

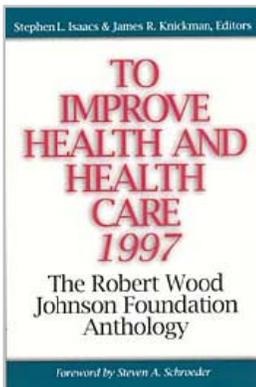
Developing Child Immunization Registries: The All Kids Count Program



Robert Wood Johnson Foundation

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Chapter Nine,
excerpted from the Robert
Wood Johnson Foundation
Anthology:
**To Improve Health
and Health Care, 1997**



Edited by
Stephen L. Isaacs and
James R. Knickman
Published 1997

Editor's Introduction

Many of the social problems affecting the health of Americans do not have known technical solutions. As a society, we continue to struggle with questions about how to convince people to stop smoking or to be less violent, how to improve the way health care services are coordinated for people with Alzheimer's or how to finance such services equitably. But in the area of early childhood diseases—such as measles and whooping cough—we have well-known technical solutions for reducing the incidence of these diseases. Available vaccines can dramatically reduce the onset of a wide range of childhood diseases, and the vaccines are not particularly expensive or difficult to administer.

So the goal of immunizing all or most children should be attainable. As a nation, however, we have not succeeded at getting some children from low-income families—and particularly younger children—vaccinated. Barriers to medical care generally facing these families lead to low vaccination rates.

Chapter Nine reviews a national program supported by the Foundation and other funders to use computer technology to design vaccination registries that facilitate the monitoring of childhood immunizations and allow outreach workers to get in touch with the families of children needing vaccinations. The program supported a range of efforts in twenty-four geographic areas to improve immunization rates for very young children.

As this chapter makes clear, even when technical solutions to a social problem exist, there are incredibly complex issues of implementation that need to be addressed. It explains in detail the barriers faced and some of the creative solutions devised by many of the grantees to make these registry systems work. The chapter also sets the work of the grantees into a context of the problems associated with immunization in this country.

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The United States has achieved the highest immunization levels for preschool children ever recorded, but we still may not be doing enough to protect them from diseases that can be prevented by vaccination. As impressive as the rates are, a quarter of the nation's very young children have still not completed their basic immunization series on time. The societal consequences of this lapse were directly illustrated in the late 1980s, when an epidemic of fifty thousand cases of measles resulted in some eleven thousand hospitalizations and the death of 130 children nationwide.¹ Such problems motivated the Robert Wood Johnson Foundation to launch the national All Kids Count childhood immunization initiative in 1991. This program sought to identify communities and states that were capable of developing immunization monitoring and follow-up systems to "improve and sustain access to immunizations for preschool children."

The rate of immunization is very high for children who are old enough to enter school—as high as 95 percent, including all recommended vaccines in most jurisdictions—but this level has been achieved only through public health laws that require proof of immunizations before the students enroll. For preschool age children, the rates have been much lower—reaching an all-time high of 75 percent in 1995. Fortunately, the incidence of vaccine-preventable diseases has dropped sharply; in 1995 it was at the lowest reported level ever. The number of measles cases reported nationwide was below three hundred, compared to twenty-seven thousand cases in 1990.²

Despite this evidence of progress, however, estimates derived from the National Immunization Survey by the Centers for Disease Control and Prevention's National Immunization Program (CDC/NIP) indicated that in 1995 approximately 25 percent of preschool-age children had not received at least one dose of the recommended series of vaccines.³ The failure to meet the minimum levels of immunization for preschool-age children—90 percent coverage for measles; diphtheria and tetanus toxoids and pertussis (DTP); polio; and *Haemophilus influenzae type b* (Hib); and 70 percent coverage for hepatitis B—is cause for serious concern.⁴ Such failures impose not only a public health risk but also financial costs that are associated with diagnosing and treating the illnesses. It is estimated that every dollar spent on MMR[®] vaccine can result in a saving of twenty-one dollars in future medical care costs.⁵

The National Immunization Program of the CDC aimed at increasing immunization levels so that:

- By 1996, at least 90 percent of children under the age of two would have received the initial and most critical doses of the recommended vaccine series.
- By the year 2000, at least 90 percent of the children under age two will have received the complete series of routinely recommended vaccines.
- By the year 2000 and beyond, a sustainable system will be established that ensures a level of 90 percent coverage of all two-year-old children with all recommended vaccines.

