

**LI Patient Safety Advisory Council
February 2012**

Patient Safety and the Intellectually and Developmentally Challenged Child

Patient safety advocacy is an essential part of improving healthcare outcomes. Too often the most vulnerable patients are without advocates. Patients with IDD (Intellectually and Developmentally Disabled) are in a much more precarious position than most due to their disability. Many patients with IDD cannot communicate with medical staff about their symptoms or pain. It is also difficult for them to comprehend their condition, treatment, or care.

Arlene Reith is a dedicated patient safety advocate who personally understands the difficulties that individuals and families dealing with IDD face. Two of Arlene's children were diagnosed with both Down syndrome and autism. One of those children, Gabriel, suffered from leukemia. During his treatment, Gabriel struggled to communicate. His sensitivity to texture, movements, and loud sounds made hospitalization a frightening experience. He became aggressive, yelled, threw food, and ripped a port out of his chest. Gabriel eventually succumbed to a sepsis infection. This experience motivated Arlene to become an advocate. She is now parent family advocate at Stony Brook University Hospital, a patient safety advocate with PULSE of New York, and a member of the Long Island Patient Safety Advisory Council.

Arlene is passionate about providing a voice to patients with IDD. IDD centered advocacy is now more important than ever as 800,000 children with autism will enter adulthood in next 10 years. There is currently a shortage of medical professionals with in depth knowledge of the specialized needs of IDD patients and many families do not know how to advocate on behalf of their loved ones. Many healthcare staff members do not know how to handle patients with sensitivity issues like Gabriel's. This puts both medical professionals and patients at risk for error. The Joint Commission has launched a campaign to encourage patients to become active participants in their own care. Patients with IDD cannot advocate for themselves and thus the responsibility falls on those who provide care to fill that role. Arlene reminds us that in order to educate, we will need to communicate and when we can communicate, we can advocate.

Recommendations: Develop ways to create a *safer environment* during hospitalization for patients with intellectual or developmental disabilities (ID/DD). This plan will be developed by families and advocates in partnership with hospital leaders, medical providers and clinical staff.

History: Health care disparities faced by individuals with (ID/DD) are on the rise due to:

Increased numbers of children diagnosed with *autism*.

Improved medical and assistive technologies that have increased life expectancies of people with ID/DD and enabled even those with complex medical conditions to reach adulthood and old age.⁽¹⁾

However, there is shortage of qualified, trained health care professionals with in-depth knowledge of the specialized health and mental health care needs of ID/DD individuals.⁽²⁾

Objective: Enhance the knowledge of health care providers and staff members to improve the quality of care for patients with ID/DD.

Promote Family Centered Care for patients with ID/DD. From a parent/family perspective, advise hospital and medical center administration, health care providers and clinical staff about the needs of patients with ID/DD. Educate and empower parents and families about their role in their children's (or family members') care thus creating a Patient Safety environment for all.

Process: Gather input from community and medical professionals to develop a program to educate hospital health care providers, clinical staff, and administration about the special needs of patients with ID/DD (directly related to Patient Safety). Design workshops that feature speakers on topics such as:

Applied Behavioral Analysis (ABA) associated with *autism*.

What is a Dysfunctional Sensory System?

Oral Hygiene and the ID/DD patient and how it is connected with infection (sepsis) during long-term hospitalization.

In-Service meetings with parents as educators and staff:

Parents/family members and caregivers provide health care providers with particular strategies and effective interventions when caring for children or adults with *ID/DD*.

Provide emotional support, resources and strength for parents/families when loved ones with ID/DD are hospitalized or treated in intensive care for chronic illnesses.

Enhance parents/families' confidence to help care for loved ones cope with illnesses.

Educate and empower parents/families about their role in patient care.

(1) <http://www.arcmass.org/ArcMassHome/WhoWeAre/ServicesatTheArc/HealthCareProject/HealthCareProjectReport2009/tabid/848/Default.aspx>

(2) <http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=mretard>

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