

The Regionalized Perinatal Care Program

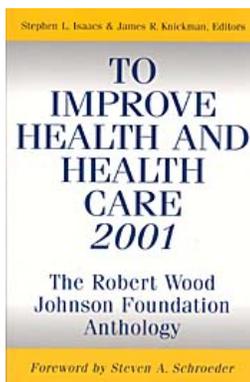
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Robert Wood Johnson Foundation

Chapter Eight,
excerpted from the Robert
Wood Johnson Foundation
Anthology:

**To Improve Health
and Health Care,
2001**



Edited by
Stephen L. Isaacs and
James R. Knickman
Published 2001

Editor's Introduction

In this chapter, Marguerite Holloway, a contributing editor for *Scientific American* and an adjunct professor of journalism at Columbia University, looks back at the efforts of the Robert Wood Johnson Foundation in the 1970s and 1980s to encourage the regionalization of perinatal services—the care delivered to mother and child shortly before and after birth. The development of high-technology care delivered in neonatal intensive care units made it possible to save the lives of low-birthweight babies who previously might have died. But not every hospital could have the sophisticated equipment and specialized staff to care for the small percentage of infants requiring intensive care. It made sense, in the eyes of many maternal and child health experts, to organize services along geographic lines in a pyramid fashion. Pregnant women at risk of delivering a low-birthweight baby would be identified early and transferred up the pyramid to a hospital capable of offering the care necessary. At the top of the pyramid would be a level III hospital—often at an academic medical center—that would treat the most needy newborns in a high-tech neonatal intensive care unit.

Building on regional arrangements to provide care for specific illnesses in the United States and reports of success with regional perinatal care networks in Canada, the Foundation funded an eight-site demonstration program—the Regionalized Perinatal Care Program—to determine whether the regionalization of perinatal services would work on a large scale and with heterogeneous populations.

As Holloway observes, the path has been rocky, and long-term successes have been elusive. While the grantees funded under the program—as well as the comparison sites—made progress toward regionalization and lowering neonatal mortality rates, these achievements often evaporated after funding ended. And from the mid-1980s on, managed care organizations seemed to be directing people to their own networks rather than to networks built along geographical lines.

What is most disturbing about the story is that while infant and neonatal mortality rates have declined over the past 30 years, severe racial, economic and class differences in low-birthweight, preterm delivery and infant mortality rates persist. Even though this is a retrospective review of past programs, the hope is that it will stimulate new thinking on strategies that the nation can pursue to improve perinatal care.

Two or three times a week, David A. Yost, clinical director at the Whiteriver Indian Hospital in Arizona, transfers a pregnant patient by plane or helicopter to the Good Samaritan Hospital in Phoenix, some 200 miles away. "It is for a wide variety of causes: from a teenage mother with early labor, or twins, to complications from trauma or diabetes," he says. "We have a lot of preeclampsia, infectious disease and diabetes, and a lot of that leads to prematurity. We also have a lot of alcoholism, fetal alcohol syndrome and trauma from car accidents in our pregnant patients." Because the Whiteriver Indian Hospital, which is on the Fort Apache Indian Reservation in the eastern part of the state, does not have a neonatal intensive care unit, or NICU, these women and their babies—90 percent of whom are covered by Medicaid—would be in danger unless they could be quickly moved to a fully equipped center.

To try to ensure that Yost and his counterparts in remote areas throughout Arizona have access to university hospitals and large medical centers with perinatologists or NICUs, the state maintains a voluntary perinatal referral and transportation network called the Arizona Perinatal Trust. "The system works," Yost says—except, he adds, sometimes in the winter. "This is a high area and there is lots of snow and in bad weather, if you can't get the airplane on the ground or the patient out the door, you are stuck. But that is just part of living rural."

