



Transforming Maternity Care

A High Value Proposition

Priorities for Moving to a High Quality, High Value Maternity Care System from the Perspective of Consumers and their Advocates

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Transforming Maternity Care Consumers and Their Advocates Stakeholder Workgroup

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Introduction

This workgroup represents consumers of maternity care and the individuals and organizations that advocate on their behalf. Although we have adopted the widely used term, "consumer", we do not view health as a market-based, consumable good, but rather a state of being to which all childbearing women aspire. We view women as "consumers" of maternity care before they are pregnant, when they attempt to become pregnant, throughout pregnancy, while giving birth, and through the postpartum period, which extends well beyond the clinical definition of six weeks. The organizations and persons who advocate on their behalf include those whose efforts are specific to pregnant women — including a growing number of local and regional "birth networks" — as well as those who advocate more generally for higher quality health care for women and/or women's rights. The sector also includes members of the health research community and childbirth educators, doulas and clinicians who actively advocate on behalf of consumers.

Each member brings to the workgroup a different set of experiences and views the state of the current maternity care system from a different vantage point. All of us, however, are united by our shared conviction that we can – and must – do a much better job of providing high quality maternity care in the United States. The group also strongly supports the principle that consumers and advocates must participate meaningfully in all policy deliberations about providing access to high quality affordable maternity care.

In common with the four other stakeholder workgroups, we agree that improvement is desperately needed in four areas:

- Scope and use of performance measurement
- Payment reform
- Improvements in the liability system
- Reduction of disparities in access, quality and outcomes of care

In the area of *performance measurement* we envision consumers playing a stronger role in identifying measures that focus on effective, relatively low-cost maternity care practices that improve outcomes and incorporate a more holistic, women-centered approach to maternity care. We also believe we as advocates have some responsibility for assuring those measures are developed and used, and the results are widely shared and easily understood by consumers. To that end we will continue to offer our support and skills to entities like the National Quality Forum, the Institute for Healthcare Improvement, Childbirth Connection, and the National Committee for Quality Assurance, as well as encourage and participate in other initiatives at both the national and local levels that share those objectives.

We believe *payment reform* can be a powerful tool that drives the delivery of better quality maternity care. The current payment system provides financial incentives only for the most expensive procedure- and technology-intensive maternity care, care that is inappropriate for most women. At the same time, there are no financial incentives for the delivery of safe, effective prevention- and wellness-oriented care. Purchasers, public and private, should be encouraged to revise the current payment policies to ones that align more closely with the goal of providing effective care with least harm.

Most consumers and their advocates have only limited knowledge or experience with the *liability system*, but we are concerned that the dysfunctional liability system hangs as a cloud over maternity services, while largely failing to achieve its core aims. We are

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concerned that liability pressure contributes to current patterns of overused procedures and that liability insurance costs can contribute to diminished access to midwifery and birth center care. We expect that large, achievable improvements in the quality of maternity care will increase the confidence of health professionals, childbearing families, and other stakeholders in maternity services and will reduce the likelihood of claims, defensive behavior, and liability-associated professional unhappiness. We also recognize that there is an urgent need to align legal standards of evidence with best evidence for appropriate practice, rather than the status quo and expert opinion.

Maternity care consumers have diverse cultural backgrounds, are situated in different economic strata, speak diverse languages, and span an age range of over 30 years. Research on their childbearing experiences has revealed that significant differences persist in the quality of those experiences. For example, black non-Hispanic mothers have higher rates of preterm birth, low birthweight babies, and fetal, perinatal, and maternal mortality than other segments of this population. The elimination of these disparities will require change not only at the coverage and health care delivery system levels but also improvements in consumer education, maternity support in the workplace, and other areas.

In addition to these four topic areas, the consumer stakeholder workgroup addressed three other areas of special concern to consumers: *current clinical controversies impacting care trends and options*, *women's decision making and informed choice*, and *coordination of care*. While there are overlaps and interconnections across the topics in this report, each offers important opportunities for improving maternity care and thus warrants focused attention, as provided in the problem statements and recommendations that follow. The aim is to create a maternity care system with women and families at the center.

Performance Measurement and Leveraging of Results

Current Problems

A comprehensive set of maternity care performance measures that meet endorsement criteria of the National Quality Forum (NQF) is not available. Due to severe limits in widely collected data that can be used to measure performance without undue collection burden, many measures of interest for improving maternity care quality cannot be collected now. Consumers and many others give special priority to outcome measures, and childbearing women report in the postpartum period many new-onset physical and emotional problems, which can persist over many months. As there is no standard documentation of these outcomes, they are largely invisible to the health care system, as women transition from maternity to other health care without good care coordination and health records. There are presently no endorsed measures for many other crucial maternity topics, including informed decision making, care coordination, vaginal birth after cesarean (VBAC), comfort measures and pain relief, positions for giving birth, third and fourth degree lacerations, and postpartum hospital practices that impact attachment and breastfeeding. The U.K. has for many years reported a "Normal Birth" measure, which should be adapted, endorsed and implemented in the United States, as technology-intensive maternity care has become the norm in healthy low-risk women.

Currently-endorsed maternity measures focus especially on facilities, even when they are "roll-ups" of clinician-level measures. This makes it hard to encourage clinician accountability and to help women choose caregivers wisely. Current measures are not stratified by race/ethnicity and language to aid in measuring and reducing disparities, and none directly assess disparities. Many are not risk-adjusted, making interpretation of comparisons difficult. There are serious shortcomings in applying the generic Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys to maternity care. CAHPS Maternity surveys are needed to help assess and report on the range of maternity caregivers and settings and to measure well pain and medication experiences.

Evidence is clear that performance report users are not interested in measures they think are inappropriate, unimportant or incomprehensible. However, childbearing women have not been actively engaged in defining maternity measures that are of greatest interest to them, existing measures have not been tested with this population, nor have efforts been made to develop new measures based on open-ended research with them. NQF identifies relevance of measures to audiences as an important endorsement criterion, but does not require evidence of relevance to consumers and patients for endorsement. Instead, its process uses the opinions of a variety of stakeholders involved in the endorsement process to judge probable relevance. Evidence exists that this is an inadequate approach, and it particularly disadvantages consumers and patients whose voice is often drowned out in these discussions.

Very few public performance measurement reporting systems on comparative quality use evidence-based reporting practices¹, which greatly reduces the likelihood that

¹ Key summaries of current knowledge and a commentary about current practice include the following: Faber M, Bosch M, Wollersheim H, Leatherman S, Grol R. Public reporting in health care: how do consumers use quality-of-care information? A systematic review. *Med Care* 2009;47(1):1-8. Peters E, Dieckmann N, Dixon A, Hibbard JH, Mertz CK. Less is more in presenting quality information to consumers. *Med Care Res Rev* 2007;64(2):169-90. Hibbard JH. What can we say about the impact of public reporting? Inconsistent execution yields variable results. *Ann Int Med* 2008;148(2):160-1.

childbearing women will see, understand, and use the reports. However, *pregnant women are an ideal population for comparative quality reports*. They have the time and the good health to gather and assimilate information; they are highly motivated to find the best possible care for themselves and their newborn; and they are likely to be familiar with web-based searches and sites, although this may be less true for women with lower education and income and for those in truly remote areas.

For certain key measures such as cesarean section and VBAC rates, there is controversy about appropriate threshold rates. Healthy People 2010 established target cesarean and VBAC rates, and the United Nations recommends a cesarean rate range of 5% to 15%. However, the national cesarean rate reached 31% in 2006, and maternity professionals frequently resist any targets or ranges. If these rates are publicly reported without such thresholds, then it is difficult or impossible to determine absolute or comparative quality. In many communities, all cesarean section rates may be considered too high and VBAC rates too low. Comparing to an “average” in this context is meaningless and misleading, particularly for consumers and patients. Some reporting systems withhold cesarean rates entirely on the grounds that an optimal rate is not known, a disservice to childbearing women. Despite the obvious need to move toward an optimal range, and growing evidence of harm and expense associated with current trends, current reporting systems do not give childbearing women needed guidance

Recommendations

1. Create an ongoing structure and process for 1) identifying consumers and consumer advocates with the potential to exercise ongoing leadership in multi-stakeholder efforts related to the development of performance measures, their reporting to the public, and their use in quality improvement efforts, and 2) providing them with training and ongoing support to maximize their effectiveness.

a. Strategies

- Provide these individuals with initial training on both the technical aspects of these issues and the political and process dynamics that characterize various multi-stakeholder settings.
- Facilitate participation of consumers with enhanced policy capacities in key performance measurement efforts.
- Provide them with ongoing technical and social support as they carry out their responsibilities.
- Develop an “action alert” network to notify individuals and advocacy groups of time-sensitive outreach opportunities for increased participation and effective mobilization when needed.
- Consider as a model the Project Lead advocacy training program of the National Breast Cancer Coalition.
- Due to the significance of health information technology (HIT) for future performance measurement, include in the scope of the project participation in evolving HIT policy decisions.
- Since most advocates participate as unpaid volunteers, consider providing stipends to help grow a more diverse corps of consumer advocacy leaders.

