ADVOCATE

SPOTLIGHT ON OPERATION HOUSE CALL

► *See pages 6-13*

A CRUCIAL TIME

A look at Government Affairs with outlines and areas of focus for 2026. ► *See page 4*

ON THE COVER: In September, The Arc of Massachusetts hosted a briefing on the vital importance of Home and Community Based Services.

2025 | ISSUE #3

SCAN QR CODE
For resources and to stay connected!

The Arc™
Massachusetts

ABOUT THE ARC

Editor
Katerina Daley, MA

Associate Editor
Katrin Aback, MA

Production Coordinator
Kalea Amundson

Publisher
Maura Sullivan, MPA

Published by
The Arc of Massachusetts
217 South Street
Waltham, MA 02453
(781) 891-6270
www.arcmass.org

Steering Committee
Karen Mariscal, Esq., *Chair*
Robert Beckett, Esq.
Scott Borchardt
Hillary Dunn Stanisz
Rosalie Edes
Christopher Fox, Ph.D.
Roxanne Hoke-Chandler
Sarah Jerome
Barbara Pilarcik
Maura Sullivan, MPA, *Ex officio*
Janet Sweeney Rico, Ph.D., *Ex officio*
Danielle Terrell

The Arc of Massachusetts Staff

Maura Sullivan, MPA
Chief Executive Officer

Katrin Aback, MA
Senior Director of Development and Communications

Kalea Amundson
Development Operations Associate

Nora Bent
Director of Government Affairs and Strategic Partnerships

Katerina Daley MA
Director of Communications

Jackie Doherty
Director of Education and Outreach

Charlie Fiske
Government Relations Specialist

Susan FitzPatrick, MBA
Finance Director

Rachel Hayward
Pathways to Friendship Program Director

Dianne Huggon
Education and Outreach Consultant

Stephanie Lowell
Director of Academic Programs and Partnerships, Operation House Call

James Morgan
Bookkeeper

Emilia Niyangoda
Government Affairs Associate

Leo Sarkissian
Innovation Development Director

Stephanie Shore
After I'm Gone Project Manager

Ashley Waring
Family Engagement Director, Operation House Call

LETTER FROM THE **CEO**

In November, I completed my first year as CEO of The Arc of Massachusetts. I want to express my deepest gratitude for the honor of leading the advocacy efforts for this extraordinary community. This past year has been characterized by a coordinated series of attacks on the infrastructure and safeguards that protect our most vulnerable children and adults.

The Arc has doubled down on our advocacy with all of you for essential programs like Medicaid, SNAP, and Special Education that are facing existential threats. The Arc has pushed back on dangerous immigration policies, such as those impacting people with Temporary Protected Status (TPS). These policies would dismantle our workforce and directly harm members of our community. And, on a broader scale, we are all facing profound concerns about the devastation of our democracy itself. This fight is bigger than our community alone.

In the face of these challenges, I am proud of the exemplary work of our team. The Arc is a timely and reliable source of information, advocacy, and resources. When faced with federal impacts, we rallied thousands to march, write letters, attend trainings and webinars, and build vital relationships with lawmakers here in Massachusetts to strengthen our state services.

The Challenges Ahead

We continue to find success here in Massachusetts, but the road ahead is full of challenges. A tightening state budget and continued workforce shortage will inevitably impact our home and community-based services and other critical supports. We must engage more lawmakers. They must step up to ensure that our community, which intersects with every marginalized and underserved group, is not forgotten. The Arc is mobilizing, organizing, and amplifying your voices.

With the shocking actions and systemic misinformation coming from the administration, The Arc has embarked on an aggressive public media approach. Our goal is clear: we must reach beyond the disability community to secure the broad public support we need.

Reaching Beyond our Community

We are succeeding. We have significantly strengthened partnerships with key news outlets, including The Boston Globe, WBUR, the Boston Business Journal, The Washington Post, and multiple news channels. You can see highlights of our coverage at thearcofmass.org/media. This strategic work has propelled our stories into the mainstream, ensuring our message is heard statewide and nationally.

The Commonwealth must understand that their most vulnerable neighbors are direct targets of these federal cuts. Adults with disabilities, especially those with complex medical and behavioral conditions, are at high risk. Our waitlists continue and the lack of meaningful options are causing our community to suffer.

Your Call to Action:
Bring Someone New to the Table

No one in the Commonwealth of Massachusetts wants to see human suffering. Getting the word out beyond our disability community is absolutely crucial.

My call to action for you is simple: bring someone new into this advocacy movement. Engage your coworkers, extended family members, neighbors, and friends. Open the door to The Arc for them. If we are united in this advocacy, if we expand our reach, we will increase understanding, force social and legal change, and protect our essential community-based services.

In addition to reaching out to new people, there are other ways you can make a difference: join our advocacy network and take action, donate generously to support The Arc's work, and volunteer to build a stronger tomorrow.

Thank you for your courage, your commitment, and your trust in The Arc. Together, we will continue to fight for the dignity and rights of every individual we serve.

