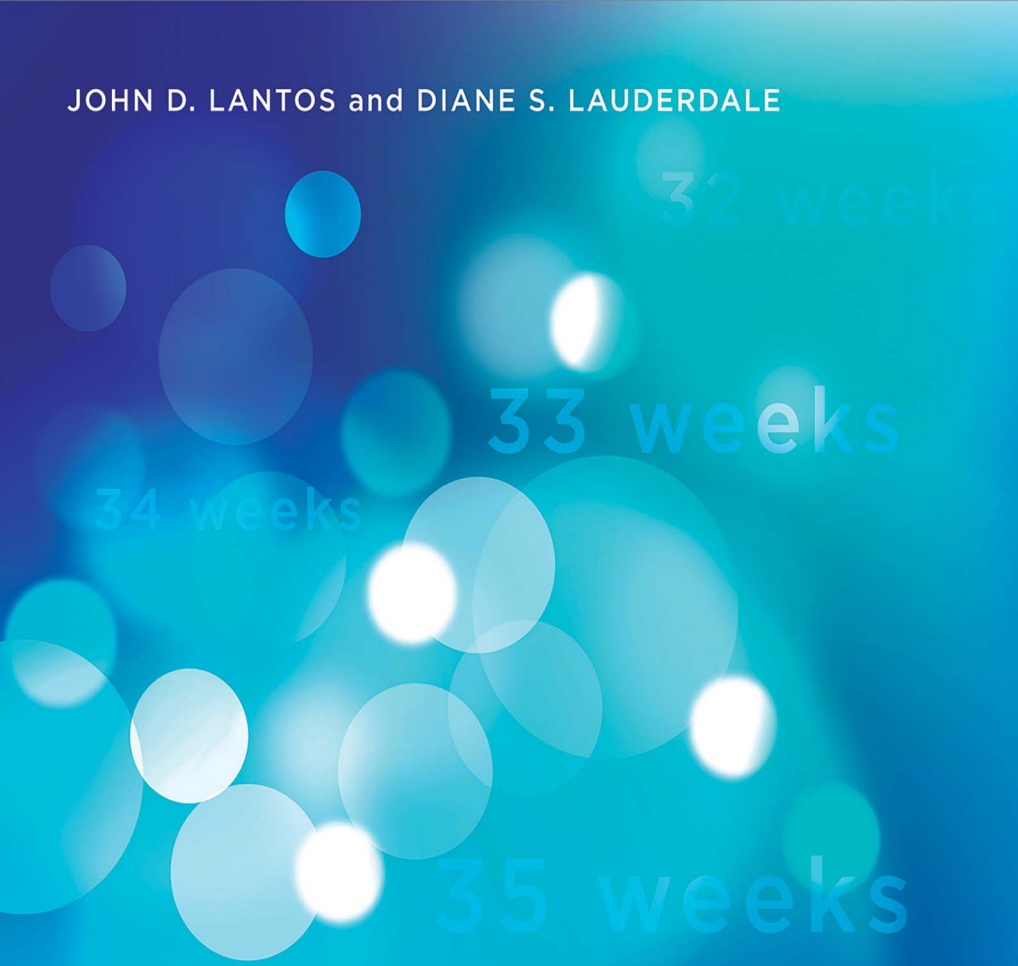
JOHN D. LANTOS and DIANE S. LAUDERDALE



Preterm Babies, Fetal Patients, and Childbearing Choices

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Basic Bioethics
Arthur Caplan, editor

A complete list of the books in the Basic Bioethics series appears at the back of this book.

Preterm Babies, Fetal Patients, and Childbearing Choices

John D. Lantos and Diane S. Lauderdale

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Series Foreword

Glenn McGee and I developed the Basic Bioethics series and collaborated as series coeditors from 1998 to 2008. In Fall 2008 and Spring 2009 the series was reconstituted, with a new Editorial Board, under my sole editorship. I am pleased to present the forty-sixth book in the series.

The Basic Bioethics series makes innovative works in bioethics available to a broad audience and introduces seminal scholarly manuscripts, state-of-the-art reference works, and textbooks. Topics engaged include the philosophy of medicine, advancing genetics and biotechnology, end-of-life care, health and social policy, and the empirical study of biomedical life. Interdisciplinary work is encouraged.

Arthur Caplan

Acknowledgments

This book has had a decade-long gestation. It would not have been possible without a grant from the Robert Wood Johnson Health Policy Investigators Program. That grant would not have been possible without discussions about the problem of preterm birth that we had with many colleagues at the University of Chicago. William Meadow and Larry Casalino made valuable comments on our earliest proposals to study the problem of preterm birth. The RWJ program not only provided funding for the project but also provided an opportunity to present our work in progress at annual meetings to a group of attentive, critical, and helpful scholars.

We were lucky to work with Tyler VanderWeele and Juned Siddique. Both helped design and carry out the empirical analyses about changes in childbearing over the last few decades that formed the first stage of our project. Both were lead authors of papers whose results informed our evolving understanding of preterm birth. Scott Moses gave valuable feedback on an earlier draft of the manuscript. Katharine Lauderdale created the figures for the book.