THE EMERGENCE OF PERINATAL CARE

The Arizona Perinatal Trust arose out of a program funded by the Robert Wood Johnson Foundation in the 1970s to regionalize administration of perinatal care—that is, the care offered to a mother and child just before and just after birth. Perinatal intensive care is a relatively young field, one that emerged in the 1950s and 1960s as a result of technological innovations. The development of ventilation machines and better incubators led to the creation of modern NICUs. In addition, ultrasound, amniocentesis, electronic monitoring of fetal circulation during labor, and various biochemical tests could reveal whether the baby's growth was slow, whether it was in distress and whether it would be able to breathe on its own. Armed with this detailed information and new technology, pediatricians were able to identify high-risk mothers and infants and make a difference.

The results of these interventions were dramatic. Reports from several researchers showed that the interventions had a powerful effect on mortality and morbidity. Working in the 1960s in Quebec, Mary Ellen Avery, currently at Harvard University, showed that state-of-the-art intervention reduced the incidence of neurosensory damage—such as mental retardation, cerebral palsy and epilepsy—in very low-birthweight babies from between 75 and 70 percent to between 20 and 15 percent.¹ A 1973 paper in the

British Medical Journal reported that among 500 high-risk births at St. Thomas' Hospital in London there were no cases of mental retardation if modern methods were used; normally, 10 such cases would have been expected.² Reports from various other areas—including Arizona and Ohio—also pointed to increased survival when newborns were given access to special care.³

But "the study that had really excited the attention of pediatricians and pediatric nurses was a report from Toronto," recalls Kenneth G. Johnson, a physician who directed the Foundation-funded Regionalized Perinatal Care Program. "There were two very good perinatal networks, and they showed that it was just the access to specialized care that was needed."

Thus by the late 1960s and the early 1970s, it had become clear to the medical community that neonatal mortality could be dramatically curtailed if patients had access to specialists, to newly proven technologies and to NICUs. These things were in short supply at the time, however, and it seemed apparent to many people practicing and studying perinatal care that one cost-effective way to improve access for parents in need would be to establish regional networks. In such systems, hospitals with different capabilities would coordinate care. A rural or community health center such as Whiteriver Indian Hospital could transfer a mother whom doctors deemed to be at high risk for premature delivery to a facility that had the requisite NICU. Ideally, such regional organizations would permit every mother and infant access to the right level of care. And they would contain medical costs, because hospitals would not have to build NICUs or recruit perinatologists if they were part of a network with a center that was already so equipped.

The medical community responded quickly. In 1971, the American Medical Association issued a statement on the benefits of regionalized perinatal care. The following year, experts from the American Academy of Pediatrics, the American Academy of Family Physicians, the American Medical Association, the American College of Obstetricians and Gynecologists and the March of Dimes Birth Defects Foundation (then the National Foundation-March of Dimes) met in San Francisco to discuss regionalization. The participants formed a Committee on Perinatal Health, and agreed that implementing systems of community or regionalized perinatal care was imperative. Other changes soon followed: the American College of Obstetricians and Gynecologists formed a maternal-fetal medicine sub-board in 1972; the American Academy of Pediatrics established a specialization in neonatology-perinatology in 1973, and in 1975, neonatal-perinatal medicine became a board-certified subspecialty.

The growing consensus of the medical community was gathered in what has come to be called by many the bible of perinatal care: "Toward Improving the Outcome of Pregnancy: Recommendations for the Regional Development of Maternal and Perinatal Health Services." Published in 1976 by the March of Dimes Birth Defects Foundation, the report outlined the need for a consistent system to screen mothers and infants to determine who was at high risk; it defined levels, or types, of hospitals and the care that was appropriate to receive at each; it emphasized the need for a uniform data system, and it stressed the importance of education and outreach within the medical community.

THE REGIONAL PERINATAL NETWORK

Regionalization of care was not a new idea. Certain areas in the United States had coordinated aspects of their medical services during the 1940s. And in 1965, the federal government had authorized the funding of so called Regional Medical Programs to increase the access of heart disease, stroke and cancer patients to new equipment and procedures.⁴ But opposition by elements of the medical profession was fierce, and the results of these efforts were ambiguous. For the most part regionalization remained untested. "At that time, there was a lot of disbelief," recalls George A. Little, a neonatologist at the Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire. "People needed to be convinced about applying care in a regional fashion. It was not the way that acute care was practiced."

