

AUTISM PROGRAM RESEARCH HIGHLIGHTS



Looking back on a year of research in the Autism Program and sharing the latest updates and future directions of our work

Our Research Journey

The Autism Program has been providing direct support to patients and families since its inception in 2007. In 2017, the program launched the Autism Friendly Initiative, which aims to create system level changes to improve the overall hospital experience for autistic patients and their families. Along with the expansion of focus from individual patient care to system level efforts, the Autism Program has also increased its attention to research and evaluation to track progress. Since 2019, the Autism Program has been disseminating findings of various research studies in 20+ conferences worldwide. Our research efforts are overseen by our Scientific Advisory Board and a 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 autism community.



If you are interested to learn more and/or be involved in our research, please contact our research coordinator, Belinda O'Hagan at belinda.ohagan@bmc.org.

Research At a Glance

So far this year, we have presented our research at four conferences worldwide including the International Society for Autism Research, Pediatric Academic Societies, European Congress in Psychiatry, and the International Association for the Scientific Study of Intellectual and Developmental Disabilities. We are currently working on dissemination materials for multiple studies and are expecting to submit additional abstracts this fall.



Teens Engaged as Mentors (TEAM) Study

Background. Past studies indicate a decline in services for autistic youth exiting the American public education system.¹ However, many autistic youth benefit from support navigating complex processes involved in developing social relationships, seeking employment, exploring leadership opportunities and engaging in post-secondary education.²⁻⁴ Teens Engaged as Mentors (TEAM) is an innovative mentoring program that provides socialization and community engagement opportunities in a safe environment for youth with and without autism. Notably, TEAM includes autistic mentors as well as mentees.



Methods & Findings. This study explored how participants and their caregivers perceived participation in TEAM. Stakeholder focus groups were conducted annually from 2016-2020 with 16 autistic mentees, 27 autistic and neurotypical mentors, and 40 caregivers. We found that participants viewed TEAM as promoting peer socialization in a safe environment, community engagement, and self-confidence. Mentees tended to focus on the socialization opportunities that TEAM provided whereas mentors and caregivers mentioned how the diversity in TEAM allowed participants to be more open-minded as they interacted with different people.

Collaboration. The Autism Program is collaborating with Dr. Zachary Rossetti, an associate professor of special education at Boston University Wheelock College of Education & Human Development, whose interests include social belonging and participation of people with intellectual and developmental disabilities (IDD). This study was recently submitted for publication and is currently under review.



Teens Educating, Advocating, and Consulting in Healthcare (TEACH) Study

Background. There are studies documenting the healthcare experiences of autistic individuals from the perspectives of autistic adults, healthcare professionals, and caregivers.^{5–7} However, there is a lack of data from the direct perspectives of autistic adolescents and young adults.

Objective. To bridge this critical gap, we are conducting a series of four focus groups with our patient advocacy group, Teens Educating, Advocating, and Consulting in Healthcare (TEACH) to gather their perspectives on topics such as positive vs. negative healthcare experiences, helpful accommodations, and what they wish healthcare professionals know.

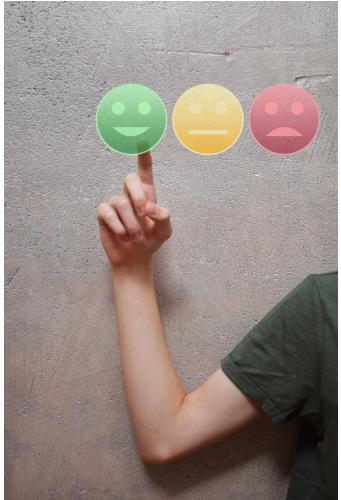
Methods. The focus groups were (or will be) held in January, April, July, and October 2021. Focus groups are audio recorded, transcribed, and qualitatively analyzed. Transcripts are verified by independent research assistants for quality control. Currently, all transcripts from the first three focus groups have been transcribed and verified.



Collaboration. We are collaborating with Dr. Erika Crable, a postdoctoral scholar at University of California San Diego who have been involved in Autism Program research efforts since her prior employment at the Boston University Center for Improvement and Implementation Science. Dr. Crable is an expert in qualitative research and her research interests include behavioral health and safety-net populations. Our plan is to analyze all focus group data this fall and submit abstracts for conferences by the end of the year.

