



All Kids Count

An RWJF national program

SUMMARY

The *All Kids Count II* program, funded by the Robert Wood Johnson Foundation (RWJF) from 1998–2000, sought to make 16 immunization registry projects based in local, county, and state health departments fully operational by January 1, 2000. The program also sought to develop a long-term policy to ensure registries are implemented and sustained nationwide. The program built on progress made under *All Kids Count Phase I*, 1992–1997, an RWJF program to begin the development of registries.

The national program office was based at the [Task Force for Child Survival and Development](#) in Atlanta. With guidance from the program's National Advisory Committee, the national program office gave grants ranging from \$300,000 to \$700,000 to 16 projects.

RWJF's Board of Trustees authorized up to \$11.25 million for phase II beginning in 1997.

Key Results

- *All Kids Count* played a primary role in spurring the development of immunization registries nationwide and in providing the encouragement and advocacy to maintain their momentum.
- Although progress on the individual indicators varied considerably among registries, in the aggregate, significant progress was made on several key indicators:
 - Providers submitting data to registries.
 - Children age 2 and older in registries.
 - Children age 2 and older in registries with shots.
- By June 2000, six registry projects had almost achieved the goal of being fully operational, as defined by *All Kids Count*. All projects made significant progress. This report includes stories from the field that illustrate the challenges faced by the *All Kids Count II* registry projects in achieving their goal. [Click here for stories.](#)

- An *All Kids Count* study, published in the July 2000 issue of the *American Journal of Preventive Medicine*, showed that a nationwide population-based system of registries would save more than it would cost.

About This Report

This report was produced by the national program office and edited by the Program Results Reporting Unit.

FOREWORD

by William H. Foege, M.D., M.P.H., Original National Program Director

Throughout the world, even in the poorest of nations, computerized information systems have revolutionized the way business is done.

No responsible leader in the financial, insurance, agriculture, or energy industries of today can imagine forfeiting the speed and accuracy of computers and returning to the days when their customers' transactions were recorded on pieces of paper and placed in file folders on a shelf until they were needed again.

Yet in the United States, that is how most critical information about our children's health is managed.

Each day in the United States, 11,000 children are born, and each of these children needs 18 to 22 immunizations by age 6. That equates to 250,000 immunizations each day, or more than 91 million shots a year—and most of these are still being managed using paper records.

This tried and true system works for children who are fortunate enough to see the same doctor throughout childhood, but what about the increasing numbers of children whose families move frequently, change providers, and change insurers? We know that many of these children are falling through the cracks, placing them at risk of life-threatening diseases.

With the advent of biotechnology, children in the United States today are better protected against vaccine-preventable diseases than ever before. But vaccines do no good if they are not used.

Creating a system to administer vaccines properly is as important as developing the vaccines in the first place. The latter is the product of good science; the former is the product of good governance.

The world looks to the United States for leadership in technology. Let the rest of the world look to us, too, in applying the power of technology to improving health care for children and communities.

INTRODUCTION

by Kristin N. Saarlus, M.P.H., Deputy Director, All Kids Count

The United States now enjoys the highest immunization rates and lowest disease levels ever, but the growing complexity and volume of immunization information makes it difficult to sustain those levels consistently.

In the early 1970s, experts in disease prevention recognized the potential of immunization registries—confidential, computerized information systems—as tools to help prevent the "peaks and valleys" of disease outbreaks by more accurately and efficiently managing information about the immunizations that children receive.

By the 1980s, several large HMOs were developing registries to serve their enrollees. In the early 1990s, the CDC collaborated with large health maintenance organizations (HMOs) to establish immunization registries that also served as vaccine safety monitoring systems. In 1991, RWJF and several other foundations funded the initial development of 24 state and local immunization registries under the umbrella of *All Kids Count*.

All Kids Count, Phase I

The progress that *All Kids Count* projects achieved during its first phase, 1992–1997, showed that although immunization registries can fulfill their promise, the challenges were greater than originally believed.

Among those challenges were:

- The rapid pace at which information technology was evolving made it difficult for public health departments to stay abreast.
- The cost of developing registries was more than anticipated.
- Recruiting doctors in private practice to participate in a registry took longer and was more difficult than anticipated.
- Issues of privacy and confidentiality were complex.

In 1997, after five years of development, only one of the 24 *All Kids Count I* projects (Chatham County, Ga.) had reached fully operational status. We defined fully operational status as having all children in a community with all their shots in the registry and all providers in the community participating.

However, despite the above mentioned challenges facing registry developers, *All Kids Count* staff believed that many projects were positioned to reach that goal given more time, funding, and assistance.

Federal Impetus

In late 1997, public policy set the stage for *All Kids Count* projects and other state and community registries to take a giant step forward. President Bill Clinton issued a presidential directive to Secretary of Health and Human Services Secretary Donna Shalala "to start working with states on an integrated immunization registry system...we have to do it and do it right."

As a result, an Initiative on Immunization Registries was undertaken by the National Vaccine Advisory Committee (NVAC), with support from the National Vaccine Program Office (NVPO) and the National Immunization Program of the CDC.

At the same time, more communities and states were developing or implementing registries. In 1998, when *All Kids Count II* began:

- All 50 states had begun developing immunization registries.
- Some 18 states had a law or rule authorizing immunization registries.
- Ten states and several cities had mandated private provider reporting of immunizations to registries.

In 2001, 25 states had a law or rule authorizing immunization registries, and several states planned to introduce legislation or rules authorizing registries.

Report Overview

This report describes the problem that all immunization registries, including *All Kids Count II* projects, address: how to provide information about individuals' and communities' health and information that meets the needs of the private provider and public health officials.

It describes how *All Kids Count II* projects addressed their individual goals, and the goals, strategies, and achievements of the *All Kids Count II* program. It relates the key lessons learned about immunization registry development from these experiences. Finally, it describes six *All Kids Count II* projects that are representative of registries' experiences.

As the development of immunization registries enters its second decade, both public health officials and clinicians are carefully watching its progress.

