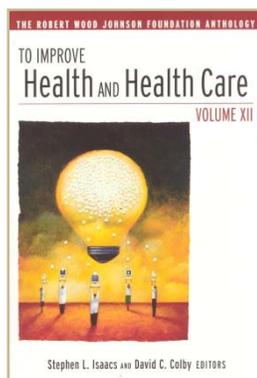




Chapter Two,  
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Edited by  
Stephen L. Isaacs and  
David C. Colby  
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## *Editors' Introduction*

The second in the triumvirate of chapters on health insurance in this year's *Anthology* looks at Foundation-supported research. Carolyn Newbergh, a freelance journalist and contributor of many chapters to the *Anthology series*, examines the research that the Foundation has funded on health insurance and on the uninsured. This includes research on just about every aspect of health insurance, including the economics of insuring employees of small businesses; the number of uninsured and who they are; the consequences of being uninsured on people's health; and various proposals to cover the uninsured. The Foundation and its grantees have given the results of this research broad distribution through articles in professional journals, issue briefs, speeches, and conference presentations, among other means.

Although the Robert Wood Johnson Foundation may be the most prolific funder of health insurance-related research, it is far from the only one. The Commonwealth Fund gives high priority to research on the uninsured; the Henry J. Kaiser Family Foundation funds its own research and disseminates the research of others on its Web site; the California HealthCare Foundation and The California Endowment support research on health insurance in California; and the Blue Cross Blue Shield Foundation of Massachusetts funded research that helped advance that state's health insurance reforms. And this is only the research funded by a sampling of private foundations; it does not take into account research funded by the Census Bureau, the Centers for Medicare & Medicaid Services and other federal agencies, state governments, insurance companies, labor unions, and trade organizations.

Clearly, there is considerable research on coverage. The question the chapter raises is, has research had an effect on policy? Newbergh explores this toward the beginning and the end of the chapter, along with two related questions: first, whether the nonpartisan research the Foundation funds is geared to influencing policy and, second, whether policy change is the right measure of the effectiveness of research (or whether simply getting the facts out and influencing the course of the dialogue and debate is itself a sufficient justification). Thus, the chapter not only traces the major strands of Robert Wood Johnson Foundation-funded research but also explores pertinent issues related to the importance of research on health insurance. In the mix, it provides a brief summary of

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many of the important findings that have emerged from Foundation-funded research.

It can be hard to recall that we didn't always know how many people are uninsured in the United States. Or that people without coverage are in worse health than those with coverage. Or that uninsured individuals come mainly from the lower-middle and middle-middle classes and largely are working for employers that do not offer health insurance. Yet these basic facts, which seem so obvious now, are the result of years of research funded by private foundations and the government. "The research base out there makes the facts that people cite all the time," said John Holahan, director of the Urban Institute's Health Policy Center. "It's amazing the things people think they know because they're smart. It's because of all the research and surveys that have been produced over time. That's why people know what they know about the uninsured."

As the largest foundation devoted strictly to health and health care, the Robert Wood Johnson Foundation has been a leading funder—the leading philanthropic funder in terms of dollars allocated—of research on health insurance. The Foundation considers this research a priority in both building a knowledge base and creating a case for health care reform. Whether the research influences policy is debatable. What is not debatable is the extent to which the research funded by the Robert Wood Johnson Foundation and other foundations—especially the Commonwealth Fund, the Henry J. Kaiser Family Foundation, and the California HealthCare Foundation—has provided a body of knowledge that has set the terms of the debate about the problem of the uninsured and what to do about it. To obtain this body of knowledge and disseminate it widely to policymakers and the public, the Robert Wood Johnson Foundation has funded research that looks at the problem through two distinct but sometimes overlapping lenses.

The first looks at who the uninsured are, why they are uninsured, the characteristics of the uninsured, the effects of being uninsured, and the pros and cons of various proposals—especially at the federal level—to reduce the number of uninsured. More specifically:

- To gain a better understanding of how changes in insurance coverage and the health care system affect access to care, the Foundation established the Center for Studying Health System Change. It has been tracking changes in the way health care has been delivered since 1995.
- To understand how the health care system is financed and organized and ways in which these

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could be improved, the Foundation has, since 1989, supported a wide-ranging research effort called Changes in Health Care Financing and Organization (HCFO).

- To shed light on the economics of health insurance, the Foundation has funded research carried out at the Economic Research Initiative on the Uninsured (ERIU) at the University of Michigan School of Public Health since 2000.
- To build a consensus on the meaning of the research on lack of insurance and its effects, the Foundation supported the Institute of Medicine's reports on the consequences of being uninsured that were published between 2001 and 2004.

The second lens examines health insurance at the state level, explores state-federal relations, and assists states in planning and carrying out research needed to support insurance expansion. In particular, the Foundation has helped three state-level efforts:

- As part of an effort to provide technical assistance to states developing their own plans to expand health insurance and to conduct research on state-level health insurance, the Foundation awarded grants to the Alpha Center and its successor, AcademyHealth, a Washington-based health policy research center.
- To help states understand the number and composition of their uninsured and better utilize federal data, the Foundation has supported research and technical assistance at the University of Minnesota School of Public Health's State Health Access Data Assistance Center (SHADAC).
- To better understand the relationship between state and federal efforts to expand insurance, especially as they play out in Medicaid and the State Children's Health Insurance Program (SCHIP), the Foundation has supported the Assessing the New Federalism Project at the Urban Institute, a Washington-based think tank.

