From Idea to Mainstream: The Robert Wood Johnson Foundation Experience

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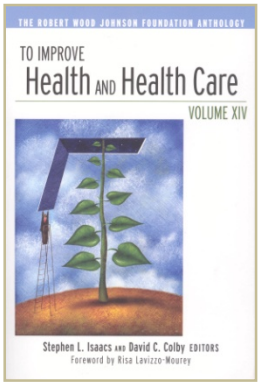

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In the early 1970s, a time when hearses were used to transport sick or injured people to the nearest hospital and getting hold of someone—anyone—who could help in an emergency was a catch-as-catch-can experience, the Robert Wood Johnson Foundation funded one of its first national programs, the Emergency Medical Services Program. It led to the near-universal use of the 911 phone number. To this day, the program offers a model of a foundation-funded program that took off and entered the American mainstream.

The Emergency Medical Services Program was the first, but not the only, example of an idea tested and disseminated by the Foundation that made it into the mainstream. Some ideas were widely replicated and received government funding, thus assuring their continuation. Others became widely accepted and part of the fabric of American society without benefit of legislation. Among the Foundation-supported ideas that have entered the American mainstream are these:

- *Nurse practitioners* were a newly emerging but still marginal profession until the 1970s. Thanks in part to a series of Foundation-funded programs, nurse practitioners became a widely recognized and prestigious profession.[1]
- *Community-based services for people with HIV/AIDS.* In the 1980s, the Foundation tested, in a number of locations, a community-based program that previously served those with AIDS in San Francisco. It became the model for the federal Ryan White Comprehensive AIDS Resources Emergency Act, a law that provides funding for community services for people with HIV/AIDS.[2]
- *Homeless families.* Similarly, the Foundation-Pew Charitable Trusts' Health Care for the Homeless Program served as the model for the McKinney-Vento Act, which funds supportive services for homeless people.[3]

- *Palliative care.* Thanks in part to the support of the Robert Wood Johnson Foundation and the Open Society Institute, palliative care is now a widely accepted element of hospital care.[4]
- *Tobacco control.* The Foundation's efforts in tobacco control in the 1990s are widely credited with playing a role in the dramatic drop in smoking throughout the nation, particularly among young people.[5]

The federal government has adopted and expanded programs initiated by the Foundation. Congress has appropriated funds for programs giving homebound seniors the power to select their own caretakers (Cash & Counseling),[6] enabling Medicaid and insurance companies to team up to give people better long-term care insurance options (Partnership for Long-Term Care),[7] allowing older people the chance to remain at home rather than go to a nursing home (Program of All-Inclusive Care for the Elderly–PACE),[8] and establishing community anti-drug programs (Fighting Back and CADCA).[9, 10] The U.S. Health Services and Resources Administration provides funds for primary care residencies in general medicine and pediatrics, building on pilot programs funded by the Robert Wood Johnson Foundation. Although these programs have not yet entered the mainstream, several appear to be poised to do so.

The Nurse-Family Partnership program, in which public health nurses visit young, low-income, first-time mothers in their homes, is another Foundation-funded initiative that may be ready to enter the mainstream.[11] Starting in 1979, the Foundation provided support for approach to improving the health of babies and their mothers. In the thirty-one years since the Foundation's first grant, it has given nearly $27 million to build evidence about the effectiveness of this approach and to support its replication. In 2002, the Edna McConnell Clark Foundation (along with other foundation and corporate funders, including the Robert Wood Johnson Foundation) funded a major expansion of the program. The recently enacted health reform law authorized $1.5 billion for states that adopt home-visitation programs, such as the Nurse-Family Partnership, that serve young, low-income mothers.

Other Foundation-funded programs appear to have the potential to enter the mainstream, among them programs to develop small and more humane nursing homes (Green House) and to improve the way schools structure recess (Playworks).

Diffusing Innovations

Why have some programs or ideas worked their way into the mainstream while so many others have not? What elements have led to their widespread diffusion and adoption? What more can be done to help move good ideas into the mainstream?

