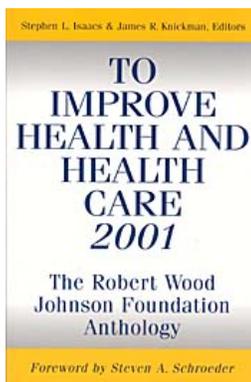




Chapter Three,
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Anthology:

**To Improve Health
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Editor's Introduction

Although improving the health of children has never been an explicit goal of the Robert Wood Johnson Foundation, its investments in the area have been substantial. In 1999, for example, slightly more than a third of the dollars awarded by the Foundation supported efforts to improve children's health. Given the scale of the Foundation's efforts, it is not surprising that each of the first three volumes of the *Anthology* included chapters examining specific children's health programs.

In this fourth volume of the *Anthology*, Sharon Begley, a senior editor at *Newsweek*, and Ruby Hearn, a senior vice president who has been an active advocate for children's concerns during more than a quarter-century at the Robert Wood Johnson Foundation, have undertaken a comprehensive look at the approaches the Foundation has adopted, and the programs it has supported, to improve children's health and well-being. They begin with some of the Foundation's earliest grants in the 1970s and take us through its latest investments.

Why the long-lived commitment to children? For some, the reasons are economic: investments in children's health can have enduring payoffs, enabling the young to become productive and healthy citizens in the future. For others, it is a matter of fairness: while children as a whole tend to be healthier than people in other age groups, children of minorities and lower-income families and those who live in rural areas and urban slums suffer disproportionately and have limited access to health care services. For many, it is a matter of morality: Most of us would find it unconscionable to live in a society that scrimps on the care of its young people and turns the other way when children experience problems that could be avoided with new approaches to care and services.

This chapter examines the wide range of approaches employed by the Foundation—research, demonstrations, coalition building, communications and financing strategies—to improve the health of children from newborns to adolescents. It shows how the Foundation's strategies have evolved in response to the changing social and political environment. And it offers observations on approaches to improving children's health based on more than a quarter-century of experience.

Since 1972, when the Robert Wood Johnson Foundation was established, it has awarded more than 2,000 grants, totaling over \$860 million, to improve children's health and health care. That's a lot of grants and a lot of history.

From the beginning, grants in the field of children's health have been shaped by the Foundation's overall mission—to improve the health and health care of *all* Americans, young and old. Since the Foundation has never had an explicit goal of improving children's health, its children's health programs have generally followed its overall priorities. In the early years, that meant improving access to medical services. In the 1980s, improving the care of people with chronic illnesses began to receive the Foundation's attention. In 1991, the Foundation adopted three explicit goals: increasing access to care, reducing the harm caused by substance abuse and improving chronic care services. As it happens, each of these is particularly relevant for children. In 1998, some 11.1 million children had no health insurance coverage, compared with 9.6 million in 1993. Many chronic illnesses have their antecedents in childhood. And among the many risk factors for substance abuse are the economic, social and psychological forces that shape an individual's early years.

CHILDREN'S HEALTH AND THE FOUNDATION'S PRIORITIES IMPROVING ACCESS TO CARE

EARLY CHILDHOOD PROGRAMS

One of the most serious problems facing America's children in the 1970s was the unacceptably high infant mortality rate. As one of its earliest efforts in children's health, the Foundation chose a program to reduce deaths of newborns. The 1960s and 1970s saw the emergence of technologies (including those to stabilize a premature baby's respiration and control body temperature) that promised to do just that. The Foundation funded the Regionalized Perinatal Care Program (1975 to 1982), which organized hospitals in eight areas of the country into regional networks to make perinatal technology available to more women and their at-risk babies.¹ (Perinatal applies to the period shortly before and after birth.) The regionalization of perinatal services throughout the country—including those funded by the Robert Wood Johnson Foundation—contributed to a reduction in the nation's infant mortality rate from 18.5 deaths per 1,000 live births in 1972 to 7.2 deaths per 1,000 in 1997.

The next logical step was to bring the benefits of perinatal regionalization into the most isolated rural communities: thus was born the Rural Infant Care Program (1979 to 1985), which helped states organize

collaborations between medical schools and public health departments to offer outpost clinics for underserved women and children. But would babies survive their infancy only to suffer later from developmental disabilities? To find out, the Foundation funded a study of the long-term development of low-birthweight babies. It found that these children were at an increased risk of cognitive and developmental problems by the time they reached 8 to 10 years of age.²

To improve the prospects for low-birthweight babies, the Foundation funded a large randomized clinical trial called the Infant Health and Development Program (1982 to 1991 and 1992 to 1994). This program provided the most promising interventions then available, such as home visits and infant day care with a defined curriculum, to low-birthweight babies. It then compared their health and development with low-birthweight babies who received only standard medical services. The evaluators found some differences in cognitive and developmental functions, though not enough to justify the high cost of the interventions. They also found that children could receive care in a communal setting without increasing the risk of infection.

