



The Autism Program

AT BOSTON MEDICAL CENTER

Annual Report 2019

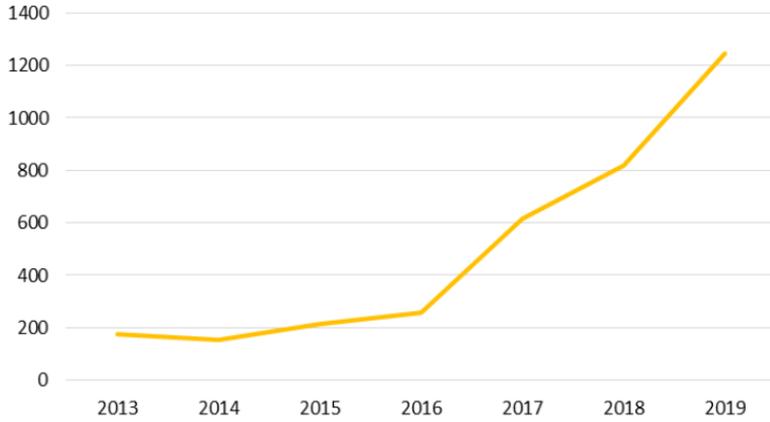
Assisting and empowering individuals and families affected by Autism Spectrum Disorder (ASD) through direct patient and provider support, community-based outreach, and system-level interventions since 2007.

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

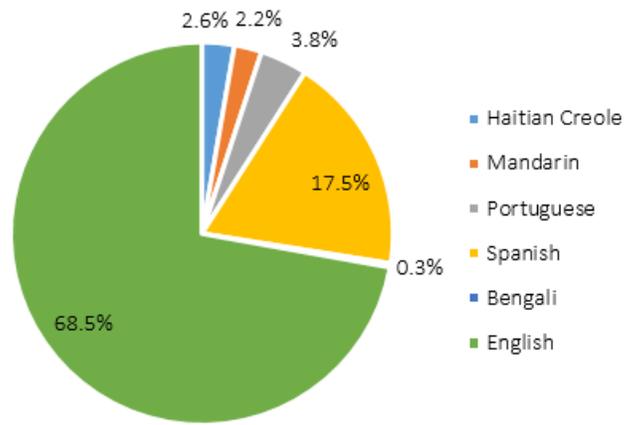
DIRECT PATIENT SUPPORT

We receive the majority (>90%) of referrals for family support from the Developmental and Behavioral Pediatrics clinic at Boston Medical Center. Other departments that regularly refer to us include neurology, psychiatry, and primary care.

