



## **Service Delivery Innovation Profile**

# **Comprehensive Program to Support Patients and Staff Improves Hospital Experience for Adult Patients With Intellectual and Developmental Disabilities**

### ***Summary***

Rush University Medical Center developed a comprehensive set of strategies for patients and staff designed to improve the hospital experience for adult patients with intellectual and developmental disabilities. Led by a multidisciplinary staff committee, the program provides patients, their families, and caregivers with prehospitalization tours, a telephone “helpline” to request special accommodations, procedure-specific informational booklets, participation in a buddy program, and a collection of multisensory materials for relaxation and distraction. The program supports nurses and other staff in serving these patients more effectively by offering additional information on the nursing admission form about patient needs and preferences, a consultation service, and ongoing training and education. The specific nursing standard of care used for patients with intellectual and developmental disability is accessible through the electronic medical record. Although the program has not been formally evaluated, feedback from patients, family members, and staff suggest that it has improved the hospital experience for adult patients with intellectual and developmental disabilities, and enhanced staff’s understanding of and ability to communicate with and effectively serve these patients.

### ***Problem Addressed***

**Adult patients with intellectual and developmental disabilities face unique challenges when receiving care in a hospital. Many providers lack the training and resources needed to calm these patients, communicate effectively with them, assist them in coping with hospitalization, and coordinate their care, leading to longer patient stays.**

- **Negative hospital experiences:** Hospitalizations can be confusing and frightening for adult patients with intellectual and developmental disabilities; many report feeling vulnerable, fearful of encountering unfamiliar people and procedures, and unsure of how to communicate needs and preferences to hospital staff.<sup>1,2,3</sup> These feelings may lead patients to display an unwillingness to cooperate with medical care, which can compromise patient care and safety.

- **Inadequately prepared providers:** Although frontline hospital staff across many departments serve patients with intellectual and developmental disabilities, many lack the knowledge and training to effectively address their needs.<sup>1,3</sup> At Rush University Medical Center, a hospital-wide staff survey found that 30 percent of respondents reported at least weekly contact with adult patients with intellectual and developmental disabilities; however, many staff reported feeling ill prepared to communicate with these patients about hospital procedures, pain levels, and care plans.
- **Longer hospital stays:** Patients with intellectual and developmental disabilities often face longer hospital stays than do other patients, including those with other types of disabilities.<sup>1,4</sup>

**Sarah Ailey, PhD, RNC**

Rush University  
College of Nursing, Community and Mental Health Nursing  
600 South Paulina  
1080 Armour Academic Center  
Chicago IL 60612  
(312) 942-3383  
E-mail: [Sarah\\_H\\_Ailey@rush.edu](mailto:Sarah_H_Ailey@rush.edu)

**Robyn Hart, MEd**

Rush University Medical Center  
Director, Child Life Services  
1653 W. Congress Parkway, 559 Jones  
Chicago, IL 60612  
(312) 942-7842  
E-mail: [robyn\\_hart@rush.edu](mailto:robyn_hart@rush.edu)

**Footnotes**

<sup>1</sup> Sowney M, Barr OG. Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. J Adv Nurs. 2006;55(1):36-45. [\[PubMed\]](#)

<sup>4</sup> Walsh KK, Kastner T, Criscione T. Characteristics of hospitalizations for people with developmental disabilities: utilization, costs, and impact of care coordination. Am J Ment Retard. 1997;101(5):505-20. [\[PubMed\]](#)