

If Only There was Healing After Harm



Almost 27 years ago I eagerly anticipated the birth of my third child. Like my other two pregnancies, this one had been difficult. I had been on bedrest since the fourth month. Now, after being induced, I looked forward to finally having my baby to hold. But it didn't work out that way.

The induction was mishandled. I was given increasing amounts of Pitocin, a hormone meant to cause contractions. As I writhed in pain, the nurses alleged I wasn't having contractions at all because they didn't see them on the monitor. Three attempts to start an epidural failed.

After hours of extreme pain, the Resident decided to break my waters and insert an internal monitor. At that point the contractions were so hard they were off the chart on the monitor. The nurses who had been telling me I was exaggerating my pain level ran in and turned off the Pitocin drip.

I measured just five centimeters dilated. The nurses told me I had hours of labor to go. Twenty minutes later I pushed out a baby. My blood pressure was dangerously high. No one ever even said, "Sorry that was hard."

My baby had to be resuscitated. Skyler (previously known as Kirsten) had a hard time breathing and had low Apgar scores. Nonetheless, the baby was taken to the regular newborn nursery. Two hours later, I was wheeled in to meet my new little person.

A Resident Physician trying to feed my baby casually turned to me and said, "So do clefts run in your family?" I dissolved into tears at the news of a cleft palate. Then a nurse, just starting her shift, scooped my little five-pound baby up saying, "She has never pinked up." The nurse ran with my new baby to the Newborn Intensive Care Unit. There, the baby was diagnosed as having a severe birth defect called Pierre Robin Sequence (PRS). Basically, she needed help breathing, eventually a tracheotomy, and she couldn't swallow, needing to be tube fed.

No one disclosed the two hours that my child spent without support, struggling to breathe. At least not until sixteen years later when I introduced myself to the Nurse Educators from the Labor and Delivery Unit at that hospital. We were at a dinner and offering introductions. I said my baby had been born sixteen years earlier with PRS and they wouldn't remember me. They said, "Oh we remember you. It's because of **you** we train annually on difficult airways."

Our Pediatrician often said that the complications my kiddo faced didn't necessarily come from PRS. Neither he nor I was told at the time about the two hours my baby spent hypoxic. I had to figure it all out later. The challenges we faced included epilepsy, cerebral palsy and neurodevelopmental issues. We had no Communication and Optimal Resolution (CANDOR) or Restorative Practice. If we had, managing the issues we faced and continue to deal with may have been easier.

This month, Mary Ellen Mannix, MS, and Martin Hatlie, JD, will present CAPS Monthly Webinar on Recovery after Medical Harm. Mary Ellen has shared information about Restorative Practice from Pennsylvania to Ireland. Marty has worked with several hospitals and State Hospital Associations on how to implement a CANDOR approach to addressing medical harm. Please join us at Noon Central Time on Thursday, January 16 for this important Webinar. See dial-in information below.

-Lisa Morrise

Webinar Planned:

Mary Ellen Mannix, MEd, MS RP

and

Martin Hatlie, JD

Will Address

Recovery After Medical Harm

Restorative Practice and

CANDOR: Communication and Optimal Resolution

January 16, 2020 – Noon Central Time

Please join my meeting from your computer, tablet or smartphone.

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Webinar Objectives:

1. Attendees will become familiar with Restorative Practice.
2. Attendees will know how they may implement Restorative Practice in their setting whether small or large and regardless of the event.
3. Attendees will understand the CANDOR: Communication and Optimal Resolution process.
4. Attendees will learn how CANDOR may be implemented in their setting.

CAPS AT WORK

CAPS' Consultant Rachel Weissburg, MS, worked from Spring 2019 through last September on developing Guides for each of the CMS HIIN PFE Program Metrics in coordination with the American Institutes of Research (AIR.ORG). Those HIIN PFE Metrics were:

FIVE METRICS FOR PATIENT AND FAMILY ENGAGEMENT



SOURCE: Centers for Medicare and Medicaid Services (2014)

AMERICAN INSTITUTES FOR RESEARCH | AIR.ORG

The Guides for each Metric can be found on the CAPS Website, www.patientsafety.org and are linked below.

PFE Resource Guides

- [Metric-1-508](#)
- [Metric-2-508](#)
- [Metric-3-508](#)
- [Metric-4-508](#)
- [Metric-5-508](#)

We will feature key information from each guide over the next several months. In the first PFE Implementation Guide for Hospitals Metric 1: Preadmission Checklist Planning find the following:

Five Suggested Steps to Implement PFE Metric 1

1. Secure support and buy-in from leaders and hospital staff
2. Create or adapt a draft checklist
3. Pilot the checklist in one unit or department
4. Identify opportunities for improvement and refine the checklist
5. Expand use of the checklist and evaluate for continuous improvement

Be sure to click on the link above for PFE Metric 1 (508 Compliant) to get more in-depth information about how hospitals may implement Preadmission Planning Checklists at the Point of Care. Stay tuned for more information from the PFE Resource Guides, developed for AIR and the CMS HIIN PFE Program.

Consumer Advocacy Panel (CAPS CAP) Interview – Ilene Corina



CAPS: *I took the Long Island Railroad from my son Michael's place in Manhattan to meet Ilene and have a nice, long chat at her local Panera Bread, where her PULSE CPSEA community meets. So, this CAP Interview was a bit different. Ilene has been a highly successful Patient Advocate in Long Island for years, and importantly, has spread her concepts and tips to many other Long Islanders. Ilene has evolved what was known as PULSE of New York into the Pulse Center for Patient Safety Education and Advocacy, or **Pulse CPSEA**.*

When did you start your advocacy?

