UNSTOPPABLE:
Transforming Lives, One Family at a Time

MASSACHUSETTS DOWN SYNDROME CONGRESS

2024 ANNUAL REPORT

MESSAGE FROM OUR LEADERSHIP

Together We Are Unstoppable: A Year of Community-Driven Change

For more than four decades, we at MDSC have been absolutely UNSTOPPABLE in our determination to innovate, improve, and push boundaries to create meaningful, lasting change in the lives of people with Down syndrome and their families.

With this Annual Report, we are proud to celebrate our organizational and community accomplishments which proved that, collectively and individually, we are truly UNSTOPPABLE when we work together.

After more than a decade of tireless advocacy, we have once again demonstrated our UNSTOPPABLE ability to achieve major legislative victories on the state level when Governor Maura Healey signed MDSC's ABA Therapy Bill into law. This landmark legislation once and for all requires private insurance and MassHealth to cover the cost of in-home Applied Behavioral Analysis therapy for individuals with Down syndrome — correcting a critical gap that previously mandated ABA coverage only for those in our community also diagnosed with autism. Beginning in January 2026, this law will expand access to proven, evidence-based intervention that improves behavior, communication, and daily living skills.

We have been UNSTOPPABLE in strengthening our employment programs, hosting our first-ever Your Next Star Academy Graduate Refresher Course by bringing together graduates from seven academies in collaboration with PwC Boston. This year, we are celebrating the 10-year anniversary of our Philip Donahue Your Next Star Employment Center, one of MDSC's four Centers of Excellence.

Maureen Gallagher, M.S.

Stacy R. Lindborg, Ph.D.

We have been UNSTOPPABLE in addressing lifespan needs with our groundbreaking new initiative for aging adults with Down syndrome and their families. This critical work will go beyond our traditional services and address a significant gap in programmatic offerings for our aging loved ones and their families. This year, we piloted our first Caregiver Support Group for parents and caregivers of aging loved ones experiencing cognitive changes, including dementia due to Alzheimer's disease. We also launched a new Aging Advisory Committee to help guide our new work in providing comprehensive, specialized support and resources tailored to the needs of aging adults with Down syndrome.

We have been UNSTOPPABLE in expanding our national leadership role. Our National Parents First Call Center developed a novel collaboration with Best Buddies International's new Eunie's Buddies program, providing training on our gold standard mentoring support program so that new and expectant families nationwide navigating the journey of raising a child with intellectual or developmental disabilities have the critical supports and resources they need. And, our National Parents First Call Training Center has continued to expand our replication model; having now trained 35 organizations in 21 states since 2011.

Cover photo by Eddie Vargas Photography

We are proud to be recognized this year with two national awards. In February, Down Syndrome Affiliates in Action, representing 80 member organizations around the country, honored MDSC at their national conference with their *Best Advocacy or Policy Initiative Award* for passing the ABA Bill and other advocacy efforts. And over this summer, during our Down Syndrome Awareness Day celebration at Fenway in collaboration with the Red Sox, the Professional Baseball Athletics Trainers Association presented MDSC with their *Ability Transcends Challenges Award*. The commendation, which honors champions of disability employment in 20 MLB cities, recognized the impact of our Your Next Star Employment initiative in changing the hiring landscape for people with Down syndrome and other disabilities.

Of course, day in and day out we continue to be UNSTOPPABLE in delivering our foundational programs that provide support to families across Massachusetts. Our signature Parents First Call Program continues to serve as a lifeline for families, with our trained parent mentors available 24/7 to provide guidance and support. We successfully hosted our two major annual conferences, bringing together national and international experts to share the latest research and best practices with our community. Our Buddy Walk, Bruins partnership and Boston Marathon programs celebrated our community while raising critical awareness. Through our Self Advocate programs, including Advocates in Motion and Self Advocate Advisory Council, we empowered teens and adults with Down syndrome to develop leadership skills and advocate for themselves. And through MDSC Cares, we provided essential support packages to families navigating extended hospital stays and complex medical care for their children, ensuring no family faces these challenges alone. These core programs remain the heartbeat of our organization, making a real difference in the lives of thousands of our families every year.

Today, while we celebrate these achievements, we also remain UNSTOPPABLE in preparing for future challenges. With significant changes being proposed in federal disability policy, MDSC is working closely with our local and national partners to advocate for critical funding for education, health care, research and community-based services that are essential for our loved ones to lead meaningful fulfilling lives. With our collective voices and by sharing our personal stories with legislators, we aim to help them understand what's at stake when they make funding and policy decisions.