Although the nation appears to be well on its way to meeting these goals, a gap of 15 percentage points remains between the national goal of 90 percent coverage for the year 2000 and the 1995 average of 75 percent for children age 19–35 months. Once that gap is closed, however, perhaps the most daunting challenge facing us is that of *sustaining* levels of 90 percent coverage, once attained, into the next century.

The potential consequences of this unmet public health need are clear, but there nonetheless continue to be many barriers to immunization for preschool children. Most children in this country receive all the medical care they need from single health-care providers, yet many poor children lack a regular source of primary medical care, and many low-income parents must rely on hospital emergency rooms to deal with the medical needs of their children.⁶ Many health insurance plans available to families do not cover the costs of childhood immunizations, and there is considerable variability among state Medicaid programs in the extent of coverage for these services, leaving these as out-of-pocket costs to be borne by parents.⁷

When we take these many barriers and systemic problems into account, it is evident that economic considerations are only one of the many reasons for the underimmunization of preschool children. Even when the vaccines are made free for children whose parents cannot pay, as happened after the passage of the Comprehensive Childhood Immunization Act of 1993 and establishment of its Vaccines for

Children Program, inadequate immunization rates persisted in many areas. Besides the problem of ensuring adequate insurance coverage and access to regular pediatric care for all children, child health care providers have often found it difficult to determine which preschool patients who come to them for other reasons actually need immunizations.⁸

Many providers miss opportunities to immunize young children who are brought to them for care by not checking the child's immunization status at the time of these visits or because the records are incomplete. This may be because the child is a new patient or has been taken to several providers. Add to this the relatively complicated—at least in the minds of some parents—nature of the recommended immunization series and the fairly mobile nature of many American families, and the barriers to full early childhood immunization coverage continue to be significant.

These barriers must be taken into account when considering the potential for *sustaining* the higher rates of immunization coverage that have already been achieved and to which we still aspire, since these rates were achieved at great expense, in terms of money, time, and effort contributed by public and private organizations. These have involved the extensive efforts of private companies and many dedicated civic organizations in communities nationwide in bringing about multimedia public awareness campaigns, incentives to parents to immunize their children, door-to-door campaigns, and immunization opportunities in countless shopping malls and health fairs. President and Mrs. Clinton have directed considerable attention to these efforts, as have elected and appointed officials at all levels; the CDC; and a host of federal, state, and local agencies. To what extent can we expect these efforts to continue year after year? What will it take to achieve and maintain our goal of realizing the public health potential of the vaccines at our disposal?

Informed observers of this situation argue for multiple interventions structured to meet the needs of different regions and populations. Among the strategies most often discussed, one stands out as meriting special attention: the establishment of comprehensive, computer-based information systems, at the state or local level, to monitor the immunization status of individual children and trigger efforts to assist children who are not being immunized. For these systems to deal with the entire population of preschool children in a community, they should be accessible to, and involve the participation of, all immunization providers. Then they should be used to facilitate service delivery through coordinated outreach and follow-up measures. Finally, the systems should be used to determine coverage rates for individual and institutional providers and to target populations in need of more attention. (Although the National

Immunization Survey provides annual immunization coverage data for states and municipalities, there is some concern that the survey methodology does not permit the identification of smaller areas or populations that are seriously underimmunized.⁹)

THE ROBERT WOOD JOHNSON FOUNDATION'S RESPONSE

Although the CDC had piloted automatic immunization registry systems in eleven state and local health departments between 1979 and 1985, there was no organized extension of this concept until the measles outbreaks in the early 1990s called attention to low immunization coverage levels. In 1991, motivated by these problems and their potential solutions, the Foundation launched the All Kids Count Childhood Immunization Initiative. It stated in its solicitation of proposals:

