



MassGeneral Hospital
for Children™

CENTER
BOSTON
MEDICAL

Getting an “A” in Inpatient Autism Care

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Disclosures

- We have no financial relationships to disclose.



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Objectives

- “At the end of this plenary we want you to....”
 - 1) Understand the Unique Challenges in providing High Quality Inpatient Care to Children with Autism Spectrum Disorder
 - 2) Know the current Best Practices in Inpatient Care of Children with Autism Spectrum Disorder
 - 3) Obtain strategies to leverage the Electronic Health Record in standardizing and improving Inpatient Care of Children with Autism Spectrum Disorder
 - 4) Get a glimpse into the state of research and the future of Inpatient Autism Care.



Patient M

- 8 y.o. 10 m.o. male with a history of ASD, ADHD, anxiety/mood disorder (s/p 3 inpatient admissions; managed with clonidine, trazodone, amitriptyline), nocturnal, and severe chronic constipation, who presented with worsening constipation, progressive abdominal distension and irritability.
- Over the last few months prior to admission, his anxiety around stooling intensified and he was very violent towards his parents and younger sister. He would not go near a toilet or even talk about the bathroom. At the time of admission, he had not stooled in 20 days.



The Parent Perspective

- [Video of Anne F. Parent of child w/ Autism](#)



Disruptive Aspects of Hospitalization

Hospitalization is uniquely disruptive for persons with ASD which may result in increased **stress**, **anxiety** and **inability to cope**.

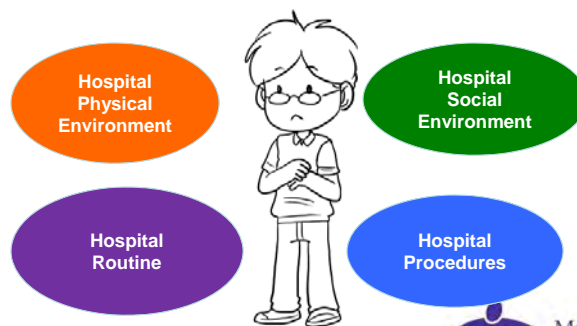


Illustration from Rebecca Burgess "Understanding the Spectrum"
<http://theoraah.tumblr.com/post/142300214156/understanding-the-spectrum>



Unfamiliar Hospital Physical Environment

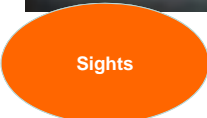


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Unfamiliar Hospital Social Environment



