



The Autism Program

Annual Report 2023

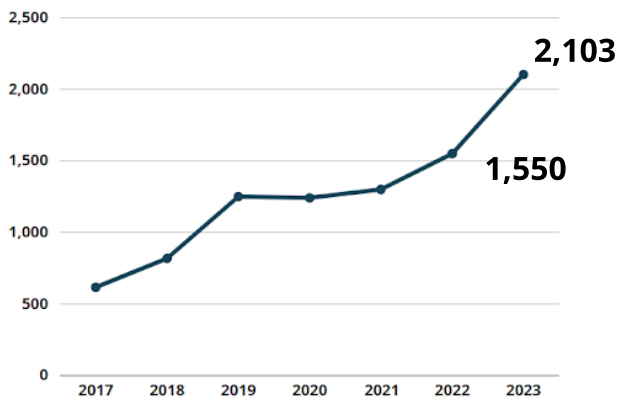
Assisting and empowering individuals and families affected by Autism Spectrum Disorder (ASD) through direct patient and provider support, community-based outreach, and system-level interventions since 2007.



Boston Medical Center
801 Albany Street, Floor 1E
Boston, MA 02119
www.bmc.org/autism

Direct Patient Care

Number of Referrals, 2017-2023

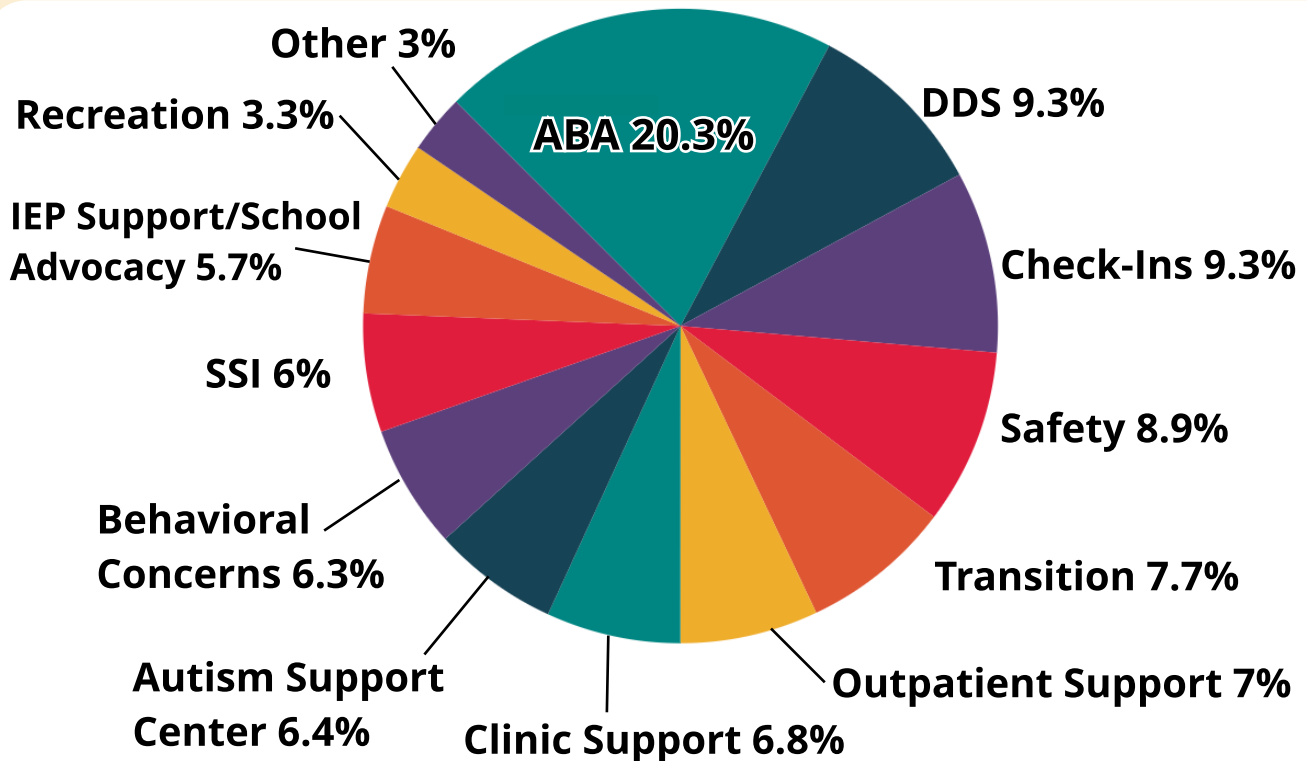


2103

Autism Program Referrals
in 2023

35.7% increase from 2022
(1550 referrals)