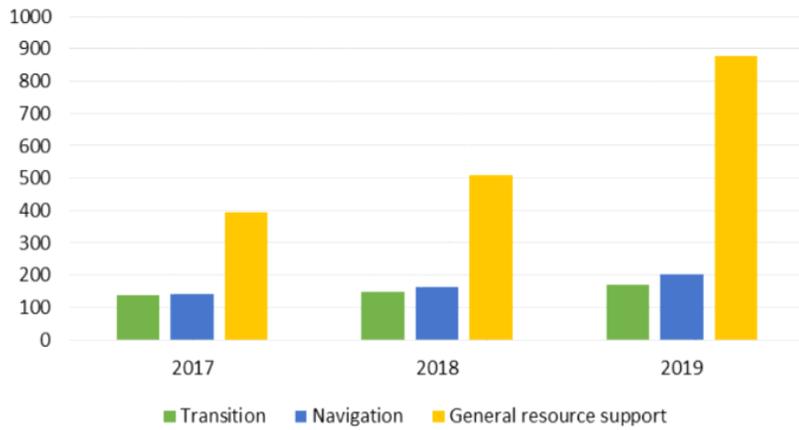
Number of Annual Referrals



Languages Spoken by Families

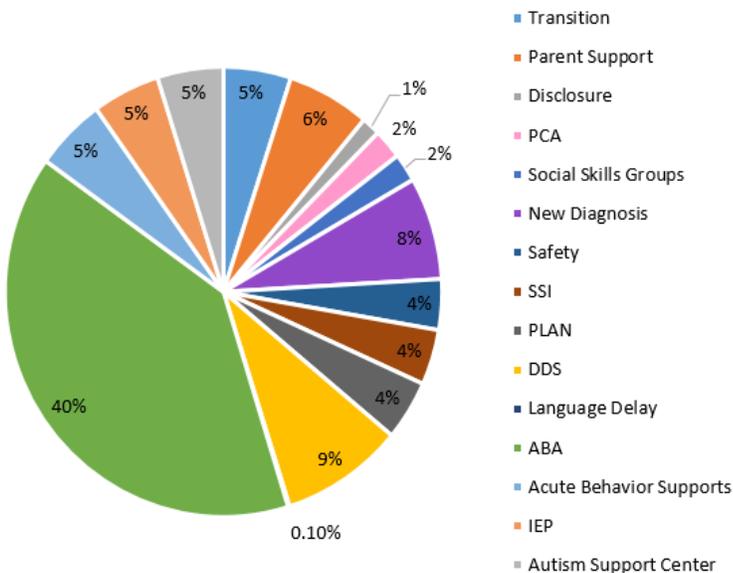


Number of Annual Referrals by Type



“We strive to meet the needs of the community in Boston and its surrounding areas in a culturally competent manner by offering high quality and comprehensive care to all.”

Reason for Referral



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 development and employment.

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., Social Stories).

Navigation support is provided to families who could benefit from extra support due to cultural, linguistic or social barriers. Our bilingual (Spanish-English) Family Navigator assists families with services such as IEP review and participation at team meetings, public benefits enrollment and more.

COMMUNITY-BASED OUTREACH



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

- Throughout the 2019-2020 school year, 30 participants engage in monthly events held within the city of Boston designed to promote positive community engagement and build friendships, leadership, self-confidence, and independent skills.
- Events include: Cradles to Crayons volunteering, laser tag, Museum of Fine Arts, etc.
- Annual focus groups to obtain participant feedback. Examples of extracted themes include: (1) teamwork, (2) confidence, and (3) inter-personal connections.

"I notice that [my child]'s more comfortable in different situations...He seems to be more comfortable... It's like he's confident with what he is doing. He doesn't look to me so much as before. We were on the [subway] not too long ago, and we needed to get a Charlie Card and he just walked right up to the machine and pushed the button, and looked at me for money!" (Confidence)

- TEAM Parent



Holiday Party



Pottery Class at the Museum of Fine Arts

"I expected to see people work together and be patient and open minded and that was what I saw" (Teamwork)

- TEAM Mentor



A Day at the Rose Kennedy Greenway



Volunteering at BMC Rooftop Farm



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 are trained and matched with other parents of children with ASD who may benefit from support surrounding 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.
- Members regularly participate in local and statewide trainings, conferences and exhibition fairs.

*“I am originally from Jamaica, where some of my own people think that autism is a curse. It can be very emotional. Being open about it helps me to help my son. The more open and educated you can be about it, the more you can attack it. Autism plays a big role in my son’s life, but it doesn’t have to be a negative one. Let’s walk with each other like we walk for cancer. **Let’s walk together to find that missing piece.**”*

-Dianna, Parent Leader



Everyday ABA

Free 6-part training in Applied Behavior Analysis (ABA) for parents/caregivers of children with ASD in partnership with New England ABA to teach fundamentals of ABA and practical strategies to apply them in home/community settings.

- Held fall/spring sessions for all parents/caregivers of children with ASD, regardless of whether their children receive care at BMC.
- Video recording classes with plans to create online webinar, translatable into all languages
- Conducting program analysis via mixed methods to measure participants’ knowledge and comfort-level with ABA techniques and strategies

“I really enjoyed this series and feel that I am leaving with more tools to make things happen. Less help needed [for my child] with the morning routines. I [am] better equipped to introduce new everyday skills that should be done on his own”

