Issue 84 | August 7, 2025

DEVELOPMENT AND BEYOND NEWSLETTER

BOSTON MEDICAL CENTER
The Autism Program

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

Hello August!

As we step into August, it feels clear that the season is slowly beginning to set. Just like the cooler temperatures, there are many changes on our way! With preparing for back-to-school, setting up new daily routines, and just tackling all the new situations that may arise each day, there are many moving parts to our summer days. For this month's newsletter, we wanted to highlight resources that can support with some of these moving parts such as **free school supplies**, **learning opportunities** on how to better manage challenging situations & more. We also featured an **interview with an autistic young adult** - catch our conversation around the female autism diagnosis, young adulthood, and self-advocacy on page 7!

8/15 2025

The Autism Program is hosting a virtual conference for families & care providers on August 15th! See page 5 for more details.

Upcoming event

Sept 6th

2025 Calmer Con

Sensory Friendly Comics & Pop Culture Convention

Calmer Con is specifically designed to meet the needs of those with sensory processing challenges, autism, and anxiety concerns while providing an authentic comics & pop culture convention. Coming up this year on September 6th in Weston MA, join your community & all the exciting stuff that the day has to offer including cosplay, Jedi training, drawing workshops, superhero academy, artist alley, Pokemon club, and more! This event offers free admission to everyone with registration.

In this edition:

Learning Opportunities

Upcoming community workshops & webinars where you can learn about resources and receive guidance. All events below are virtual.

Back to School Anxiety Workshop

August 12th & 19th | 12 - 1:30pm

This workshop for parents will share how to support your child with back-to-school anxiety. Two sessions are offered. First session covers what aanxiety looks like, the role of parental accommodation, and providing support & building your child's confidence. The second session will cover how to reduce accommodation, helping your child cope with anxiety, and tips for implementing a plan.

Registration is required - more info on website.

How Can You Identify & Support a Black Youth with a Mood Disorder?

August 12th | 10 - 11:30am

Although Black youth may face systemic barriers when it comes to addressing mental health, there are ways in which adults can help. This virtual workshop is facilitated by FFDA (Families for Depression Awareness) staff and delivered by a licensed mental health professionals. Join to learn how to recognize someone who needs help and assist them in accessing services.

Registration is required - more info on website.

Planning for a Loved One with Special Needs

August 13th | 7pm

During this presentation, you will learn why a special needs trust is a "must have" and how to fund it effectively, how to save money for retirement and fund the special needs plan, and discover what an ABLE account can do.

Registration is required - more info on website.

IEP 101 & Beyond

Thursday, July 24th | 6pm to 8pm

Join to share your stories and tips for how to be prepared to advocate for your child before and during an IEP meeting.

Registration is required - more info on website.

Managing Fears & Phobia in Kids and Teens

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

Jacqueline Sperling, PhD, breaks down common fears for kids and teens, offers strategies for parenting children who are feeling scared, and answers questions about specific phobias and how they're treated.

Registration is required - more info on website.

Essential Communication Skills for Mental Health Caregiver

Tuesday, July 29th | 10am

In this webinar, Dr. Chris Segrin will guide you through real-world scenarios caregivers often face supporting loved ones through depression. You'll learn practical communication techniques for discussing depression symptoms, navigating conversations about professional help, using de-escalation strategies, and addressing trauma-related challenges with sensitivity.

Registration is required - more info on website.

BACK TO SCHOOL:

Resources that you should know about!

Looking for help with school supplies?

8/13 Salvation Army's Back-to-School Celebration

TD Garden, Boston

Get ready to join this celebration at TD Garden for families and students! It will include giveaways, health & fitness activities, and more. All registrants grades K-12 will receive a backpack filled with essential school supplies and a warm winter coat.

8/21 Back-to-School Open House & Resource Fair

1250 West Chestnut St, Brockton

Join the Arc of Greater Brockton from 4 to 7pm for their annual backpack giveaway! They will also be hosting a resource fair on the same day. Register for this event by contacting Tracey Glynn at (339) 837-1923. Click or scan the QR code for more information!