As the groundswell of national interest was emerging, the Robert Wood Johnson Foundation began to explore whether regional perinatal networks were indeed feasible, whether they could reduce neonatal mortality, and if so, whether decreasing mortality resulted in an increase in developmental or other problems as low-birthweight babies survived. One of the principle catalysts for the Foundation's involvement was Irwin R. Merkatz, now chairman of the Department of Obstetrics and Gynecology at the Albert Einstein College of Medicine of Yeshiva University in the Bronx and then at Case Western Reserve University in Cleveland, Ohio. During 1972 and 1973, Merkatz spoke with Walsh McDermott, special adviser to the Foundation, and David E. Rogers, president of the Foundation, about the importance of undertaking a perinatal demonstration project. It was an opportunity, they agreed, to do widely what had been shown in only a few places as workable. Within the Foundation, McDermott developed the idea of funding a demonstration to test the feasibility of establishing regional perinatal networks.

In 1974, the Foundation issued a Call for Proposals. "The nuts and bolts were pretty straightforward," Johnson says. "All the hospitals in a defined area had to come together. And the level I, level II and level III hospitals had to agree to follow a protocol and the use of a systematic problem-oriented risk

assessment system." Although definitions can vary by state, in general, level I refers to a facility that can care for normal or mildly ill newborns; level IIs can deal with infants at moderate risk; and level IIIs have NICUs and can tend to very sick infants. The networks also had to establish a system of referral and maternal or infant transportation, and had to conduct outreach and education. In other words, the project would test the major elements that were being discussed in the perinatal community—and that came to be enumerated in the March of Dimes report.

After reviewing 34 applications, the Foundation selected eight sites (see Table 8.2) and awarded \$17.6 million in grants between 1975 and 1979. The grantees were chosen because they were geographically, socially and economically diverse: the state of Arizona, Cleveland, Dallas County in Texas, three contiguous areas in Los Angeles, Manhattan's Upper West Side, and a 15-county area around Syracuse, N.Y. The thought was that if the demonstrations of regional networks worked in these very different places, they would serve as models for similar regions elsewhere.

Although there were vast differences among the sites, many of the challenges they faced in implementing networks were the same. According to Johnson, friction between the community hospitals and the level IIIs sometimes became debilitating. Doctors often did not want to lose their patients; for some, it was simply a matter of ego. In other places, reimbursement for transportation expenses became a source of conflict.

Record keeping also proved to be a challenge. Merkatz and Calvin J. Hobel, who served as director of the Los Angeles South Bay Regional Perinatal Project, designed a record-keeping system called The Problem Oriented Perinatal Risk Assessment System, or POPRAS. POPRAS enabled every participating institution and health care provider to assess and record risk factors, medical information and care in a consistent way—a crucial need since patients were going to be moving around. All pregnant women were to be evaluated at least twice during the prenatal period, again during delivery and after birth. "It was a kind of sea change in the whole movement," comments David E. Gagnon, president of the National Perinatal Information Center in Providence, Rhode Island. POPRAS was an extensive risk identification system that many later imitated."

Although POPRAS was designed to be the centerpiece of the program—Kenneth Johnson recalls that 60 to 70 percent of the grant money was spent on this aspect—many of the participants had trouble initially setting up the system. It was adopted by four of the sites. Moreover, for some physicians, the uniform

risk identification system was threatening. They were worried that if a mother's risk score was high and they decided not to transfer her, they would be vulnerable to malpractice action. "It was very difficult to get the hospitals and the physicians used to the assessment system," Johnson says. "They just hated it." Other health care workers were concerned about the privacy of their patients, an issue that still resonates today. Johnson recalls that the program attempted to deal with both concerns—by getting informed consent from the patients and by showing that the scoring system was not perfect and that physician judgment remained an important part of risk assessment.

