



**CHOC Children's Hospital**  
*Best Evidence and Recommendations*

**Best Practices for Hospitalized Pediatric Patients with Autism Spectrum Disorder**

Kylie Castro RN, BSN, CPN  
[kmccormick@choc.org](mailto:kmccormick@choc.org)

**PICO:** In hospitalized pediatric patients with autism spectrum disorder, what are the best practices in behavioral support to optimize the delivery of care, increase patient and family satisfaction, and prevent injuries to staff and patients?

**P (Population/problem):** hospitalized pediatric patients with autism spectrum disorder

**I (Intervention/issue):** best practices in behavioral support

**C (Comparison):** no specialized practices

**O (Outcome):** increase patient and family satisfaction and prevent injuries to staff and patients

**Background:**

According to the CDC (2018), one in 59 children in the United States has been diagnosed with autism spectrum disorder (ASD). ASD is a neurodevelopmental disorder characterized by impairments in social interactions, communication, and repetitive behaviors (American Psychiatric Association, 2013). Each child with ASD has a different severity of social and communication impairments. As the prevalence of children with ASD increases, healthcare providers must understand the unique challenges of this population. Children with ASD have increased rates of comorbidities, are more likely to be hospitalized, and have longer lengths of stay than their typically developing peers (Johnson & Rodriguez, 2013). The hospital environment is stressful for all children, but for the child with ASD, the stress can be exacerbated. The hospital environment tends to be loud, fast-paced, and invasive. For children with ASD, this may not create an environment for healing or cooperation to care. Overstimulation of the child with ASD can lead to behavioral outbursts, which can create difficulty in providing care, administration of sedating medications, or use of physical restraints. There is often a stigma associated with the diagnosis of ASD. Patients are often perceived as dangerous and challenging to provide medical care for. This project aimed to identify best practices in creating a healing environment to optimize care for patients with ASD and their families in an acute care setting.

There is a wealth of information regarding caring for patients with ASD in the perioperative and emergency room environments. However, there is little research on how to care for children during inpatient hospitalization. The acute care setting area provides a specific challenge when caring for patients with ASD because they are not in a familiar environment for an extended period, they encounter many new people, and it is difficult to maintain their typical schedule.



The added stress of hospital admission can be challenging for the patient and the family and may inhibit family-centered care (Johnson & Rodriguez, 2013). Many children with ASD exhibit stress or frustration through “challenging behaviors.” Challenging behaviors include non-compliance, hyperactivity, sensory defensiveness, and self-injurious behaviors (Johnson & Rodriguez, 2013). By partnering with the parents, the healthcare provider can learn the patient’s different social, communication, and emotional needs to improve care for the patient and family and decrease the frequency of challenging behaviors.

Currently, at CHOC, there is no formal way to prompt healthcare providers to get a better understanding of the patient’s needs. Many times, when a child with ASD is admitted to the Neuroscience Unit and has known aggressive behaviors and a diagnosis of autism, the patient is given medications to sedate them or put in physical restraints to allow for procedures to be completed. The tests are often unsuccessful because the patient does not tolerate the over-stimulation of the procedures or the over-stimulation of the new environment and adds staff. Inquiring with the parents about what techniques work best to allow the patient to cooperate in tasks or invasive procedures is left up to the nurse. However, there is no formal way of partnering with the family to provide a comfortable, thriving environment for the patient. There is little formal education on how to care for a child with ASD. This evidence-based practice project aimed to determine the best practices to help provide medical professionals with the best ability to provide high-quality care for patients diagnosed with ASD.

### **Search Strategies and Databases Reviewed:**

- Databases searched for this review included CINAHL and Pub Med. Key search words: autism, autism spectrum disorder, inpatient, individualized care plan. This search yielded seven articles- two articles discuss care for the patient with ASD in the inpatient setting, and the remaining five were focused on the peri-operative or emergency departments.
- Websites reviewed included Google Scholar and Autism Speaks.

### **Synthesis of Evidence:**

- Broder-Fingert et al. (2016) developed an autism-specific care plan to help improve the hospital experience for these patients and families. Through a retrospective chart review, the authors determined that “the majority of parents (88%) reported that the Autism Care Plan (ACP) “definitely” improved their hospital experience” (p. 201). No length of stay or safety-reported events changed when comparing the ACP group and the control group. They learned they did not properly train the nursing staff on the care plan, though nurses were most likely to use the tool. They could not correlate the effectiveness of the care plan when related to the patient’s severity of ASD diagnosis.
- McGuire et al. (2016) developed a multidisciplinary workgroup in partnership with Autism Speaks and The Autism Intervention and Research Network to develop a practice pathway to help PCPs evaluate and treat irritable and problem behaviors.