In Solidarity,

Maura Sullivan

MAURA SULLIVAN, MPA
Chief Executive Officer

GOVERNMENT AFFAIRS

A CRUCIAL TIME FOR ADVOCACY: WHAT'S TO COME IN 2026

By Nora Bent

While 2025 has been a year of twists, turns, and challenges, it also showcased our community's resilience and strength. We saw record-breaking engagement and advocacy in amplifying the priorities and concerns of people with intellectual and developmental disabilities (IDD) and autism at both the state and federal levels. As 2026 promises to be equally demanding, we are ready to face it with focus, strategy, and determination.

Your advocacy has never been more important. As we navigate the challenges stemming from Medicaid cuts, the persistent human services workforce shortage crisis, and the federal changes impacting state budgets, we need your voices and your stories to break through the noise.

Despite uncertainty, we must do all we can to prepare and protect our community. Here is an overview of our plan and focus areas for 2026.

State-Level Advocacy Roadmap

January marks the beginning of the second year in the two-year legislative cycle. This means that our priority bills have completed their initial hearings and some will be ready for final action. We continue to have productive conversations with legislators about these bills, including legislation to finally rid our state laws of offensive and archaic language, codify the Blue Envelope program, ensure meaningful healthcare standards, create a framework for supported decision-making, and more.

The period from January through July is when we expect to see more significant movement. Many bills will move out of the critical Ways and Means Committees, from which they can head to the House or Senate floors for a vote. As a wave of legislation moves out of committees and between chambers, your role is to help legislators prioritize. Your outreach will ensure our community's priorities do not get lost in the shuffle of thousands of bills.

Please check out our **state legislative platform** and identify the one or two bills that are most meaningful to you or your family. Let us know what they are to engage in coordinated advocacy efforts and write to your legislators about why they matter to you.

The formal process for the Fiscal Year 2027 state budget also officially begins in January. This year's budget is particularly critical as we navigate deep federal funding cuts and policy changes that will constrict and place stress upon the state budget.

The budget process takes several months, beginning with the release of the Governor's proposal in mid-January. The budget then moves to the House of Representatives in April and the Senate in May. The different House and Senate versions are then negotiated and debated in a Conference Committee, where they are finalized by the summer. The Arc engages in strong advocacy throughout this process, closely analyzing the different versions of the budget, working with legislators to file needed amendments, and organizing grassroots advocacy efforts in the community. You can learn more about the budget process and see updates and advocacy needs as they happen on our **state budget webpage.**

This budget year will be challenging, and we will need to be firm and focused. We will continue to prioritize workforce stability, protecting Medicaid, and preventing service and eligibility loss. The impacts of recent federal actions on the state budget cannot be overstated. Even a state as resource rich as Massachusetts cannot make up for the gaps being left by the federal government. Our advocacy must focus on thinking creatively, safeguarding the system, protecting access to services, and ensuring that the state is prioritizing the disability community.

Federal Challenges and Focus Areas

Federally, it seems like there are new policy changes, funding cuts, misinformation, and concerning proposals every day. Despite the uncertainty, we are continuing to focus on Medicaid, SNAP, immigration, Social Security, and special education. We've put together several fact sheets to make sense of these complex topics. Please use our **state and federal policy issues webpage** as a resource.

We will continue to work with our congressional delegation and The Arc of the United States to advocate, navigate, and communicate these changes as they happen in real-time. Your stories about how these programs affect you are crucial to ensuring policymakers hear from those who are directly impacted.

Together in Action

It is easy to feel overwhelmed right now. We're all saturated by news and information each day, and much of it feels scary and concerning. At The Arc, we are busier than ever as we navigate this environment and push for our priorities at the State House. We find our motivation in the strength, resilience, and passion of this community.

Please stay engaged with our **Massachusetts-focused action alerts**, **federal action alerts**, and our new **advocacy resource center** that offers guides and resources.

Your stories are the most powerful tool. They make a tangible difference in conversations with congressional staff and in the halls of the State House. We must buckle down and continue to face these fights together. Stay engaged, stay connected, and reach out for support.

YOU ARE NOT IN THIS ADVOCACY ALONE, AND WE WILL WEATHER THIS STORM TOGETHER.

SCAN QR CODE
To view more resources related to this article.

1

OPERATION HOUSE CALL

SNAPSHOTS

1. OHC co-teacher Braeden Yee entertained guests with his musical talent
2. A full house at historic Gore Place for the celebration of Operation House Call
3. Board President Brian Cusack, CEO Maura Sullivan, and Board member Jamie Katzman
4. Sammi Robertson and Dan Joyce of Bailey's Team for Autism **5.** CEO Maura Sullivan presented longtime OHC champion Susanna Peyton with a plaque commemorating her support of the program
6. CEO Maura Sullivan addresses the evening's attendees **7.** OHC host family Sarah and Matthew Cullen
8. OHC host parent Cynthia Laine and her son **9.** Panelists Dr. Mojdeh Mostafavi, co-teacher Isaiah Lombardo, and OHC Family Engagement Director and Parent Instructor Ashley Waring **10.** Dr. Benjamin Siegel, who was instrumental in the founding of OHC in 1991 **11.** Panelists Val Ortiz Jimenez, a Harvard School of Dental Medicine student, and Dr. Mojdeh Mostafavi **12.** Representative John Lawn (second from left), who was integral in passing the OHC legislation as Chairman of the Joint Committee on Health Care Financing
13. The Arc's Nancy Gardner, Nora Bent, and Jonathan Gardner