of interactions

Mode of interactions

Unpredictability and variability

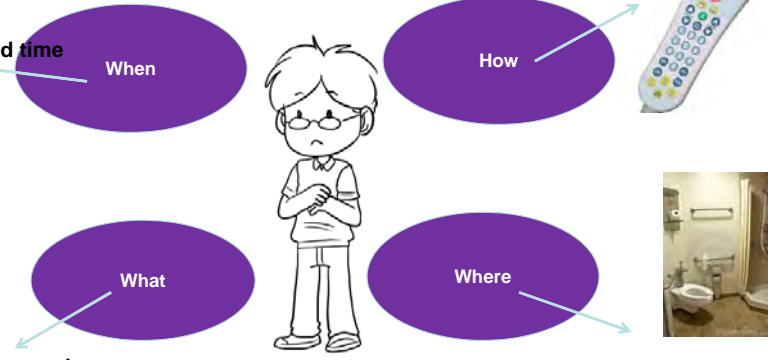


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Unfamiliar Hospital Routine

- Meals
- Self care
- Wake/Sleep
- Medication
- Unstructured time

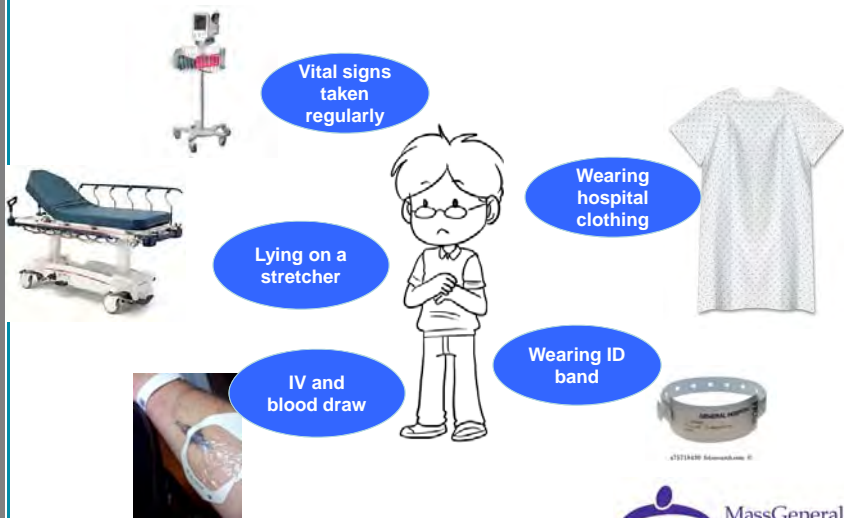


- Tests and procedures
- Inconsistent or unexpected people and events
 - Vital signs, examinations

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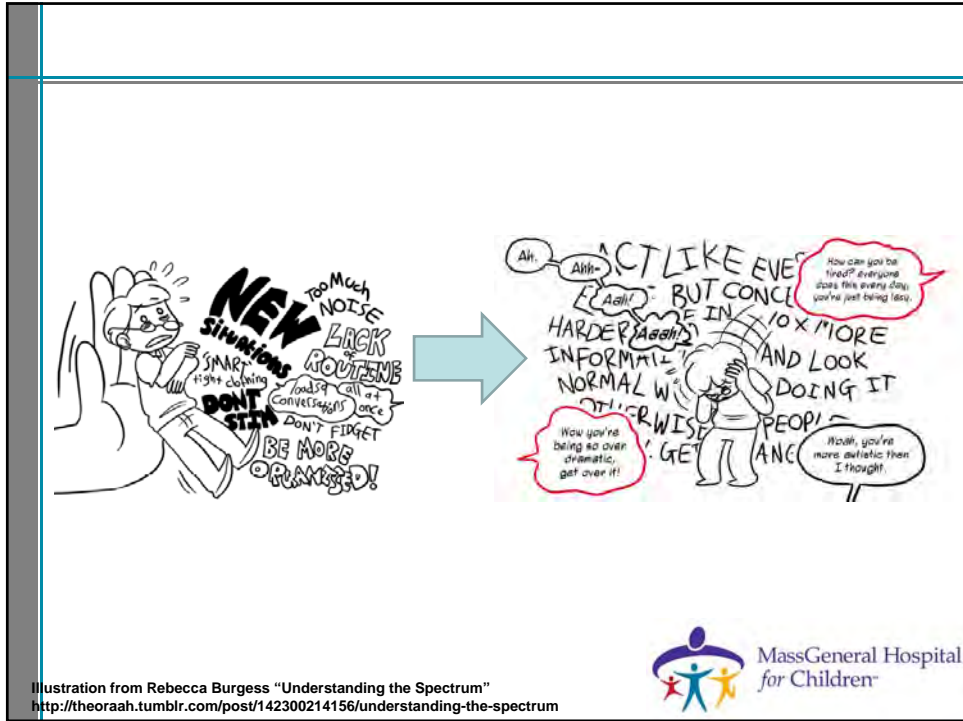


Hospital Procedures



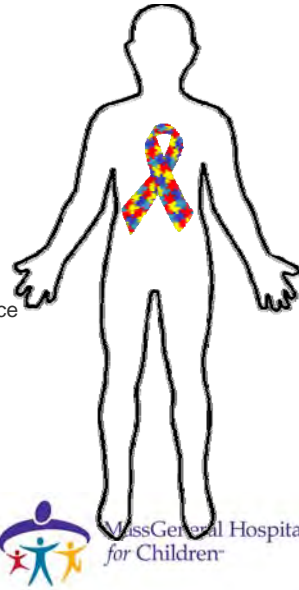
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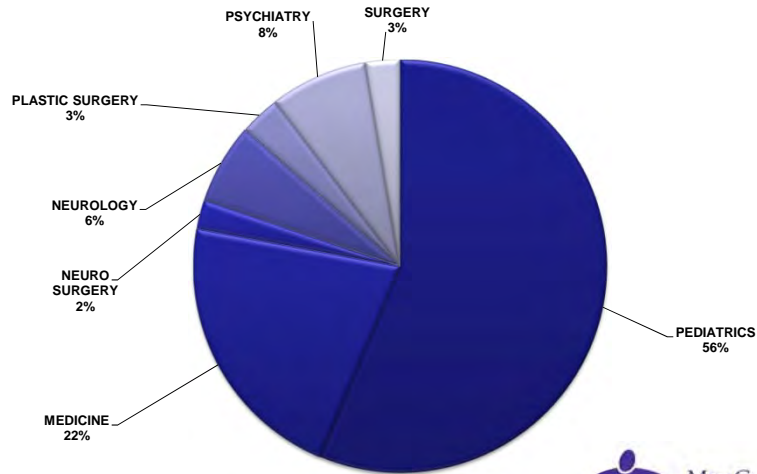


