

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

April Showers Bring May Flowers

Happy April! Along with the noticeably warmer and longer days, we hope that April brings us not only Spring, but also light, joy & peace for our friends and families.

Autism Acceptance Month!

April is Autism Acceptance Month - the Autism Program's favorite month of the year! Every day, but especially in April, let's celebrate the shining uniqueness, brilliance and contributions of all people with autism, family members, and this vibrant community of open hearts. We are so excited for all things we plan to share this month - make sure to keep an eye on our

social media so that you don't miss anything! We have included our content calendar in this newsletter, so read on to learn more and follow us on Instagram to join the fun :)



Scan this QR code using your phone camera!



Teens Engaged as Mentors (TEAM)



Last month, our TEAM participants gathered together at SPARK Center to pack outreach kits for the **Pine Street Inn** to support individuals experiencing homelessness. It was a great way to give back and make a positive impact in our community. At the end, we were able to deliver a total of **544 snack and hygiene kits!**



Interested in learning more about TEAM? Contact us at autismprogram@bmc.org.

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Strength in Softness: Interview with Kenny, twin brother of Taiwo

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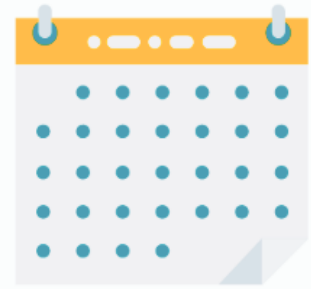
April Recap: DBP Virtual Cooking Class

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2024 Autism Program Annual Report

Autism Acceptance Month

The Autism Program has an exciting month planned out for Autism Acceptance Month - check out the calendar below for an overview and the next page for more information. Don't miss out, follow us on Instagram!



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Make sure to follow us to catch these Autism Acceptance Month posts & much more!







[bmc autism program](#) Follow

561 posts 905 followers

The Autism Program at BMC
Community
The Autism Program @bostonmedicalcenter assists and empowers individuals and families affected by Autism Spectrum... more
linktr.ee/autismatbmc

Followed by [whoischelseaa](#), [neha.shabeer](#), and [veersawhney](#)

-  Newsletters
-  Resources
-  Activities
-  Conferences
-  Autism Friend...
-  Meet our staff



Autism Acceptance Month

April
1st

Hello from the Autism Program!

Instagram post

Get to know about us :)

April
17th

Ask a Behavior Specialist! Instagram story takeover

Follow along Jacqueline to ask your questions on behavior, while learning about desensitization & how to utilize it in practical ways.



April
3rd

Day in a Life as an Autism Resource Specialist

Instagram story takeover

Follow Maddy through her exciting day as an ARS!



April
4th

Welcome to SPARK Center!

Instagram post

Did you know that BMC has a satellite location in Mattapan? Let's walk through with Liz!

April
22nd

Let's Chat: Autism in Adulthood

Instagram post

Listen in on an insightful conversation between Katie, Adult Autism Resource Specialist, and an autistic adult with lived experiences.

April
8th

What is TEAM?

Instagram post

Learn about our teen mentoring program for autistic youth.

April
24th

ASD Resource Fair

Live virtual event

Join us to meet many community organizations and learn about the support they offer for families & individuals with ASD!

April
11th

Family Fun Day!

In-person event

A day of celebration! Stay tuned for more info.

April
28th

DIY Sensory Bin

Instagram post

Make a Sensory Bin for your family with Hillary!

April
15th

DBP Cooking Class

Instagram post

Meet Katie Campbell & learn about DBP's monthly virtual cooking class.

April
30th

Our Favorites

Instagram post

Close out this month with some fun recommendations from us & our clinicians!

Follow us on Instagram @bmcautismprogram to join us this month!

Strength in Softness

MEET KENNY OBIDELE :
TAIWO'S TWIN BROTHER

Can you introduce yourself?

My name is Kehinde Obidele, but everyone calls me Kenny. I was born and raised in Lagos, Nigeria, a fairly large but niche community in the southwestern part of Nigeria. I am currently a graduate student in Northeastern University in Boston, which puts me about over 5,000 miles away from home and the people I love the most in the entire world. I am also honored to be part of the Autism Program at Boston Medical Center as an intern this semester.

What is your relationship with autism?

