Stronger Together: Discovering our community’s collective power to make a difference and change the world
It goes without saying that 2021 was a challenging year for so many in our community in unprecedented and unpredictable ways.

With your support, MDSC made a significant impact in the lives of people with Down syndrome and their families across the Commonwealth.

As a community, we learned invaluable lessons that helped us through even some of the most demanding times — that our biggest strength as a community IS our community.

Our theme for 2021 said it all — We are Stronger Together!

Since our founding, we at MDSC have prided ourselves on being there for our families, ensuring that all our loved ones with Down syndrome have every opportunity to lead meaningful fulfilling lives. Still, never had we faced quite the types or degrees of challenges that the Covid–19 pandemic presented.

The novel pandemic required us as an organization to “dig deep” and take full advantage of all the expertise we accumulated over our nearly four decades of disability advocacy. In doing so, MDSC was able to respond swiftly, forcefully and comprehensively to the needs of our community.

We pivoted our programs and services in unexpected ways, developing new approaches to meet our members’ needs, whether new & expectant parents, school-age families, or teens and adults — while also pushing the envelope in the areas of advocacy and public policy. We succeeded in large part because of your unwavering support and trust in us!

Throughout 2020 and 2021, MDSC sought to strengthen collaborations with local, statewide and national disability partner organizations as well as legislative and administration leaders. Independently and through our partnerships, MDSC worked to address critical policy concerns to ensure that people with Down syndrome in Massachusetts and throughout the country were not disproportionately negatively impacted by the pandemic.

Working hand in hand with partners, we advocated fiercely for a broad range of emergency policy and funding priorities — funding for Covid Relief packages and Home & Community Based Services (HCBS); remedies for restrictive hospital visitation and supports for students struggling with remote schooling.

As the Covid vaccine was rolled out in Massachusetts, MDSC, working in consultation with our Medical & Scientific Advisory Council, was on the frontlines. Early on, we advocated strenuously that people with Down syndrome, including those over 40 as well as those in congregate care and community-based day program settings, receive top priority.

During this time, MDSC also took concrete action to deepen our commitment to our founding ideals of Diversity & Inclusion, hiring a Diversity Outreach Coordinator and a Bilingual (Spanish) Community Outreach Specialist, who facilitated monthly Zoom calls, Cultural Diversity Committee meetings and activities, as well as outreach and support to ensure all families would be welcomed and engaged in MDSC.

Early on in the pandemic, the MDSC team took on the task of helping members navigate Covid information overload by publishing the most essential resources on a page on our website. This work of reviewing, culling and organizing only the most informative and helpful resources continued in
earnest throughout 2021, with categories expanding to include Vaccine Information, Re-entry, Educational Tools & Resources, Medical & Health Information (including Mental Health), Public Policy Action Alerts as well as information for self advocates and how to talk to your children.

Likewise, MDSC’s four Centers of Excellence and Resource Library launched with the new state-of-the-art website that proved to be invaluable in an increasingly virtual world. Each of the centers — Legislative Action Center, National Parents First Call Center, Center on Inclusive Education and Your Next Star Employment Center — enables members, wherever they live, to take advantage of our expertise in key areas of our work. And the Resource Library serves as a comprehensive database of Down syndrome resources that are culled from some of the nation’s leading experts.

Of course, when Covid hit, MDSC moved quickly to adapt all our programming. This included establishing a steady stream of webinars on timely medical and educational topics hosted by national experts in their field and designed to meet the needs of families and their loved ones with Down syndrome across the lifespan. These webinars, many of which were presented through our Annual Conference and Educators Forum, were geared toward helping families manage some of the most pressing issues that arose or were exacerbated as a result of life under the pandemic.

Among the topics covered were: Safety Considerations as the Re-Entry Process Begins; Issues Related to School Reopening for Students with Down Syndrome; Behavioral Therapy for Children with Down Syndrome; Education Rights & Advocacy for Students with Down Syndrome During Covid-19; Promoting Friendship and Social Connections during a Pandemic; Planning for Employment During a Pandemic; and Teaching Children with Disabilities to Read During a Pandemic.