Medical Co-Morbidity in ASD

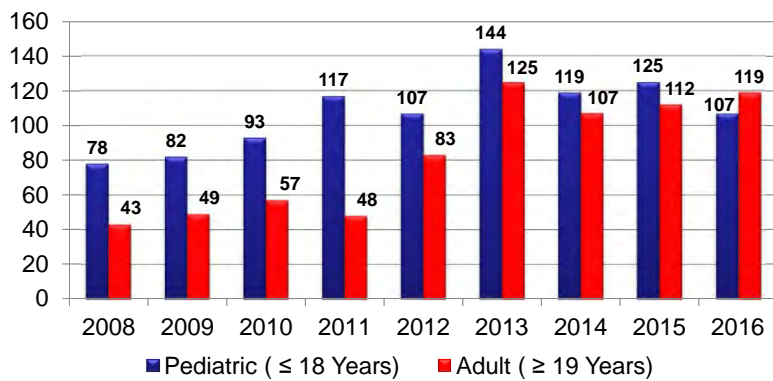
- Head:** Headache, seizure, sleep
- Eyes:** Allergy, poor vision
- Ears:** Ear infections, foreign body, noise supersensitivity
- Nose/sinuses:** Allergies, sinus infections
- Mouth/Throat:** Cavities, abscess, strep infection, tonsillitis
- GI:** Reflux, ulcer, constipation, diarrhea, food allergy/intolerance
- Abdominal:** Appendicitis, hernia
- Genitourinary:** menstrual problems, kidney problems
- Musculoskeletal:** Fractures, reduced bone density
- Cutaneous:** Skin-picking (lesions/infection)



MGH Inpatient Services for Patients with ASD



Pediatric/Adult ASD Admissions 2008-2016



Impact Beyond Volume

- **2013 hospital self-assessment reflected the following concerns:**
 - Patient and family experiences
 - Patient safety concerns
 - Inconsistent staff knowledge
 - Staff discomfort in providing care
 - Pediatric family-centered care versus adult care models
 - Hospital administrative systems challenges
 - Admissions, check-in, wait times
 - Communication challenges



Patient Experience of Hospitalization

- *Video of patient describing hospitalization*

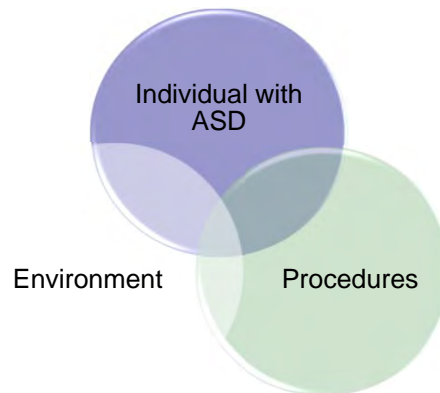


“BEST PRACTICES”



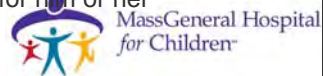
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Strategies are Possible for All Areas



Strategies for Optimizing Comfort

- **Individual**
 - Pro-actively learn about a person's needs and what may trigger anxiety and discomfort
 - Prepare the person for demands with the methods that work best for him or her
 - *Supports:* Closely involve the individuals who know the person best (family, caregivers, outpatient team)
- **Environment**
 - *Physical environment:* Modify the environment to minimize sensory 'overload'
 - *Social environment:* Collaborate with staff to provide consistent interaction approach
- **Procedures**
 - *Modifications:* Determine what procedures can be modified to meet the person's needs
 - Ease anxiety or discomfort by allowing the person to participate in procedures using the methods that work best for him or her



