

Strategic Plan

July 2023 - June 2028



Acknowledgements

Nearly fifty people across MDSC's community were involved in some aspect of the strategic planning process, participating in interviews and focus groups, engaging in planning sessions, and reviewing research on other local, national, and international organizations in the Down syndrome sector. The individuals contributing to this plan included self-advocates, family members, educators, healthcare and medical professionals, researchers, partners, donors, and MDSC board and management team members. The diverse and varied perspectives and people informing this process were key to its development and will be critical to its impact in the coming years.

We are grateful to everyone who was a part of developing this Strategic Plan. Each piece of input we received was essential and valuable.

We would also like to acknowledge and express our special thanks to the individuals – both board and management team members – who comprised the planning committee. They spent hours, both within and outside of planning meetings, identifying critical issues and developing the strategic goals and objectives. They successfully leveraged this opportunity to reflect on MDSC's evolving and critical role within the wider community of individuals, providers, and organizations working to support and empower people with Down syndrome and their families.

The entire strategic planning process was designed and facilitated by the University of Massachusetts Donahue Institute (UMDI). The UMDI team included the following individuals:

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COVER: The MDSC word cloud was created from the minutes of the final MDSC planning session. It includes the most frequently repeated significant words.

¹ MDSC self-advocates are adult leaders who direct the MDSC on how the organization should best serve teens and adults. MDSC self-advocates speak up for themselves and on behalf of other people with Down syndrome. Drawing from their lived experience, self-advocates are often involved in raising awareness, educating the public, and advocating for programs and solutions that help the Down syndrome community.



Prepared by UMass Donahue Institute - March 2023

Massachusetts Down Syndrome Congress (MDSC)

Established in 1983, the MDSC has been the premier organization representing people with Down syndrome in Massachusetts for four decades. MDSC provides educational programs, direct support, publications, information and referrals, and individualized services to people with Down syndrome and their families, educators, healthcare professionals, and the wider community. The MDSC works to ensure that all people with Down syndrome have the opportunity to lead meaningful fulfilling lives in the community and fiercely advocates for critical policy priorities that will make that possible.

The MDSC traces its roots back to a living room gathering of parents who first came together to chat about their children with Down syndrome and to explore how they could connect and educate families, schools, and communities. Today, MDSC serves over 7,000 families (children and adults with Down syndrome and their families) every year. MDSC also partners with more than 30 like-minded organizations and groups. MDSC's broad array of programs serve people with Down syndrome throughout their lifespans, as well as families throughout the state and beyond. MDSC also has four Centers of Excellence, each providing a unique and invaluable service for communities both locally and across the U.S.: Legislative Action Center, National Parents First Call Center; Center on Inclusive Education; and Philip Donahue Your Next Star Employment Center.

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UMass Donahue Institute (UMDI)

Established in 1971, the UMass Amherst Donahue Institute addresses critical questions and develops innovative solutions to help organizations and agencies from both the public and private sector meet challenges, measure success, and set goals. UMDI's mission is to advance equity and social justice, foster healthy communities, and support inclusive economies that alleviate poverty and promote opportunity. In collaboration with partner organizations and clients, UMDI carries out its mission through research, education and training, capacity building, and direct services to strengthen collective impact.

MDSC's strategic planning process was managed through Nonprofit Funding & Fiscal Solutions (NFFS), one of the Institute's ten divisions. NFFS supports public and private nonprofits to create cultures and systems that result in sustainable programs, fundraising success, and stable infrastructure. NFFS services focus on building agency capacity in areas that are essential to nonprofit sustainability: planning, community engagement, measuring impact, and fund development.

Integral to the work of NFFS is elevating the voices of BIPOC communities, people with disabilities, youth, and individuals from diverse economic and educational backgrounds. NFFS helps organizations turn vision and intent into action and results.

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INTRODUCTION

In late summer 2022, MDSC began a strategic planning process designed to focus its energy, ensure that members of the organization continue to work towards shared goals, and shape and guide MDSC's work over the next

MDSC is the best thing that ever happened to me in my whole life. They are the best."