Finally, throughout the pandemic, we were reminded that while everyone faced hardships, for some families, the challenges were particularly acute, sometimes heartbreaking. For them, we greatly expanded our MDSC CARES Program, providing critical support at particularly vulnerable times, including extended hospital stays, critical health challenges or other extenuating circumstances.

Today, we are grateful to be in a position to look back and see that we could not have made it through the darkest times of the pandemic without you. Like our theme for the year, we survived because we were STRONGER TOGETHER!

Together, we persevered, and now, more than ever, MDSC is committed to helping our members navigate this still-changing landscape with as much information, tools, and resources as possible so that each of our loved ones with Down syndrome can go on to achieve their dreams. We hold great hope for the future.

We succeeded in achieving our mission in 2021 as a direct result of steadfast supporters like you who understand the importance of the work we do to positively impact 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 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.

Your leadership and support is truly valued and appreciated.

We are Stronger Together!

Maureen Gallagher, MS
Executive Director, MDSC

Richard Downey
Board Chair, MDSC
About The MDSC

For nearly 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 7,400 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

The MDSC wants to be recognized by people with Down syndrome and their families, educators, health care professionals, and the community-at-large as the preeminent organization in Massachusetts for information, networking, and advocacy for and about Down syndrome.

Our Purposes

- To engage, educate, and involve the public in advancing the possibilities and potential of all people with Down syndrome throughout their lifetime.
- To continue to create and foster opportunities for meaningful employment and meaningful societal engagement for adults with Down syndrome in the community.
- To enable networking, social/friendship and partnerships, in person and virtually, to support all people with Down syndrome and their families.
- To advocate that all individuals with Down syndrome have high quality education, which includes transition planning and life-long learning.
- To advocate for improved systemic change and policy in issues such as community inclusion, higher education, and employment for adults with Down syndrome.
- To develop and disseminate best practices through MDSC’s Centers of Excellence for the benefit of the broader Down syndrome community.
- To advocate for all individuals with Down syndrome to have access to high quality medical and behavioral services and research.
- To empower all people with Down syndrome to have the opportunity to become effective self-advocates.
- To ensure that expectant and new families receive accurate and up-to-date information and desired supports.
- To continue to provide a clearinghouse of information and resources related to Down syndrome and other intellectual and developmental disabilities.
When MDSC was founded in 1983, the world was a different place for our loved ones with Down syndrome. Medical professionals were not trained on best practices for delivering a diagnosis, early intervention was rare, an inclusive education was virtually unheard of, and there was no expectation that students with Down syndrome would go on to college or competitive employment.

Fortunately, in part because of the work of MDSC, we have come a long way. Students with Down syndrome can now experience an inclusive education. Employers are starting to understand the value that employees with Down syndrome add to the workforce. Life expectancy has more than doubled, and the general public is becoming aware of the amazing qualities of people with Down syndrome.

As an organization and a community, we have worked diligently to get to where we are today. Still, there remains much work ahead to ensure that all our loved ones with Down syndrome have every opportunity to lead inclusive, fulfilling lives in the community, a mission made even more challenging because of setbacks caused by the Covid pandemic.

That’s why we chose as our theme for 2021, Stronger Together! As the premiere Down syndrome organization in Massachusetts and a national leader in the field, we take great joy in envisioning an even brighter future for our loved ones with Down syndrome.

Yet, we know that such a bright future is not a foregone conclusion. It will require us sticking together and speaking up with one powerful voice so that every person with Down syndrome has the chance to pursue a meaningful, rewarding life across the lifespan. The fact is, our biggest strength as a community IS our community, and that we truly are Stronger Together!
2021 FINANCIAL STATEMENT
Connecting Revenue with Expenses
For Fiscal Year Ending June 30, 2021

REVENUE
Total Revenue $2,003,900

EXPENSES
Total Expenses: $1,600,000

For more detailed financial information, please contact us at mdsc@mdsc.org.
PARENTS FIRST CALL
Embracing new parents and welcoming them into the MDSC family

Sharon Tate of Dorchester always considered herself a private person. That began to change in early 2021 when, pregnant with her third child, she got the results of a non-invasive prenatal test, which indicated her baby was likely to have Down syndrome. Not knowing anyone with Down syndrome, Sharon found herself asking, “What even is Down syndrome and what will my baby’s life be like?”