More than ever, we need your support to continue to be UNSTOPPABLE in our mission to meaningfully improve the lives of people with Down syndrome and their families. Whether you served in a leadership role, significantly contributed to one of our events, hosted a community fundraiser, made a contribution to one of our many programs, or funded a grant to make our work possible, we salute you for your UNSTOPPABLE support.

Your commitment, partnership and trust ensure that we can offer the very best programs to meet the needs of the entire Down syndrome community in Massachusetts and beyond.

As we have proven time and again, when we work together as a community, we are truly UNSTOPPABLE in creating the meaningful change our loved ones deserve!

Maureen Gallagher, M.S.
Executive Director, MDSC

Stacy Lindborg

Stacy R. Lindborg, Ph.D.
Board Chair, MDSC

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DOWN SYNDROME
CONGRESS

ABOUT THE MDSC

For four decades, the Massachusetts Down Syndrome Congress has fought to ensure that all individuals in Massachusetts with Down syndrome are valued, included, and given every opportunity to pursue fulfilling lives.

Today, MDSC has over 8,000 members, a professional Board of Directors, a dynamic Management Team, and a vision to ensure that every person with Down syndrome has the opportunity to reach his or her full potential.

Our broad array of programs, our four Centers of Excellence and our comprehensive Resource Library, serve people with Down syndrome throughout their lifespans; and families throughout the state and beyond, putting MDSC on the cutting edge of Down syndrome advocacy nationwide.

MISSION STATEMENT

To ensure that individuals with Down syndrome in Massachusetts are valued, included, and given the opportunities to pursue fulfilling lives by providing information, networking opportunities, and advocacy for people with Down syndrome and their families, educators, health care professionals, and the community-at-large.

OUR VISION

MDSC will be sought after locally, nationally and internationally for its forward-thinking approaches, collaborative partnerships, and proven excellence in advancing opportunities for individuals with Down syndrome to reach their full potential across their lifespan.

OUR PURPOSES

- To engage, educate, and involve the public in advancing the possibilities and potential of all people with Down syndrome throughout the lifespan.
- To advocate for improved systemic change, policy and sustainable funding sources to support advances in community inclusion, higher education, employment, housing and benefit programs for people with Down syndrome
- To foster an environment of belonging and increase access to programs and services for diverse populations within the Down syndrome community.
- To continue to create and foster opportunities for meaningful employment and ensure the availability of resources to support meaningful societal engagement for adults with Down syndrome in the community.
- To enable networking, social/friendship opportunities and partnerships, in person and virtually, to support all people with Down syndrome and their families, including aging individuals and their families/caregivers.
- To advocate that all individuals with Down syndrome have high quality education, which includes transition planning and life-long learning.
- To advocate for all individuals with Down syndrome to have access to high quality medical, dental and behavioral services and research opportunities, leading to lifelong health and well-being.
- To empower all people with Down syndrome to have the opportunity to become self advocates.
- To continue to ensure that expectant and new families receive accurate and up-to-date information and desired supports.
- To maintain the development and dissemination of information and best practices through the Resource Library and MDSC's Centers of Excellence, covering the lifespan of individuals with Down syndrome.