These questions have generated considerable thought and debate. Rural sociologist Everett Rogers developed a theory that ideas spread into the mainstream because they are picked up initially by change agents who influence the rest of society until a critical mass of people finds it is in their best interest to adopt an innovation.[12] Economist Walt Rostow coined the term "take-off point"–the accretion of small advances to the point at which economic change becomes unstoppable–to explain how developing countries grow into developed ones.[13] Malcolm Gladwell observed that the spread of ideas was akin to the spread of a disease; ideas spread through what he calls mavens, connectors, and social marketers. By taking one step at a time, an innovation affects enough people to reach a tipping point, from which it races through the population.[14]

Although these theories are all relevant, they do not explain how ideas advanced by foundations seeking social change go from small, often pilot, efforts to become widely accepted. As Joel Fleishman, former president of the American branch of the Atlantic Philanthropies, observed, "Those foundations that are truly interested in using their resources in ways that will have the greatest positive impact on the world around them should study the stories of the most successful and effective foundation initiatives."[15] The experience of the Robert Wood Johnson Foundation can provide some of those stories.

Emergency Medical Services

As late as the 1960s, emergency medical care was a hodgepodge of different systems–transportation, emergency care, and hospitals–that did not talk to one another. The idea that people having a medical crisis could call a single phone number, wait a short time for an ambulance to show up, and then be transported to a hospital emergency room had not yet entered the public's consciousness.

That began to change in the 1970s. Cities from Miami to Seattle developed systems to dispatch ambulances in response to calls to a specially designated emergency phone number. Scholars began to estimate the number of deaths due to the lack of an emergency medical system (EMS), and the press picked up on this. AT&T designated 911 as *the* emergency number. Trauma care was becoming recognized, and emergency medicine was developing as a field; emergency rooms began to proliferate. Paramedics, having served in Vietnam, were providing care in ambulances taking patients to the nearest emergency room. President Richard Nixon acknowledged the need to improve EMS in his State of the Union address in 1972.

Perhaps most important, millions of television viewers were tuning in to the television show *Emergency!*, which featured the exploits of emergency medical system personnel from the Los Angeles County Fire Department saving lives that would have been lost only a short while earlier. "*Emergency!* was the prairie fire," said Eugene Nagel, a Miami physician who was one of the people behind the creation of the EMS system. "The show lit the spark of public awareness."

A new foundation created in 1972–the Robert Wood Johnson Foundation–fanned the flames by working with government and helping to shape development of this new field. Earlier in 1972, the Department of Health, Education, and Welfare had funded EMS demonstration projects at five sites. The Foundation upped the ante by launching the Emergency Medical Services Program to test the EMS concept in forty-four sites and by commissioning the National Academy of Sciences and the RAND Corporation to evaluate

it. To run the program, the Foundation named as vice president one of the nation's leading experts in emergency care, Blair Sadler, from the Yale Trauma Program. The Foundation also recruited a high-powered national advisory committee for the program.

At the time, it was possible for a foundation's staff members and executives of the federal government to work hand in glove. That was exactly what happened. When Congress passed the Emergency Medical Services Systems Act in November 1973, eleven of the fifteen federal components of regional EMS were the same as the components of the Foundation's program. President Gerald Ford appointed David Boyd, a member of the Robert Wood Johnson Foundation's national EMS advisory panel, to run the new Division of Emergency Medical Services at the Department of Health, Education, and Welfare. Emergency medical services experts who were advising the Foundation also advised the federal government. They became advocates for development of a nationwide EMS program–testifying before Congress, writing journal articles, and making radio and television appearances.

Taking advantage of the changing circumstances in the country, the Foundation was instrumental in bringing about change. It built on on steps taken by others, on the public's interest (due largely to the TV show *Emergency!*), and on close collaboration with the federal government. It supported demonstration projects to test EMS in different places, rigorously evaluated the projects, and publicized the results widely. As writer Digby Diehl noted, "In 1976, just 17 percent of the population of the United States had 911 service; by 1979, more than a quarter of the population was served by 911. Today, more than 85 percent of the country is covered by some type of 911 system."[16]

Nurse Practitioners

One of the earliest priorities of the new Robert Wood Johnson Foundation in the early 1970s was to increase the access of people living in rural areas and inner cities to non-hospital care. To advance this priority, the Foundation funded a series of programs to train nurse practitioners and, initially, physician assistants.[17] As early as 1973, the Foundation

funded an expansion of a nurse practitioner program at the University of California, Davis that placed emphasis on rural health care. By 1977, more than 230 family nurse practitioners had graduated from that program. This program was followed by the funding of four additional nurse practitioner training programs, with the hope of improving access in underserved areas. The Foundation then made grants to six universities to develop master's degree programs in primary care for nurses; these grants helped the recipients build and sustain the field.