Sharon realized there was only one way to find out — through connection and community. That spring, through a friend of a friend, she got linked in to 21 Shades, one of many support groups MDSC collaborates with across Massachusetts.

In an instant, she was talking with 21 Shades leaders Jessica Avila and Roxanne Hoke-Chandler trying to take it all in. (“After my first conversation with Roxanne, I just cried,” she says.) Soon after, a care package from MDSC Family Support Director Sarah Cullen arrived in the mail for her expectant baby and family. The message from everyone at MDSC was clear and consistent: We have a wealth of resources and supports. Go at your own pace. Whenever you’re ready, we’re here for you.

Melvin Steven Tate, Jr. was born September 14 into a family that is “in love and obsessed with him,” including his dad, 10-year-old sister (right) and 19-year-old brother. By that point, Sharon had a sense that MDSC had their back, a feeling that solidified as time went on. She was touched when a gift card arrived during the holiday season, allowing them to buy things for the baby. When Melvin was hospitalized after starting to have seizures, another gift card helped them buy groceries and supplies during a stressful period. In March, when Sharon received a complimentary admission to MDSC’s Annual Virtual Conference, their family gathered around the computer to watch, learn and celebrate with our community.

The safety of the MDSC community has helped her to open up, posting questions on online message boards and joining MDSC’s virtual offerings. “I’m just so grateful. It’s great to be embraced, to know that you’re not the only family going through this. I’ve been able to relax and be comfortable telling my story. I’m just very proud of my baby and thankful to MDSC for all their support.”
new and expectant families received personal one-on-one support, information and guidance from our First Call Program
Sheri Dion of Carver remembers vividly the moment she glimpsed the future she dreamed of for her daughter, Becca. Sheri was attending MDSC’s Annual Conference at the DCU Center in Worcester when a young woman with Down syndrome strolled past wearing a bright dress, pumps and makeup.

“She was walking down the hall like she knew exactly where she was going,” says Sheri, whose daughter was around 7 years old at the time. “I said to myself, ‘That’s what I want for Rebecca. That’s what I see for her.’”

By 2019, when Becca joined MDSC’s Advocates in Motion Program, she had come a long way. She was an accomplished Girl Scout, a singer in junior choir, a worship leader at church and a veteran performer at the Carver Dance Center.

A.I.M. was a great addition, and she “absolutely loved it from the beginning,” Sheri says. When Covid hit, and the whole world went virtual, Sheri noticed that A.I.M. became something even more; it was a lifesaver. “Without it, I don’t know what we would have done. It kept us connected.”

As the pandemic dragged on, and Becca continued attending A.I.M. virtually, Sheri noticed changes in her daughter. At first, it had fallen to Sheri to remind Becca about the date and time of virtual A.I.M. meetings and to make sure Becca’s computer was set up and ready. But before long, the opposite was true — Becca was getting set up and ready herself, and reminding her mother about the parent learning sessions (which Sheri described as invaluable).

“Becca’s become so much more independent. I can’t stress that enough.”

Becca adds that “being in A.I.M. is more than a dream for me. This is where I belong.” As a result, Becca’s confidence has skyrocketed. She was proud to speak up to suggest that A.I.M. put on a karaoke event; and even prouder when the idea was adopted.

Meanwhile, Sheri notes that her daughter’s self-advocacy has translated well beyond A.I.M. When MDSC sent out a call to action for members to ask MA Governor Baker to support higher education opportunities for people with disabilities, Sheri told her daughter they could work on it together once she got home from work.