UnstoppABLE!
BUDDYWALK
2024


UnstoppABLE!
BUDDYWALK
2024

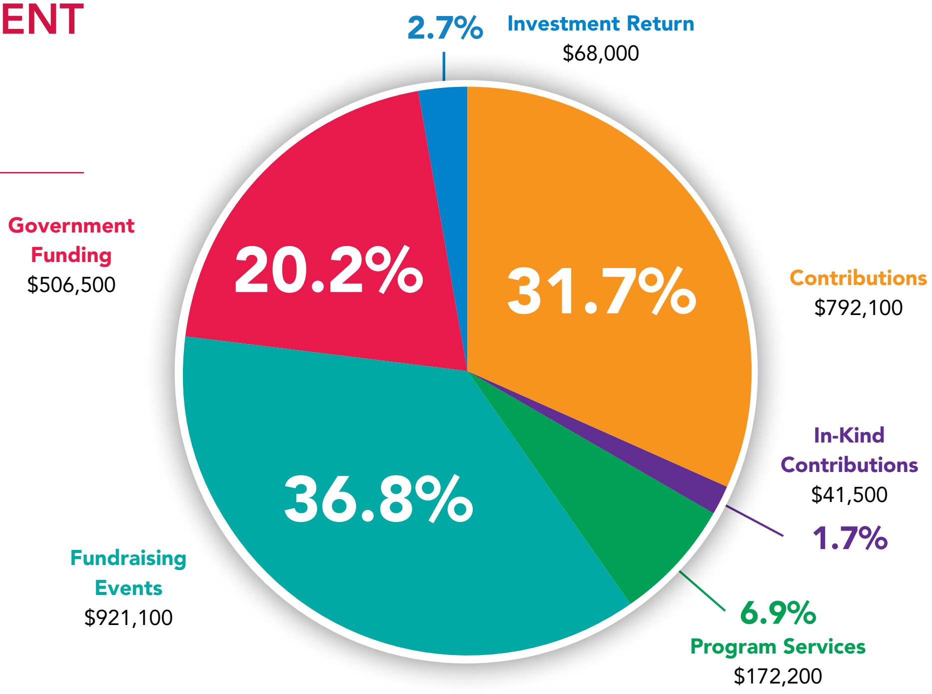
2024 FINANCIAL STATEMENT

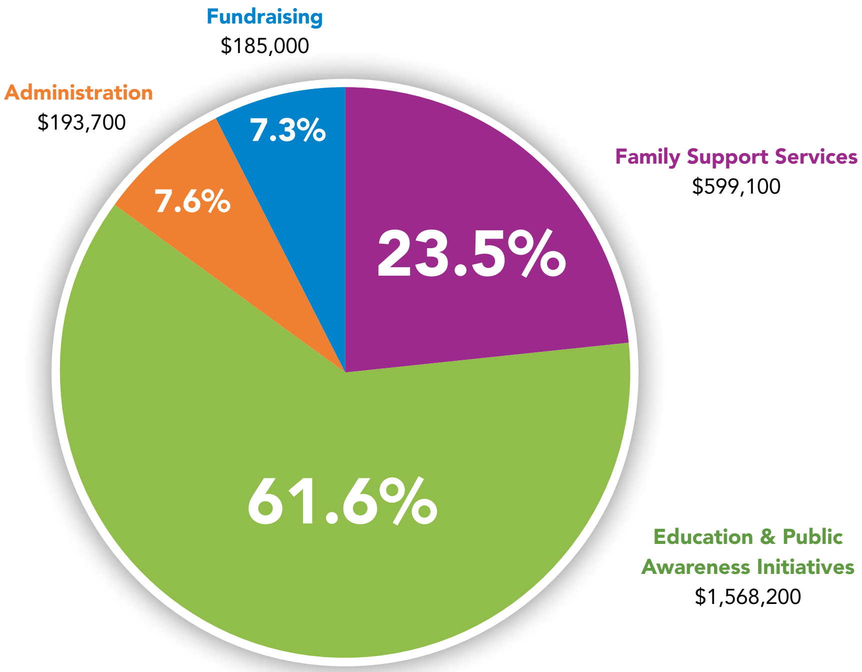
Connecting Revenue with Expenses

For Fiscal Year Ending June 30, 2024

REVENUE

Total Revenue $2,501,400





EXPENSES

Total Expenses: $2,546,000

For more detailed financial information, please contact us at mdsc@mdsc.org.


BUS
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mdsc
Richard K. Donahue
mdsc
MDSC New Family Social 12-14-24

PARENTS FIRST CALL

A lifeline of support during the most critical time

When Danielle Coughlan got a call from her doctor's office midway through her pregnancy telling her that her baby would most likely have Down syndrome, it "rocked my world in a way that is super hard to describe," she says.

She and her husband Joseph tried to process the news themselves the first couple of weeks. "We were cycling through the same conversations over and over again, not really getting anywhere," Danielle recalls.

> What MDSC does as an organization is unreal. The First Call program came to me when I didn't know how badly I needed it. I will be forever thankful.

For Danielle, a school nurse, and Joseph, who works with adult cardiac patients, a subsequent diagnosis of a heart defect only made matters worse, as they worried they were being spared hard truths by doctors putting on a positive spin. Desperate for grounding, Danielle reached out to MDSC's First Call program, and was connected with Cristina Colanti, a physician assistant whose 8-year-old daughter Mae not only had Down syndrome but also the same heart condition. The match was perfect. "When I say cosmic shift, it was an absolute game changer for me," Danielle says about speaking with another clinical professional who had such a similar lived experience.

