

PULSE of NY, BOCES TAP and Mommas House team up to offer support to young mothers **April 2013**

By David Halperin

Becoming a mother in your teens isn't for the faint-hearted. It's especially difficult for girls who have had few resources, difficult home lives, and little opportunity for education. When they need medical care and advice they may face obstacles ranging from their ignorance of their rights to the mysterious complexity of institutional healthcare. Limited language skills will only add to the difficulty.

These young mothers describe their own reactions to their encounters with the healthcare system as angry, annoyed, embarrassed, nervous, scared, confused, hurting, tired, overwhelmed, stressed, outraged and worried.



Leslie Farrington MD speaks to the students of BOCES TAP about Ask Me 3

What they need is education, and advice on what to expect and how to get the care they need. Under the leadership of the PULSE of NY Patient Safety Advisory Council, two Long Island-based organizations - BOCES TAP and Mommas House - have recently taken steps to provide that. PULSE is a patient safety education and advocacy group, while Mommas House runs homes for young mothers aged 17- 23, and their children. BOCES Tap enables pregnant and parenting teens to continue their high school education and become responsible, competent mothers.

Early in 2012, PULSE conducted two training sessions for a dozen teenaged mothers at BOCES TAP. In late summer, PULSE staff, led by its president Ilene Corina, presented three sessions and follow up sessions of training and education for about 15 young mothers staying at Mommas Houses in Jericho, Hempstead and Glen Cove, NY.

PULSE of NY has been active for years in educating patients and their families about the risks inherent in medical treatment, and in training advocates - whether within or from outside the family - to communicate effectively with healthcare professionals. Often receiving input from leading patient safety experts around the world, PULSE addresses such issues as medication safety, falls and infections, procedures and surgery, preparing for visits to doctor or hospital, patient advocates, healthcare proxies, and effective communication.

One of Mommas House's goals is to help young mothers learn how to support themselves and their children independently. Mommas House encourages professionals in the community to volunteer their time to teach Life Skills to their residents.

PULSE's work with these young mothers is one example of its work with groups of people who have specific needs. These groups have also included the Hispanic community, disabled, transgender, families of dementia patients, and low-literacy adults.

Countering fear, confusion and frustration

In a typical training session, anything up to a dozen young women would be gathered around a table with Ilene Corina and her team, and in some cases a social worker. The small, informal setting encourages participation and sharing of experiences.

Each group had its own concerns, but common themes emerged.

Communication - or the lack of it - with doctors and other healthcare staff led to frustration, annoyance and hostility, with many of the women perceiving a lack of respect in dealing with them on account of their age and status - and in the case of Mommas House, their residence in a shelter. At the same time many said they felt stupid+asking questions of medical staff, and did not know where to turn for help if their doctor was unavailable.



John Bilello, R.Ph. talks about medication safety to the girls of the BOCES TAP program

Many complained about what they felt was the slow and inadequate care they received from local healthcare providers, including misdiagnoses. Many reported that their doctors seemed to hand off their cases to social workers, and others expressed concern that their private details were shared without their consent.

Most participants were not clear about the differences between Healthcare Proxies and living wills, and few knew about advance directives.

Other concerns included the reduced healthcare choices that result from dependence on public transport.

Learning by doing

As well as providing concrete aids - checklists of documents or questions to take to the doctor or hospital, for example - and teaching patients to spot potential safety risks, PULSE's training programs are highly interactive, allowing a lot of productive free discussion and mutual support. But beyond that, two practical techniques highlight its approach: communication exercises and role-plays.

Communication exercises are important because every conversation has two participants: it's just as important for patients to communicate clearly as it is for doctors or nurses. Most of us use lazy language shortcuts that may only confuse. In one such exercise, the young mothers tried using words that don't explain the whole story, and then improving them. They learned that "the baby has been crying all night+isn't as useful to the doctor as, "the

baby has been crying for three hours.+Or that "the pain is killing me,+isn't as helpful as rating it: "On a scale of 1 to 10 the pain is a 10.+"

Role-play too demonstrates, as no lecture could, how conversations with healthcare providers can be clear, cordial and productive, or the exact opposite. In one scenario, the young woman playing the patient learned how to respond to a sentence such as, "you wouldn't understand, we will wait for your mom to come.+"

What next?

The Mommas House training sessions resulted in a concrete set of recommendations for further action. Many of these related specifically to Mommas House, while some would be beneficial anywhere.

- Encourage opportunities for doctor shopping, allowing young mothers to choose a clinician who makes them feel comfortable.
- Make information available about the Medicaid Taxi service.
- Establish a buddy system to choose a peer who can accompany young mothers to the doctor or hospital, to help them understand the treatment plan and ask questions.
- Have each of the young women create her own healthcare notebook: a place for the mother to keep all her and her child's medical information and lists of questions as they come up.
- Staff at local hospitals should be instructed about the unique needs of young mothers.
- Physicians, social workers and hospital staff should learn to be more sensitive to the privacy of the young women living in shelters.
- Information should not be shared with hospital staff without the permission of the young mother.
- PULSE of NY Patient Safety Advocacy information should be presented to all new women upon their arrival at Mommas House, and PULSE of NY is invited to return for yearly visits and updates.

In the years since its inception, PULSE of NY has reached many milestones, (its work with young mothers is just one) and there is much we are proud of. While the organization has grown over the years, we realize that in order to take our organization to the next level we must develop even more effective ways of fulfilling our mission. In addition to building our organizational capacity, we are actively seeking community partnerships to advance our mission. We are developing new programming and are seeking the funding necessary to support our current goals.

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