2


3


4


5


6


7


8


9


10


11


12


13

OPERATION HOUSE CALL

15 YEARS WITH THE ARC OF MASSACHUSETTS: CELEBRATING **GROWTH**, **LEADERSHIP**, AND THE **POWER OF FAMILIES** AS **EDUCATORS**

On October 22, The Arc of Massachusetts and Operation House Call (OHC) celebrated 15 years of partnership at the historic Gore Place Carriage House in Waltham. As the Director of Operation House Call, I had the privilege of facilitating the event. The evening honored Susanna Peyton, an OHC champion, as well as families, teachers, and co-teachers who shaped OHC into a nationally recognized model for inclusive medical education and healthcare equity.

Operation House Call began in 1991 at Boston University School of Medicine (BUSM), where Dr. David Coulter and Dr. Benjamin Siegel responded to parents' concerns that future physicians lacked understanding of patients with intellectual and developmental disabilities (IDD). Their innovative solution placed families at the center of medical education, inviting students into their homes to learn directly from lived experience. The power of family as the educator became, and remains, OHC's foundation.

In 2011, OHC found its true home at The Arc of Massachusetts. At the time, I was teaching at BUSM. Soon after, Susanna Peyton launched OHC at Yale School of Nursing. We grew our partnership with Tufts University School of Medicine and then Simmons University. Over the next decade, I knocked on many doors to bring OHC to UMass Chan Graduate School of Nursing, UMass Chan Medical School, Harvard Medical School, and most recently to Harvard School of Dental Medicine. OHC now trains more than 1,300 students annually – for an incredible total of over 8,000 students reached since 2011. In recent years, with the help of a dedicated team, the program's family network has more than doubled, become more diverse, and extended OHC's reach into communities across the state.

The Arc made OHC a health policy priority. In my role as Director of Government Affairs, I led the advocacy campaign to pass OHC legislation. Proudly, the bill was codified into Massachusetts law in 2023. We were honored to be joined for this evening by Representative John Lawn, who was integral in passing the legislation as Chairman of the Joint Committee on Health Care Financing. The bill provides a path to certification of schools through the Massachusetts Department of Public Health. It also allowed The Arc to build an infrastructure and a strong, growing team.

During the celebration, Susanna Peyton was honored for her pivotal role in the development of the program and especially her tireless work to solidify OHC at Yale School of Nursing.

The highlight of the evening for me was facilitating a dynamic panel with Val Ortiz Jimenez, a Harvard School of Dental Medicine student; Isaiah Lombardo, a self-advocate and OHC co-teacher; Mojdeh Mostafavi, MD, an internist, pediatrician, and OHC alumna; and Ashley Waring, OHC Family Engagement Director and Parent Instructor. Together, they reflected on how learning directly from those with lived experience transforms healthcare practice.

OHC has received national recognition through our work with our community partners to publish in The Journal of the American Medical Association (JAMA), the Journal of Autism and Developmental Disorders, and Medscape. I was proud to bring OHC to national conferences and summits such as the National Academies of Science, Engineering, and Medicine; The Arc of the United States; and the Accreditation Council for Graduate Medical Education (ACGME).

As the OHC team looks ahead, the program will continue to expand to address the oral healthcare crisis in our community. We will continue to grow our nursing school education and other health disciplines. OHC will pioneer new national opportunities as a model of medical and disability community partnership. Our vision remains clear: a future where every person with IDD and autism receives equitable, inclusive healthcare.

Families are our teachers. Their stories and experiences have the power to change how healthcare is delivered, not just in Massachusetts, but across the nation.

WHAT **OHC STUDENTS** ARE SAYING

“[OHC] reshaped how I think about my role as a future provider as someone who doesn't deliver care in a vacuum, but as a partner who must be attentive to the small but powerful ways that care can be adapted to truly fit the individual.”
2025 HARVARD SCHOOL OF DENTAL MEDICINE STUDENT

“[The family visit] reminded me that medicine is not just about diagnoses and treatments—it is about relationships, patience, and a deep appreciation for the resilience of those we serve.”
2025 TUFTS UNIVERSITY SCHOOL OF MEDICINE STUDENT

"This experience will stay with me forever, shaping the kind of physician I aspire to be."
2025 UMASS CHAN MEDICAL SCHOOL STUDENT

"[I learned] more in one afternoon than I could have learned from any textbook.... I feel incredibly fortunate to have been part of OHC, and I know the lessons I learned will follow me throughout my nursing career."
2025 YALE SCHOOL OF NURSING STUDENT

WHY OHC?

The Arc’s Operation House Call is our health policy priority due to the health disparities and access issues which exist for people with intellectual and developmental disabilities and autism.