We were given opportunities to try out the arguments in the book at medical conferences and grand rounds presentations at

the University of Chicago, Children's Mercy Hospital in Kansas City, Northwestern University, Vanderbilt, and meetings of the American College of Epidemiology and the Pediatric Academic Societies.

1 Two Narratives about Pregnancy in the Twentieth Century

A little girl is born weeks before her due date. Her mother looks at the new tiny person and worries about her future. She is such a fragile little wisp. Will the prematurity cause problems down the road? Will her eyes or her lungs be weak? Will she have trouble in school? Will she have emotional problems? Her mother worries about when her baby will be able to leave the hospital. She is afraid that breast-feeding will be impossible.

In addition to all these worries about the baby, the new mother also has another set of worries. She wonders whether her baby's early arrival was her fault. Was there something about her own health and her actions during pregnancy that caused this? Was it the flu she had in the fifth month? The acetaminophen she took for headaches before she knew she was pregnant? She has been stressed at work and having trouble sleeping. Could that have caused the premature birth? Was all this preventable?

She is also grateful. She is grateful for the technologically sophisticated obstetric care that enabled her to see ultrasound images of her tiny fetus. On the ultrasound screen, she could see the heart beating. She could count the fingers. She could sort of see that her baby looked normal. She was grateful for the technology that monitored the infant during delivery. She knew

that, but for the miracle of modern neonatal intensive care, her baby would probably not have survived. Preterm infants like hers all used to die. Now they can grow strong and go home, cooing and crying like normal, full-term babies. Now they can go on to live happy, normal lives.

While her baby is in the neonatal intensive care unit (NICU), a mother's every day is a rollercoaster of emotions. In any single hour, she will feel fear, guilt, gratitude, anxiety, hope, and confusion. She will be told things that are reassuring and things that she doesn't understand. She will be addressed with sensitivity and with condescension. She will sometimes feel supported. At other times, she will feel judged. She will absolutely love some of the nurses. Others will always be just "the blond one" or "the mean one."

Many parents in the United States go through such experiences after a premature birth. The United States has one of the highest rates of premature birth among industrialized nations. Our preterm birth rate is nearly twice as high as in many European countries (though preterm birth rates are rising in Europe, too).[1] The percentage of babies born preterm in the United States (11.5%) is closer to the rates found in India (12.9%) or Ethiopia (10.1%) than the rates found in France (6.7%) or Sweden (5.9%).[2] Within the United States, rates vary greatly by race and ethnicity. In 2012, the preterm rate was 10.3% for non-Hispanic white infants and a similar 10.2% for Asian and Pacific Islander infants, but 16.5% for non-Hispanic Black, 13.3% for American Indian and Alaskan Native and 11.7% for Hispanic infants. Note that *all* of these rates are higher than European rates.[3]

Although the preterm birth rate in the United States has stopped increasing in the past five years, and has even ticked downward, it remains much higher than in comparably wealthy

countries. In 2012 the state with the lowest preterm birth rate, Vermont, still had a higher rate than almost every European country. Even with the recent decline, the preterm birth rate could be seen as one of the major public health failures of the United States in our time.

This book is an exploration of why so many preterm babies are born in the United States, why the rate has risen over the last few decades, and why, even though preterm birth is a leading cause of infant mortality, the U.S. infant mortality rate has been steadily falling. We have two central theses. One is that the problem of premature birth is complex and multifactorial. It cannot be understood as simply a medical problem or a social problem or a problem of access to prenatal care. There are no simple solutions and no single solutions to prevent preterm birth. Some of the immediate causes of early birth can be attributed to the mother and her health and health behavior. Other causes reflect larger contextual factors that have contributed to our very high rate of preterm births, factors that include social and cultural changes. They also include changes in the clinical practices and the technologies used in obstetrics and pediatrics. We will even suggest that some of the most widely touted and ardently defended responses to the problem of premature birth, such as increased emphasis on comprehensive prenatal care, may paradoxically lead to more premature births rather than fewer.

That leads to our second thesis in the book. Premature birth may not mean what it meant a few decades ago. Then, reducing preterm birth was a priority because it was a means to reducing infant mortality. The correlation between premature birth and infant mortality today is not as tight or as straightforward as it used to be. As the preterm birth rate rose in the United States over the last few decades, the infant mortality rate fell. This can

be seen in figures 1.1 and 1.2. The first graph shows that infant mortality rates dropped from 6.91 in 1,000 in the year 2,000 to 6.05 per 1,000 in 2011, a 12% decline.[4]

The second graph shows that during those same years the preterm birth rate reached an all-time high. Between 1981 and 2008 it rose nearly 20%, from 10.5% to 12.6%.[5] Over the last five years, the preterm birth rate has started to drop. Neither the early rise nor the most recent fall seems to have had much effect on infant mortality.

