ADVOCACY WORKSHOP

MARCH 27 & 28, 2026 • WORCESTER, MA

BRIGHTER FUTURES Conference

Your Voice, Your Power

Advocacy That Makes a Difference

National Down Syndrome Society • Massachusetts Down Syndrome Congress • The Arc of Massachusetts

national down syndrome society ndss

mdsc MASSACHUSETTS DOWN SYNDROME CONGRESS

The Arc Massachusetts

YOUR PRESENTERS

Maureen Gallagher

Massachusetts Down Syndrome Congress

Kandi Pickard

National Down Syndrome Society

Maura Sullivan

The Arc of Massachusetts

Session Overview

Maureen

- Why advocacy matters now more than ever
- Policy priorities at state & national levels
- Getting involved & sharing your story
- Staying informed
- Q & A

Why Advocacy Matters

Maureen

- Policies don’t change on their own—people change them
- Lawmakers respond to the voices they hear
- Every story, every call, every action makes a difference
- Advocacy turns lived experience into meaningful change

THIS IS A PIVOTAL MOMENT FOR ADVOCACY

Why Speaking Up Is Critical Right Now

Policies Are Shifting

Decisions affecting people with Down syndrome, IDD, and Autism are happening now

Funding Is at Stake

SNAP, Medicaid, IDEA, and other vital supports are under pressure

Silence Has Consequences

Legislators need to hear from real families and self-advocates — silence can mean lost services

Maureen

Shifting Policies: what’s happening in DC

Federal decisions are reshaping disability policy

- **The OBBBA is Law**: The "One Big Beautiful Bill Act" (OBBBA) was signed into law on **July 4, 2025**. It delivered significant cuts and fundamental changes to health insurance and Medicaid-funded programs.
- **Medicaid Work Mandates**: National work requirements are now federal law. Most "able-bodied" adults (ages 19 - 64) must complete **80 hours of work** or "community engagement" per month to keep coverage.
- **More Frequent Checks**: Federal law now requires states to conduct Medicaid eligibility checks **every six months** instead of annually.
- **SNAP (Food Stamps) Changes**: Work requirements were expanded to adults up to **age 64**. States are currently implementing these rules, with many beginning enforcement in late 2025.

Funding at Stake: how it affects real people

- **Essential Lifelines**: These programs are **not extras**—they are foundational for independence.
    - **Medicaid**: Covers healthcare, therapies, and Home & Community-Based Services (HCBS) that allow people to live at home.
    - **SNAP**: Ensures basic nutrition for millions of families.
    - **IDEA**: Funds school-based supports, therapies, and **IEPs** for students.
- **The Impact of Cuts**: Reductions lead to longer waitlists, increased financial strain on families, and a loss of the Direct Support Workforce (caregivers).
- **Risk of Coverage Loss**: The Congressional Budget Office (CBO) projects that over 5 million people could lose Medicaid coverage and 2.4 million could lose SNAP benefits over the next decade due to these specific policy shifts.

Why Speaking Up Matters Right Now

The Power of Your Voice

- **Stories Over Data**: While data is important, **real stories from families and self-advocates** are what actually influence legislative votes.
- **Challenging Assumptions**: When communities stay silent, policymakers often assume programs aren't needed or that cuts won't have real-world consequences.
- **Visibility**: Advocacy ensures that people with disabilities are **seen, heard, and prioritized** in every budget negotiation.

Actionable Opportunities for Advocacy

- Because the U.S. Department of Health and Human Services must issue final implementation rules by June 1, 2026, the window to influence how "disability" and "medical frailty" are defined is closing.
- **FY 2027 Budget**: Negotiations for next year's funding are beginning. Lawmakers need to hear that **HCBS and IDEA funding** must be protected to prevent service gaps.
- **State-Level Implementation**: States have discretion until **January 1, 2027**, on how they roll out these changes. Advocates can push for:
  - Simplified paperwork to prevent "procedural" losses of coverage.
  - Automated renewals using existing data to lower the burden on families.