*(Figure 2.1: Robert Wood Johnson Foundation Funding of Health Insurance Research)*

## Foundation-Supported Research on Health Insurance at the National Level

### **The Center for Studying Health System Change**

In the mid-1990s, in the aftermath of the collapse of the Clinton health reform plan, the Foundation began to consider ways to keep abreast of the rapidly changing health care system in a more orderly manner. In 1995, it created the Center for Studying Health System Change in Washington, D.C., an ambitious research effort that, through its Health Tracking Initiative, began to monitor market forces, identify trends, and analyze what they meant in terms of access to medical services—in other words, to provide insight into what was happening in the real world.<sup>1</sup> It was a time of rapid movement toward managed care in the country, and this program's Community Tracking Study would conduct a series of surveys of approximately 30,000 households in sixty communities along with a national sampling, interview 12,000 physicians in these communities about how their practices were changing, and conduct site visits in twelve of the communities for in-depth interviews about the local health care system.

The Center's top priority, which evolved over time, was providing reliable data and analyses that would be relevant to local, state, and national policymakers considering matters that affected health care in the United States. After a slow start in gaining attention, the Center was, by 2007, recognized as a top-notch and nonpartisan source of information, with a good chunk of it on the uninsured. "The Center is one of the few organizations in Washington that has credibility on both political sides," said Liz Fowler, senior counsel to the chairman of the Senate Finance Committee. "Everyone looks to that Center for solid technical analysis."

From the start, learning about coverage was an important part of the Household Survey, said the Center's president, the health economist Paul Ginsburg—measuring how many people lacked coverage, broadening understanding about why this was happening, learning more about what being uninsured meant for access to care, and, increasingly, studying the financial burdens on people who pay for care out-of-pocket. Ginsburg's annual reports on health care were much anticipated and widely reported in the media. He was the first to point out in the 1990s that managed care was in fact bringing costs down; he later reported when the backlash of the late 1990s against managed care's aggressive gatekeeper restrictions and capitation grew so fierce that its cost-cutting teeth were removed, leading health care expenditures to climb again. A 2001 *Data Bulletin* from the Center had

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alarming news: employer-based health insurance premiums were rising more that year—11 percent—than they had since 1993, with no sign of stopping.<sup>2</sup> Among other insights to emerge from the Center’s research are these:

- Health insurance coverage rates vary across states and communities.<sup>3</sup> “I think we contributed to that understanding,” said Peter Cunningham, a senior fellow at the Center, who, with Ginsburg, published research in 2001 that dug into why this occurs. Some of the explanation could be found in the differences in local economies and public program eligibility as well as whether the culture of a particular community led more employers to offer coverage to workers and local government to cover low-income people. “Even among employers of equivalent size and type, we know that employers in the upper Midwest are more likely to offer coverage than similar employers in the South,” Cunningham said.
- Physicians with the most managed care contracts give the least amount of charity care to patients.<sup>4</sup> The Physician Survey, generally conducted every two or three years, has allowed the Center to stay on top of declining charity care and the acceptance of Medicare and Medicaid by physicians.
- Great disparities exist in health insurance coverage between whites and racial and ethnic minorities. A study of data from 2001 to 2003 found a continuing gap in coverage, with “one in three Latinos, one in five blacks, and one in ten whites under the age of 65 lacking health insurance.”<sup>5</sup>
- Employer-based insurance coverage declined substantially for people under age 65, from 67 percent in 2003 to 63 percent in 2004.<sup>6</sup> A study by Peter Cunningham and Jack Hadley, visiting senior fellow at the Center for Studying Health System Change and professor at George Mason University, published in 2004, found that expanding insurance coverage has a greater impact on access to health care than expanding the safety net, but that access improves even more if both occur.<sup>7</sup>
- Although employers and health plans are promoting consumer-directed health plans that include high-deductible and tax-preferred health savings plans, these plans have not taken hold. A report published in late 2007 found that fewer than 20 percent of employees chose a health savings

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account or health reimbursement account when offered a number of health plans.<sup>8</sup>

- Community health centers, which care for more than 16 million patients, are straining to meet increased demand coming from a surge in the uninsured, a greater number of uninsured immigrants, cuts in Medicaid, and less charity care by physicians.<sup>9</sup>
- Being uninsured keeps people from getting the medical care they need. A 2005 study found that when people are short of breath, have blurred vision, or have some other serious new symptom, the uninsured were less than half as likely as the insured to talk to or visit a doctor.<sup>10</sup>

### **Health Care Financing and Organization**

Established in 1988 as the successor to two earlier programs that explored containing costs through research and demonstrations, HCFO, short for Changes in Health Care Financing and Organization, is administered by AcademyHealth in Washington, D.C. As its name suggests, HCFO funds research on the financing and organization of health care. Over the years, the organization has funded about sixty coverage-related studies that look at cost, quality, and access. HCFO funds researchers who propose their own topics on health services or policy research, and its emphasis is on studies that will significantly advance the understanding of an issue or a problem, such as the Harvard University health economist Katherine Swartz's groundbreaking work on spells of uninsurance.