The purpose of this initiative, called All Kids Count, is to establish immunization monitoring and follow-up systems that—when combined with other local, state, and federal immunization efforts—will help increase immunization rates among preschool children and reduce rates of illness, disability, and death from vaccine-preventable diseases.¹⁰

The Foundation sought to identify communities and states that were capable of developing these immunization monitoring and follow-up systems. In 1991, there were few local or statewide immunization registry systems that were fully operational and included the full participation of both public- and private-sector providers. The effort by the Foundation had the support of the CDC, which was preparing to stimulate state registry planning efforts.

Although these ideas had been discussed before 1991, when All Kids Count was launched, no consensus existed regarding the technology that should be used to support these registry systems, and the cost of starting and maintaining the systems was relatively unknown. Consequently, applicants for All Kids Count planning grants were allowed considerable latitude in the direction their efforts would take, in the shape and scope of the immunization registries they would develop, and in the way these efforts would unfold.

The Foundation received 114 proposals, and in November 1992 twenty-three applicants were given one-year planning grants of up to \$150,000. In November 1993, fourteen of these projects received grants

from the Foundation, in most cases for two years, to launch their efforts. Twelve of the projects have received an additional two years' funding, for a possible total of \$525,000 per project over four years.

The family of All Kids Count initiative projects was expanded significantly when four additional projects were supported by the Packard Foundation, two additional projects were assisted by the Annie E. Casey Foundation, and three more were funded (one each) by the California Wellness Foundation, the Flinn Foundation, and the Skillman Foundation. In addition, the Robert Wood Johnson Foundation made a special grant to fund a statewide childhood immunization effort in New Jersey in 1993. This brought the total of All Kids Count projects to twenty-four, including six statewide and eighteen municipal or county-based projects. Most of the All Kids Count grantees are based in public health department immunization units that also receive support from the CDC.

ISSUES AND CONSIDERATIONS IN NATIONAL PROGRAM DEVELOPMENT

The All Kids Count initiative illustrates how an idea that is simple in concept can be complex and difficult in practice. The technology and protocols needed to develop registries may be routine in fields like law enforcement and motor vehicle registration, but they are not so easy in the field of public health. The task is complicated by the American system being built around a loose (and often ineffective) intersection of public- and private-sector responsibilities for child health care. These sectors must cooperate in the process of monitoring a series of immunizations for each child over a period of at least two years, during which child and family names, child guardianship, and residences may change. The great data management and technological challenges are compounded by the numerous providers using, entering, and accessing the systems. Also, some groups are suspicious of computerized monitoring of individuals, even for a good cause, and have occasionally objected to immunization registries as invasion of privacy. This tension between the public good and the individual rights of citizens is being played out in other, more publicized and generally more controversial arenas; it may continue to be an issue as the registries reach full operation and if (or when) data linkages are instituted between registries.

Defining Immunization Registry Systems

When the Robert Wood Johnson Foundation asked communities and state health departments to develop a "childhood immunization monitoring and follow-up system," there was no commonly accepted definition of what was intended. The terms *monitoring system* (or *monitoring and follow-up system*), *tracking system*, and *registry system* have been used interchangeably by those developing the systems. The term *registry system* was once applied exclusively to the core database containing descriptive and demographic information on each child (usually derived from hospital birth records) and to which all

immunization history was added when a child received immunizations. There is now a consensus that these systems can all be conveniently referred to as *registry systems* and defined this way:

Manual or computer-based information systems by which to follow the immunization services provided to individual children in defined populations and to enable health care providers to ascertain (by computer or other means) the immunization status of individual children in a timely and accurate manner when immunization opportunities occur. Such systems should allow health care providers to input information on vaccines given at the point of service.¹¹

Even before defining the terms "childhood immunization monitoring and follow-up systems," the Foundation requested proposals, appointed a national advisory committee to review them, conducted site visits, and selected an initial group of projects to receive planning grants.