MDSC: Making Systemic Change

Maureen

One of the most effective Down syndrome advocacy organizations in the country —
7 groundbreaking pieces of legislation passed in the past 13 years.

- **Down Syndrome Information Act**
- **National Background Check Bill**
- **Real Lives Bill**
- **ABLE Act (Federal)**

- **Organ Transplant Bill**
- **Higher Education Bill**
- **ABA Therapy Bill**
- **2026 Top Priority - Human Services Workforce**

Building Relationships and Sharing our Stories

Maureen

Effective Strategies to Share Your Stories and Build Alliances

- Organize Advocacy Days at the Massachusetts State House
- Build alliances with key legislators to sponsor bills, advocate for our community
- Testify at critical hearings to share family and self-advocate stories
- Work with other Advocacy Organizations to align advocacy efforts

- In addition to legislation, follow budget process so that key programs you rely on get fully funded
- Volunteer to serve on key Committees where you can be part of critical conversations
- Meet and greet your State and Federal Legislators to share what's important to you and your family

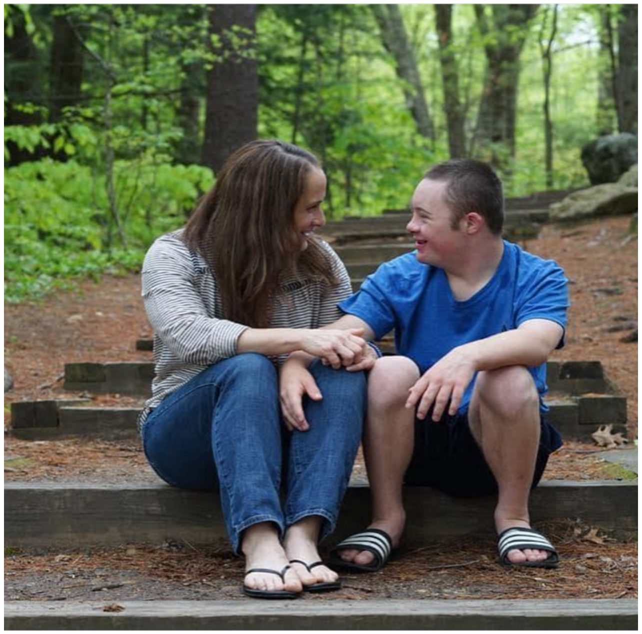
Voices That Made a Difference

Matthew Cullen

Ipswich, Massachusetts

- Matt Cullen, 29, of Ipswich is a 2018 graduate of Salem State University's MAICEI program.
- Through his advocacy for Massachusetts' landmark Higher Education Bill — The law removes barriers for people with IDD and Autism attending state colleges and is now a model for other states.
- Matt has spoken at MDSC's Down Syndrome Advocacy Day, testified twice before the Joint Committee on Education, and met privately with legislative leadership.
- He and his mom Sarah, developed a close relationship with their State Senator.
- At NDSS's Champions of Change ceremony in Washington — where Congresswoman Katherine Clark presented his 2023 Advocacy award, Matt said: *"It is not just about me. It's about what I can do for our greater community. Dreams do come true!"*

Voices That Made a Difference



Emily & Cole LaMarca

Ashburnham, MA

Emily has been a dedicated and passionate member of the MDSC since her son Cole was born 19 years ago, an experience that she says flipped her world upside down in the best possible way.

Over the years, Emily has become a tireless advocate, mentor, and leader within the MDSC community and beyond, participating in fundraising events like the Buddy Walk, Boston Marathon, and Falmouth Road Race, serving as a Parent Mentor in the Parent's First Call Program, and contributing her voice on the Government Affairs Committee.

Her advocacy is deeply rooted in their personal journey: when Cole was ten, he experienced restraint and seclusion in school, leaving a lasting impact on his sense of safety and well-being.