Public health officials and policymakers are learning that developing immunization registries is no small task, but that fully operational registries, well-integrated with programmatic aspects of immunization programs, can have tremendous payback for clinicians, managed care organizations, and public health.

THE PROBLEM: SUSTAINING HIGH IMMUNIZATION RATES

by National Program Office Staff

Although the United States currently enjoys record high rates of immunizations and record low levels of disease, sustaining these rates is not easy.

From 1970 to 1989, immunization levels were relatively high and stable as a result of federal initiatives that brought large public education programs and new legislation to ensure that the school-age population was immunized.

But a 1989–90 resurgence of measles among preschool children that resulted in 120 deaths and thousands of hospitalizations underscored the need for a way to systematize immunizations for infants and toddlers.

Yet another immunization initiative in 1993 brought unprecedented levels of support and intensive and extensive efforts by communities and states to increase immunization levels.

The result is that today immunization levels are at record highs, and the reported incidence of vaccine-preventable diseases is at record lows. Because of vaccines, illnesses caused by nine childhood diseases have dropped 97 to 100 percent compared to pre-vaccine era levels.

However, "pockets of need," principally in poor, under-served populations remain. In addition, immunization levels for toddlers in some inner-city areas remain at 50 to 60 percent—up to 30 percent lower than comparable suburban or state immunization levels. History has taught us that past success is no guarantee of future success.

Several challenges remain to sustaining today's high immunization rates among all children. These include:

- **Concerns about adverse reactions.** In Japan, Sweden, West Germany, and the United Kingdom, concerns about vaccine safety have caused major drops in vaccine coverage in recent years, with the subsequent return of epidemics. No major epidemics have yet occurred in the United States as a result of vaccine safety scares. Smaller outbreaks have occurred in areas where parents seek religious or philosophical exemptions from school immunization requirements.

- **An increasingly complex vaccine schedule.** In the United States, approximately 4 million infants are born each year, or 11,000 each day. Each of these newborns needs to receive 18 to 22 immunizations if they are to remain protected against vaccine-preventable diseases.

The complex and ever-changing nature of the childhood immunization schedule makes it difficult for many clinicians to keep up, even with the help of charts, books, and training. Thanks to biotechnology, new single and combination vaccines are quickly becoming available, increasing the schedule's complexity.

- **Societal changes.** Children and families are more mobile than ever before. They change employers, insurers, and health care providers. As many as 25 percent of children visit two or more providers for immunizations before their third birthday, resulting in medical records and immunization records scattered among different providers, offices, and clinics.
- **Parents and providers mistakenly think that children are up-to-date on their immunizations.** Studies show that both parents and providers believe that immunization coverage levels for children are higher than they actually are.
- **Decreasing awareness of vaccine-preventable diseases.** As disease levels have fallen, so has awareness of these life-threatening preventable diseases. Many nurses and doctors today have no first-hand knowledge of the diseases that vaccines prevent. The same is true for parents. Such lack of awareness makes it easy to skip an immunization or to fear the vaccination more than the disease.

PROGRAM DESIGN

Recognizing the progress that was achieved and the growing momentum of immunization registries, RWJF funded *All Kids Count II* to:

- Bring 16 *All Kids Count II* immunization registry projects to fully operational status by January 1, 2000.
- To develop a long-term policy to ensure immunization registries are implemented nationwide and sustained.

THE PROGRAM

The national program office based at the [Task Force for Child Survival and Development](#) in Atlanta, which was formed to direct the first phase of *All Kids Count* (1992–97), was expanded during *All Kids Count II*.

Staff included:

- William H. Foege, M.D., M.P.H., program director and principal investigator.

- William C. Watson Jr., M.P.A., the second program director.
- Kristin N. Saarlal, M.P.H., deputy director.
- Two project officers (one on assignment from CDC); a communications specialist; and program and administrative assistants. A second CDC assignee provided projects with technical consultation on request. (See [Appendix 1](#) for a complete list of national program office staff.)

The National Program Office Role

All Kids Count II called for a broader role for the national program office than is traditional with RWJF national programs. National program office staff assisted projects in reaching their joint goal of achieving fully operational status, as well as their individual project goals, through three primary activities:

- Convening immunization registry stakeholders and facilitating communication and learning among them.
- Synthesizing and disseminating information about registries.
- Advocating for action. (See the [Bibliography](#) for a list of publications and key meetings and conferences.)

Key activities included:

- Regular site visits to projects.
- National meetings and conferences that brought registries together to share ideas, progress, and challenges, and to learn from one another.
- Special consultations.
- Presentations to national conferences and meetings.
- Facilitation of workgroups to address specific registry issues.
- Communication of registry progress through publication of peer-reviewed papers and electronic and printed publications.
- Education of policymakers and other registry stakeholders about registries and registry funding.
- Development of working relationships with partner organizations.

Together these activities assisted projects in reaching their goals, but perhaps more importantly, the national program office provided leadership and encouragement that bolstered registry developers' conviction in what they were doing.

In undertaking these activities, the national program office also created an informal community of individuals who were dedicated to improving the health of individuals and communities through use of health information systems, and who understood that they could learn from one another.

Site Selection

With input from the National Advisory Committee (see [Appendix 2](#)), in July 1997 the national program office and RWJF awarded two-year immunization registry implementation grants, ranging from \$300,000 to \$700,000, to 16 city, county, multi-jurisdictional, and state health departments.

The projects were selected from a field of applicants representing rural and urban environments, and birth cohorts ranging from less than 20,000 to as many as 133,000.

Half of the grantee organizations were former *All Kids Count I* projects. The projects selected were considered those most likely to succeed. Given their maturity, technology, and support from the health department and community, the selection committee believed these immunization registries would be able to meet the criteria of fully operational by January 1, 2000.