Reasons for Referral

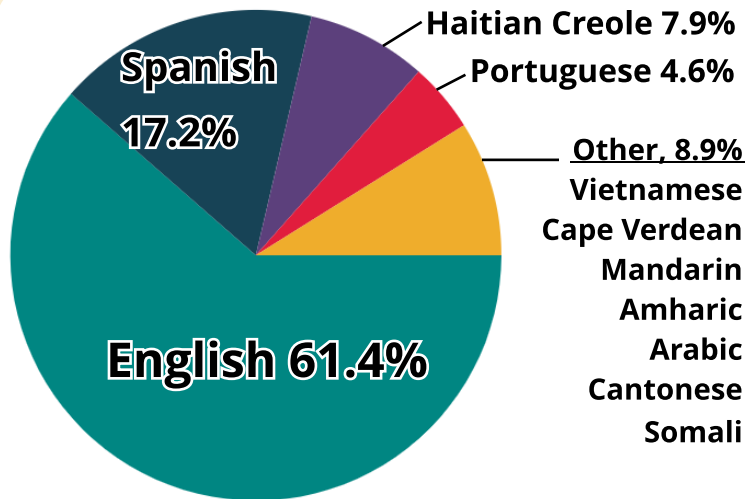


General resource support includes connecting families to local services (e.g., Applied Behavior Analysis (ABA) therapy, speech therapy) and providing families with tailored resources (e.g., visuals, social stories).

The **Behavior Consultation Clinic** provides short term behavior analytic consultations to patients and their caregivers. Patients referred to the clinic often engage in significantly challenging or potentially dangerous behaviors at home and in the community, and are unable to access in home behavioral supports for a variety of reasons.

Transition services are provided for families with a child with ASD who is within the transition age (14-22), who are navigating issues such as guardianship, life skills, higher education and employment.

Direct Patient Care

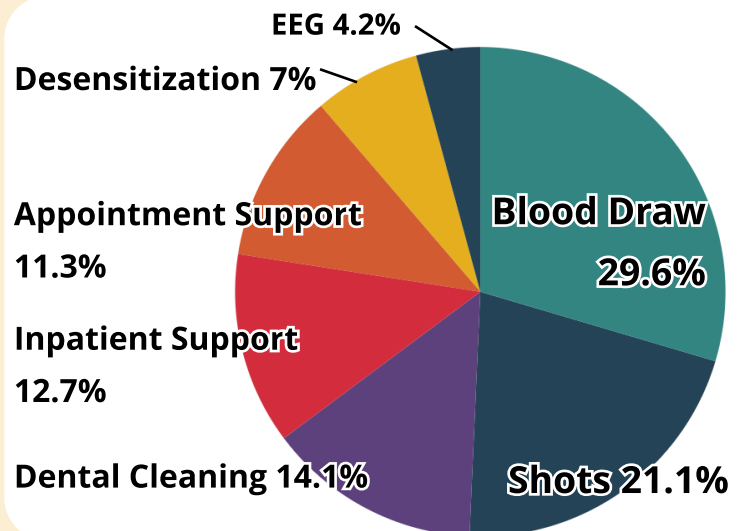


>13

Languages served
in 2023

7

Types of
procedures
supported
in 2023



Khanh comes in to the BMC every three months to work on *desensitization* to dental procedures. We have been working with Khanh on finding *sensory accommodations* to help him in his appointments. Khanh likes to play with bubbles and a light up wand when the dentist has to look in his mouth. Each time Khanh visits the dentist, he gets more comfortable.

"I was scared and...very worried, [but] after I [met] the doctor...they let me know that they [were] there to help me and to help me with finding resources for my child, and [let] me know he's going to be okay...[**They're**] **here to help [me]** on everything."