I am a twin – my twin brother, Taiwo, has severe autism. Autism has always been a part of my world. It has shaped how I grew up, how I see people, what I care about. Most of my days growing up was filled with learning how to understand Taiwo, even when he couldn't explain in words. I learned to notice the small things – what made him calm, laugh, safe. It wasn't always easy, but it was a journey that was filled with love. Autism for me isn't just a diagnosis, it is my twin brother's love – the way that he lights up when he sees me, the routine that gives him comfort; as well as the challenges – the frustrations, meltdowns, heartbreaks and sufferings of being misunderstood. Most importantly, my relationship with autism is rooted in being my twin brother's brother and best friend.

How old were you when Taiwo was diagnosed with ASD?



Taiwo (left) & Kenny (right)

So, we didn't get an official diagnosis until we were 18 years old. That was a lot, thinking about the missed opportunities for early intervention; that we spent 18 years figuring things out on our own, in the dark.

What was it like navigating autism in Nigeria?

Being a sibling of someone with autism in Nigeria was layered. **There was love – of course, so much love – but also isolation and silence.** Growing up, not many people understood autism, including myself and my family. It often felt like we were figuring things out in the dark. It was really, really tough. I come from a culture where women who gave birth to children with disabilities were seen as cursed; I remember the way the people looked at my mom, the things they said, whispered. But over time, I came to understand that it wasn't really their fault; they didn't know any better. There was just so much fear and misinformation.

I remember one particular memory of when we went to church with my twin brother on a Sunday. I think we were maybe 5 or 6 years old at the time – and if you know, Nigerian church music can be really loud. It was very overwhelming for Taiwo and made him anxious, covering his ears and making him cry. Everybody's eyes were on us. I remember Taiwo reaching out to my hand and squeezing it

I learned to notice the small things – what made him calm, laugh, safe. It wasn't easy, but it was a journey filled with love.

so tightly and at that moment, it felt like my hand was his anchor. I thought in my little brain, *yeah, don't worry, I got you bro*. I didn't have the words then, but at that moment I knew I had a job to do: always be his anchor, always be there, and hold his hand tightly.

In terms of support, it was really just my family and I trying to make it work. There were not many resources. What really helped was just love – loud, stubborn love. But looking back, I know how different it could have been if we had more support earlier on.

I knew I had a job to do: always be his anchor, always be there, and hold his hand tightly.

Definitely. Love goes a long, long, long way, but so does clarity and community. I know that you felt this lack of resources, so you kind of went on to create your own – could you tell me a little bit about that?

Where do I begin – I started the AA (Autism Awareness) Group during the pandemic, which was the darkest time I can remember. I know that the pandemic was really hard for everyone around the world; but in Nigeria, especially for families raising children with autism, it was almost unbearable. In a country where healthcare and support systems barely existed (even before COVID), you can imagine the isolation, fear, the lack of resources. It's still very painful to talk about because I saw so many people suffer and so many children left behind.

It was in that darkness and deep loneliness that I had the idea to start the AA Group. I thought I was the only one feeling that way – lost, overwhelmed, and feeling lonely – but it turns out that so many families had been feeling the same way, silently. Once we started the group, the idea spread very quickly. Today, the AA Group has over 1,500 members and serves as a community where people can be vulnerable, understood, and feel deeply supported.



One of the things I am really proud of is that every new member of the group receives a packet. Inside is something I designed called **For the Hard Days**, a collection of handwritten letters from other parents, siblings and caregivers. The letters say that you are not alone, you are doing your best, and more, and it's something that I wish my family had growing up. Just a little bit of light in the dark.

Starting and leading this group is one of the things I am most proud of in my life. It's also a big part of why I am currently in graduate school, to equip me with the skills and the knowledge that I need to take the AA group across Africa someday – that's the dream – to build something rooted in compassion, empathy and community.

We know that many families of children with autism in America also feel isolated and left without community support. Do you have any messages for families who are seeking that connection and are looking for courage in creating that for themselves?

You are doing the best you can, and that's enough. It's okay to not have all the answers, to feel tired, confused, even feel overwhelmed. **You are not a bad parent or sibling – you are just navigating something that no one ever prepared you for.** That takes courage. So you're doing good. You can ask for help and keep pushing for answers. You deserve support and you don't have to do all of it alone. Write things down – the good days, the breakthroughs, funny things, the little moments. They will become anchors later on. Don't be afraid to let joy live alongside the hard stuff. You may find joy and beauty in the things that you least expect.