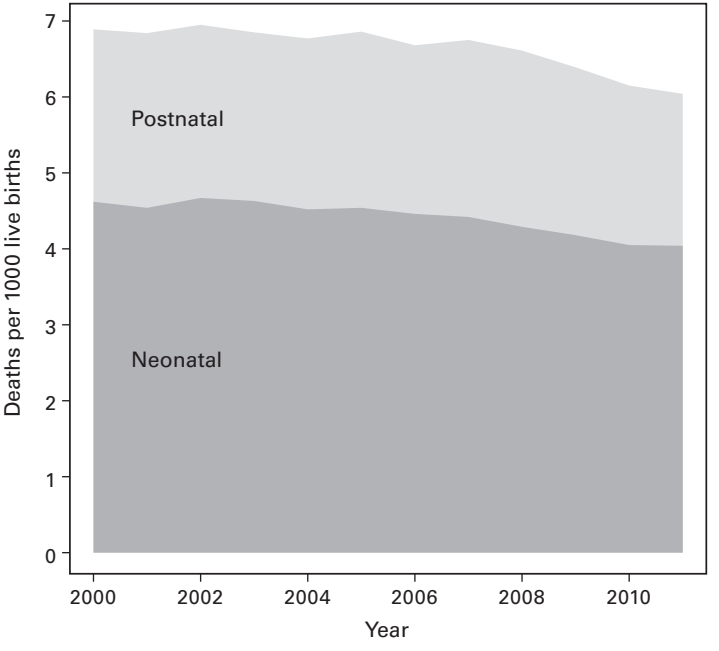

Figure 1.1
Neonatal and postnatal mortality rates in the United States, 2000–2011. Source of data: Martin JA et al., Births: Final data for 2012. National vital statistics reports; vol 62 no 9.

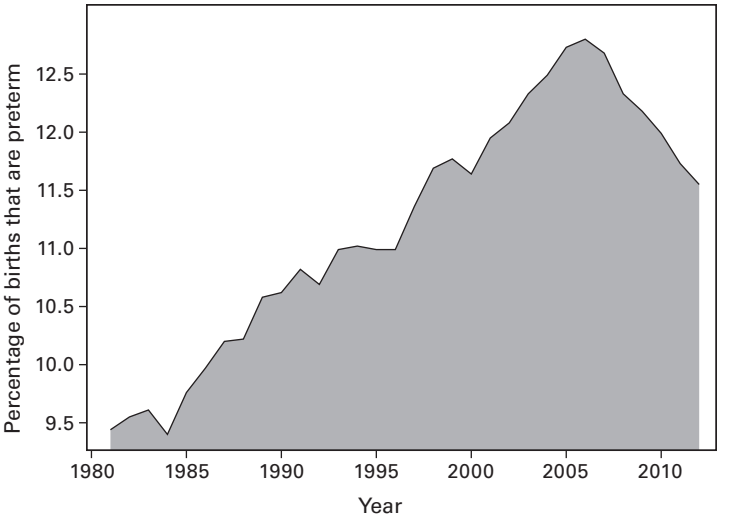

Figure 1.2
The U.S. preterm birth rate from 1981 to 2012, showing an increase from 1981 through 2006 and then a steady decline since 2006. Source of data: Martin JA et al., Births: Final data for 2012. National vital statistics reports; vol 62 no 9.

For at least thirty years, then, we have had rises and falls in the rate of preterm birth accompanied by steadily falling rates of infant mortality. We will examine the implications of these trends in preterm birth rates and infant mortality in detail and try to figure out why our preterm birth rate remains high and why, in spite of that, our infant mortality rate is getting steadily lower.

One factor that may be crucial is that over the last half-century there have been many changes in the ways that we go about having babies in the United States. Women have fewer babies over the course of their lives than they used to. As demographers

would put it, our total fertility rate is falling. Women are having babies at a different stage of life. More women are delaying childbearing than ever before, so the average age of women at the time of childbirth is going up. There are fewer births to teenage mothers today than at any time in our history. More people use effective contraception, so the number of pregnancies and the number of births for the average woman in the United States is lower than ever. These changes have been made technologically possible by better techniques to control fertility. Advances in prenatal diagnosis and the legalization of abortion have made delayed childbirth possible without the otherwise inevitable rise in the number of babies born with chromosomal anomalies. We will explore the impact these changes have had on the rate of preterm birth.

Our exploration leads to a surprising realization. Preterm birth, while obviously not desirable, may no longer be synonymous with a bad birth outcome. Rates of preterm birth have long been a focus of attention because they served as a surrogate measure for tracking the much lower infant mortality rate, allowing researchers and policy makers to identify trends, and differences between population groups, that could not be seen as clearly from an examination of infant mortality. Preterm birth was considered a key preventable cause of infant mortality, even though prevention has not been very successful. If the trends in preterm birth and infant mortality do not move in parallel, then it is less clear what preterm birth rates tell us. The fact that the rate of preterm birth has risen while the rate of infant mortality has fallen shows, at the very least, that preterm birth is not a measure of the risk of infant mortality on a population level. The corollary is that preventing preterm birth may not necessarily bring about a lower rate of infant mortality.