- b. Lead responsibilities:
 - Consumer-Purchaser Disclosure Project
- c. Challenges and solutions:
 - As there are usually too few representatives of “consumer voice” in these multi-stakeholder efforts, identify a “critical mass” of individuals so they can provide mutual support and avoid burnout.
 - Staff of these multi-stakeholder efforts are often critical to shaping agendas and processes; as few consumers and their advocates have built relationships with these staff, focus on the development of relationships with staff and other stakeholder groups
 - Ongoing funding support is needed to put an effective and continuing program in place; a foundation such as Disclosure Project funder Robert Wood Johnson Foundation is a possibility.
- d. Mechanisms for collaboration:
 - BirthNetwork National, Childbirth Connection, Our Bodies Ourselves. and other women’s health and childbirth advocacy organizations that could be natural allies
- e. Timeline for achievement:
 - This effort should begin as soon as funding is available.

2. Consumer advocates should work together and with other key stakeholders to, over time, press the new federal and regional health information technology (HIT) infrastructure to include standards and a uniform maternity data set to enable collection of priority performance measures and data needed to provide good clinical care. Maternity care consumers and advocates are an essential stakeholder participant in the development and implementation of this data set, which must be able to measure priority outcomes and priority care processes among other measures.

- a. Strategies:
 - A transparent multi-stakeholder process with strong consumer and advocate participation is essential.
 - Give strong attention to data needed to develop and implement optimal performance measures as well as data needed to provide optimal clinical care, including care coordination.
 - Processes are evolving: ensure promulgation in federal HIT standards of systematic collection and reporting of uniform maternity data set.
 - Work to build relationships with the HHS HIT infrastructure, as well as with the members of Policy and Standards Committees.

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- Work to build relationships with Regional Health Information Organizations and other local, state and regional efforts to build and sustain effective HIT.
- b. Lead Responsibilities:
- There is a need for a well-funded project within a major health consumer organization to enable consumers to be at the needed tables during the coming period of rapid HIT development.
- c. Challenges and Solutions:
- HIT is rapidly evolving and significant resources are needed to engage meaningfully and without delay with the relevant groups and processes.
 - The crucial role of uniform data sets for interoperability is not visible as a priority in current HIT discourse, and an important precedent is a model electronic health record for children in Medicaid and CHIP, authorized in the Child Health Insurance Program Reauthorization Act (CHIPRA) of 2009.
- d. Mechanisms for Collaboration:
- The American Association of Birth Centers and the Midwives Alliance of North America, two national organizations that have made considerable progress toward developing Uniform Data Sets should be represented at the table as state and federal initiatives unfold.
 - It is also essential to collaborate with key health professional, health facility, health purchaser and HIT groups.
 - Markle Foundation is a possible funder.
 - To help ensure that elements of primary importance to women are captured in a uniform data set for maternity care, consider the outcomes of The Birth Survey conducted as part of the Transparency in Maternity Care Project of the Coalition for Improving Maternity Services.
- e. Timeline for Achievement:
- Funding should be secured as soon as possible, and this effort will take at least three years.

Payment Reform

Current Problems

The current reimbursement system includes incentives for overuse of potentially harmful and costly interventions and practices while not supporting many safe and effective lower-cost interventions.

Given the perverse incentives in the current system, and absent availability of a national maternity care standards measurement and reporting system that could be used to compare providers and care settings, it is difficult for consumers to choose and obtain high quality, better value care and avoid experiencing unneeded procedures, drugs and tests.

Many women think that interventions that are widely used and paid for by Medicaid or other insurance plans must be in their best interest. Therefore, consumers generally do not understand when they are exposed to overuse of potentially harmful interventions or technologies. Consumers may not value, be directed to, or have access to high quality, lower cost interventions because they are not paid for or adequately reimbursed by Medicaid or other insurance plans. Women who do prefer and seek high quality, better value maternity care often cannot obtain it, either due to lack of ready access or because some or all costs must be born out-of-pocket.

Supportive services that address social determinants of health are rarely considered in conversations about payment reform. Many of these factors — e.g., housing, physical safety, social support, and access to healthy food and safe water — have a profound influence on pregnancy and childbirth. Critical aspects of a woman's history, current situation or plans are often disregarded by our current system, both from a lack of expertise on the part of the providers and because our reimbursement does not support this level of care.

Medicaid steadily assumes responsibility for a growing proportion of maternity care, and the Child Health Insurance Program Reauthorization Act of 2009 (CHIPRA) has reduced barriers and expanded options for maternity coverage of uninsured women without access to affordable private insurance. Private insurance, still the predominant source of coverage of maternity services in the nation, has barriers and exclusions that reduce access. Concerns include:

- states that do not require employers with fewer than 15 employees to include maternity care in a basic health insurance benefits package
- in individual health policies: typical exclusion of maternity care or access only through purchase of prohibitively expensive riders, exclusion of coverage when pregnancy or a past cesarean section are "pre-existing conditions" (about .5 million childbearing women annually had cesarean in past), and failure to provide comprehensive maternity benefits
- in "consumer-directed" policies: high deductibles that may double if the care spans two calendar years; high out-of-pocket costs, especially when experiencing complications, which impact many due to widespread use of cesarean section and lack of access to VBAC.

Recommendations

1. **Consumers and advocates should work to raise national awareness of overuse and underuse of many maternity interventions, as well as the need to eliminate perverse incentives in the current system that discourage lower cost, high quality, evidence-based options.**
 - a. Strategies:
 - Launch an effective public awareness campaign involving national and internationally recognized organizations.
 - To reach a wide audience of childbearing age, use social networking sites and services, e.g., youtube.com, discussion boards, and other newer media, as well as conventional media (e.g., print, radio, TV).
 - b. Lead responsibilities:
 - A national consumer advocacy group; Ad Council might contribute major in-kind resources if very substantial money for other expenses could be brought to the table.
 - Various grassroots organizations can facilitate use of new media for communicating key messages and building awareness.
 - c. Challenges and solutions:
 - Consumer and advocacy community must develop a cohesive voice calling for improved quality and greater cost-efficiency in maternity services.
 - The women's health advocacy community focuses especially on "reproductive" health and much less on maternity issues; continuing dialogue and representation of maternity issues are essential.
 - Considerable resources are needed for a public awareness campaign with large reach and impact, especially when using conventional media; but smaller scale grassroots efforts can be carried out with fewer resources, and contests are an effective way of mobilizing participation.
 - When available, results of maternity care performance measurement will highlight the need for improvement; national data about maternity trends and practices, such as *Listening to Mothers* survey results, can also highlight the need for improvement when compared to results of systematic reviews clarifying exemplary practice.
 - d. Mechanisms for collaboration:
 - Engage as priorities State Medicaid programs and other public payers, civic organizations, and non-profits serving vulnerable populations.
 - Engage schools, public and community health providers, faith-based organizations.

- Engage women's health and childbirth advocates, including BirthNetwork National, Childbirth Connection, Citizens for Midwifery, La Leche League, Lamaze International, March of Dimes, National Advocates for Pregnant Women, Our Bodies Ourselves, and others that could play a role in implementing this recommendation.
 - Engage state legislatures, U.S. Congress including Congressional Women's Caucus, state and federal agencies, and White Office of Health Care Reform.
- e. Timeline for achievement:
- Smaller, grassroots "new media" outreach is ongoing and can accelerate; a major campaign is dependent on significant funding and would require several years.

2. Consumers and advocates should engage consumers and other stakeholders in advocating for access to and coverage of safe, effective services for common conditions and situations, including those that address social determinants of health, by a) advocating for reimbursement for proven priority practices, and b) advocating for priority research to identify effective maternity practices that should be available as benefits.