- Self-Advocate, Focus Group, 9/2022

five years. The process was designed to build on the organization's prior five-year Strategic Plan, which launched in 2016 and, with the interruption of Covid, was extended through 2022.

Under the prior plan, from 2016-2022, a number of major goals were accomplished, including establishing MDSC as a repository of best practices, resources, and information; increasing the number of MDSC Centers of Excellence from one to four; and expanding programs and initiatives targeted at supporting the needs of adults with Down syndrome and their families. The MDSC also continued to diversify its funding and build strategic alliances and collaborative relationships. Most importantly, the MDSC increasingly drove transformative change across the sector by identifying common issues arising in the lives of people with Down syndrome, developing innovative solutions and approaches, and providing critical assistance, support, advocacy and resources. Through its active partnerships with more than 30 organizations and coalitions, energetic Board of Directors, and dynamic management team, the MDSC has not only continued to meet the diverse needs of its participants through longstanding, proven programs and bold new initiatives, but it also showed remarkable agility and effectiveness in the face of a historic global pandemic. Despite the unprecedented challenge of Covid-19, the organization continued to effectively manage dramatic growth in its programs, services, and Centers of Excellence.

Since 2016, tens of thousands of individuals – from those directly affected by Down syndrome, to educators, health care providers and the general public just learning about the cause – have volunteered with MDSC, made donations, and participated in community fundraising events and conferences. MDSC's significant success in galvanizing individuals, families, communities, and partners around a common mission has helped transform the landscape for people with Down syndrome.

Those working inside and on behalf of MDSC share a deep commitment to the mission and take enormous pride in MDSC's accomplishments. And that work continues. MDSC's board and management team members understand that continued growth and innovation depend on a clearly articulated plan for moving into the future.

MDSC's leadership – board of directors, executive director, and staff team – developed this Strategic Plan to shape and guide the organization's work over the next five years, as well as to ensure that MDSC board members, staff, volunteers, self-advocates, families, and a diverse array of community stakeholders work together towards common goals.

The strategic planning process was divided into two distinct phases: 1) situation assessment; and 2) facilitated planning sessions. The situation assessment, which was conducted from August-September 2023, included interviews with 16 key stakeholders identified by MDSC's leadership. Interviewees represented a range of perspectives, from family members of people with Down syndrome to professionals at the highest levels in their respective fields.

In addition to the interviews, two focus groups were conducted. One focus group was comprised of ten professionals working in the Down syndrome field, including MDSC board and management team members, advisory council members, and individuals working in a variety of different roles related to

Down syndrome. Six of the nine focus group participants described having a child, grandchild, or other close personal connection to individuals with Down syndrome. A second focus group was held with eight self-advocates to explore important ways MDSC supports people with Down syndrome, the impact of the pandemic on themselves and the broader Down syndrome community, and what they would advise to make MDSC even better. Finally, an in-depth landscape scan was conducted on 24 organizations engaged in the Down syndrome sector in Massachusetts, New England, the U.S., and/or other countries. The landscape scan provided information on each organization's location; focus; target population and numbers served; primary programs/services; net assets; and top foundation funders.

Repeatedly and across all interviews, interviewees expressed their feeling that MDSC stood out in the field of Down syndrome organizations as being innovative, cutting-edge, and an exemplary leader both nationally as well as locally and regionally. In addition, MDSC's value and critical importance to people with Down syndrome, their families, and professionals across the Down syndrome community was one of the predominant themes that emerged from the interviews and both focus groups. Other common themes and recommendations from the situation assessment:

- MDSC should continue to be responsive to the needs of people with Down syndrome and their families across the lifespan.
- MDSC should continue to focus on fostering accessibility, inclusion, and belonging among families both locally (across Massachusetts) and across the country.
- Despite the proliferation of organizations in the Down syndrome space, MDSC is a leader in the field, with national impact and influence.