Modified Delphi Study

Background. Multiple studies have found that autistic individuals use healthcare services at higher rates compared to non-autistic individuals and those with other disorders.^{8,9} However, autistic individuals and their caregivers are also more likely report lower care satisfaction due to various healthcare barriers, including unaccommodated communication preference, unmet sensory needs (e.g., bright lights, strong smells), and lack of staff knowledge.^{5,10,11} Currently, there is no standard of best practice about caring for autistic patients.



Methods. We aim to identify features of “Autism Friendly” practice according to key stakeholders (i.e., healthcare and education professionals, autistic individuals, and family members) using a modified three-round Delphi. Statements about components of an “Autism Friendly” healthcare were compiled based on the literature and in consultation with the steering committee of the Autism Friendly Initiative at a single, urban academic medical center. A purposeful sample of participants were recruited through our professional networks and patients/families mailing lists. Examples of invited professionals include researchers, healthcare workers, and educators. In the first two rounds, we distributed electronic surveys to participants, who scored statements from 1-9 in terms of importance. In the third round, participants ranked statements from most to least important.

Findings. Themes that emerged from highly ranked statements include environmental/operational modifications (e.g., longer appointment times) and staff training to support autistic patients. Highly ranked statements represented previously reported barriers, including the need for staff training and inclusive engagement with the autistic community, which is consistent with our hypothesis. Stakeholder groups disagreed regarding the importance of some components of “Autism Friendly” healthcare. Findings can help inform healthcare organizations to determine priorities when building an “Autism Friendly” healthcare. This study was recently submitted for publication and is currently under review.

DID YOU KNOW?

The Delphi method is named after the Oracle of Delphi in Greek mythology, who answered questions posed by visitors who are seeking guidance for their future actions.

Delphi 2.0 Study (new!)

Follow up study. At the end of the Modified Delphi study, we realized that our sample consisted of mainly family members of autistic individuals and professionals whose interests include autism or who works with autistic individuals. However, there were few autistic individuals included in the final round. To better understand the perspectives of autistic individuals about what “Autism Friendly” healthcare practice means to them, we will conduct a follow up study to discuss this topic exclusively with autistic individuals. We plan to conduct focus groups with about 20 autistic individuals, during which we will present and discuss the results of the first Delphi study. This study was recently approved by the Institutional Review Board and we will proceed with recruitment and data collection soon.

Hospital-wide Autism Resource Specialist (ARS) Study (new!)

Background. The Autism Program has been supporting families to access resources outside of Boston Medical Center since its inception in 2007. However, we acknowledge that there is plenty of work that we can do to support autistic patients and their families who seek medical care at Boston Medical Center. Hence in 2017, the Autism Program launched the Autism Friendly Initiative, which aims improve the overall hospital experience of autistic patients and their families. One of the latest Autism Friendly projects launched is the Autism Resource Specialist Visit Support (ARS-VS).

ARSs are full-time employees of the Autism Program and responsibilities through ARS-VS include liaising with families and clinicians to prepare for an upcoming visit, developing tailored resources, providing in-person visit accompaniment and behavioral support, as well as conducting post-visit debriefs with families and clinicians.



Objective. The current study aims to assess the acceptability, appropriateness, and feasibility of ARS-VS and its components from the perspectives of autistic patients, caregivers, and staff. Data collection measures include caregiver interview, patient brief survey, clinician survey, and visit observation.

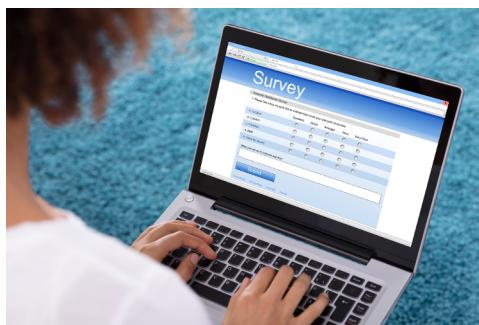
Image. The image on the left depicts one of our Autism Resource Specialists, Liz Ferriero (left) with a patient (right) who she has supported during a visit. Image was taken from Boston Medical Center Instagram account.