Although Emily could not change what he went through, she was determined to turn that experience into meaningful change. She connected with MDSC, state legislators, family members and others to better understand these practices and push for reform.

Today, Emily continues to use Cole's story to drive statewide efforts to reduce and eliminate restraint and seclusion, shaping policies, advocating for funding for training, and creating safer, more supportive environments for all children—while inspiring others to raise their voices for change.

Voices That Made a Difference

The Spittles

Salem, Massachusetts

2014 — Twin daughters Emma Grace and Sophia Joy born; both spend first four months in the NICU.

2015–2021 — Through many hospitalizations and Covid isolation, MDSC provides consistent support, resources, and community.

2020–2021 — MDSC successfully advocates for people with Down syndrome to be prioritized for Covid vaccines.

2022 — Jeremy joins MDSC's Government Affairs Committee and plays a critical role shepherding the landmark Higher Education Bill and the more recent ABA bill through the state legislature.

"Thanks to the work of MDSC, the future for our family and thousands of others is bright." ***Jeremy and Mandee Spittle***

From Advocacy to Law

National Policy Priorities

Kandi Pickard
National Down Syndrome Society (NDSS)

NDSS advocates for federal policies and regulations that positively impact people with Down syndrome across the country.

- Organ Transplant Discrimination Prevention
- Raising SSI Asset Limits and Eliminating the Marriage Penalty
- Medicaid/HCBS
- Special Education Funding and Services
- Alzheimer's Disease Research and Treatment
- Removing the R-word from Federal Language
- Eliminating Subminimum Wage

Federal Legislative Successes

National Down Syndrome Society

Key Wins

- Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act
- ENABLE Act
- ABLE to Work Act
- ABLE Financial Planning Act
- National Alzheimer's Project Act (NAPA) Reauthorization Act

- Congenital Heart Futures Reauthorization Act
- ACE Kids Act
- Kevin and Avonte's Law
- Charlotte Woodward Organ Transplant Discrimination Prevention Act (House passage)

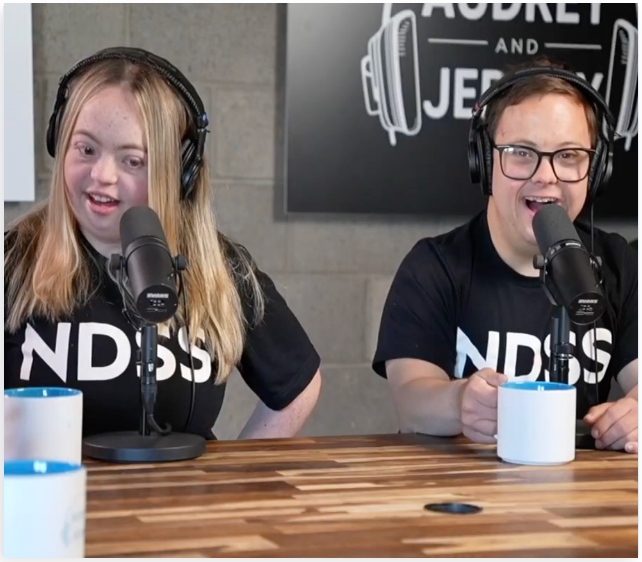
Emerging/Future Policy Priorities

National Down Syndrome Society

Emerging Priorities

- Housing
- Transportation / Autonomous Vehicles (AVs)
- Artificial Intelligence (AI)
- Direct Care Workforce

Voices That Made a Difference



Audrey and Jeremy

California

January 2025 – Audrey Presby and Jeremy Fraser, a young couple from California, launch their podcast, The Audrey and Jeremy Show.

April 2025 – Audrey and Jeremy attend the NDSS Down Syndrome Advocacy Conference.

June 2025 – Energized by their experience at the Advocacy Conference, Audrey and Jeremy invite NDSS staff to join their podcast to discuss NDSS' policy priorities. The post goes viral on social media, receiving over 1 million views on Instagram.