Educational Support

For students:

Tumble Book Library

Enjoy an online library full of free interactive books for kids! Includes story books, read-alongs, non fiction books, graphic novels, language learning books, as well as fun puzzles and games.

Khan Academy

An excellent free learning platform for students of all grades. Utilize the free tools such as worksheets, videos, and quizzes to boost your academics!

For caregivers:

If your student is struggling to access accommodations and services that they would benefit from, consider getting in touch with an **Educational Advocate** & other available resources. Check out this list by Mass.gov for more information.

Additional Resources

Beverly Bootstraps provides free backpacks and school supplies to students living in Beverly, Manchester, Hamilton, Wenham, and Essex of MA.

Cradles to Crayons provides school supplies, seasonal clothings, books, and more to Boston families in need.

Create a New Routine

With back-to-school around the corner, comfortable routines can feel disrupted. Try these steps to help transition into the fall!

1

Children thrive with **structure** & **consistency**. Creating a **written and/or picture schedule** as part of your daily or weekly routine can support maintaining structure!

2

Start to fill in your schedule with **consistent eating, sleeping, and hygiene routines** (i.e. set wake-up time, mealtimes, bedtimes, times for hygiene tasks). Add in other activities around these specific routines.

3

Be specific with your child regarding what exactly needs to be completed for each activity. **Breaking each activity down into smaller steps** can be very helpful! **Using pictures** can support your child's understanding of the activity.

4

Goals should be **clear** & **realistic** for your family! **What exactly** do you want your child to accomplish each day?

5

Once your routines have been set, identify **easy to deliver rewards** for your child to earn when following through with their routines.

What does your child REALLY want to play with or do during the day?

Keep these items **out of reach** until your child has completed the identified tasks.

Provide them with the item/activity immediately after they have "earned" it.

Set clear expectations for engaging with this reward.

How long will your child be allowed to engage with this?

Throughout each day, provide your child with more **praise instead of negative consequences.**

Kids want attention (it's normal!) & you want them to learn that the best way to get your attention is by following expectations.

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

BOSTON MEDICAL CENTER
The Autism Program

Register Today!

➡ http://bit.ly/**AutismAcceptanceIntoAction**

Autism Acceptance *into* Action:

Crafting an Inclusive World

AGENDA 2025

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

★ 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

BOSTON MEDICAL CENTER
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http://bit.ly/AutismAcceptanceIntoAction

Approaching Life Head On:

Conversation about female autism diagnosis, transition to adulthood, and self-advocacy

Can you introduce yourself?

I am an upper classman in college and am currently studying biology, which I really love and am passionate about. I'm part of a bunch of clubs on campus. I love art, even though it's not something I'm going to pursue, and I like bugs.

Bugs! That is definitely something I can't say for myself. So, biology - were you always interested in it?

Yeah, a lot of it was influenced by being autistic and having to figure that out myself, and being the person that had to push to get myself evaluated. When you spend so much time learning and gathering the vocabulary and the scientific background behind what you need to understand, you've already set yourself a step ahead. It was very easy to fall into, it was something that has always interested me, and I'm really happy to be able to do it. 10 percent of autistic people get to go to college, and I'm really proud to be part of that 10 percent.

You mentioned having to do a lot of work with pushing for an evaluation. What was that like for you?

Yeah, so something that a lot of autistic people say and relate to is that it took doctors years to figure out that I was autistic, when all of my classmates always knew. And that's in the sense that other people know you're different and that is something very easy to understand. If other people see you as different - you can't interact with people in the way other people do - you recognize that. I didn't have a lot of friends growing up, a lot of autistic people don't, it was very hard to relate to others. My brain just didn't work like that.