All Kids Count II Projects

- [Arizona State Immunization Information System \(ASIIS\)](#)
Arizona Department of Health Services
- [Arkansas Immunization Network for Children](#)
Arkansas Department of Health
- [Baltimore Immunization Registry Program \(BIRP\)](#)
Baltimore City Health Department
- [Connecticut Immunization Registry and Tracking System \(CIRTS\)](#)
Hartford Health Department
- [Michigan Childhood Immunization Registry \(MCIR\)](#)
Michigan Department of Community Health
- [Southwest Minnesota Immunization Information System \(SWMN-SIIS\)](#)
Minnesota Department of Health
- [Immunization Program, Bureau of Disease Control and Intervention Services \(BDCIS\)](#)

- Nevada State Health Division
- [Citywide Immunization Registry \(CIR\)](#)
New York City Department of Health
 - [Oklahoma State Immunization Information System \(OSIIS\)](#)
Oklahoma State Department of Health
 - [Oregon Immunization Alert \(ALERT\)](#)
Oregon Health Division
 - [Philadelphia Kids Immunization Database/Tracking System \(KIDS\)](#)
Philadelphia Department of Public Health
 - [Rhode Island KIDSNET](#)
Rhode Island Department of Health
 - [San Bernardino County All Kids Count II Project](#)
San Bernardino County Health Department
 - [Santa Clara Immunization Registry Information System \(IRIS\)](#)
Santa Clara Valley Health and Hospital System, Department of Public Health
 - [South Carolina Statewide Immunization Information System \(SIIS\)](#)
South Carolina Department of Health and Environmental Control
 - [Washington State CHILD \(Children's Health, Immunization, Linkages, and Development\) Profile](#)
Snohomish Health District

OVERALL PROGRAM RESULTS

- *All Kids Count* played a primary role in spurring the development of immunization registries nationwide and in providing the encouragement and advocacy to maintain their momentum.
- All 16 projects made significant progress toward reaching fully operational status. Although progress on the individual indicators varied considerably among registries, in the aggregate, significant progress was made on several key indicators:
 - Providers submitting data to registries.
 - Children age 2 and older in registries.

- Children age 2 and older in registries with shots.
- By June 2000, six registry projects had almost achieved the goal of fully operational, as defined by *All Kids Count*. All projects made significant progress. This report includes stories from the field that illustrate the challenges faced by the *All Kids Count II* registry projects in achieving their goal. [Click here for stories](#).
- An *All Kids Count* study, published in the July 2000 issue of the *American Journal of Preventive Medicine*, showed that a nationwide population-based system of registries would save more than it would cost.

Below is a description of how the national program office and the sites reached these goals. This section also describes some of the challenges that the projects faced.

Goal One: Bring 16 Projects to Fully Operational Status by January 1, 2000

The bar was set high for *All Kids Count Phase II* projects. Based on experience in *All Kids Count I*, the national program office staff established a definition of fully operational that was ambitious, yet achievable, and that could be measured. It included the factors that have proven critical to the success of a registry:

- Percentages of children in the registry and children with immunizations.
- Percentages of public and private providers submitting data to the registry.
- Policies on protecting confidentiality and security of data.
- Production of reminder and recall notices and immunization coverage reports.

Measuring Progress

The national program office used several methods to measure progress toward its definition of fully operational status, as well as to improve understanding of the different factors affecting the development of registries. Methods included:

- Bi-annual quantitative performance indicator surveys.
- Bi-annual site visits.
- Annual profile surveys.
- Annual progress reports.
- Ad-hoc surveys.

Most significant among these was development of a quantitative indicator survey by national program office staff, with participation by the 16 registry projects and experts

from the Sheps Center at the University of North Carolina and CDC's National Immunization Program.

Previously, no quantitative method for measuring progress had been used in the registry field. The eight indicators developed and refined during the survey covered four broad areas of immunization registry development:

- Database maturity.
- Timeliness of record entry.
- Provider participation.
- Immunization coverage levels.

While the *All Kids Count* national program office staff wanted to measure individual project progress, they also wanted to determine if they could compare results across projects.

figure 1

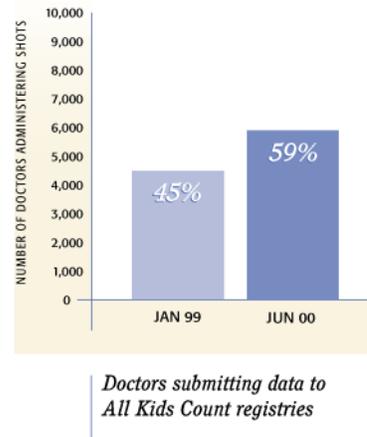
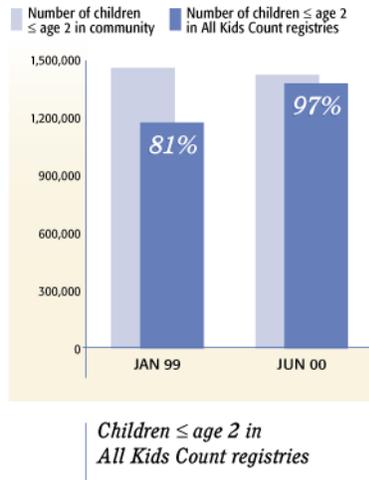


figure 2



This comparison proved difficult because the *All Kids Count* projects varied considerably in geographic size, birth cohort, health care environment, technical sophistication, and political structures.

Yet to be accountable to policymakers and funding agencies, indicators of progress are needed that can be measured consistently across all registries.

The indicators for database maturity level proved comparable across all projects. The indicators for the other areas of registry development proved more problematic because they were considerably

influenced by external factors, operational, or technical issues. Over the period of study, projects made progress in refining registry software to facilitate data collection, clarify definitions, and train staff on indicator methodology, thus improving indicator reliability.

Although progress on the individual indicators varied considerably among registries, in the aggregate, significant progress was made on several key indicators. (See Figures 1, 2, and 3.)

It is clear, however, that not all the characteristics of a successful registry can be quantified. For example, strong leadership is needed for a registry to succeed.

While a registry needs to be fully populated or have complete provider participation; it also must have high quality data about all children and return value to both health care providers and the health department. Other performance measures will be necessary as registries mature.