Throughout her pregnancy, MDSC's support network surrounded the family. Cristina shared helpful tips based on her experiences with medical appointments and offered an honest, hopeful perspective. An MDSC prenatal support group led by First Call Parent Sarah Twomey-Mercurio and genetic counselor Mary-Frances Garber gave Danielle even further support and additional connections.

Baby Charlotte ("Charlie") arrived on February 10 and immediately required a 26-day NICU stay. When Charlie needed open heart surgery in May, the First Call program was there every step of the way, providing an MDSC Cares package and supporting Cristina to offer in-person comfort by sitting with Danielle throughout the entire procedure.

Charlie started improving immediately. Today, the Coughlans are preparing their "Charlie's Angels" team for their first Buddy Walk this October.

"What MDSC does is unreal," Danielle says. "The First Call program came to me when I didn't know how badly I needed it."

Parents First Call remains MDSC's cornerstone program, providing 24/7 support to new and expectant families through trained parent mentors. In 2024, we supported 135 families, ensuring each connects with a mentor within 24 hours of diagnosis and receives a personalized welcome package.

Our expanding offerings include bi-monthly New Family Socials, New Mom (0-18 months) and Toddler Mom (1½ - 3½ years) gatherings, Julia's Way Breastfeeding Support, our first-ever New Dads Group, Prenatal Support meetings, and Baby Sign Language workshops in English and Spanish. These intimate, supportive environments help families form close, meaningful connections that often last a lifetime.

Parents First Call has also taken the lead in deepening our commitment to our founding ideals of Diversity & Inclusion, ensuring our Bilingual (Spanish) Community Outreach Specialist can help all families feel welcome.

135 new and expectant families received personal one-on-one support, information and guidance from our First Call Program in 2024

ADVOCATES IN MOTION

Finding confidence through connection

When Melissa and Jason Winchell of West Bridgewater signed their daughter up for MDSC's Advocates in Motion program two years ago, Melissa wasn't optimistic. "I thought, she's not even going to go in the building," she says about her daughter Moriah, who has both Down syndrome and selective mutism.

> Moriah is usually very anxious in new settings. I couldn't believe she had such a good time and said she wants to go back. This is huge for her.

Melissa's concerns weren't unfounded. The Covid pandemic had been particularly difficult for Moriah, who was isolated for 17 months while waiting for the vaccine. Her selective mutism — a communication anxiety disorder — had worsened during this period. "She needed to get out and be involved in activities," Melissa says.

Melissa did extensive preparation for that first AIM meeting, looking up photos of the Brookline Teen Center online to show Moriah. What happened next exceeded all expectations. After Moriah gravitated toward painting bird houses, she stayed for the duration, though not speaking to anyone.

Moriah immediately asked to return. As Melissa wrote to MDSC Programs and Services Director Brooke Kulik afterward: "Moriah is usually very anxious in new settings and I couldn't believe she had such a good time and said she wants to go back....This is HUGE for her."

Moriah became a regular at AIM meetings, growing more comfortable each time. MDSC has continued working with her family to find what works best, including ensuring that she made meaningful connections with peers. Now she attends independently, enjoying music, dance, foosball and air hockey while building confidence.

For Moriah, who was the only student with Down syndrome in her school district through sixth grade, seeing other teenagers with Down syndrome has been transformative. "Representation is so important," Melissa says. "To see herself reflected — that's a confidence booster."

As an unexpected bonus, the program has been equally valuable for Melissa, who describes the Parent & Caregiver Sessions as profound: "It struck me how much meaning-making was going on in our conversation, as we each tried to make meaning of our kids' lives, our lives with them, their futures...I left with a very full heart."

In 2024, MDSC's A.I.M. Teen & Young Adult Program returned to fully in-person programming for the first time since the pandemic. Our Advocates in Motion (ages 13-22) and Self Advocate Advisory Council (ages 20+) consistently created innovative, enjoyable experiences that fostered self-advocacy skills, leadership development, and meaningful peer relationships.

Events included "Brunch Bunches" where participants learned to prepare nutritious meals, a Valentine's Day Friendship Dance with Mansfield High School Best Buddies, Live Pro-Wrestling, Picnic in the Park at Hopkinton State Park, and a Halloween "Dance, Shake and BOOgie" event. SAAC Socials, planned by council members themselves, featured quarterly gatherings including Karaoke Night and a Winter Wonderland Dance with Bentley Best Buddies. We also partnered with Inclusive Fitness for a Group Exercise series with expert coaches.