Our community has:

- Higher care needs, yet lower levels of access
- Healthcare professionals have: Limited training
- Healthcare professionals report: Lack of confidence in serving this population

Recent studies show:

- Only **40%** of physicians feel confident providing same quality of care to patients with disabilities.
- Just **56%** strongly agreed that they’d welcome patients with disabilities into their practice.
- **77%** of physicians reported only poor or fair ability to care for autistic individuals.

The Ongoing, Serious **Oral Health Crisis**

For too many families, the search for a dentist ends in denial. This is a heartbreaking crisis and a reality OHC is working to change.

“I’m sorry, our practice doesn’t treat special needs patients.”
“Our practice is not equipped to treat patients with autism.”
“We don’t take MassHealth.”
“The wait will be at least 12 months.”

The Arc’s work: We are building a future where these responses are obsolete. Our unique dental curriculum, informed by lived experience and included by institutions like Harvard Medical School, is training a generation of dental students who are ready, willing, and qualified to provide compassionate care for people with autism and IDD.

OPERATION
HOUSE CALL

FAMILIES TEACHING DOCTORS:
A SPOTLIGHT ON OPERATION HOUSE CALL FAMILIES

By Ashley Waring

Host families are the heart and soul of Operation House Call (OHC). Our innovative experiential learning program could not exist without the families who open their homes to students, generously sharing their time and stories. There are over 250 families in our network, representing a diverse array of backgrounds and experiences. We hope you enjoy getting to know four of them here.

MEET THE LOMBARDO FAMILY

Angela and Isaiah Lombardo have been dedicated OHC participants for over 15 years. Angela is the Program Manager for the Down Syndrome Program at Boston Children's Hospital and the Training Director for LEND Boston. Isaiah is a 29-year-old with Down syndrome and some other medical conditions. He is a full-time team member at Shake Shack, participates in Special Olympics, and dances with the Boston Conservatory at Berklee in a class for adults with Down syndrome.

Many lucky students have been able to learn from visiting Angela and Isaiah in their home. Angela shares that hosting students has benefited Isaiah, too: "Isaiah grew his voice by sharing his story over the years and learned how to share his personal thoughts and feelings about his medical care, his schooling, and his experiences living life with Down syndrome. The students had a special window where they could learn about him in our home rather than a clinical setting which shows a whole different side of Isaiah."

Isaiah is also an important part of the OHC instructional team, as he is one of our outstanding co-teachers! Over the years, hundreds of students at Simmons University, Harvard Medical School, and Boston University School of Medicine have met and learned from Isaiah. He shares about his life and medical experiences with honesty, warmth, and plenty of humor. Isaiah says that when he co-teaches, he hopes the students "learn about how to communicate with patients, how to make kids and adults with disabilities be comfortable, and how to be right here, right now with me." You can learn more about Isaiah and some of our other OHC co-teachers in our recent article in Helen: The Journal of Human Exceptionality entitled "You Can't Learn to Swim on the Shore: Teaching Medical Students Based on Lived Experience with IDD and Autism."

MEET THE BASAK FAMILY

Una and Amit Basak have three children: Maya, Anjan, and Sachin. Maya is 24 years old, a graduate of Emory College, and a Consulting Analyst at a Boston-area investment consulting firm. She is big sister to Sachin and Anjan, 22-year-old twins, who both have profound autism. Although they are twins with the same diagnosis, Sachin and Anjan are very different. Sachin loves to be around people, and while he needs significant support to do so, he enjoys trying new things and exploring in the community. Conversely, Anjan tends to self-isolate and feels most comfortable at home with his family or spending time in his room. Both young men are recent graduates of Nashoba Learning Group and now attend the school's Adult Services Program.

When students meet the Basak family, they learn valuable lessons about understanding behaviors as a form of communication, family impact and resilience, and partnering with caregivers to provide accommodations for inclusive care. Crucially, students also learn about how families navigate having multiple children with high support needs and the drastic change in services and supports that happens when individuals transition at age 22. Both Una and Amit are strong advocates for organizations that support individuals with profound autism, and they are collaborating with other stakeholders on creating innovative adult housing and service solutions for this population.

Reflecting on hosting for OHC, Una observes, "Meeting medical students provides hope for the healthcare future of our community of deserving individuals with profound autism. We discuss misconceptions and challenges in treating people like Anjan and Sachin. I like to encourage that there is no incorrect question – and that often autism families love to share and are thrilled to be asked what works best!"

BECOME AN OPERATION HOUSE CALL FAMILY!

If one of your New Year's resolutions is to become more involved in advocacy, Operation House Call (OHC) is a great place to start!

The Arc's groundbreaking health equity program teaches medical students the skills and mindsets to provide inclusive care for individuals with IDD and autism. A key component of OHC is the home visit, where a small group of students meet with a family and get a window into their daily lives.

The time commitment is small – a few hours every few months – but the impact is huge. Our host families strengthen their advocacy skills and are empowered to share their experiences (both medical and otherwise) with the students, who learn crucial lessons not taught in the classroom. Families with loved ones of all ages can participate! We are most eager to grow our network in the Worcester and Boston areas (within 30 minutes of each city).

Interested in learning more?

