



The Advocate

July 2018

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

Welcome to the first edition of the Advocate!

The newsletter of the Self-Directed Advocacy Network

SDAN is committed to helping Marylanders with developmental disabilities lead remarkable lives through self-direction. We support program integrity and participant choice and control of services. Having initially focused on public advocacy, we now turn to public outreach. Our newsletters will provide stakeholders with news

SDAN Volunteer
Board

Alicia Wopat

Meg Carter

Carol Custer

Mat Rice

Marylynn Brennan

Karen Bowers

they can use. To learn more about SDAN's guiding principles, see the profile of Board member Mat Rice in this inaugural newsletter.

SDAN Updates:

SDAN's next regular meeting: Thursday, August 2, 11:00 a.m. at the Odenton Library, 1325 Annapolis Rd. Odenton, Md. 21113. All are welcome.

On May 3rd, SDAN board members met with DDA Deputy Director Bernard Simons and staff. The DDA response to questions we raised at that meeting is posted on the SDAN website, marylandsds.org.

On June 9th, 30 participants and advocates attended the June General Membership meeting in Columbia Maryland.

What every SD Participant should know: DDA has major changes planned for our state's self-direction program, which *will affect every self-directing participant*. Some changes are already

Since 2016, SDAN volunteers have

- Gathered input from stakeholders around the state
- Sponsored regular meetings to inform stakeholders of impending changes
- Testified at the state legislature
- Advocated for participants at DDA listening sessions
- Conducted a successful petition drive to halt "Amendment 2"
- Organized work groups to make recommendations on program changes
- Submitted detailed input to DDA and CMS on the Waiver renewal draft
- Participated in regular meetings with DDA administrators

accomplished while others are still in process. All participants and family members should be aware of the following four crucial issues.

1. Revisions to the self-direction option that appear in the recently approved HCBS Waiver.

The new Waiver is scheduled to take full effect by July 1, 2019. It involves major changes to DDA's self-directed option.

2. The Request for Proposals for a new fiscal management service to administer both DDA's self-directed option and the Office of Health Service's Community First Choice program. DDA and OHS are seeking a single large vendor which operates on an economy of scale to replace our current FMS providers. In addition to acting as the participant's "bank" and employer agent, this new provider would take on many non-administrative duties that will affect participant programs.

3. Waiver implementation policies and regulations currently being drafted by DDA. These regulations and policies will dictate *how* the self-directed program described in the Waiver will actually be applied. To date none of these policies have been provided to stakeholders. *SDAN will share information on this crucial topic when DDA makes it available.*

4. The Electronic Visit Verification system. EVV results from the 21st Century Cures Act and is required by federal law. It will eventually be implemented in Md. This system will dictate how employees submit their hours and how employers can track those submissions. SDAN will provide more information on EVV as it develops.

To learn more about these issues, please visit marylandsds.org.

SDAN Board Member Spotlight Mat Rice- Bulldog and Bridge Builder

By Meg Carter

"Doctors must get paid extra to use the word 'Never,'" says Mat Rice. "Because they said it an awful lot to my Mom when I was born. Never, Never, Never."

"He will never walk."
"He will never talk."
"He will never be independent."

AND

"You should never take him home-- He would be better off in an institution."
Mat's mom did take him home, and by doing so she changed more than one life. "When I was born in 1986 I was diagnosed with cerebral palsy," Mat explains, "and at the time, they didn't even yet know that I was also legally blind. That diagnosis came later."

A self-direction participant, Mat Rice has been advocating for himself for as long as he can remember. Now a Public Policy Specialist at People on the Go of Maryland, Member of the Developmental Disabilities Coalition, a Board Member of MACS (Md. Association of Community Services), and an SDAN Board Member, Mat works daily to remove barriers that prevent people with disabilities from living freely. He also works to strengthen connections among people with disabilities advocates, family members and policy makers throughout the State. Progress is slower than he would like but Mat is tenacious. Mat lives and works by three core principles.

1. Expectations matter.
2. Everyone can self-advocate.
3. We are all connected.

Mat's mom pushed him from the start towards self-reliance and self-advocacy. "She is the greatest influence in my life, he says. She always said, 'I'm not going to be here forever,' and I realized that whether I wanted it or not, I had to become independent." When doctors wanted to include 10-year-old Mat in a study involving a neurosurgery Mat's mom included him in the decision. Mat remembers, "There were all these white-coated doctors sitting around the conference table, and they were talking to *her*. She surprised them by turning to me and saying, 'what do *you* think, Mat?'" He

now both laughs and grimaces remembering that moment, “I told them I didn’t like the idea. And we didn’t do the surgery.” That early experience shaped Mat’s view of self-advocacy. He believes that given appropriate supports everyone is capable of some level of self-advocacy. Mat applauds parents who speak up and speak out for those they love, but he also offers a caveat, warning parents not to confuse their own desires with those of their adult children. In Mat’s view, personal autonomy is a precious commodity, one that should be carefully guarded. “Parents sometimes say I am my child’s voice,” says Mat. “That bothers me because no matter how hard you try, you can never really know how it feels to *be* that person.” Mat believes that people who support individuals who face communication challenges must do all they can to gain input from the person, including observing behavior and using augmented communication devices and strategies to discover the individual’s desires and needs. We should never assume that individuals have no desire to participate in decisions that affect their lives.

