

## Supporting Patients with Developmental and Behavioral Challenges in the Healthcare Setting

### *Utilizing the Adaptive Care and Behavior Safety Teams*

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### Learning Objectives:

- Verbalize current evidence-based need for individualizing healthcare for patients with developmental delays, as well as challenging and aggressive behaviors
- Recognize how pre-visit planning and interdisciplinary collaboration - when combined with supportive interventions - lead to increased positive outcomes for patients, families, and the healthcare team



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### Key Educational Points to be Covered:

- Individual needs of patients with developmental delays and challenging and aggressive behaviors in the healthcare setting
- Overview of Adaptive Care and Behavior Safety Team goals, criteria, and services
- Pre-visit planning, interdisciplinary collaboration and supportive intervention techniques leading to increased positive outcomes for patients, families, and the healthcare team



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## Patient Needs & Challenges



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## Developmental & Behavioral Diagnoses:

- Increasing population
- Chronic, lifelong impact
- Numerous diagnoses – Down syndrome, ADHD, sensory processing disorder, intellectual disability, autism spectrum disorder (ASD), etc.
- Each individual is unique



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## Identified Problems Related to Healthcare

- **Patient** concerns
  - Post Traumatic Stress Disorder (PTSD)
  - Canceled appointments, late or inconsistent follow-up
- **Families** judged
- **Staff** have minimal training in developmental disabilities, alternative strategies and protocol adaptation
- **Systems** care delivery not consistently effective
  - Good practices for typically developing (e.g. social interaction)
  - Psychosocial support services varied (e.g. staff allocation)



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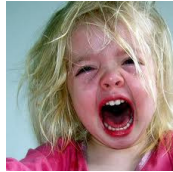
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## Effects of Healthcare

- All patients are at risk for psychological distress from healthcare encounters
  - Short term – regression, behavior changes
  - Long term – nightmares, anxiety, fear of separation, PTSD, phobias
- Patients with ASD and other challenges are at higher risk for psychological distress
  - Unfamiliar routines
  - Transitions
  - Waiting
  - Communication issues
  - Sensory issues
  - High anxiety




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## After a difficult healthcare encounter have you ever thought, "I wish...."

- I knew that "Johnny" was coming in today
- I could have made a plan for this procedure
- "Johnny" had been prepared BEFORE walking in the door
- I knew more about this patient's stressors
- I knew more about this patient's motivators
- I had visual supports for this patient ahead of time
- The unit knew more information about this specific patient
- I knew the patient had special needs




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## Have no fear, support strategies are near!




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## Adaptive Care Team (ACT)



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### ACT History

- Created in 2009
- System to identify patients with special needs when they are accessing healthcare
- Make adaptations/individualize care based on patient-specific needs



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### Adaptive Care Program Criteria

Any patient of Cincinnati Children's Hospital Medical Center who:

1. Has a current diagnosis or is being evaluated for a developmental and/or behavioral condition

**AND**

2. Has a difficult time coping and cooperating during a healthcare visit



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### Adaptive Care Program Goals



- Promote safe, sensitive care for individuals with developmental and behavioral challenges in the healthcare setting.
- Plan care to facilitate less traumatic and more productive healthcare encounters through collaboration with parents and staff.
- Implement personalized preparation, adapted protocols, and special support strategies to improve the experience of care.




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### Adaptive Care Team (ACT) Referrals

- Patients can be referred to the program by healthcare professionals or family members.

– Phone: 513-803-2327 (ADAP)  
 – E-mail: [adaptivecareteam@cchmc.org](mailto:adaptivecareteam@cchmc.org)  
 – Epic In-basket: Send message to the AdaptiveCareTeam Pool




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### Referral Action Steps

- A Child Life Specialist assesses the patient utilizing the Psychosocial Risk Assessment in Pediatrics (PRAP).
- The Child Life Specialist creates an Adaptive Care Plan using informal assessments, chart reviews, and patient/caregiver interviews and places it into EPIC as an FYI.
- A report is triggered to be sent out prior to each visit everywhere patients go throughout the hospital setting.
- A Child Life Specialist creates an individualized plan for specific visit, if necessary.




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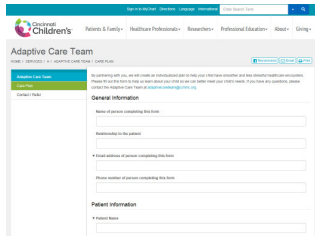
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## ACT Questionnaire for Families

- Link: [www.cincinnatichildrens.org/careplan](http://www.cincinnatichildrens.org/careplan)




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## Psychosocial Risk Assessment in Pediatrics (PRAP)

Level 1: Low Risk (0-7 Points)	Minimal distress is experienced. Patient has coping ability to meet healthcare encounters. Provide general support.
Level 2: Moderate Risk (8-14 Points)	Patient has coping limitations and may exhibit acute distress. Provide psychosocial support and interventions to minimize negative psychological effects. Monitor closely for escalating distress.
Level 3: High Risk (15-24 Points)	Patient has persistent or escalating distress and significant coping limitations. Patient should be a high priority for psychosocial support and intervention. Collaborating with or consulting other disciplines such as Behavioral Medicine is recommended. Anxiolytic medication may be beneficial to help minimize distress and increase the likelihood of a safe, productive encounter.

