

DEVELOPMENT AND BEYOND NEWSLETTER

A monthly newsletter by The Autism Program at Boston Medical Center for families and individuals with Autism Spectrum Disorder (ASD) & other neurodevelopmental diagnoses

Happy July!

As we reach the height of the season (& humidity, it seems like), we hope that all friends and families are finding ways to stay cool and enjoy the summer fun!



We Belong Here & We're Here to Stay

On July 26th, 1990, the Americans with Disabilities Act (ADA) was written into our law. This was the monumental outcome of fierce & persistent advocacy by disability activists and community members all over America! Since then, every July is celebrated as Disability Pride Month, reminding us of the importance of advocacy, thoughtful inclusion in our communities, and the necessity of an accessible world for all.

Disability Pride Flag:

What does it represent?

The disability pride flag (shown right) was created in 2019 by the artist Ann Magill. Like any flag, the purpose is to honor and represent the members of the disabled community and its history. Each component has its unique meaning!

LEARN MORE:



*Why & How to
Celebrate Disability
Pride Month by
The Arc*



Red stripe: Physical disabilities

Yellow stripe: Neurodivergent disabilities

White stripe: Undiagnosed and/or invisible disabilities

Blue stripe: Psychiatric conditions & disabilities

Green stripe: Sensory disabilities (such as hearing loss, visual impairments, sensory processing disorders, etc.)

In this edition:

PG 2

Upcoming Learning
Opportunities &
Community Events

PG 4

2025 Autism Program
Virtual Conference:
Flyer & Agenda

PG 6

Financial Support &
Water Safety
Resources

PG 8

ASD Research
Participant
Recruitment

Learning Opportunities:

Upcoming community workshops & webinars where you can learn about resources and receive guidance for **free**



Disability Housing Workshops

Wednesday, July 16th | 10am to 12pm



Join the Boston Center for Independent Living (BCIL) to learn all about & how to apply for affordable housing options in your area. The session will include a Q&A.

Registration is required - more info on website.



The Mental Health IEP

Thursday, July 24th | 6pm to 8pm



Build confidence for your next IEP meeting with tips specific to children and youth with mental health needs. Join to learn about school -

based evaluations related to mental health, accommodations and modifications for students with mental health needs, and much more.

Registration is required - more info on website.



Advocating While Black

Friday, July 11th | 10am to 12:30pm



Led by renowned advocate Cheryl Poe, this training is designed for educators, professionals, and parent advocates who want to better understand and address the unique

challenges Black families face when navigating the special education system. Gain legal knowledge around IDEA & Section 504 to protect student rights, strengthen your ability to create culturally affirming & equitable IEP and 504 processes, and much more.

Registration is required - more info on website.

Mental Health First Aid Training

July & August & September 15th | 9am to 5pm
@ 1 Southside Road in Danvers, MA



This free, in-person course by Northeast Arc will teach you skills to help adults, including those with disabilities, who are facing mental health crises. Learn about the common signs & symptoms of mental health and substance use challenges, how to interact with someone in crisis, and how to connect a person with support.

Registration is required - more info on website.



Disability Transition Planning & Post Secondary Options

Friday, July 25th | 10am to 11:30am



Learn about transition planning, a formal process to help students with special needs think about what they want to do after high school, how to get there, and what supports and services can help them along the way.

Registration is required - more info on website.



Disability Advocacy Workshop

Tuesday, July 29th | 10am



Learn about ways that friends, family, and self advocates with I/DD can advocate for rights on the legislative, community, and individual levels.

Registration is required - more info on website.



Recreation & Community:

Upcoming events for both sensory-friendly fun and meeting your village - why choose between one?

*** all events are in-person*

Sensory-Friendly Time with the Atlantic White Shark Conservancy

Sundays & Wednesdays | 9:15am
@ 235 Orleans Road in Chatham, MA

Tickets are \$10 for adults & youth (6+), FREE for kids 5 and under!

Registration is required.



Arts & Crafts Club for Teens and Adults in Concord

Tuesdays | 4:30pm to 5:30pm
@ Fowler branch of the Concord Library

Open for all teens & adults with cognitive differences! Contact Laurie@artforallconcord.org if you are interested.