Despite the kinks, most participants reported that the networks functioned well,⁵ and that regional involvement was between 80 and 100 percent except in some of the rural areas, such as Arizona and upstate New York, where facilities were far-flung and only about 60 to 70 percent of the hospitals in the region became partners.⁶ It was also apparent that the identification of high-risk mothers led to many more instances of maternal, as opposed to neonatal, transfer—a sign of success to perinatologists. "There was a shift from the emphasis on the transport of the infant into the referral center to the transport of the mother prior to birth," Gagnon says. "The whole idea was that the best transport unit is the mother's uterus."

Wendy Reynolds of Cleveland agrees that this approach probably saved one of her children. In July of 1977, her daughter, Alicia, was born two-and-a-half months early. "She was in a hurry. She was going to come whether we wanted her to or not," Reynolds says. "It was fairly early in the morning, around 1 a.m., and I woke up because I had to sneeze, and when I sneezed, my water broke. My husband was home, thank God, and he took me to the hospital then. And they monitored me for a little while. They were trying to see if I was really going to give birth. And when they determined I was, they transferred me." Reynolds was moved by ambulance from a level I hospital to a nearby university hospital. Twelve hours later, Reynolds gave birth to Alicia, who stayed in the NICU until she was out of danger. She finally came home in September—almost exactly to the day that she was originally due.

EVALUATING THE PROGRAM

Once the Regionalized Perinatal Care Program ended, the next step was to quantify the project's effects, and, in particular, to address a concern that had been raised at the outset. "The Foundation had many critics at the time we announced the program," Johnson notes. "One serious criticism was that we would reduce mortality, but that these kids would have other problems and that we were not addressing root causes."

In 1980, the Foundation awarded \$2.8 million to three researchers for a two-year evaluation of the project. Marie C. McCormick, who was then at Johns Hopkins University (and who is currently a professor of pediatrics at Harvard University) and her colleagues Sam Shapiro and Barbara H. Starfield set out to determine whether infant mortality had fallen at the eight sites and, if so, whether that decline was due to increased survival of high-risk infants or to a decrease in the number of low-birthweight babies, to regionalization, or to other factors. Their review ultimately appeared in *The Journal of the American Medical Association* in 1985.

The team found that so much had been happening to improve perinatal health nationally that it was hard to see any effect at the eight projects that differed from effects that were occurring in the rest of the country. Neonatal mortality rates had fallen not only at the eight sites but also in the comparison regions: an 18-county area around Albany; six health districts in Brooklyn, New York; a six-county area around Buffalo, New York; Harris and Tarrant counties in Texas; an 11-county area around Rochester, New York; San Diego county; and, finally, Wayne County, Michigan. Between 1974 or 1975 and 1978 or 1979, neonatal mortality in the funded areas fell an average of 19 percent, while it dropped by 25 percent in the comparison areas.⁷ The evaluators attributed two-thirds of the decline to the increased survival of low-birthweight babies. This increased survival was due, in turn, the authors noted, to the early identification of at-risk mothers and to the increased delivery of high-risk infants in tertiary centers—that is, level IIIs. Regionalization had clearly shifted the location of delivery: by the end of the decade, 50 percent of low-birthweight babies and 60 percent of very low-birthweight babies were being delivered in level III centers in the foundation-funded areas. And, according to Johnson, whereas before the program about 90 percent of the transfers were made after the baby was born, about half of the transfers were now made before birth.

Again, in the comparison areas, the same shift had occurred. "The centralization of high-risk deliveries appeared so widespread that the special effect of the RWJF program could not be detected," the authors concluded. They noted that although the degree of change in the comparison areas could not have been predicted at the start of the program, the March of Dimes recommendations published in 1976 and the publicity given to the Foundation's program "may have encouraged regionalization in the absence of specific funding."

The evaluation also addressed the issue of morbidity. The study found that, at one year of age, there was no increased incidence of congenital anomalies or developmental delays among low-birthweight babies.

Developmental delays and congenital anomalies actually decreased by about 15 percent, and most dramatically in the very low-birthweight group: by about 22 percent.⁸ This was not, however, the final word on low birthweight and child health.