- a. Strategies:
- Use social networking sites and services to reach a wide audience of childbearing age, as well as conventional media (e.g., print, radio, TV).
 - Consider seeking immediate coverage for the following priority services that are supported by existing systematic reviews: smoking cessation interventions for pregnant women, interventions to increase initiation and duration of breastfeeding, labor doula care, interventions for postpartum depression, and birth center care for low-risk women.
 - Consider as priority research topics clarifying effectiveness of interventions for: pre- and interconceptional health; healthy nutrition, weight gain and postpartum weight loss; group prenatal care (such as the CenteringPregnancy model); pregnancy stress and depression; exposure to domestic violence; exposure to street, over-the-counter or prescription drugs; periodontal disease and other oral conditions; postpartum doula services. Also consider research topics comparing effectiveness of interventions with the outcomes of non-intervention.
 - Advocate as well for research to evaluate payment reform for Woman- and Family-Centered Maternity Care Home to address social factors, health education and other prevention, continuity of care, culturally and linguistically appropriate support, and appropriate use of maternity interventions (see *Care Coordination section of report.*)

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- b. Lead responsibilities:
 - A national consumer advocacy group such as MomsRising could inform large numbers of women through existing networks and mobilize them to undertake targeted actions.
 - c. Challenges and solutions:
 - Consumers must develop a cohesive voice calling for improved quality and greater cost-efficiency in maternity services.
 - Considerable resources are needed for a large reach and impact when using conventional media, but use of existing electronic communities and smaller scale decentralized, grassroots efforts can be carried out with fewer resources.
 - Policy makers will be concerned that coverage of new services would increase health care costs; however, the net effect could be a reduction in health care costs, and economic analyses could greatly facilitate expanded coverage (e.g., showing impact of investment in smoking cessation programs on costs associated with prematurity and of labor support investment on cesarean section costs).
 - d. Mechanisms for collaboration:
 - Engage public and private purchasers whenever possible.
 - Engage as priorities State Medicaid programs and other public payers, civic organizations, and non-profits serving vulnerable populations.
 - Engage schools, public and community health providers, faith-based organizations.
 - Engage women's health and childbirth advocates, including BirthNetwork National, Childbirth Connection, Grassroots Network, La Leche League, Lamaze International, March of Dimes, National Advocates for Pregnant Women, National Partnership for Women and Families, and Our Bodies Ourselves, and others that could play a role in implementing this recommendation.
 - Engage state legislatures, U.S. Congress including Congressional Women's Caucus, state and federal agencies, and key federal agencies (e.g., Agency for Healthcare Research and Quality, National Institute of Child Health and Human Development for evaluation; Health Resources and Services Administration).
3. **Consumers and advocates should work to raise public awareness of the many barriers to access to comprehensive maternity services through the private health insurance market and should provide continuous pressure to ensure that comprehensive maternity care is designated as an essential component of a core health insurance benefits package in national health care reform policies.**

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- a. Strategies:
- Launch an effective public awareness campaign involving national and internationally recognized organizations.
 - Use new media, such as youtube.com and bookmarking and sharing websites to inform women of childbearing age, the women's health and reproductive rights communities and other key groups about the need to eliminate the current problems through health care reform.
 - Build broad multi-stakeholder coalition of supporters.
 - Reach out to members of Congress involved with health care reform and to the Congressional Women's Caucus, as well as to the White House Office of Health Care Reform.
- b. Lead responsibilities:
- National Women's Law Center gives priority to health care access and has already begin to raise awareness about these issues.
- c. Challenges and solutions:
- Considerable resources are needed to mount public awareness campaigns and to play active policy roles; and grassroots outreach using new media are ready ways to begin immediately with awareness building.
- d. Mechanisms for collaboration:
- A very broad multi-stakeholder coalition of supporters, including but going far beyond the maternity and women's health advocacy communities listed in previous recommendation, can help to ensure that favorable policies are put into place.
- e. Timeline for achievement:
- Awareness-building and outreach should begin immediately and should continue throughout the process of implementing major access, quality and payment reforms in the U.S. health care system.

Improving Functioning of Liability System

Current Problems

The present, rising cesarean section rate far exceeds the range recommended by the United Nations, Healthy People 2010 targets, and achievable benchmark rates reported for some studies in North America. Excess cesareans are associated with considerable short- and longer-term maternal and newborn morbidity, and costs. There is some evidence that defensive medicine is associated with a small proportion of cesareans. There is virtually no evidence of liability pressure 1) to carry out full, exemplary informed consent about mode of birth, including information about associated morbidity in women and babies, 2) to avoid performing a cesarean that is not needed, or 3) to provide access to vaginal birth after cesarean (VBAC) in healthy women who do not want a repeat cesarean.

Liability concerns of maternity clinicians and obstetric legal claims especially involve adverse outcomes in newborns, with a focus on avoiding and responding to the tragedy of lifelong disability or early death. The number of perinatal legal claims has been relatively stable in recent years, but the size of awards has greatly increased. We call out two concerns related to this focus on long-term injury in newborns.

First, parents of babies with long-term disabilities may feel pressure to file a lawsuit to obtain financial assistance in the absence of negligence because they lack other sources of assistance for the considerable associated expenses. This situation may worsen as more and more babies survive at earlier gestational ages. The legal system is an inappropriate solution to families' need for help with expenses in the absence of negligent injury. Second, studies that have attempted to measure the incidence of such injury have found that childbearing women are much more likely to sustain negligent injury than newborns. Increased focus on safe and appropriate care for childbearing women is warranted.

Systematic reviews were initially developed to assess care during pregnancy and childbirth, and a very large, growing body of systematic reviews is available to guide maternity care practice. Although current practice frequently does not reflect best evidence, the legal system upholds as a standard for practice what a reasonable clinician would do in a specific situation. When the weight of the best available evidence clarifies that a change in practice standards is needed, the legal system impedes quality improvement by providing incentives to adhere to obsolete patterns of care. Further, this system relies extensively on opinions of expert witnesses, although expert opinion when not explicitly reflecting best evidence is considered to be the lowest level of evidence. Lagging behind the movement for evidence-based practice, these legal standards poorly serve women and families and those who provide and pay for their care.

Claims are filed on behalf of just a small fraction of patients who sustain negligent injury. Of filed claims, only a small proportion result in awards. Awards generally fall far short of compensating injured parties for damage. Thus, the legal system compensates patients for just a miniscule portion of the negligent injury they sustain, at tremendous cost.

It is common for obstetrician-gynecologists to express a high level of discontent about liability matters. In studies across many medical specialties, their level of professional satisfaction is lower than nearly all other specialties, and liability matters appear to play a role. There are concerns about the impact of this discontent on the quality of maternity care.

Recommendations

The Consumers and Advocates Workgroup had difficulty identifying priority strategies that our sector could undertake to address problems that involve the legal system, the liability insurance industry, and liability insurance regulators. We are not including in our report recommendations for our sector's direct involvement in these matters. However, we take this opportunity to identify serious concerns with the functioning of these institutions and to frankly state that the abysmal functioning of the liability system serves childbearing women and newborns poorly.

We urge *public and private purchasers*, who indirectly absorb costs of the liability system through their payments to health professionals and facilities, to use their purchasing power to play a strong role in fostering improved functioning of this system. We urge *state regulators* to exercise stronger oversight of liability insurers on behalf of those who receive care. We also urge *health professionals* to provide leadership in reducing the adverse effects of the liability system through changes in the way that care is delivered by: committing to a culture of continuous quality improvement, building safety systems into maternity care delivery, and — when things go wrong — embracing transparency, accountability, apology, and analysis and improvement.

An important solution to both claims that are filed for negligent injury and the far greater number of individuals who experience but do not file claims for negligent injury is to prevent harm in the first place. We anticipate that large, achievable improvements in the quality of maternity care and reduction of unwarranted practice variation, including more reliable provision of appropriate care consistent with the principle of effective care with least harm, will increase the confidence of health professionals, childbearing families, and hospitals and health systems in the quality of maternity care and will reduce the likelihood of claims, defensive behavior, and liability-associated professional unhappiness. We therefore anticipate that strategies in other sections of our report to improve the quality of maternity care can indirectly reduce adverse effects of the liability system on maternity care. In some recent reports, systematic programs to improve the quality of maternity care have been associated with a reduction in malpractice claims.

The legal system must urgently develop mechanisms to align legal incentives with best evidence for appropriate practice, rather than the current standard that is tied to the status quo and expert opinion.

We believe that families anticipating costly long-term care of newborns with disabilities should receive help with needed resources and services without going through wasteful and potentially fruitless legal proceedings. Lessons from birth injury compensation funds in Florida and Virginia and "no-fault" programs in countries such as New Zealand and Sweden could be used to design effective compensation programs. Unfortunately, the relatively few affected families face caregiving and financial demands that limit their ability to advocate on their behalf, and there is no strong political will for such programs. Health care reform leading to expanded and perhaps universal access to health care could ease some of the burdens of families with long-term high-cost caregiving responsibilities.