In essence, the systems are intended to perform three basic functions. First, they identify children who are due or overdue for immunizations and notify parents, prompting them to make appointments for their children. Similarly, providers or outreach workers can be notified of missed immunizations for follow-up. Second, the systems provide a database for health care providers to monitor the immunization status of their patients as a reference point during patient encounters. By allowing all providers of child health services to enter immunization-related data into these systems, providers serving a particular child have a comprehensive information source available at the time they see a patient, no matter where a child may have received immunizations in the past. Third, these systems can provide a database to enable immunization program planners to identify populations at risk for delayed immunizations, to target interventions appropriately, and to evaluate the success of immunization efforts.

Defining the purpose and functions of an immunization registry system was an important step in the national effort to promote the development of these systems. Equally important is the effort to specify the key functional components of such systems. The national evaluation team, with assistance from the National Program Office and the CDC's National Immunization Program, sought to define the major functional expectations of such systems, realizing that many of the systems would address the issues in ways that would vary from approaches taken in other projects. The key functional components described in Exhibit 9.1 address capabilities expected of registry systems in four areas of activity: database, inputs, outputs and system factors.

Most of the first generation of grantees reported the twenty-item list of key components to be useful in describing their registry systems. These criteria were never intended as a rigid set of expectations; rather, projects were expected to vary a great deal in the order in which they would address these functional task areas. However, there were expectations that at least some effort would be made in each of these twenty areas.

Registry System Sponsorship and Infrastructure

In most cases, local or state public health departments were the applicants for planning or implementation grants. It appears that they are often of pivotal importance and have the legal authority to address this important set of public health issues. The applicants hoped to involve private-sector providers of child health services—including individual physicians and group practices in pediatrics and family practice, community health centers, hospital clinics, and emergency rooms—in the registry systems. Although many public health departments have had interactions and cooperative arrangements with these entities in the past, the collaboration required to implement childhood immunization registries may require a significantly higher degree of collaboration than ever before.

Although the emerging "community health information networks" (CHINs) tend to focus on inpatient care, these organizations may be able to take the lead in some communities as the emphasis of these systems shifts to include more ambulatory and managed care data. Some of them may be able to use their information-systems capability to handle the data-management aspects of local immunization registry systems. If they do, public health agencies or private-sector managed care organizations could perform the outreach needed to establish the registries.

At the time the All Kids Count initiative was beginning, there was a feeling that state and local immunization registries would lead to the creation of a *national* immunization registry system. This idea has since been discarded. It is unlikely that all communities will develop childhood immunization registry systems. Moreover, the challenges and costs associated with sustaining an enormous, constantly updated, and instantly interactive nationwide system are immense. This realization has led instead to a focus on the state and local levels as the appropriate places to house registries.

There are, however, important reasons to explore ways to link local or state registries for the purpose of creating national indicators of immunization coverage. The Subcommittee on Vaccination Registries of the National Vaccine Advisory Committee (NVAC), which reports to the U.S. Department of Health and Human Services, recommended the establishment of a "system of state-based registries that can be

linked nationwide" in its 1994 report.¹² The sum of the information would yield state, and then national, estimates of immunization coverage. Local registry systems would be the principal source of immunization status data for child care providers.

Communities vary considerably, however, in the technical and financial resources available to implement and maintain an immunization registry system, and there is insufficient information by which to calculate the costs of such systems. Even in those projects assisted by the Robert Wood Johnson Foundation and other private philanthropies, it may not be easy to separate the costs of mounting an immunization registry project from the costs of maintaining other local public health immunization, information, and surveillance activities. It remains to be seen whether those public health agencies with substantial experience in epidemiological and other aspects of disease surveillance, or those with outreach programs designed to identify those adults, children, and families with greatest need for health services, have an advantage in the effort to develop immunization registries. Surveillance units of these agencies usually have persons with computer and data management skills as well as the computer equipment to implement a basic immunization registry effort. When these agencies have established mechanisms for integrating hospital birth records with records of existing public health outreach programs, they may be well positioned to develop key components of registry systems.