240 self advocates between the ages of 13 and 22 gained leadership skills and life skills with friends while family members connected with one another to share support and resources in our AIM Program

MDSC CARES

Turning isolation into connection

When Helena Desir of Haverhill got the news that her baby would have Down syndrome, she felt alone, shocked, and heartbroken.

> Right away I knew MDSC was an amazing support system. It was nothing but love.

Shaken, Helena shared the diagnosis with very few family, friends or co-workers. Still, through a close friend, she eventually learned about Roxanne Hoke-Chandler, founder of 21 Shades, MDSC's support group for Black and African American families. Though initially not ready to answer Roxanne's calls, when she did, "right away I knew it was an amazing support system. It was nothing but love."

It turned out to be an entry point to the MDSC Cares program, which provides comprehensive support for families navigating extenuating circumstances and medical complexities. Before Helena could even speak with MDSC Family Support Director Sarah Cullen, a welcome package arrived with books, a baby blanket, and Helena's absolute favorite: a tiny "Downright Perfect" onesie.

The thoughtful outreach continued throughout her pregnancy, and Helena found herself looking forward to the regular check-ins, which helped ease her anxiety about the unknown. "Every conversation gave me more confidence," she recalls. The team connected her with resources and prepared her for what to expect after Gabriel's arrival.

Once connected, Helena remembers receiving supportive calls and texts from Sarah and Roxanne, including resources she "didn't even know existed."

In December of 2022, Gabriel was born, weighing 6 pounds 4 ounces, but his medical journey was just beginning. At one month old, he was back in the hospital for open-heart surgery. MDSC Cares provided critical support with gift cards, baby equipment and more. During his recovery, MDSC helped coordinate services and navigate the complexities of early intervention.

Today, as Gabriel approaches his third birthday, he is "so loving and so funny" and "a big blessing." His medical journey remains complex, requiring oxygen 24 hours a day, a feeding tube, and early intervention therapies, and MDSC Cares continues to be there when needed.

As Gabriel grows, Helena says, there is nothing more comforting than "knowing MDSC is just one phone call away...They are a constant in my life."

When a child with Down syndrome faces an extended hospital stay or ongoing complex medical care, families often find themselves navigating overwhelming challenges alone. MDSC Cares provides comprehensive support during these critical times, recognizing that medical complexities can create both practical and emotional burdens.

MDSC Cares delivers thoughtfully curated care packages containing comfort items, practical necessities, and resources for children and parents. Beyond material support, the program offers ongoing connection through regular check-ins, resource coordination, and guidance through complex healthcare systems.

Families appreciate having advocates who understand their unique challenges and can connect them with other families facing similar circumstances. Whether provided prenatally, during the early years or adulthood, MDSC Cares is there during life's most uncertain moments to provide steady, reliable support.

147 families received financial assistance and direct support from the MDSC Cares Program in 2024

EDUCATION

The power of presuming competence

For Hollie Mendillo and Joe Beaulieu, MDSC became their anchor from the beginning. When their son Eli was born, MDSC was one of their first calls, and they quickly became immersed — attending New Family Socials, participating in playgroups, and never missing the Annual Conference.

But it wasn't until Eli's transition to kindergarten that MDSC's true value became clear. When miscommunication arose with their school about whether Eli would be fully or partially included, Hollie found herself navigating unfamiliar territory. MDSC Education Director Carlyn Foreman stepped in.

"Carlyn read his IEP — and it was not short," Hollie recalls. "She graciously offered to talk to me, and through that conversation, we figured it out and got him fully included." What impressed Hollie most was how Carlyn's educational expertise added critical value. "She's not just knowledgeable; she understands how to talk to the school."

> If we didn't know how to ask for more, he wouldn't be succeeding like he is now. I don't know what we would have done without MDSC.

Next, Eli participated in MDSC's Learning Program Boston, and the experience was transformative. Teachers Alex and Crista "are so knowledgeable. They suggest many techniques, saying 'This is what helped our kids, maybe it'll help yours too.'" Hollie developed a "bag of tricks" — strategies and confidence to support Eli at home. Now, Eli, opposite page, is reading close to grade level and thriving in his fully inclusive classroom.

Hollie's mindset shift proved invaluable, like when Eli's teachers wanted to pull him out of Spanish class, suggesting that a second language would confuse him. Armed with knowledge from MDSC's guidance, Hollie confidently advocated for her son. "I said, 'He was fluent in American Sign Language — let's just try Spanish.'" The school conceded and immediately realized their error. "They said, 'He's not confused. He pays attention.'"