The Regionalized Perinatal Care Program was followed by a study of long-term development in babies of varying weights, to see how they fared at 8 to 10 years of age, and by a study of the effects of educational intervention.⁹ Marie McCormick, the leader of the evaluation team, and several colleagues continued to monitor some of the babies born at the eight sites. They—and other researchers—found that low-birthweight babies are at increased risk for behavioral and learning disorders, asthma and other health problems, and that the incidence and severity of those problems increases as birthweight falls.¹⁰

The findings from the evaluation of the Regionalized Perinatal Care Program indicated that a national trend toward regionalization of perinatal services had emerged, to the degree that the Foundation-funded sites represented, as L. Joseph Butterworth, a pediatrician at the Children's Hospital in Denver, Colorado, remarked many years ago, "eight large boulders in a landslide."¹¹ Yet the Foundation's role was not insignificant, "What the Foundation did was, in a sense, to support something that was emerging at a critical time," says the National Perinatal Information Center's Gagnon. "They tested it and drew attention to it."

THE REGIONAL NETWORKS AFTER THE PROGRAM

Over the years, the eight Foundation-funded networks each went their separate ways. Some fell apart—including the networks in Los Angeles and Dallas County, Texas¹²—while the others evolved. Arizona, for its part, took the money left over from its grant, combined it with funds from Samaritan Health Services and St. Joseph's Hospital in Phoenix, and in 1980 established the Arizona Perinatal Regional System, Inc. This body oversees a voluntary certification system for participants: the Arizona Perinatal Trust, which David Yost is part of today. Cleveland and New York, in turn, received state support to continue the networks in some form.

But Arizona and New York were not able to keep the records system in place. "One of the big problems we had was that the Robert Wood Johnson Foundation had funded a huge statewide data system," says Deb Christian, executive director of the Arizona Perinatal Trust. "After the program ended, entry of that data stopped." Christian notes that the lack of a continuing record system hinders the effectiveness of the

network. The same holds true in New York, where the state Department of Health is just starting a statewide Perinatal Data System.

A dearth of data is something that many perinatologists around the country are decriing, particularly as they struggle to understand the persistence of preterm delivery, low birthweight and racial differences in neonatal mortality. "A major barrier to monitoring neonatal intensive care on a large scale is the lack of adequate data sources," note Jeffrey D. Horbar and Jerold F. Lucey in "The Future of Children," a report published in 1995 by the David and Lucile Packard Foundation.¹³

The fact that perinatologists are still calling for a uniform perinatal data system angers Irwin Merkatz, who argues that POPRAS should have been maintained and extended—with Foundation money. "There were many systems that needed not only initial investment but continued investment," he says. In addition, Merkatz believes that the Foundation should have worked to get states more focused on maternal and child health, to leverage the experience of the networks while it was still hot. "My view is that the Foundation was uniquely placed to build upon their success and to make the next level of investment to keep that moving forward," he says. "Now here we are in 1999, and we are still lacking a comprehensive system of maternal and child health."

Within the Foundation, there is some consensus that there should have been more follow-up for the Regionalized Perinatal Care Program. "The prevailing philosophy at that time was that we would absolutely not do follow-up grants," says Frank Karel, vice-president for communications at the Robert Wood Johnson Foundation. "We would plot out what was a reasonable trajectory and then it was on its own." Today, he says, the Foundation has seen the error of that rigidity; there is more openness to longer programs and to follow-on initiatives.

THE RURAL INFANT CARE PROGRAM

Although the Foundation did not sustain its involvement with the eight regional perinatal networks, it did continue to examine perinatal health through a variety of programs, trying to identify gaps in the medical delivery system and to address infant mortality and morbidity. Between 1980 and 1985, the Foundation, under the Rural Infant Care Program, gave \$8.3 million to 10 medical schools to work with state and local health departments in rural areas that were isolated, where poverty was high, and where residents had poor access to care. The project activities ranged from organizing meetings among physicians, hospital administrators, and public health department staff to expanding prenatal services and instituting regionalization of perinatal care. A later evaluation found that in funded areas neonatal

mortality decreased by 2.6 per 1,000 births; among blacks, that figure was even higher: a reduction of 4.5 per 1,000.¹⁴ Three groups of comparison areas that did not receive Foundation funding experienced no significant changes in neonatal mortality rates. The decrease in mortality was attributed to reduced mortality among low-birthweight babies—many more of whom were being born in tertiary centers. The incidence of low-birthweight deliveries remained the same, however.