Between 1975 and 1981, the Foundation made small grants to the University of New Mexico to establish guidelines for the training of nurse practitioners. These grants created the basis for accreditation of the new nurse practitioner programs. From 1978 to 1983, the Foundation supplemented this support by funding the training of ninety-nine nurses to be the academic leaders for this new profession. From 1994 to 2004, the Foundation funded the Partnership for Training program with eight sites that used Web and video conferencing to educate 1,140 nurse practitioner, certified nurse midwife, and physician assistant students in underserved areas.

The Foundation's early nurse practitioner efforts were in the forefront of a movement that led to the widespread acceptance of nurse practitioners as recognized health professionals. In many ways, the Foundation's approach to nurse practitioners exemplifies the "disruptive innovations" approach to change articulated by Harvard Business School professor Clayton Christensen.[18] The Foundation supported a less costly group of health professionals, nurse practitioners, so they could carry out many of the functions performed by a more costly, and often inaccessible group, namely physicians. A similar disruptive solution to improve access to dental services in Alaska is described in Chapter 6.

AIDS Health Services Program

In 1981, the Centers for Disease Control reported cases of opportunistic diseases among gay men, which we now know to have been acquired immune deficiency syndrome (AIDS). The time between identification of this disease with those first five cases and recognition that

one million Americans might have been infected seemed unexpectedly short. Even more disturbing than the numbers was the recognition that there would be no quick cure, treatment, or vaccine for HIV/AIDS.

With no cure in sight, San Francisco developed a community-based model of care for patients with AIDS in the early 1980s. The San Francisco model included a case management system to coordinate care, an AIDS clinic staffed with all the necessary professionals, and a community-based counseling and supportive services team staffed by volunteers. The model was expected to provide humane care and prevention education at a reduced cost. Nevertheless, there was concern it could not be replicated in other cities.

In 1986, the Foundation authorized a four-year $17 million grant to test the San Francisco model in eleven other cities. It also funded a rigorous evaluation of the AIDS Health Services Program. Shortly after the Foundation board had authorized the AIDS Health Services Program, the Department of Health and Human Services, responding to a nonbinding "sense of the Congress" resolution highlighting the need for the federal government to do more to address the AIDS crisis, sought the counsel of Robert Wood Johnson Foundation staff members. It developed a four-city AIDS demonstration project (later expanded to twenty-four cities) patterned after the Foundation's program. "The work that the Robert Wood Johnson Foundation was doing," said Sheila McCarthy, a high-ranking official with the U.S. Health Resources and Services Administration (HRSA), "helped HRSA grantees shorten the learning curve and use their funds more efficiently."[19]

In 1990, Congress used the Foundation's AIDS Health Services Program as the model for Title I of the Ryan White Comprehensive AIDS Resources Emergency Act. In their evaluation of the AIDS Health Services Program, Brown University professor Vincent Mor and his colleagues concluded that the program had "shaped public policy by providing examples of certain types of community-based service delivery systems and by creating a climate that favored community-based care."[20]

Tobacco Control

The Surgeon General's report on smoking in 1964, which brought together the research on smoking and health, concluded that cigarettes caused cancer. The report was widely publicized and made a powerful impact throughout the nation. It was followed by other reports by the Surgeon General, most notably one in 1986 that detailed the health hazards of secondhand smoke. With the scientific evidence becoming incontrovertible, the federal government stepped in, requiring that cigarette packs carry warning labels, banning radio and TV ads, and prohibiting smoking on planes. People whose health had been ruined by smoking began to bring lawsuits against tobacco companies. Despite the soothing voices of the tobacco industry, even people who smoked were aware of the risks they were running. From the 1960s on, smoking rates began to decline among adults.