MDSC's philosophy of presuming competence became Hollie's mantra. "I was able to say to his teachers, 'You shouldn't underestimate this kid,' and because I went in with knowledge, they were like, 'Okay, you're right.'"

Looking back, Hollie can't imagine their journey without MDSC. "If we didn't know how to ask for more, he would have been isolated in a separate classroom."

In 2024, we hosted the third year of MDSC's Learning Program Boston (LPB), a parent-focused educational intervention program featuring virtual workshops from September to May, plus a special in-person Curriculum Day.

MDSC's 2024 Educators Forum: Pathways to Meaningful Inclusion brought together more than 200 general and special educators, administrators, paraprofessionals, support professionals, and parents from around the state. The event featured keynote presentations by Dr. Zach Rossetti from Boston University and 9th grader Micaiah Elow, along with expert-led sessions on educating students with Down syndrome and other intellectual and developmental disabilities.

We continued our robust webinar series with myriad offerings, including "Improving Literacy Outcomes for Learners with Down syndrome" and "Building an Inclusive IEP."

3,068

general and special educators, paraprofessionals, administrators, specialists and parents learned best practices in educating students with Down syndrome through MDSC webinars, workshops, educators guide and our two major conferences

PUBLIC AWARENESS

From baby steps to leading the way

For Kathleen and Ryan Christensen, it feels extraordinary to consider where they started six years ago when their amazing daughter Annie was born and where they are today.

Back then, with Annie just two months old, Kathleen attended her first MDSC Buddy Walk on Wakefield Common. Hesitant about joining the Down syndrome community, she went quietly with her sister to "scope it out," rather than setting up a team.

> MDSC is going to be part of our lives forever. And it becomes impossible not to think about how much more we can do.

Gradually — after New Family Socials and a New Moms group — Kathleen and Ryan began to see MDSC as their community. With Covid hitting, the Christensens opted to try MDSC's first-ever Buddy Walk in Your Own Community. "It felt comfortable to bring our family and neighbors together at our house without having to join the larger community," they said.

That's when their investment in MDSC really gained steam. "Other people acknowledged how committed we were to the community. The buy-in and support for our little girl was really evident," Kathleen said. Soon they were attending every MDSC event: educational offerings like the Educators Forum, Annual Conference and Learning Program Boston, plus awareness events like the Bruins Alumni Game and Red Sox Down Syndrome Awareness Game.

By the next Buddy Walk, the Christensens were all-in, establishing their Annie's Angels team as a perennial top 5 fundraiser, joining the Buddy Walk Committee and dreaming up creative ways to spread awareness in Stoneham. They launched Annie's Lemonade Stand and held an "Annie's Angels in the Outfield" softball tournament fundraiser. For World Down Syndrome Day, they worked with Stoneham Police to create custom awareness patches for their uniforms. Kathleen ran the Falmouth Road Race as part of Team MDSC.

Now, there's no stopping them. In 2025, Ryan and Kathleen are stepping into the role of Buddy Walk Committee Chairs, leading the charge to energize MDSC's 100-plus teams across the state.

"MDSC is going to be part of our lives forever," Kathleen said. "We have an opportunity to make a difference in Annie's life and thousands of others through our public awareness efforts."

Helping the public understand the value of our loved ones with Down syndrome is critical to the MDSC mission. We do this by leveraging the power of social and mass media to extend the voice of our community.

The Buddy Walk remains our flagship public awareness event. In 2024, we offered Buddy Walk teams two ways to walk — in person in Wakefield or in their own communities. Along with other annual events — like the Boston Marathon, Falmouth Road Race, Bruins Alumni Game and Red Sox Down Syndrome Awareness Game — we continue to open eyes in Massachusetts and beyond.

Our 2024 efforts included partnerships with Boston25 News, Lamar Billboard campaigns, and community venues like the Discovery Museum — initiatives that raise awareness about abilities and community needs.

mdsc
MASSACHUSETTS DOWN SYNDROME CONGRESS

Photo by Keith Toffling Photography

8,546 families, self advocates and friends came together at our Buddy Walks and other awareness and fundraising events to celebrate the lives of people with Down syndrome

PUBLIC POLICY

Self advocates leading the charge for change

When MDSC's 17-person delegation arrived in Washington, DC for the National Down Syndrome Society's Advocacy Conference April 28-30, they joined over 400 advocates from across the country with one shared mission: to ensure federal legislators hear directly from those most affected by the policies they create.