“When I got home, she showed me a letter from Governor Baker that said thanks for reaching out. She had done it herself. I couldn’t believe it.”
self advocates between 13 and 22 gained leadership skills, life skills, and made friends in our Advocates in Motion Program.
Jennifer Guan has been on the move much of her adult life. After graduating from High School in New Jersey, she moved with her family (diploma in hand) to Shanghai, China. In 2017, she moved back stateside, relocating to Greater Boston.

According to her mom, Bei, joining MDSC’s Self Advocate Advisory Council (SAAC) has helped Jennifer feel settled while continuing to expand her horizons as an adult with Down syndrome. “The SAAC program has made Jennifer more confident about herself,” Bei says. It has also improved “her ability to accomplish tasks at work and at home.”

A truly committed SAAC member, Jennifer has yet to miss a meeting. She has helped host a variety of SAAC events, including the Halloween Party and World Culture Trivia at MDSC’s Annual Conference, and raised funds for her SAAC Buddy Walk team.

In turn, the gain in self-assurance has had real impacts in a range of ways in Jennifer’s life, most notably at her job as a Research Assistant at the Boston Children’s Hospital (BCH) Down Syndrome Clinic & Research Program, where she handles data entry duties for the patient database as well as other tasks. According to her parents, Jennifer has been more able and willing to put herself out there, like traveling recently to the NDSC Conference in New Orleans, where she independently presented a session titled “All About Me and My Crafts,” and co-led a series of yoga sessions with her BCH colleague Dr. Emily Davidson.

Back in Boston, Jennifer recorded a video for the Opening Ceremony of MDSC’s Annual Virtual Conference and learned to take a Lyft to her job downtown rather than getting a ride from home. “I was really proud to do that on my own,” Jennifer said. And even at home, her parents note, Jennifer has learned to occupy herself in healthy ways for much longer periods of time.

Her parents, and Jennifer herself, say that SAAC has a lot to do with her growth, boosting not only her confidence but also her social skills. Behind it all, Jennifer says, she herself is motivated, ultimately, by a deep desire to “make a difference for people with Down syndrome.”
adults with Down syndrome participated in leadership activities and joined networking and socializing events organized by self advocates for self advocates
After nearly four decades, MDSC's Annual Conference remains true to its founding vision — bringing together families to learn from each other while taking in the latest, most pertinent information about Down syndrome from the region’s leading experts.

Yet, with incredible advances in cutting edge medical, scientific and educational research, MDSC's Annual Conference as well as our Educators Forum have also evolved drastically. Our conferences and other programs have not only kept pace but also led the charge to advance our families’ understanding of the latest research and data-driven best practices as it relates to Down syndrome.

Shifting gears from our “traditional” Annual Conference, we branded our flagship educational event with a research-based theme, putting a bright spotlight on the latest information and resources related to research and education for our families, as well as self advocates, educators, health care professionals, siblings and grandparents.

At MDSC’s 37th Annual Conference in 2021, our health & research related presentations were wide-ranging:
- What You Need to Know about Covid-19 and Down Syndrome
- Behavior Therapy for Children with Down Syndrome: Advocacy & Research Updates
- The Evolving Landscape of Down Syndrome Associated Alzheimer’s Disease
- Congress & the Health Research Agenda
- Mental Health Causes for Behavior Change during a Pandemic in Adolescents & Adults
- Translating Down Syndrome Neuroscience Research
- Advancing Down Syndrome Research at the NIH
- DSC2U: A New Virtual Clinic for All Families

Key to our success in drawing top experts in research and medicine to our conferences as well our year-round webinars has been our ability to forge strong local and national partnerships. Regionally, this includes close relationships with Massachusetts’ three top-flight Down syndrome clinics — Boston Children’s Hospital, Mass General Hospital, and the UMass Medical Center.

In addition, we collaborate closely with the OB-GYN departments in all the major hospitals and their affiliated world-class universities, which have often been on the front lines as the Commonwealth has become a hub of innovative Down syndrome–related advancements. Nationally, we have formed alliances with leaders like our Annual Conference presenting sponsor the National Down Syndrome Society, as well as other conference sponsors LuMind/IDSC, Down Syndrome Affiliates in Action and the Down Syndrome Diagnosis Network.