Reaching Fully Operational Status

A 25-point scale using six criteria (See box What is "Fully Operational"?) was devised to measure progress of the *All Kids Count II* projects toward fully operational status by June 2000.

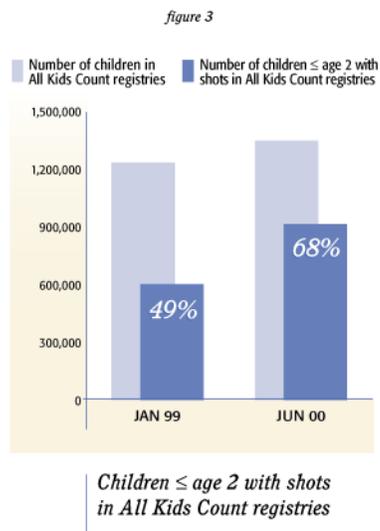
Information for four of these six criteria was gathered by the indicator survey; information for two criteria was gathered from an annual profile survey.

All 16 projects made significant progress toward reaching fully operational status, although no project scored all 25 points. Six scored 20 to 24 points; eight scored 15 to 20 points; and one scored less than 15 points. (See Figure 4.)

Goal Two: Develop a Long-Term Policy to Ensure Registries are Implemented Nationwide and Sustained

The national program office also played a key role in the establishment of policies to institutionalize and sustain immunization registries.

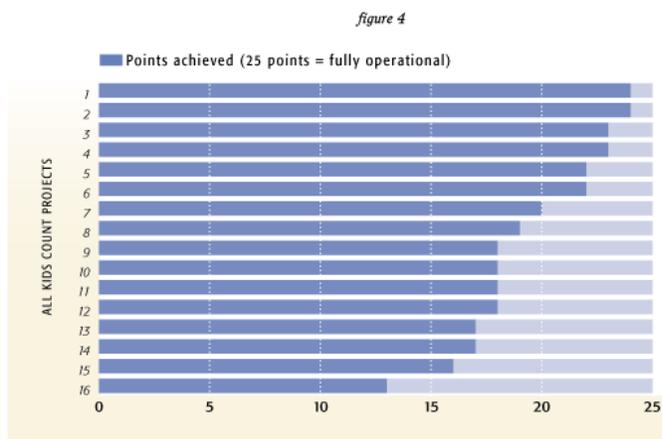
The 1998 Initiative on Immunizations Registries, undertaken by the National Vaccine Advisory Committee (NVAC) in response to President Clinton's directive to develop an integrated immunization system, resulted the formation of a workgroup to develop a plan to facilitate and coordinate a nationwide network of community- and state-based immunization registries.



What is "Fully Operational?"

All Kids Count II projects were charged with becoming fully operational by January 1, 2000. As defined by All Kids Count, fully operational registries would have:

- *95 percent of target population less than 2 years of age in the registry.*
- *95 percent of children in the registry with at least one immunization recorded.*
- *90 percent of private and public sector immunization providers submitting data to the registry.*
- *Policies on the protecting the confidentiality and security of data in the registries.*
- *Ability to produce reminders and recalls on children in need of immunizations.*
- *Ability to produce immunization coverage reports on the target population*



Registry progress toward "fully operational status" June 2000

Public hearings sponsored by the CDC's National Immunization Program were held across the country, with testimony given by experts in the areas of immunization, information systems, privacy and confidentiality, and provider participation.

The result was the NVAC report *Development of Community- and State-Based Immunization Registries*.

Alan Hinman, M.D., M.P.H.,

of *All Kids Count* was a key author of the report, which was approved by NVAC on January 12, 1999.

The report called for the development of a system of state and local registries capable of sharing information while protecting privacy and confidentiality. The report recommended that activities be conducted in four key areas to move immunization registries toward their goal of a nationwide system. Those four areas are:

- Sustainable funding.
- Privacy and confidentiality.
- Provider participation.
- Appropriate functioning.

These recommendations helped to guide the subsequent work of the *All Kids Count* national program office.

Sustainable Funding

By 1998, it was clear that registries were costly to develop, even though exact cost figures were unavailable. Equally important to complete the financial picture, no information was available yet on the cost offsets of registries, e.g., what funds are not expended because of the registry?

The NVAC report recommended studies of registry costs and cost offsets and the introduction of a legislative proposal for a five-year grant program.

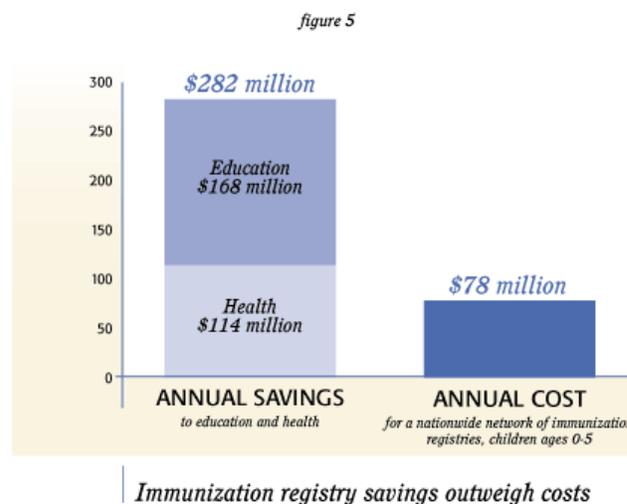
All Kids Count began a study of the costs and cost offsets of registries in early 1998. Staff presented their results at NVAC hearings in fall 1998. The study, "Costs of Immunization

Registries: Experiences from the All Kids Count II Projects," was published in the July 2000 issue of the *American Journal of Preventive Medicine*.

The authors—Phil Horne, Kris Saarlal, and Alan Hinman—presented the following findings:

- They estimated the total cost to maintain a nationwide population-based system of registries that included children aged 0–5 to be \$78 million annually and the cost per child to be \$3.91 per child per year. (A later study by the CDC's National Immunization Program produced similar results.)
- A fully operational system of registries could eliminate approximately \$114 million annually in health care costs.