June 2025 – Audrey and Jeremy go on MSNBC, with NDSS CEO Kandi Pickard, to discuss the proposed Medicaid cuts in the One Big Beautiful Bill Act.

2026 – Audrey and Jeremy continue to stay engaged with NDSS and are raising awareness and changing perceptions of Down syndrome on their podcast.

national down syndrome society®

Down Syndrome Advocacy Conference

MAY 11-13, 2026 | WASHINGTON, D.C.

Join us for the annual Down Syndrome Advocacy Conference to make a difference for the Down syndrome community on Capitol Hill!

For more information and registration details, scan the QR code or the visit website below.

https://ndss.org/down-syndrome-advocacy-conference

State & Local Priorities

Maura Sullivan
The Arc of MA

State and regional priorities

The Human Services Workforce

Home and Community Based Services

Housing

Healthcare Equity

Top Policy Priority: Human Service Workforce

- **The Goal:** Require wage rates for direct care staff and support professionals meet or exceed the 75th percentile of the Bureau of Labor Statistics (BLS) for comparable jobs.
- **Who It Impacts:** This bill targets frontline workers, supervisors, and clinicians - the backbone of day programs and group homes - while explicitly excluding top-level executive raises.
- **The Benefit:** Competitive wages lead to lower turnover and higher safety for the individuals receiving care. Importantly it will reduce waitlists. With immigration impact on HS workforce, we will have worsening vacancies and need higher rates of pay to recruit and retain.

Why Speaking Up Matters Right Now

- **Legislative Momentum:** in MA, as of January 29, 2026, this bill was reported favorably and referred to the Joint Committee on Health Care Financing.
- **Final Budget Deadline:** Lawmakers are making key decisions on FY 2027 funding right now. Without pressure from constituents, this vital wage increase could be deferred.
- **Countering Silence:** If policymakers don't hear real stories about waitlists and staff shortages, they may assume the current system is "good enough"

Organizational Success

Key Wins

- Workforce Rate Increases, Budget Advocacy
- Abuser Registry Law
- Police Training in Autism and IDD Law
- Operation House Call, Inclusive Health Care Law
- Affordable Homes Act, Accessory Dwelling Units

Voices That Made a Difference

Isaiah Lombardo

Harvard MEdical School 2025

Isaiah has been a star advocate and co-teacher for The Arc's Operation House Call for over 15 years!

Operation House Call (OHC) teaches students in medical and graduate nursing schools, the essential skills and mindsets to enhance the health care of people with autism and other intellectual and developmental disabilities (IDD).

Our network of families and students provides crucial testimony in support of bills that will improve health equity for individuals with IDD and autism.

The Arc worked to pass legislation that codifies OHC into law. In our partnership with the Massachusetts Department of Public Health (DPH), schools can be certified for incorporating the full 6-hour OHC program into their curriculum.

Voices That Made a Difference

SDM Coalition

Massachusetts State House

The Arc's Supported Decision Making Coalition is making their voices heard with the MA Legislature have moved the SDM bill into a viable position to pass this session.

Supported decision-making (SDM) allows adults, including those with disabilities and elders, to maintain their rights, dignity, and independence by choosing one or more trusted supporters to aid in making decisions about their lives.

These adult self-advocates have become champions for SDM, perfecting their testimony in front of the legislature and working as a united coalition to negotiate changes in the bill and understanding the often complex legislative process.

Their passionate stories demonstrate their deep desire to pass SDM and the impact it would have on their lives and their community.

From Parent to Advocate: Our Stories

Maureen Gallagher

MDSC

Kandi Pickard

NDSS

Maura Sullivan

The Arc of Massachusetts

Getting Involved: Practical Steps

- Write emails to legislators
- Join campaigns and coalitions
- Attend advocacy events
- Tell YOUR story
- Testify at hearings
- Sign up for action alerts and stay informed

Take Action: Legislative Action Centers

MDSC

URGENT ACTION ALERT: Protect Special Education and Disability Supports — Reverse the OSEP and RSA Layoffs

On October 10th, nearly all staff within the Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA) were notified that they will be laid off, effective December 9, 2025.OSEP implements the Individuals with Disabilities Education Act...