But among MDSC's diverse group — parents, grandparents, siblings, and staff members — five voices were particularly powerful: the self advocates themselves. Ned, Peter, Molly, John, and Mia didn't just attend the conference; they led it, sharing their personal experiences with lawmakers in ways that no policy brief or statistics sheet ever could.

For decades, advocacy organizations have spoken on behalf of people with disabilities. What makes MDSC's approach different is the recognition that the most compelling testimony comes from those who live the reality of these policies every day.

> Speaking to people in positions of power takes courage, and [MDSC self advocates] brought our community's voice exactly where it needs to be heard.

During Capitol Hill meetings with both Massachusetts U.S. Senators and the majority of the state's U.S. Representatives, these five self advocates transformed federal policy discussions into human stories. Whether connecting directly with Rep. Jake Auchincloss, Rep. Katherine Clark and Senator Elizabeth Warren, or meeting with congressional aides, their personal testimony was received with open ears.

"Ned, Peter, Molly, John, and Mia spoke with poise and shared their stories so beautifully during the meetings," said Lauren Foley, MDSC Community Engagement & Research Coordinator. "Speaking to people in positions of power takes courage, and they all successfully brought our community's voice exactly where it needs to be heard."

Facing unprecedented challenges to disability services and supports, MDSC understands that the voices of self advocates and families are critical to ensuring that government policies and funding meet community needs.

As former MDSC Board member Shey Jaboin reflected: "Our children can't do it without their voices and MDSC's, and all the other supporters in this needed space."

As seasoned self advocate Peter Johnson explained to lawmakers, there should be "nothing about us, without us." In the halls of Congress, MDSC self advocates are sending that message loud and clear.

MDSC's track record as one of the nation's most effective Down syndrome advocacy organizations continued in 2024. Over the past dozen years, legislative victories included landmark laws like the Organ Transplant Bill, Real Lives Bill, National Criminal Background Check Bill, Down Syndrome Information Act, federal ABLE Act, and the Higher Education Bill.

Through our state-of-the-art Legislative Action Center, we launched nine Action Alert campaigns in 2024, generating hundreds of messages from our members to their legislators on critical disability rights issues.

Our top state priority remained the Applied Behavioral Analysis (ABA) Bill, MDSC's advocacy focus since 2019. At the federal level, MDSC continued pushing to end subminimum wage practices for people with disabilities.

555

advocates connected with their legislators by responding to an MDSC action alert or attending an MDSC advocacy event

RESEARCH & MEDICINE

Making every voice count

When the University of Illinois Beckman Institute launched the Speech Accessibility Project, they needed trusted partners to reach communities who could benefit from their groundbreaking research. The project aims to improve speech recognition technology for people whose disabilities affect their voices — including individuals with Down syndrome — by collecting diverse speech samples to train AI systems.

The challenge was significant: current voice-activated devices like smartphones, smart speakers, and home appliances often fail to understand people with speech differences, effectively excluding them from essential technology. These devices control everything from televisions to transportation and cell phones, with applications that could lead to better inclusion in schools and employment opportunities.

When researchers needed to connect with the Down syndrome community, they turned to MDSC.

> Our community, and every community, deserves to be included.

“The research team has learned that connecting with trusted partners is key to showing the credibility of our work and how much it could improve the lives of people with disabilities,” says Mark Hasegawa-Johnson, the project’s leader and professor of electrical and computer engineering. The project, funded by Amazon, Apple, Google, Meta, and Microsoft, represents a national effort to make speech recognition more inclusive.

MDSC’s expert Medical & Scientific Advisory Council put the Speech Accessibility Project through a rigorous approval process reviewing content, ethical standards, and feasibility while ensuring privacy for families.

Once approved in fall 2024, MDSC began spreading the word, helping recruit English-speaking adults with Down syndrome across Massachusetts and beyond. As Executive Director Maureen Gallagher explained, “Speech technology is playing an increasingly vital role in daily life, and we believe the Down syndrome community will benefit significantly from improved accessibility.”

The results have been promising. Microsoft’s Azure AI Speech platform has shown significant improvements in recognizing non-standard English speech — achieving accuracy gains from 18% to 60% depending on the speaker’s disability.

The project’s success has led to expansion plans including non-English speakers, children, and teens, with researchers seeking to partner with MDSC again.

“Our community, and every community, deserves to be included,” Gallagher says.

MDSC’s expertise in research and medicine enables us to track scientific developments as they happen, disseminating critical information to our members. Leading this effort is our Medical & Scientific Advisory Council, chaired by Dr. Brian Skotko and comprised of 18 prestigious Down syndrome experts from across the region.