The Rural Infant Care Program was intended to follow up on the insights gleaned during the Regionalized Perinatal Care Program. "We brought the same approach to the 10 states with excessive infant mortality," Kenneth Johnson says. "And there again we were able to form a partnership between a maternal and child health department in the state and the hospitals and the practitioners taking care of their patients."

REGIONAL PERINATAL SERVICES TODAY

The landslide to which the Foundation contributed eight boulders in the 1970s continued into the 1980s. In 1978, the Department of Health and Human Services issued guidelines mandating that neonatal and maternal obstetrics be planned on a regional model,¹⁵ and by the end of the 1980s, 26 states had established referral systems or had guidelines for perinatal networks in place.¹⁶

Regional networks have been widely credited as one of the principle reasons for the rapid decline in neonatal mortality rates in the last several decades. (The other principal reason is the introduction in the late 1980s of surfactant replacement therapy, which reduced the incidence of lung disease in newborns.) Over the years, several studies have confirmed the value of transferring high-risk mothers and infants into level IIIs. For example, Nigel S. Paneth of Michigan State University found that mortality of low-birthweight babies was significantly higher in level I and level II centers than it was in level IIIs—in some areas, mortality decreased by one third to one half when the babies were tended to in tertiary centers.

Despite their recognized effectiveness, however, regional perinatal networks have begun to fall apart. They began to unravel in the 1980s, and the process continued with greater velocity in the 1990s. Two primary reasons explain this: first, the competition for patients that has developed between level II and level III hospitals and, second, the effect of managed care, which encourages the transfer of patients within the managed care company's network rather than within geographically constructed networks.

The first of these reasons stems, paradoxically, from the very recommendations the perinatal community made in the early 1970s. Because of the new programs in perinatology, a wealth of specialists began to hit

the job market and, since the level IIIs were filled up, started working in level II hospitals. At about the same time, in the 1980s, the number of obstetrical malpractice suits rose, so more obstetricians started demanding that perinatologists or neonatologists be in attendance in their hospitals. Currently, these specialists appear to be in anything but short supply: by some estimates, there are 3,500 neonatal physicians. "I always incur a lot of rancor, because my sense is that we have about twice as many as we need or should have," says James Lemons, professor of pediatrics at Indiana University and chair of the American Academy of Pediatrics Committee on Fetus and Newborn.

In addition, hospitals began trying to attract a clientele in an increasingly competitive market, and having an NICU was one way to do this. Indeed, the proliferation of neonatal units has been stunning. In 1979, there were about 315 units in the United States; by 1997, there were 1,085.¹⁷ And between 1983 and 1997, according to David Gagnon of the National Perinatal Information Center and his colleague Rachel M. Schwartz, the number of neonatal beds has grown from 6,893 to 11,908.¹⁸ Gagnon estimates that there are twice as many beds as needed.

These changes have meant that level II hospitals increasingly want to hold on to their pregnant patients and newborns. The perinatologists, understandably, want to practice their craft; the hospitals want to get some return on their NICU or other neonatal investments. As a result, says George Little of the Dartmouth-Hitchcock Medical Center, "women with high-risk pregnancies may not be moved as quickly as they were in the past because of interest in maintaining these systems." The problem with this trend is that level IIs still may not always have the volume of patients needed to keep their practitioners as honed and skilled as they should be.