URGENT: Tell Congress to Protect Medicaid and SNAP!

Congress is advancing a bill that would threaten essential programs like Medicaid and SNAP, and it could be voted on as early as today or tomorrow. A version of this bill has already passed the House. If passed, this legislation would cut $1 trillion from Medicaid - nearly...

Action Alert: Protect Access to Food for People with Disabilities & Their Families

Food is NOT optional. Congress must act now to restore food assistance for millions of Americans. As of November 1, 2025, many individuals and families who rely on food assistance have had their SNAP benefits suspended due to inaction at the federal level.Programs like the...

NDSS

NDSS Action Alerts

National Call-In Day to Protect IDEA in the Department of Education

NDSS is joining other disability advocacy groups to ensure IDEA stays within the U.S. Department of Education!

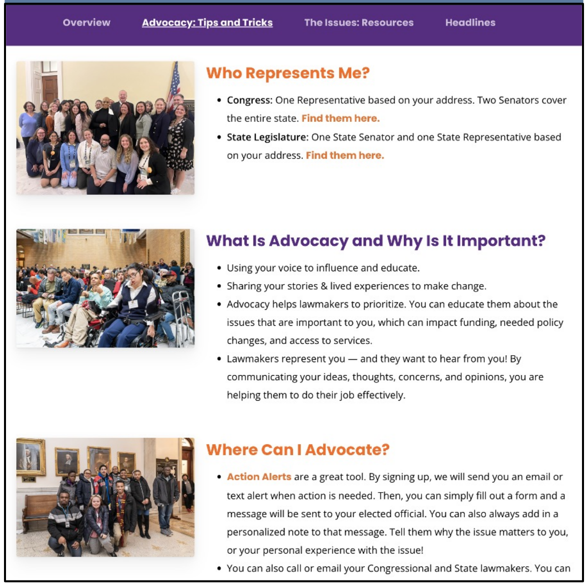
Take Action to Protect Section 504!

Nine states are suing the Department of Health and Human Services over updated Section 504 rules from 2024.

Take action to end harmful restraint and seclusion practices in schools!

Ask your Members of Congress to support the Keeping All Students Safe Act, which will protect students with disabilities from dangerous restraint and seclusion practices in schools.

The Arc of MA



Who Represents Me?

- **Congress:** One Representative based on your address. Two Senators cover the entire state. Find them here.
- **State Legislature:** One State Senator and one State Representative based on your address. Find them here.

What Is Advocacy and Why Is It Important?

- Using your voice to influence and educate.
- Sharing your stories & lived experiences to make change.
- Advocacy helps lawmakers to prioritize. You can educate them about the issues that are important to you, which can impact funding, needed policy changes, and access to services.
- Lawmakers represent you — and they want to hear from you! By communicating your ideas, thoughts, concerns, and opinions, you are helping them to do their job effectively.

Where Can I Advocate?

- Action Alerts are a great tool. By signing up, we will send you an email or text alert when action is needed. Then, you can simply fill out a form and a message will be sent to your elected official. You can also always add in a personalized note to that message. Tell them why the issue matters to you, or your personal experience with the issue!
- You can also call or email your Congressional and State lawmakers. You can

What You Can Do Today

- Sign up for action alerts from NDSS, MDSC, and The Arc of Massachusetts
- Subscribe to advocacy emails and legislative updates
- Follow key legislation as it develops
- Ask how you can help — each organization has opportunities to get involved

YOUR VOICE MATTERS.
YOUR STORY IS POWERFUL.

Change happens when people speak up.
Together, we can shape a better future.

Whether you're new to advocacy or a seasoned advocate, you'll leave with concrete tools and renewed confidence to make your voice heard.

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Questions & Discussion

Contact Us

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