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Improving hospital care of patients with intellectual and developmental disabilities

Sarah H. Ailey [a, *], Paula J. Brown [b], Caitlin M. Ridge [c]

[a] Rush University Medical Center College of Nursing, United States
[b] Rush University Medical Center Office for Equal Opportunity, United States
[c] Saint Barnabas Medical Center, RWJBarnabas Health, United States

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ABSTRACT

People with intellectual disabilities and developmental disabilities (IDD) face poorer care and outcomes when hospitalized than patients without IDD. A panel discussion *Hospital care for individuals with IDD: The Issues and Challenges* was held at the Annual Conference of the American Academy of Developmental Medicine and Dentistry, held in Chicago July 8–10, 2016. Among the panelists were representatives from Rush University Medical Center in Chicago, IL and Saint Barnabas Medical Center in Livingston, NJ who discussed efforts to improve hospital care of patients with IDD at their institutions. Systemic changes are needed to improve care, however, programs that target improving care for patients with IDD are possible within current systems and with current staff who are empowered to make changes that improve the quality of care.

At the Annual Conference of the American Academy of Developmental Medicine and Dentistry, a panel discussion was held on *Hospital care for individuals with IDD: The Issues and Challenges*. In opening the discussion, it was noted that individuals with intellectual and developmental disabilities (IDD) have poorer outcomes during hospital admissions than persons without IDD across countries and types of healthcare systems.[17] More likely to be hospitalized for ambulatory sensitive conditions, they are more likely to have ICU days and complications than individuals without IDD hospitalized for the same reasons.[5] The Joint Commission (TJC) notes, in its white paper *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals,* that the quality of care in hospitals differs by patient characteristics, including disability.[16] Barriers to quality care for individuals with IDD include delays in treatment and diagnosis, poor following of basic care standards, inconsistent staff communication practices, inadequate staff education, and systematic flaws such as inadequate coordination of care, and inadequate information systems and systems to manage patients with complex needs.[7,11,17,21]

The Institute of Medicine *Crossing the Quality Chasm* report, highlighting the need for redesign of the healthcare system, was discussed, centering on the need for change at three levels, the environmental level (interface of laws, systems, policies, funding), the health care organization level (including how units of care delivery provide care and how organizations support care delivery) and the interface between clinicians and patients.[22] Recommended policy and system changes include laws that improve insurance coverage and access to care for individuals with IDD; improved funding and organization for managing complex care needs that many individuals with IDD have; improved funding and organization for coordinating and integrating care between individuals with IDD and family caregivers, community providers, health care providers and healthcare organizations; and improved training of health care providers.[14,19] While pushing for policy changes at the environmental level, changes can be made at the organizational level and the level of interface between clinicians and patients that improve care.

Most hospital staff will have at least some experience in caring for patients with IDD and some will have frequent experience, particularly in areas such as the Emergency Department, neurology, and ICUs.[3,5,6] Representatives from two hospital systems, Rush University Medical Center in Chicago, Illinois and St. Barnabas Medical Center in Livingston, New Jersey discussed efforts in their institutions to improve care of patients with IDD.

* Corresponding author. Department of Community, Systems and Mental Health Nursing, Rush University Medical Center, 600 S. Paulina #1080, Chicago, IL 60612, United States.
E-mail address: Sarah_H_Ailey@rush.edu (S.H. Ailey).

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Both speakers related efforts to improve care of patients with IDD at their institutions to characteristics of high-performing health care organizations such as the commitment of senior leadership to quality improvement, empowering people to act, standardization of best practices, and commitment to communication across the organization.[13,18] They spoke of efforts to make changes at the organizational level in order to improve care delivery and to improve the interface between clinicians and patients.

1. Rush University Medical Center

Rush University Medical Center (RUMC) is a not-for-profit, 664-bed academic medical center in Chicago. RUMC is consistently ranked among the nation's top hospitals in *U.S. News & World Report*.[9] The hospital includes a new *Tower,* which opened in 2012. The *Tower* incorporates universal design, making it accessible to patients, family and community members, and employees with disabilities. Design of the *Tower* was driven by considerations of the optimal environment for providing the highest quality of care. Recognizing the need for communication and input, nurses and doctors drove early planning with early and continued input from patients.[25]

1.1. Cultural environment of care

Paula Brown spoke of efforts at RUMC to transform the culture at the organizational level toward one of cultural humility. She noted that creating a culture of humility affords everyone the opportunity to be seen as a person of value, including persons with disabilities. Since 1974, RUMC has had policies on equal opportunity that include 14 protected classes of people, in order to make sure that everyone is afforded the opportunity of being included. Disability as defined by Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, is one of those protected classes.