Registration is required.



Bird Walk & Resource Fair

Saturday, July 12th | 8am to 12pm
@ 444 Lynn Street in Malden, MA

Spread your wings at The Great Malden Outdoors Birding event, where nature meets community in celebration of Disability

Pride! Alongside the chirping birds and scenic trail, don't miss the vibrant Resource Fair featuring amazing organizations like Molina Healthcare, Boston Center for Independent Living, My Ombudsman, and many more.

Registration is required.



Sensory-Friendly Saturdays at Altitude Trampoline Park

Saturdays | 9am to 10am
@ 700 Boston Road in Billerica, MA

Discounted tickets for \$12

Registration is required.



Youth Summer Workshops by Boston Center for Independent Living (BCIL)

Every day programming until August 21st
In-person & virtual options available

FREE summer program for students ages 14-22 with any disability! Enjoy fun community outings and workshops that will teach students many important skills for more independence.

Registration is required.



Check out these links to find a list of accessible pools, spray decks, and beaches across MA!

Autism Acceptance *into* Action:

Crafting an Inclusive World

Register here!



Virtual Conference
August 15 2025
9 AM to 3:30 PM

Join the Autism Program at Boston Medical Center for a day of learning about tips, strategies, and resources to best navigate the autism landscape. This virtual event is available to all families and the professionals who support them.

Continuing Education Credits will be available to nurses, social workers, and BCBAs.

\$250
Professionals

\$15
Family
Members

FREE
BMC Families
& Staff

Register Today!

➔ <http://bit.ly/AutismAcceptanceIntoAction>

Autism Acceptance into Action:

Crafting an Inclusive World

Starred sessions feature members of our community with **lived experience!**

AGENDA 2025



9:00 - 9:15

Welcome: Why We're Here

Shari Krauss, Autism Program Director

9:15 - 9:45

Small Steps, Big Impact: Supporting Medical Readiness in Autistic Patients

Jacqueline McKendry, Behavior Specialist

9:45 - 10:15

Bridging the Gap: Enhancing Collaboration Between Schools and Medical Teams

Katherine Shields, Adult Autism Resource Specialist

10:15 - 10:45

Make It Easier: How to Create Your Own Visual Resources

Juju Ha, Autism Resource Specialist

10:45 - 11:15

Include, Engage, Empower: Practical Strategies for Making Community Programs Autism-Friendly

Katie Campbell, Senior Community Wellness Advocate

11:15 - 11:45

Understanding Feeding Challenges in Children with Autism: Strategies for Success

Madelyn Goskoski, Autism Resource Specialist



11:45 - 12:30

Lunch

Stick around for a **talent show!**

12:30 - 1:15

Safety in the Home and Community

Christina Chow, Autism Resource Specialist

1:15 - 2:00

What to Do When You Receive an Autism Diagnosis

Hillary Hollis & Elizabeth Ferriero, Autism Program Leads

2:00 - 2:30

Advocating for Autism Friendly Healthcare

Alexander Friedman, Autism Program Manager



2:30 - 3:15

Growing Up with Autism

Members of our teen mentoring program and patient advocacy board (TEAM/TEACH)

3:15 - 3:30

Putting it All Into Practice: Lessons Learned

Shari Krauss, Autism Program Director



Are you looking for financial resources?

Financial support is both important and complicated. Check out these resources that can help!



Upcoming Webinar

8/5 at 12pm

8/13 at 7pm

Planning for a Loved One with Special Needs:

Planning for Two Lifetimes

Every family is different, and each of us must create financial strategies with our circumstances in mind. This is especially true for families that care for children with special needs.



Join Mike Ringel in this presentation to learn:

- ▶ Why a **special needs trust** is a "must have" and how to fund it effectively
- ▶ How to **save money for your retirement AND fund your special needs plan**
- ▶ Discover what is an **ABLE account** & how it can help

Financial Aid Opportunities

AANE (Association for Autism and Neurodiversity) is currently presenting TWO funding opportunities for families and individuals with autism. For more information about the grant and how to apply, please visit the [AANE website](#).