A subsequent *All Kids Count* study obtained data on costs for school systems to annually review immunization records, a task that would be done automatically using registries. Data show that more than \$280 million would be saved by health and education systems combined if a nationwide system of population-based registries was operational. (See Figure 5.)



Educational Effort

All Kids Count began an intensive effort with immunization partners, especially the National Immunization Program, American Academy of Pediatrics and Every Child by Two (a non-profit organization that raises awareness of the importance of getting children fully immunized by the time they are two years old) to inform policymakers about the benefits, costs, and savings of registries, and the need to find a sustained source of funding if the promise of registries were to be realized.

The recommendation of the NVAC report—a five-year federal grant program for registries—had not materialized. In addition, federal funds had been declining since 1994, and state, local, and private funds were unstable or inadequate to ensure continued development of registries.

Program staff disseminated *All Kids Count's* policy brief on immunization registries to:

- Policymakers.

- Constituents of partner organizations such as the American Association of Health Plans, American Public Health Association, National Association of County and City Health Officers, and the American Academy of Pediatrics.
- Registry projects nationwide.

Through one-on-one meetings with key health organizations concerned with immunizations and children's health, staff garnered additional support immunization registries. Key organizations sent letters of endorsement or support.

The education effort culminated in a legislative briefing held May 1, 2000, in Washington, D.C. Hosted by former First Lady Rosalynn Carter and Mrs. Betty Bumpers, co-founders of Every Child by Two, the briefing had bi-partisan sponsorship from members of the Senate and House. Leading health organizations, health care professional organizations, and education organizations co-sponsored the briefing.

Carter and Bumpers urged legislators to find the political will and financial backing for development of immunization registries.

Other speakers explained the benefits of registries and the short-sightedness of not funding information systems that help to deliver immunizations.

William Foege, M.D., M.P.H., *All Kids Count* principal investigator and program director and a world-renowned immunization policy expert, said, "It is a gift of U.S. science that we have so many vaccines," but this same gift has created a dilemma: How do we keep track of all the information about the vaccines? Information science, he concluded, holds the answer. "The question is no longer can it be done, but 'Will it be done?'"

New Federal Attention and Funding

The education effort paid off. At the July 2000 National Immunization Conference, Secretary of Health and Human Services Donna Shalala promised support through the Medicaid program.

"Congress must 'find the political will and financial backing' for development of immunization registries that can ensure every child is immunized on time by age 2."

*—Former First Lady Rosalynn Carter
Immunization Registry
Legislative Briefing, May 2000*

"The US Dept. of Education is pleased to endorse a nationwide system of immunization registries that will provide accurate, up-to-date information about children's immunizations. We recognize the value of this program for children and schools. The automatic printout of a student's immunization status will provide greater accuracy of records and avoid duplication of immunizations. This will enable school officials to focus on other important health-related activities."

*—Richard W. Riley
Secretary of Education*

In Fall 2000, Medicaid announced its commitment to fund development and implementation of immunization registries at an enhanced rate of up to 90 percent matching funds for registry costs associated with Medicaid-eligible children (approximately 26 percent of children under age 7).

In June 2000, the Institute of Medicine issued *Calling the Shots: Immunization Finance, Policy and Practices*, a report on the future of the nation's immunization system. It noted that community immunization information systems are an important tool to help keep children from but that a commitment must be made to ensure their success.

At the end of *All Kids Count II*, a progress report on immunization registries was being written by the NVAC registry workgroup that had issued the 1999 recommendations for moving registries forward.

The report, approved by NVAC in January 2001, recommended:

- Continued and increased support for registries through the federal immunization grant program.
- Wide promotion of use of Medicaid funds for registries.
- Seeking approval to use the CDC's Vaccines for Children operational funds for registries.
- Discussions with insurers/health plans urging them to provide support for registries.
- Development of a five-year, \$60-million a year grant program to support further development and initial operation of registries.

Privacy and Confidentiality

Throughout *All Kids Count II*, privacy, confidentiality, and security issues remained a top concern for registries.

No comprehensive federal statute on health information confidentiality existed, although it was under development.

Instead, registries developed under a diverse set of state laws governing data collection and sharing, making data sharing among states a huge hurdle.

Who Supports Immunization Registries?

More than a dozen national organizations concerned with the health and well-being of children have issued resolutions or written letters in support of immunization registries:

- *American Academy of Pediatrics*
- *American Association of Health Plans*
- *American Medical Association*
- *American Osteopathic Association*
- *American Public Health Association*
- *American School Health Association*
- *Association of State and Territorial Health Officials*
- *Informed Parents Against Vaccine Associated Paralytic Polio*
- *National Association of County and City Health Officers*
- *National Association of Pediatric Nurse Associates and Practitioners*
- *National Association of School Nurses*
- *National Medical Association*
- *National School Boards Association*
- *US Secretary of Education*

In 1999, the NVAC report recommended development of stringent specifications to protect privacy and confidentiality in immunization registries.

A CDC-led implementation team, with participation of *All Kids Count*, developed specifications consistent with Department of Health and Human Services Secretary Shalala's recommendations to Congress for privacy legislation.

These specifications were also consistent with the proposed federal regulations as required by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

An update to the chapter on confidentiality included in the 1996 *Community Immunization Registries Manual* was approved by NVAC in February 2000. Registries must meet the specifications to be in compliance with national confidentiality policies.

The document also addresses administrative, technical, and physical safeguards to ensure the security of data. It has been widely disseminated and is available on the [CDC's National Immunization Program website](#).

Privacy, confidentiality, and security issues must and will continue to be a top concern for registries and other health information systems. HIPAA regulations, which apply to all providers of health care, were being issued in 2001. Their implications for public health providers, in particular, were not yet clear.

Health care providers have two years to come into compliance with the regulations. Like Y2K, HIPAA is anticipated to have a deep impact on information technology costs for health care providers, insurers, and health care agencies.