Another interesting feature of childbearing in the United States today, one that is less widely publicized than the preterm birth rate or the infant mortality rate, is that the rate of fetal mortality—that is, of stillbirth—has also fallen dramatically over the last thirty years. Fewer pregnancies end in stillbirth today. This change, which we discuss in more detail in chapter 3, has enormous implications both for individual decisions and for public health policy.

Our analyses raise questions about some of the conventional wisdom about pregnancy, childbirth, and infant mortality. To focus these questions, we suggest that two very different and competing narratives have been told about the development of the modern American way of pregnancy and childbirth. These narratives are at odds with one another.

One is the story of women's long march to reproductive freedom. This story begins with Margaret Sanger's rejection of her mother's Catholicism, her civil disobedience, and her brave attempts to provide birth control to all women who wanted it. It goes on to tell how Sanger collaborated with scientists and philanthropists to develop the oral contraceptive pill. The story then shifts from the laboratory to the courtroom, where litigators eventually convinced the United States Supreme Court to strike down laws that prohibited women from buying birth control, which led to the eventual legalization of abortion and the establishment of women's right and ability to control their own fertility and their own bodies. The same values allow women today to choose to schedule their cesarean deliveries, to have their babies in hot tubs, or to avail themselves of in vitro fertilization. By this story, these are the best of times. Pregnancy is safer than ever for women, and infant mortality is lower than it has ever been.

A counternarrative sees modern obstetrics as fundamentally hostile to women. By this telling, women are the victims of a culture in obstetrics that has turned pregnancy into an illness. The empowering phenomenon of childbirth has been transformed into a disempowering experience in which unnecessary medical interventions are provided in settings that prohibit women from having their babies in a healthy way. This view of pregnancy and childbirth today sees the rising rate of C-sections and medical inductions of labor as a sign of the abject failure of the entire enterprise, one that harms women and leads to outcomes for both women and babies that are far worse than in other industrialized countries.

Tellers of the first story point to the dramatic drops in pregnancy-related mortality and in complications of delivery such as incontinence, sexual dysfunction, and chronic abdominal pain. Tellers of the second story point to the fact that maternal mortality rates have leveled off or perhaps even begun to rise in the United States and are higher than in most European countries.

In these debates about obstetrics, the focus is typically on women. In this book, we will try to connect changes in reproductive health care, contraception, and obstetrics with outcomes for babies. In particular, we will examine infant mortality rates and preterm birth rates in order to see whether changes in obstetrics are making things better or worse for babies. Here, too, different stories can be told. On the positive side, the infant mortality rate in the United States is lower than it has ever been. More than 99 of every 100 live-born babies now live to see their first birthday. On the negative side, our infant mortality rate in the United States remains much higher than in many other countries. More problematically, racial disparities in survival rates, always large, are getting bigger rather than smaller.

This book is an attempt to make sense of these competing stories by analyzing the facts that lie behind them. It began as an attempt to understand why prenatal care did not seem to be working the way it was supposed to work. Better access to prenatal care was supposed to lead to lower rates of preterm birth. But more women get prenatal care today, and they get more of it than ever. What went wrong?

Preterm birth has long been recognized as the leading cause of infant mortality and morbidity. Preterm babies who survive are at heightened risk for a lifetime of medical problems and medical costs. Both preterm birth rates and infant mortality rates are among a small number of markers or "sentinel events" that are used to measure the overall efficacy of a nation's health care and social welfare systems. For many policy analysts, measuring preterm birth rates is like taking the temperature of a nation. The implications of high rates of preterm birth go beyond purely medical considerations. Higher national rates of preterm birth or infant mortality can be correlated with many other national characteristics and indexes (though not necessarily in a cause-and-effect relationship). Countries that spend a higher percentage of their GDP on their militaries have higher rates of infant mortality.[6] Better access to clean water and effective sewage disposal are associated with lower rates of infant mortality.[7] Countries with more teachers in their schools have lower rates of infant mortality. These sorts of associations do not necessarily reflect causation or, if they do, it may be direct or indirect. But the associations are suggestive of the symbolic ways in which high infant mortality rates are seen as a sign of a sick health care system—or a sick society. Lower rates signify that the health care system and, by analogy, the society that creates and supports it, is working.

The World Health Organization publishes international rankings of preterm birth rates that look like the standings of sports teams in a league. By these rankings, the United States should have fired our coach long ago. We have been falling slowly and steadily in the international rankings for the last thirty years. The frequency of preterm births is now about 12% in the United States and 5% to 9% in most other developed countries.[8] The comparison can be seen in figure 1.3.