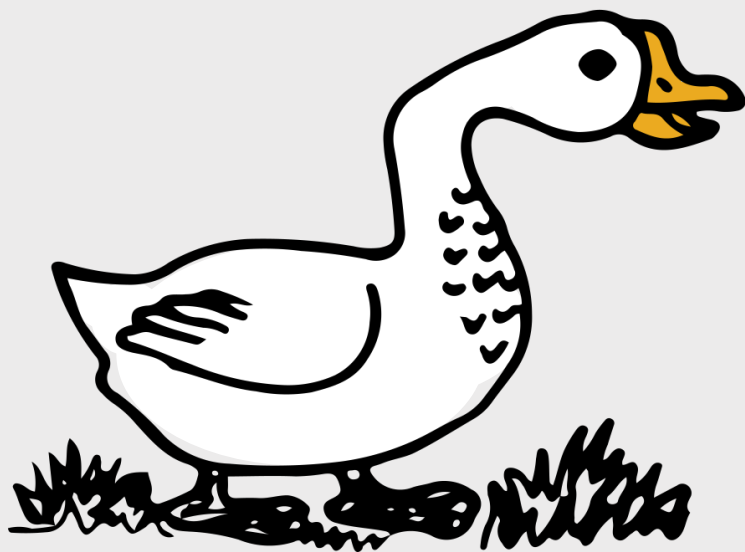


Doug Flutie, Jr. Foundation for Autism

This grant provides up to \$500 for a limited number of Autistic adults & families in New England to help pay for the services & programs that benefit them.

The Daniel Braun Memorial Scholarship Fund

This grant provides up to \$500 per individual for a limited number of Autistic adults and teens (12+ years old) who need help paying for group recreational and/or social activities.



Funding Resources Guide

Financial Resources Guide

Finding financial support can often feel overwhelming for families with children on the autism spectrum. This guide is designed to simplify the process by offering a categorized list of potential funding opportunities. Please note, all options below require an application and funding is not always guaranteed. If you are interested in applying for any, please make sure to check each organization's website for their most up-to-date details.

Reach out to your family's DDS Service Coordinator
If your family is already connected with Department of Developmental Services (DDS), we recommend reaching out to your Service Coordinator or other case manager to inquire about potential funding opportunities.

General Assistance

Autism Care Today

- Offers grants up to \$5000 to families, with priority given to those with a household income under \$100,000. Funding may be used for ABA, speech, OT, medications, home safety devices, social skills groups, and more.
- <https://www.autismtoday.org/apply-for-grant>
- Email: grants@autismtoday.org
- Phone: (855)450-5253 or 317-972-4893

Flirtie Foundation

- Provides a variety of funding opportunities for children with ASD in many different areas of support, such as:
 - Jessy's Fund: Help's Fund - with a range of needs
 - Kadi Lee Givens Back Grant - music/art opportunities
 - Community Inclusion Grant - community participation
 - Ongoing Immediate Financial Assistance - emergency aid
- <https://flirtiefoundation.org/helping-families-direct-financial-support/>

Willpower Foundation

- Provides grants to families and individuals living in Western Massachusetts. Their grant specializes in funding products and services that are not typically covered by insurance or other resources, including but not limited to mobility and sensory equipment, therapeutic recreation programs, educational advocacy, private tutoring and camp experiences.
- <https://www.willpowerfoundation.org/overview/>
- Email: grants@willpowerfoundation.org
- Phone: 413-341-3151

Medical Assistance

Modest Needs

- Offers Self-Sufficiency Grants to qualified individuals/households in need of the following types of financial support:
 - Unexpected or emergency expenses
 - Monthly bills that an individual or family cannot afford to pay at the time of their application because of an extenuating circumstance within the past year
- <https://www.modestneeds.org/information-for-applicants>
- Phone: (845) 667-3776

Recreational & Educational

Association for Autism and Neurodiversity (AANE) (Ages 12 and up)

- The Daniel Brown Memorial Scholarship Fund provides financial assistance for a limited number of autistic individuals ages 12+ who need help paying for group recreational and/or social activities.
- <https://www.aane.org/enhance-program/grants-scholarship-program/grants-for-adults/fund/>
- Email: grants@aane.org
- Phone: (617) 393-3524