Collaboration. We are collaborating with Dr. Erika Crable, who as aforementioned, is an implementation science expert and is overseeing the methodology of this study. In addition, we are also collaborating with Dr. Russell Maguire, an associate professor and chair of the Department of Behavior Analysis at Simmons University, who is advising our ARSs on the clinical aspects of providing behavioral support to autistic patients during medical encounters. We recently submitted a research grant proposal to the Organization for Autism Research and are currently working on obtaining approval from the Institutional Review Board.



Medical Student Autism 101 Training Study (new!)

Background. Lack of staff knowledge about autism is a commonly reported barrier in healthcare by autistic patients, caregivers, and healthcare professionals.^{11–13} The Autism Program regularly provides training to various groups at the Boston University Medical Campus. In particular, the Autism Program provides Autism 101 training as part of the standard curriculum for Boston University School of Medicine Students. This study aims to examine the gains in knowledge, self-efficacy, and comfort-level of medical students who receive the Autism 101 training. The training itself runs for about 90 minutes and consists of a lecture and a parent panel, which provides important context to the lecture content through real-life experiences. The content includes basics of autism (e.g., diagnosis, prevalence, treatments, and services) and specific strategies that healthcare professionals can use when interacting with autistic patients.



Methods. The data collection procedure consists of three surveys, which are administered before, immediately after, and three months after the training using an adapted survey that was originally used by Dr. Audrey Christiansen to assess a training program for public safety officers at another institution.¹⁴ Currently, this study is under review by the Institutional Review Board.

New and improved. In 2019, we conducted a similar study that involved surveys administered before and after our Autism 101 training with Boston University medical students. We found that participants reported increased self-reported knowledge and comfort-level in interacting with autistic patients. The new study will consist of an improved data collection protocol with the inclusion of an objective knowledge section (i.e., quiz) and an additional follow up survey to measure retention in knowledge and attitudes.



Future Directions

To date, most of our research efforts have focused on assessing the current practice and needs of autistic patients, as well as examining how our efforts are received by stakeholders. There is evidence from qualitative data and anecdotes that our Autism Friendly work is needed and well-received by stakeholders (i.e., patients, families, staff). Moving forward, we will expand our research and evaluation focus to include identification and measurement of outcomes and barriers on both the individual patient and clinic/departmental levels. These are outlined in our updated logic model as represented by the table below, which was drafted in collaboration with our Scientific Advisory Board.

Context	Program Resources	Activities	Outputs	Short-term Outcomes	Intermediate Outcomes
Autistic patients report higher rates of various medical and psychiatric conditions, as well as higher use of medical services. Despite higher use, they also report lower satisfaction with care. Healthcare professionals have reported not feeling comfortable caring for autistic patients.	Sensory Accommodation <ul style="list-style-type: none"> Sensory toolboxes Sensory tool packs (single-use) Training <ul style="list-style-type: none"> Lecture slides Handouts Visit Preparation <ul style="list-style-type: none"> Autism Resource Specialist Visit Service (ARS-VS) Tailored support and resources Social Stories web application Individualized Care <ul style="list-style-type: none"> Autism Support Checklist 	<ul style="list-style-type: none"> Procure supplies Assemble toolboxes and tool packs Provide clinics with Sensory Toolboxes and Tool Packs Train staff to use and maintain sensory items to support patients <p>Provide tailored trainings to groups of health care professionals</p> <ul style="list-style-type: none"> ARS-VS: liaise with families/clinicians, develop tailored resources, provide in-person support Social Stories app: ongoing addition of stories and language capacities <ul style="list-style-type: none"> Collect patient ASC information from caregivers Enter patient ASC information into electronic medical record (EMR) Update individual patients' ASCs as needed 	<ul style="list-style-type: none"> 20+ clinics provided with Sensory Toolboxes and Tool Packs to date 1000+ Sensory Tool Packs deployed in ~12 months ~750 health care professionals trained every year 20+ healthcare social stories entered into web application to date 600+ ASCs entered into EMR to date 	<ul style="list-style-type: none"> Positive patient satisfaction with health encounters Increased staff knowledge, comfort-level, and self-efficacy about autism and useful strategies when interacting with autistic patients Reduced staff burn out Reduced safety incidents Reduced preventable procedures/admissions (e.g., restraints, sedatives) 	<ul style="list-style-type: none"> Prepared and proactive staff to interact with autistic patients Productive interactions between staff, patients, and families Smooth flow of medical encounters for autistic patients and their families Informed and prepared patients and families to navigate the hospital space
Long-term Outcomes					
<ul style="list-style-type: none"> Improved hospital experience for autistic patients and their families Increased autism awareness on a hospital-wide level Improved health outcomes for autistic patients 					