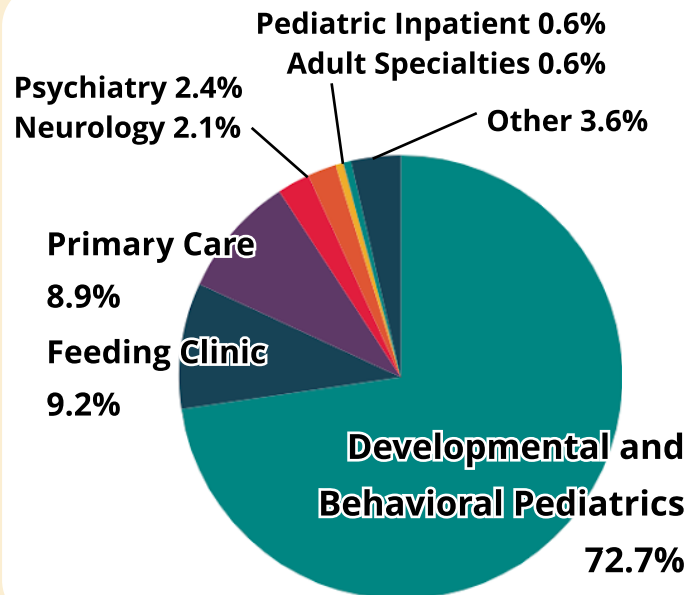
—Sorange, mother of child supported by ARS

Direct Patient Care

>12

Referring Departments
in 2023

Compared to 10
departments in 2022



Adult Autism Services

Thanks to the generous funding from a philanthropic donor, the ASD Program recently created a staff position of **Adult Autism Resource Specialist**, which supports patients in our adult primary care settings at BMC. Our adult ARS provides resources to patients and training to adult providers in key areas, including: change of PCP and subspecialists, guardianship, access to diagnostic evaluations, change of insurance, behavioral health, the departure from school and entry into adult-based community systems, housing, higher education and/or employment pursuits and day programs. The adult ARS role also addresses the myriad of issues faced by BMC's racially, ethnically, and linguistically diverse population, who face many barriers accessing services for which they are eligible from state agencies and community based systems.



"To help young adults become as independent as they can be is life-changing. When the school resources end, BMC can be there to say, **'here's what's next.'**"

Karen Kames, BMC Board of Trustees member

"We're paving the way for what support for adults should look like."

Shari Krauss, Program Director

Community Outreach

Teens Engaged As Mentors



TEAM | TEENS
ENGAGED
as MENTORS

AN INITIATIVE OF THE AUTISM PROGRAM AT BOSTON MEDICAL CENTER

Novel mentoring program that pairs teens with and without ASD to work together to mentor younger children on the autism spectrum. Established in 2015.



Throughout 2023, **21 participants** engaged in monthly events held in Boston designed to promote positive community engagement and *build friendships, leadership, self confidence, and independent skills.*



Events included: roller skating, yoga and mindfulness, harvesting produce at BMC's Rooftop Garden, and indoor rock climbing.



Annual focus groups to obtain participant feedback. Examples of extracted themes include: (1) teamwork, (2) confidence, and (3) inter-personal connections.

"[My son] loves the idea of becoming a mentor rather than being a mentee...he likes the idea of that **progression.**"

—Rachel, parent of mentee

"[He] meet[s] some kids from different schools, not just his own school...you're **building networks through the city** and other families...it's just been a really nice way for him to meet some more people."

—Rose, parent of mentor

In 2023, we recruited **6 new facilitators** including from various BMC departments including ophthalmology, infectious disease, and hematology, and created a **summer activity guide** for TEAM participants with activities related to previous events.



Parent Leadership in Autism Network

Diverse network of empowered and trained parent leaders who offer free peer support to caregivers who have children/adolescents/adults of any age with ASD. Established in 2012.



Parent leaders meet bi-monthly to discuss issues such as: new diagnosis, community resources, communication and behavior strategies, school services, etc.



Since 2012, we have trained 64 parent leaders who speak 12 languages and represent towns from all across greater Boston



Autism Friendly Initiative

The **Autism Friendly Initiative (AFI)** at Boston Medical Center works to improve the healthcare experience for patients with autism and their families.

Our Values

Broad engagement of stakeholders
Patient and family voice
Strategic multi-tiered interventions
Real-time monitoring/evaluation
Commitment to values

Our Advisors

TEACH (Teens Educating, Advocating, and Consulting in Healthcare) is comprised of youth with ASD who convene quarterly to share critical insights on healthcare experiences to inform the work of AFI.