Swartz found that a curious thing happened when the Census Bureau asked people whether they had been uninsured in the last year: they tended to state their insurance status at that moment and didn't recall the past. As a result, the report didn't pick up most of the people who had stints without insurance earlier in the year. The count that resulted gave a distorted picture, weighted more heavily with long-time insured people and leaving out those with "spells of uninsurance."

Although a spell without insurance might not seem like much, the chances of getting sick or injured during these periods are just as great as when someone does have coverage. As Swartz observed in an interview, "If you get really sick, no insurance company will let you buy individual insurance, or they'll charge you so much that you won't buy it."

Swartz found that certain characteristics were predictive of how long a person is uninsured. Those who had higher monthly incomes in the month before they lost insurance, were on a probationary

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period before insurance started at a new job, had attained a higher level of education, were married at some time in their life, or worked in certain industries (including manufacturing, trade, transportation, finance, and real estate) were more likely to have a shorter spell of uninsurance.<sup>11</sup> Different coverage expansion strategies would have to take into account these different needs.

“No one had looked at spells of insurance when analyzing the Census Bureau data before,” said Anne Gauthier, director of the HCFO program until 2005. “It turns out that understanding the dynamics of how long people are uninsured matters a lot. This changed the course of the debate. It helped to illustrate in a new way that the uninsured are not a homogeneous population. Therefore, you need to adjust policy options, because people do go on and off insurance.”

The topics funded by HCFO have covered the entire field of health care financing and organization. Some of the highlights are:

- Health insurance purchasing coalitions, which were viewed in the early and mid-1990s as a way to make coverage available to uninsured workers, especially in the small-group market, never gained much acceptance. Researchers Elliot Wicks and Jack Meyer, both of the Economic and Social Research Institute, and Mark Hall of the Wake Forest University Law School suggested, however, that they might still be able to if legislative changes were made.<sup>12</sup>
- Many studies looked at consumer-directed health products such as health savings accounts and high-deductible insurance plans, which were designed to control costs by giving consumers more responsibility to reduce the unnecessary use of medical services. A 2005 study found it was unclear whether these vehicles “signal a permanent shift in the way health care is financed and delivered or merely a fad.”<sup>13</sup>
- A study by Karen Pollitz of Georgetown University in 2004 that examined subsidizing coverage for the uninsured through tax credits found that only 7 to 21 percent of the people in the study (uninsured early retirees and workers “displaced by international trade”) chose to participate.<sup>14</sup> Pollitz concluded that to attract more takers, a tax credit program would need to have simpler enrollment processes, and that greater subsidies might be necessary.<sup>15</sup>
- Research on the purchase of insurance policies by individuals found that 74 percent of

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purchasers had full- or part-time jobs, that a self-employed person was seven times as likely to purchase insurance as an employed person, and that one-sixth of individual plan purchasers give them up without having another source of insurance coverage. Research found that tax credits would help people stay on individual plans longer, but noted that too much of this help could encourage people to give up employer-based insurance.<sup>16</sup>

- A number of grants looked at aspects of the State Children’s Health Insurance Program (SCHIP). Linda Blumberg and Lisa Dubay, both of the Urban Institute, found “crowd-out” (that is, replacing private with public insurance) was not an issue in SCHIP’s early years.<sup>17</sup> Other researchers found that SCHIP and Medicaid expansion for children didn’t do much to close the gap in immunization rates between children of low-income and higher-income families.<sup>18</sup>
- Ten grants were devoted to developing a risk-adjustment tool, which would give insurers incentives to cover groups with more high-risk patients. Through the grants and brainstorming conferences HCFO held, early versions of this methodology were tested. Modifications that built on it resulted in risk-adjustment mechanisms being used by Medicare and some state Medicaid programs in the payments they make to private plans.
- Four studies looked at ensuring more prenatal care for poor pregnant women by raising the income levels at which pregnant women could enroll in Medicaid. The studies found that higher income eligibility levels led to more poor women obtaining prenatal care early in their pregnancies, but did not increase the number who received comprehensive care, as had been anticipated.<sup>19</sup>

Because HCFO’s mission is to be relevant to policy, it is dogged by questions of whether its work has in fact been useful. This has been hard for HCFO as well as other research programs to assess. “The research findings always join with findings from other research to become a body of evidence, some of which may influence policymaking directly or indirectly,” said HCFO’s deputy director, Deborah Rogal. In fact, HCFO staff members and researchers have often met with policymakers when they were contemplating action. For example, HCFO brought together a number of experts to consult with Department of Justice officials about how to measure competition as the department was considering whether to allow hospital mergers.

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Although it has its detractors, who say investigator-initiated research is not all it's cracked up to be and that it has led to faddish areas of study,<sup>20</sup> HCFO generally receives praise for the work it has funded. "It is the only substantial source of support for investigator-initiated projects that deal with health care finance and governance type issues," said the Urban Institute's president, Robert Reischauer. "It is extremely nimble relative to other sources of grant funding [and] carefully examines the participation by emerging researchers as opposed to the tried and true."