About writing things down to collect anchors – I know that you are working with the Autism Program to develop something in that note, coming soon. We hope that folks will keep an eye out!

You are navigating something that no one ever prepared you for. That takes courage.

Going back to your brother, I know it has been a long journey – how has your relationship with him evolved over time?

Growing up, my relationship with Taiwo was everything. I mean, we are twins after all. I know when people imagine twinhood, they picture playing together, sharing secrets – for us, it was different. Taiwo didn't communicate the way that I did. But somehow, I still always felt connected to him. When we were younger, I didn't quite understand what autism was. I just knew that my brother experienced the world differently than I did and that he didn't always respond when I spoke. But I never saw him as different – only as someone I loved deeply and wanted to protect with everything I had. So when we finally had the formal diagnosis at age 18, it explained so much to me. It broke my heart a little – not because of the diagnosis itself, but because of the years that have gone by without answers and supports.

Love can look like a hand squeeze at the church, a steady routine, a shared quiet moment in a noisy world.

Over the years, our relationship has evolved and so have I. I have become more patient, curious, in tune with his needs, and have learned to listen in different ways – his eyes, hands, the way he moves when overwhelmed and excited... **Taiwo has taught me that love doesn't always need words.** Now that we are much older and that we live far away from each other, I miss him every single day. But I know for a fact that the bond is still there. I carry him with everything that I do, the work I have chosen to do, and the future that I am trying to build.

Having Taiwo in my life has also shaped the way I see everything. **It has made me more compassionate and more willing to sit with discomfort and complexities.** I learned that communication is not always about words; that **silence doesn't mean absence.** Love can look like a hand squeeze at the church, a steady routine, a shared quiet moment in a noisy world.

He has also made me more aware of the system that fails people; the way that society is not often built for someone like my twin brother; how much advocacy, empathy and awareness is still needed today. **When you grow up with someone you love constantly misunderstood and left out, it changes you.** It teaches you to speak up, pay attention, and never take access and inclusion for granted.

Beyond the challenges, Taiwo has also taught me joy. His laughter is pure, his perspective is refreshing; and reminds me constantly to find beauty in the simple things. The same routine walks every day, favorite song that we love to listen to, favorite food that I know he likes... Being his brother has changed me, stronger in softness.

Do you have any messages for other siblings of autistic individuals?

To every sibling out there walking this journey, you are not alone. I know from experience that it can feel like

you are **constantly balancing love with responsibility;** that sometimes, your needs shrink quietly in the background because your sibling's needs are so much greater. Maybe, no one says it out loud, but you feel it – the unspoken pressure to be the “easy one”, to always be strong, and to never cause trouble. **Don't lose yourself.** Your story matters just as much. You are not selfish for needing space or rest. It's okay to say that this is hard, even when you love them with all of your heart.

Make room for joy. Take those silly videos, dance in the kitchen, write things down – these memories are yours. Find your people whether it is sibling support groups, trusted friends, or online communities, because you deserve space where you don't have to explain and can just be yourself. I promise you that the love you carry, the way you show up again and again and again, even when no one is watching – yeah, it matters more than you know.

We would also love to hear if you have any messages for medical providers who serve individuals with autism and their families.

I promise you that the love you carry, the way you show up again and again and again, even when no one is watching – yeah, it matters more than you know.

Being his brother has changed me, stronger in softness.

First of all, to all medical providers (serving autistic individuals or not) – thank you. You are doing an amazing job. But I want you to know something: technical expertise is not enough. From our perspective, **what we need most is empathy**. We need people who will slow down, not talk over us, make assumptions, and really listen. Every child, family, sibling, comes with their own story. When I was growing up, what we longed for more than anything was someone to tell us that we were not alone; that it was not our fault; that there were things that we could do to better our situations.

My advice would be to ask families what they need. **Be curious, not clinical**. Speak simply and don't focus only on the child. When the entire family feels heard and supported, everything shifts for the better.