Scientific Advisory Board provides guidance, support, and insight to ensure that interventions are driven by best practice.

Steering Committee is a multidisciplinary group of hospital and community leaders that assists with strategic planning, decision-making, and overall optimization of the Initiative.

Our Interventions

Autism Support Checklists (ASC) collect individualized patient information to create more respectful, comfortable encounters at BMC. So far, AFI has compiled information for over 1,000 BMC patients.

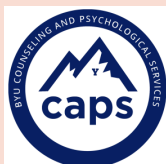
AFI has created and distributed over 3,500 **sensory toolpacks** across BMC's campus at no-cost to the receiving departments. These toolpacks help to calm, distract, and redirect patients during challenging appointments at the hospital.

AFI maintains a **publicly-accessible "Healthcare Social Stories" website** meant to prepare patients for a range of different medical procedures. These social stories are currently available in Spanish, Portuguese, Mandarin, Korean, Russian, Albanian, and Greek. [Click here to check it out.](#)

AFI routinely **trains thousands of healthcare trainees and professionals**, including **all Boston University medical students, dental students**, and **genetic counseling students**, as well as **all Boston Medical Center public safety officers**. These trainings help to improve professional comfort, familiarity, and knowledge in caring for autistic patients.



AFI routinely consults with medical practices from all over the world, including (but not limited to):



Autistic Patient Bill of Rights

Autistic Patient Bill of Rights



I have the right to

- be treated with equal respect.
- advocate for what I need.
- have my individual preferences and needs considered.
- understand what will happen before, during, and after my visit.
- have all my questions answered.
- information to be explained in a way that I can best understand.
- be offered a quiet alternate waiting space whenever possible.
- accommodations for my individual sensory and communication needs.
- make requests that will help make my experience more positive.
- a satisfactory healthcare experience.

Our **TEACH board** worked hard in 2022 to develop an **“Autistic Patient Bill of Rights,”** which can help to guide healthcare professionals towards **respectful, high-quality care for their autistic patients.** This Bill of Rights was created *directly* by our TEACH participants and written in their own words. In 2023, our Bill of Rights **was published in the *Journal of Developmental & Behavioral Pediatrics***, and has been shared with healthcare practices across the world. We are so grateful for the tremendous work of our TEACH members!



Developed by the Autism Friendly Initiative's TEACH Board
(Teens Educating, Advocating, and Consulting in Healthcare)

Doctor's Day

In April, the BMC Autism Friendly Initiative partnered with BU medical students and the Joseph Lee K-8 School in Dorchester to conduct an **medical simulation event for nearly 200 students with ASD.** During our Doctor's Day event, Lee School students met one-on-one with medical students for a mock visit to experience what happens during a typical doctor's visit, including having their eyes, ears, height and blood pressure checked. Going to the doctor can be an incredibly challenging experience for individuals with autism but with proper preparation and with *competent, caring, and knowledgeable* clinicians, these barriers can be reduced.



Trainings

In 2023, we worked hard to expand autism friendly competency directly at BMC. We've built partnerships with our **Post-Anesthesia Care Unit (PACU), Phlebotomy Department, Section of General Internal Medicine, Endoscopy Team, Ophthalmology Department, and Department of Family Medicine.**

We look forward to continuing and expanding upon this work in 2024.

Resource Development

Navigating ASD and Safety Guide

In 2023, our team developed two new guides, which are freely available on our [website](#). *Navigating ASD* is a comprehensive guide of autism support resources, and the *Safety Guide* directs caregivers on how to keep their child safe inside and outside the home.

Additionally, the Autism Program received funding to translate these guides into six other languages, including **Spanish, Portuguese, Chinese, Haitian Creole, Cape Verdean Creole, and Vietnamese.**

Workday Learning

The Autism Program worked with BMC's Human Resources team to build two courses within BMC's employee learning platform. These professionally-produced videos educate staff on the basics of working with autistic patients. **Over 750 staff** have completed the videos, and **have been added to our BMC Wall of Fame!**

Navigating ASD

Types of EI Professionals



Navigating ASD: Portuguese



Safety Guide: Vietnamese



Navigating ASD: Haitian Creole

2023 Conferences

The Autism Program is committed to the training of healthcare professionals and expanding system capacity of caring for patients with autism. In 2023, we trained and presented to **over 3,000 individuals** via local, national, and international venues.