Concurrent with these efforts was a trial that tested a different approach to improving the prospects of high-risk children. In 1979, the Foundation joined other institutions³ in funding Dr. David Olds's plan to establish a program of home visits by registered nurses to about 400 unmarried, low-income pregnant women—most of whom were teenagers—in Elmira, a semirural town in upstate New York. The nurses provided prenatal care in-home visits every other week, and offered counseling on nutrition, avoiding smoking, parenting skills, and crisis management. They were available by phone at night and on weekends, and typically worked with the mothers for two years after the baby's birth. Unlike the Infant Health and Development Program, which provided services after babies were born, the visits by nurses began while women were still pregnant, in the expectation that better prenatal care would reduce the number of low-birthweight babies. In addition to providing prenatal care, the nurses encouraged women to stop smoking or using drugs; educated families about how to improve the baby's health; and, perhaps most important, helped the women become economically self-sufficient by getting them to plan subsequent pregnancies, continue their education and find a job.

Follow-up studies—the children with whom Olds began the program in Elmira have been studied for more than 15 years—have found striking differences between children in the program and a control group. The program group experienced 79 percent fewer reports of child abuse and neglect, 44 percent less incidence of alcohol and drug use by the kids, and 54 percent lower frequency of arrests by age 15.⁴ A

RAND study concluded that for every dollar invested in visiting the at-risk women and their children, society reaped \$4 in benefits.⁵ "The differences arose, we think, not only from helping the mothers be more competent parents but also from helping them make better decisions about what kind of lives they wanted and what kind of men they wanted in their lives," says Olds, now a professor of pediatrics and nursing at the University of Colorado Health Sciences Center and director of the Kempe Prevention Research Center for Family and Child Health. "One woman told the nurse, 'I don't want to hang out with Tony anymore—he'll be a bad influence on the baby.' Through the continuing nurses' visits, the women developed a vision of what their life could be, and we think that is directly due to their involvement with the nurse." To test whether the approach would achieve the same results in a different setting, Olds repeated the program in 1987 in Memphis, Tennessee. Providing services to 1,100 families, the program had similar positive results. The Robert Wood Johnson Foundation is now supporting the replication of Olds's work by funding the development of technical resource centers across the country.

SCHOOL-BASED HEALTH PROGRAMS

A different approach to improving access to health care for children and adolescents is bringing services to the place where young people spend most of their time—the school. The Foundation has supported school-based health services almost continuously since the 1970s.⁶ The School Health Services Program (1977 to 1984) tested the benefits of providing a nurse practitioner to elementary schools. In 1986, the Foundation launched the School-Based Adolescent Health Care Program. With grants of up to \$600,000 for each location, the program established health centers in 24 high schools in 14 cities, including Detroit, Los Angeles, Miami, New Orleans, New York, San Fernando and San Jose. To engage the communities at an early stage, the Foundation required that each center be planned in consultation with parents, school officials, health and welfare departments, and the business community, and that each clinic cooperate with the school nurses, counselors and other staff members. Furthermore, each clinic had to work with a community advisory board that would both raise funds to support the clinic during the six years of the Foundation's grant and to keep it running after the grant expired.

By many measures, the school-based clinics seemed to be just what the doctor ordered. Despite concerns from the Catholic Church and some parents about the reproductive health services that the clinics made available, participation was high: 70 percent of the kids at the 24 schools got parental permission to use the facilities, and about 70 percent of those (half of the students) actually availed themselves of one service or another. The school-based clinics were particularly important in providing mental health services to students. Even though the clinics were able to provide many medical services to students, a

1993 evaluation found that they did not have a significant impact on two areas of particular concern: teenage pregnancy and drug use. In some schools, these issues were not even addressed. Where they were, whatever intervention was offered to head off those problems was apparently too little and too late.

Moreover, funding problems loomed, for neither Medicaid nor other insurers reimbursed the clinics for many of the preventive or mental health services they offered. The biggest blow came with the rise of managed care. Many Medicaid managed-care plans, which states were adopting because of the cost savings they promised, balked at designating the school clinics as eligible providers. Many health maintenance organizations and other managed-care plans feared that the clinics would not be able to provide all the health services the children needed. Partly as a result of these factors, the number of school-based clinics has stalled out at roughly 1,200—out of a total of 88,000 public schools in the country.⁷ The Foundation's current school-based health program, Making the Grade (1992 to 2001), directly addresses the financing issues. It supports efforts in nine states to find mechanisms to improve the financing of school-based services. Most states in the program are trying to facilitate negotiations between school-based health centers and Medicaid managed care plans.