- MDSC can serve as a convener of partners, helping both practitioners and families adapt and understand the new options available for people with Down syndrome and their families.
- MDSC has been able to export best practices in a scalable way that has not taken away from the organization's core strengths/services. MDSC has never lost sight of the core community it serves.
- MDSC will need to navigate a path between being an advocacy organization, driving change at a regional/national level, and being a provider of direct services to people with Down syndrome and their families, as well as educators, medical professionals, and others.
- Self-advocates reinforced their desire to be able to access college, be employed, and have families. They also asked that MDSC help them be able to have an impact on the world and to help others.

The second phase of the strategic planning process, the six facilitated planning sessions, began with the first planning session in October 2022, and concluded with the final planning meeting in March 2023. The planning members included MDSC board and management team members.

Strategic planning, as used in this document, is a process by which MDSC has taken charge of its future by asking the question, "Where do we want to go in the next five years?" and answering it in light of opportunities on the horizon and existing strengths that will help the organization get there. By anticipating both the challenges and opportunities ahead, MDSC is shaping its own future.

The entire organization will be involved in implementing this plan, identifying tasks, timelines and accountability, and evaluating whether and how the work is accomplished. By staying focused on the plan outlined in this document, MDSC's board and management team members, and wider community will increase the quality and accessibility of MDSC programs, build on current strengths and past successes, and mobilize partners to – in the broadest sense – "ensure that individuals with Down syndrome are valued, included, and given the opportunities to pursue fulfilling lives."

MISSION

To ensure individuals with Down syndrome 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.

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.

PURPOSES

- To engage, educate, and involve the public in advancing the possibilities and potential of all people with Down syndrome throughout their lifetime.
- 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 to 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 provide a clearinghouse of information and resources related to Down syndrome and other intellectual and developmental disabilities.

COMPONENTS OF THE PLAN

MDSC's Strategic Plan has been organized into the following three interrelated components:

- Strategic Directions represent the primary areas the organization will be focusing on in the next five years. This plan identifies five strategic directions: A. Lifespan Commitment; B. Diversity, Equity & Inclusion (DEI); C. Systemic Change/Policy Development; D. Leadership in Down Syndrome Sector; and E. Funding & Sustainability.
- Strategic Goals are the numbered, action-oriented statements that follow each strategic direction and which clarify what aspects of each strategic direction are most important to MDSC. Strategic goals serve to focus the organization's work in response to the strategic directions.
- ❖ Implementation Objectives are the lettered statements a, b, c, d that follow each strategic goal. They provide a blueprint for how MDSC will advance the Strategic Plan over the years, and they may change year-to-year based on new information, assessment of progress, or emerging needs/issues.

Together, the strategic directions and strategic goals form the core of the organization's Strategic Plan. While the implementation objectives (and the program plans derived from them) are likely to evolve and change over the next five years in response to new information and emerging needs, the strategic directions and goals will remain essentially constant – serving as a "North Star," a fixed guide around which the organization's programs and activities will be developed through FY 2028.



THE STRATEGIC PLAN:

July 2023 – June 2028

A. LIFESPAN COMMITMENT

1. Develop programs and initiatives focused on creating opportunities and empowering individuals and their caregivers to address needs across the lifespan.

B. DIVERSITY, EQUITY & INCLUSION (DEI)

- Foster an environment of belonging and increase access for diverse populations, with a
 particular focus on historically under-resourced areas and populations within
 Massachusetts.
- 2. Increase the diversity of MDSC's engagement, representation, and leadership to reflect the diversity of the population of individuals with Down syndrome.

C. SYSTEMIC CHANGE/POLICY DEVELOPMENT

1. Advance and advocate for systemic change and policies that empower people with Down syndrome to lead meaningful and fulfilling lives.

D. LEADERSHIP IN DOWN SYNDROME SECTOR

- 1. Serve as a strong advocate on behalf of the Down syndrome community in Massachusetts and beyond.
- 2. Build Centers of Excellence into locally-concentrated and nationally-influential, standard-setting programs.