Music Movement

- Offers annual grants in several areas of support, such as:
 - Music Therapy & Instrument Donations
 - Wireless Family Fund (for families within the wireless/tech industries): Living expenses, medical bill, tuition support, etc.
 - Independent Living Initiatives (for 18+): independent housing programs, camps/retreats, education/therapy
 - Keys & Kingdoms Grant - instruments, tech/computers
- <https://www.musicmovement.org/>
- Email: info@musicmovement.org

Maggie Welby Foundation Scholarships (Grades K-12)

- Offers scholarships for school children grades K - 12 in need of financial assistance, in memory of Maggie Welby, a 7 year old girl, who was taken very suddenly from her family and friends in 2020.
- <https://www.maggiewelby.org/scholarship-grants>
- Phone (text): 314-330-6947

Did you know that we have a [Funding Resources Guide](#) available on our website for free? View this resource for a comprehensive list of funding opportunities for families & individuals with ASD (note: many grants are not specific to ASD)!



SAFETY TIP OF THE MONTH



Autism, Wandering, and Water Safety

WHAT YOU NEED TO KNOW

Safety Checklist

- ☐ Lock windows, doors, yards, and water access
- ☐ Know the dangers in your neighborhood
- ☐ Use a GPS or tracking device to support supervision
- ☐ Write down important information to share with emergency responders
- ☐ Teach neighbors about your family's concerns and how to contact you
- ☐ Ask your child's doctor, behavior specialist, and teacher, for help
- ☐ Introduce your child to local police, firefighters, and EMTs
- ☐ Teach your child to swim and create safe water habits

Know the Dangers

Children with **ASD** are more likely to leave a safe place without an adult. This is called **wandering**. Some people call it elopement or bolting. Many children with autism are interested in water. If they wander to water, it can be **dangerous**.

The #1 cause of death for children with autism is drowning, usually after wandering.

There are things you can do to help stop wandering and help emergency workers to find your child if they go missing.



If your child is missing, call 911 immediately.

Research shows that up to 50% of children with Autism may leave a safe environment without telling anyone — a behavior known as wandering, elopement, or bolting. This can occur for a variety of reasons, including trying to get something they want or like, trying to escape overwhelming feelings or sensations, or simply exploring their surroundings.

Many children with ASD are also drawn to water, which significantly increases the risk of drowning — the leading cause of death among children with autism.

To help address these critical safety concerns, the Department of Developmental Services, in collaboration with the Office of the Child Advocate, Department of Children and Families, Department of Elementary and Secondary Education, the Federation for Children with Special Needs, and other partners, has launched a **new online resource**.

This webpage offers tailored information for families, educators, service providers, and emergency responders.

It outlines evidence informed strategies and practical tools to build layers of prevention and improve safety outcomes for children with autism.





SEEKING RESEARCH PARTICIPANTS

PROJECT AFFINITY



Why?

- To help us understand how autistic children engage with the world through their focused interests

Who?

- Parents and caregivers of autistic children aged 5-12 years

What?

- 1 survey and interview about your child's skills
- 1 interview about how their focused interest affects their engagement with you and others

Where?

- Over a zoom meeting or in person at Boston University for 2 hours total

Participants may withdraw at any time, and will receive a \$25 gift card as compensation.

Scan the barcode or contact us to learn more:
jayw@bu.edu 781-627-5552



BOSTON UNIVERSITY

Project Affinity at **Boston University** is currently recruiting autistic children (ages 5-12) to be a part of their research study. They aim to learn about how kids on the spectrum engage with their focused interests in their everyday lives, and how it is viewed by family, community and service providers. Participants will complete a survey & interview over Zoom or at Boston University.



- ▶ If you or someone you know may be interested, please contact jayw@bu.edu.
- ▶ Visit this [website](#) for more information.

Do you have a child with autism?

Do you have another child 8 months or younger?

Researchers at the UMass Chan Medical School are interested in learning more about the language and social communication skills of children with siblings with ASD.

The study will consist of virtual support and 6 home visits from 6-8 months of age to when your child is 24 months.