INSURANCE COVERAGE

Providing health services—through perinatal networks, in schools, or wherever—is one way of improving children's access to care; another way is offering insurance coverage to children.⁸ The Healthy Kids Replication Program (1996 to 2001) took one approach to enrolling children in health insurance, helping states emulate a Florida program in which a school district is used as an insurance risk pool, thereby making thousands of kids eligible for group insurance. (Federal, state, and family funds are pooled to pay the premiums.)

The Covering Kids Program (1997 to 2002) takes a different approach. It seeks to identify uninsured children who are eligible for Medicaid or other state health insurance programs. Initially, the program contained funds to support programs in 15 states. However, shortly after the trustees approved the program in 1997, Congress authorized \$24 billion over five years for a State Children's Health Insurance Program, or CHIP, with a goal of enrolling five million low-income children in Medicaid or state health insurance programs. With the passage of CHIP, the Robert Wood Johnson Foundation expanded Covering Kids to cover all 50 states and the District of Columbia. The two approaches complement each other: Federal and state funds are used primarily to buy care for eligible children; the Foundation's funds are used largely to find them. CHIP, however, has fallen far short of its target; in 1999, President Clinton called it "simply inexcusable that we're sitting here, and have been, with the money for two years to

provide health insurance to five million kids, and 80 percent of them are still uninsured." Early in 2000, the Foundation intensified its efforts, authorizing a \$26-million, three-year effort to enhance the public's understanding of why covering children is so important and to reach out to eligible children and their families.

IMMUNIZATIONS

One long-standing challenge has been getting children vaccinated at the appropriate time. This problem is due, in part, to the lack of any systematic way of knowing which children have been immunized and when their next shot is due. With the rise in managed care turning the doctor-patient relationship into a version of musical chairs, children's vaccination records often get lost in the shuffle, and doctors overestimate the percentage of their patients who are up-to-date on their shots by 40 percent.⁹ A logical approach is to create immunization registries for children. The All Kids Count Program (1992 to 1997 and 1998 to 2002) seeks to improve the rate of childhood immunization by creating a database that records all the vaccinations a child receives and provides reminders when another is due.¹⁰ Even as the Foundation has supported the effort to develop registries, a small backlash against immunizations has arisen. This led the Foundation to fund, in 2000, a new program of the American Society of Infectious Diseases to help patients and providers understand the risks and the benefits of vaccinations.

CHRONIC CARE

In the late 1980s, when the Foundation began to address certain chronic illnesses and after 1991 when improving chronic care became a Foundation goal, programs for children followed. The Mental Health Services Program for Youth (1988 to 1997) reorganized available funding for children with severe mental illness so that, instead of being institutionalized, they could receive community-based care or home-based care.¹¹ It placed the children and their parents at the center of a system of services involving health care, mental health care, education, child welfare and, when needed, juvenile justice. The evaluators found that the eight sites in the program expanded the range and the flexibility of services available to children, but "fell short of fully developed systems of care."¹²

One of the most ambitious attempts to help children with chronic illnesses was a demonstration project called the Child Health Initiative. (More formally, it was named Improving Child Health Services: Removing Categorical Barriers to Care—1990 to 1997.) It grew out of the recognition that the services and interventions that children need are often compartmentalized in many different programs administered by an alphabet soup of federal, state and local agencies. By 1994, there were nearly 500 federal programs funding children's services in narrowly defined categories.¹³ Each service has a different funding source,

different eligibility requirements, and different application procedures—not exactly what poor families need. The idea of the Child Health Initiative was to pool existing funds that a family or a child was eligible for and use them where they were most needed. This was called decategorizing funds.

More recently, since asthma is the most prevalent chronic illness among children, the Foundation is supporting Allies Against Asthma (1998 to 2003), a program designed by the federal Centers for Disease Control and Prevention to help communities reduce allergens by teaching families how to rid a home of, say, dust mites.

SUBSTANCE ABUSE

When the Foundation began to address the harm caused by substance abuse in the late-1980s, the children's health programs took up the cause. The Fighting Back Program (1988 to 2003) takes a community approach to reducing the demand for tobacco, alcohol, and illegal drugs. Although Fighting Back supports community coalitions to decrease substance abuse among people of all ages, in practice it has focused largely on children. In Newark, N.J., for example, the grantee uses the program's funds to station police officers in drug-ridden public housing projects with the simple goal of getting kids to school safely and without encountering dealers. A different approach has been taken by the Free to Grow Program (1992 to 2005) which works with Head Start—the nation's largest publicly funded early childhood development program—to strengthen families and communities in their efforts to prevent substance abuse. In Puerto Rico, for instance, the Head Start program went beyond its usual mandate of getting preschoolers ready to learn, and paired troubled families with godparent families that helped the former find jobs and counseling.