What Can Help

Extra time when transitioning to a different activity/demand

Wear personal clothing

First-then visual schedule for the day

Place the blood pressure cuff on nurse first

Presence of a family member or caregiver



No or dimmed florescent lights

Private room/space

Physical space and time

Communicate with my iPad

No more than 2-3 doctors or nurse in the room at once



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Autism Care Questionnaire

- Lists the non-medical needs of individuals with ASD within acute care settings
 - Methods of communication
 - Tolerance of hospital visit and examination
 - Unique sensory needs
 - Dietary needs and preferences
 - Safety concerns and preferred coping mechanisms
- Recommend ACQ is updated a minimum of every 2 years or as needed

Autism Care Questionnaire (ACQ)

Patient name: _____ Patient current age: _____

Patient date of birth: ____/____/____ Date: ____/____/____

Name of person completing this form: _____

Relationship to the patient: _____

GUARDIANSHIP/REGISTRATION (only for patients age 18 years or older)

Does the patient have a guardian? Yes No Not applicable

If yes, please enter name: _____

If the patient has been appointed by the court, a copy of the guardianship should be submitted to the hospital or clinic.

We want to make sure that your visits to the hospital or clinic are a positive experience. Please fill out this form to help us learn about you/the patient so we can better meet your/the patient's needs.

COMMUNICATION:

1. How does the patient like to communicate needs/wants? (check all that apply)

<input type="checkbox"/> Talking	<input type="checkbox"/> Facial or communication device	<input type="checkbox"/> Making sounds
<input type="checkbox"/> Sign language	<input type="checkbox"/> Handwriting/typing	<input type="checkbox"/> Facial expressions/body language
<input type="checkbox"/> Pictorial words	<input type="checkbox"/> Pictures or symbols	<input type="checkbox"/> Drawing, etc.
<input type="checkbox"/> Handwritten words	<input type="checkbox"/> Pictures with words	<input type="checkbox"/> Other

2. What other ways will the patient tell or what he/she wants/wants? (check all that apply)

<input type="checkbox"/> Talking	<input type="checkbox"/> Facial or communication device	<input type="checkbox"/> Making sounds
<input type="checkbox"/> Sign language	<input type="checkbox"/> Handwriting/typing	<input type="checkbox"/> Facial expressions/body language
<input type="checkbox"/> Pictorial words	<input type="checkbox"/> Pictures or symbols	<input type="checkbox"/> Drawing, etc.
<input type="checkbox"/> Handwritten words	<input type="checkbox"/> Pictures with words	<input type="checkbox"/> Other

3. How does the patient communicate "yes" or "no" when asked a question?

<input type="checkbox"/> Talking	<input type="checkbox"/> Facial or communication device	<input type="checkbox"/> Making sounds
<input type="checkbox"/> Sign language	<input type="checkbox"/> Handwriting/typing	<input type="checkbox"/> Facial expressions/body language
<input type="checkbox"/> Pictorial words	<input type="checkbox"/> Pictures or symbols	<input type="checkbox"/> Drawing, etc.
<input type="checkbox"/> Handwritten words	<input type="checkbox"/> Pictures with words	<input type="checkbox"/> Other

4. How does the patient know what time it is/going? (check all that apply)

<input type="checkbox"/> Talking	<input type="checkbox"/> Facial or communication device	<input type="checkbox"/> Making sounds
<input type="checkbox"/> Sign language	<input type="checkbox"/> Handwriting/typing	<input type="checkbox"/> Facial expressions/body language
<input type="checkbox"/> Pictorial words	<input type="checkbox"/> Pictures or symbols	<input type="checkbox"/> Drawing, etc.
<input type="checkbox"/> Handwritten words	<input type="checkbox"/> Pictures with words	<input type="checkbox"/> Other

ACQ Instructions: Scan completed ACQ into LHM and upload into the "Patient" section of a "Communication" folder on the Microsoft Azure Cloud (Communication_of_all_orgs). This data never should be the data in the ACQ webcomponent.

for Children

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Autism Care Questionnaire (ACQ)

- Developed to improve the experiences of individuals with ASD when receiving medical services
- Helps medical staff better interact with individuals with ASD in order to deliver quality medical care

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UNIVERSITY OF CHICAGO MEDICAL CENTER

PARTNERS IN HEALTH
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Autism Care Questionnaire
A quality and safety tool for medical care

Complete and download an Autism Care Questionnaire to share with healthcare providers

The Autism Care Questionnaire (ACQ) can provide medical staff with a quick and easy way to learn about a patient's communication methods, sensory differences and other potential stressors or safety concerns.