- Parent

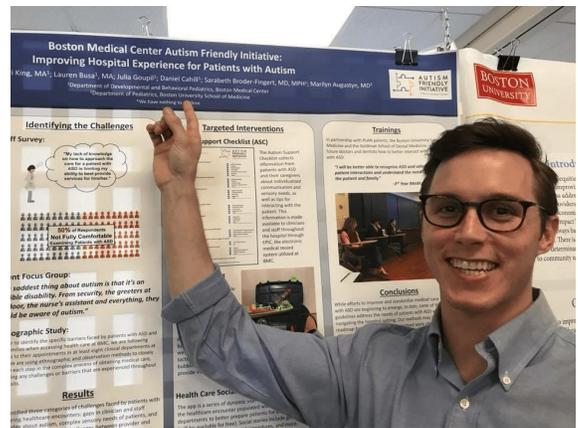
“My son is less aggressive than before. [I enjoyed the] examples, feedback from parents who are going through the same issues”

- Parent

INTERNSHIP PROGRAM

Provides undergraduate, graduate, and post-degree students the opportunity to participate in a rich applied experience.

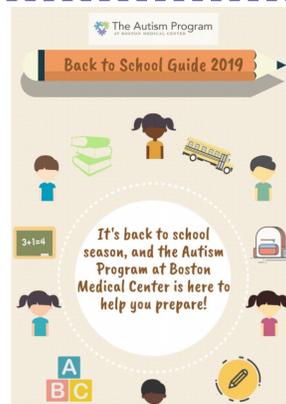
- Since 2013, 179 neurodiverse students have been placed.
- Formed formal partnerships with local universities such as: Massachusetts Institute of Technology (MIT), Tufts University, Harvard Graduate School of Education (HGSE), and Northeastern University.
- Former interns have gone to medical school, landed careers in healthcare consulting, education, and research.
- Interns assist staff with ongoing programmatic activities (e.g., family referrals, managing social media accounts, research projects), produce independent deliverables (e.g., resource guides), and attend hospital-wide talks and trainings according to their unique interests.



Former intern presenting a poster at the 1st annual meeting of the BUMC Health Equity Symposium



Former intern presenting an abstract at the 12th Annual Conference on the Science of Dissemination and Implementation in Health in Washington, DC



PAST INTERN PROJECTS

Autism Friendly Social Stories

Getting to the doctor's office	Getting a shot	Blood draw	Blood pressure	Height and weight
Dentist appointment	Physical exam			

MassHealth CommonHealth Coverage: A Guide to Getting Secondary Insurance

This guide is meant to assist you in understanding the MassHealth CommonHealth plan as a secondary insurance plan and guide you through the application process.

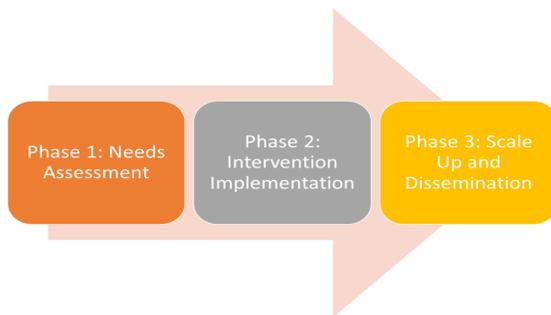
How do I apply?

Online	Mail/Fax	In-Person	Phone
<p>Visit myhealthchoices.net to create a profile and complete the application!</p> <p>For fastest processing time, it's highly recommended that you apply online. Regardless of how you apply, the application materials will be the same.</p>	<p>Print bit.ly/mhchidsupp or Adult Disability Supplement</p>	<p>Visit a MassHealth Enrollment Center at:</p> <ul style="list-style-type: none"> 45 Spruce Street, Chelsea, MA 02119 80 Berkeley Avenue, Suite 10, Springfield, MA 01104 23 Spring Street, Suite A, Taunton, MA 02780 367 East Street, Taunton, MA 02786 1501 Hancock Street, 4th Floor, Quincy, MA 02261 	<p>Call 800.842.2950 or 877.744.ENROL. In-person services available! (TTY) 800.657.4668 or 877.632.7773 for people who are deaf/hard of hearing, or speech disabled.</p> <p>MassHealth has Certified Application Assistants (CAAs) who can help you apply for services. They are free services but you must be a MassHealth member. Call 800.842.2950 or 877.744.ENROL to be included.</p>