### Assesses:

- Communication
- Anxiety & Coping During Medical Encounters
- Parent/Caregiver Stress
- Special Needs
- Temperament
- Past Healthcare Encounters
- Invasiveness of Procedure/Encounter
- Developmental Impact




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## Adaptive Care Plan

- Staff & parent recommendations
- PRAP Scores
- Special needs description
- Past healthcare experiences
- Temperament
- Communication
- Sensory information
- Stressors/reactive behaviors
- Pain responses
- Interests/motivators
- Additional considerations




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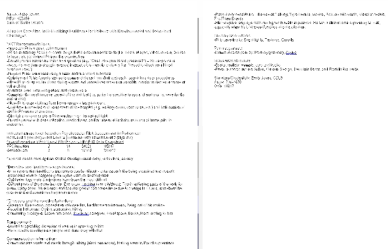
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### Completed Care Plan



**Cincinnati Children's**  
changing the outcome together

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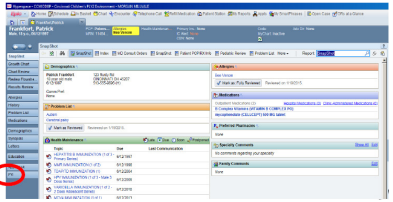
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### Finding Helpful Information – The ACT Flag

1. Open Pt chart
2. Click on **FYI** (upper right hand corner) to view patient specific information, adaptatic recommendations.



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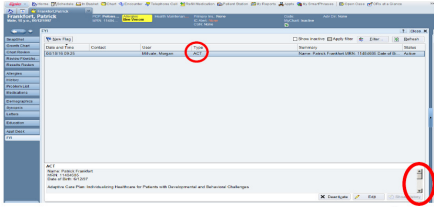
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### Finding Helpful Information – The ACT Flag

3. Open FYI
4. Scroll down for full Adaptive Care Plan



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### ACT Reports

- "FYI" generates reports of appointments/admissions:
  - Outpatient: List of patients tomorrow & list of patients one week from today
  - Inpatient: List of patients currently admitted, list of planned admissions for the following week

Cincinnati Children's			
ADMISSIONS BY THE WEEK: February 22, 2017			
AND SPEECH			
Appointment Time	22:07 - 4:00pm	Room	
Area		Bedside	
Area		Provider	APPT:1-400-401
Appointment	AND SPEECH		
Ref Type	SP/SL/LS		
CURRENT			
Appointment Time	22:07 - 4:00pm	Room	
Area		Bedside	
Area		Provider	LEGAL:3000010
Appointment	CURRENT		
Ref Type	SP/SL/LS		




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### Providers' Role with ACT

- Read the Adaptive Care Plan
- Individualize a plan for the healthcare encounter based on patient's specific needs
- Make ACT referrals for appropriate patients




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### Behavior Safety Team (BST)




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### Behavior Safety Team (BST)

*Our mission is to ensure individuals receive the medical care they need while maintaining their safety and the safety of caregivers and staff.*



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### BST Criteria

Any patient on inpatient unit at Cincinnati Children's Hospital Medical Center who:

- 1. Has a behavioral risk of aggression or self-injury.
- OR**
- 2. Whose behaviors are preventing the patient from getting essential medical care.



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### BST Services

- Primarily provides coverage to inpatient units
- BST is not currently a Rapid Response Team, however continues to follow high-risk ESR patients throughout the medical center, **when appropriate** to ensure the safety of everyone



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### BST vs. ACT

#### BST

- Psychologist, Behavior Specialist and Child Life Specialist may consult
- Assess the patient and determine:
  - Basic supports
  - Comprehensive behavior plan
  - Safety strategies
  - Need for additional consults
- Provide input regarding need for 1:1 staffing
- Behavior plans focus on behavioral intervention, safety and coping strategies
- Staff training in behavioral strategies, de-escalation, and safe management are provided

#### ACT

- Child Life Specialist will assess the patient for vulnerability
- When appropriate an Adaptive Care Plan is created in collaboration with the family
- ACT plans include:
  - Focus on personalized preparation
  - Adapted protocols
  - Special support strategies to improve the experience of care and assist the child cope throughout the medical center
- Refer to BST when patients pose a safety risk




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### What to do for a patient in crisis?