See reverse to learn more!



Autism Care Questionnaire

- Flexibility
 - Patient driven → Completed by patients, families, or caregivers
 - Clinician driven → Completed with patient and/or family upon admission or in outpatient office
- Relevant Across Settings
 - Outpatient offices
 - Procedural areas
 - Inpatient settings
 - Emergency department

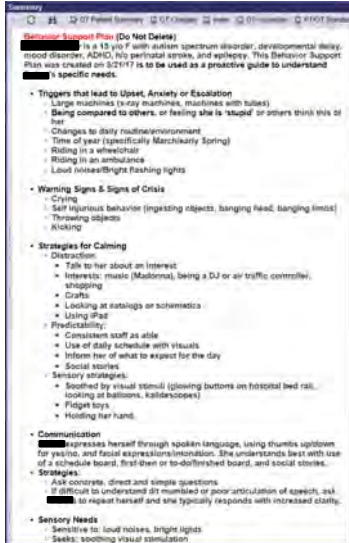


Behavior Support Plan (BSP)

- Clinician Driven
- Integrates multiple sources of data from multidisciplinary team, patient and family
 - ACQ, OT/SLP Evaluations, Plan for Hospital Course, Modifications to Hospital Environment and Routine
- Goal to provide access to most relevant information 'at a glance'



Creation of Behavior Support Plan



- Brief
- Practical
- Highly Individualized
- Remain “live” as challenges arise
- Multidisciplinary
- Includes triggers, warning signs, strategies for calming, strategies for communicating geared toward caregivers



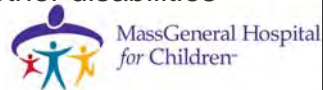
Patient Navigator for Autism

- **Creation/hiring of Patient Navigator for Autism**
 - Resource and advocate for individual patients
 - Development of staff ‘champions’ across departments
 - Electronic Medical Record
 - Staff education
 - Systems development
 - Help guide future initiatives



Navigator Priorities

- **Direct Clinical Care and Coordination**
 - Advocacy and support for parents
 - Support for nursing and other hospital staff
- **Education**
 - Needs of patients with ASD
 - Connection of outpatient and inpatient
- **Systems Development**
 - “Every patient with ASD is NOT really unique” for developing hospital systems
 - ASD patient care can be applied to other disabilities



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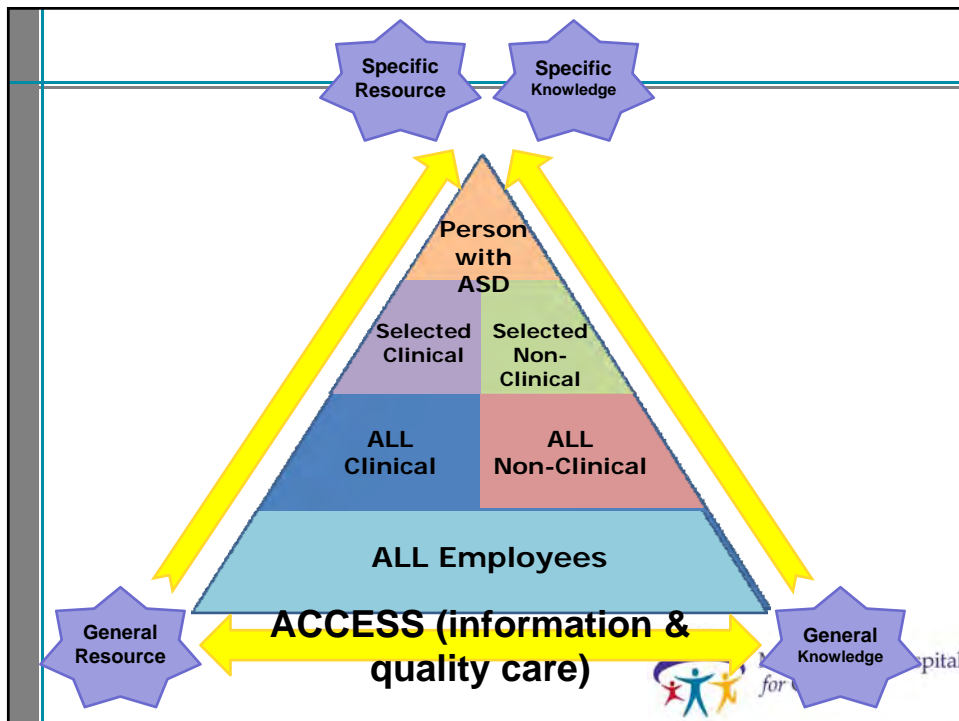
Role of Inpatient Occupational Therapy