To capitalize on the stature of athletes in their communities, the Foundation is supporting the Jacksonville Jaguars Honor Rows Program (1995 to 2001). The team offers free home-game tickets to disadvantaged kids who sign pledges to avoid tobacco, alcohol and illegal drugs, successfully do so, and attain certain academic, behavior and public service goals. Recognizing that many people get hooked on tobacco as teenagers, the foundation joined with 20 other organizations in the mid-1990s to develop a Campaign for Tobacco-Free Kids. This led to the establishment of the National Center for Tobacco-Free Kids (1996 to 2004), which focuses on countering the tobacco industry's youth-oriented advertising with an antismoking campaign. The Smoke-Free Families Program (1993 to 2003) funds projects aimed at preventing the birth of low-birthweight babies by helping pregnant women kick the nicotine habit. The

idea is that expecting a baby—when women are the most concerned about the harm that tobacco might do to their child—gives women an extra incentive to quit.

EVOLUTION OF THE FOUNDATION'S APPROACHES TO IMPROVING CHILDREN'S HEALTH

Beyond evolving to fit within the Foundation's priorities, the Foundation's children's health programs have changed over the years to meet the shifting environment of social policy. In the process of this evolution, a number of insights have emerged about developing programs to improve children's health.

FROM DEMONSTRATION PROGRAMS TO LARGE PROGRAMS THAT ENGAGE THE COMMUNITY

In the 1970s, the Foundation developed the model of testing different approaches to solving problems through demonstration programs carried out at different locations around the country. These controlled studies were carefully evaluated in the expectation that the federal government would pick up and expand those approaches that appeared successful. That model worked in the case of AIDS patients, for instance. When the program demonstrated that this model of care worked beyond San Francisco, where it began, it paved the way for the Ryan White Act, which funded such care. That was the traditional Robert Wood Johnson Foundation model.

By the late 1980s, however, it was clear that this "build it and they will come" (or, at least, fund it) approach would no longer fly. Even a program shown by follow-up evaluation to have worked will not necessarily be scaled up or expanded on that basis alone. It rarely happens "that facts determined by scientific method...lead to policy change," a 1992 evaluation of the Foundation's maternal and child health programs warned.¹⁴ Take school-based health care. As noted earlier, the programs have reached only 1,200 of 88,000 elementary and secondary schools in the country. For kids with access to one of those 1,200 schools, of course, the clinics are as welcome as a hot shower after a gritty soccer practice: the staff treats sore throats before they bloom into full-scale strep infections, oversees asthma medication before the wheezing child lands in the emergency room and even runs interference with teachers for troubled kids. And the concept of providing health care in schools is now part of mainstream policy thinking. But if making a difference implies something on a larger scale, then school-based clinics have fallen short of the mark.

With the devolution of social programs to state and local governments in the 1980s, the federal government could no longer be counted on to expand successful demonstration programs. The changed

social and political environment led the Foundation to modify its approach and to begin working directly with state and local governments and developing partnerships with community groups. Rather than testing and evaluating models, the Foundation now looks to fund programs that engage the community, are large enough to meet the need, and will continue after the Foundation's funding ends. How has it gone about developing programs based on these principles? What factors have influenced the Foundation?

- *The quality of a program's leadership.* This determines whether a program will be able to engage the community and formulate a vision. It is therefore crucial to identify local leaders and allow them the freedom to identify problems and formulate appropriate strategies. The Urban Health Initiative (1995 to 2002), for example, which is designed to improve child health outcomes in entire cities, does not fund particular programs. Rather, by encouraging community leaders to spearhead the push for reform, it supports leadership training for local organizers, who tend to be former public officials or executives of charitable organizations. The idea is that these participants will tap into their professional and personal networks to raise funds and recruit staff to effect change—and, just as important, that members of an existing local power structure will come to have a stake in making the program work and continuing it even after the Robert Wood Johnson grant ends. In fact, some recent Foundation programs have focused not on providing a specific service but on leadership training and community mobilization.
- *Collaboration among local leaders.* If local leaders cooperate in determining what needs to be done and in committing resources to support a plan, the program is more likely to succeed and last. One of the most important tasks the collaborative effort can carry out is to identify and involve influential players in the public and private sectors in order to alter systems in a way that will support long-term change and sustain new approaches. If influential constituencies are involved from the beginning, the program is more likely to attract funding from local agencies, and thus to last beyond the term of the Foundation's grant. This principle has informed the approach taken by the Urban Health Initiative. The Foundation required that applicants submit a "single letter of interest" reflecting the contributions of many community organizations, so that collaboration between groups that might not have previously worked together could be established from the start. By involving community leaders at the outset, the Urban Health Initiative is expected to build a constituency that has a stake in sustaining the program.
- *Community participation.* Being too prescriptive with grantees may help reach a program's goals in the short term but sabotage it in the long term. In the Foundation's early days, it tended to

develop relatively rigid guidelines so that, much like a clinical trial of a new drug, approaches to problems could be evaluated and compared: for the project on the regionalization of perinatal care, it developed a standard risk assessment to determine which mothers-to-be required transport to a perinatal center; for the Rural Infant Care Program, the Robert Wood Johnson Foundation defined precisely the population to be served; with the Infant Health and Development Program, the day care curriculum was defined down to the toys available. With David Olds's program to have nurses visit pregnant women at home, too, the Foundation specified the frequency of visits and the services the nurses would offer the mothers. One risk of conducting such scientific studies, however, is that programs could be viewed as "belonging" to the Foundation, and not to the community. Without a feeling of ownership, a political entity appears less likely to allocate scarce resources to a new program; without the feeling that a community is guiding a program, there is no public pressure to continue it once the Foundation ends its support.

