported Decision Making, I said, ‘that’s it, that’s what I have been looking for,’” Alicia remembers. Although most people see Supported Decision Making (SDM) only as an alternative to guardianship, Alicia insists it is much more than that. SDM allows an individual with a disability to work with a team and make his or her choices. Its fundamental principles are the same as those in self-direction. “We all use Supported Decision Making in our everyday lives,” she says. “None of us can function without it. We trust our doctors, lawyers and mechanics to help us make decisions we can’t make alone. Some people just need much more support than others.” Alicia believes that SDM offers a spectrum of support and should be available to all people with disabilities according to their needs—even those under guardianship. Al’s team works together to help him to both express and implement his goals. His words and actions are always treated with respect. Alicia believes the SDM team approach is a far better option for a self-directing participant like Al than appointing a “designated representative” who would make decisions on his behalf.

“Al is a mover and a doer,” Alicia explains. “He enjoys getting out and visiting venues such as Fort McHenry, the B & O Train Museum and the sensory friendly trail at Patapsco State Park.” Each day Al chooses what he will do and where he will go. Although he still uses his captioned picture menu, he now increasingly relies on verbal expression. And when all the right words aren’t there he finds creative ways to communicate his desires. One morning after apparently choosing to go to Robert E. Lee park in Baltimore, Al grew agitated and repeated the phrase “The Boy, The Boy” on the way south on Interstate 83 from his home in Monkton. Al’s staff member, Tim Lilley, finally pulled the car over to find out what was wrong. “Yes, I’m a boy

and you're a boy. What's the problem?" Al pulled out his menu and pointed to a picture of Prettyboy Reservoir in Northern Baltimore County. Tim promptly exited the expressway and headed north.

Since then Al has continued to demonstrate growth. He now regularly finds innovative ways to explain his desires to his employees. It took two days and several trips but Al persisted in finding ways to explain when he wanted a **Berger Cookie** at the Grilled Cheese & Company or a real **burger** at Five Guys, another favorite restaurant. And the day Al finally said, "I want a Burger, **I want the Guys!**" there was a small celebration at the Wopat house. Tim has also realized that Al understands the geography of his community surprisingly well. Over the summer, Al chose the Snickerdoodles bakery in Hampstead for lunch one afternoon, but when they reached the door he asked for pizza. Confused, Tim hesitated—until Al pointed out the New York J&P Italian restaurant a few doors down. It requires tremendous effort from his parents, therapists and staff members to help Al understand that WORDS give him the power to make his choices a reality. But there is more at stake than which park to visit or where to eat lunch. The team's real goal is to help Al to expand his self-advocacy to other areas of his life and to become a more active member of his own community.

Alicia also notes that while it's important to encourage Al to express his own needs and desires, it is equally important for his employees and family members to communicate information to him in ways he can process. Alicia develops detailed social stories to introduce Al to new places, and new activities so he always knows what to expect. "There are some activities, like medical care, that aren't optional," says Alicia, "and we need to anticipate those too." To prepare Al for a trip to the blood lab, Alicia created a story in words and pictures that detailed every step from

driving to the lab, meeting the tech, having blood drawn, and being "all done." Alicia believes that adequately preparing for medical procedures would reduce the need for sedation for many people—especially those with autism.

There is no doubt Al's self-directed program enriches his life and reflects federal mandates for community integration and person-centeredness. But it is not yet possible to measure the practical effects of his increasing ability to make his own choices. Will it preclude the need for emotionally and financially draining "behavior interventions" that are so frequently implemented for people with autism? Will it mean access to a less costly, more integrated living situation when his parents are no longer there to support him? Alicia believes so.

Meanwhile, Alicia continues to promote Self-Determination for Al and other self-directing participants, celebrating victories along the way. In September on yet another lunch date with Tim, Alicia recalls, "Al pointed to his plate and said 'Share!' How cool is that?"

## Upcoming SDAN Event!

Thursday December 6: next General Membership meeting at 11:00 a.m. at the Severn Branch Library, 2624 Annapolis Rd. Severn, Md. 21144.



*October 4<sup>th</sup> General Membership Meeting in Savage, MD.*