E. FUNDING & SUSTAINABILITY

- 1. Increase and sustain the overall funds available to support MDSC's programming, and ensure that the organization has a secure and diversified base of support.
- 2. Build and support the sustainability of MDSC's management team through ongoing leadership and professional development.
- 3. Determine areas for future growth that are consistent with MDSC's mission and focus by engaging in regular planning and evaluation.

A. LIFESPAN COMMITMENT

One of the clear directives to emerge from the surveys and interviews is the critical importance of responding to the needs and concerns of people with Down syndrome (DS) and their caregivers *across their entire lifespan*. While expressing appreciation for the many ways the MDSC is already a leader in delivering programs for people with Down syndrome at every life stage, starting before birth, interviewees and focus group participants consistently pointed to the need for expanding resources and supports related to aging (including Alzheimer's) and aging caregivers. Suggestions included building the Stages of Life Plan, expanding support for people with DS entering the workforce, providing resources to aging caregivers, and increasing awareness about promising medical interventions and treatments. As one focus group participant remarked, "MDSC must continue to be cutting edge about how to address the needs of people with Down syndrome at every age, including as they grow older."

- 1. Develop programs and initiatives focused on creating opportunities and empowering individuals and their caregivers to address needs across the lifespan.
 - a) Develop, increase awareness of, and maintain programming focused on engaging and meeting the needs of individuals with Down syndrome across the lifespan, including through the Stages of Life Plan.
 - b) Build and broadly disseminate resources to aid individuals with Down syndrome and caregivers in meeting needs across the lifespan.
 - c) Host and collaborate with others to create opportunities to gather, support, inform, and empower individuals with Down syndrome, their families, and others who support them at various stages of the lifespan.
 - d) Develop pathways to connect people with Down syndrome to medical services and research on promising therapies and treatment options, with a focus on Alzheimer's and aging.



B. DIVERSITY, EQUITY & INCLUSION (DEI)

MDSC's commitment to reaching under-resourced areas and marginalized individuals and families across Massachusetts was affirmed throughout the planning process. At the same time, planners acknowledged that MDSC can do more, and take more intentional and strategic steps, to ensure that all individuals with Down syndrome and their families have access to MDSC programs and services — and that all families feel welcomed, supported, engaged, and connected. The work of expanding access, increasing the diversity of MDSC's members and leaders, and fostering a culture of belonging begins with reaching out to diverse communities across the state to build connections, network, learn about critical priorities, and understand how to best work with and engage different groups and communities. MDSC partners will also play a critical role in identifying and supporting outreach to under-resourced areas and populations.

- 1. Foster an environment of belonging and increase access for diverse populations, with a particular focus on historically under-resourced areas and populations within Massachusetts.
 - a) Continue to build DEI outreach initiatives to ensure a welcoming, responsive, and engaging organization for members of all backgrounds, with special attention by the MDSC Diversity Task Force.
 - b) Provide resources and supports to increase accessibility to MDSC programs for people with Down syndrome and their families.
 - c) Establish MDSC outreach programs focused on intentional and ongoing relationship-building with diverse communities to:
 - Understand and address their needs/concerns.
 - Identify and support community leaders to serve as a bridge to MDSC programs.
 - Encourage participation in MDSC programming and leadership groups.
- 2. Increase the diversity of MDSC's engagement, representation, and leadership to reflect the diversity of the population of individuals with Down syndrome.
 - Diversify leadership at all levels of the organization: board, management team, committees/task forces, Self Advocate Advisory Council.



C. SYSTEMIC CHANGE/POLICY DEVELOPMENT

The MDSC is committed to continuing to lead in the disability policy arena. Through partnerships with legislators, their constituents, and other disability organizations, MDSC works to advance legislation and other policies that benefit people with Down syndrome and their families. MDSC's advocacy in the public policy arena has led to the passage of numerous bills, including landmark legislation that ensures equal rights, inclusion, and



support for the Down syndrome community. Planners affirmed the need for MDSC to continue to advocate for beneficial policies on both a state and federal level, as well as to support the implementation of legislation after its passage.