Provider Participation

For immunization registries to succeed, all providers, both public and private sector, must be enrolled and submitting data on the immunizations they give their patients. This has not proven easy to achieve for many reasons, among them:

- Major private provider organizations have not taken a strong position in support of registries because they are too new and questions remain about their cost to providers.
- Historically, private sector providers—who deliver most of the immunizations—have not worked closely with public health departments, the principal entities developing registries.
- Registry developers—usually individuals with background in public health—lack expertise in "marketing" registries to providers.
- Registry systems are not always easy to integrate with existing practice management systems in providers' offices, resulting in providers' staff doing double data entry and often incurring extra costs.

The 1999 NVAC report addressed these issues, recommending:

- Development of organizational/institutional support.
- Development of educational materials for parents/patients and providers.
- Working with vendors to make the registry use as simple as possible.
- Facilitating integration of registry functions into existing health information systems.

Communicating with Providers

To increase providers' understanding of immunization registries, the *All Kids Count* national program office developed several communications vehicles. Its semi-annual newsletter, *Focus On Immunization Registries*, was disseminated to providers within *All Kids Count* projects' catchment areas and to leaders of professional associations, including American Academy of Pediatrics and American Association of Health Plans. *All Kids Count* targeted private health care sector organizations as part of its registry funding education efforts.

To help recruit private providers, *All Kids Count* program staff facilitated a workgroup to develop a provider recruitment tool kit that focused on the importance of understanding what the registry's customers—doctors, nurses, and office staff—want in a registry and including them in its planning, development, testing, and improvement processes.

The tool kit was disseminated in late 2000 to state and local registries and registry partners, such as local immunization coalitions.

The American Academy of Pediatrics (AAP), the medical organization that establishes policies on immunization and immunization practice for private providers, has supported the concept of registries, but has expressed concerns about the costs of registries—both time and money—for providers to participate.

Some information is available on the cost to public health to develop and implement registries. For example, the *All Kids Count* study of cost and cost offsets provided information on the savings to health care in the larger sense, but no published data exist on the burden to individual providers. AAP's Task Force on Medical Informatics has been charged with writing a technical report on immunization registries to inform AAP policy.

New Trade Association for Immunization Registries

Recognizing that many of the education, communication, and partnership activities that it undertook would cease at the end of the *All Kids Count II* grant period, the national program office staff helped develop a trade association for immunization registries, the [American Immunization Registry Association](#).

This association, with membership representing registries and registry vendors around the country, was developed to:

- Better share lessons learned.
- Provide a unified voice on policies and programs.
- Host meetings and conferences to discuss common issues.
- Promote widespread acceptance of registries among providers and other stakeholders.

All Kids Count supported the American Immunization Registry Association by funding a feasibility study to investigate the options for organizing, and provided a year of funding to initiate planning, education, and communications activities.

To better understand the barriers to private health care sector participation in immunization registries, *All Kids Count* awarded a contract to [Partnership for Prevention](#) to explore managed care involvement in development, implementation, and funding of registries.

Partnership for Prevention, a nonprofit organization based in Washington, D.C., that works to emphasize disease prevention and health promotion in national policy and practice, will conduct interviews with key informants to produce a white paper on the issue by fall 2001.

Appropriate Functioning of Registries

When registries first began in the early 1990s, few technical standards existed. The field was a true frontier, with wide variations in registries' approaches to development, definitions of registry functions, requirements, hardware, and software.

Although this era of experimentation no doubt yielded creative solutions, lack of standardization also impeded registries' progress as a whole, and may have contributed to higher costs of registry development.

The 1999 NVAC report on immunization registries recommended formation of a technical working group to:

- Reach agreement on standard vocabularies and protocols for data transfer.
- Develop benchmarks for accreditation/certification.
- Carry out ongoing quality assurance monitoring.

The report recommended that CDC monitor implementation of registries and provide technical assistance.

Since those recommendations were made, considerable progress has occurred. The technical working group formed in 1999 and is composed of:

- Representatives from the American Academy of Pediatrics.
- Informatics and standards-making organizations.
- Health care software vendors.
- Field registry managers.
- Managed care organizations.
- State and local health departments.

The group is staffed by the National Immunization Program of the CDC.

The technical working group is reviewing the immunization registry functional standards and determining how they could serve as criteria for evaluating registries.

Implementation guidelines for exchanging immunization information using Health Level 7 (HL7) protocols (a standardized format for transmitting health information) were developed through a collaboration of the National Immunization Program of the CDC and six registries, Kaiser Permanente, Indian Health Service, and *All Kids Count*.

Adherence to these guidelines will enable ready exchange of information in a standard format between registries.

A Committee on Immunization Registry Standard and Electronic Transactions (CIRSET) was formed to promote data exchange capability following the HL7 implementation guide. *All Kids Count* has a representative on this committee and has facilitated discussions among several registries regarding an HL7 data-exchange pilot project.

Immunization Software Vendor Declares Bankruptcy

In 1998, the largest immunization software vendor, Humansoft, filed for bankruptcy. Its collapse created a crisis for many public health projects around the country, including three *All Kids Count* immunization registry projects (South Carolina; Nevada; and Santa Clara County, Calif.).

The CDC commissioned an independent evaluation of the software products to assess their long-term viability, with the CDC assignee to *All Kids Count* facilitating the evaluation process. The study found significant problems with the products and recommended that projects using them find alternatives, if possible.

With a dearth of products available to the public health market, many registry projects had difficulty procuring new software and experienced long delays in implementing their

registries. As an alternative, many chose to try to develop their own registry software, with the result that they often "re-invented the wheel" at great expense.

This dilemma—a market too small for most information systems companies to operate profitably while also offering affordable products and consistent technical support—is an obstacle that must be addressed for information technology to be financially viable in the public health domain.

LESSONS LEARNED, QUESTIONS FOR THE FUTURE

During the course of *All Kids Count II*, 1998–2000, each of the 16 *All Kids Count II* immunization registry projects made considerable progress toward becoming fully operational.

Important lessons about technology, private provider participation, privacy / confidentiality / security, and funding that had begun to emerge during *All Kids Count I*, 1992–1997, gained clarity in this second phase of the program.