Preterm birth is defined as birth before 37 weeks of gestation, measured from the woman's last menstrual period. Low birthweight—that is, birthweight of less than 2,500 grams—is not synonymous with preterm birth, although the terms are sometimes used as if they are interchangeable. A baby can be preterm but weigh more than 2,500 grams, or low birthweight but full term. However, there is significant overlap between the two classifications. From a public health perspective, either can be used to monitor health policies, although a third category, "small for gestational age" is also used to describe low birthweight, full-term infants. Preterm birth rates are generally higher than rates of low birthweight because many babies born close to term have "normal" birthweight. Even when preterm birth is the conceptually preferred metric, low birthweight may be used because weight is almost always accurate on birth records while gestational age may be imprecise.

Our failure to reduce the rate of preterm birth has not been for lack of effort. Like a drumbeat, national commissions periodically recognize and highlight preterm birth as a significant medical and public health problem. Those reports invariably set ambitious goals of reducing preterm birth or low birthweight. Often, they recommend concrete mechanisms for achieving that goal.

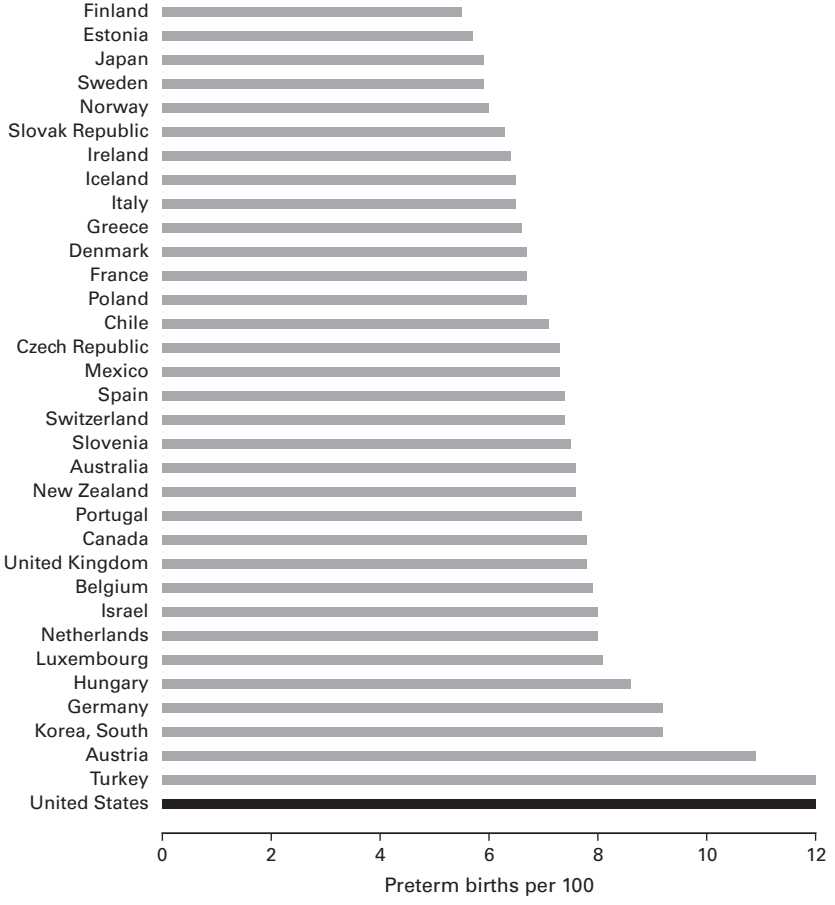

Figure 1.3

Preterm birth rates in 2010 among countries in the Organisation for Economic Cooperation and Development (OECD). Data based on Liu L, Johnson H, Cousens S, et al., Global, regional, and national causes of child mortality: an updated systematic analysis for 2010 with time trends since 2000. *Lancet* 2012;379:2151–2161.

In 1985, the Institute of Medicine (IOM) issued one such report. It was entitled *Preventing Low Birthweight*. That report laid out the stark facts,

> Low birthweight is a major determinant of infant mortality in the United States. In addition to increasing the risk of mortality, low birthweight also increases the risk of illness…The association of neurodevelopmental handicaps and congenital anomalies with low birthweight has been well established; low birthweight infants also may be susceptible to a wide range of other conditions, such as lower respiratory tract infections, learning disorders, behavior problems, and complications of neonatal intensive care interventions.[9]

The report offered a solution to the problem. Better access to prenatal care, the authors claimed, would lead to lower rates of preterm birth. This solution reflected the consensus among experts at the time who saw the lack of access to prenatal care as the major correctable cause of low birthweight and preterm birth. Epidemiologists noted that "low birthweight, neonatal mortality, and infant mortality were 1.5 to 5 times greater with late, less frequent prenatal care than with early, frequent care. Multivariate analysis demonstrated a positive relationship between prenatal care and birthweight."[10] Many studies showed similar associations and echoed the claim that better access to prenatal care would lead to lower rates of preterm birth.[11]