So far, it appears that local public agency management of immunization registries brings the best results. That said, there remains the problem of ensuring that these agencies have the necessary infrastructure to reach beyond their traditional boundaries and assume a role as coordinator of communitywide efforts in behalf of all children, regardless of their primary source of health care. Not only do these agencies need their own solid resource base; they must be able to draw upon the resources of private-sector health care organizations in these efforts.

Legislative Mandates to Support Registry System Efforts

In a number of states and communities, including eight All Kids Count regions (Baltimore, New York City, California, Georgia, Philadelphia, Virginia, Mississippi, and Arizona), officials have acted under their public health authority to authorize or mandate immunization registries and/or the reporting of immunization events to a registry or to the public health authority.¹³ In those communities, All Kids Count project directors have indicated that these regulations could facilitate their work. In other cities, registries are being developed without specific statutory authorization. While there is no current federal legislation requiring that these systems be developed, there are federal policies that support registry development; however, there is no single source of funding sufficient to develop them in every state and

community. The collaboration of the public and private sectors at the national, state, and local levels continues to be essential. The fostering of public policy support of immunization registry and follow-up efforts may prove very helpful to their success but cannot substitute for energy and commitment at the community level.

Public- and Private-Sector Collaboration

One of the most difficult aspects of community-level efforts in developing childhood immunization registry systems concerns the participation of private-sector providers. Childhood immunization services vary widely from community to community. In many counties and cities of the American South and in California, the local health department is likely to serve as a major provider of direct primary care services to otherwise underserved and uninsured populations, but, with the exceptions of New York and New Jersey, this level of care would not be common among public health departments in the Northeast or the Midwest. In those regions, therefore, public health agencies may have very different ideas about how to achieve a central role in creating a community-based immunization registry system that involves both public- and private-sector providers. If both public- and private-sector providers do take part in developing an immunization registry, all children who use the health care system can be monitored and receive their immunizations on time. In some areas, a significant portion of the population may have limited contact with health care providers, public or private. In Mississippi, for example, the All Kids Count project staff members speculate that the 10 percent of children who are most difficult to reach, and those most likely to be underimmunized, simply do not seek health care of any kind. Immunization registries that use data from birth certificates as a base may be the most effective means of identifying this vulnerable population and ensuring that they receive not only vaccines but other primary care as well. (However, some All Kids Count registries are finding that birth certificate data can be inaccurate or incomplete and do not provide addresses through which parents can be reached.)

It is with regard to these children that immunization registries may have their greatest "value-added" impact. A child monitored through one of these registry systems can then be brought into contact with more general health care services. A child who comes in for a vaccination may well have other health needs that the health care provider can see to. If registry systems can be combined with an effective outreach program, access to primary health care in general can be improved.

There may be increased potential for this benefit with the widespread movement in the 1990s toward the delivery of services to Medicaid-eligible children through managed care contracts. Managed care organizations use immunization coverage rates as one indicator of the quality of services delivered under

their plans, and this emphasis may bring about improved overall primary care for underimmunized children enrolled in both the immunization registry and the managed care plans.

During the early years of All Kids Count, managed care, including Medicaid managed care, increased in many areas of the nation. This environmental change has affected private practitioners and has brought about changes in the development of a number of the immunization registries. Grantees have begun to work out cooperative arrangements with managed care organizations so as to secure access to immunization updates and to bring their providers into the registries.

For their part, health plans across the country are demonstrating a corresponding interest in immunization registries. The 1996 Childhood Immunization Practices Survey, conducted by the American Association of Health Plans,¹⁴ showed that more than 70 percent of those responding supported the concept of registry development, with particular interest in the ability to have access to data or to interface with the registries. The survey also indicated that 42 percent of 116 respondents were involved in some way in the development of registries by other organizations. More than half of the responding health plans reported having difficulty collecting immunization data from providers, and even more (69 percent) had difficulty acquiring data on immunizations given to children outside of their plans. Issues of concern cited by the health plans included the cost of registry development and participation, the potential for the unauthorized use of data, and the burden of data-entry requirements. Representatives of managed care organizations have voiced concerns that registry data (such as parents' names and addresses) might be used improperly to recruit clients from one health plan to another.