SYSTEM-WIDE INTERVENTION



- Aim: to **improve the hospital experience** for patients with ASD and their families by multifaceted interventions targeted at the individual and institutional levels.
- Launched in January 2017 by the following key personnel: Marilyn Augustyn, MD; Sarabeth Broder-Fingert, MD; Shari King, MA MPH; Lauren Bartolotti, MA
- Assembled a multidisciplinary steering committee of 20+ members representing departments across BMC (e.g., Child Life, Public Safety, Pediatrics, Emergency Department etc.)



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

Phase 1: Needs Assessment

Project Name	Description	Key Findings
Hospital-wide staff survey	Online survey to all hospital staff (n=110) about caring for patients with ASD.	50% reported being uncomfortable caring for patients with ASD, Many reported wanting more resources and training
Parent focus group	Focus group on hospital experiences of parents (1 male, 8 females) who have children ages 3-28 with ASD (n=9). Four themes were extracted from parents' responses.	Lack of provider knowledge, Waiting room environment or sensory overload, Provider inflexibility, Parents as experts of their children's needs
Literature review	Building ongoing repository of journal articles regarding the healthcare needs and experiences of individuals with ASD	Patients with ASD have higher healthcare needs, utilization, and costs, Despite higher use, patients with ASD and families reported lower care satisfaction., Limited information on ASD adult population.
Ethnographic study	Followed 16 patients (12 male, 4 female) ages 3-17 during an outpatient visit between January and March 2018.	Identified barriers to patient care: patient behavior, hospital environment, and communication.
Patient data analysis	Retrieved data from BMC clinical data warehouse for patients with ICD-9 and ICD-10 codes who were seen in 2017.	1,787 unique pediatric (≤22 years old) patients generated 8,000 encounters. 304 unique adult (≥23 years old) patients generated 1,953 encounters; The ED was one of the most visited departments for all patients (#4 for pediatric and #2 for adult patients); 1 in 4 pediatric ED encounter was due to behavioral/situational crisis.

Phase 2: Intervention Implementation

Individualized Care

The **Autism Support Checklist (ASC)** collects information about a patient's communication style, triggers, safety concerns, and de-escalation strategies. Administered by phone by Autism Program staff and interns. Information is summarized and entered into EPIC.

- 430 ASCs completed by December 2019

Visit Preparation

The **Healthcare Social Stories App** uses "Social Stories" to help patients navigate their visits by breaking down steps using simple narratives, pictures, and built-in reinforcements.

- Tool is customizable based on patient gender, transportation mode to BMC, clinic location, and type of visit (e.g., routine check-up, blood-draw, x-ray, etc.)

Case Coordination: We are piloting the use of Autism Resource Specialist (ARS) to support patients through outpatient visits. This effort involves coordination with providers and primary support/visit accompaniment given to families.

- We partnered with Ophthalmology, Psychiatry, and Primary Care.

Sensory Accommodations

The **Sensory Toolbox** was developed in collaboration with Child Life. At present, 20 toolboxes have been distributed to departments across BMC and collaborate with toolbox champions in each department to implement and maintain them.

- Conduct toolbox trainings regularly and currently collecting usage and user satisfaction data overseen by our Quality Improvement Board.



*"I love the fact that there is such a variety in the box so that if one thing doesn't work, there is always something else to try. It is great that I can keep so many items in one box. It makes it very easy to just grab the entire box and have everything at a moments notice. When we have patients that require special care, the last thing you want to do is run around trying to find things... It **really has made a difference** to both staff and patients and their families."*

-Radiology Technologist

"The training reinforced the importance of listening to both the patient and the parents, and treating the person and not their disability."

"I previously considered becoming a developmental specialist, and this really reinvigorated that desire."

-Medical Student Feedback for Autism 101 Trainings

Trainings

Autism 101

- Lecture + parent panel, providing unique rich insight into the family experience, and what clinicians/staff need to know when caring for patients with ASD.
- In 2019, 750+ people have been trained in 35 lectures delivered within and outside Boston University Medical Campus.
- Ongoing trainings include Department of Security, Interpreter Services, Boston University Medical School, Genetics Counseling, Boston University School of Dental Medicine.