Our repositioning to a research-based focus has proven prescient as the pace of scientific and medical innovations related to Down syndrome grows exponentially. Both promising developments on the horizon as well as unforeseen challenges, such as the Covid pandemic, point to a future that is increasingly research-focused. Our families can trust that MDSC will be there whatever this future brings.
individuals received up-to-date, accurate information about Down syndrome through MDSC research and education programs

2,646
Recognizing that people with Down syndrome should have every opportunity to lead inclusive, fulfilling lives in the community, MDSC has made public awareness a top priority for many years. We achieve this goal by engaging our members to do their own outreach while also striving to leverage the power of mass media, social media and other partnerships to extend our voice across the state and country.

Despite the Buddy Walk shifting to an “In Your Community” event in 2020, MDSC worked tirelessly with Team Captains and team members to spread awareness wherever they lived. Likewise, MDSC made nimble adjustments to ensure that our other public awareness and fundraising initiatives such as the Boston Marathon and Falmouth Road Race, as well as our beloved annual hockey game with the Boston Bruins Alumni, would be successful.

We know that by working together to engage our community, we can educate others about the immeasurable value that all people with Down syndrome bring to the world.
families, self advocates and friends came together at our Buddy Walk in the Community and other awareness and fundraising events to celebrate the lives of people with Down syndrome.
PUBLIC POLICY

Shifting gears under Covid to protect and support our loved ones

With the outbreak of Covid 19, MDSC responded swiftly and forcefully, shifting gears in a range of programmatic areas, perhaps none more critical than public policy.

From Early Intervention services to Home & Community Based Support funding, school reopening to special education support services, and Covid vaccine access to health care triage and hospital visitation policies, our families with loved ones with Down syndrome were counting on MDSC to be in their corner. Leveraging robust partnerships forged over decades in the field, we were able to make a real difference in the lives of families across the state and beyond.

“We have been through so much and the MDSC has been there since day one.”

For Lindsay Logan of Lowell, MDSC’s advocacy for a MassHealth policy to extend Early Intervention services to 3-year-olds was critical. The policy ensured that her daughter Rylin, who turned three in May 2020, didn’t face an abrupt end to services at a tumultuous time. “We thankfully got to stay with our EI until the fall,” she notes. “Obviously, doing it by Zoom was hard, but I truly believe that because of the extension, she did not regress as much and was able to hop right into her inclusive pre-k classroom.”

For Susanna Peyton of Lexington, she was concerned about how Covid could impact her son Graham, now 35, whose health was compromised by severe sleep apnea. Fortunately, she knew she could “100 percent trust MDSC in this area.” Noting that she works in health care, she “was keen to make sure Graham got his vaccine as early as possible,” and appreciated MDSC’s advocacy with the Baker Administration. Graham got his vaccine in late January 2021, which she says protected not only him but his vulnerable relatives and friends and “absolutely improved his quality of life.”

For Angela Lombardo of Somerville, not only is she thankful that MDSC helped ensure that her son Isaiah, now 26, got early access to the Covid vaccine. She also deeply appreciates MDSC’s advocacy for hospital visitation rights. Isaiah unfortunately had several lengthy hospital stays throughout Covid, and it would have been unbearable for both of them without the daily visits. “There was no way he would have agreed to be there on his own and cooperated,” she says. “That would have changed everything.”

Caren D’Agnese of Rowley is grateful that MDSC was there for her 4th grade son Marco when schools prepared to reopen. With other organizations, MDSC formally requested the state keep people with disabilities in mind when setting reopening policies. Plus, MDSC webinars, like “Issues Related to School Opening”, with special education attorney Daniel Heffernan were a lifeline. “MDSC’s webinar gave me the info I needed in case our district didn’t follow through. It was comforting to know I had help available when I needed it.”

According to Lindsay, “We have been through so much and the MDSC has been there since day one.”