### **The Economic Perspective: The Economic Research Initiative on the Uninsured**

The Robert Wood Johnson Foundation funded the establishment of the Economic Research Initiative on the Uninsured (ERIU) at the University of Michigan School of Public Health in 2000, with the idea of incorporating something that it felt was missing from the field of research on the uninsured—the perspective of economists versed in labor, business, and public finance. It hoped that bringing them together with the health economists and health policy researchers who had had this field virtually to themselves would stimulate new thinking and rigorous economic analysis. After all, at the heart of the uninsurance conundrum are money and labor issues—the cost of health care and insurance, the inability of increasing numbers of working people to afford it, and employers' shedding of the responsibility to offer it. "Quite frankly, those of us studying the uninsured for quite a while were looking for new ideas," said Catherine McLaughlin, a health economist and University of Michigan professor who heads ERIU. "We were always waiting for the latest version of the national survey for new data so we could run regressions for an update. That's not going to help us make progress on understanding the causes and consequences of lack of coverage. We needed economists who know about the labor market and public finance issues to help us, to shake us up. Eighty-five percent of the uninsured are workers and their families, so obviously you can't ignore the labor force."

With \$9 million in funding for an initial three years that would stretch from 2000 into mid-2008, ERIU commissioned nine research papers and funded forty-three research projects selected through a call for abstracts competition. It also held well-attended and popular annual conferences where papers were presented and extensively discussed. Although no studies were commissioned after 2003 because the Foundation didn't award new additional funding, the Web site—with data, the research findings, new useful information, and staff analyses of current trends—continued, as did the annual

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conferences. The most recent and final conference was held in 2007.

“ERIU tried to step back from the political ideology and look at the issues purely through an economic lens,” said the Robert Wood Johnson Foundation program officer Brian Quinn. ERIU studies examined such matters as cost and demand for insurance, labor markets, employer-sponsored insurance, vulnerable people, older people, and public health insurance programs such as SCHIP and Medicaid. Among the findings from ERIU-funded research are these:

- Uninsured people are a diverse population, though they tend to be somewhat lower income and in somewhat poorer health.<sup>21</sup>
- Rising premiums were responsible for more than half of the 17 percent increase in the number of people uninsured from 1990 to 1998. The study forecast that 1.8 to 6 million more people could be uninsured by 2015 if medical care costs continued to rise at the same rate.<sup>22</sup>
- Employees and their dependents who wish to have insurance from their job but don’t account for one in six uninsured people in the United States.<sup>23</sup>
- Immigrants who are not citizens are less likely to have employer-sponsored insurance because they tend to work for companies that do not offer insurance.<sup>24</sup>
- Tax credits would not be an effective method to expand coverage rates among the uninsured who are offered health insurance by their employers.<sup>25</sup>
- Small businesses are less likely to hire employees they expect will have high medical expenses, and state reforms for small-group coverage haven’t diminished these employment distortions.<sup>26</sup>
- Racial and ethnic minorities have been harder hit by the decline in employer-based health care. This is because minorities—especially foreign-born minorities—tend to work for small firms that do not offer insurance coverage to their employees.<sup>27</sup>
- Twenty percent of workers turn down employment-based insurance, some because they can’t afford to share the cost of the premium.<sup>28</sup>

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- The causal relationship between health insurance and health status is not as strong as it could be, since other factors such as diet and exercise play an important role in health. Health insurance has, however, been shown to benefit the poor, the old, children, and the very sick.<sup>29</sup>

Beyond the value of its research in adding to the understanding of the economics of health insurance, ERIU influenced young economists to start conducting research in this area—another of the Foundation’s goals in establishing the Initiative. “This is the dream—you sow seeds, you have a lot more people really doing research,” McLaughlin said in 2007.

### **The Consequences of Uninsurance: The IOM Reports**

There may be no other piece of Foundation-supported research on insurance coverage more cited for high impact than the series of reports the esteemed Institute of Medicine (IOM) produced on the consequences of being uninsured.

This work was spurred by the lack of persuasive information about people who don’t have insurance. Beliefs still lingered among some that the uninsured either simply didn’t feel the need to be covered or actually got enough medical care through the local safety net or emergency room. In a Foundation-supported survey conducted in 1999 by Robert Blendon, a professor at the Harvard School of Public Health and former Foundation vice president, 57 percent of the participants said that uninsured people received all the health care they needed from hospitals and doctors.<sup>30</sup> Stepping into the misinformation gap in 2000, the Foundation commissioned the IOM to state definitively what is known about who the uninsured are, what the consequences of lacking coverage are, and why this matters. The IOM was viewed as a highly credible body that could stay above the political fray and pull all that was known about uninsurance together in a way that would be influential throughout the nation.

The IOM Committee on the Consequences of Uninsurance conducted a comprehensive review (considered by many to be a secondary form of research in itself), evaluating studies on uninsurance for quality and strength of evidence. The outcome was six book-length reports, published from 2001 to 2004.<sup>31</sup> The \$3.7 million project drew the following conclusions:

- About 18,000 uninsured people die unnecessarily each year because they don’t have access to

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the medical care they need.