This was the environment in 1991 when the Robert Wood Johnson Foundation made reducing smoking by young people (and implicitly the entire population) one of its priorities. Between 1991 and 2009, the Foundation invested $700 million in its tobacco-control work. Having absorbed some of the lessons from its grantmaking in the 1970s and 1980s, the Foundation adopted a wide-ranging approach. It funded policy research that found that raising taxes on tobacco products resulted in young people buying fewer packs of cigarettes and that banning smoking in public places reduced smoking. In collaboration with the American Medical Association, it developed statewide tobacco-control advocacy coalitions. By requiring matching funds as a condition of these grants, state coalitions were able to use other, non-Foundation funds to support increases in tobacco taxes, laws banning indoor smoking, and inclusion of cessation treatments in state Medicaid programs and state employee health insurance. The Foundation and its tobacco-control partners also established the Center for Tobacco-Free Kids, a national communications and advocacy organization founded to counter the influence of the powerful Tobacco Institute.

How significant was the Foundation's role in reducing smoking rates? Joel Fleishman, author of *The Foundation: A Great American Secret*, listed the Foundation's tobacco control work as one of the twelve highest impact foundation-funded activities of the twentieth

century.[21] In a retrospective look at the Foundation's investments in tobacco control, George Grob, president of the Center for Public Program Evaluation, concluded, "Recalling again that any success in the story belongs not only to the Robert Wood Johnson Foundation but also to many collaborators, the results are impressive."[22] The results depended largely on changes in public policy. In seeking to affect policy change, the Foundation employed the full range of tools available to it: policy research and analysis, advocacy, coalition building, convening, and communications, among others.

End-of-Life Care

During the 1970s and 1980s, concern mounted about the care people were receiving toward the end of their lives, especially hospitalized patients being kept alive by machines neither they nor their families wanted. The Right-to-Die Movement and Death with Dignity gained popularity. Dr. Jack Kevorkian took matters one step further by helping people to end their lives. The first hospice in the United States opened in 1974, and Medicare began paying for hospice care in 1982. Words such as *living will* and *health care proxy* entered the language. Two widely publicized court cases–Karen Ann Quinlan, decided by the New Jersey Supreme Court in 1976, and Nancy Cruzan, decided by the United States Supreme Court in 1983–held that a person's desires about medical treatment must be honored, even if it meant ending life support for patients with little or no hope of recovery.

With the great attention being given to end-of-life care, the Robert Wood Johnson Foundation hosted a meeting of experts in 1985 to provide guidance about what contribution the Foundation could make. Out of that meeting grew a large research study called SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) that gave special training to hospital nurses, who would then discuss with terminally ill patients and their families the patient's wishes for care and relay them to physicians. Although the study unearthed a trove of data, the intervention failed. "The problem was not just that physicians were not asking patients their views," wrote Joanne Lynn, the co-principal investigator of SUPPORT. "No one involved talks much–not

physicians, families, or patients."[23]

In 1994, SUPPORT's lack of success led the Foundation to embark on a renewed effort to improve the care of seriously ill people. The Foundation, in an informal collaboration with the Open Society Institute, employed a full range of strategies to improve end-of-life care. It worked to add end-of-life care to medical and nursing licensing examinations and to incorporate material on end-of-life care in medical and nursing textbooks and curricula. It funded fellowships in palliative medicine and promoted hospital-based palliative care, mainly through the Center to Advance Palliative Care located at the Mount Sinai School of Medicine in New York City, which became a national resource center. The Foundation funded communications and advocacy to rally advocates and to support coalitions of concerned individuals, and it developed an active communications program, the centerpiece of which was a widely watched PBS special hosted by Bill Moyers called *On Our Own Terms*.

