

Background

The prevalence of autism spectrum disorder (ASD) is rising, however, there are significant barriers to quality healthcare for patients with ASD. Patients with ASD experience more outpatient visits and their annual healthcare costs are higher than patients without ASD. Patients with ASD encounter high levels of unmet need and lower levels of satisfaction with care. To address these issues at Boston Medical Center (BMC), we have launched the Autism Friendly Initiative to improve the healthcare experience for our patients with ASD.



ASD



2.2 visits



8.0 visits

Average number of annual physician visits*

*Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: data from U.S. national samples. J Autism Dev Disord 2006;36:871-9.

Methods

In order to achieve our goal of improving the health experience for our patients with ASD, we first developed partnerships with key stakeholders including clinicians and staff throughout BMC, as well as patients and families. To identify the specific challenges faced by patients with ASD, we have undertaken surveys, focus groups and studies. Based on our assessments, we have developed, and are piloting a range of interventions.

Steering Committee

Categories of Personnel:

Administrators, Physicians, Nurses, and other Clinicians

Departments Include:

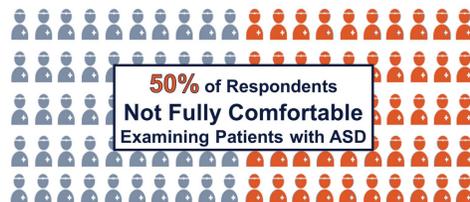
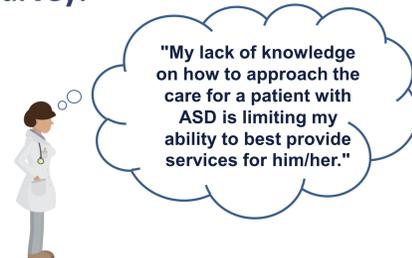
- Pediatrics
- Nursing
- Social Work
- Child Life
- Emergency Department
- Adult Medicine
- Dentistry
- Security
- Patient Advocacy
- Facilities

Partnership with Parents

We have a strong partnership with The Parent Leadership in Autism Network (PLAN), an initiative of the BMC Autism Program. PLAN is comprised of a diverse, multilingual group of parent leaders. Their feedback on the Autism Friendly Initiative efforts is consistently incorporated.

Identifying the Challenges

Staff Survey:



Parent Focus Group:

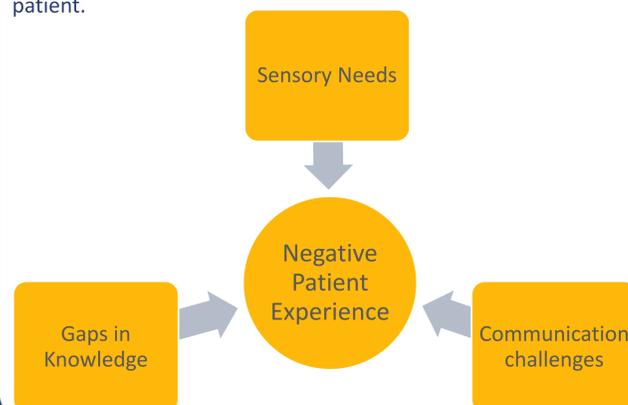
"The saddest thing about autism is that it's an invisible disability. From security, the greeters at the door, the nurse's assistant and everything, they should be aware of autism."

Ethnographic Study:

In order to identify the specific barriers faced by patients with ASD and their families when accessing health care at BMC, we are following patients to their appointments in at least eight clinical departments at BMC. We are using ethnographic and observation methods to closely observe each step in the complex process of obtaining medical care, identifying any challenges or barriers that are experienced throughout these visits.

Results

We identified three categories of challenges faced by patients with ASD during healthcare encounters: gaps in clinician and staff knowledge about autism, complex sensory needs of patients, and bidirectional communication challenges between provider and patient.



Targeted Interventions

Autism Support Checklist (ASC)

The Autism Support Checklist collects information from patients with ASD and their caregivers about individualized communication and sensory needs, as well as tips for interacting with the patient. This information is made available to clinicians and staff throughout the hospital through EPIC, the electronic medical record system utilized at BMC.

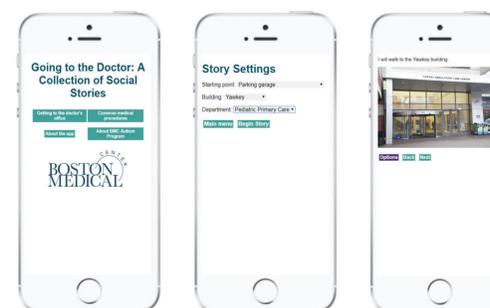
Autism Toolbox

The Autism Toolbox contains objects to enable patients to better cope with sensory needs, for example, sunglasses and noise cancelling headphones. For patients with ASD who are sensory seeking, items like stress balls and pop tubes, and a weighted lap pad provide tactile input. Similarly, bubbles and a light-up toy provide visual stimuli.



Health Care Social Stories App

The app is a series of dynamic user-informed social stories about the healthcare encounter populated with photographs of BMC departments to better prepare patients for their appointments (will be available for free). Social stories include getting a blood draw, taking vital signs, dental procedures, and more.



Trainings

In partnership with PLAN parents, the Boston University School of Medicine and the Goldman School of Dental Medicine, we train future doctors and dentists how to better interact with patients with ASD.

"I will be better able to recognize ASD and adapt to patient interactions and understand the needs of both the patient and family."

-3rd Year Medical Student



Conclusions

While efforts to improve and standardize medical care for patients with ASD are beginning to emerge, to date, none of these guidelines address the needs of patients with ASD when navigating the hospital setting. Our methods may provide a roadmap for approaching the important work of tackling this critical issue.



Contact Information

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