Lastly, representation matters a lot – be mindful of culture, language and access, especially for people who look like me. Some families may have never been in a room where autism is understood. **Your compassion can be the difference between a family drowning in confusion and finding a steady ground to move forward on.**

*Be curious, not clinical.
Speak simply and don't focus
only on the child. When the
entire family feels heard and
supported, everything shifts
for the better.*

So, what's next for Kenny?

This summer, I got an internship to work at Google to be a part of the technical team of building an incredible platform to support people with autism utilizing AI and machine learning. I also have plans to go back home in the summer to see my twin brother, who I have not seen in such a long time!



Thank you
Kenny for
sharing your
story! If you or
someone you
know would
like to share
theirs, send us
an email :)

From Kenny:

What is Taiwo's favorite recipe?



Jollof Rice,

but not just any kind. He prefers it just the way I make it: soft, not too spicy, with shredded chicken and veggies mixed in. We call it “Taiwo’s Jollof.” It’s one of our love languages and the way he lights up when I make it never gets old. I used to joke that if all else failed, at least I could always reach him with a spoonful of Jollof rice :)

Favorite song?



**You & I
(Nobody in the World)**

By John Legend

The lyrics are originally about a girl, but when Taiwo and I sing it together, we swap the word *girl* for *boy*. It’s our little remix. The chorus is our favorite part:

“Out of all of the boys, you’re my one and only boy. Ain’t nobody in the world tonight. All of the stars, you make them shine like they were ours. Ain’t nobody in the world but you and I.”



Cooking Together

This month, the BMC Teaching Kitchen hosted another exciting **virtual cooking class** for BMC's Developmental and Behavioral Pediatrics (DBP) patients (between ages 12-22). Class participants gathered together just in time for dinner with Paige Rizzuto (MPS, RDN) from the Teaching Kitchen.

Menu of the day? **Fruit Salsa and Cinnamon Sugar Tortilla Chips!**



We know that cooking is not easy, especially if you are just beginning to learn. So to break it all down, students received helpful visuals prior to the event containing the ingredients, tools, and steps that are required to bring the dish into life.

With all the preparations set up, we were ready to get cooking! During the class, Paige guided the group step-by-step through this delicious and versatile recipe. We also learned some important cooking skills about how to use a knife safely (see *right*). It was a night filled with lots of great questions, delicious sights, and smiles! A lot of cooking joy was also spread with many participants cooking for their loved ones.

How to make Fruit Salsa & Cinnamon Sugar Tortilla Chips:



What did we learn?

Knife Safety!



- **Slow and steady is the key:** Don't feel the need to rush when you are using a knife. Going slow will give you more control over the tool as well as confidence!
- **Cutting board keeps wiggling?** Try placing a damp (not wet) paper towel underneath the cutting board. This will help glue it down!
- **Instead of cutting up and down, try rocking the knife back and forth.** This will help you cut things with more ease!



Explore BMC's Teaching Kitchen!

About the BMC Teaching Kitchen



Free Cooking Class Descriptions



Recipe Library (over 400 easy & healthy recipes!)



Make this at home using the simple & healthy recipe from **BMC Teaching Kitchen!** Click the quesadillas or scan the QR code.



To register for our next cooking class, contact:

- katie.campbell@bmc.org
- (617) 414-7947

Special thanks to Paige from the Teaching Kitchen, BMC Transition Specialist Katie Campbell, and all our participants for another wonderful class! For those of you who missed it, no worries - this class will be held every month. Don't hesitate to reach out to us with any questions or to register for our future events! We look forward to cooking together again during our **next class on May 7th**.

Connect with us!

Cooking is a life skill that many youth & young adults are learning when transitioning to adulthood. **We would love to hear feedback** from individuals about their experiences in learning how to cook, as well as what supports might be helpful in building cooking skills. Please feel free to share your thoughts with us at autismprogram@bmc.org!



Up next: Roasted Veggie Pasta

Boston Medical Center's Teaching Kitchen presents:

Developmental & Behavioral Pediatrics Virtual Cooking Class

Open to all DBP Patients **Ages 12-22**



- Wednesday, May 7th**
5-6 pm
- Zoom**
link provided upon registration
- Recipe**
Roasted veggie pasta
- Skill Focus of the Class**
Cooking Methods



Join us to expand your cooking skills and learn a new recipe! No previous cooking experience is required to join.