Contact Ashley Waring at **awaring@arcmass.org.**

MEET THE BASSEY-MANCZUK FAMILY

Ebbe, Mark, and their daughter Anoushka are one of our Connecticut families, who host advanced practice nursing students from the Yale School of Nursing. Anoushka is a sassy and fun second grader with Down syndrome. Their family is full of heart, creativity, and curiosity. Mark is a percussionist and educator; Ebbe is a civil servant, actor, producer, and writer; and Anoushka is already making her creative mark as a young model!

The Bassey-Manczuks are passionate about advocacy and inclusion. Ebbe wrote a children's book, Anoushka's Extraordinary Heroes, and founded Anoushka's Helping Hand, a nonprofit organization dedicated to empowering and supporting individuals with Down syndrome.

When students meet the Bassey-Manczuk family, they are greeted warmly with a delicious spread of food, receive a tour of Anoushka's favorite toys, and play pretend with her. They also hear about Ebbe's personal birth story. Ebbe shares, "In my culture, childbirth is viewed as a sacred journey – a passage to the edge of life and back. When a mother returns from that journey with a living child, it is not just a moment – it is a triumph. And that triumph should always be honored."

We are so grateful that Yale School of Nursing students have the opportunity to learn from Ebbe, Mark, and Anoushka. Spending time with their family opens the students' minds and hearts and reinforces the lessons that every child is unique; no one should be seen as just a diagnosis; and families are important partners in providing exceptional medical care.

CONTINUED FROM PREVIOUS PAGE

MEET THE DUBOIS FAMILY

Jacki, Derek, Warren, and Haddie DuBois have been an OHC host family since 2018. Warren is 16 years old, a junior in high school, and an avid hockey player. Haddie is 13 years old and has intellectual disabilities as a result of a 1q44 partial chromosome deletion that impacts all areas of her functioning. Haddie is in her second year at Cotting School, where she plays basketball and baseball and does cheerleading. Outside of school, Haddie participates in many activities including Special Olympics and the Tri-Town Rock Band.

The DuBois family have a lot to share about how future health care providers can support families. In their experience, the best practitioners are those who think outside the box, who address Haddie's concerns first, and who approach her with patience, humor, and flexibility. Haddie has recently had more success at the dentist office thanks to an outstanding provider, and she was able to share about this experience at an OHC class with Harvard School of Dental Medicine students.

During home visits, Jacki loves witnessing the students' curiosity and hearing their questions about both medical care and family life. One theme that always comes up is the importance of listening to parents as they are the first experts on their child. Jacki shares, "If providers want to know how to engage or get a procedure done as smoothly as possible, trust and listen to the parent." By spending time interacting with Haddie and her family, OHC students learn this firsthand.

SCAN QR CODE
To view more resources related to this article.

Monthly Giving

Join the Champions for Change monthly giving program and provide steady, dependable support that powers advocacy for individuals with autism and IDD. By setting up an automatic monthly gift, you reduce administrative burdens and allow more of your dollars to go directly toward programs that matter. It's simple to enroll, easy to manage, and can be adjusted anytime. Your consistent gift becomes a powerful foundation, helping The Arc maintain momentum year-round and enabling deeper impact with every contribution.

Qualified Charitable Contribution via your IRA

For donors age 70½ or older, an IRA charitable rollover can be a smart way to give. You can instruct your IRA custodian to transfer funds directly to The Arc, and the distribution may count toward your required minimum distribution while remaining excluded from your adjusted gross income. It's a tax-efficient way to make a gift that supports our work. Consult your financial advisor or IRA custodian for guidance.

WAYS TO **GIVE**: MAKING AN IMPACT, **YOUR WAY**

Donate Your Car or Other Vehicle

Drive change by donating your car, boat, RV, or other eligible vehicle to The Arc. Whether your car is running or not, this convenient option lets you convert an asset into vital resources for disability advocacy and inclusion in Massachusetts.

Make a Tribute Gift

Honor a loved one, remember someone special, or celebrate a meaningful occasion by making a tribute gift to The Arc. Whether in honor or in memory, your thoughtful donation becomes a powerful acknowledgment of someone's legacy while advancing advocacy.

Donate Stock

Donating appreciated stock or mutual funds can be one of the most tax-advantaged ways to give. By donating stock directly to The Arc of Massachusetts, you can avoid capital gains tax on the increase in value while also receiving a charitable deduction for the full fair market value of the stock. That means your gift can go further by supporting our mission while also providing benefits for you.

Donor-Advised Fund (DAF)

If you have a Donor-Advised Fund, directing a grant to The Arc will put your funds to work immediately for advocacy and programs The Arc provides for people with IDD and autism. Charitable dollars set aside in DAFs are ready to be put to use in the community. Quickly and easily recommend a gift from your Fidelity Charitable, Schwab Charitable, or BNY Mellon DAF to The Arc via our website. Neither you nor The Arc of Massachusetts pay any transaction fees. Once your request has been approved by your DAF, your gift goes directly to The Arc of Massachusetts.