- Assess a patient's prior and current level of function
 - Cognition, sensory, functional communication, emotion regulation, physical abilities
- Determine how the changes in environment and context (i.e. disruption in daily routine) will affect a person with autism in the hospital setting
- Provide interventions to facilitate:
 - Participation in medical care (i.e. procedures, vitals)
 - Tolerance of environment (i.e. physical environment, social environment of staff)
 - Adjustment to changes (i.e. new routine, unexpected events)



When OT Can Help

- Difficulty with communication, expressing basic needs, pain
- Difficulty tolerating necessary nursing and medical care
 - Dressing changes
 - Tests
 - Self care/hygiene
- Difficulty managing hospital routines
- Difficulty tolerating hospital environment
 - Social and physical
- Most successful when **proactive**
 - Coping when weaning from sedation



Outcomes from ACQ

- Parents who used the Autism Care Questionnaire reported a better hospital experienced and staff attention to their child's ASD-specific needs (Broder-Fingert et al., 2016)



Family Feedback

“We were treated with respect.”

“The attending this morning said ‘I’m glad you came.’ So many times we’ve felt that they [other hospitals] didn’t want us there - this was the first time someone ever said that to us - many people think that would be a little thing, but it’s not so little.”

“The doctors spoke without being in a hurry to get out. They were receptive to hearing what I had to say. It was one of the few times I’ve ever had a chance to have an MD hear me and be open to what I had to say...”



Physician Feedback

“Our entire service would look so different to us and to our patients if we had people in your role for other conditions, as well.”



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USING THE EHR



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Autism Add-on Order Set for Pеди and Adult

Autism Add On Orders Pediatric/Adult Manage My Version

General Collapse

- Nursing Orders
 - Autism Care Questionnaire
Routine, Please complete or update the Autism Care Questionnaire with the family, which can be found in the More Activities navigator section
 - Non Violent/Non Self Destructive Restraints
 - Single Room / Cot for Parents
 - Seizure precautions
Routine, Railing pads
 - Floor Pads
Routine
 - Minimize Vital Signs
Routine
 - Fall precautions
Routine
 - On Unit Safety Orders
Routine

Consults Collapse

- Autism Consults (Adult)
 - Speech Language Pathology Consultation and Treatment
Once First occurrence Today at 1143
Reason for SLP consult order? Language/Communication
Relevant history to consult? Patient with Autism
 - Occupational Therapy Consultation and Treatment
Once First occurrence Today at 1143
Reason for OT? Other
If help needed regarding: communication, mobility, sensory stimulation / calming materials
 - IP consult to Social Work
If help needed re: guardianship, care coordination regarding: home /community services, support to family
 - IP Consult to Nutrition Services



Best Practice Advisory

Best Practice Advisory interface showing a patient summary for a 4-year-old male with Autism Spectrum Disorder. The 'Orders' section is active, displaying a list of orders and their status. A key advisory message is highlighted in yellow, stating: "Please ensure the patient's Autism Care Questionnaire is completed and correct." Other advisory messages include "Autism Care Questionnaire" and "Allergies".

Autism Care Questionnaire

Allergies



Patient Care Coordination Note

Chart Review

Snapshot Encounters Labs Imaging Cardiology Procedures Other Orders Meds Episodes Letters Notes Referrals Media LDAs Misc Reports

Care Everywhere

PHS Viewer

Care Team Pa...