Just as important, the momentum of immunization registries across the country grew. However, in order for this momentum to continue to build, issues that surfaced from the experiences of the All Kids Count projects and the national program office during *All Kids Count II* must be addressed.

Technology

- 1. Policymakers, local health officials, and immunization providers need increased understanding of the critical role of technology in improving the public's health and health care.** Through its efforts to educate policymakers and health officials at the local, state, and national levels, the *All Kids Count* national program office and its partner organizations helped to bring attention to the benefits returned to a community by immunization registries, which are just a single aspect of public health infrastructure.

Most policymakers are unaware that health departments do not have adequate funding for the technology that can provide timely and accurate information about the health of the communities they serve. Unfortunately, funding for public health infrastructure is difficult to justify in the absence of a crisis, such as a rise in disease rates. But without the catalyst of a public health crisis, how can public health communicate the

The Challenge of Health Care Informatics

In the new field known as health care informatics—the application of technology to public health practice, research and learning—it is estimated that just one-sixth of projects are "successful," i.e., achieve all their goals on time and on budget. Another half of all projects are "challenged," i.e., over-budget, over the time estimate, and offer fewer features and functions than planned. The remaining one-third of projects are cancelled.

critical need for a strong public health infrastructure, including funding for health information systems?

2. **National standards must be widely implemented that will facilitate data exchange among registries and from providers to registries.** Immunization registries being developed at the state, county, and local levels have envisioned exchanging data so that a child's immunization record could move with a child to other locales.

But for this goal to be achieved, registries, practice management system vendors, managed care organizations, and private physician offices must widely implement the HL-7 standard that has been developed to facilitate data exchange.

Success will require a high level of collaboration among state and local public health agencies, as well as with private health care organizations, providers, and the information systems industry.

3. **A stable environment that provides consistent, affordable health information technology products and customer support must be developed.** In the early years of registry development, not much was known about what was entailed in undertaking a health information technology project. In fact, registry development has proved to be a risky proposition for health departments, with few realizing their anticipated return on investment.

Some health departments decided to buy an existing registry product produced by for-profit companies. The bankruptcy of HumanSoft in 1998, however, made registries sensitive to the precarious nature of the health technology marketplace.

Others chose to develop their own technology, and found that they did not have, nor could they afford, the expertise for a complex technology initiative. A third alternative for public health departments seeking technology solutions is software developed in the public sector. Such software often is available without cost to other health departments, but the programs may allow only limited code alterations and the developers may not provide technical support.

Today, after 10 years of experience with more than 250 registries in operation, considerable information exists about different products and technology models, what they cost to develop and support, different features, and the advantages and disadvantages of each. The information, however, is not available from a single source, nor has it been evaluated by an impartial source so that a "customer" looking for immunization registry or other public health software applications can make an informed decision. Who can assume this role?

4. **Data quality methodologies must be developed for registries that ensure the accuracy of data used within the health department and by providers.** Incomplete, irregular, or inaccurate reporting of data can compromise the quality of

the data in a registry and result in undermining provider, health plan, and parent confidence in the accuracy of the information received from the registry.

Registries must institute quality checks in providers' offices to help ensure data reporting is complete and accurate, but data quality methodologies must also be employed by the health department to eliminate record fragmentation and duplication of records that result from multiple different sources contributing to the registry.

Numerous methodologies have been developed by immunization registries, varying in degree of automation and sophistication in accordance with the size of the database, the technical environment, and other factors. How can registry developers best share this information so that they don't spend critical funds on developing and testing methodologies that are available elsewhere?

Privacy, Confidentiality, and Security

5. **National standards for privacy, confidentiality, and security must ensure consistency of state/local laws.** Until 1996, when HIPAA was passed, states operated under a diverse set of state laws governing data collection and reporting. Often the result was that conflicting laws inhibited sharing of immunization information across state lines and even among agencies within a state.

The final rules issued under HIPAA were rolling out as 2001 began. For the private health care sector—hospitals, health plans, and other health providers—the message is clear: change the way they do business in order to protect health information and streamline electronic data interchange.

Because the various entities are at risk for fines if they do not comply within two years, many are developing enterprise-wide HIPAA implementation plans to ensure their compliance with the complex rules. The cost of HIPAA implementation is expected to be higher than that of Y2K compliance.

For public health agencies, which do not provide direct service, the message is not so clear. It appears that the intent of HIPAA was to have exempted public health from many of the regulations.

However, public health entities often have complex relationships in which they also act as providers of health care, as health plans, and as business partners of covered entities, thus requiring their compliance with HIPAA regulations. Cities, counties, local health jurisdictions, and the departments within them—are struggling to determine the impact of HIPAA on their operations.

States and local health agencies need to make interpretation of and response to HIPAA a priority. Yet they should not have to untangle this complicated knot alone. Without coordination, states will have yet another jumbled mess of compliance that inhibits sharing health information. How can state and local health agencies best

coordinate their HIPAA compliance efforts with their local business partners and with one another?

Provider Participation

- 6. Immunization registry developers need to view the registry from the local providers' perspective, e.g., What value does a registry bring to providers?** Seeking stakeholders' input and involvement in the development of a product is a basic principle of successful product marketing.

In the case of immunization registries, the providers who will use the information produced by immunization registries must have a substantial voice in planning and developing their community's immunization registry, and in determining how it will be funded.

It must be designed to produce the information that they will need, with a technology they will use, and at a cost they can support. Registries that are developed without the active participation of their providers are unlikely to be embraced.

Registry developers must keep in mind that providers want to know what value an immunization registry brings to their practice. Could that same increase in immunization rates be achieved with less investment of time or money? What other aspects of the practice, such as billing procedures, does it improve?

Registry developers must consider how more value might be returned to providers if immunization information and other child health information, such as metabolic, hearing, or lead screening results, were available through a single computerized information system. Reimbursement rates for preventive health services such as immunization and other screenings are marginal. Providers are seeking the greatest value for their investment.

What's needed for public and private health care to develop a shared vision for technology that meets the health information needs of providers, payers, and public health officials?