To help women become more informed and actively engaged in decisions about their maternity care, we identify the need for greater and more effective focus of the health care and legal systems on women's legal right to informed consent and informed refusal, with special emphasis on "patient" legal standards that disclose what a reasonable patient wants to know, in contrast to the increasingly obsolete clinician standard relying on clinicians' judgments about what patients need to know. Studies repeatedly clarify

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that the great majority of childbearing women want to be appraised of all or most known harms before agreeing to an intervention, while other studies suggest that very few women actually have access to such information. For fuller discussion of informed decision making, please see the Decision Making section of this report, below.

Reducing Disparities in Access, Quality and Outcomes of Care

Current Problems

In the United States, women of color and low-income women are significantly more likely to report worse overall health. More specifically, they experience higher rates of maternal mortality, infant mortality, low birth weight, preterm birth, perinatal depression, delayed or no prenatal care, breastfeeding for a short time or not at all and gestational diabetes compared to their white and wealthier counterparts. Much of the research in health inequities in perinatal outcomes does not attempt to analyze the complex interplay of disparities in socioeconomic status and political power that lead to poor birth outcomes. There are multiple, interacting conditions that produce such outcomes:

Structural determinants such as: the lack of health insurance offered in low-wage jobs; little or no opportunity for quality secondary, vocational and university-level education; a lack of workplace support for pregnant and parenting women, and discrimination based upon race or class.

Neighborhood level determinants such as lack of access to: healthy food; affordable, reliable transportation; adequate air quality; communities with low rates of violence; and decent housing stock.

Health system determinants such as: a lack of health insurance; health care appointments that are not timely and affordable; fragmented, poorly coordinated sources of care, especially for women who use safety net programs; a lack of infrastructure to provide adequate preventive care, including health education; services offered without appropriate language and literacy levels; provider-patient encounters without enough time and careful communication to foster good quality care; and under-resourced, under-staffed facilities, especially those that primarily serve low-income women and women of color.

Consumers are not widely well-informed of particular issues that produce inequitable maternal health outcomes nor of their rights and responsibilities concerning maternity care decisions. Moreover, consumers are not traditionally decision-makers at the program or policy level on maternal health care issues. There are few avenues by which consumers can influence efforts to eliminate maternal health disparities.

Recommendations

1. Organize consumers and their advocates to call for implementation of proven approaches to high quality, culturally competent health education as part of standard maternity care.

a. Strategies:

- Ask departments of health, maternity care facilities, and other maternal care providers to identify, scale up, and fund approaches to prenatal care and education that have demonstrated the ability to improve birth outcomes.
- Ask departments of health, maternity care facilities, and other maternal care providers to implement programs for improved *health literacy*. This will include special efforts to reach low-income women and women of color *with* easily understood,

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evidence-based information to enhance informed decision-making for themselves as well as more effective advocacy for needed institutional reforms.

- Advocate for health insurance reimbursement systems that pay providers and facilities to invest in better health education and communication (for example, by supporting lengthier patient visits and an emphasis on preventive services).

b. Lead responsibilities:

- Consumer advocacy organizations should connect consumers' perspectives with safety net and private health insurance entities to begin the process of negotiating reimbursed preventive care and health education.
- Consumers and their advocates should work with health educator organizations and professionals to ensure that a wide range of data is presented to policymakers including evaluations, systematic reviews, and testimony that point to the potential for improved health literacy and education to reduce specific disparities in health behaviors and outcomes.
- State departments of health should fund program development, evaluation, and systematic reviews of promising programs integrating health literacy education into perinatal care, such as *CenteringPregnancy* and *the Baby Basics Program*.
- Federal and state governments should provide start-up grants to Federally Qualified Health Centers, hospital-based clinics and other providers for low-income communities to integrate these models into their maternity care.
- Monitoring and evaluation by departments of health and community based non-profit organizations should document the programs' outcomes.
- Funding should be flexible to allow community based service and advocacy organizations to partner with providers in implementing such programs, either as a contractor or direct service provider.

c. Challenges and solutions:

- Consumers and advocates have historically had no role in structuring and developing maternal care standards and programs. Therefore, advocacy organizations, including community-based organizations, must create their "place at the table" via testimony and demonstration of political power that will enhance the influence of consumers and advocates.

d. Mechanisms for collaboration:

- Federal, state, and local departments of health should make grants to service providers to integrate evidence-based health education programming into their maternity care services. Such grants would provide an incentive for committed participation of the required stakeholders (community-based

advocacy and service provider groups and maternity care facilities).

- The National Center for Medical-Legal Partnership could facilitate at local and regional levels.

e. Timetable for achievement:

- Begin immediately, and anticipate the need for ongoing monitoring and advocacy.

2. Organize consumers and advocates to participate in campaigns to increase a) comprehensive health insurance and b) access to comprehensive reproductive health care services among low-income women and women of color.

a. Strategies:

- Educate and mobilize consumers to campaign on the state or federal level for several key policy advancements:
 - a) Encourage states to take the option to cover pregnant immigrant women who have been in the United States for fewer than 5 years as now permitted under CHIPRA 2009.
 - b) Encourage federal government to adopt legislation that would expand this eligibility to all immigrant women who qualify, not just pregnant women.
 - c) Remove citizen documentation requirements for Medicaid and CHIP applicants.
 - d) Expand eligibility for Medicaid to 200% of the federal poverty line in all states.
 - e) Assure provision of comprehensive sexual and reproductive health services for women who are enrolled in Medicaid, CHIP and private health insurance plans.

b. Lead responsibilities:

- Maternity care advocacy organizations

c. Challenges and solutions:

- Not all advocacy organizations have the capacity or in-house skills to do direct organizing. Therefore, creative strategies for reaching on-the-ground consumers will have to be identified. For example, organizations that cannot organize a broad base of consumers could work to involve individual women from grassroots networks in providing testimonies or commentary or connect them to advisory board opportunities. Funding for systematic organization with training and advocacy would make a difference.

- d. Mechanisms for collaboration:
 - Maternity care advocacy groups should partner with such natural allies as immigrant rights groups, welfare rights groups, and others concerned with the scope and coverage of safety net programs.
 - e. Timetable for achievement:
 - Advocates could pursue in the next year legislation for individual pieces of this recommendation, such as removing the 5-year bar or expanding the scope and eligibility of Medicaid at the state level. With dedicated funding, a coalition of consumer advocates and other partners could be formed in several months to then begin to pursue a strategy for policy change at the national level, including building relationships with federal agencies such as the Centers for Medicare and Medicaid Services.
- 3. Organize consumers and their advocates to call for an increase in the low-income students and students of color that are in the pipeline to enter health professions, especially nurses, midwives, nurse-practitioners and primary care providers that care for women and babies.**
- a. Strategies:
 - Ask Federal, state, and local governments to create financial and social benefits to equalize access to health professions training, including grants and scholarships.
 - Provide housing stipends that allow for full-time study, health insurance for students and their families, and subsidized on-campus child care services for student-parents.
 - Provide community-based training programs for women in underserved communities who wish to become doulas, childbirth educators, and peer breastfeeding counselors.
 - Expand scope and eligibility for the National Health Service Corps (NCSC) program to increase the capacity of maternity care providers who can provide culturally competent care and are fluent in diverse languages.
 - Conduct outreach to students in high school, community college, and early in four-year college degree programs.
 - b. Lead responsibilities:
 - Maternity care advocacy organizations should take the lead to reach out to Federally Qualified Health Centers, professional associations, student-led and serving organizations (like American Medical Students Association) to establish campaign goals and strategies for reaching key decision in federal agencies; Health Resources and Services Administration (HRSA) could fund community-based training programs; National Health Service Corps should strengthen its ability to build maternity care capacity.

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- c. Challenges and Solution:
 - Federal agencies such as HRSA are not typical targets for consumer advocacy and activism. Therefore, different approaches for influencing legislators or other policymakers may be necessary to identify the most effective strategies for mobilizing consumers and advocates.
- d. Mechanisms for collaboration:
 - Maternity care advocacy organizations should partner with professional associations to build consumer- and provider-led coalitions aimed specifically at campaigning for expanding training opportunities, program funding, and establishing measurable benchmarks for how achievements in this recommendation will reduce maternal care disparities. Organizations that are demonstrating effectiveness, such as HealthConnectOne (doing community-based doula training) and The International Center for Traditional Childbearing (recruiting and training black women who wish to become midwives and doulas), should be integral partners in providing compelling testimony and evidence to policymakers.
- e. Timeline for achievement:
 - Work should begin immediately and implementation, monitoring and advocacy would be ongoing.