Review Flow

Results Review

Synopsis

History

Allergies

Problem List

Medications

Immunizations

Demographics

Patient Station

FYI

Growth Chart

Customize

More

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Snapshot with Recent Visits Comp FlowSheet Labs Meds 60 Day Micro Fever Pain Asthma Action Plan More Report Snapshot with Recent Visits

Patient Care Coordination Note

Karen Ann Turner, OT Thu Jun 15, 2017 11:50 AM

Behavior Support Plan

Last Modified: 1/31/17

By: Lauren Cosgrove, OT

M [REDACTED] is a 7 year 8 month old boy who was seen for follow up developmental behavioral pediatrics consultation in the Lurie Center due to history of Disruptive Mood Dysregulation Disorder in context of symptoms related to autism spectrum, AD/ID-combined type, and generalized anxiety. His behaviors have improved since recent hospital stay at Bradley, but is reported to have worse behavior specifically after school on Wed-Fri, suggesting that school supports are inadequate. He is followed by Dr. M [REDACTED] and is getting intensive outpatient supports, but still needs more support to access respite and DDS. He continues to have urinary incontinence, despite ongoing treatment of constipation, and is on DDAMP, and is making some improvement since seeing Urologist Dr. [REDACTED]. Additional supports are needed at school to help him in the areas of social skill development and emotional regulation skills.

- Triggers: Too much talking, overstimulation, discomfort in stomach
Triggering words: Shots, needles, anything to do with enema, the toilet, bowel movement, when Matt "doesn't know what to do next."
- Warning Signs/Signs of Crisis: increased threats of violence, hitting others, restlessness, raising voice, is less likely to use language during crisis, screaming
- Strategies for Calming: Provide space, leave alone, playing video games, playing with stuffed animal
 - Decrease auditory stimuli, puzzles/coloring
 - Mine craft on youtube
 - Soft talk, limited talking
 - underwater relaxation channel on television
 - warm blankets-wrapped tightly
 - noise cancelling headphones
 - can trial weighted lap pad
 - trial calming song
 - trial directing him to "pecs" on visual schedule board to help him understand what is next, allow choices if appropriate



Patient Care Coordination Note

- Communication
 - Strategies: Briefly explain interventions prior to doing them however try to minimize talking. Requires increased time for processing of verbal information. May be helpful to use pictures. First, then works well. Positive reinforcement. May benefit from picture board of daily schedule, will continue to follow
 - Language: English
- Sensory Needs:
 - Movement-Mom reports M [REDACTED] likes movement
 - Deep pressure: has weighted vest and body sock at home (at time of interview Mom she felt like he is more sensitive to touch right now)
- Further recommendations: (established in collaboration with Karen Turner, Patient Navigator from Lurie Center)
 - Offer M [REDACTED] music therapy sessions
 - Offer M [REDACTED] pet therapy sessions when available
 - Offer M [REDACTED] time with child life volunteers to do craft activities or coloring
 - Parents to offer (new) superhero game on Kindle

Other:

- NO Pretzels
- Loves superheroes (Mom reports she prefers discussion re: Batman/the Flash compared to other more inappropriate characters (ie Deadpool))
- Noise cancelling headphones may be helpful
- Mom reports she at times feels she triggers/escalates M [REDACTED] during episodes of aggression. May benefit from Mom being out of room at times if he is triggered.

Toileting strategies for M [REDACTED]: "social story in room"

- M [REDACTED] will benefit from being read a social story as a visual cue and warning that he is expected to sit on the toilet
- Try to have M [REDACTED] have a schedule of when he tries to go to the bathroom
- Examples: after breakfast, after lunch, after dinner
- M [REDACTED] will be expected to sit on toilet for a certain amount of time (this will require ongoing monitoring for how long); initial start time 3 minutes.
- He may benefit from a visual timer/auditory timer
- M [REDACTED] will benefit from a 'reward' after he sits on the toilet
- Recommend prize box of assorted, small items that seems sustainable to keep up for Mom and Dad
- M [REDACTED] will need **outpatient follow up** in his home and school setting with a behavioral therapist as this will require **ongoing monitoring, trial and error over time and**