Ilene: I have three sons, including my Michael who passed away from blood loss after a tonsillectomy in 1990. But that was not what led me into advocacy. It really started with my son, Matt, who had been born at just 23 weeks gestation in 1993. When Matt needed surgery when he was in pre-school, I wanted better information about who would be caring for my son. That's when I started to lobby for physician profiles

in New York. I started speaking to groups and then I started to hear other persons stories about bad outcomes. I wanted to turn those stories into lessons on how things could be done better.

CAPS: How did your advocacy evolve?

Ilene: I started to see a need to help patients and their family members advocate for themselves and how to partner with providers. So much of quality and safety in healthcare is focused on the providers, which is important. We work closely with healthcare professionals to make their job easier and care more accurate. But, it's also important to think about what the patients can do. We had Patient Activation Through Community Conversation. I started to see patterns emerge and we developed education around how to be a more effective patient. We're very fortunate to have had support over the years from the South Nassau Unitarian Universalist Congregation in Freeport on Long Island, NY. I also sought grants and our "Comedy for a Cause" fundraisers to support our education and outreach work. We have had a number of different projects, but all aim to improve a patient's advocacy expertise. Those projects range from helping patients be able to discuss their symptoms in non-emotional, non-exaggerated language to the Twizzler for Hand Washing Campaign, where patients ask providers if they'll wash their hands for a Twizzler. The Twizzler approach helps both patients and providers approach the request with a more congenial attitude.

CAPS: What are you focusing on now?

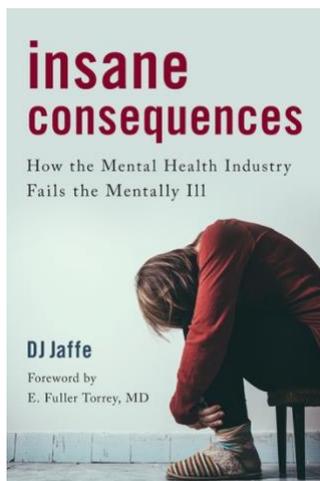
Ilene: We will be launching a new effort in March, called Take Charge Campaign. We will be focusing on five areas and will have a call on January 24 to discuss the planned Campaign.

CAPS: What do you recommend health systems do to improve Quality and Safety?

Ilene: We need to learn how to talk to each other. I used to work for the Post Office. We have our own language in the Postal business. I sometimes ask medical professionals if they know the difference between Certified and Registered Mail. Most people do not. Just like they don't know the ins and outs of mail, patients don't know the languages of healthcare. We can help educate patients and caregivers about common terms. But healthcare professionals can improve Quality and Safety by making sure that their patients and caregivers understand what is being said to them and have the resources necessary to follow through on a healthcare plan.

CAPS: Check out the PULSE Center for Patient Safety Education and Advocacy at www.pulsecenterforpatientsafety.org or email at icorina@pulsecenterforpatientsafety.org.

CAPS Book Club



DJ Jaffe's book, *Insane Consequences: How the Mental Health Industry Fails the Mentally Ill*, is a must-read manual of failed policies that have helped to fill our jails, streets and graveyards with people who live heroically with a serious mental illness. The book provides a scathing rebuke of the fiscal and human waste that the deinstitutionalization movement created by assuming that all mentally ill people could survive in community based voluntary only system of care. He provides a road map of science based public policy solutions that will guide a course correction.

He was recently invited to a White House Mental Health Summit where he shared his insights and bold ideas for reform. DJ Jaffe's book is a call to power, leadership and collective action.

I stumbled upon DJ's work during my early years of advocating in California for people and families struggling with serious mental illnesses. I was a rookie advocate and he was a pro. I friended him and followed him and learned everything I could from him because he was one of the few advocates who was "getting real" about serious mental illness. He was shattering the status quo about the insanity of the system that is killing families like mine.

He is a hero to moms like me because he refuses to settle for a health system that is designed to intentionally harm our children and the sickest among us. He teaches us all to demand radical reform, now.

Teresa Pasquini
December 2019

Teresa Pasquini advocates for reforming and improving the nation's mental health system. As a family member of a son and brother living with serious mental illness, her 45-year personal experience drives her passion. As a nine-year member of the Contra Costa County Mental Health Commission, she was an outspoken champion for all. She's a founding member of the Behavioral Healthcare Partnership at Contra Costa Regional Medical Center, a California safety net hospital. She's a co-founder of Mental Illness FACTS/Right 2 Treatment, a grassroots campaign focused on quality standards and equity in care for serious mental illnesses. She's provided testimony in multiple forums including the Institute of Healthcare Improvement, the National Quality Forum, and an event on Capitol Hill advocating for The Helping Families in Mental Health Crisis Act. The Bay Area Newsgroup recognized Teresa for her local mental health advocacy during 2017's Women's History Month.

Archived Event:

Rachel Wiessburg, MA, CAPS CAP
and

Claudia Ricks Hubbard, MDiv, BCC
Senior Staff Chaplain / Educator

Children's Mercy Hospital Kansas City, Missouri
A Person-Centered Approach to Meaning Making:
Rituals and Celebrations in Health Care Settings

This Webinar is now available at:

[A Person-Centered Approach to Meaning Making](#)

Webinar Objectives:

1. The attendee will understand the importance of providing whole person care and how that alleviates the sense of stress and isolation a person may encounter.
2. The attendee will learn JACHO and Chaplaincy standards for serving the needs of all patients, families and staff with awareness of cultural humility for various traditions.
3. The attendee will learn the importance of connection in meaning making and how staff can support patients, families and other staff.

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Patient Safety
321 N. Clark Street
Suite 545
Chicago, IL 60654
312-445-6477
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