The oldest of four children, Mat grew up in Frederick, Md. His Mom regularly reminded him that he needed to look out for his younger, able-bodied, siblings. He received special education services at Frederick County’s inclusive public schools. “People don’t believe it now because I talk so much, but I actually needed a lot of speech therapy to learn to speak.” He worked hard and made the honor roll twice. But by age 13 it was clear that despite his outstanding academic progress, he needed serious help with essential daily living skills. Mat and his mom agreed that he should attend the residential program at the Md. School for the Blind near Parkville, Md. Mat now credits MSB with teaching him the life skills he needed but describes his “love-hate relationship” with MSB. “I went there as an honor student, and they told me soon after I arrived that I would be on a certificate track because there was no point in working towards a diploma.” At that time the

only workshops in the school involved paper shredding and can crushing. With his mom’s support, Mat insisted on following an academic track while continuing to attend MSB. Some staff supported his ambitions, and some were naysayers. He and his mom negotiated a dual-enrollment at both MSB and the local public schools so Mat could get all of the services he needed.

Eventually Mat used Family Support Services funding to get an apartment of his own in Towson while he attended MSB and Parkville High.” A lot of MSB people told me ‘You’re not ready for your own apartment. Don’t do it!’” Mat acknowledges now that in some ways they may have been right. But he wonders if any of us are ever *ready* for the big challenges in our lives. We all learn from our mistakes—and why should people with disabilities be any different.

“I’ve made *a lot* of mistakes,” he laughs. Living in his own apartment with few supports was difficult. “Getting myself up as early as I had to every morning was really hard, and sometimes I



SDAN board member, Mat Rice

missed the bus to MSB. Finally, an administrator told me that if it kept happening I might not graduate from Parkville.” Soon after that warning, Mat missed the bus again. He decided to take a fixed line metro

bus that accommodated his motorized wheelchair, and could drop him at the entrance to the MSB campus. Confident that he was familiar with the obstacles he needed to

negotiate to get to his classroom, he forged ahead. But he was unaware that one of the campus streets he needed to cross lacked a sidewalk cutout for his wheelchair. Unable to see the hazard ahead, he drove his chair off the curb and overturned in the road. “The really embarrassing thing is that the person who stopped his car to help me was one of my biggest detractors.”

Mat laughs about the incident now, but believes it’s a great example of how people learn. He acknowledges that mitigating risk is important but stresses the need to balance risk mitigation with personal autonomy. Should family members ask themselves if they are overprotecting their loved ones with disabilities? He thinks so. He believes that people with disabilities have the same right to learn from their mistakes as anyone else. And learning from our mistakes is as natural a part of the human experience as is maintaining family bonds throughout our lifetimes.

After graduation from Parkville High in 2007 Mat took some classes at CCBC, but he struggled with the reading load because of visual tracking. He began self-directing his services in 2009 and eventually took a job as support broker with Shared Supports, where he learned to extend lessons from his own life to improving self-direction programs for others. He was thrilled in 2012 to land a life-changing position as a legislative intern with People On the Go, which specializes in promoting self-advocacy for people with disabilities. P.O.G. was the driving force in passing the Ken Capone Equal Employment Act, which Governor Hogan signed into law in April 2016. Other important issues addressed by P.O.G. are crisis resolution for individuals in dire need of services, and civil rights protections for people who are subject to behavior intervention protocols.

Mat acknowledges that people with disabilities need varying levels and differing kinds of support. However, he believes we must focus on

providing the assistance people need to thrive, not on labels that de-emphasize our common humanity. Mat’s core value of bringing people together and his belief in the value of self-direction are the factors that moved him to join SDAN Board in May of 2017. Since then, he has worked to safeguard the autonomy of each participant and to preserve and improve Maryland’s Self-Direction program. Mat’s mother should be proud. Her oldest son is changing lives every day.



Upcoming SDAN Event!



*General
Membership
meeting August
2nd at 11am
Odenton Library
1325 Annapolis
Rd., Odenton, MD 21113.*

SDAN is run entirely by volunteers

**We need you—as much as you
need us!**

Support self-direction by joining us at
marylandsds.org, or emailing
info@marylandsds.org.

Our mailing address is:

Self-Directed Advocacy Network of Maryland, Inc.
3527 Chick Lane
Knoxville, MD 21758