- Johnson & Rodriguez (2013) stressed the importance of partnering with parents or caregivers. Creating a family-centered care environment is very important to provide the best care for patients with ASD because their family knows their needs and how to provide that care best. Parents are often important to providing care because they are familiar with the patient and have created that trusting relationship.
- Scarpinato et al. (2018) discussed the importance of continuity of care in this population. Things like having the same nurse, using the same methods of communication, and simply creating a reliable environment for the patient.
- Placing signs outside the door to alert staff to the child’s sensory needs and to create a quiet environment was identified as an effective strategy (Scarpinato et al., 2018).
- No information on staff education was found in the research. However, Boston Medical Center is currently working on a research study to determine the most effective educational method for healthcare providers to use the autism care plan.

Children diagnosed with autism typically express challenging, aggressive behaviors when they cannot communicate their needs and wants or are overstimulated (Table 1). The purpose of the care plan is to create an environment that will minimize overstimulation and triggering behaviors for these patients, ultimately increasing patient and family satisfaction and safety for staff and family.

<b>Challenging Behavior</b>	<b>Description</b>	<b>Strategies to improve care</b>
Non-compliance	The emotional outburst, temper tantrums, or behavioral outbursts when asked to comply with instructions	<ul style="list-style-type: none"> <li>• Calm, concrete language</li> <li>• Communication with pictures or a visual schedule</li> <li>• Be patient, reduce the number of commands, use gentle praise, positive reinforcement, and distraction</li> <li>• Decrease stimulation: cluster cares, close the door, spot check vitals</li> <li>• Do not break rituals</li> </ul>
Hyperactivity	Impulsive, may run, or constantly be getting into something in the room	<ul style="list-style-type: none"> <li>• Plan for physical activity during the day</li> <li>• Pharmacology treatments</li> </ul>
Sensory Defensiveness	Aversion to certain environmental elements (sounds, textures, and odors). They may use self-stimulating behaviors to comfort them.	<ul style="list-style-type: none"> <li>• Do not interrupt self-stimulation behaviors</li> <li>• Consistent caregivers, distraction, parental presence, and planning ahead</li> <li>• Alert the child to change</li> <li>• Ask permission to perform tasks</li> </ul>
Self-injury	Pinching, head banging, biting, self-induced vomiting. Result of	<ul style="list-style-type: none"> <li>• Increased communication</li> <li>• Pause to allow the child to answer</li> </ul>



	difficulty in communicating needs or wants.	
--	---	--

Information from: Johnson, J.L., & Rodriguez, D. (2013)

Employ best practices to create an environment and engage in relationships that support the needs of a patient with ASD. See Table 2.

<b>Table 2: Recommendations for Best Practices for Caring for patients with ASD</b>	
Environment	<ul style="list-style-type: none"> <li>• Bring in items from the home to create a familiar environment</li> <li>• Low stimulation, quiet environment</li> <li>• Remove equipment that is not necessary</li> <li>• Allow the patient to touch or see all equipment used for procedures when possible.</li> <li>• Spot check or turn alarms in the room to silent</li> </ul>
Schedule	<ul style="list-style-type: none"> <li>• Benefit from having a reliable daily schedule</li> <li>• Keep meals and bedtimes the same as at home</li> <li>• Visual schedule</li> <li>• Attempt to keep the patient's bedtime/sleep routine</li> <li>• Preadmission visits when possible and orientation to the unit with child life and nurses</li> <li>• Provide step-by-step instructions when possible</li> </ul>
Partnering with Family	<ul style="list-style-type: none"> <li>• Parents and caregivers know the patient the best and what strategies work best to increase compliance for the patient and decrease challenging behaviors.</li> <li>• Determine successful strategies used in other settings</li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Primary nurses help build trust and a familiar relationship</li> <li>• Clear, direct, simple sentences</li> <li>• No sarcasm</li> <li>• Discuss effective communication techniques</li> <li>• Speak directly to the child to hold their focus</li> <li>• Use pictures, sign language, word processing, texting, and modeling to communicate</li> <li>• Use positive reinforcement</li> </ul>
Sensory	<ul style="list-style-type: none"> <li>• Set monitors to silent, or remove them when possible</li> <li>• Cluster care and attempt to minimize medical interventions</li> <li>• Reduce the number of commands, cluster cares</li> </ul>
Stereotyped Behaviors	<ul style="list-style-type: none"> <li>• Not being able to complete rituals or have control over the situation can trigger challenging behaviors</li> <li>• Do not interrupt</li> <li>• Comply when asked to complete a ritual task</li> <li>• Allow for adequate time to prepare the patient for a procedure</li> </ul>

Information from: Johnson & Rodriguez, 2013; Scarpinato, Bradley, Kurbjun, Bateman, Holtzer & Ely, 2018