Funding

- 7. Policymakers and health department officials need a clearer understanding of the costs of health care technology, as well as the costs of not funding health care technology.** *All Kids Count's* study of the costs and cost-offsets of immunization registries provided important information for policymakers considering immunization registry funding. This study and a subsequent survey of school costs showed that although a nationwide system of immunization registries would cost \$125 million annually, it would be offset by savings of \$280 million annually—the cost of eliminating record pulls in health care provider and school offices.

Individual health department officials and those who make funding decisions must learn to think about the consequences of investing as well as not investing in health care technology such as immunization registries. How can they be encouraged to think strategically about such investments?

THE FUTURE

by William C. Watson Jr., M.P.A., second National Program Director, All Kids Count

In the second phase of *All Kids Count*, we challenged 16 *All Kids Count* projects to achieve fully operational status within 29 months. Based on our experience developing immunization registries from 1992 to 1997, we knew that it was an ambitious agenda to be achieved within a very short time frame.

Acceptance of information systems in health care, especially by health care providers, is slow. Long-term support for health information systems is fragile, at both a national and local community level. Indeed, the community and state health departments that embarked on making their registries fully operational were embarking on high-risk ventures.

Nonetheless, the 16 *All Kids Count II* projects made remarkable progress toward the fully operational goal. In addition, as a program, *All Kids Count* helped to develop the momentum that is required to push forward the national and local policies that will help ensure that registries are implemented and sustained nationwide.

We developed the first methodology for measuring the progress of registries. And perhaps most important, because it will help sustain registries despite the political, financial, and technical obstacles they encounter, we succeeded in developing a "community" of registries across the country within which they can share experiences, ideas, and best practices for their mutual advancement.

Along the way, we learned many valuable lessons that have important implications for the future of health information systems that serve individual and population health.

AFTERWARD

As *All Kids Count II* closed in 2001, the Robert Wood Johnson Foundation funded *All Kids Count* for three years to develop a vision for information systems that will integrate data about multiple health services.

The data will include metabolic and hearing screening, immunizations and lead screening. It will also have Women, Infants and Children (WIC) data and Medicaid data

to help ensure that all children receive all recommended services and follow-up care for optimal health.

The *All Kids Count II* experience made an important contribution to the nascent field of public health informatics. The tremendous power of information systems is just beginning to be tapped to aid clinicians and public health in providing the best possible care for children.

Program Director: David A. Ross, Sc.D.

Former Program Directors: William H. Foege, M.D., M.P.H. (December 1991 through July 1997) and William C. Watson, Jr., M.P.A. (August 1997 through July 2001)

APPENDIX 1

National Program Office Staff

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

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APPENDIX 2

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Press Kits and News Releases

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Immunization Registries Save More Than They Cost, September 20, 2000.

Sponsored Conferences

National Immunization Registry Conference, April 1998, New Orleans.

National Immunization Registry Conference, May 1999, St. Paul, MN (co-sponsored with the Minnesota Department of Health).

National Immunization Registry Conference, March 2000, Newport, RI (co-sponsored with the National Immunization Program, Centers for Disease Control and Prevention and the Rhode Island Department of Health).

Presentations and Testimony

"Legislative Briefing," May 2, 2000, Capitol Hill, Washington. *Legislative Sponsors in the Senate*—Jack Reed, Arlen Specter, Tom Harkin, Edward Kennedy, Dianne Feinstein, Mike Enzi, Richard Durbin, and James Jeffords. *Legislative Sponsors in the House*—Henry Waxman, Gene Green, and James Greenwood. 29 co-sponsoring organizations, including American Academy of Pediatrics, American Association of Health Plans, Association of State and Territorial Health Officials, National Association of County and City Health Officials, Every Child By Two, and March of Dimes.

Speakers

- Former First Lady Rosalind Carter
- Betty Bumpers
- William Foege, M.D., M.P.H., senior advisor, Bill and Melinda Gates Foundation, and program director, *All Kids Count*
- Gregory Gilmet, M.D., M.P.H., medical director, Medica Health Plans
- Walter Orenstein, M.D., director, National Immunization Program, Centers for Disease Control and Prevention
- Margaret McChesney, R.N., public health nurse
- Alan Hinman, M.D., M.P.H., senior consultant, *All Kids Count*/Task Force for Child Survival

PROJECT LIST

Reports on the projects managed under this National Program are listed below. Click on a project's title to see the complete report, which typically includes a summary, description of the project's objectives, its results, post grant activities and a list of key products.

Full Project Reports

- [Arizona Takes Lead in Developing Capacity for Immunization Information Exchange \(June 2002\)](#)
- [Complex, High-Volume Immunization Registry Established In Michigan \(June 2002\)](#)
- [Getting an Immunization Registry Up and Running After Its Software Vendor Goes Bankrupt in Nevada \(June 2002\)](#)
- [Improving Data Quality in New York City's Immunization Registry \(June 2002\)](#)
- [Improving Immunization Rates in Rural Southwest Minnesota \(June 2002\)](#)
- [Washington State: How an Immunization Registry Is Funded Can Determine Its Success \(June 2002\)](#)

Short Project Reports

- [Arkansas Struggles in Upgrading Its Immunization Registry \(June 2002\)](#)
- [Baltimore Immunization Registry Campaigns to Enroll Providers \(June 2002\)](#)
- [Connecticut Immunization Registry Focuses on Quality, Not Expansion \(June 2002\)](#)
- [Data from Oklahoma's Immunization Registry Helps Shape CDC Policy on Polio Vaccine \(June 2002\)](#)
- [Overcoming Barriers to Using South Carolina's Immunization Registry \(June 2002\)](#)
- [Philadelphia Registry Increases Immunization Rates \(June 2002\)](#)
- [Planning a Web-based Immunization Registry for Rhode Island \(June 2002\)](#)
- [San Bernardino's Registry Improves On-Time Immunizations \(June 2002\)](#)
- [Tailoring a Immunization Registry Technology to Its Users' Needs in Santa Clara, Calif. \(June 2002\)](#)
- [Unique Funding Partnership for Oregon's Immunization Registry \(June 2002\)](#)