Part of my experience was definitely marked by having a brother with autism. I was diagnosed in late adolescence, while he was diagnosed much earlier. He and I operate at the same level, both what many people would describe as low support needs or high functioning autism - whatever you want to call it. But because he was diagnosed long before I was, I was expected to be more understanding of his needs when I had the same needs that were not recognized. A lot of autistic girls in particular are very good at controlling ourselves and hiding our needs, not because they are less important, but because we have been socialized to think that *"you can help it, so you have to."* My brother had a very specific stim need where he needed noise all the time. He was always playing music. I am hypersensitive to noise. When you grow up with that and your parents only understand that he needs to make the noise and not that the noise is actively harming you, it makes it very difficult.

It's important to acknowledge the **diagnostic disparity.** My parents were told directly that *"she can't be autistic because she is a girl."* This was in the past 10 years by a licensed psychologist. I figured it out about 5 years before I was officially diagnosed, so I had to learn to advocate - not through watching others and being guided, but through necessity. Until I was diagnosed, it was very much the idea that I was doing things for attention, which is common. A lot of the advocacy skills I had were self-honed. I want it to be known that even if you don't have parental support, a diagnosis, or your needs are sidelined, you can still be the person that you need for yourself.

I would love to hear more about your learning process with self-advocacy skills.

In order to self advocate, you need to know three things: **what to say, how to say it, and who to say it to.** And all of these steps are way more difficult for autistic people - how do you know what you need if you have trouble interpreting your own body's signals? I can't tell when I'm hungry, so how can I tell when I'm being discriminated against? We have trouble articulating ourselves and making our needs known - how are we going to reason through someone for accommodations that are only allowed if deemed "*reasonable*"? So, knowing these things are the key to advocacy. It's not all you need, but definitely the first steps.

In order to know what you need, you have to get in tune with your body. For example, when I find a sensation in my body, I find a lot of help in just taking a second and really focus on where it is and what its sources could be, as opposed to assigning a source immediately.

Being able to reason through what you need is also immensely difficult. This is where I would actually recommend studying up on cause and effect, logic and debate skills. Autistic people tend to have very logical brains, so this is actually something we can read and get instructions on. **Self-advocacy is a back and forth. A conversation, not a statement.** You are entitled to reasonable accommodations, but what is reasonable?

For example - in college, you have to be able to explain why something is reasonable for you using reasons that are protected under federal civil rights law. You can't ask to have no morning classes because it's hard to get up in the morning. It's hard for everyone to get up in the morning. If you ask for no morning classes because your ADHD medications don't kick in until the afternoon, that provides you with an equal opportunity to succeed as other people because their brains are always working at that level.

In order to self-advocate, you need to know three things: What to say, How to say it, and Who to say it to.

You're not asking for special treatment. The things that you are asking for are not extra; you are not asking for anyone's work to be increased or for things to be harder for anyone. You are asking for your civil rights to be respected.

Throughout your process of seeking accommodations in school, did you find that they were usually responsive and respectful of these requests?

On paper, all schools have to provide reasonable accommodations to students with disabilities under the Americans with Disabilities Act and Section 504. Unfortunately, the law on paper can look differently to that in practice. Just because schools have to provide those opportunities does not mean they will make it easy. People can want to help you and be in positions of being able to help you, but still find it difficult to help you.

What could you do in those situations?

One thing you can do is escalate. If someone is supposed to be helping you and is not, they probably have a boss they need to answer to.

Something important is that you are legally allowed to have a **disability advocate** in the meetings with you that are about your disability. The advocates don't necessarily need to have any training or be anyone in particular - they can be someone who can hold your hand so that you can be more comfortable. Sometimes, even just having two people there who are on your side can be really helpful.

I also think that speaking with other students is one of the best ways to get information about your school's disability services. Some schools have students who work in disability offices to give advice. There are also sometimes disability-affinity organizations on campus you can reach out to. And talk to other students! Reach out to current students when you are looking into different schools.