The IOM report argued that expanding Medicaid to provide better access to prenatal care would not only be effective in reducing low birth weight and preterm birth but would also be cost-effective. The authors argued for the following causal chain: (1) poor people without health insurance were less likely to seek and receive prenatal care than wealthier, insured people; (2) programs to provide insurance to poor people would lead to higher rates of prenatal care; (3) higher rates of prenatal care would lead

to lower rates of preterm birth; (4) lower rates of preterm birth would mean less need for expensive neonatal intensive care, which was already paid for by government insurance programs; therefore, (5) increased access to prenatal care would lead to a net cost savings for government insurance programs. The IOM estimated that every dollar spent on prenatal care would save $3.37 in neonatal care expenses. This led one legislator to conclude, "It is not often that a person in public life gets to say, 'I know how to save the lives of American children and save taxpayer money at the same time.'"[12]

In response to this report, Congress passed legislation in the late 1980s providing funding to expand the Medicaid program in order to improve poor women's access to prenatal care.[13] This legislation passed with bipartisan support. President George H. W. Bush signed it into law.

In one sense, the Medicaid expansions worked. More poor women did, in fact, enroll in Medicaid, and more of these women received prenatal care. From 1990 to 2003, the percentage of women who received prenatal care during the first trimester of pregnancy increased in all racial and ethnic groups. Over these years, the percentage of pregnant women who received no prenatal care was cut in half.[14]

But in a more important sense, these Medicaid expansions did not work at all. National rates of both preterm birth and low birthweight birth continued to rise during the same years.

In 1991, the U.S. surgeon general issued a report, "Healthy People 2000," setting ten-year goals for the nation's health. One of the goals was to reduce the rate of low birthweight births from 6.9% to 5%. Over the ensuing decade, the rate rose to from 6.9% to 7.6%.[15] Undaunted, the surgeon general issued a new set of goals, "Healthy People 2010," calling once again for a reduction

in low birthweight to 5%. That report also called for a reduction in preterm birth from 11.6% to 7.6%. Over the next years, both low birthweight and preterm birth continued to rise.

In 2007, the IOM issued its own report. Once again, the authors presented the compelling case for a new national effort to reduce the rate of preterm birth. They noted,

> Infants born preterm are at greater risk than infants born at term for mortality and a variety of health and developmental problems. Complications include acute respiratory, gastrointestinal, immunologic, central nervous system, hearing, and vision problems, as well as longer-term motor, cognitive, visual, hearing, behavioral, social-emotional, health, and growth problems. The birth of a preterm infant can also bring considerable emotional and economic costs to families and have implications for public-sector services, such as health insurance, educational, and other social support systems. The annual societal economic burden associated with preterm birth in the United States was at least $26.2 billion in 2005.[16]

In 2008, in a third report, the Surgeon General of the United States echoed the IOM's call for more attention and research to the problem of preterm birth.[17]

And the preterm birth rate continued to rise.

Over these years, the relative international ranking of the U.S. infant mortality rate steadily worsened.[18] In 1960, only a few European countries had lower infant mortality rates than the United States. Now, we are not in the lowest fifty.[19] We seem to be even worse at perinatal health care than we are at soccer and math.

Preterm birth is one of the leading causes of infant mortality. So it seemed that our failure to prevent preterm birth was one of the reasons why we were also unable to lower our rate of infant mortality. By 2010, CNN could report that

The United States has the second worst newborn mortality rate in the developed world, according to a new report. American babies are three times more likely to die in their first month as children born in Japan, and newborn mortality is 2.5 times higher in the United States than in Finland, Iceland or Norway. Only Latvia, with six deaths per 1,000 live births, has a higher death rate for newborns than the United States, which is tied near the bottom of industrialized nations with Hungary, Malta, Poland and Slovakia with five deaths per 1,000 births.[20]

What has gone wrong? Better access to comprehensive prenatal care for more pregnant women was thought to be the best means to reduce the rate of preterm birth and thus the rate of infant mortality. But improved access to prenatal care did not seem to be helping in the way it was supposed to help. The United States kept trying harder but seemed to be moving in the wrong direction.

In order to investigate what was behind this phenomenon, we sought and were awarded a grant by the Robert Wood Johnson Foundation's Health Policy Investigator Program. Our project was entitled "Prenatal Care: Wise or Wasteful?" We set out to examine whether prenatal care was an ineffective waste of money. Our inquiry began as a narrowly focused analysis of the content and the efficacy of prenatal care. It gradually expanded. Prenatal care, it turns out, has changed dramatically over the last 100 years. There are many reasons for that. Some reflect advances in technology such as amniocentesis, fetal ultrasound, or intrauterine fetal monitoring. Others reflect changes in patterns of childbearing, particularly the tendency of women today to delay childbearing until they are older. That tendency leads to both infertility and higher-risk pregnancies.

We realized that preterm births had also changed. Many preterm births now are medically induced. We needed to explore the ways that obstetricians think about the risk of stillbirth and

the benefits of induced preterm birth. Those risks cannot be understood without also analyzing the rise of neonatal intensive care. So the problems of prenatal care, preterm birth, and infant mortality must be understood in the context of a long and complex story about the ways that we go about having babies and how that has changed in the past century.

