Continuing Education Module

Transparency in Maternity Care: Empowering Women to Make Educated Choices

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ABSTRACT

The author of this guest editorial calls for a higher level of transparency in maternity care. The public should have access to information about hospital and provider policies and practices so that women and their families can determine where and with whom to birth. Currently, many grassroots-level projects, including The Birth Survey, are addressing this need.

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Transparent: easily seen through or detected; obvious. Free from guile; candid or open.

For too long, medical institutions and practitioners have withheld critical information that would enable the public to make more fully informed health-care decisions. This information includes rates of commonly practiced medical procedures, outcome results such as infection, morbidity and mortality rates, patient satisfaction data, and a sharing of the current medical evidence that informs hospital and physician practices, policies, and protocols.

Fortunately, there is a movement in health care right now toward an increased level of transparency as part of a larger effort to fix what is generally perceived as a broken system. Many organizations and

government agencies are calling for quality improvement measures and are citing transparency as an important step toward this end. In 2001, the Institute of Medicine (IOM) published a report wherein they called for an overhaul of the U.S. medical system and identified transparency as one of the 10 necessary steps to achieve system-wide improvement. The IOM report states:

Health systems must be accountable to the public; to do their work openly; to make their results known to the public and professionals alike; and to build trust through disclosure, even of the system's own problems. . . all information [should] flow freely so that anyone involved in the system, including patients and families, can make the most

informed choices and know at any time whatever facts may be relevant to a patient's decision making. (Committee on Quality Health Care in America, IOM, 2001, p. 79)

In 2006, The White House released an executive order calling for increased transparency in health care. Boiling it down to consumer rights, the order states:

[T]o spend their health care dollars wisely, Americans need to know their options in advance, know the quality of doctors and hospitals in their area, and know what procedures will cost. When Americans buy new cars, they have access to consumer research on safety, reliability, price, and performance—and they should be able to expect the same when they purchase health care. (The White House, 2006, para. 1)

Transparency not only enables informed decision-making, it also creates a greater level of accountability for facilities and practitioners because their policies and, especially in the case of maternity care, their rates of intervention are reviewable by the public. Increased accountability will trigger a direct improvement of the quality of care provided because practitioners will have to justify their practices and will ultimately be encouraged to bring their intervention rates closer to evidence-based, recommended levels. Presumably, this will lead to health care that is safer, cheaper, and more satisfying.

Due to the magnitude of the U.S. health-care crisis, the findings of the IOM report, and the President's executive order, several health-care institutes, universities, and foundations are currently engaged in research or developing projects to increase health-care transparency. Unfortunately, these groups have largely overlooked maternity care, so birth activists and maternity-care organizations have had to take up this urgent issue for themselves. The necessity for transparency in maternity care is the same as for the rest of the medical system and, arguably, is among the areas that most urgently need this change.

In the current maternity-care system, women are experiencing ever increasing rates of obstetric interventions such as induction, episiotomy, and cesarean section, without experiencing better birth outcomes. Meanwhile, ample research affirms that where and with whom a woman births directly affect her risk of experiencing these interventions. In

most communities, intervention rates vary widely between hospitals. Recent studies suggest that obstetric practice, rather than clinical or demographic factors, is the leading cause of this variation (Main et al., 2006). In other words, a healthy, low-risk woman increases her chance of having a cesarean birth if she chooses a facility with a high rate of c-sections. The same applies when choosing a practitioner. If a particular obstetrician has a high episiotomy, induction, or cesarean-section rate, his/her patients run a higher risk of ending up with one of these interventions, regardless of the woman's baseline of health. Since this is the case, it becomes essential that expectant parents have access to information about their practitioners' and facilities' practices before deciding where and with whom to birth. Without this information, they are essentially birthing in the dark and leaving far too much to chance.

I first became engaged in birth activism in 2004 with the intention of improving maternity care by providing the public with information about women's rights and options. I'd been a birth doula for a few years by then and was appalled by what I was witnessing in that capacity and simply could no longer keep quiet about it. I cofounded a not-for-profit organization in New York City called Choices in Childbirth with the hope that it would serve the dual function of educating and empowering women as well as providing a constructive outlet for all of the other frustrated birth practitioners in the city who were feeling hopeless and defeated by the current oppressive medical climate. At the time, I wasn't familiar with the term "transparency," but in hindsight it is clear that it's been central to all of the projects that I've taken on. Over the last four years, Choices in Childbirth has worked on its own as well as in partnership with the Public Advocate for the City of New York, and with the Coalition for Improving Maternity Services on a number of projects dedicated to improving transparency.

THE MATERNITY INFORMATION ACT

The first project that Choices in Childbirth took on was the enforcement of New York State's Maternity Information Act. This legislation requires the New

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York Commissioner of Health to ensure that every hospital and birth center prepares an informational pamphlet for the public that defines obstetric procedures and provides the annual rates of performance of these procedures by the hospital. This includes the annual percent of cesarean sections, births attended by midwives, vaginal births after prior cesarean, episiotomy, vaginal breech births, induction and labor augmentation, anesthesia, electronic fetal monitoring, and forceps births, as performed in the most recent 1-year aggregate. Under this law, hospitals are directed to automatically give the pamphlet to every perspective maternity-care patient, as well as to any member of the public upon request.