Some of the literature seems to support this conclusion. A recent study conducted in Missouri found that there had been a shift of deliveries into level IIs that had designated themselves perinatal centers, but that neonatal mortality in those centers remained twice that of the level IIIs.¹⁹ Another study found the same thing in South Carolina: "Very low birthweight infants are more likely to survive if born in level III hospitals than in level I or level II facilities, with or without neonatologists."²⁰ And a report by Ciaran S. Phibbs of Stanford University and his colleagues concluded that "the rapid expansion of level II and level II+ NICUs in California in the 1980s has probably resulted in significantly higher risk-adjusted neonatal mortality than would have occurred if more of the care for high-risk deliveries had been concentrated in hospitals with level III NICUs."²¹

David Gagnon is not sure he agrees that the proliferation of level IIs inevitably leads to poorer care. "My own personal feeling is that that is not necessarily the case," he says. And he notes that the ability of community and level II hospitals to deal with high-risk infants is often comforting for mothers, who sometimes ended up far from their homes, families and physicians when they were transferred—which was one of the criticisms of regional perinatal networks.²² But, he adds, the proliferation "certainly cannot be justified on an economic basis." Gagnon suspects that the surplus of beds and specialists will lead to consolidation, which he is already seeing in places like Minnesota, where there used to be 10 NICUs in the state and there are now only four, concentrated in urban areas.

Another challenge comes from managed care, with its financial incentive to refer patients within its own managed care network rather than to a competing network. In some areas, hospitals that would have referred high-risk mothers to a nearby university center are instead holding on to their patients, hiring perinatologists and upgrading their facilities—many have gone to the multi-million dollar expense of building an NICU. Although definitive answers are not yet available, this situation worries some observers who fear that managed care is undermining the proven effectiveness of regional networks and in some cases may be jeopardizing infant health. "There is a basic mismatch between managed care populations versus geographical populations," notes Bernard Guyer, a professor and chair of the Department of Population and Family Health Sciences at Johns Hopkins University. "From what I am seeing, managed care is changing the pattern of referral," adds Michigan State's Nigel Paneth. "Those patterns clearly have a lot to do with mortality."

WHAT'S NEXT FOR REGIONAL PERINATAL NETWORKS

The crumbling of regional perinatal networks is occurring within a health system that continues to lag behind those of other developed countries. Although infant and maternal mortality have declined steadily since 1900—by more than 90 percent in total—America ranks 25th in the world in terms of infant mortality, with an average of 7.2 deaths per 1,000 live births in 1997.²³ By contrast, Japan has the lowest infant mortality rate, with 4 deaths per 1,000, and Sierra Leone has the highest, with 170 deaths, according to the United Nations.²⁴

A closer look at the statistics reveals another disturbing trend as well—the persistence of a severe racial and economic gap in infant mortality rates despite the overall national decline. In 1997, 13.7 per 1,000 black infants died in the United States as opposed to 6 per 1,000 white infants.²⁵ In 1980, 22.2 per 1,000

black infants died compared to 10.9 per 1,000 white infants.²⁶ Neonatal mortality rates exhibit the same racial and economic gap.

In addition, neither the low-birthweight rate nor the preterm delivery rate has improved in America in the past 30 years.²⁷ Indeed, the rates in the past decade and a half have been increasing. Preterm deliveries increased from 9.4 per 1,000 in 1981 to 11.4 per 1,000 in 1997 for all newborns.²⁸ Likewise, low-birthweight newborns increased from 6.8 per 1,000 in 1981 to 7.5 per 1,000 in 1997.²⁹ Low-birthweight occurs in 7 percent of births—and those babies are 40 times as likely to die as are heavier babies. And, again, the incidence of low-birthweight and preterm delivery is about two times as high among African Americans as it is among whites.³⁰ Although African Americans are responsible for 17 percent of the country's births, they have 33 percent of low-birthweight babies and 38 percent of very low-birthweight babies.³¹

In 1998, for the first time in decades, the neonatal mortality rate did not fall,³² but it is too early to tell whether this marks a decline in the quality of perinatal care, and if so, whether that decline has anything at all to do with the erosion of regional referral systems and perinatal networks. What does seem clear, however, is that the regionalized perinatal networks that emerged in the 1970s introduced the possibility of bringing maternal and child health into a unified system—and that this approach powerfully improved health.