Doctor's Day

- Boston University medical students volunteer to help students with ASD complete simulated medical check-ups (e.g., height and weight, blood pressure measurement)
- Partner with Boston Public Schools K-8 Joseph Lee School to implement Doctor's Day annually, serving ~200 students with ASD ages 3-14.

Training videos

- Produced four 5-min training videos for providers, including patient roleplay and clinician and family interviews.

Phase 3: Scale Up and Dissemination



Train, support, and provide resources for **all staff in the pediatrics department**.



Conduct and publish a **Delphi study to identify components of an Autism Friendly healthcare practice** to inform best-practices guideline.



Work with BMC Business Strategy team to **develop a business model** for training and consultation packages.



Host Autism Friendly workshop as a precursor to the Steven J. Parker Memorial DBP Conference and the **first Annual Autism Friendly Conference on April 3, 2020**.



Continue to establish **partnerships** and collaborations with external healthcare organizations.

Ongoing Studies

- **Autism 101 training:** Examining the effectiveness of a 1-hour lecture training in improving the perceived knowledge, preparedness, and comfort-level of participants in interacting with patients with Autism Spectrum Disorder (ASD) and families. (IRB H-39313)
- **Internship program:** Examining the effectiveness and implementation of a 4-week undergraduate internship program in improving participants' knowledge and comfort-level in working with populations with Autism Spectrum Disorder (ASD). (IRB H-39506)
- **Autism Support Checklist:** Implementation of an Autism Support Checklist at Boston Medical Center: A Pilot Intervention. (IRB H-38132)
- **Everyday ABA:** Examining the effectiveness of a 6-part parent and caregiver training in improving participants' knowledge and comfort-level in applying Applied Behavioral Analysis (ABA) strategies. (IRB H-39340)
- **Delphi Study:** Identifying Components of an Autism Friendly Healthcare Practice Using the Delphi Method (IRB H-39547)
- **Doctor's Day:** Examining the effectiveness and implementation of experiential training for medical students in caring for pediatric patients with Autism Spectrum Disorders (ASD). (IRB H-39433)

Selected Publications and Conferences

- King, S., Qin, S. (Chairs). (2019, April). **Challenges to caring for children with autism in inpatient/hospitalist, outpatient, and emergency care settings**. Panel presented at the annual meeting of the Pediatric Academic Societies, Baltimore, MD.
- Goupil, J., King, S., Bartolotti Busa, L., Qin, S., Cahill, D., Park, S., Broder-Fingert, S., Augustyn, M. (2019, April). **An ethnographic study of the experience of patients with autism spectrum disorder during outpatient encounters**. Presented at the annual meeting of the Pediatric Academic Societies, Baltimore, MD.
- King, S. (2019). **Making the pediatric practice autism friendly**. *AudioDigest Pediatrics*, 64(24).
- O'Hagan, B., Bays-Muchmore, C., Friedman, A., Busa, L., King, S., & Augustyn, M. (2019) **Implementation of an Autism Support Checklist (ASC) at Boston Medical Center: A Pilot Intervention**. Poster presented at Boston Medical Center Quality and Patient Safety Week Conference. ***Award winner for the "Quality Research" category**.
- O'Hagan, B., Bays-Muchmore, C., Sonikar, P., Huang, C., Qin, S., Friedman, A., Busa, L., King, S., & Augustyn, M. (2019) **Healthcare Utilization Patterns of Patients with Autism Spectrum Disorder (ASD)**. Poster presented at Boston University 8th Annual CTSI Symposium.
- Bays-Muchmore, C., Tanuwijaya, B., Bartolotti, L., King, S., & Augustyn, M. (2019) **Testing Implementation Strategies for the Autism Support Checklist: A Pilot Study**. Presented at the 12th Annual Conference on the Science of Dissemination and Implementation in Health.
- Busa, L., Ferriero, E., King, S., Augustyn, M., Clark, A., Qin, S. **Preparing medical students to interact with patients with autism spectrum disorders (ASD) and their caregivers**. Presented at the 13th meeting of the BUMC McCahan Education Day. ***Winner of the Best Staff Abstract - Education Innovation & Research award**.
- Qin, S., King, S., Busa, L., Goupil, J., Cahill, D., Broder-Fingert, S., Augustyn, M. **Boston Medical Center Autism Friendly Initiative: Improving hospital experience for patients with autism**. Poster presented at the 1st annual meeting of the BUMC Health Equity Symposium, Boston, MA.
- Broder-Fingert, S., Qin, S., Goupil, J., Rosenberg, J., Augustyn, M., Blum, N., Bennett, A., Weitzman, C., Guevara, J.P., Fenick, A., Silverstein, M., Feinberg, E. (2019). **A mixed-methods process evaluation of Family Navigation implementation for autism spectrum disorder**. *Autism*, 23(5), 1288-1299. doi:10.1177/1362361318808460