Autism and Health Outcomes: How Can We Achieve Healthcare Equity for Individuals with Autism? Presentation at Autism New Jersey Annual Conference 2023, Atlantic City, NJ.



Perspectives of Autistic Youth about Their Healthcare Experiences. Presentation at Autism New Jersey Annual Conference 2023. Atlantic City, NJ.



Using Behavior Analysis to Create an Autism Friendly Environment in a Healthcare Setting. Presentation at the Nursing World Conference 2023, Woburn, MA.



Establishing a Hospital Environment that Supports a Neurodiverse Patient Population. Presentation at Berkshire Association for Behavior Analysis and Therapy Conference 2023, Worcester, MA.



Elucidating the Perspectives of Autistic Youth about Their Healthcare Experiences: Findings From A Qualitative Study. Presentation at the Society for Developmental and Behavioral Pediatrics 2023 Annual Meeting, Minneapolis, MN.



Creating an Autism Friendly Hospital Environment. Presentation at the Women in Behavior Analysis Conference 2023, Nashville, TN.



Elucidating the Perspectives of Autistic Youth about Their Healthcare Experiences: Findings From A Qualitative Study. Presentation at the Pediatric Academic Societies Conference 2023, Washington, DC.



Improving healthcare experiences of autistic individuals: A scoping review. Poster presented at the International Society for Autism Research Annual Meeting 2023, Stockholm, Sweden.



Elucidating the perspectives of autistic youth about their healthcare experiences: Findings from a qualitative study. Poster presentation at the Academic Pediatric Association Region 1 Annual Meeting 2023, Boston, MA.



Research

Our research efforts are overseen by our **Scientific Advisory Board** and youth patient advocacy board, **Teens Educating, Advocating, and Consulting in Healthcare** (TEACH). Collectively, these two boards consist of researchers, clinicians, autistic individuals, and family members of autistic individuals who provide us with valuable insight to ensure that our research is rigorous and responsive to the needs of the autistic community.



Ongoing Studies



2023 Publications

Harris, H. Weissman, L., Friedlaender, E., Neumeyer, A., Friedman, A., Spence, S., Rotman, C., Krauss, S., Broder-Fingert, S., Weitzman, C. (2023). **Optimizing Care for Autistic Patients in Health Care Settings: A Scoping Review and Call to Action.** *Academic Pediatrics*. [10.1016/j.acap.2023.11.006](https://doi.org/10.1016/j.acap.2023.11.006).

O'Hagan, B., Foster, S., Ursitti, A., Crable, E., Friedman, A., Bartolotti, L., & Krauss, S. (2023). **Elucidating the Perspectives of Autistic Youth About Their Health Care Experiences: A Qualitative Study.** *Journal of Developmental and Behavioral Pediatrics*. [10.1097/DBP.0000000000001228](https://doi.org/10.1097/DBP.0000000000001228).

"It can be **really hard, not seeing yourself**, not seeing people like you...just assuming that you're not good enough. [TEACH] is a great space for autistic people of all ages...a **very accepting space**."

—Tris, TEACH Board Member

Autism 101 study: Assessing changes in knowledge, comfort-level, and attitude of participants of an hour-long lecture training about autism. Participants include BU medical students, dental students, genetics counseling students, BMC safety officers, and other BMC staff members.

Doctor's Day: Mixed-methods evaluation of an experiential training program for medical students during which they interact with autistic school age children and model common procedures during medical checkups (e.g., height, weight, blood pressure).

Safety intervention chart review: Retrospective chart review of autistic and non-autistic patients seen in the emergency department and inpatient unit from 2015-2021. We are assessing predictors of safety intervention orders.

Hospital-wide autism resource specialist: Assessing changes frequency and duration of distressed behaviors in autistic patients during medical encounters.

Internship Program

The Autism Program provides undergraduate, graduate, and post-degree students the opportunity to participate in a rich, applied internship experience. In 2023, the program hosted **45** internship slots.



Our interns are exposed to all areas of our Autism Program, and help to support our patient needs in a variety of structured, educational roles. Our interns routinely collect *Autism Support Checklist* information from patient families, write new *healthcare-oriented social stories* for our publicly-available website, curate and provide resources directly to families, and provide *translation support* if they are able to communicate fluently in a language other than English.