Our inquiry into the causes of preterm birth grew broader. During the last decades of the twentieth century, people were changing the way they thought about and organized family life. Marriage did not mean what it used to mean. Career paths were different. The demographic makeup of our society was changing. Many of those changes were related to the rising rates of preterm birth—some as cause and some as effect. It was hard to make sense of the story of rising preterm births without placing it in the context of a society in which so many other things were changing. So the two narratives of childbearing do not tell the whole story. Instead, it is a story with a number of subplots, many possible protagonists, and ambiguous heroes, heroines, and villains.

One subplot began in 1913, when the newly formed Children's Bureau of the Department of Labor issued its first handbook on prenatal care. That handbook expressed a clear view of the role of prenatal care. After extensive discussions of diet, exercise, and psychological health, the book concluded, "If the pregnant woman lives in such a manner as to establish and conserve her own health, taking plenty of sleep and exercise, eating sensibly of simple food, and in every way striving to take the best possible care of her own body so that the digestive, assimilative, and excretory functions are carried on in the highest degree of efficiency, she can be quite sure that the child will be able thereby to build up for himself a sound and normal body and

brain."[21] This was the prevailing view of prenatal care throughout most of the twentieth century. It is the view that informed the 1985 IOM report. Prenatal care was seen essentially as a preventive sort of therapy focused on the health and well-being of the pregnant woman.

Another subplot began a few years later, in 1916, when Margaret Sanger was arrested for daring to dispense birth control in a clinic she had started for that purpose in New York City. Sanger also wanted to improve the health of babies and mothers. She sought to do so by giving women some control over their fertility so that they could limit the number of babies they bore and thus bear healthier ones. Forty-four years later, scientific research inspired by Sanger led to the first FDA-approved oral contraceptive pill.

An important chapter of the story we tell about the ways that we go about having babies concerns the events of 1942. In that year, Wilson demonstrated that supplemental oxygen could improve respiratory status in premature babies.[22] This breakthrough marked the beginning of modern neonatal intensive care. The development of neonatal intensive care would eventually lead to therapies that would reduce infant mortality not by preventing preterm births but by saving preterm babies who were dying of respiratory distress syndrome and other problems associated with prematurity. The next big advance in the neonatal care piece of the story came in 1964, when Delivoria-Papadopolous and colleagues in Toronto showed that they could intubate the trachea of a dying premature baby and keep her alive using intermittent positive-pressure ventilation.

Other highlights of the narrative include the work of Jerome Lejeune and that of Arthur Liley. In 1959, Lejeune showed that Down syndrome was caused by an extra chromosome, a

discovery that led to amniocentesis and the ability to diagnose a variety of diseases in the fetus. Liley developed techniques to measure bilirubin levels in amniotic fluid and to perform intrauterine blood transfusions on babies with Rh disease. With these extraordinary interventions, for the first time the fetus became a patient, whose treatment was separate from that given to the pregnant woman.

Liley's work to make the fetus a patient who could be treated was given a further nudge in 1962 when Hon showed that he could continuously monitor fetal heart rate patterns. He began to understand the relationship between fetal heart rate abnormalities, fetal distress, and stillbirth.[23] Nadler's 1968 report of the first diagnosis of trisomy 21, made using cultured cells from amniotic fluid, was a key development in the evolution of prenatal care from a purely preventive treatment to one focused on diagnosis of diseases in the fetus.

These discoveries had complex ramifications. They expanded the range of choices available to women. Safe, effective, and available birth control allowed women to control their fertility. The ability to diagnose fetal disease and fetal anomalies allowed women not just to manage their fertility but also, to a certain extent, to have healthier babies; or, conversely, to know when the health of a fetus was so impaired that it made sense to terminate the pregnancy. The ability to diagnose fetal disease in these new ways allowed obstetricians to tell pregnant women if their babies would be born with severe congenital anomalies. This knowledge was a key component of the rationale and cultural support for the legalization of abortion.

A new chapter in the long story of changing reproductive practices began in 1970 when the Boston Women's Health Collective published the first edition of *Our Bodies, Ourselves*. That

book would change the ways that women thought about pregnancy and childbirth. It encouraged women to discuss health and sexuality with each other, to learn about the medical controversies associated with common practices in obstetrics and gynecology, and to question some of those practices.

All of these developments form the story of changes in the ways in which we have babies. Direct assessments of fetal health and wellbeing allow obstetricians to make decisions based upon those assessments, and to calculate the benefits and risks of particular interventions for the fetal problems they have diagnosed. Sometimes, these assessments lead to the conclusion that the best thing to do for both mother and baby is to medically induce a preterm delivery. The net effect of these changes has been to sever the previously tight connection between preterm birth and infant mortality. Today, those two measures no longer move in lockstep. Even as preterm birth rates have climbed steadily higher, infant mortality rates have just as steadily dropped.