- 1. Advance and advocate for systemic change and policies that empower people with Down syndrome to lead meaningful and fulfilling lives.
 - Collaborate with state and national organizations to enhance the depth and breadth of MDSC advocacy efforts.
 - b) Build and strengthen the leadership skills of individuals with Down syndrome and family members to empower them to play a key role in MDSC's advocacy efforts.
 - c) Support policies leading to:
 - Advancement of the human services workforce to ensure that programs and services for people with Down syndrome and other intellectual or developmental disabilities (IDDs) are fully available to all who need them.
 - Promotion of meaningful integrated employment opportunities for people with Down syndrome and other IDDs.
 - Educational attainment and advancement (including higher education) for people with Down syndrome and other IDDs.
 - Increased supports/safety net, in collaboration with state and local agencies, for people with Down syndrome as they age.
 - Advancing the concept of a Living Income.
 - Enhanced research and better health-related outcomes.
 - Financial well-being and meaningful participation in all aspects of the community.
 - d) Support implementation of recently passed legislation, including the Student Opportunity Act, Real Lives Bill, and Higher Education.

D. LEADERSHIP IN DOWN SYNDROME SECTOR

Throughout the interviews and focus groups, participants repeatedly pointed to MDSC's effective leadership on advancing cutting-edge programs and addressing issues of importance to the Down syndrome community. As one focus group participant remarked, "MDSC is a hidden powerhouse, delivering new ideas, innovation (advocacy, employment programs, working with hospitals, First Call, and more)." The term "humble leadership" – leadership that is authentic and collaborative, considers others' opinions, and acts with self-awareness – was also frequently used to describe MDSC's approach. Despite the proliferation of organizations in the Down syndrome space over the past two decades, MDSC is seen as occupying a unique role both in advancing innovative services through its Centers of Excellence, building leadership through self-advocates and others; and mobilizing families, providers, and communities across the Commonwealth.

1. Serve as a strong advocate on behalf of the Down syndrome community in Massachusetts and beyond.

- a) Maintain, build, and strengthen relationships with the executive and legislative branches of government on a state and federal level.
- b) Maintain, build, and strengthen relationships with state agencies; educators, school systems, and institutions of higher education; health care/research institutions; national Down syndrome organizations; and others serving the IDD community.

2. Build Centers of Excellence into locally-concentrated and nationally-influential, standard-setting programs.

- a) Maintain and build Centers by deepening existing relationships and developing new ones that will increase the visibility and impact of MDSC's Centers of Excellence on a local and national level.
- b) Establish public awareness campaign leading to increased participation in the Centers' activities and services (i.e. disseminate newsletter highlighting four Centers).
- c) MDSC Centers to serve as state and regional-level navigators, linking people with Down syndrome, caregivers, and associated organizations with essential resources.
- d) Convene forums for specific national audiences to learn from and collaborate with each other on MDSC's Centers of Excellence (i.e. assemble the MDSC National First Call Center replication sites).



E. FUNDING & SUSTAINABILITY

The organization's annual program and fund development plans evolve from the Strategic Plan. In this way, the fund development plan functions as one component of the larger program plan. Fund development consists of more than writing grants or leveraging donations; it involves networking, building relationships, researching new funding prospects and emerging trends in philanthropy, and ensuring that MDSC's mission and vision are being communicated effectively to the public. While the Strategic Plan will provide the framework and foundation for MDSC's program plan, the fund development plan – guided by the Strategic Plan – will guide the work of securing financing to support the Strategic Plan and the work outlined in the program plan.