- People do not get all the care they need in hospital emergency rooms. When compared with the insured, they get less care or go without it, endangering their health.
- The uninsured get less preventive care; have fewer health screenings to catch diseases like cancer, diabetes, and hypertension early; and suffer greater health declines as a result. Uninsured people with serious chronic conditions are not given the regular follow-up care and health monitoring they need.
- People who live in the South and the West are the most likely to lack coverage. The states with the most uninsured people were California with 6.7 million and Texas with 4.9 million.
- Hispanics are three times as likely to be uninsured as whites, and African Americans are twice as likely.
- Eighty percent of uninsured people under 65 live in families in which someone has a job.
- About 76 percent of workers are offered insurance through their job. The leading reason why uninsured workers turn down this coverage is that they can't afford to share the premium's cost; 13 percent of those who decline coverage have insurance through a spouse's plan.
- People are more likely to be uninsured if they work for small, low-wage, or nonunionized companies.
- A full two-thirds of the uninsured belong to families that earn less than 200 percent of the federal poverty level.

“The IOM conveyed the reality of the costs that the uninsured impose on society,” said Len Nichols, a health policy expert currently with the New America Foundation. “This work is invaluable. It has helped create common ground. This is a problem that can't be ignored.”

With such a bleak picture of the consequences of being uninsured, many observers were

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disappointed that these reports didn't inspire the nation to act. But others reflect that although the reports may not have brought immediate change, they are a continuing resource that strengthens the hand of reform proponents by providing proven facts. "This information is used when there's a political opportunity to make use of it," said Wilhelmine Miller, the IOM reports' co-director. "I don't know that the evidence itself creates the opportunity. Research conclusions can be ignored until there's some political will to face up to them."

### State-Level Research and Technical Assistance

#### **The Alpha Center**

In 1985, the Robert Wood Johnson Foundation funded a program called Health Care for the Uninsured, a thirteen-state demonstration project that explored different ways of extending coverage to uninsured people working for small businesses. The states tried various approaches, from subsidies to regulatory changes, to make coverage financially accessible. The program, directed by the Alpha Center in Washington, D.C., revealed a great deal about the small business market. In a 1992 *Health Affairs* article, the Alpha Center's president, David Helms, and two co-authors wrote that two-thirds of the working uninsured are employed by small businesses, and went on to explain that cost is the main reason these employers don't offer insurance. Small employers are at a disadvantage, since insurers price products for them higher than for larger businesses. Insurers do this for a number of reasons: they expect to spend far more for administrative costs for small groups than for large groups; they anticipate that they will have greater risk of high medical bills from a small group, because it has fewer people to spread the financial risk; and they believe that small employers who seek insurance may have sicker workers than those who don't.<sup>32</sup>

The authors called for government to help out the small-group insurance market by providing subsidies to cover increased administrative costs, to push for purchasing cooperatives to share risk, and to put curbs on unfair insurance rating methods. "Any attempts to achieve universal access must recognize that the small-group insurance market is fundamentally flawed and must mend those flaws or replace it with a new system," they wrote.

The Foundation's interest in state health reform grew into another Foundation program to help states expand coverage of the uninsured, State Initiatives in Health Care Reform, which ran from

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1991 to 1999. At the start, however, many states found that they needed better, more detailed data than was available from the U. S. Census Bureau's Current Population Survey. "The federal data available to states lacked basic information about, for example, health status," said Joel Cantor, who currently directs the Center for State Health Policy at Rutgers University and was a Foundation official at the time. "If you were designing a program, you might be able to count people without insurance, but you didn't know if they were comparatively sick or healthy and who was likely to enroll. The states didn't have the comprehensive information they needed to do modeling of different reform ideas."

The Alpha Center and its successor, AcademyHealth, which also served as the national program office for the State Initiatives on Health Care Reform program, did not want to fund many expensive, uncoordinated surveys that might not be comparable. Instead, it commissioned two surveys in 1993—one of families and the other of employers—by the RAND Corporation's Susan Marquis and Stephen Long.<sup>33</sup> These would be viewed as landmark surveys. "It was a data point in history that we will never see again," said Nancy Barrant, the Foundation's special adviser for program development, who oversaw the State Initiatives program. "It was the first and only state-specific data that had been made available."

In 1993 and 1994, the Family Health Insurance Survey interviewed more than 27,000 households in ten states, finding wide differences in how many people had coverage, how healthy they were, and whether they had adequate access to care. For example, 27 percent of New Mexicans lacked insurance, compared with 10 percent of Minnesotans. People who lived in states where there was less coverage, such as Florida, New Mexico, and Oklahoma, had poorer health and access to care than states with more insurance, such as North Dakota, Vermont, and Minnesota.

The Employer Health Insurance Survey sought to learn about firms that do and do not offer insurance and workers who do and do not take coverage when it's offered. Although it was widely known that many uninsured individuals worked for small businesses, the survey confirmed what was not commonly known—that a worker's level of pay also matters. Large and small employers that paid the minimum wage or just above it were equally likely not to offer coverage. "Just that knowledge informs policymaking," Rutgers' Cantor said. "You can't just mandate these businesses to offer coverage and require them to pay for a benefit that maybe costs half of what their employees' wages cost or more. It also told us that subsidies should be targeted not just to small businesses but

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to low-wage businesses.”

One of the first surveys of its kind to look at employer-sponsored insurance on the state level, the employer survey became part of the Community Tracking Survey carried out by the Center for Studying Health System Change. It also became the model for the insurance component of the federal government’s Medical Expenditure Panel Survey.