Our intern Blythe, created promotional material for the TEAM program!

We are thankful for our 2023 interns!

Boston Collegiate High School:
Ariana Wilson Elysee

Boston University:
Samantha Brayton, Blythe Brenner, Juju Ha, Yixin Ke, Mary Ladas, Samantha Ma, Christina Matta, Diane Suba, Jian Yang

Johns Hopkins University:
Nubaira Milki

Massachusetts Institute of Technology:
Caroline Bao, Srihitha Dasari, Jeffrey Kwon, Paridhi Latawa, Sabrina Meng, Charvi Sharma, Katherine Xie

Northeastern University:
Katie Edson, Chloe Shanebrook-Wein, Dana Tessler

Suffolk University:
Kian McCabe

Tufts University:
Claire Ammirato, Poorvi Sethi

University of Central Florida:
Chelsea Pierce

University of Cologne, Germany:
Maja Kalkofen

University of Massachusetts Amherst:
Keerti Daesety

University of North Carolina at Chapel Hill:
Devika Manoj

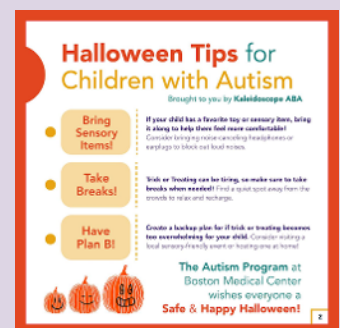
Postbaccalaureate:
Zachary Barsdale

Social Media

DEVELOPMENTAL & BEHAVIORAL PEDIATRICS NEWSLETTER

DBP releases a **monthly newsletter** showcasing showcasing seasonal and informational content related to autism

The Autism Program is active on Facebook and Instagram, building a robust network of caregivers of autistic individuals.



What Our Patients, Families, and Partners Say...

"I believe your training had a **direct impact** on the positive outcome of this incident. Officers were able to respond appropriately, help calm the situation and help the family."

"With the use of emla cream, distraction, sitting on his sister's lap and more – he walked out of the room calm and relaxed. Mom states **this is the best experience she has ever had** here with him needing to have a painful procedure done."

"It's lovely to see other people with shared experiences where, you know, our kids get kicked out of so much stuff. And it's just so nice to drop him off and **know that he's gonna be taken care of in the right way.**"

"The [Autism Support Checklist] is a great way to make sure that everyone's needs are met because **every patient is different.**"

"Having this expertise so readily available was a **huge bonus** to the patient and the team."

"But now being part of the program and having that team of support really helped me...and then **helped me to educate other parents** at his school more, not being afraid to tell. Because a lot of parents might be ashamed...but I'm learning that my son is so smart. He's very smart and all his teachers are telling me how caring he is, and well educated and smart. So I'm like, why does [autism] have to be a curse? No! It's a blessing, because people get to know him."

"I find that, it's not my strong suit to go... into new situations, to really reach out and initiate conversations...but I think being a part of TEAM has encouraged me to do that and **really learn to communicate with everybody** and appreciate everybody I'm surrounded with."

"It was so important for me to share the positive...[autism] will challenge [us] for the rest of our lives, but **you are not alone.**"

"Many, many thanks to you staff for going into this young man's room and **paving the way for...a positive experience** for our pediatric staff, our patient and his mother. You somehow turned his room into a place for fun (despite the tests) and helped us form a relationship with our patient through your examples of acceptance and caring and when to stop. You left us information on what to do, what to avoid and how to identify our patient's strengths and challenges so we could support him until he transitions. **We are going strong with a much more effective care plan.**"

Our Team



Shari Krauss, M.A., MPH | Program Director

shari.krauss@bmc.org

Shari conducts clinical oversight, personnel management and public relations for the Autism Program in addition to leading strategic planning and program implementation. She actively participates in the delivery of trainings, clinical consultation, advocacy and outreach efforts, as well as community networking and initiatives.

Alexander Friedman, MPH | Program Manager

alex.friedman@bmc.org

As Program Manager for the Autism Program, Alexander is responsible for overseeing all aspects of the Autism Friendly Initiative at BMC, which aims to improve the hospital experience for patients with autism spectrum disorders (ASD). In doing so, Alexander supervises hospital-wide projects related to staff training, systems improvement, and resource development to ultimately address barriers in caring for patients with ASD. Alexander also manages the Autism Program's wide-reaching internship and volunteer program in order to provide students with a meaningful, productive, and applied learning experience.