The Council identifies and promotes only the highest-quality studies with our membership, helping families and researchers make mutually beneficial connections. In 2024, they reviewed and approved 10 research projects presented to MDSC membership for participation, including groundbreaking studies like the Speech Accessibility Project and the ABATE Study.

Members are kept informed through Medical & Research Updates. At MDSC, we understand both the promise and pitfalls of scientific innovations, striving to provide the support and guidance our members need to make informed decisions.

17,846 individuals benefited from MDSC's research programming, participating in studies, or accessing expert-led content and specialized resources

EMPLOYMENT

Building skills, confidence, and careers

When a 19-year-old participant joined a Your Next Star Career Exploration Academy over her April school vacation week, she discovered something beyond job skills training. “It was fun meeting other people and they all had a lot of enthusiasm,” she said about developing employment skills, boosting confidence, and strengthening interpersonal abilities.

For her parents, watching their daughter’s transformation was remarkable. “We are so amazed at how much she got out of it. She learned about vocational exploration, resume writing and was able to practice interview skills. It really helped her gain the confidence she’ll need as she transitions to adulthood.”

Since August 2022, MDSC’s Philip Donahue Your Next Star Employment Center has offered eight such Academies — experiential trainings for aspiring employees and entrepreneurs with Down syndrome and other intellectual and developmental disabilities. Each Academy provides hands-on practice for job seekers to explore their interests, gain critical skills, and pursue career goals.

> We are so amazed at how much she got out of it. It really helped her gain the confidence she’ll need as she transitions to adulthood.

After 20-year-old Patrick Bell of Essex attended a Career Exploration Academy this April, his parents noted immediate results. “He loved it,” they said. “We had dinner with the Endicott College Lacrosse team. He was shaking their hands, introducing himself and making eye contact. He told everyone that he learned it at the Academy. They were very impressed with his strong handshake.”

What makes these Academies particularly effective is their experiential approach, made possible through partnerships with organizations like Colletey’s Cookies, RSM, Revere Hotels, PwC Boston, and Omar’s World of Comics. The program continues evolving — in December, MDSC hosted the first-ever Graduate Refresher Course, bringing together 23 graduates from 7 Academies at Babson College.

For Liam Fitzgerald of Northborough, right, the timing of his Academy experience couldn’t have been better. “It provided him a unique opportunity to learn and practice skills like interviewing,” said his mom Christine. “Overall a wonderful 3 days tailored to their needs as they prepare for their journey to independence.”

Now, as Liam heads to Vanderbilt University to begin their Next Steps program, these skills will continue to serve him well.

Since re-launching in August 2022, MDSC’s Your Next Star Employment Academies have continued to evolve with offerings that include Career Exploration for students ages 17-21, full Employment Academies for individuals 18+, and an Entrepreneurship Academy. Through partnerships with organizations like Colletey’s Cookies, RSM, PwC Boston, Revere Hotels, and Omar’s World of Comics, MDSC has delivered eight comprehensive Academies serving dozens of participants, with a format that includes resume writing, interview practice, and workplace communication.

In 2024, MDSC launched a redesigned yournextstar.com website with modern interface, streamlined navigation, curated employer resources, YNS Job Alerts, and the new YNS Entrepreneur Shop. Looking ahead, MDSC is continuing to refine our Academy model while establishing new employer partnerships to create pathways from training toward meaningful employment opportunities.

6,501 employers, human resource professionals and others reached through the Your Next Star Employment Center website and outreach efforts

MDSC LEADERSHIP

MDSC Board of Directors

Board Officers:
Chair: Stacy Rachelle Lindborg, Ph.D.
Vice Chair: Jonathan Tabasky, Esq.

Board Members at Large:
Judson DeCew, Ph.D.
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Richard Fleming, Ph.D.
Dave Granfors
Victor Hernandez
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Roxanne Hoke Chandler
Drew Keller
Jessica McCready, Ph.D.
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Jim Molla
Stephanie Santoro, M.D.
Margaret Van Gelder

MDSC Management Team

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Executive Director

Reaghan Bik
Deputy Director of Development

Tara Buffum
Employment & Special Events Coordinator

Elaine Crowley
Administration & Finance Director

Sarah Cullen
National First Call Center Director

Ashley DeNoble
Program Specialist

Lauren Foley
Community Engagement & Research Coordinator

Carlyn Foreman
Education Director

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Program Specialist

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