This realization has shaped the more recent Foundation-supported programs in children's health. The Urban Health Initiative offers the best example of this. The application process for the Urban Health Initiative, for instance, asked grantees, "What factors most influence the health and safety of the children in your area?" The answers, and the choices for how to use the grants, have sometimes been surprising: the most frequent responses cite violence, poor education and the lack of meaningful (and safe) after-school and weekend activities for children. The result has been an impressive diversity of programs. In Philadelphia, the program's leaders concluded that having no place but the streets or unsupervised homes to return to after school posed one of the greatest threats to their children; they chose to establish after-school centers with sports, art, and mentoring programs. Urban Health Initiative leaders in Baltimore are working with the police chief and the district attorney to establish an antigang program modeled on a successful program in Boston. In Richmond, the program's leaders are helping schools figure out ways to get every child reading by third grade. Detroit's leaders used the Urban Health Initiative to establish a mentoring program; by linking volunteers and children who are at risk for substance abuse and dropping out, these community leaders believed that they could do more for the health of Detroit's children than, say, a more traditional health program such as asthma screening. In Oakland, the leaders are simply trying to get children to and from school safely; they have established a neighborhood watch plan whose linchpin is placing police officers in drug-ridden public housing projects.

- ***Partnerships with public or other agencies.*** The National Council on Aging's Family Friends Program paired older volunteers with chronically ill children and their families, and continued years after the Foundation's six years of support ended, in 1991. In addition to being sustained at its original sites in eight cities, Family Friends expanded to new cities. The Rural Infant Care Program funded 10 medical schools for a collaboration with local and state health agencies to reduce infant mortality in isolated rural areas. Although university faculty members made themselves less available to the projects after the Foundation's support ended, that did not necessarily spell the end of the effort; the state of Oklahoma and some counties in other states continued to fund the program, and local health departments took over six sites. In Yakima, Wash., the formation of a regional perinatal care steering committee made up of local leaders and of officials from the state health department allowed the Rural Infant Care Program to stay alive. In all cases, the program endured by cultivating a base of political and bureaucratic support. Similarly, Healthy Children (1983 to 1990), a program to develop new children's services, especially school-based health services, set up some two dozen clinics. The American Academy of Pediatrics took over the program, recruiting "facilitators" from 56 of the Academy's 59 chapters. This commitment was the key to sustainability.
- ***Paying attention to political turf and targeting the right level of government.*** The Child Health Initiative—the pilot program to decategorize funds—offers a clear example of this. The Foundation awarded grants to six local governments (Marion County, Oregon; Minneapolis; Monroe County, N.Y.; San Francisco; Scott County, Iowa; Seattle/King County), one state agency (in Miller County, Ark.), and two nonprofit community groups (in Cumberland County, Maine, and in Flint, Mich.). Each was to pool existing funds for children's health programs and lift restrictions on the use of categorical funds so that health services for (usually) impoverished and often chronically ill children would be delivered more efficiently. A typical patient might be a 15-year-old diabetic who also abuses alcohol and is sexually active. She needs inpatient care to control her diabetes, treatment for alcoholism, and family planning services. Her family is ineligible for Medicaid but has no health insurance. Eligibility criteria for available programs (Maternal and Child Health block grant programs, lead screening, mental health services, WIC) differ, as do enrollment procedures and reimbursement policies. In short, there is a bureaucratic morass that few families can wade through.

According to an evaluation by a team led by Paul Newacheck of the Institute for Health Policy Studies of the University of California at San Francisco, not a single Child Health Initiative site

managed to create a pool of flexible funds out of money from categorical programs; only Monroe County made any progress toward that goal by trying to decategorize the multiple funding streams from state and federal programs. What went wrong? On the tactical level, Newacheck says, the Foundation failed to provide clear guidance to the sites. It prepared no formal documents to describe the purpose or the expectations of the projects. A change in leadership at the program's national office left grantees without daily guidance for several months, Newacheck found, and "created an information vacuum." But there were larger, strategic problems, too.