Supporting The Arc of Massachusetts has never been easier or more meaningful. In addition to making a contribution online or via mail, there are several other ways to advance the rights and inclusion of people with intellectual and developmental disabilities (IDD) and autism across our state. Explore the many ways you can give that fit your life, maximize your impact, and sustain The Arc's vital advocacy for a more equitable future for all. Learn more at **thearcofmass.org/giving.**

Planned Giving

Planned giving offers you an opportunity to leave a lasting legacy and have a meaningful impact beyond your lifetime. By including The Arc in your estate plan through bequests, trusts, or other gift arrangements, you support systemic change for people with disabilities while enjoying potential tax advantages and thoughtfully aligning philanthropy with your values. This option empowers you to strengthen the future for the disability community and ensure your support endures.

Facebook Fundraisers

Harness the power of your social network to support The Arc by starting a Facebook fundraiser. Invite friends, family, and colleagues to rally around your cause, amplify awareness, and channel collective generosity toward inclusive change. It's an easy, effective way to engage your community and support The Arc's work in advocating for people with disabilities.

EDUCATION UPDATES

CHANGE IN GRADUATION RULE REQUIRES EARLY FOCUS ON TRANSITION

By Jackie Doherty

In November 2024, Massachusetts voters removed passing MCAS as a requirement for earning a high school diploma through a ballot initiative that passed with 59% of the vote. For some students, both with and without disabilities, this decision eliminated a major graduation obstacle. As the statewide test that measures student academic performance, MCAS will continue to be taken at various times in a student's education, and school districts will continue to be judged by their overall student test scores. For individual students, however, passing MCAS is no longer a graduation requirement.

Instead, the state requires students demonstrate competency by passing classes in key subjects such as English, math, and U.S. history, as well as meeting local requirements determined by their individual school district. While removing MCAS as a graduation requirement may enable more students to earn their diplomas more quickly, it also may cause challenges for those who achieve academic success but need additional support before being able to fully engage in the adult world.

For instance, a high-achieving student with autism may meet the academic requirements to earn a high school diploma at 18 and be set to graduate with their peers. Upon graduation, their eligibility for special education services ends even if they still struggle with anxiety, social isolation, or behaviors that limit their ability to work or engage in the adult world. While these graduates may be eligible for adult services through agencies such as the Department of Developmental Services or MassAbility, the support offered is much less than what's provided in school.

While schools cannot deny a student a diploma if they've earned it, the district must fulfill other requirements before graduating students with disabilities. For instance, students on an Individual Education Program (IEP) and their families must receive support for transitioning to adult services that reviews the planning process and recommends an appropriate adult support agency. From the district perspective, the transition process formally begins at age 14, but families should be thinking about preparing their child for adulthood and being as independent as possible well before high school, beginning in middle school if possible.

Once the district makes the 688 referral to the appropriate adult support agency (typically around age 16-17), families will know the agency designated to support their student after adult eligibility is confirmed. Establishing a relationship with this agency is important: the more information families share about their child, the higher the likelihood that appropriate supports will be identified.

In addition to transition support, the district cannot graduate a student with disabilities without providing a Free Appropriate Public Education (FAPE) over the last school year, which is a right under federal law based on the Individuals with Disabilities Education Act. FAPE is meant to ensure children with disabilities make progress toward achieving goals that are uniquely appropriate for them, which means their IEP goals were relevant, challenging, and achievable. Districts must meet a FAPE standard based on a 2017 Supreme Court decision, Endrew F. vs. Douglas County School District, which requires setting person-centered goals that enable a reasonable expectation for making progress. If a student with an IEP has met academic requirements for graduation, but the family can make a case that the district did not provide an appropriate education, those services must be offered to the student.

Keep in mind that the IEP states the student's expected year of graduation. Regardless of the date, it is helpful to document concerns and goals that support independent living skills/ access to the adult world and progress made (or not) toward achieving them. It's also worth noting that independence and functional skills may get sidelined, and rightly so, for more-pressing concerns around behavior, medical issues, and other physical or attitude changes that may occur.

Whenever possible, parents and students should use each IEP meeting as an opportunity to document concerns, their vision for a good life, the student's interests and skills needed to pursue those interests, and requests for goals that focus on important skills for your student to live as independently as possible when they become an adult. Concerns about behavior at home that impact the student's ability to access his/her education should also be shared, along with asking for home support if needed. When there is a pattern of these concerns and/or limited progress in resolving them, you have a stronger case to extend school years up to age 22 because FAPE has not been met.

Like any organization, school districts operate under budget constraints and graduating special education students sooner rather than later saves money. You must be a strong advocate for your student throughout their school years, making sure they are fully supported to become as independent as possible.

If your student has demonstrated academic competency at 18, and you disagree with the district's decision to end their schooling, your options are limited. You can file with the Special Education Board of Appeals, which may result in a hearing or mediation and often involves getting a lawyer. A documented trail of FAPE concerns will strengthen your case in this situation.

Another option is to reject the IEP. This triggers a stay-put action, which means your student does not leave school and the IEP remains the same as last year. Until this is resolved, the IEP basically repeats instead of moving forward with new goals.

When planning for your child's transition to adulthood, keep your focus centered on your student. Who are they as a person? What goals and supports are needed to make the most out of these precious school years? The best way to avoid disputes between families and school districts – and prevail if they do happen – is to communicate fully, work collaboratively, know your rights, and advocate strongly each step of the way!