Technology Choice and Implementation

One of the most interesting elements in developing immunization registries involves the choice of a technological strategy. This choice is constrained by the availability of technical personnel, the interest and awareness among registry system and public health agency personnel of developments in information technology, the state of the art in medical and public health informatics, and the available financial resources to experiment with and adopt these technologies.

It is important to realize the complexity and level of administrative commitment that a comprehensive childhood immunization registry and follow-up system entails. In addition to maintaining a database updated from multiple sources, the systems must use the database to ensure that individual children are immunized. Systems must be in place that identify the immunization schedule for a child based on date of birth. Then these systems must be capable of providing prompts (to parents and providers) or must

enable individual providers to do so for their patients. The number of events (clinical immunization encounters) such systems would have to track is usually five: (1) soon after birth; (2) at age two months; (3) age four months; (4) age six months; and (5) between fifteen and eighteen months.

For registry systems to send reminders both that immunizations are due *and* that immunizations are overdue (which is the case for more than half of the All Kids Count projects), this means a minimum of five notifications (to parents who have their children immunized on schedule) and a possible total of ten separate communications.

For children who receive their scheduled immunizations late or miss them, interventions must be designed, and these must involve collaboration with providers. Providers having experience with registries have found the "reminder" function of the registries to be worthwhile, as it can increase the percentage of scheduled—and kept—appointments and can stimulate parents to bring children for needed well-child care, not just for illnesses.

For an ongoing registry system to be cost-effective, the agencies operating the system must be prepared to analyze their databases over time in order to target populations or areas where underimmunization is most prevalent, and then design outreach efforts to provide services or interventions. Further, the advances in information technology that have made computer-based registry systems possible are continuing, and there are periodic costs associated with technology upgrades that have to take place from time to time. This has already been the case for one of the All Kids Count projects, which began with a commitment to a mainframe-based system and then had to make changes in technology and design in midcourse in order to interact with private providers. Obviously, this entailed substantial costs and staff time, in addition to delaying implementation of the registry.

Many All Kids Count registry projects have developed contractual relationships with private companies, such as software or systems design firms or in one case a university department, to obtain technical assistance needed in designing, staffing, and maintaining their systems. There can be an advantage, especially in the early stages, to having access to a substantial resource of additional expertise. However, there can be a loss of control; modifications can be more time-consuming when taken out-of-house, and if the contractual arrangement is not fulfilled by the outside contract organization, the project can be compromised. During the first three years of the All Kids Count program, several projects experienced delays related to difficulties with such outside organizations; in one case the resulting setbacks brought

the project to a temporary, but very serious, halt. It seems certain that any collaborative or contractual arrangement is stronger where the agency responsible for the registry maintains both a high degree of commitment to the registry system effort and strong managerial control.

As the All Kids Count projects began to take shape, there was considerable interest in the application of new and often untested ideas for how computer-based technologies might augment the basic registry system efforts. Consideration was given to such technologies as "smart cards" (identification cards that can be read by machines for data entry and reimbursement information), patient-carried immunization records, computer-assisted telephone prompting, and online and fax-based systems for provider data input and querying.

The projects have recognized that a range of computer systems, both high-tech and low-tech, are necessary to permit users of the registries to supply and provide information. Most sites chose to build databases on powerful personal computers. A small number of projects, primarily among those based in larger areas, chose at least initially to build their databases on a mainframe computer. The form of database management and provider access most commonly selected was the client-server or file-server format, which permits users to conduct most of their interactions with the database on their own computers after having obtained the required files from the central server and which then allows them to return the updated or reviewed data to the central server for processing and storing. In this way some of the responsibility for database management is "distributed" among those generating the data.