One way to fast-track the process is to see if there are any forms available before your meeting. You very likely will need your physician's signature to show that you do, in fact, need that accommodation. Before you have the meeting, find the form, get it filled out, so that you don't need to have two meetings.

Based on your experiences, what do you think schools can do to make the process easier & more accessible on your end?

I think one of the easiest things that can be done is to have a step-by-step guide at the top of the disability services page - *"Here is what you need to do to get accommodations, you will need xyz…You will have to fill out abc…"* I also think if disability services can send out an email once a semester to check in on how they are doing, and to share any opinions, that would be great.

For work environments, anonymous forms could be good if there was a problem and a lot of people were hesitant to be the person to speak up about it. Another thing in particular: maybe like a quarterly email to employees asking, *"hey guys, how's the temperature in the office?"*

You can still be the person you need for yourself.

I want to scroll back in time and explore what it was like for you to go from being an adolescent to a young adult. That is a very big transition that is very challenging for almost everyone.

What did you find to be the most salient takeaway?

I will say, people with autism have a lot of struggle with transitions. In particular big transitions and life changes. So even if you are really excited for college - if it's the thing you've been waiting for - you are still going to feel this intense ball of terror in your chest for a couple of months. I want people to know that it's not a sign that you're making the wrong decision; that it's not a sign that you should back out; and that this is your body going through change and trying to cope with it. **Good change can feel bad.**

Such an important reminder. What were some things that helped you navigate through the emotional transition?

I really liked being able to pick out my dorm theme and furniture ahead of time. Being able to visualize in my head what my space would look like was a lot more comforting, and when I got there I was more prepared because it was already familiar to me. I brought comforting objects, little trinkets from my room that brought me joy. I did not bring my rock collection to college, only a couple, just a few… You can't make the change any less scary, but you can make the new thing more familiar.

Good change can feel bad.

Anything else you would like to mention about navigating the transition into adulthood?

Part of the transition is becoming independently responsible for your specific needs. And that is going to be difficult in relationships because you are now in a position where you're an adult and you're expected to have adult reactions and behave like an adult. Sometimes behaviors autistic people need to do to feel comfortable are seen as not mature. And so, I'm not saying that you should stop behaving how you are, you should never change who you are for other people - what I'm saying is that there are people who will accept you for who you are and if the people that you find are not doing that, find new people.

So many people - and I've heard from parents of autistic folks as well - feel anxiety around social relationships and worry that they won't be accepted for who they are. This is a great reminder that you can always find new people who will accept you for who you are, and that is not too much to ask for.

Yeah. I think particularly with the social struggles that a lot of autistic people have, it's very important to remember that it's better to have no friends - it is so much better to be alone than to be around people who are actively making you miserable. Don't be afraid to be alone.

How was it like going to college? You have mentioned before that you were home schooled before college. What was that transition like?

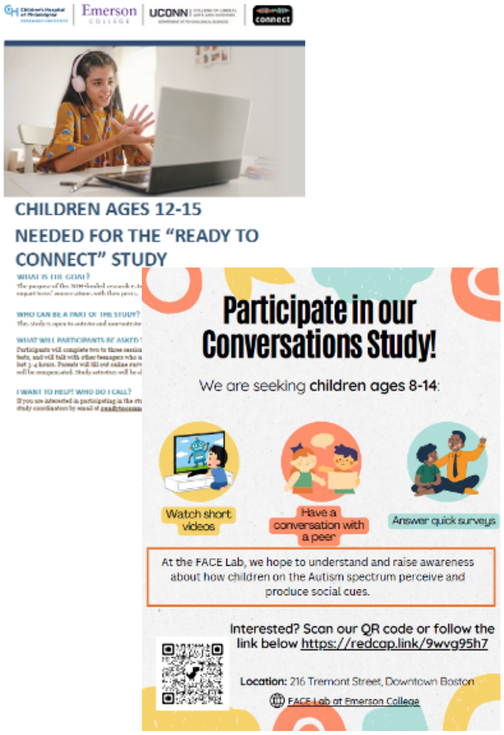
Oh my goodness - so for me in particular, I did a lot of self education in home school life. I was always very used to being very self-driven. So getting to college and having to hit the ground running was something that I was very comfortable doing, but I know that a lot of people do struggle with. And in that vein, you also have to learn that some people are going to be more prepared than you are. Some people are just going to be better at some topics than you are and that is fine. **It's fine to be a little slow, it's fine to have a little failure launch - who cares, genuinely. You are not going to be the only person who's unprepared, guaranteed.**