### **The State Health Access Data Assistance Center**

By the early 2000s, it was clear that states were hungry for better data about the uninsured within their borders than could be found in federal counts. The states needed more accurate and complete information in order to develop their own plans to expand insurance coverage and also to help the federal government determine the level of funding that states would receive under SCHIP and Medicaid. The Foundation addressed the states’ needs by providing the University of Minnesota with funds to establish a new entity at its School of Public Health, the State Health Access Data Assistance Center (SHADAC).

SHADAC was envisioned as helping states by translating various federal data sets to enhance understanding of uninsurance estimates pertinent to them and by providing technical assistance to states that planned to develop their own surveys. SHADAC was also expected to serve as something of an intermediary: working with federal officials to make sure that federally collected data served the needs of states and communicating the states’ needs for data with federal offices that collect it. “State policy-makers really want to make decisions based on information about their own populations,” said Lynn Blewett, SHADAC’s director. “National estimates are very difficult to drill down to the state level. They give general characteristics. If you want information about low-income uninsured kids, race and ethnicity, and geographic areas like counties, you can’t do that with the CPS”—the U. S. Census Bureau’s Current Population Survey. “Legislators want to know ‘What about my area—am I above or below in my area?’ It’s very difficult to do with the CPS.”

At first, SHADAC assisted states conducting their own surveys (supported by the federal Health Resources and Services Administration) to get a better handle on local trends and pockets of need. SHADAC helped the states design requests for proposals for contractors to conduct the surveys, gave guidance on questions, and assisted in analyzing the data that flowed in. SHADAC also helped state officials digest the numerous federal reports containing data on the uninsured, putting them in

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contact with the federal agencies that produced the reports and facilitating communication with them. Every year, SHADAC organizes a conference call between state analysts and the Census Bureau to review and explain the latest state and national figures on insurance coverage from the Current Population Survey's Annual Social and Economic Supplement.

"We regard SHADAC very highly," said Chuck Nelson, a Census Bureau assistant division chief. "They're able to tell us things we didn't know about our data and put us in contact with people to give us insights into our data that we wouldn't get on our own. Their research staff is tremendously helpful to us."

SHADAC has done extensive work to understand and improve the way that estimates of the number of uninsured are gathered and analyzed. Here are some examples:

- It was able to help the Census Bureau improve the way that it "imputes," or makes estimates when data is missing from participants in a survey.
- It explained why the three federal government surveys that count the uninsured—the Census Bureau's Current Population Survey's Annual Social and Economic Supplement, the National Health Interview Survey, and the Medical Expenditure Panel Survey's Household Component—come up with different estimates of the number of uninsured people, and found that they nevertheless "all show similar trends."<sup>34</sup> It also looked at why states' own estimates of the number of uninsured are generally lower than those of the most widely used federal survey, the Current Population Survey.<sup>35</sup> SHADAC found in both reports that the different surveys are designed for different purposes and that each uses different methods to conduct interviews and make estimates. "It is important to recognize that the number of uninsured will never be exactly pinned down. . . . While research should focus on producing better estimates, the number remains just that: an estimate," SHADAC concluded.<sup>36</sup>
- SHADAC also sought to get to the bottom of why the Current Population Survey systematically estimates that fewer people are enrolled in Medicaid than the Medicaid program itself has on its books. This "Medicaid undercount" matters because it implies that the Current Population Survey may be overestimating the number of uninsured. When SHADAC ran an experiment in Minnesota, it found that although the Current Population Survey underestimates the number of

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people on Medicaid, the effect of the undercount was probably very modest.<sup>37</sup>

SHADAC's State Health Access Profile provides a broad look at access to health care and coverage for every state and the District of Columbia. It can be used to make comparisons of how many residents are insured and uninsured; how many employers offer insurance and how many employees take it up; the number of hospital beds, community health centers, and physicians per 100,000 population; eligibility requirements for public programs; and poverty levels. SHADAC has also provided state-level analyses for the annual Foundation-funded Cover the Uninsured Weeks. With an increasing number of states interested in expanding insurance coverage, in December 2006, the Foundation kicked off a new program, State Health Access Reform Evaluation (SHARE), which SHADAC manages. Its purpose is to evaluate the state reforms that are occurring so that the lessons from them can be used by other states and the federal government.

By 2008, SHADAC was widely recognized for its technical expertise and high-quality research, and SHADAC's research projects were receiving half of their financial support from organizations other than the Robert Wood Johnson Foundation, including federal agencies such as the Centers for Disease Control and Prevention and the National Institutes of Health. "SHADAC has done a remarkable job establishing credibility as a research organization looking at health insurance issues," said Linda Bilheimer, an associate director of the National Center for Health Statistics and a former Foundation official. "The credibility has extended beyond state work to looking at methodological issues in national survey design."

#### **Federal and State Financing of Health Care: The Urban Institute**

From 1995 to 2007, the Foundation provided \$16.5 million to support the health coverage component of the Assessing the New Federalism project of the Urban Institute, a Washington-based research and policy organization. This \$92 million initiative, also supported by the W. K. Kellogg Foundation, the Annie E. Casey Foundation, and other funders, was an enormous undertaking, telling a finely grained story of how welfare reform and the transfer of social, health, and employment programs from the federal government to the states affected low-income families and their children, state by state. The Robert Wood Johnson Foundation money was earmarked solely for health-coverage aspects of the project.