Clinical Controversies Impacting Knowledge, Preferences and Care Options

Current Problems

Primary care — focusing on prevention, wellness and care coordination; facilitating the innate childbearing, breastfeeding and attachment capacities of women and newborns; and avoiding unwarranted intervention — is optimal for the majority of women and newborns who are healthy and at low risk for complications. However, this population largely has access to and receives intervention-intensive specialty-oriented maternity care with many elective procedures, such as labor induction for convenience and a cesarean section simply because of a past cesarean. Liberal or routine use of elective procedures involves harm without benefit and wastes resources. Both clinicians and women initiate unnecessary procedures, often in the absence of adequate awareness and discussion of potential harms and benefits. What appear to be *women's* choices are often acceptance of caregivers' recommendations without adequate informed consent.

Consistent with their education and values, midwives and family physicians most reliably provide primary maternity care, but are least likely to attend births in the United States. Similarly, the freestanding birth center has been much more successful than acute care hospitals in making primary maternity care available to healthy low-risk women, yet just a fraction of women have access to care in freestanding birth centers. Certified Professional Midwives (CPMs) hold a national recognized credential with training and experience in attending birth in out-of-hospital settings. This relatively new credential is recognized in about one-half of states. Efforts to extend regulation and licensure to other states often face stiff opposition from influential medical trade groups.

Women increasingly lack access to essential practices that foster vaginal birth and reduce the likelihood of cesarean section. These include offering planned vaginal birth after cesarean (VBAC), planned vaginal breech birth, and planned vaginal twin birth; using external version to turn fetuses to a head-first position; facilitating labor progress through diverse non-drug techniques; using intermittent auscultation to monitor fetal well-being; and using vacuum extraction and forceps skillfully and judiciously. Best current evidence supports providing access to these practices. However, decreased use is leading to loss of skills and unsupportive environments, even though many women want access to these forms of care or would choose them if they had proficient, supportive caregivers and exemplary informed decision making processes. Excessive reliance on cesarean section involves troubling avoidable shorter-term and downstream harm in mothers and newborns and considerable avoidable maternity care costs, also short-term and in subsequent births. This is an urgent matter due to rapidly deteriorating practice patterns, loss of essential skills and knowledge, and major capital investment in facilities suited to highly interventive care. The National Priorities Partners have recognized this problem by collectively committing to address "unwarranted maternity care interventions, targeting cesarean section."

Some women desire and plan to give birth at home. Results of systematic and narrative reviews of studies of planned home birth and a large recent study of home birth in North America (primarily the United States) consistently suggest that this is a reasonable choice for low-risk women with qualified caregivers. Many women who choose home birth wish to avoid the intervention-intensive care of U.S. hospitals, and others find it well-suited to their cultural or religious traditions. Honoring this choice is consistent with

the bioethical principle of autonomy of competent patients and women's legal right to informed consent and informed refusal. Other affluent nations have policies that protect and support home birth.

Over-reliance on technology, loss of core skills and limited capacity for out-of-hospital maternity care also leave us ill-prepared to provide safe, effective maternity care in unexpected situations for individuals (e.g., precipitous labor, undetected breech) and communities (e.g., weather-related disaster, pandemic disease, terrorist attacks, war).

A very large body of systematic reviews is available to provide guidance about many maternity care questions. However, current U.S. obstetric guideline recommendations rely extensively on the lowest level of evidence, expert opinion, or on weaker or conflicting studies. This compounds the problems noted above.

Recommendations

1. **Consumers and advocates should take opportunities to build awareness among women, the general public and obstetric professionals of the growing problem of loss of core professional skills and knowledge and women's corresponding lack of access to essential forms of care (including support for physiologic birth, vaginal birth after cesarean and vaginal breech and twin birth), articulate the importance of the underused practices, and encourage increased access to them.**
 - a. Strategies:
 - Engage women's, health, and childbirth advocacy organizations (including birth networks) in building awareness of these issues among women and the general public through consumer-oriented websites, discussion boards, youtube.com postings and competitions, film showings, books, local library information nights, and other readily available media and outreach opportunities.
 - Develop consumer and advocates policy engagement capacity through advocacy and policy training, modeled on National Breast Cancer Coalition advocacy training and Project Lead program.
 - Advocate with the Office of Health Reform, key members of Congress, and the Medicaid and CHIP Payment and Access Commission (MACPAC) for maternity care quality and payment reform that fosters appropriate use of these practices.
 - Call for the development, endorsement and use of performance measures that strategically address essential endangered practices, including adaptation of "Normal Birth" measure that has been used across the U.K. for many years.
 - Call for evaluation of physician and midwife laborist models of care, which have the potential to alter skill sets and incentives (<http://www.oblaborist.org/hospitalistsreviewessay.htm>).
 - With supportive obstetric leaders, such as educational leaders at the joint meeting of Council on Residency Education in Obstetrics and Gynecology (CREOG) and Association of

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Professors of Gynecology and Obstetrics (APGO), and safety and quality leaders at ACOG Committee on Patient Safety and Quality Improvement (CPSQI) meeting, plan presentations to enable their colleagues to hear from women, and initiate dialogue at key professional forums.

- b. Lead Responsibility:
 - Women's, health, and childbirth advocacy organizations (including birth networks)
- c. Challenges and solutions:
 - Consumer and advocacy organizations generally have ambitious agendas, limited person power and tight budgets, so creative uses of new and available media are of special interest for quick action.
 - Capacity development requires significant funding; however, smaller number of experienced individuals and organizations can engage in the policy process with creative use of more limited resources.
- d. Mechanisms for collaboration:
 - Grassroots organizations continue and ramp up advocacy as possible including linking information on opportunities and activities through electronic and other mediums of information exchange.
 - Seek foundation funding for project to develop consumer policy and advocacy capacity.
 - Collaborate on needed performance measures with measure developers, such as California Maternal Quality Care Collaborative, and encourage the measures be submitted to the National Quality Forum as the lead measure endorser.
 - For dialogue with professional leaders, collaborate with supportive individuals and with CREOG, APGO and CPSQI.
- e. Timetable for implementation:
 - Outreach to women and the general public is ongoing and can become more creative in use of available media and strategies such as contests and awards.
 - Collaborate with MACPAC, as it is established and begins its work.
 - Initiate organizing to build policy and advocacy capacity as soon as funding is secured.

2. **Consumers and advocates should build awareness among women and the general public of the value of primary maternity care and the twin problems of 1) the primary maternity care workforce shortage of midwives with national credentials (CNM, CM, CPM) and of family physicians who include maternity care in their scope of practice, and 2) limited access to freestanding**

birth center care. They should advocate for more consistent provision of primary maternity care and increased primary maternity care capacity.

a. Strategies:

- Engage women's, health, and childbirth advocacy organizations (including birth networks) in building awareness of these issues among women and the general public through consumer-oriented websites and blogs, discussion boards, youtube.com postings and competitions, film showings), performing plays, airing radio shows, promoting books, regional resource directories (e.g., *New York Guide to a Healthy Birth*), holding local library information nights, and other low-resource activities.
- Communicate available comparative effectiveness data to the White House Office of Health Reform, the Secretary of Health and Human Services, key members of Congress, and the Medicaid and CHIP Payment and Access Commission (MACPAC), support expanding the primary maternity care workforce and access to freestanding birth centers, and continue to press for implementation of mechanisms for these purposes.
- Communicate available comparative effectiveness data to relevant members of Congress, MACPAC, and state Medicaid agencies, support guaranteed adequate payment for primary maternity care at a rate of not less than 100% of fees for specialists reimbursed for providing similar episodes of care.
- Communicate to relevant members of Congress, MACPAC, and state Medicaid agencies the importance of guaranteed adequate payment for birth centers at a rate of not less than 100% of reimbursement levels for equivalent codes in hospitals.

b. Lead responsibilities:

- Women's, health and childbirth advocacy organizations (including Birth Networks)

c. Challenges and solutions:

- These organizations generally have ambitious agendas, limited person power and tight budgets, so creative uses of new and available media are of special interest in raising awareness among women and the general public.

d. Mechanisms for collaboration:

- Collaborate with initiatives to foster supportive, enabling legislation to strengthen the primary maternity care workforce at the state level by soliciting support of medical leaders, communicating support to state legislators, and writing letters to editors (including use of comparative effectiveness data).

- e. Timeframe for Implementation:
- These efforts should begin immediately and should continue until primary maternity care is the norm for healthy low-risk childbearing women.

3. Consumers and advocates should encourage alignment of the views of women and their caregivers with best current evidence (and with performance measures and payment incentives reflecting this evidence).