Over the past decade, MDSC has established itself as a powerful disability advocate on both Beacon Hill and Capitol Hill. Our work has led to the passage of many pieces of landmark legislation — the Organ Transplant Bill, Real Lives Bill, National Criminal Background Check Bill and Down Syndrome Information Act, and on the national level, the ABLE Act.

Before Covid, our Annual Advocacy Day at the State House was a launching pad for the eventual passage of our key policy initiatives. Now, since 2020, MDSC’s state-of-the-art Legislative Action Center makes it even easier for constituents to reach out to their lawmakers on the issues important to our community, like our top federal priority of ending the outdated practice of paying people with disabilities sub-minimum wages, and statewide, the Higher Education Bill, which will help ensure that people with Down syndrome have access to higher education opportunities.
individuals with Down syndrome in Massachusetts benefitted from MDSC’s advocacy efforts

4,500
As MDSC continues to expand our horizons, grow our programs and better serve all our families across the lifespan, we are proud to shine a spotlight on certain key programmatic areas in which our expertise is highly unique, highly regarded and national in scope.

Consolidated on our new mdsc.org website, MDSC’s four Centers of Excellence — the Legislative Action Center, the National Parents First Call Center, the Center on Inclusive Education and the Your Next Star Employment Center — offer members and partners concrete ways to engage substantially with our mission and benefit from our flagship programs.

Each of MDSC’s Centers of Excellence is a one-of-a-kind hub of information through which member, partner and organizational engagement is helping change the landscape for people with Down syndrome in a critical aspect of life.

Legislative Action Center Provides members information on MDSC’s state and national public policy priorities, and gives them a streamlined platform to take action by connecting directly with their lawmakers.

National Parents First Call Center A first-of-its-kind, full-service center that serves new and expectant parents, medical providers, Down syndrome organization leaders and parent volunteers around issues related to Down syndrome diagnosis and early life.

Center on Inclusive Education Provides a wealth of tools, training, and adapted curricular materials for parents and educators, grounded in best practices for teaching students with intellectual and developmental disabilities.

Philip Donahue Your Next Star Employment Center MDSC’s employment initiative, which helps prepare qualified candidates with Down syndrome for the workforce, while partnering with employers to build inclusive hiring programs.

While striving to meet the most critical needs of our membership, the Centers also serve to engage our disability, political and business partner leaders and work collaboratively with them to make a real difference in the lives of people with Down syndrome. Through the work of MDSC’s Centers of Excellence, as well as our Resource Library, the future for our loved ones with Down syndrome is bright.

“Each of MDSC’s Centers of Excellence is a one-of-a-kind hub of information that is helping to change the landscape for people with Down syndrome.”

With the launch of MDSC’s new website in 2021, MDSC concluded a major multi-year undertaking that would prepare us organizationally for years to come and for the new virtual world we’re now living in.

The development of the new website gave MDSC an opportunity to consolidate our existing groundbreaking centers in the areas of employment and First Call, with our two new, equally unique centers, in the areas of public policy and education, ultimately creating a set of four unparalleled Centers of Excellence to serve all our loved ones with Down syndrome and their families throughout their lifespan.

With the website launch, MDSC simultaneously unveiled its comprehensive Resource Library, a fully searchable collection of over 400 resources available to members on a complimentary basis and serving parents and family members, self advocates, employers, educators, healthcare professionals, policymakers, advocates and researchers.
Legislative Action Center

There is no more effective way to improve the lives of people with Down syndrome than through public policy. See our Action Alerts to make a difference now!

National First Call Center

First-of-its-kind, comprehensive, full-service center that serves expectant parents and medical providers as well as Down syndrome organization leaders and parent volunteers.

Center on Inclusive Education

Tools, training, and adapted curricular materials for parents and educators, grounded in best practices for teaching students with intellectual and developmental disabilities.

Philip Donahue Your Next Star Employment Center

MDSC’s employment initiative, which helps prepare qualified candidates with Down syndrome for the workforce and partners with employers to build inclusive hiring programs.

2,411 participated in and benefited from the MDSC’s Centers of Excellence
MDSC LEADERSHIP

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