The key component of the New Federalism project was the National Survey of America's Families,

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which interviewed 40,000 primarily low-income families in thirteen states in 1997, 1999, and 2002. The New Federalism project produced a wealth of data—and about 450 publications—that will be mined for years. Its findings were presented in congressional testimony and received wide media coverage. Its reports led Congress to allow states more time to expand SCHIP coverage without fear that they would lose federal funds, and were referred to in Congressional Budget Office background papers used to evaluate the proposed bills to reauthorize SCHIP. These are some of the survey's major findings on health coverage:

- SCHIP resulted in a decline in uninsured children and was truly benefiting children. There were 7.8 million uninsured children in 2002, down from 9.6 million in 1999. Lack of coverage declined for African American and Hispanic children during this period by more than 4 percent. This translated into more health care for low-income children: they had 3.4 percent more well-child care visits, 2.4 percent more office visits, and 1.6 percent more dental visits.<sup>38</sup>
- Nearly 70 percent of eligible children were enrolled in SCHIP by 2005, but nearly 2 million qualified kids remained uninsured. A significant increase in funding would be needed to cover the additional children.<sup>39</sup>
- SCHIP and Medicaid were putting substantial strain on state budgets; under budgetary pressure, the states reduced their Medicaid and SCHIP expenditures in 2003 and 2004 by restricting eligibility or increasing cost sharing.<sup>40</sup>
- Health insurance coverage rates varied among the states in large part because of differences in the amount of coverage employers offered their workers in those states.<sup>41</sup>
- Employer-based insurance for low-income people dropped from 41.6 percent in 1999 to 37 percent in 2002. Two-thirds of this change resulted from employees not accepting employer coverage.<sup>42</sup>
- Medicaid beneficiaries had access problems in numerous states.<sup>43</sup>

Based on the variations among the states that the survey data revealed, the Urban Institute concluded that no single solution to health insurance and other problems will work for all states and that both

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Medicaid and SCHIP needed a restructuring that would provide for more coverage and more federal money.

The New Federalism project also found, through its own survey, a major flaw in how the number of uninsured was determined in the Census Bureau's Current Population Survey, the most commonly used count of the uninsured and the basis for SCHIP allotments to states.<sup>44</sup> As a result of this discovery, the Census Bureau, using the approach of the Urban Institute, reduced the count of uninsured people in 1999 from 42.6 million to 39.3 million that year. "It certainly made us feel more confident that our estimates were accurate," said the Census Bureau's Chuck Nelson. "Whether it's 42 million or 39 million, that's still a lot of people going without health insurance coverage."

In 2007, the Foundation turned to the Urban Institute again for the preparation of "quick-strike" briefs on insurance coverage matters as they arise. The intent was for the Urban Institute to respond with dispatch to policy debates while they were occurring. Dubbed "Timely Analysis of Immediate Health Policy Issues," this \$1.2 million project is expected to run for two years.

In September 2007, its first quick-strike addressed contention over two proposed bills in Congress reauthorizing SCHIP—specifically the effect of raising eligibility levels for the program. The analysis found that "very few" children would come from families over 300 percent of the federal poverty level and that 70 percent of new and continuing children would come from families with incomes under 200 percent of the federal poverty level.<sup>45</sup> The Urban Institute data was cited during the congressional debate on the proposed legislation.

Another September 2007 quick-strike looked at a persistent area of concern—crowd-out; that is, families replacing employer-sponsored coverage for their kids with SCHIP. This is a controversial subject, because public programs are intended to cover the uninsured, not people already insured. The quick-strike analysis found that it would make sense for low-income families to enroll their children in SCHIP; it would cut their out-of-pocket costs to 4 to 5 percent of the family income rather than the 6.1 to 12.9 percent that they would have to pay under an employer-sponsored plan.<sup>46</sup>

A quick-strike in October 2007 found that more uninsured children would be covered under SCHIP than under a Bush administration proposal to provide tax deductions to buy insurance. This is because families would still have to spend far more for private insurance than they would for

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SCHIP.<sup>47</sup>

The quick-strikes were viewed favorably by health policymakers and shapers. Mark McClellan, former administrator of the Centers for Medicare & Medicaid Services under the George W. Bush administration, found them “helpful in getting out a few facts.” Judith Feder, the dean of Georgetown University’s Public Policy Institute and a noted health policy expert, said, “I think quick-strikes are about taking evidence into the ongoing debate in real time. Research can be used as a tool—and this gets it out there when it’s needed.”

### **Assessing the Value of Research**

Foundations’ support of research on the uninsured has grown as it has become clearer that the nation’s system for financing the health care services of Americans is in trouble and as the federal government has shown greater reluctance to support this kind of research. “If foundations don’t do it, it doesn’t get done,” said Drew Altman, the president and CEO of the Henry J. Kaiser Family Foundation (and a former vice president of the Robert Wood Johnson Foundation in the 1980s). “It begins and ends with leadership from the major health foundations. It’s not something the government has been interested in funding, particularly in recent years.”

With the number of uninsured greater today than when the Robert Wood Johnson Foundation started directing research dollars toward the problem, it is worthwhile to step back and consider what the return has been on the Foundation’s substantial investment.