- a. Strategies:
- Communicate to the White House Office of Health Reform, the Secretary of Health and Human Services, key members of Congress, the national comparative effectiveness entity (when established), and the leading national health professional associations the urgency of establishing a transparent multi-stakeholder process involving all of the relevant clinical disciplines and consumers and their advocates in the development of maternity care guidelines that are informed by best available evidence, similar to the development of *Canada's Family-Centred Maternity and Newborn Care: National Guidelines* and the United Kingdom's National Institute for Health and Clinical Excellence (NICE), and by participating in the development of such an entity and guidelines.
 - Communicate to the White House Office of Health Reform, the Secretary of Health and Human Services, and key members of Congress about the urgency of developing and making available complementary up-to-date comprehensive evidence-based professional and consumer decision support tools for priority topics. Priority topics include: choice of caregiver, choice of birth setting, continuous support during childbirth, vaginal birth versus primary cesarean section, vaginal birth after cesarean versus repeat cesarean section, watchful waiting versus elective labor induction, medical indications for labor induction, drug-free pain relief measures versus epidural analgesia, intermittent versus continuous fetal monitoring, pushing phase of labor (initiation, duration, positions, episiotomy, assisted delivery), breech presentation fetus (external version and mode of birth options), and mode of birth with twins. Dissemination channels include health information technology, the Internet, community health centers, integrated health systems, childbirth educators, and CenteringPregnancy programs.
 - Communicate to MACPAC, the White House Office of Health Reform, the Secretary of Health and Human Services, and key members of Congress the importance of reimbursing clinicians for time spent helping women make evidence-informed maternity care decisions, both during pregnancy and around the time of birth (see Care Coordination section of this report).

- b. Lead Responsibilities:
 - Childbirth Connection, which has promoted evidence-based maternity care in the United States since 1999.
 - c. Challenges and solutions:
 - Meaningful communication with the relevant stakeholders, including the women who give birth to 4.3 million babies annually, requires resources that are not currently in hand.
 - The development and implementation of decision tools requires exceptional resources, which may be increasingly available as health information technology grows in implementation and sophistication.
 - Despite growing recognition that many guidelines developed by U.S. specialty organizations do not reflect best current evidence and important transparent multi-stakeholders guideline development models in other countries, there are political obstacles to moving in this direction in the United States, and the first step is to raise awareness about the need for new policies and available precedents.
 - d. Mechanisms for collaboration:
 - White House Office of Health Care Reform, new federal comparative effectiveness entity, interested members of Congress including Congressional Women's Caucus, interested members of health professional organizations
 - Centers for Medicare and Medicaid Services, state Medicaid programs, MACPAC
 - Women's, health, and childbirth advocacy organizations
 - e. Timeline for achievement:
 - These efforts should begin immediately and continue in tandem with continuing federal comparative effectiveness work and other work throughout the world to develop systematic reviews clarifying best maternity evidence.
4. **Due to the desire of many women for home birth; the best available evidence about planned birth for low-risk women at this site of care; women's right to autonomy and to make informed decisions; the availability of caregivers with a nationally recognized credential and skills and expertise for out-of-hospital birth; and the importance of building capacity for all-hazards disaster preparation, consumers and advocates should support women's right to choose a home birth within an integrated system of care and to have access to qualified caregivers and good care coordination with the rest of the health care system.**
- a. Strategies:
 - Build awareness of these issues among women and the general public through consumer-oriented websites, discussion boards, youtube.com postings and competitions, film showings, and other readily available media.

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- Support legislative initiatives to increase access to regulated and licensed Certified Professional Midwives, who have training and experience in attending out-of-hospital births, by communicating support to legislators, attending support events, writing letters to the editors of key newspapers, reaching out to opposing forces, and exploring other ways to collaborate with professional organizations supporting the legislation.
 - Ensure that evolving mechanisms for care coordination (see Care Coordination section of this report) support women who choose home birth with seamless consultation, referral, and transport, consistent with well-established principles for safe, collaborative practice.
- b. Lead responsibility:
- Many organizations currently advocate for access to home birth in the United States with qualified caregivers and seamless care coordination with the rest of the maternity care system; an upcoming home birth consensus planning meeting may help identify an organization that is well-positioned to take the lead.
- c. Challenges and solutions:
- Based on assertion and without presenting evidence, and despite strong support for patient autonomy and informed decision making, two key medical trade organizations — American Medical Association and American College of Obstetricians and Gynecologists — categorically oppose home birth; this opposition has proved a powerful barrier to inclusion of home birth coverage in insurance programs and to licensure of midwives with expertise in out-of-hospital birth; however, some women will always choose to give birth at home, and their choices should be honored and supported with access to qualified caregivers and care coordination.
- d. Mechanisms for collaboration:
- Collaborate with professional organizations (e.g., National Association of Certified Professional Midwives) that are working to address other potential barriers to access, such as lack of recognition of CPMs as qualified Medicaid providers in some states and lack of reimbursement by private insurers.
 - Engage women's, health, and childbearing advocacy organizations (including birth networks) in building awareness and supporting state-level legislation.
- e. Timeline for action:
- Begin immediately, and continue as long as appropriate support is not available for all women who desire home birth.

Decision Making, Consumer Choice, Informed Consent and Refusal

Current Problems

Improving patient decision making and enabling patients to make informed choices are difficult tasks in clinical care generally. In the specific context of maternity care, these tasks are further complicated by the need to consider the well-being of both the woman and the child, as well as the fact that pregnancy and childbirth are normal (i.e. non-pathological) physiologic processes, not an illness or injury. Having “a healthy baby” certainly matters, but it should not be all that matters in maternity care. Women’s own health outcomes and experiences of care matter, too. Transforming maternity care will require widespread recognition at cultural, institutional and individual levels that childbirth is a personally meaningful *process*, not just a clinical event. Women should be able to incorporate their preferences and values into decision making about pregnancy and childbirth. Women also do not currently have access to a wide range of choices along key dimensions: *where* to give birth (hospital, birth center, home); *how* to give birth (e.g., unmedicated vaginal birth; vaginal birth for twins; vaginal breech delivery; vaginal birth after cesarean); *with whom* to give birth (e.g., obstetrician, family practitioner, midwife, with doula or not). Women also do not currently have access to comprehensive and comprehensible data evaluating the performance of maternity care providers and institutions that would facilitate their choice of a provider. All too often, women are not full partners with providers in decision-making, but rather experience care paths based on decisions that others make about them.

The current cultural emphasis on the pain, fear and risks associated with childbirth, coupled with an overriding emphasis on medical technology and interventions as the solution to the “problem” of childbirth seriously limit awareness of alternative approaches to birth. The prevailing culture of maternity care as well as popular media representations of childbirth (e.g. “Baby Story” on The Learning Channel) make it difficult for women to approach childbirth in a “climate of confidence.”

There is a lack of complete, balanced information on risks and benefits of various options for childbirth. It is difficult for women to find comprehensible information that is in consumer-friendly formats/language. This lack of information is further complicated by the complexities of the choices themselves, which involve multiple, sometimes incommensurable trade-offs, as well as by the time pressures associated with medical care during labor and delivery. In addition, women are often asked to give their consent to procedures at the urging of a health professional without adequate help sorting through and understanding provider recommendations.

Few standardized, validated quality or performance measures exist for maternity care, and none explicitly address adequacy of informed decision-making regarding maternity care choices. Existing measures are neither widely disseminated nor easily understood by consumers.

Prevailing institutional arrangements in the maternity care system often mitigate against informed decision making. For example, large group practice models may inhibit the establishment of trust between care providers and consumers, thus limiting the partnership model of decision making that is the ideal. In addition, women’s choices may be constrained by (a) institutional policies (such as those that categorically prohibit VBAC); (b) provider preferences (e.g. delivery of twins); (c) loss of clinical skills (e.g. fading access to vaginal breech delivery); (d) reimbursement schemes (e.g. lack of reimbursement for home birth).

A moribund system of childbirth education is inadequate to the needs of contemporary women. Enrollment in childbirth education has been declining for several decades. This trend may reflect diminished recognition of the value of childbirth education and/or a failure on the part of childbirth education to remain relevant and convenient for consumers today. In addition, the tight intertwining of childbirth education with hospitals may compromise the independence of childbirth education, thereby affecting consumer access to unbiased information on the risks and benefits of various options.

Recommendations

1. **Use the model of the cultural transformation around end-of-life care that the death-and-dying movement has achieved to change the culture of childbirth and promote the idea that childbirth is a personally meaningful *process*, not just a clinical event; birth is a meaningful life experience that can be profoundly transformative.** Women need to feel empowered in the context of maternity care, not disenfranchised by a system that emphasizes risk, pathology, fear, pain and the necessity of medical intervention.