REFERENCES

1. Shattuck PT, Garfield T, Roux AM, et al. Services for Adults With Autism Spectrum Disorder: a Systems Perspective. *Curr Psychiatry Rep.* 2020;22(3):13. doi:10.1007/s11920-020-1136-7
2. Curtin C, Humphrey K, Vronsky K, Mattern K, Nicastro S, Perrin EC. Expanding Horizons: A Pilot Mentoring Program Linking College/Graduate Students and Teens With ASD. *Clin Pediatr (Phila)*. 2016;55(2):150-156. doi:10.1177/000992281558882
3. Lucas R, James AI. An Evaluation of Specialist Mentoring for University Students with Autism Spectrum Disorders and Mental Health Conditions. *J Autism Dev Disord*. 2018;48(3):694-707. doi:10.1007/s10803-017-3303-1
4. Siew CT, Mazzucchelli TG, Rooney R, Girdler S. A specialist peer mentoring program for university students on the autism spectrum: A pilot study. *PLOS ONE*. 2017;12(7):e0180854. doi:10.1371/journal.pone.0180854
5. Nicolaïdis C, Raymaker DM, Ashkenazy E, et al. "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*. 2015;19(7):824-831. doi:10.1177/1362361315576221
6. Cheak-Zamora NC, Teti M. "You think it's hard now ... It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services. *Autism*. 2015;19(8):992-1001. doi:10.1177/1362361314558279
7. Cheak-Zamora NC, Nowell K, Helterbrand E, Tait A. Investigating health-related knowledge and independence for physical and mental health conditions in young adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2021;85:101801. doi:10.1016/j.rasd.2021.101801
8. Brooks JD, Bronskill SE, Fu L, et al. Identifying Children and Youth With Autism Spectrum Disorder in Electronic Medical Records: Examining Health System Utilization and Comorbidities. *Autism Research*. 2021;14(2):400-410. doi:10.1002/aur.2419
9. Cummings JR, Lynch FL, Rust KC, et al. Health services utilization among children with and without autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2016;46(3):910-920. doi:10.1007/s10803-015-2634-z
10. Davignon MN, Friedlaender E, Cronholm PF, Paciotti B, Levy SE. Parent and provider perspectives on procedural care for children with autism spectrum disorders. *Journal of Developmental & Behavioral Pediatrics*. 2014;35(3):207-215. doi:10.1097/DBP.0000000000000036
11. Muskat B, Burnham Riosa P, Nicholas DB, Roberts W, Stoddart KP, Zwaigenbaum L. Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. *Autism*. 2015;19(4):482-490. doi:10.1177/1362361314531341
12. Broder-Fingert S, Ferrone CF, Giaquque A, Connors SL. Residents' knowledge and comfort with caring for children with autism spectrum disorder. *Clinical Pediatrics*. 2014;53(14):1390-1392. doi:10.1177/0009922814526982
13. Corden K, Brewer R, Cage E. A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People. *Rev J Autism Dev Disord*. Published online May 14, 2021. doi:10.1007/s40489-021-00263-w
14. Christiansen A, Harstad E, Sideridis G, Weissman L. Development of a Training Curriculum for Hospital Security About Autism Spectrum Disorder. *Journal of Developmental & Behavioral Pediatrics*. 2021;42(3):191-197. doi:10.1097/DBP.0000000000000888

ABOUT THESE HIGHLIGHTS

These research highlights are brought to you by the Autism Program at Boston Medical Center, a family support program of Developmental & Behavioral Pediatrics. We are committed to continue seeking ways to improve our support toward patients with autism and their families through rigorous research and evaluation.



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The Autism Program at Boston Medical Center



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