STAY TUNED FOR MORE ON TRANSITION AND INFORMATION ON THE ARC'S TRANSITION CONFERENCE SCHEDULED TO BE HELD IN FALL 2026.

SCAN QR CODE
To view more resources related to this article.

PATHWAYS TO FRIENDSHIP

BUILDING BELONGING ACROSS LANGUAGES

By Rachel Hayward

Massachusetts is a national leader in disability services. Access to these resources, however, is largely dependent upon being in the know, as well as the ability to communicate in a language that is mutually understood. This means that many in the disability community who do not speak English are excluded from vast supports.

Pathways to Friendship was founded in 2012 to widen social circles so people with and without disabilities could form friendships. While relationships are part of a good life, far too often people with disabilities are limited to relationships with family members, support staff, and others living with disability. Since then, we have created trainings, resource sheets, toolkits, and videos, and we offer workshops, consultations, summits, and conferences. These are valuable resources to support relationships and friendships that are all too rare. However, language and cultural barriers have prevented Pathways to Friendship from reaching many non-English speaking communities.

To address this gap, Pathways to Friendship is piloting the Building Belonging Grant, a 12-month statewide project. In each region, we are partnering with one Family Support Center and two non-disability focused community organizations that serve non-English speaking populations. With input from the community organizations, we will produce culturally and language-appropriate friendship-building resources and trainings.

These new resources will be shared widely across the state, with the goal that community organizations serving non-English speaking populations are empowered to integrate inclusive friendship-building strategies into their own programming and offerings.

While we are in the early months of this grant and are still identifying community organizations as well as a Family Support Center in the Central Region, Pathways to Friendship is proud to partner with the Family Support Centers below:

- **Metro Region:** Advocates Intercultural Family Support Center: Focusing on Portuguese-speaking population
- **Western Region:** Multicultural Community Services (MCS) Family Support Centers: Focusing on Russian-speaking population
- **Northeast Region:** Bridgewell Family Support Center: Focusing on Spanish-speaking population
- **Southeast Region:** Old Colony YMCA Family Resource Centers: Focusing on Cape Verdean Creole-speaking population

We are grateful for the partnership of these Family Support Centers! We aim to continue this grant in future years and to focus on additional communities who speak other languages. The Building Belonging Grant offers an opportunity to bridge this very real need across languages.

To learn more, contact me at **rhayward@arcmass.org.**

THE ROLE OF FRIENDSHIP IN POSITIVE BEHAVIOR **SUPPORT**

By Dotty Foley

Friendship is a cornerstone of well-being, especially for adults with intellectual and developmental disabilities and autism. The Role of Friendship in Positive Behavior Support is a new interactive training from Pathways to Friendship that explores how friendship and social connection can serve as powerful tools to support positive behavior.

Traditionally, Positive Behavior Support (PBS) has focused on identifying the reasons behind challenging behaviors and teaching alternative skills through structured supports and environmental changes. While this approach has been highly effective, it has often emphasized behavior management over relationship-building. By integrating friendship and belonging into PBS, we recognize that meaningful social connections are not only protective factors but essential components of emotional regulation, motivation, and quality of life.

Through stories of four fictional individuals – Aisha, Michael, Jamal, and Mia – participants are invited to see PBS in action. Each story highlights unique communication styles, strengths, and support needs, bringing to life how meaningful relationships can reduce behavioral challenges while increasing happiness and belonging.

Attendees will learn to apply practical PBS-informed strategies that foster real friendships, promote inclusion, and shift from simply “managing behavior” to actively supporting social and emotional well-being. Interactive discussions and hands-on tools will guide participants in embedding relationship-centered practices into daily routines while aligning with Department of Developmental Services (DDS) PBS guidelines. This three-hour training is designed for Direct Support Professionals, clinicians, and service coordinators seeking to strengthen relationship-centered supports.

Thanks to a grant from DDS, this training is free of charge, reflecting The Arc’s ongoing commitment to advancing inclusion and person-centered support.

To schedule a training for your organization or to learn more,
please contact Pathways to Friendship at **friendship@arcmass.org.**

LEO SARKISSIAN | **New Initiatives Fund**

WHAT HAPPENS AFTER I'M GONE?

By Stephanie Shore

Earlier this year, The Arc of Massachusetts began work on an important new initiative, After I'm Gone. It is the inaugural program of the Leo Sarkissian New Initiatives Fund, which was created to foster forward-thinking projects that tackle longstanding challenges families with loved ones who have intellectual and developmental disabilities (IDD) and autism face as they confront key life events.

Spearheaded by Leo Sarkissian, The Arc's Innovation Development Director, After I'm Gone is developing solutions for families and self-advocates as they address one of the most challenging and emotionally fraught questions: what happens to a loved one with IDD or autism when a primary caregiver is no longer able to fill that role. After I'm Gone incorporates creativity, compassion, and impactful advocacy to support families as they look to the future.

The best way to secure the future is to **start planning now.**

For families of loved ones with IDD and autism, the future can feel uncertain, overwhelming, and even frightening. That is particularly true when faced with the question of "what will happen to my loved one after I'm gone or no longer able to provide the care they need?"