Decategorization requires support from those with the authority to grant exemptions or waivers from categorical programs such as those for maternal and child health care; these people are generally in state or federal offices, but the project was largely confined to the local level, which Newacheck says was "probably a mistake." Asking a locality to lead the effort to decategorize funds is like giving Sisyphus shoes with better traction: the task is still nearly impossible because of the typically weak relationships between local staff and higher-level policy-makers who run the programs and control the money. "Placing responsibility at the local level to achieve decategorization without connections to the state and federal policy level placed the sites at a distinct disadvantage," the evaluation team concluded.¹⁵ "High level political commitments to the effort are needed between all levels of government." Otherwise, turf and control issues trump recognition of what might be best for the recipients of services.

Even at the local level, turf battles flared. Decategorization, by definition, wrests control of funds from particular agencies and individuals. The department in charge of, say, substance abuse treatment wasn't thrilled about siphoning off part of its budget into a general pool of funds to be administered by someone else. Agencies wanted assurance that their own clients would receive special consideration when funds were decategorized. Monroe County was the only site to achieve even partial success, because the funds it targeted for decategorization were administered through its own health department—that is, the grantee itself. The project director was the director of the health department. The state health department signed on to the cause, and the county retained consultants who facilitated negotiations with the federal government to waive categorical restrictions on the use of funds.

The Covering Kids program, too, acknowledges the importance of involving stakeholders and building political coalitions. To apply for funding, each state had to form a coalition and designate a single agency to lead it; that lead agency could be anything from the state health agency or a state medical association to a child advocacy group, a religious association or a philanthropy. But involving the agencies that have the power to effect change or thwart it was critical. "The old idea was that states have been slow to help the poor, so you need strong outside advocates to get anything done," says Michael Rothman, a senior program officer at the Foundation, who had worked previously in the Colorado governor's office. "But we've learned that you have to engage the decision-makers." With as many players as possible given a stake in the program's success, bureaucratic hurdles would be lowered and turf battles minimized.

- *Developing larger programs.* The Foundation is urging more and more of its grantees to think of meeting children's needs in an entire city or area. "We're actually having some success in changing the mindset that going from 100 kids to 200 counts as a triumph," Foundation vice president Paul Jellinek says. Program officers of the Urban Health Initiative have been relentless in hammering home the idea that it is time to help all the kids in a city—creating some bad feelings in agencies that aren't used to thinking this way. But, slowly, grantees are recognizing that their approaches are too narrow. "We are trying to leverage change," Jellinek says. "Of course, the amount of the grant isn't nearly enough"—enough, that is to improve the health or health care of a city's entire population of kids. "But we are getting people to see that setting up after-school programs in three or four schools is a non-starter if it's going to reach no more than 5 percent of your kids. So instead of working to convince a few principals to institute the program, we're showing grantees that they need to change the policy at the level of the school system. They need to work to keep schools open after hours, to train volunteers, to involve the parks and recreation department and the faith community." The program thus becomes a challenge of a different magnitude, and one that service agencies are generally unaccustomed to. But that's why the Urban Health Initiative supported only coalitions that showed signs of being able to push for change at this level.

Beyond modifying its programs to adapt to the changed social and political environment, the Foundation has recognized the importance of giving program managers the flexibility to deal with unforeseen economic changes and new market forces. Without this flexibility, even successful programs vetted by sound scientific assessments can founder. Consider one of the Foundation's earliest children's health efforts, the Regionalized Perinatal Care Program. The goal was to make the then-emerging technologies of caring for high-risk

fetuses and newborns, especially premature babies, available to women regardless of where they lived. The program was therefore funded from 1975 to 1983 to organize hospital collaborations so that expensive perinatal technologies could be shared. Eight sites received a total of \$17.6 million to test regionalization: three areas in Los Angeles, the Upper West Side of Manhattan, Arizona, Cuyahoga County in Ohio, Dallas County in Texas, and 15 counties around Syracuse, New York. The results in both the study regions and the comparison regions were positive but not appreciably different from one another: Neonatal mortality in the study regions fell 19 percent from 1974 or 1975 to 1978 or 1979, and by 25 percent in the comparison areas. One feared consequence of saving preemies was that the babies would survive only to be forever handicapped. But this, by and large, did not occur in the short term. In fact, at one year of age, the percentage of low-birthweight babies with disabilities had decreased, and the program could boast of "graduates" like Adam Gensel, born four weeks early in 1978 and weighing only 4 pounds, 1 ounce. After his mother was admitted to her local hospital in Painesville, Ohio, in her 36th week of pregnancy with high blood pressure and a smaller than normal uterus, she was transferred to University Hospitals of Cleveland, part of the Cleveland Regional Perinatal Network. Adam spent his first 13 days in the neonatal intensive care unit. He went home in good condition, and had a normal, healthy childhood.¹⁶