- 1. Increase and sustain the overall funds available to support MDSC's programming, and ensure that the organization has a secure and diversified base of support.
 - Build MDSC's capacity to expand development efforts through enhanced tools, technology, fund development skills-building, and communications.
 - b) Further develop and expand opportunities for individuals to support MDSC through named funds, endowments, planned giving, and community events.
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- c) Leverage public funding to support key initiatives such as education and employment.
- d) Develop ways to fund the MDSC Centers of Excellence to increase each Center's capacity and services.
- 2. Build and support the sustainability of MDSC's management team through ongoing leadership and professional development.
 - a) Review management team structure and increase management team capacity by adding members focused on specific needs and priority areas (i.e. lifespan commitment; systemic change priorities; development/funding; administrative support, etc.) to support organizational growth.
 - b) Provide leadership and professional development opportunities for the management team.
 - c) Utilize consultants with expertise on varied subjects to bring specialized knowledge, capacity, and skills to the MDSC.
- 3. Determine areas for future growth that are consistent with MDSC's mission and focus by engaging in regular planning and evaluation.
 - a) Continue the MDSC's best practice of hosting Board and management team annual retreats to discuss key issues facing MDSC's community and to set priorities for the organization.
 - b) Continue to implement annual, metrics-based management plan to demonstrate progress towards achieving the Strategic Plan's goals and objectives.
 - c) Offer opportunities for MDSC members to provide input and feedback to the MDSC through evaluation surveys, membership surveys, focus groups, etc.

Next Steps

Through the strategic planning process, MDSC's leadership has developed a shared understanding of the organization's current situation; a shared vision for the organization's future; and a shared commitment to the strategic goals. Developing the Strategic Plan is only the first step towards achieving impact year after year. This document will be most valuable to MDSC as the board and management team move forward to bring this plan from the page into the day-to-day life of the organization. The following "next steps" will be integral to "living the Strategic Plan" in the months and years to come.

Step 1: Complete the annual Program Plan

The annual program plan (also referred to as an implementation plan) is a schedule of events and responsibilities that details the actions to be taken in order to accomplish the objectives outlined in the Strategic Plan. Thus, completing MDSC's "Program Development Plan," is the next step in the organization's planning process after the Strategic Plan is finalized. This tool will be used by MDSC management team to outline specific tasks, identify the people responsible for overseeing the completion of those tasks, establish the timeline for completing each task, and track progress over time. The Plan is organized in relation to each objective set forth in the Strategic Plan. Ideally, the plan will be detailed enough to ensure that everyone understands what is expected from whom and by when. This tool also provides space for outlining evaluation methods in order to track progress made towards achieving the strategic goals and objectives over time.

Step 2: Mobilize MDSC's Community

Share the plan within and outside of MDSC. Use multiple formats, adapted to MDSC's audience, including community meetings, one-on-one engagement, written materials, discussions of key priorities during Zoom meetings, and overviews on the organization's website.

Engaging many people, and a diverse cross-section of MDSC's stakeholders, will make it possible to spread the workload. Those people engaged in implementation will feel ownership for the plan and the resulting activities.

Also be sure to set priorities. All of the goals and strategies in the plan cannot be implemented and accomplished at the same time. Spread activities out over the five-year life of the Strategic Plan. Review the strategies and determine the best places to start. This may be influenced by opportunities for quick successes, by a logical ordering of activities that depend on actions completed earlier, or by the annual cycle of organizational activities.

Step 3: Ensuring the Strategic Plan Has Impact

Board and management team members' use and respect for the plan will influence the plan's acceptance across the organization and beyond. MDSC's board and management team should take steps to:

- Actively use the plan as a management tool.
- Actively use the plan for short-term guidance and decision-making.
- Incorporate sections of the plan in everyday management.
- Formalize the usage of the plan into the day-to-day activities of the organization. For example, this
 can be done by reading the mission statement at the opening of every meeting to remind everyone
 of the organization's purpose, or by requiring that all ideas for program changes or expansion
 directly address how the changes relate to the organization's strategic goals.

• Approach MDSC's work in the context of the plan. For example, include goals and objectives in program evaluations or have staff refer to the plan to provide guidance in decision-making.

Step 4: Monitor Progress

Regularly (for example, every six to 12 months) hold meetings to assess progress made towards achieving the objectives set forth in the Strategic Plan and the activities outlined in the program plan. Ensure that mechanisms are in place (e.g., evaluation meetings, progress reports) to inform the board on progress. Revisit the plan annually, viewing the strategies as anchors, not constraints, to what can be achieved.