The predominant early vision of these systems was based on the expectation that most providers would interact online with the registry using their office-based computers. That model has posed technological challenges, because providers have varying computer systems—or none at all—in their offices, and varying levels of in-house expertise and staff time. Accordingly, most projects have developed systems to accept and process periodic batch entries of computer data, submitted daily or perhaps weekly. Also, all of the projects have put in place systems to accept by mail or fax information sent to the registry and then entered centrally, or submitted over the telephone. Most have technologies allowing immunization information to be submitted over telephone lines to and from providers. This has involved establishing telephone lines, in some cases with toll-free numbers, and training registry staff to deal with telephone inquiries.

Projects have encountered problems getting consistently accurate and complete data from multiple providers, regardless of which technology is employed. Acquiring and maintaining a complete and accurate database has been a greater challenge than anticipated, even within an organized health department system. This problem can be compounded exponentially in settings where numerous private-sector physicians' offices or clinics provide immunization data updates, because these sites have varying in-house reporting systems, different computer systems, and differing degrees of staff commitment. Each provider organization participating in the registry must receive some form of training, either through instructional materials or on-site; staff turnover may result in untrained personnel submitting data, with the obvious potential for inaccuracies.

Security and Confidentiality

Support for the registries from providers, managed care organizations, and the general public rests in part on the ability to ensure the security and confidentiality of registry information. The All Kids Count project staffs have invested considerable effort in developing policies and procedures to protect individual privacy and prevent unauthorized or improper use of their records. These include methods to prevent "browsing" (viewing numerous records at one time), identify authorized users, and establish different levels of access based on the need to know.

At the outset of the All Kids Count initiative, there was much enthusiasm for the development of linkages between immunization data and other child health datasets. The original concept was to tie registry data to other relevant health data on a child so that more comprehensive primary care could be provided to children. For example, a provider seeing a child for the first time could, through linked or integrated datasets, learn that a child not only needed immunizations but was being followed for lead exposure. The provider could then determine if any further assessment was required. However, there have been many concerns about the advisability of such integrated databases, primarily for reasons of security and confidentiality. There are concerns that the nonimmunization data could be obtained and used improperly, for example by insurance companies that might choose to deny coverage.

About half of the All Kids Count projects have established or planned linkages to other data; those projects that are not linked tend to cite confidentiality as their primary reason for establishing stand-alone databases.

In most cases where databases have been or will be linked or integrated, they are linked only through the public health agency and primarily relate to public health programs such as WIC (a federally funded

nutrition program for women, infants, and children) and lead screening. Only one registry system, still under development, envisions a more comprehensive child health database.

The issues of security and confidentiality, particularly of linked databases, remain very much on the agenda and continue to be of considerable importance as the data accumulate, the number of records increases, and more providers participate.

Area Size and Scope of Services

As the focus on local immunization registries has become clearer, the question of whether some communities are able to implement these systems arises; and, of course, some communities may have advantages associated with how delivery of local health services has developed. For example, in those communities with large numbers of Medicaid-eligible children and families, the advent of Medicaid managed care may make it easier to recruit private sector providers who participate in the registry through their affiliation with the health plans under contract to provide Medicaid services.

Community size and population density may affect the practicality of implementing computer-based information systems. In some rural counties where no more than half a dozen children in any birth cohort are scheduled for a particular immunization in a given month, there are concerns about the benefit to be gained from an investment in computer-generated reminders and overdue notices. A statewide registry might be particularly important in those states with many sparsely populated areas where the local population and public health infrastructure would not support multiple local registries. It may be that the outreach and follow-up efforts stimulated by the centralized registry database should vary by region; for example, outreach workers in less-populated areas might personally encourage parents to obtain immunizations for their children.