The Regionalized Perinatal Care Program met its stated goal of furthering hospital collaborations and reducing infant mortality, but fell short of the Foundation's expectation that it would make a lasting difference. After Foundation support ended, few of the regional compacts endured. Perhaps this should not have come as a surprise: after all, regionalization meant that a woman's primary hospital not only would lose a paying patient but also would see a decline in its caseload. (Caseload helps determine reimbursement eligibility under state and federal regulations.) But regionalization faced two other hurdles. First, with an increasing number of perinatologists, the idea of placing neonatal intensive care units only into sophisticated, tertiary care hospitals fell by the wayside; other hospitals, too, began establishing neonatal intensive care units and competing for patients with the tertiary care hospitals. Second, it ran smack into the onslaught of managed care, with its networks of physicians and hospitals determining more than any other factors where a woman would deliver her baby. Competition reduced the willingness of physicians and hospitals to cooperate in establishing an integrated perinatal health care system. The 1992 evaluation of the Foundation's maternal and child health grants concluded, "The competitive environment of today has undermined many aspects of the perinatal regionalization."¹⁷ To have a meaningful and lasting effect on children's health, the Foundation must understand—and even

anticipate—changes in health care policy and practice, such as the push to enroll Medicaid patients in managed care.

Over the years, the Foundation has learned the value of supporting programs and people that push health and health care beyond the boundaries of the clinic. The Foundation recognized from its inception that health neither begins nor ends at the provider's office, but instead exists against a backdrop of socioeconomic status and the larger culture. Children's health, in other words, means more than medical care. "The factors contributing to so many of the disorders we label 'health problems' are part of the social and economic fabric of families and communities," an evaluation team led by Dr. Robert J. Haggerty concluded in 1992, citing an estimate that only 25 percent of changes in child health occur as a result of medical services.¹⁸

Although this was hardly mainstream thinking, respected medical professionals suggested ways of going well beyond the walls of the clinic. In 1988 Dr. Margaret Heagarty, chief of pediatrics at Harlem Hospital, sought support for a program she had launched that aimed at reducing the number of emergency room admissions. Dr. Heagarty had an unusual way of achieving that: she wanted to get neighborhood kids into Little League, to clean glass out of playgrounds, to put bars on apartment windows—in other words, to take actions that do not usually qualify as "health care." The Foundation supported her initial effort, and the program grew into the Injury-Free Coalition for Kids (1988 to 1992 and 1994 to 1997). Led by Dr. Barbara Barlow, director of pediatric surgical services at Harlem Hospital, this program established a number of after-school programs, among them art, gardening, bicycle repair, and fencing. Barlow also created a home-safety checklist, warning parents about household poisons, kitchen burns, and windows that lack safety bars. In the first year of the program, Harlem Hospital's emergency room admissions of children fell 55 percent. In the years from 1988 to 1992, admission to Harlem Hospital's emergency room because of children's injuries decreased by 41 percent, compared with baseline data gathered for the period 1983 to 1988.

The Foundation funded similar projects in five other cities, each of which also used a greatly expanded definition of health. The Chicago program, at the Cabrini Green and Washington Park housing projects, also distributed a home-safety checklist; in addition, it recruited volunteers to teach kids ballet, reading, computers, science, and other topics, with the goal of preventing street violence and teenage pregnancy.

Girls who stayed in the program were three times as likely to graduate from high school, and to avoid jail and pregnancy, as girls who dropped out.

The Foundation has also learned that there is no single right approach to improving children's health and that it must tailor its approaches—in some instances, funding categorical programs, in other instances more comprehensive programs—depending on the circumstances. "Categorical" means interventions for a single need; "comprehensive" describes a range of services given over the years to the same high-risk child. Because the risks that children face do not exist in isolation, "it is illogical, inefficient, and ineffective to devise programs that address each problem separately," concludes a report on 20 years of Robert Wood Johnson Foundation grantmaking.¹⁹ Indeed, many of the more recent programs—particularly those intended to reach children living within a certain geographic area—are designed to offer a wide range of services. The Nurse Home Visiting Program of David Olds is one of the longest-established examples of the comprehensive approach. More recent examples are the Urban Health Initiative and the Injury Free Coalition for Kids. All of these offer a wide range of services—some of them clinical but many of them nonmedical. Still, this does not represent the totality of the Foundation's approach. It recently funded a program to test different ways to reduce asthma, and its All Kids Count program focused exclusively on immunization—both of them categorical programs focused on a single problem.