REGISTRATION REQUIRED:

To register contact BMC DBP's Transition Specialist via email or phone

katie.campbell@bmc.org

(617) 414-7947

Visual supports for the ingredients, kitchen tools and recipe steps will be provided prior to the class.

Participants are responsible for **purchasing the ingredients** and kitchen tools needed for the class.

Family members are welcome to join their participant during the class to provide support and join in the fun.

Let's get cooking!



BMC Teaching Kitchen



BMC Teaching Kitchen is a dynamic program that offers interactive, patient-focused nutrition education through hands on learning. Visit their website to sign up for free cooking classes, view a library of healthy recipes, and more!

2024

Annual Report

The Autism Program is beyond thrilled to share our **2024 Annual Report!** This report captures the essence of our program's work throughout the past year. We hope that it creates space to celebrate and offer gratitude for all the accomplishments of our program, as well as our incredible families and collaborators who make this work possible.

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Our Impact

Since 2012, the Autism Program at Boston Medical Center... provides direct patient support, provides education and community-based outreach. We strive to meet the needs of the community in Massachusetts in a culturally competent manner by offering high quality and compassionate care to all.

The Autism Program is a one-stop-shop that provides individualized support & resources for patients across their lifespan.

New Diagnosis | Transition to Adulthood | School Age | Adult Support

...and everything in between & beyond!

At a glance: Services provided

"The work of the Autism Program is so important because it creates better communication, understanding, and creating a safer environment for everyone."

"Finding ourselves with all of this... has been something that has greatly changed our understanding of the diagnosis and the support we receive."

"As a primary care physician, the support and coaching of the Autism Resource Specialist have been irreplaceable to getting my patients through challenging trading studies, complex eye exams, and dental exams, many for the first time."

"You just feel safe with the Autism Program team... My child considers the Autism Program team to be his family."

- Direct Patient Care Support**
 - General Resource Support
 - Behavior Consultation Clinic
 - Specialty services
 - Adult services
- Autism Friendly Initiative**
 - Individualizing patient care
 - Modifying sensory environment
 - Training clinicians, staff and students
 - Providing visit preparation
- Community Engagement**
 - TEAM (Team Engaged as Mentors)
 - Specialty services
 - Adult services
- Autism Friendly Initiative**
 - PLAN (Parent Leadership in Autism Network)
 - Internship & Volunteer Placement
 - Training clinicians, staff and students
 - Providing visit preparation

Autism Friendly Initiative

53% of Autistic individuals report difficulties with communicating with doctors

51% of Autistic individuals face challenges with waiting room environments

40% of U.S. physicians are confident in their ability to provide quality care for patients with disabilities

1,000 Autism Support Checklists gathered, collecting patient-specific information to improve respectful, comfortable care at BMC.

1,500 sensory tool packs distributed to BMC departments in Boston Medical Center

Visit Preparation: Healthcare Social Stories available in 10 languages to prepare patients for various medical procedures, in addition to providing during procedure support.

Training & Education: Provided training for BMC staff across departments, including embryology, dental, ophthalmology, public safety, and more.

Our Autism Friendly Initiative (AFI) works to improve the healthcare experience for patients with autism.

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Direct Patient Care

In 2024, we supported...

2,541 Patient Encounters

- 40%** involving non-English languages
- 10+** types of hospital-wide support
- 30+** different types of resource support

Direct Patient Care

Support Across The Lifespan

Transition to Adulthood
240+ Referrals in 2024

Behavior Consultation Clinic (BCC)

Supporting Autistic Adults
130+ Referrals in 2024

Navigating New ASD Diagnosis

Join our Autism Resource Specialist, we recognized by the Parent Resource & Information Center, Federation for Children with Special Needs (FCNS) for her work in supporting a novel digital Portuguese speaking family in navigating state & community services as well as special education.

Community Engagement

Teens Engaged As Mentors (TEAM)

11 Mentors
13 Mentees
20 Activities

Wright Locke Farm

Healthcare Education: Boston Medical Center & Beyond

1,100+ Individuals provided with training & consultations in 2024

Critical presentation for my development as a doctor.

Some of our staff have had minimal if any interaction with dealing with Autistic individuals. This program has shown our offices increased awareness of sensory needs and have given us tools to better understand autistic individuals.




Resources



The Autism Program 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!