Much of the Foundation’s research on expanding coverage was begun or conducted during Steven Schroeder’s tenure as president and CEO, between 1990 and 2002, but he often thought about pulling the plug. Nearly everything that could be studied was being studied, and the case was strong that too many millions of people were uninsured, jeopardizing their and their families’ health and stability and the health system itself. Journals favored by policymakers were filled with thought-provoking articles containing the kind of pertinent information that ought to fire them up for change and told them ways to do it. Nevertheless, even through prosperous economic times, the studies “didn’t move the needle one bit,” Schroeder said. “This said some very harsh realities about our country and how cruel it can be and the role of power. It was the single biggest disappointment of my twelve years at the Foundation—that we couldn’t even get a big bite out of it, though we did get

SCHIP. I would have settled for 20 million more people insured, I wasn't a purist. It was a failure."

Other people in this field of policy research concur that it *is* frustrating work that doesn't produce direct results, but they are also quick to say that Schroeder's laments sell the Foundation's research, and the research funded by others, short. It may not have led—yet—to universal coverage, but it has made substantial contributions that shouldn't be overlooked.

"The biggest impact of the Foundation's work had to do with the continued repeated showing that insurance coverage mattered in today's America and people without it got into real trouble," said Harvard's Robert Blendon. "That had a great significance—it ran against a share of the political culture that did not want to accept it." Even such incremental movement in public and policymaker opinion is progress, said the Kaiser Family Foundation's Altman. "Partly as a result of the research community's just relentlessly nailing the facts on this issue, while there remains a huge debate about how to solve the problem, there no longer is much of a debate about whether it is a problem."

Although staggering numbers of people remain uninsured, it should not be lost on anyone that the research has led to some coverage gains, the Urban Institute's Robert Reischauer pointed out. "If we weren't doing all this work, what would the uninsurance rate be?" he asked. "My guess is it would be much higher than it is now."

Historically, division over national health care reform has been fierce, with opponents labeling it "socialized medicine" and both political parties digging in their heels and playing hardball. "To the extent that the debate becomes ideologically driven, it doesn't matter what the research says," said Georgetown's Judith Feder. To judge research by whether it has a desired impact is asking too much of the studies, said the Commonwealth Fund's president and CEO Karen Davis. Instead, her organization views research as successful if leaders are asking about and using it. "We look at that rather than the count of the uninsured as a measure of progress," she said. "We tend to assess what we do more in terms of things within our control or our grantees' control."

Nevertheless, some observers say that the Robert Wood Johnson Foundation might have gotten more results if it had gone more out on a limb, vigorously and publicly championing the case for insuring everyone or pushing a particular approach as it has done, for example, with substance abuse, tobacco, and childhood obesity. "I think there has not been what I call a concerted effort to put

pressure on policymakers to address the problem,” said the New America Foundation’s Len Nichols. “It’s been more ‘Here are some data, we hope you like them, we hope you draw the right policy inferences, we’re not going to beat you over the head.’ The approach has been cautious. That’s certainly not the fault of the research—it is a manifestation of a lack of an aggressive strategy.”

Brandeis University’s Stuart Altman said the Foundation might have been able to accomplish more from its investments in coverage research if it had been more focused, as small foundations must be of necessity. For example, creating a Robert Wood Johnson Foundation Center for National Health Insurance with a sizable budget might have allowed it to manage a research program in a more concentrated way.

Mark McClellan, the former head of the Centers for Medicare & Medicaid Services, pointed out one area that he said foundations don’t address: how the federal government can come up with a huge amount of additional money to cover the cost of any universal plan that would be adopted. “The challenge we face now is that the pressure for doing something is higher than ever,” he said. “People are more worried about the security of their coverage, but budgets are very tight. The hard question of how you pay for expanding coverage has gotten harder as well.”

Former president Steven Schroeder and current president Risa Lavizzo-Mourey agree that expanding health insurance is too important to abandon and that research is a critical component of the Robert Wood Johnson Foundation’s work. “To admit defeat on this issue would have been so devastating that we couldn’t do it,” Schroeder said. Lavizzo-Mourey drew the same conclusion. “This is such a big, thorny issue that information is necessary but not sufficient,” she said. “We can’t walk away from it. How can you walk away from the biggest policy issue when you are a Foundation that focuses on that area?” They also agree that research is not enough. Research on its own cannot drive policymakers to expand insurance coverage to all Americans. It will take political will and a concerted push by those with a stake in the outcome, such as business, consumers, labor, the two political parties, health professionals, and academics.

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## Notes

1. In a sense, Health Tracking was the successor to a series of access-to-care surveys that the Foundation funded in 1976, 1982, 1986, and 1994. Over the years, the surveys provided a picture of both the potential access to medical services and how much people were, in practice, taking advantage of them. See Newbergh, C. “The Health Tracking Initiative.” *To Improve Health and Health Care: The Robert Wood Johnson Foundation Anthology*, Vol. VI. San Francisco: Jossey-Bass, 2003; and Berk, M. L., and Schur C. L. “A Review of the National Access-to-Care Surveys.” *To Improve Health and Health Care: The Robert Wood Johnson Anthology Foundation*, 1997. San Francisco: Jossey-Bass, 1997.
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## Figures

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