Experts agree that even though the unified record-keeping model and the region-wide system of communication were never universally adopted, they are still relevant today: they offer a means of tracking risk and care in a way that could shed greater light on the persistent and poorly understood issues of preterm delivery, low birthweight and racial differences. So it remains perplexing and upsetting to many observers—James Lemons and Irwin Merkatz among them—that by the end of the 1970s the country seemed ideally poised to build on the regional perinatal networks and to further improve and integrate maternal and child health care services, and that now, at the beginning of the twenty-first century, such a system is not in place. Given this, the strengths and failings of the Foundation's Regionalized Perinatal Care Program have particular resonance today. The program's accomplishments as well as its limitations—and, some would argue, its failings—suggest that a stronger national mechanism needs to be in place in order to better protect infant and maternal health.

Notes

¹ Study cited by W. McDermott in *The Madonna Paper*, a proposal for a Robert Wood Johnson program in perinatal and infant care and development, presented to the Foundation's Policy Committee on April 27, 1973.

² Ibid.

³ The Robert Wood Johnson Foundation. *Regionalized Perinatal Services*, Special Report Number 2, 1978.

⁴ M. C. McCormick and D. K. Richardson. "Access to Neonatal Intensive Care." *The Future of Children*, 1995, 5(1), 162–175; M. C. McCormick, S. Shapiro and B. H. Starfield. "The Regionalization of Perinatal Services: Summary of the Evaluation of a National Demonstration Program," *Journal of the American Medical Association*, 1985, 253(6), 799–804.

⁵ K. G. Johnson. *Regionalized Perinatal Program*. Program director's report to The Robert Wood Johnson Foundation, 1982.

⁶ K. G. Johnson. *Report on the Foundation's Regionalized Perinatal Program*. Presented to the Robert Wood Johnson Foundation, October, 1980.

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⁸ Ibid.

⁹ M. C. McCormick et al. "The Infant Health and Development Program: Interim Summary." *Journal of Developmental and Behavioral Pediatrics*, 1998, 19(5), 359–370.

¹⁰ M. C. McCormick et al. "The Health and Developmental Status of Very Low-Birth-Weight Children at School Age." *The Journal of the American Medical Association*, 1992, 267(16), 2204–2208.

¹¹ The Robert Wood Johnson Foundation. *The Perinatal Program: What Has Been Learned*. Special Report Number Three, 1985.

¹² R. J. Haggerty and B. Guyer. *Evaluation of Grant Made 1972 to 1992 in Maternal and Child Health*. The Robert Wood Johnson Foundation Internal Report, November, 1992.

¹³ J. D. Horbar and J. F. Lucey, "Evaluation of Neonatal Intensive Care Technologies." *The Future of Children*, 1995, 5(1), 139–161.

¹⁴ S. L. Gortmache et al. "Reducing Infant Mortality in Rural America: Evaluation of the Rural Infant Care Program." *Health Services Research*, 1987, 22(1), 91–116.

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¹⁶ J. D. Yeast et al. "Changing Patterns in Regionalization of Perinatal Care and the Impact on Neonatal Mortality." *American Journal of Obstetrics and Gynecology*, 1998, 178(1, Part 1), 131–135.

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³¹ N. S. Paneth, "The Problem of Low Birth Weight." *The Future of Children*, 1995, 5(1), 19–34. Low birthweight and very low birthweight can mean a host of problems throughout life. These babies are at risk for neurodevelopmental and other problems such as asthma, attention deficit disorder and learning disabilities. Brain injury, including cerebral palsy, occurs in 6 to 8 percent of infants weighing between 1,500 and 2,500 grams and in 20 percent of infants weighing between 500 and 1,500 grams. Although educational and social intervention can ameliorate some of the developmental problems associated with low birthweight, such programs are often expensive and are not widely available.

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TABLES

8.1 Glossary of Terms

8.2 The Eight Sites in the Regionalized Perinatal Care Program