- a. Strategies:

- Conduct national and local “childbirth literacy campaigns” to inform women of the ranges of options available for maternity care and for childbirth.
- Seek partnerships with producers of popular culture to change the depiction of childbirth in the mass media.
- Develop alternative visions and voices, with careful attention to positive messaging to transmit key concepts and cue healthy behaviors and care choices.

- b. Lead responsibilities:

- Women’s health and childbirth advocacy organizations like Childbirth Connection, Lamaze International, Coalition for Improving Maternity Services, National Women’s Health Network, National Partnership for Women and Families, Birth Networks and the March of Dimes. Consumer groups should also partner with professional organizations like American College of Nurse-Midwives, DONA International, International Childbirth Education Association, Association of Women’s Health, Obstetric and Neonatal Nurses, and Midwives Alliance of North America, as appropriate, to work with the mass media.

- c. Challenges and solutions:

- Media stereotypes of birth can be difficult to change. Cultural stereotypes of birth as inordinately painful and risky are often used to heighten drama—or comedy—in popular entertainment.

- d. Mechanisms for collaboration:

- Entertainment producers have been eager to work with advocacy and professional groups to improve the depiction of

medical issues on popular programs such as E.R. Look to other organizations that have successfully placed educational and advocacy pieces in popular media for guidance.

- Women’s magazines are another target outlet for raising awareness.
- Secondary schools and college campuses should be targeted to achieve early consciousness raising among the next generation of mothers.
- State and local public health agencies and staff of the Title V programs could also be enlisted as partners in these efforts.

e. Timeline for achievement:

- Ongoing

2. Expand the opportunities and structures that facilitate women’s decision-making and informed choices in maternity care.

a. Strategies:

- Invest in research to understand how best to support women’s decision-making. One possible model would be to encourage women to develop “maternity care plans” that move beyond the narrow time frame involved in “birth plans.” As currently conceived, birth plans address only labor and delivery; they are often not formulated until relatively late in pregnancy and they are frequently disregarded by care providers during labor. Like advance directives, living wills and other forms of end-of-life planning, maternity care plans would encourage women to think through what they want and expect during pregnancy and childbirth. Maternity care plans could also be used to help women clarify their own values in advance of actual decision making points, and could be expanded to include interconception planning and reproductive healthcare goals across the lifespan. Consumer and advocacy groups should work to develop templates for maternity care plans.
- Develop consumer decision aids and checklists—for example, what to look for in a maternity care provider and in a birth setting; questions to ask your provider; values clarification tools from women and their partners. In particular, there is evidence of the effectiveness of individualized decision aids that solicit a woman’s preferences and values and then “feed back” options most compatible with what that woman deems important.
- Develop parallel consumer education materials and training modules for maternity care professionals, clarifying the rights of childbearing women to informed consent and refusal, and describing processes for addressing grievances.
- Support the use of electronic medical and personal health records that provide readily accessible information on women’s preferences for maternity care to help ensure that those choices are honored by care providers regardless of

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setting and throughout the woman's maternity care experience.

- Consider giving prenatal records to women to carry over the course of pregnancy, as an interim solution pending interoperable EHRs, and as a concrete symbol of a shift in authority to the childbearing woman.
- Support community-based consumer education initiatives that will help women to be comfortable in assuming more responsibility for making choices about health care.
- Conduct a public education campaign to help childbearing women understand existing legislative and administrative barriers to safe, effective, high quality maternity care, to engage consumers more effectively as advocates on their own behalf.
- Support the development of performance measures of consumer involvement in maternity care, including informed decision making, and of CAHPS Maternity clinician, facility and health plan surveys to measure experiences of childbearing women.

b. Lead responsibilities:

- Performance measure developers should collaborate with consumer and advocacy groups to develop and pilot measures to assess informed maternity care decision making processes. and should seek endorsement from National Quality Forum.
- Agency for Healthcare Research and Quality should adapt generic CAHPS clinician, hospital and health plan surveys for the childbearing population.
- Lamaze International and Childbirth Connection have experience in and resources for helping women to clarify values and make informed choices about childbirth.

c. Challenges and solutions:

- A large proportion of pregnancies in the U.S. are unplanned; women may not give much thought to childbirth until they are pregnant.
- Dissemination to the large population of childbearing women is a challenge, although it may soon be possible to include up to date, high quality decision making tools in health information technology.

d. Mechanisms for collaboration:

- The current pre-conception health movement provides opportunities to encourage women to think about maternity care as part of broader women's health.

e. Timeline for achievement:

- Many efforts to promote informed maternity decision making are under way; there is a need to expand this work and ensure that the needed resources are available, accessible and up to date.

3. Examine carefully the role of formal childbirth education in women's decision making, with the aim of expanding models of childbirth education and broadening the reach of childbirth education.

a. Strategies:

- Investigate where, how and from whom women today get information about pregnancy and childbirth.
- Expand the role of peer education in childbirth education. Nurture “good birth ambassadors” to act as change agents in local communities and serve as media resources.
- Foster independent childbirth education.
- Explore alternative media (e.g. web-based) for childbirth education. One example might be a series of podcasts on birth options.
- Evaluate the various models to identify and obtain policy support for effective models.

b. Lead responsibilities:

- Lamaze International, International Childbirth Education Association, other organizations that provide childbirth education and train educators

c. Challenges and solutions:

- Decreasing enrollment in formal childbirth education suggests that current models do not adequately meet the needs of today's consumers. Traditional childbirth educators should consider new forms of online learning and other ways of delivering information, particularly for the next generation of tech-savvy mothers.
- Reimbursement for childbirth education is limited, and independent, community-based educators and agencies are at a disadvantage when compared with hospitals and health systems; it will be important to seek reimbursement for models of demonstrated effectiveness.
- Content of childbirth education can create unrealistic expectations if it describes care options that are not available to women in their communities but this concern must be balanced with women's right to know.

d. Mechanisms for collaboration:

- The National Priorities Partners (NPP) have committed to work together to engage patients and families in managing their health and making decisions about their care, and NPP members should be engaged in implementing the various strategies.
- Health Resources and Services Administration to support development and evaluation of peer education models
- Agency for Healthcare Research and Quality to support development and evaluation of web-based models

- e. Timeline for achievement:
- Begin immediately, and as this is an aspect of maternity care that has not been adequately evaluated, the development, evaluation and dissemination of effective models of childbirth education may require a decade although a shorter timeframe is optimal.

Coordination of Maternity Care Across Time, Settings and Disciplines

Current Problems:

The Consumers and Advocates workgroup identified serious care coordination challenges impacting childbearing women and their families. These include many points of transition with great potential for communication failure, reimbursement problems and other barriers. Ideally, women and families would experience seamless transitions:

- Across maternity care professionals and settings before, around the time of, and after birth
- Between maternity care and mental health, pharmacy, lactation support and other ancillary services that improve maternity outcomes
- Between maternity care and primary care leading up to, during, and following the full episode of maternity care
- Between maternity care and specialty medical care for chronic and acute non-maternity conditions
- Between more readily available care for physical needs and conditions and less accessible social and behavior care

Prevalent concerns that all too often fall between these system cracks include:

- Imbalance for the majority of women and newborns who are healthy and at low risk in the proportion of primary and specialty maternity services, with overuse of care suited to higher risk women and underuse of effective preventive services
- Limited time and tools for education and engagement of women and families leading to high-quality informed decision-making and optimal wellness behaviors
- Pre- and interconceptional health concerns impacting pregnancy outcomes
- Appropriate care for the broad range and notable rates of new-onset physical and emotional problems experienced after birth, which often persist 6 months or longer

The vision of engaged and empowered childbearing women and families at the "center" of well-coordinated maternity care is largely unrealized at present. The current focus is often institution- and provider-oriented — for example, transitions are viewed as "hand-offs," after which time another person or setting is expected to pick up this metaphorical ball. Health professionals and systems lack tools to foster good coordination — such as high-functioning health information technology with personal health records, decision tools, and systems for measuring performance and improving the quality of care. The current procedure-oriented reimbursement system does not give health professionals financial incentives to engage in care coordination activities that foster appropriate care, and does not reliably cover many beneficial preventive and other services for women and families. Childbearing women need a reliable guide and source of support to work with them to achieve optimal care and outcomes across the maternity continuum.