In 2007, RUMC expanded its efforts to create a more inclusive environment by creating a Diversity Leadership Council, which serves as an oversight committee on equal opportunity efforts.[12] RUMC empowers staff to learn about people with disabilities in a manner that encourages the inclusion of this population in all areas of our medical center and university.

RUMC celebrates people with disabilities annually through the Thonar Award Program, which honors a person(s) who encourage(s) and/or advocate(s) for people with disabilities to turn their disability into a possibility.[26] Honorees have included employees, students, and volunteers. An Occupational Therapy (OT) student at Rush University, who was a quadruple amputee when she entered the OT program, was the 2010 awardee.[27] Four volunteers with disabilities who provide an educational program for first year medical students were the 2016 honorees.[28]

We understand that changing the culture of RUMC begins with our students, who will be our future clinicians and leaders. We know that once students have learned with, been taught by, and interacted with people with disabilities, that they will be more competent clinicians and leaders, who will approach every new interaction being intentionally more culturally humble, which will lead to better outcomes and reinforce our ICARE values mentioned earlier. Rush University also is successful in graduating students with disabilities and anticipates an increase in the number of students with disabilities entering health professional programs at Rush University. A student disability services manager has been hired.

1.2. Change at the organizational level

The Rush ADA Task Force was created in 1991, with the support and participation of senior leadership, to enable the RUMC community to be consistent champions for people with disabilities. For 25 years, the ADA Task Force has led efforts such as continued implementation of accessibility audit recommendations, adjustable mammography tables, Hoyer lifts, and other special equipment to improve accessibility to health services, electric doors at major entrances and other high use locations, more parking spaces for people with disabilities, and parking garage modifications to improve accessibility, reduced-rate valet parking for patients and visitors with disabilities, increasing number of fully accessible restrooms, teletypewriters (TTY) in key locations throughout the Medical Center and Rush University, and other efforts.[26]

The ADA Task Force has led efforts to improve the employment of people with disabilities at the medical center, by hiring a Human Resources recruiter solely dedicated to hiring people with disabilities and veterans. In 2016, The Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities,[1] in a final report to the United States Secretary of Labor, the US Senate Committee on Health, Education, Labor and Pensions, and the United States House of Representatives Committee on Education and the Workforce, noted efforts by RUMC to hire a diverse workforce, including people with disabilities. Through the PACE program, RUMC brings interns with IDD to the medical center for employment training[23,32]; and now has more requests for interns than interns to fill the spots.

1.3. Change in interface between clinicians and patients

Following a 2007 Town Hall meeting with the CEO of RUMC when employees expressed concerns regarding their own training in caring for managing patients with IDD, specific efforts are made to improve the care of people with IDD.[4] The efforts include the development of specific care plan in the electronic medical system and an educational module for staff on the care plan. Close to 300 staff have completed the module and the module is now being assigned as mandatory for staff on selected units.[15] A Joint Commission style mock tracer to follow patients with IDD through the hospital was developed and implemented at RUMC and Rush Oak Park Hospital, another hospital in the Rush system[2,3] An article in *ACP Hospitalist,* a journal of the American College of Physicians called Rush's programs the “gold standard” in hospital care of persons with IDD.[10]

As noted, education of first year medical students on caring for people with disabilities exists for the past 15 years. Policies at RUMC make sign language interpretation services readily available for patients, as other language interpretation services. RUMC was one of only a few medical centers nationally to adopt policies for service animals to be in the hospital. An annual review of patients' comments that refer to disability or accessibility in any way is done to make sure that if issues come up, that they are addressed.

2. Saint Barnabas Medical Center

Saint Barnabas Medical Center (St. Barnabus) is a non-profit hospital located in Livingston, New Jersey. Saint Barnabas is part of RWJBarnabas Health, New Jersey's largest integrated health care delivery system. RWJBarnabas Health is among The Joint Commission Top Performers for national quality measures and is among Becker's Hospital Review[8] *150 Great Places to Work in Healthcare.*

2.1. Cultural environment of care

Caitlin Ridge spoke about creating a sensory friendly initiative within the emergency department, the development of the Special Needs Ambassador Program (SNAP) at St. Barnabas Hospital[31] and

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