

Nuts and Bolts of State Advocacy

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MARYLAND DOWN SYNDROME
ADVOCACY COALITION



Who We Are

Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of self-advocates, family members, allies, and Down syndrome organizations from across the state of Maryland that are committed to ensuring that individuals with Down syndrome have the opportunity, encouragement, and support required to lead a self-determined life.

- History:
 - Founded in 2007
 - Between 2007-2015: Spearheaded legislation in Maryland legislature on Universal Design for Learning and providing accurate information to parents with a prenatal or postnatal diagnosis
 - Advocated at the University of Maryland for a Comprehensive Transition Program for individuals with ID/DD; program established 2021
 - Relunched in 2021
- Membership:
 - Currently 148 members from 19 of Maryland's 24 counties
 - Our members are constituents of 41 of Maryland's 47 State Senators and 111 of Maryland's 141 State Delegates



How We Are Organized

Steering Committee meets monthly:

- Representatives from the 5 DSAs in Maryland
- Self- Advocate Leaders
- Other experts and leaders in our community

Work Groups meet monthly:

- Birth-5 (New!) led by Liz and Amanda Mummert
- K-12 Education led by Liz and Lauren Ochalek
- Adults led by Adrian and Heather Sachs

Why are state coalitions important?

Speak with one voice for the Down syndrome community at the state level – with state agencies, legislators, governor – based on our [guiding principles](#)

Help advocates develop advocacy skills

- Trainings (e.g., how to tell your story, one-pagers)
- Providing opportunities for speaking, testifying, connecting with policy makers

Build relationships and connections

- Among our Down syndrome organizations
- Among self-advocates, families, and professionals
- Between Maryland's DS community and other disability organizations and coalitions, national organizations, and legislators and policymakers

What We've Done So Far



- Developed Voters' Guide ([English](#), [Spanish](#), [Audio](#))
- Active member of Education Advocacy Coalition
- Formed a coalition on IDD/mental health
- Submit testimony and meet with state legislators to support our Legislative Priorities (e.g., [2023](#))
- Respond to public comment opportunities (e.g., 1% Waiver, SPP/APR)
- Find opportunities and prepare self-advocates to testify and tell their stories

What We've Done So Far... World Down Syndrome Day



It started as a celebration and each year it's grown...

- Training workshops
- Advocacy Day in state capital
- Self-advocate speeches



World Down Syndrome Day 2024



NATIONAL
DOWN SYNDROME
CONGRESS

What We've Done So Far...

Supporting Advocacy at Walks



- Tabling for MDAC
- Inviting federal officials
- Led to a meeting in Washington with Senator Chris Van Hollen for MDAC representatives from across the state



What We've Done So Far...

Testifying at State Board of Education



In June 2023, 27 MDAC members including 10 self-advocates (ages 5–21), representing 6 Maryland counties attended the Maryland State Board of Education meeting to deliver a simple message: *“Every student has the right to attend school with their siblings, neighbors, and friends.”*

- 2 self-advocates and 2 parents participated in public comment (See [MDAC's YouTube Page](#))
- MDAC delivered stories (letters) from 15 Maryland families and a set of asks to the Board



What's Next

- Recruiting more self-advocates
- Preparing for the election in November 2024
 - Updating our Voters' Guide
 - Encouraging voter registration
 - Participating with coalition partners in candidate forums
- Preparing for 2025 Maryland Legislative Session
 - Considering legislative priorities
 - Planning additional elements for WDSD 2025

Thank you!

Connect with MDAC!

Email: marylanddsadvocacycoalition@gmail.com

Website: <https://marylanddsadvocacycoalition.org/>

Facebook:

<https://www.facebook.com/MarylandDownSyndromeAdvocacyCoalition>

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