CONCLUSION

Programs to promote children's health have increased steadily during the lifetime of the Foundation: in 1972, they accounted for 11 percent of total grants, while in 1997 they accounted for 35 percent. But the increase in numbers is only part of the story. The other part is how the programs have evolved. From the well-controlled demonstrations that characterized the Foundation's early years, the Foundation has moved to larger, more wide-ranging approaches that attempt to remove financial barriers to obtaining care, work to provide multiple services to defined population of kids, and, through a new center that is currently in the exploration stage, to make the latest knowledge about children's health available to families and policy-makers. The kinds of programs that now receive support—enrolling children in Medicaid with Covering Kids, building coalitions of businessmen and politicians with the Urban Health Initiative, supporting after-school programs with the Injury Free Coalition for Kids—would hardly be recognizable to a children's health program officer of a quarter century ago. They reflect both the way in which the Robert Wood Johnson Foundation has adapted to the changing social environment and the tenacity needed to achieve an important goal—improving the health and well-being of children.

Notes

¹ The program is examined by M. Holloway in this *Anthology*.

² M. C. McCormick et al. "The Health and Developmental Status of Very Low-Birth-Weight Children at School Age." *Journal of the American Medical Association*, 1992, 267(16), 2204–2208.

³ These were the Bureau of Community Health Services, Commonwealth Fund, Ford Foundation, National Center for Nursing Research, National Institutes of Health, and the W.T. Grant Foundation.

⁴ D. Olds et al. "Long Term Effects of Home Visitation on Maternal Life Course and Child Abuse and Neglect: 15-year Follow-up of a Randomized Trial." *Journal of the American Medical Association*, 1997, 278(8), 637–643, D. Olds et al. "Long Term Effects of Nurse Home Visitation on Children's Criminal and Antisocial Behavior: 15-year Follow-up of a Randomized Controlled Trial." *Journal of the American Medical Association*, 1998, 280(14), 1238–1244.

⁵ L. A. Karoly et al. *Investing in Our Children: What We Know and Don't Know About the Costs and Benefits of Early Childhood Interventions*. Santa Monica, Calif.: The RAND Corporation, 1998.

⁶ The Foundation's work in school-based health is examined in Paul Brodeur, "School-Based Health Clinics." In S. L. Isaacs and J. R. Knickman, (eds.), *To Improve Health and Health Care 2000: The Robert Wood Johnson Foundation Anthology*. San Francisco: Jossey-Bass, 1999.

⁷ J. G. Lear, N. Eichner and J. Koppelman. "The Growth of School-Based Health Centers and the Role of State Policies: Results of a National Survey." *Archives of Pediatrics and Adolescent Medicine*, 1999, 153(11), 1177–1180; and H. Lee. "Overview of Public Elementary and Secondary Schools and Districts: School Year 1997–1998." *Education Statistics Quarterly*, 1999, 1(3).

⁸ This is examined in M. Holloway, "Expanding Health Insurance for Children," in S. L. Isaacs and J. R. Knickman (eds.), *To Improve Health and Health Care 2000: The Robert Wood Johnson Foundation Anthology*. San Francisco: Jossey-Bass, 1999.

⁹ S. Basalla. *Twenty-Five Years of Children's Health Grantmaking 1972–1997*. The Robert Wood Johnson Foundation Internal Report, June, 1998, p. 39.

¹⁰ All Kids Count is examined in G. DeFries et al. "Developing Child Immunization Registries: The All Kids Count Program." In S. L. Isaacs and J. R. Knickman, (eds.), *To Improve Health and Health Care 1997: The Robert Wood Johnson Foundation Anthology*. San Francisco: Jossey-Bass, 1997.

¹¹ The program is examined in L. Saxe and T. P. Cross, "The Mental Health Services Program for Youth." In S. L. Isaacs and J. R. Knickman, (eds.), *To Improve Health and Health Care 1998–1999: The Robert Wood Johnson Foundation Anthology*. San Francisco: Jossey-Bass, 1998.

¹² *Ibid*, p. 175.

¹³ P. Newacheck, N. Halfon, C. D. Brindis, and D. Hughes. "Evaluating Community Efforts to Decategorize and Integrate Financing of Children's Health Services." *Milbank Quarterly*, 1998, 76(2), 157–173.

¹⁴ R. Haggerty and B. Guyer. *Evaluation of Grants Made 1972–1992 in Maternal and Child Health*, the Robert Wood Johnson Foundation Internal Report, November, 1992, p. 13.

¹⁵ P. Newacheck, D. Hughes, C. Brindis and N. Halfon. "Decategorizing Health Services: Interim Findings From The Robert Wood Johnson Foundation's Child Health Initiative." *Health Affairs*, 1995, 14(3), 232–242.

¹⁶ The Robert Wood Johnson Foundation, *The Perinatal Program: What Has Been Learned*, Special Report Number 3, 1985, p. 11.

¹⁷ Haggerty and Guyer 1992, op. cit., p. 25.

¹⁸ Ibid, page 51.

¹⁹ T. Cooper, et al. *Twenty Years of the Foundation Grantmaking: Five Expert Assessments*, The Robert Wood Johnson Foundation Internal Report, January, 1993, p. 54.

TABLES

3.1 National Programs on Children's Health of The Robert Wood Johnson Foundation