My grades only improved after my first year because I became more comfortable. I never had to take the SAT so my first exam in several years was a chemistry exam - and there was such an overwhelming sense of anxiety. I did not do well on that exam, but having done it once made the second time less scary. And doing it twice made the third time less scary. It really is about desensitization.

Most things you do in life aren't going to affect you forever. And, at least in my opinion, making a decision is scary and choosing the riskier option is always going to be scarier. But if I'm going to be scared no matter what, then I'm going to take that chance. I'm already feeling anxious - I might as well. I'm already here, so let's go.

Time will pass anyway.

SEEKING RESEARCH PARTICIPANTS



CHILDREN AGES 12-15
NEEDED FOR THE "READY TO CONNECT" STUDY

WHAT IS THE GOAL?

WHO CAN BE A PART OF THE STUDY?

WHAT WILL PARTICIPANTS BE ASKED

I WANT TO HELP! WHO DO I CALL?

Participate in our Conversations Study!

We are seeking **children ages 8-14**:

- Watch short videos
- Have a conversation with a peer
- Answer quick surveys

At the FACE Lab, we hope to understand and raise awareness about how children on the Autism spectrum perceive and produce social cues.

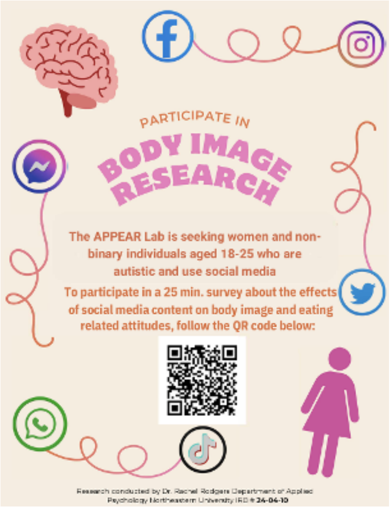
Interested? Scan our QR code or follow the link below https://redcap.link/9wvg95h7

Location: 216 Tremont Street, Downtown Boston

FACE Lab at Emerson College

FACE Lab at **Emerson College** is currently recruiting autistic and non-autistic children to be a part of their research studies. The **Ready to Connect study** (virtual) aims to learn about how language & social skills impact teens' (ages 12-15) conversations with their peers. The **Conversations study** (in-person) aims to understand how children on the spectrum perceive and produce social cues. Participants will be compensated for their time with both studies.

- Ready to Connect
- Conversations study



PARTICIPATE IN

BODY IMAGE RESEARCH

The APPEAR Lab is seeking women and non-binary individuals aged 18-25 who are autistic and use social media

To participate in a 25 min. survey about the effects of social media content on body image and eating related attitudes, follow the QR code below:

Research conducted by Dr. Rachel Rodgers Department of Applied Psychology Northeastern University IRB # 24-04-10

Social Media, Body Image, and the Autism Spectrum Study at **Northeastern University** is currently recruiting autistic individuals (ages 18-25) to be a part of their research study. They will be investigating the experiences of social media use, body image, and eating among autistic young women and non-binary people. Participants must be 1) autistic, 2) be assigned female at birth, 3) identify as either female or outside of the gender binary, and 4) be between the ages of 18-25. Upon completion of the survey, participants can choose to be included in a raffle to receive $75.

- If you or someone you know may be interested, please contact r.rodgers@northeastern.edu.
- Visit this website for more information.

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

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!