By 2010, palliative care had become part of mainstream medical care, an option available to very sick hospital patients and their families. Three-quarters of hospitals with 250 or more beds (that is, hospitals serving the majority of patients) reported having a palliative care program, and 30 percent of all hospitals had one. In 2006, the American Board of Medical Specialties recognized palliative medicine as a medical subspecialty. In a review of the Foundation's work on end-of-life care, Patricia Patrizi and her colleagues concluded, "The Foundation's impact transcended any possible list of discrete accomplishments. In fact, most credit the Foundation with 'building the field' of end-of-life care."[24]

Four Elements Needed to Move Foundation-Funded Ideas into the Mainstream

The experience of the Robert Wood Johnson Foundation indicates that four elements are usually present when an idea takes hold and makes it into the mainstream. This does not mean that an idea will necessarily take hold when all four of these elements are present, nor does it mean that an idea will not be widely adopted in the absence of one or more of these. But it does offer a perspective, based on the experience of one foundation, on how ideas get

widely diffused and on what philanthropy can do to spur the process. The key ingredients are as follows.

1. *The idea is seen by a substantial portion—or at least an influential portion—of the population as a potential solution to a pressing problem.*

   Lack of emergency medical care, an AIDS epidemic, people dying from tobacco use or exposure, shortages of health professionals, individuals in hospitals tethered to machines that preserve life but do not restore the quality of life—these issues had entered Americans' consciousness, in some cases had generated movements, and were ripe for action to address them. As it happened, methods of alleviating these problems were widely recognized, and they were tested in a variety of locations. The emergency medical system benefited from both government-funded and Foundation-funded demonstration projects. The lack of medical services in rural areas and inner cities was addressed, in part at least, by employing nurse practitioners who would actually spend some time in these areas. Although there was no cure for AIDS, San Francisco offered a model for caring for those who were HIV-positive. In testing that model, the Foundation showed it could work in places with different health systems and cultures. By the 1990s, the health hazards of smoking were widely known, and actions to help people quit (or not start) were obvious and ready for adoption on a wide scale.

   In all of these cases, the Robert Wood Johnson Foundation understood the importance of the issues to Americans, seized the initiative, and helped direct and shape the strategies to address the issues.

2. *The political system is receptive to the adoption of new ideas—especially when legislation is the means of spreading them.*

   Ideas that took hold in the 1970s, such as emergency medical services and nurse practitioners, were products of a period when government could be expected to adopt worthy demonstration programs and expand them nationwide. During this time,

government and foundations collaborated on a regular basis and experts moved between senior government positions and the national advisory committee of foundation-funded programs. In that context, it is not surprising the federal government would assume responsibility for adopting innovative programs such as EMS and funding the education of primary care providers, including nurse practitioners.

Even when political leaders see the government as the problem rather than as a promoter of solutions, however, it is still possible to spread innovations with government help and guidance. The Ryan White Act was adopted in part because of the intense pressure on Congress generated by the AIDS crisis and because Congress responded on a bipartisan basis. The Cash & Counseling program, which, because it allowed frail elders and adults with disabilities to choose the way to meet their personal care needs under Medicaid, was attractive to a Republican President and Congress and was authorized in the Deficit Reduction Act of 2005. The same is true of the Partnership for Long-Term Care, which was also adopted as part of the 2005 Deficit Reduction Act.

3. *The evidence is strong that an idea is workable and perhaps cost-effective.*

In all of the cases we have discussed, evidence of an idea's feasibility was strong and, in some cases, overwhelming. Nurse practitioners, for example, were shown to deliver primary care comparable to that of physicians and at a far lower cost; AIDS services could be delivered effectively and relatively cheaply in the community; tobacco taxes reduced smoking, saved lives, and provided some funds for prevention and cessation; Cash & Counseling gave homebound seniors control of their care and reduced Medicaid costs for participants; and palliative care was shown to be cost-effective care. These social policy changes were all built on a strong evidence base.

Unlike the political-economic environment and public opinion, over which foundations have little direct influence, foundations can develop and strengthen the evidence base, which if marketed properly can sway opinions and environments. The Substance Abuse Policy Research Program discussed in Chapter 7 provides an excellent illustration of how

a strong research base can influence policy. Similarly, random controlled trials in Elmira, Memphis, and Denver demonstrating the cost-effectiveness of the Nurse-Family Partnership program led to its expansion. Solid evidence based on research does not, of course, ensure action will be taken. But without evidence, action is unlikely.