Liz Ferriero, B.A., CEIS | Program Lead

elizabeth.ferriero@bmc.org

Liz provides guidance and support for families seen in the Developmental and Behavioral Clinic. Liz assists families in navigating local, state and federal resources and therapeutic supports. She also works closely with the Parent Leadership in Autism Network (PLAN) program, which offers individualized peer support for parents of children with ASD.



Sara Bastin, M.Ed, BCBA, LABA | Program Lead

sara.bastin@bmc.org

Sara provides support to families seen in Developmental and Behavioral Pediatrics and Child Psychiatry as youth begin their transition into adult services. She utilizes her behavioral training and experience working in adult and in-home settings to help guide individuals and families through the many tasks associated with the transition process.



Jacqueline McKendry, MS, BCBA, LABA | Behavior Specialist

jacqueline.mckendry@bmc.org

Jacqueline is a behavior analyst with experience providing and supervising ABA therapy in schools, homes, and communities. She provides support, resources, and behavioral consultation to families within the DBP clinic. Jacqueline encourages families to advocate for themselves and their child's unique needs.



Hillary Hollis, B.A. | Sr. Autism Resource Specialist

hillary.hollis@bmc.org



Hillary is a part-time resource specialist who provides support to families that have been seen in the Developmental and Behavioral Clinic. Hillary assists families in accessing community resources and therapeutic supports. She also helps families navigate the special education process and facilitates Applied Behavioral Analysis (ABA) referrals. Furthermore, she empowers families to advocate for their child's unique needs and provides support around new autism diagnoses.

Maddy Goskoski, MPH | Autism Resource Specialist

madelyn.goskoski@bmc.org

Maddy is a graduate of Boston University School of Public Health with a MPH in Program Management and Community Assessment, Program Design, Implementation, and Evaluation (CAPDIE) and a graduate of Merrimack College with a B.S. in Health Science and Public Health. At The Autism Program, Maddy assists families navigate community support resources including ABA, DDS, SSI and therapeutic services. Maddy encourages patients and families to advocate for their child's individualized needs to support their ASD diagnosis.



Katie Campbell, M.A. | Autism Resource Specialist + TEAM Coordinator

katie.campbell@bmc.org



Katie graduated with a Master of Arts in Child Study and Human Development with a concentration in Clinical-Developmental Health and Psychology from Tufts University in May 2022, and also graduated from the Leadership Education in Neurodevelopmental and related Disabilities (LEND) fellowship at Boston Children's Hospital. She is passionate about working with children, adolescents, and youth to support their development across domains and help each individual grow towards the best version of themselves. Originally from the UK, Katie loves to travel and has worked in educational settings within the US, the UK, and Switzerland including at various schools, at a summer camp, and in recreational settings.

Juju Ha, B.A. | Autism Resource Specialist

juju.ha@bmc.org

Juju is a graduate of Boston University with a B.A. in Psychology and Women's, Gender and Sexuality Studies. As an Autism Resource Specialist at the Autism Program, Juju assists families in connecting with and acquiring various support systems for their child. Additionally, she promotes diverse and accessible community resources to families through the content creation and management of our program's monthly newsletter and social media platforms.



Donors

The Autism Program relies on the generous philanthropic support from donors and funders to maintain its functioning, continued growth, and success.



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SHAPIRO
FAMILY FOUNDATION

Developmental and Behavioral Pediatrics

The Autism Program is based with the **Division of Developmental & Behavioral Pediatrics (DBP) at Boston Medical Center**. DBP provides care to children with a variety of developmental issues, including autism, ADHD, learning difficulties, and behavioral or emotional challenges. Our clinicians are available for developmental evaluations, assessments and follow up.

Our Clinicians

Marilyn Augstyn, MD

Mei Elansary, MD

Mary Ellen Killion, NP

Arathi Reddy, DO

Audrey Christiansen, MD

Arielle Spellun, MD

Rachel Amgott, NP

Sarah Canale, MD

Bridget Poznanski, PhD

Christina Lazdowsky, NP

Britany Weissman, MD

Rachel Vuolo, MD

Social Media



@BMCAutismProgram



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