- Patients with ASD have different needs and challenges, which creates difficulty in studying this population because each individual is different.
  - According to Johnson & Rodriguez (2013), there is a low level of evidence in understanding how to care for patients with ASD in the hospital, which means there is a lack of standardized care tailored to these patients' needs.
  - Scarpinato, Bradley, Kurbjun, Bateman, Holtzer & Ely (2010) found that children with ASD have other medical comorbidities, including seizures, sleep disturbances, gastrointestinal disorders, and psychiatric disorders. When doing a chart review that covered 18 months, it was noted that 36% of patients admitted to the hospital had an admission reason of epilepsy/seizures or other neurologic disorders.
  - Since patients with ASD can experience added challenges during a hospital admission, nursing staff must partner with parents and caregivers to better understand what strategies work best at home and in other familiar environments with patients.
- Developing an individualized care plan that addresses the patient's specific needs can increase patient/family satisfaction and improve the experience for staff (Broder-Fingert et al., 20015).
- Broder-Fingert et al. (2015) found that when they implemented an Autism Care Plan (ACP), family satisfaction scores increased, families felt listened to, and families felt that staff aided in dealing with their child's fear or stress. By filling out something like the ACP, families may increase their engagement in hospital stays, and it may help prepare them for what to expect.

### **Practice Recommendations:**

- Implement an individualized care plan for patients with ASD that the parents fill out. Include the care plan as a permanent part of the child's electronic medical record.
- Partner with parents to create an environment in the health care setting that is specific to their child's needs.
  - Provide child, family, and healthcare providers with supplies to provide the individualized care identified on the care plan (e.g., Sticker charts, daily schedules, picture stories).
- Have a specific, non-descriptive sign outside the patient's room to alert health care personnel to children with an individualized care plan.
- Next Steps for CHOC:
  - Partner with the Autism Center to develop an individualized care plan for patients with ASD.
  - Collaborate with the information services department to create a pathway for the care plan to be implemented into the patient's electronic medical record.
  - Provide access to parents or caregivers of children with ASD to a secure portal to complete the questionnaire.



- Educate healthcare providers on how to use and be successful with the individualized care plan.
- Evaluate the effectiveness of the individualized care plans on patient and family satisfaction and prevent injuries to staff and patients.

### **Acknowledgements:**

- The Evidence-Based Scholars Program was supported by a grant from the Walden W. and Jean Young Shaw Foundation
- Jennifer Hayakawa, DNP, PCNS-BC, CNRN, CCRN, Nurse Scientist, CHOC Children's.
- Vicky R. Bowden, DNSc, RN, Azusa Pacific University, CHOC Children's Hospital EBP Scholars Mentor.

### **References:**

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.
- Balakas, K., Gallaher, C., & Tilley, C. (2015). Optimizing perioperative care for children and adolescents with challenging behaviors. *The American Journal of Maternal/Child Nursing, 40*(3), 153-159.
- Bonis, S. A. (2018). *Autism Spectrum Disorder: A Quick Reference Guide for Pediatric Nurses*. Milwaukee, WI. Society of Pediatric Nurses.
- Broder-Fingert, S., Shui, A., Ferrone, C., Iannuzzi, D., Cheng, E., Giauque, A., Connors, S.,...Kuhlthau, K. (2016). A pilot study of autism-spectrum care plans during hospital admission. *Pediatrics, 137*(2), 196-204.
- Brown, A. & Elder, J. (2014). Communication in autism spectrum disorder: A guide for pediatric nurses. *Pediatric Nursing, 40*(5), 219–225.
- Davignon, M., Friedlaender, E., Cronholm, P., Paciotti, B. & Levy, S. (2014). Parent and provider perspectives on procedural care for children with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 35*(3), 207-215.
- Gettis, M., Wittling K., Palumbo-Dufur, J., McClain, A., & Riley, L. (2018). Identifying best practice for healthcare providers caring for autistic children perioperatively. *Worldviews on Evidence-Based Nursing, 15*(2), 127-129.
- Johnson, J.L., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. *Pediatric Nursing, 39*(3), 131-141.



McGuire, K., Fung, L., Hagopian, L., Vasa, R., Mahajan, R., Bernal, P., Silberman, A.,... Whitaker, A. (2016). Irritability and problem behavior in autism spectrum disorder: A practice pathway for pediatric primary care. *Pediatrics*, *137*(s2), 136-148.

Nicholas, D., Zwaigenbaum, L., Muskat, B., Craig, W., Newton, A., Cohen-Silver, J., Sharon, R.,... Kilmer, C. (2016) Toward practice advancement in emergency care for children with autism spectrum disorder. *Pediatrics*, *137*(s2), 206-211.

Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2018). Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing*, *15*(3), 244-254.