All participation can occur virtually and at home

- Parent fills out questionnaires.
- Developmentally appropriate activity cards, toy, and book given to families each visit.
- Virtual social and communication coaching sessions for parents.
- Assessments of language skills, cognitive skills, and brain activity.
- Parent and baby will be videotaped while they play.
- Baby wears a digital recording device in a vest to record a day's language environment.
- Standardized assessment of autism characteristics at 24 months.

Total time commitment for the study will range from 60-82 hours

You will receive a \$40 gift card after completing assessments at each study time point at 6-8 months, 9 months, 12 months, 18 months, and 24 months.

For more information, please complete a pre-screener utilizing the QR code, contact (774) 479-6025, or email petalstudy@umassmed.edu



Protocol ID: 119-02-1537 UCLL IRB Approved Approval Date: 4/26/2022 Copyright: Medical FTE 3

Do you have a child with autism?

Are you currently pregnant?

Researchers at the UMass Chan Medical School are interested in learning more about the language and social communication skills of children with siblings with ASD.

The study will consist of virtual support and 6 home visits from 6-8 months of age to when your child is 24 months.

All participation can occur virtually and at home

- Parent fills out questionnaires.
- Developmentally appropriate activity cards, toy, and book given to families each visit.
- Virtual social and communication coaching sessions for parents.
- Assessments of language skills, cognitive skills, and brain activity.
- Parent and baby will be videotaped while they play.
- Baby wears a digital recording device in a vest to record a day's language environment.
- Standardized assessment of autism characteristics at 24 months.

Total time commitment for the study will range from 80-82 hours

You will receive a \$40 gift card after completing assessments at each study time point at 6-8 months, 9 months, 12 months, 18 months, and 24 months.

For more information, please complete a pre-screener utilizing the QR code, contact (774) 479-6025, or email petalstudy@umassmed.edu



Protocol ID: 119-02-1537 UCLL IRB Approved Approval Date: 4/26/2022 Copyright: Medical FTE 3

PETAL Study at **UMass Chan Medical School** is currently recruiting research participants to learn more about the language & social communication skills of children with siblings with ASD. They are looking for families with a child with autism, as well as another child (8 months or younger) and/or is currently pregnant. Participants will receive a \$40 gift card after completing assessments at 6 different points throughout the study.



English



Spanish

- ▶ For more information, please contact (774) 479-6025 or email petalstudy@umassmed.edu
- ▶ Interested? Complete this [pre-screener form](#) (available in [English](#) & [Spanish](#))

Connect With Us!

Are you seeking to spread the word about your upcoming events, services and/or programs for individuals with neurodevelopmental disorders? Reach out to autismprogram@bmc.org to inquire about being featured on our monthly newsletter.

Resources



The Autism Program is continues to support families in many ways both inside and outside of Boston Medical Center. Check out our website to learn more about the services, supports and programs we offer including our Autism Friendly Hospital Initiative, Teens Engaged as Mentors (TEAM) program, and our training offerings. We also have a huge resource library where you can access free information on a variety of topics such as safety, behavioral support, transition to adulthood, insurance and more!



www.bmc.org/autism
Autismprogram@bmc.org



The Autism Program



@BMCAutismProgram

Clinic

Our DBP clinicians are available for developmental evaluations, assessments and follow up. To connect with the clinical team, please call 617-414-4841 and follow the prompts for Developmental Pediatrics.



Our Clinicians

Marilyn Augustyn, MD

Arathi Reddy, DO

Rachel Amgott, NP

Christina Lazdowsky, NP

Mei Elansary, MD

Audrey Christiansen, MD

Sarah Canale, MD

Mary Ellen Killion, NP

Arielle Spellun, MD

Bridget Poznanski, PhD

Rachel Vuolo, MD

Selcen YarogluKazanci, MD

ABOUT THIS NEWSLETTER

Development and Beyond is brought to you by the Autism Program at Boston Medical Center, a family support program of Developmental & Behavioral Pediatrics. **To join our mailing list for future newsletters, community resources and more, scan the QR code to the right!**



Do you have an idea for a future newsletter?

Email us at

autismprogram@bmc.org

with your suggestions!