... including De-Escalation plan

DE-ESCALATION PLAN:

If pt is in his ROOM:

- Back away and give him space as soon as he begins to escalate
- Mom will give space/leave the room
- Security - call to be present on standby (out of view from pt but present if he continues to escalate)
- Minimize talking to pt until he begins to settle (communication abilities deteriorate), if you must talk, only 1 person should speak to pt
- Allow him to yell (even if profane) and bang his head against pillow
- Once begins to settle, try distraction with an activity vs. asking him questions
- PRN medication

If pt is in HALLWAY/PLAYROOM

- Call security
- Encourage pt to return to his room to his 'safe space'
- Only physically intervene if pt is affecting the safety of other patients (attempting to enter another patient's room) before security is present
- PRN medication

Activities for Calming/Settling:

- Safe space (net bed being ordered for trial)
- Playing video games, playing with stuffed animal
- Coloring
- Mine craft on youtube

Deadpool:

It is OK for patient to talk /do activity about Deadpool. Trying to redirect from Deadpool has triggered agitation. Mom has given OK.



ONGOING INITIATIVES AND AREAS OF INNOVATION



Current Initiatives

- Boston Children's Hospital has a team of child life specialists, resource specialists, and an Autism specialist who provide ASD training for staff throughout the hospital.
- Nemours ER in Florida has a program called REACH that is added to each child's hospital chart and is hung outside their exam room to alert doctors of their diagnosis. The ER also has a separate waiting room that includes: toys, sensory brushes, iPads, headphones, music boxes, and projectors with soothing colors and stars.
- Capital Health ER in New Jersey trains their staff to recognize behaviors that are characteristic of autism, provide a calm setting, and better communicate with patients. The pediatric emergency nurses use iPads to communicate with patients, to get a better sense of their pain, discomfort, fears, and preferences.



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Current Initiatives (continued)

- Royal Manchester Children's Hospital in the UK has developed a resource called "My Traffic Light" that indicates important information that providers need to know about their patients including: allergies, medical issues, eating habits, communication tools, medication, and bathroom usage.
- The National Autistic Society created "My Hospital Passport" which includes information about the patient that providers should be reading before examining them, especially about how they experience pain and triggers.
- Indiana University developed a training manual and DVD called A Guide for Emergency Department Personnel: Assessing and Treating Individuals With Autism. Aims to educate emergency medical personnel on how to assess, communicate with, and treat the autistic patient.



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Autism Friendly Initiative at Boston Medical Center

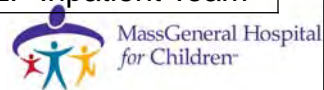
- *“The Autism Friendly Initiative will address systemic change on a hospital wide level including staff training, environmental adaptation, and protocol adjustment to best meet the needs of patients with ASD and their families.”*
- To launch the Autism Friendly Initiative, three key phases have been outlined:
 - Preliminary phase: develop, implement, and evaluate a comprehensive needs assessment to determine best practices and define Boston Medical Center (BMC) as an Autism Friendly hospital.
 - Second phase: implementation of the best practices at 1-year into the project. Grant funding will be used to implement sensory changes, develop resources, and provide comprehensive staff training to best serve our patients.
 - Final phase: develop a certification process that enables one to be Autism Friendly. The vision is for other hospitals to adopt and implement Autism Friendly.



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MGHfC Collaborative Initiatives

Autism Care Questionnaire (ACQ)	Resource Guide for Case Management
Training Videos	Internal Website Resources
3 Designated Inpatient Units	Office Visits for Adults Tip Sheet
Navigator Position Creation	First-Then Handouts for Procedures
Inpatient Admissions Guidelines	Best Practice Alert for ACQ in EMR
Autism Order Sets in EMR	EMR Alert for patients with ASD
Autism FYI Flag in EMR	OT & SLP Inpatient Team



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Patient M

- Manually disimpacted twice during the hospitalization (2 weeks apart)
- Began using the toilet while on an aggressive stool regimen.
- He had an autism care plan created.
- Psych was involved for medication recommendations and an agitation plan was created.
- He responded well to a daily schedule that included music therapy where he was the most expressive and engaged.
- He was then transitioned to Bradley Hospital in RI for continued care



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Patient Experience

- *Video of Patient M dancing*