These changes are interconnected. A woman's decision about when to bear children used to be heavily influenced by the relationship between advancing maternal age and higher risk of chromosomal anomalies, especially Down syndrome. The discovery of the chromosomal cause of Down syndrome, the invention of techniques to diagnose it in early pregnancy, and the subsequent legalization of abortion made it possible for women to think about having babies in their late thirties or early forties without increased risk of having a baby with a chromosomal anomaly.

Such developments have had some unanticipated consequences. Women who delay childbirth are more likely to have problems with fertility than younger women. Infertility treatments such as medications that stimulate ovulation or the use of in vitro fertilization (IVF), developed in the 1970s and 1980s,

allow childbearing at older ages. These drugs also increase the rate of multiple births and preterm births. Furthermore, women who are in their thirties or forties when they have babies are at higher risk of delivering preterm than are women in their twenties, even without IVF or twin pregnancies.

Advances in prenatal diagnosis and in the treatment of infertility led to new questions about the moral status of the fetus. The better we get at seeing the fetus, and at diagnosing and treating fetal diseases, the harder it is to make absolute moral distinctions between the fetus and the newborn. We end up with the paradoxical formulation that the fetus can be a *patient* without being a *person*. Arguments ricochet back and forth between the clinic and the courtroom about the implications of diagnosing and treating newborns with congenital anomalies or babies born at the borderline of viability. Should such babies be treated even though treatment is very expensive and outcomes are not always good? Should parents, or doctors, be permitted to let such babies die? How and why do moral obligations and legal restrictions change at the moment of birth? What is the legal or moral significance of that moment of marvelous transition from intrauterine to extrauterine life? Many of the doctors who pioneered the interventions that allow us to diagnose fetal disease were, or became, profoundly opposed to abortion.

Different ways of telling the stories of these developments lead to different conclusions about the implications of our rising rates of preterm and low birthweight birth. They suggest different solutions. Our understanding of the problems and our decisions about how to respond are shaped by the fact that all the debates surround very personal decisions and choices by millions of women and men about sex, love, babies, and families. Thus, discussions of law and policy, though inevitably political, are also

deeply personal. Technical discussions of the science of reproduction eventually lead to new options that shape the world of anyone who wants to have a baby. Many of the key players in these stories have taken an intensely personal interest in the outcomes. So this book became a story not only about science and health policy, but also of individuals and their struggles.

Specific developments occurred against the backdrop of the dramatic scientific and societal changes that took place during the second half of the twentieth century. Many of those changes, indirectly but profoundly, changed the way we think about health and disease, reproductive choices, infant mortality, and public health.

In 1953, Watson and Crick discovered the structure of DNA, or, in Crick's words, "the secret of life."[24] The next year saw the introduction of the polio vaccine. At that time, contraception was still illegal for unmarried women in most states. (Of course, it was only technically illegal. Since the late 1930s, birth control had been widely available, even through federally subsidized programs.[25])

The year John F. Kennedy was elected president was also the year the FDA approved the first birth control pill. By 1968 some colleges were dispensing birth control pills through their student health services. That year, Pope Paul VI addressed his "venerable brothers … and all men of good will" with these words: "The most serious duty of transmitting human life, for which married persons are the free and responsible collaborators of God the Creator, has always been a source of great joys to them, even if sometimes accompanied by not a few difficulties and by distress."[26]

In 1973, the United States Supreme Court ruled that restricting a woman's right to an abortion violated her right to privacy. Over the next decade, the number of clinics offering amniocentesis for prenatal diagnosis skyrocketed.[27]

At the time, doctors recommended amniocentesis or chorionic villus biopsy for women over the age of 35 to diagnose Down syndrome and a few other, rarer, chromosomal anomalies. Conventional wisdom held that, for younger women, the added risk of miscarriage that was a consequence of amniocentesis outweighed the benefits of prenatal diagnosis. The availability of prenatal diagnosis forced all women—and their doctors—to think about whether or not they should take advantage of prenatal diagnosis. These new tests changed pregnancy into something different from what it had been before. In 1986, the sociologist Barbara Katz Rothman coined the term "tentative pregnancy" to describe the new experience of couples awaiting the results of prenatal diagnosis to decide whether to continue or terminate a pregnancy.

For those who chose to continue pregnancy, there would be another set of decisions about when, where, and how to deliver the baby. Some people advocated low-tech home births. Others recommended high-tech tertiary care centers equipped with the most sophisticated fetal monitors and with ready availability of surgical and neonatal care.

Whichever story is told about these profound changes, there is no denying that they have deeply affected the ways people think about sexuality, fertility, pregnancy, and childbirth. They have led many people to make individual and personal choices that, taken together, constitute trends that have contributed to the rise in the rate of preterm birth.

In this book we will explore and analyze many of these changes; we will suggest that they should alter the way we think about the fetus as a patient, about prenatal care, about labor and delivery, and about the ways we measure and evaluate outcomes for women and children.

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