- Patient is currently engaged in behavior that has already or is very likely to result in injury to self or others.
- If BST is actively involved, please contact BST staff. One of the following will occur:
  - BST staff will respond if available.
  - BST will provide guidance by phone on how to approach the situation.
  - BST will prompt to call Protective Services
- If BST is not involved, **call** Protective Services, 6-4204 to activate a **Code Violet** (this is the only rapid response team)




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### New BST Referrals

- BST FYIs in Epic show up as "Potential Security Risk" alerts
- Contact BST if you identify a patient who may benefit from having a BST flag added to the chart
- Please include information on specific triggers and challenging behaviors

**Patient Chart Advisories**  
 Take notice of the following advisories for this patient before you continue.

<small>Name</small>	<small>MRN</small>
<b>Patient has an FYI of type Potential Security Risk</b>	
<small>Patient has escalating behaviors related to medical care, specifically related to any care or procedure that involves needles. Escalated behavior includes kicking, hitting and biting.</small>	




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### Contact Information

**Behavior Safety Team**  
 Call 513-636-4149  
 Pager 513-343-1738  
 Email: [behaviorsafety@cchmc.org](mailto:behaviorsafety@cchmc.org)




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### Individualized Support Strategies




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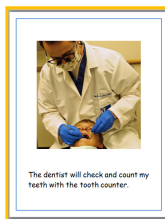
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### Individualized Support May Include:

- Preparation for healthcare experience
  - Focusing on the five senses and any stress points.
- Photo preparation books (social story™)
- Video modeling films
- Homework
- Coping practice
- Desensitization visit




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### Adapting a "typical" visit



- Minimize waiting & transitions
- Consider visual supports
- Staff interaction
- Environmental modifications
- Support sensory needs




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### Minimizing Waiting & Transitions

- Consider pre-registration
- Express patient to an exam room to prevent excess time in waiting area
- Be creative!
- Get caregiver's cell phone number and call them when it is close to the time patient will be seen
- Consider alternative waiting area
  - e.g. Hallway or consultation room
- Use a wheelchair to aid in movement from one area of the hospital to another
- Use visuals and a time to aid in transitions from one task to another




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### Consider Visual Supports

- Can help with understanding of complicated steps or demands of visit.




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### Staff Interactions

- Ask parent/guardian what might improve the experience.
- Use a quiet voice, slow approach, and few words.
- Minimize the number of staff in the room at any given time.
- Be patient. Allow for a slower process.
- Have only one person speak to the patient at a time.
- Don't talk unnecessarily. If it is a stressor, limit verbal and social interaction with a patient.
- Speak directly to the patient. Do not talk about the patient in front of them.




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### Staff Interactions continued

- Always address and explain your actions.
  - Use "Tell, Show, Do" (i.e. Explain what you will be doing, demonstrate on self or parent, then perform on patient)
  - Use "First, Then" (i.e. "First stand on scale, then choose movie.")
- Avoid stressors or complete the most invasive task last (e.g. blood pressure).
- Use protective equipment as recommended (Kevlar, hat, etc.).




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### Environmental Modifications

- Close door/Dim lights (fluorescent light issues)
  - Limit noise & other stimulation
  - Construction, cleaning, nursing desk, etc.
- Move away from stimulating waiting areas
- Limit the number of people
- Remove or cover unnecessary or threatening items




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## Support Sensory Needs

- Allow gradual desensitization to the environment and medical equipment before beginning exam or procedure.
- Be aware of sensory issues (i.e. touch, I.D. bracelet, suction, etc.).
- Minimize touch if the patient has tactile defensiveness.
- Be aware of your proximity to patient & sensitivity to eye contact.
- Facilitate breaks as necessary.



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## Patient Success Stories:



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## Questions?



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## Resources

- Johnson, N., Lashley, J., Stonek, A., & Bonjour, A. (2012). Children with developmental disabilities at a pediatric hospital: Staff education to prevent and managing challenging behaviors. *Journal of Pediatric Nursing, 27*, 742-749.
- Johnson, N., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. *Pediatric Nursing, 39*(3), 131-141.
- Jolly, A. (2015). Handle with care: Top 10 tips a nurse should know before caring for a hospitalized child with autism spectrum disorder. *Pediatric Nursing, 41*(1), 11-22.
- Scarpinato, N., et al. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing, 15*(3), 244-254.
- Souders, M. C., DePaul, D., Freeman, K. G., & Levy, S. E. (2002). Caring for children and adolescents with autism who require challenging procedures. *Pediatric Nursing, 28*(6), 555-562.
- Staab, J., Klayman, G. & Lin, L. (2013). Assessing pediatric patient's risk of distress during health-care encounters: The psychometric properties of the psychosocial risk assessment in pediatrics. *Journal of Child Health Care, 18*(4), 378-387.



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