New York State's Maternity Information Act (MIA) was first passed in 1989, due entirely to the efforts of activist Doris Haire, but by the turn of the century it had been all but forgotten. In 2004, volunteers from Choices in Childbirth took up Haire's fight and began surveying New York hospitals to determine the citywide compliance rate with the MIA. We had visited 10 of the 44 hospitals providing maternity care when the Public Advocate for the City of New York, Betsy Gotbaum, heard about our work and contacted us. With the help of her office, all 44 hospitals were contacted, and it was established that none was in compliance with the law. Gotbaum published a report titled *A Mother's Right to Know* (Public Advocate for the City of New York, 2005), and we held a press conference in July 2005. A year later, in December 2006, we repeated the exercise and once again found a 0% compliance rate with the MIA. We then released a new report, *Giving Birth in the Dark* (Public Advocate for the City of New York, 2006), and held a second press conference. This time around, we followed up by contacting hospital administrators in all of the hospitals and educating them on their responsibility to the public under the law. By March 2007, all 44 hospitals were in compliance with the Maternity Information Act and, currently, all are producing pamphlets with the most recent available intervention data. In addition, the New York State Department of Health finally agreed to put all of the intervention data up on the state's Web site. Until recently, the Choices in Childbirth Web site was the only place where this data could be accessed by the public.

Choices in Childbirth is currently working on a template to help activists in other states pass similar maternity information legislation. We are working on this with the Grassroots Advocates

Committee of the Coalition for Improving Maternity Services.

THE GUIDE TO A HEALTHY BIRTH

In an effort to educate women in New York City about their birthing rights and options, Choices in Childbirth (CIC) created a free publication, *The New York Guide to a Healthy Birth*. Now in its third edition, the guide provides expectant parents with a broad range of data, information, and resources on pregnancy and birth, including articles, hospital cesarean-section rates, maternity-care patients' rights, and listings of local mother-friendly providers. The goal of the guide is to assist expectant parents in making more informed choices by providing them with insight and information. In addition to the New York guide, CIC just released the second edition of *The Philadelphia Guide to a Healthy Birth* and the first edition of a national birth guide that is being distributed with every purchased copy of the renowned documentary *The Business of Being Born*, by Ricki Lake and Abby Epstein. In an effort to meet demand from activists and practitioners across the country, CIC is currently building up its infrastructure in order to publish birth guides in other cities and communities.

THE BIRTH SURVEY

The Grassroots Advocates Committee of the Coalition for Improving Maternity Services (CIMS) was formed in 2006 in an effort to productively engage individual activists and grassroots-level organizations under the CIMS umbrella. I've had the honor and great pleasure of co-leading this committee since its inception and helping to oversee the creation of the Transparency in Maternity Care Project. The goal of this project is to provide women with insight into maternity-care practices within their community while providing practitioners and institutions with feedback that will assist and inform them in their quality-of-care improvement efforts.

At the heart of the project is an ongoing, online consumer survey, The Birth Survey, which asks women to provide feedback about their birth experiences specific to the particular practitioner and birth environment that served them. Responses are made available online to other women in their community who are deciding where and with whom to birth. The Birth Survey is structured around the CIMS (1996, 2007) evidence-based *Ten Steps of Mother-Friendly Care* and other quality-of-care indicators. The creation of The Birth Survey was inspired

To view Choices in Childbirth's publications and to learn more about the organization, log on to www.choicesinchildbirth.org

by Childbirth Connection's *Listening to Mothers* survey (Declercq, Sakala, Corry, Applebaum, & Risher, 2002) and the A-CAHPS (Ambulatory Consumer Assessment of Healthcare Providers and Systems) program and surveys.

Paired with the experiential data gathered from women participating in the survey are official statistics from state departments of health listing obstetric intervention rates at the facility level. Currently, we only have full intervention data available from New York State, due to the Maternity Information Act, but we have volunteers engaged all across the country working to gather similar data from all 50 states.

The Birth Survey was piloted for 1 year in New York City in 2007 and was launched nationally on August 15, 2008. Women who have birthed in the last 3 years are welcome and encouraged to log on and take the survey at its Web site (www.thebirthsurvey.com). Results are available at the same address.

We are hopeful that this project will enable women to more fully exercise their rights as consumers, that they will have safer and more fulfilling birth experiences as a result, and that their feedback will enable providers and facilities to improve their quality of services.

This is an exciting time for maternity-care activists, but there is a long road ahead to achieve the goals we've set our hearts and minds on. We ask for the support of any woman out there who is, has been, or will be pregnant to consider the importance of improving the quality of maternity care in the United States and to join us in demanding transparency now!

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In Memoriam: Donna Hohmann Ewy Edwards

Lamaze International deeply regrets to announce the death of longtime Lamaze member and childbirth education pioneer Donna Hohmann Ewy Edwards. Donna died on May 14 in her mountain-top home in Colorado, with her two daughters at her side and her sons in town. Donna was an author, therapist, speaker, mentor, and Lamaze board member in the 1980s and 1990s. She also was the program director for the Lamaze Childbirth Educator Program in Colorado. Donna was preceded in death by her husband of 10 years, who died on Christmas Eve, 2007. For those who wish to honor Donna's memory, her family invites you to donate to the Lamaze Supporting Advocate fund (www.lamaze.org/Advocacy/SupportingAdvocateDonations/tabid/525/Default.aspx).