PROBLEMS AND PROSPECTS FOR THE FUTURE

The All Kids Count initiative can play a vital role in ensuring coverage levels of 90 percent or greater for two-year-old children by the year 2000 *and sustaining* those levels thereafter. History has shown that once a crisis is over, memories of low immunization levels and disease outbreaks subside, and immunization rates may drop again, only to be followed by further outbreaks and their human and societal costs. The All Kids Count registries represent an important approach to maintaining high immunization levels regardless of the ebb and flow of public awareness. By institutionalizing these programs (including both

monitoring of immunization status and outreach efforts), there is greater likelihood that recent gains can be sustained.

All of the All Kids Count registries funded by the Robert Wood Johnson Foundation are expected to be operational by the end of 1997, although several that have experienced delays may not be as fully implemented as originally anticipated. By the year 2000, most will have monitored the immunization levels of at least two annual cohorts of two-year-old children who were registered in these information systems at the time of birth. These systems will have the ability to sustain high levels of immunization in the communities they serve, and to document their results.

One lesson has emerged from these efforts so far: few very important public health accomplishments occur without broad-based, multisectoral collaboration and strategic investment of sufficient resources. A substantial investment by government, nongovernmental organizations, and corporations has brought about the highest recorded level of early childhood immunizations to date—concrete evidence that the nation's health can be protected through the use of the vaccines and the childhood vaccination schedules that medical science has so painstakingly developed. We have not yet reached our goals; although there are a number of registries in operation or under development, thanks in great part to the All Kids Count initiative, many more communities are at best in the planning stages of registry development or not yet considering it. Although the states are continuing to develop plans, there is considerable variation in their rates of progress.

As the CDC continues to work with states to develop plans for local or statewide registries, the experiences of the All Kids Count projects appear to have been beneficial. In the fall of 1996, the CDC produced first drafts of extensive guidelines for immunization registry and follow-up systems. The guidelines were produced by a group that included a number of representatives of the All Kids Count projects and the national program office in Atlanta; the documents bear the names of the CDC and All Kids Count as cosponsors. The National Vaccine Advisory Committee promptly endorsed the section addressing confidentiality, which related to the issues that were of most immediate concern to it.

Additionally, through annual national and regional meetings, the All Kids Count projects promoted and supported the development of immunization registries. The meetings were open to and well attended by participants from many other locations. Thus, the linkages among registries that are not yet technically

feasible may have begun informally and unofficially. It remains to be seen whether the function served by these meetings can be carried forward under other sponsorship when foundation funding ends.

In any event, the All Kids Count initiative has played a role in setting national policy for the development of immunization registry and follow-up systems. The experiences of the All Kids Count projects have shown that the task is a complex one, requiring technical expertise, careful administrative oversight, and long-term participation by the providers of childhood immunizations.

Notes

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³ Centers for Disease Control and Prevention, "National, State, and Urban Area Vaccination Coverage Levels Among Children Aged 19–35 Months: United States, April 1994–March 1995," *Morbidity and Mortality Weekly Report* 45(7) (Feb. 23, 1996), 145–150.

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⁹ U.S. General Accounting Office, *CDC's National Immunization Survey; Methodological Problems Limit Survey's Utility: Report to the Honorable Dale Bumpers, U.S. Senate* (Sept. 1996), P. 20.

¹⁰ Robert Wood Johnson Foundation, *All Kids Count: Establishing Immunization Monitoring and Follow-up Systems (Call for Proposals)* (Princeton, N.J.: author, 1991), p. 3.

¹¹ Robert Wood Johnson Foundation, All Kids Count. *Childhood Immunization Registry Systems: A General Definition of Terms, Scope, and Components* (Princeton, N.J.: author, 1996) p. 5.

¹² National Vaccine Advisory Committee, *Developing a National Childhood Immunization Information System: Registries, Reminders, and Recall* (Washington, D.C.: Subcommittee on Vaccination Registries, U.S. Department of Health and Human Services, U.S. Public Health Service, 1994).

¹³ L. O. Gostin and Z. Lazzarini, "Childhood Immunization Registries: A National Review of Public Health Information Systems and the Protection of Privacy," *JAMA* 274 (1995), 1793–1799.

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EXHIBIT

9.1 Model Immunization Registry System Components