Recommendations

1. **Consumers and advocates should advocate for extending the health care home model to the full episode of maternity care to ensure that every childbearing woman has access to a Woman- and Family-Centered Maternity Care Home that fosters care coordination, gives priority to prevention and health promotion, promotes accountability for outcomes, and offers high value for purchasers, beginning initially with enhanced risk-adjusted fees for coordination responsibility and moving toward a bundled comprehensive payment for pregnancy through postpartum care.**

- a. Strategies:

- Work with Center for Healthcare Quality and Payment Reform to adapt the care coordination, health care home and payment model outlined in *From Volume to Value* (<http://www.rwjf.org/healthreform/product.jsp?id=36217>) to the full episode of maternity care, with a focus on aligning incentives with high-quality care and delivering appropriate care, including primary maternity care for healthy low-risk women.
- Engage other health care advocates with an interest in reforming payment to foster appropriate, well-coordinated maternity care, to take advantage of this time when women have a point of entry into the health system and care coverage to address critical health care and care coordination needs.
- Advocate for participation of informed maternity care consumers and advocates on MACPAC, the Medicaid and CHIP Payment and Access Commission established by the Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009.
- Present MACPAC with data about women's experience of care, quality concerns with maternity care, implications for Medicaid programs and beneficiaries, and innovative maternity care organization and payment options.
- Call for Medicaid demonstrations to develop, evaluate and refine the concept of Woman- and Family-Centered Maternity Care Home, including ways of restructuring health system relationships, risk-adjusting payments, providing payments for outliers, and providing consumer incentives to choose higher value caregivers and services.
- Advocate to National Committee for Quality Assurance (NCQA) to develop standards for Woman- and Family-Centered Maternity Care Home, recognizing that family physicians and obstetricians, midwives with national credentials (CNM, CM, CPM) and nurse-practitioners all have the potential to provide exemplary maternity care coordination.

- b. Lead responsibilities:

- Childbirth Connection

- c. Challenges and Solutions:
 - The concept of Care Coordination has not been extended to maternity care, but recognition of the value of primary maternity care for the majority of childbearing women and families, of the scope and cost of maternity care services across a defined episode of care, and of the urgent need to align payment and maternity care quality can make such an extension compelling.
 - The current system is not well-organized for bundled payments and responsibility for the full episode of maternity care, but considerations noted in previous point, along with ongoing efforts for similar restructuring for Patient-Centered Medical Homes, can justify innovation.
- d. Mechanisms of collaboration:
 - Center for Healthcare Quality and Payment Reform
 - Centers for Medicare and Medicaid Services, state Medicaid programs, MACPAC
 - National Committee for Quality Assurance
 - Coalition of supportive consumer and advocacy organizations, such as BirthNetwork National, National Partnership for Women and Families, Our Bodies Ourselves
 - National Priorities Partners (as this advances 5 of their 6 priority areas, including Care Coordination)
- e. Timeline for achievement:
 - Initiate dialogue to adapt model beginning with the symposium.
 - Initiate dialogue with MACPAC as it is established and begins its work.
 - Explore options for developing and evaluating standards and set timetable with NCQA.

2. Consumers and advocates should support electronic health records and electronic health information exchange systems that promote active communication among the caregivers, include adequate protections for privacy and security, and put the woman and her family at the “center.”

- a. Strategies:
 - Identify specific “tables” at which consumers and advocates must be present and vocal as issues of data system delivery are raised and addressed. These include new Health Information Technology Policy and Standards Committees established by the American Recovery and Reinvestment Act of 2009 and other key standards and certification bodies such as the National eHealth Collaborative, the Health Information Technology Standards Panel, and the Certification Commission for Health Information Technology.

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- Support provider adoption of private and secure interoperable electronic medical records, particularly as dedicated HIT funds from stimulus legislation become available.
 - Support consumer understanding and use of Personal Health Records and the promises and limitations of health information technology, and contribute to efforts of federal agencies to address privacy and security protections for information held in these records.
 - Build on the privacy provisions enacted as part of the economic stimulus legislation and work with HHS to support adoption of workable privacy and security practices and policies that protect personal health information from inappropriate use and disclosure.
 - Engage consumers in a multi-stakeholder process of developing model Uniform Data Set and data dictionary for maternity care electronic health record, including identification of outcome and other data elements needed to evaluate health system performance.
 - Encourage purchasers (employers, health plans, federal and state governments) to reflect the cost of using such systems in their reimbursement methodologies.
- b. Lead responsibilities:
- Maternity care advocates in cooperation with other consumer advocacy organizations with experience in this domain, including the National Partnership for Women and Families, Center for Democracy and Technology, and Consumers Union
 - Federal and state agencies, notably HHS, the Centers for Medicare and Medicaid Services and state Medicaid agencies
 - Public and private purchasers
 - Technology community, including leading vendors of personal health records such as Microsoft, Google, and WebMD
 - Foundations such as the Markle Foundation and the Robert Wood Johnson Foundation
 - Health research community
- c. Challenges and Solutions:
- Providers and purchasers are skeptical of any real savings from use of electronic systems and have in the past been reluctant to make the up-front investments in technology and staff training. Funding for health information technology provided in the economic stimulus legislation — through federal grants as well as via Medicare and Medicaid payment streams — should help overcome this obstacle, but advocacy groups will need to ensure that the funding supports both the purchase of the technology and its use to specifically improve care coordination and delivery.
 - Consumers have lingering concerns about potential for inappropriate disclosure of medical information, regardless of how data are shared — electronically or otherwise. Fostering an atmosphere of trust between patient and provider, and

stressing the importance of maintaining privacy of patient-identifiable information on the part of all the medical community, can help dispel these concerns. A foundation of trust can be established through a comprehensive framework of information sharing policies that allow information to move easily for treatment-related purposes and prohibit access for inappropriate purposes. The economic stimulus legislation included some critical improvements to federal health privacy laws under HIPAA, which should help build this foundation of trust, but information sharing networks will likely need to go beyond the baseline HIPAA rules and create sound networks that facilitate better information sharing for care delivery and coordination while prohibiting (and punishing) inappropriate access.

d. Mechanisms of collaboration:

- Consumers and stakeholders should remain involved at the federal level to ensure that funds provided for health information technology in the economic stimulus legislation are effectively used to deliver better health outcomes. Consumers and other stakeholders should also become more actively involved in state and regional efforts to establish electronically networked systems of care (including by becoming actively involved in the development of, or become members of, the Regional Health Information Organizations (RHIOs), which are being established across the country to facilitate the exchange of electronic personal health information).
- The research community, with foundation or government support, could conduct studies of impact of improved data exchange on health care quality, which should then be shared with consumer and purchasers rather than just within the usual narrow confines of peer-reviewed publications.

e. Timeline for achievement:

- Over the next three or more years

Appendix B

In response to requests for feedback to this report, symposium participants proposed that the following organizations, in addition to those designated by the workgroup for Consumers and their Advocates in the body of the report, could also play an important role in implementing the recommendations:

- Advocates for Youth - <http://www.advocatesforyouth.org/>
- Big Push for Midwives – www.thebigpushformidwives.org
- Birth Network National – www.birthnetwork.org
- Birthing Project USA – www.birthingprojectusa.org
- Citizens for Midwifery (CfM) – www.cfmidwifery.org
- Commonsense Childbirth – www.commonsensechildbirth.org
- Dar A Luz Network – <http://daraluznetwork.com/index.html>
- Developing Families Center – www.developingfamilies.org
- Families USA – www.familiesusa.org
- Grassroots Advocates Committee (GAC) of the Coalition for Improving Maternity Services – www.motherfriendly.org/advocates.php.
- Grassroots Grapevine – <http://grassrootsgrapevine.ning.com>
- Healthy Teen Network – www.noappp.org
- International Center for Traditional Childbearing (ICTC) – www.blackmidwives.org
- International Cesarean Awareness Network (ICAN) – www.ican-online.org.
- Lamaze listing of birth network organizations – <http://www.lamaze.org/Advocacy/BirthNetworks/FindaBirthNetwork/tabid/114/Default.aspx>
- National Advocates for Pregnant Women – www.advocatesforpregnantwomen.org
- National Association for Certified Professional Midwives – www.nacpm.org
- National Council of Women's Organizations – <http://www.womensorganizations.org/>
- National Healthy Babies Healthy Mothers Coaliton - <http://www.hmhb.org/>
- Ounce of Prevention Fund - <http://www.ounceofprevention.org/>
- Public Citizen – www.citizen.org
- SisterSong – www.sistersong.net and Member and Affiliate Organizations (http://www.sistersong.net/member_affiliate_orgs_list.html)
- Transparency in Maternity Care Project www.thebirthsurvey.com/AboutProject.html