This is not just a question. It's a crisis in the making for tens of thousands of families across Massachusetts.

- **More than 27,000 families** in Massachusetts are caring for an adult with IDD at home.
- **Thousands** have no formal plan in place for housing, care, or financial security after the parent or primary caregiver passes away or cannot take care of them. Housing is of critical concern.
- **Existing systems** are **fragmented**, **confusing**, and often **inaccessible**, especially for underserved or low-income families.

In focus groups and town hall sessions we held in early 2025, families were asked about their struggles with planning for their loved one's future. These conversations helped us identify barriers to planning, the needs in our community, and the challenges families face. They helped to shape the initiative's steps forward which will focus on providing concrete steps and resources to overcome the hurdles to getting started and helping individuals and families with specific information regarding support services and eligibility.

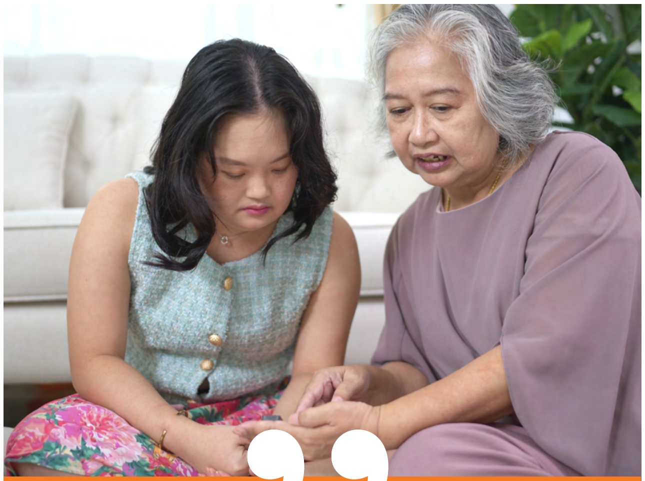
“Many siblings don’t know the basic information. There is a real need to do targeted outreach and other work to educate and provide resources for siblings who will be the ones taking over a lot.”

The first phase of After I’m Gone will provide families with critical tools, resources, and guidance. We will offer fillable templates to create documents to share with other caregivers, including frameworks that families can personalize to detail the level of support needs or a calendar of key activities and appointments. Families will be able to connect online via our new digital community and in person through a pilot group northeast of Boston. We’ll also be developing recommendations for technology that can increase an individual’s self-direction or aid in transition.

“We are in our late 70s and cannot find any company/agency/individual who has the capacity and knowledge to provide supports for the complex public benefits record keeping, maintaining his modest apartment and car, his day-to-day life, and so much more.”

Right now, too many families are navigating the future alone. They are uncertain of where to turn and terrified of leaving their loved one without a plan, a voice, or a safety net. Without action, many individuals with IDD and autism will face housing instability, social isolation, or the unthinkable: institutional placement. That is why this initiative is so vital and has already generated overwhelming interest. The Arc’s vision is to sustain After I’m Gone for the long-term. With the support of our community, including people like you, this project will change the lives of individuals and families for years to come.

Phase One is scheduled to launch at the end of January. If you would like to be among the first to know, sign up for the After I’m Gone email list at **thearcofmass.org/future.**



”

I know my son is not the only one who has very high support needs and no other parent, sibling, or extended family. It’s just me. People like him face grave danger in the future because there is no safety net at all. Terrifying! This is a group that has an especially high level of need.”

“It is TRAGIC that families spend so much time scrambling to figure out what is going on.”

“It is very challenging to actually plan for where our loved ones will live, especially when a family is caring for a person with high support needs at home. This is a huge issue for older family caregivers.”

THE ARC OF MASSACHUSETTS **WALKS, RUNS, AND ROLLS**

IN THE FLUTIE 5K FOR AUTISM

On Sunday, October 26, dozens of members of The Arc of Massachusetts community came together for the 26th Annual Flutie 5K for Autism. Thank you to all who joined us in this incredible community event!

Whether you walked, ran, rolled, donated, or just spread the word, you contributed in a meaningful way toward enhancing the lives of individuals with intellectual and developmental disabilities (IDD) and autism in Massachusetts. Even in these challenging times, our community is stronger than ever and we are so grateful for your support!


FLUTIE
5K
FOR AUTISM
RUN, WALK, ROLL
422
486
861
900


SINCE 1956


1776
1775


486


1298


275

The Arc™
Massachusetts
217 South Street | Waltham, MA 02453

**ACHIEVE
WITH US:**

SAVE THE **DATE**

Progress and
Possibility
THE ARC OF MASSACHUSETTS
2026
GALA

*An Evening of **Celebration**, **Advocacy**, and **Hope***

Thursday, March 26, 2026 at 6:00pm
UMass Club of Boston | One Beacon Street, 32nd Floor | Boston

Please join The Arc of Massachusetts for a lively and fun evening overlooking the beautiful city of Boston.

Additional details will be announced soon.

Please contact **Katrin Aback**, Senior Director of Development and Communications, at **aback@arcmass.org** or **781-891-6270 x105** to learn about sponsorship and volunteer opportunities.