MANY THANKS TO OUR GENEROUS FUNDERS AND DONORS

The needs of low-income children affected by ASD are vast and variable and yet critical support like that which is provided by Autism Specialists is neither billable nor reimbursable through insurance companies. The Autism Program thus relies on philanthropic support to maintain its functioning, continued growth, and success.



THE CONSTANCE PUTNAM FOUNDATION

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KAREN A. KAMES AND CHRISTOPHER S. GAFFNEY



BainCapital
Community Partnership

Thanks to your generosity, we are able to continue bringing positive impact to the lives of children with ASD and families.



OUR TEAM



Shari King, MA, MPH | **Program Director**

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.

617 414 3666 | Shari.King@bmc.org



Lauren Bartolotti, MA | **Program Manager**

Lauren provides clinical supervision to Autism Program staff as they execute patient and family referrals. Lauren also manages the internship program which brings undergraduate and graduate students from local colleges and universities onboard for a rich applied experience.

617 414 3691 | Lauren.Bartolotti@bmc.org



Elizabeth Ferriero, BA, CEIS | **Autism Resource Specialist**

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.

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Hillary Hollis, BA | **Autism Resource Specialist**

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.

857 310 0976 | Hillary.Hollis@bmc.org

OUR TEAM



Ana Ocasio, MEd | **Family Navigator**

Ana works closely with the physicians and staff in the BMC Autism Program to address patient barriers and help ensure timely and appropriate treatment for children with ASD. This often includes facing financial and economic concerns, language and cultural issues, patient-provider communication, healthcare system obstacles, transportation problems, and bias/stigma. Ana meets with families during clinic visits and closely assists with interactions within the school system and community agencies.

617 414 3662 | Ana.Ocasio@bmc.org



Simone Dufresne, MA, CAS | **Transition Specialist**

Simone provides support, guidance, and resources to adolescents and families served within Developmental and Behavioral Pediatrics who are transitioning to adulthood. She developed and coordinates the program's Transition Clinic, through which she discusses transition resources and topics such as goal setting, school IEP planning, adult services, and life skills development. She also coordinates the Teens Engaged as Mentors (TEAM) initiative and manages the program's website.

617 414 3847 | Simone.Dufresne@bmc.org



Alexander Friedman, MPH | **Autism Friendly Initiative Project Coordinator**

Alexander is responsible for coordinating the Autism Friendly Initiative at BMC, which aims to improve the hospital experience for patients with autism spectrum disorders (ASD). In doing so, Alexander oversees hospital-wide projects related to staff training, systems improvement, and resource development to ultimately address barriers in caring for patients with ASD.

617 414 4247 | Alex.Friedman@bmc.org | AutismFriendly@bmc.org



Belinda O'Hagan, MA | **Research Coordinator**

Belinda oversees the research activities within the Autism Program and the division of Developmental and Behavioral Pediatrics. She assists Principal Investigators in all stages of research, starting from formulating research questions, identifying stakeholders/partnerships, developing measures, collecting and analyzing data, to dissemination. She also trains and supports interns and research assistants to conduct day-to-day research and administrative duties associated with different studies.

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