4. *Committed advocates keep the idea in the forefront and fight for its widespread adoption.*

Advocates and advocacy organizations have served as the link between the research and policy-making communities. In the case of Foundation-supported ideas that have taken hold, passionate advocates, most outside of government but some inside, have made change possible. William Novelli and Matt Myers at the Center for Tobacco-Free Kids confronted the tobacco companies; Philip Brickner, a physician at St. Vincent's Hospital and Medical Center in New York City, was a tireless advocate for the homeless. His efforts led to passage of the McKinney-Vento Act; Mervyn Silverman fought to expand the community-based approaches to care for people with AIDS he had instituted as San Francisco commissioner of health.

Advocates are the ones who keep the issue alive, who don't let the public forget, and who fight to turn ideas into law.

Identifying and Nurturing the Next Blockbuster Ideas

Just as pharmaceutical companies look for a blockbuster drug, so, too, do foundations look for blockbuster ideas that will, at the very least, be sustained by government funding and, even better, become part of normal American life. But not all ideas have the potential to become widely accepted. Foundations should be rigorous in identifying ideas that have the potential to enter the mainstream and should not waste resources promoting those that are unlikely to make it. A number of promising Robert Wood Johnson Foundation–funded ideas and programs may be poised to become widely replicated and accepted. They include the following:

- *Smaller, more humane nursing homes.* The Green House Program has shown great potential in improving the lives of frail seniors. As Irene Wielawski writes in this volume,[25] the program may be the wave of the future or it may simply become an adjunct to large, impersonal nursing homes.
- *Better care for pregnant women and newborns.* Consistently evaluated as a cost-effective program to improve the health of children born to impoverished mothers, the nurse-family partnership program was initially funded by the Robert Wood Johnson Foundation and has received significant additional support, including support from the Edna McConnell Clark Foundation and, more recently, from the federal government. The program is currently active in thirty-one states.
- *Better nutrition and more physical activity for children.* The Foundation is committed to reversing the childhood obesity epidemic and has committed $500 million to the effort. Although reversing the obesity trend presents a major challenge, many of the elements common to widespread adoption of an idea are in place; attitudes are already changing, and the Foundation's impact could be similar to its impact in tobacco control.
- *Greater attention to the benefits of play and recess in schools.* The Playworks program that the Foundation has supported since 2005 appears to have the potential to spread widely. Whether it becomes part of the mainstream may depend, as Carolyn Newbergh observes in Chapter 3, on whether school districts see it as a priority in difficult economic times.
- *Improved quality and lower-cost medical care.* Concern about expanding health insurance coverage drove much of the health care reform debate in 2009 and 2010. Improving quality and lowering cost were part–but a lesser part–of that debate. The Foundation has a long track record in trying to advance high-quality, cost-effective systems of care, dating back to its support of the National Committee on Quality Assurance and the Dartmouth Atlas. With enactment of health reform, the time may be approaching when quality will make it to the top of the health care agenda. If this happens, the Foundation's investments over many years will be something to build on.
- *Accrediting public health departments.* The Foundation has been supporting efforts to

develop standards for public health departments and an organization to accredit the departments. Although these efforts are not as visible to the public as many other Foundation initiatives, they could be instrumental in improving the quality of public health departments and the services that they provide.

Whether these ideas or others become the next blockbusters, there are certain steps foundations can take to nurture ideas and increase their chances of making it into the mainstream, including the following:

1. Identify ideas that have the potential to enter the mainstream and help shape the course of their development.
2. Use all of the tools available to philanthropy. The president and CEO of the Robert Wood Johnson Foundation, Risa Lavizzo-Mourey, has defined these in terms of the "Five C's"–communicating, convening, coordinating, connecting, and counting–plus a sixth, cash.[26]
3. Nurture people. Organizations are important, but it is individual advocates, researchers, policy makers, and other leaders who move ideas. Human capital is important.
4. Support independent research to provide an evidence base that will be widely accepted.
5. Communicate promising ideas widely. For foundations interested in shaping public policy and affecting social change, communications is a key tool.
6. Stick with good ideas for a long time. An inhospitable political climate can suddenly become inviting, as the passage of health care reform in 2010 demonstrates.

Notes

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