Integrating Child Health Information Systems

The Health Resources and Services Administration and All Kids Count (a national technical assistance center fostering development of integrated child health information systems) have been working together to foster development of integrated child health information systems.

Activities have included: identification of key elements for successful integration of systems; development of principles and core functions for the systems; a survey of state and local integration efforts; and a conference to develop a common vision for child health information systems to meet medical care and public health needs.

We provide 1 state (Utah) as an example that is well on the way to development of integrated child health information systems. (*Am J Public Health.* 2005;95:1923–1927. doi:10.2105/AJPH.2004.051466)

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BEGINNING AT BIRTH, INFANTS and young children undergo an array of preventive and other clinical services designed to give them an optimal start on a healthy life. Within the first 24 to 48 hours of life, each infant receives a dose of hepatitis B vaccine, undergoes newborn dried blood spot screening for heritable disorders, undergoes early hearing detection and intervention screening to detect congenital hearing loss, and has a birth certificate established. In addition, the infant may be registered with the Social Security Administration, evaluated for eligibility in Medicaid or the Women, Infants, and Children (WIC) programs, and registered in a birth defects surveillance system (if appropriate). Typically, a record of the performance of each of these services (and the subsequent results) is entered into a separate, single-purpose information system, and health care providers must go to each of these systems to get a comprehensive picture of the child's status.

Undoubtedly, children's health and health care can be improved through the timely delivery of complete and accurate information. Unfortunately, too often, information available to the provider is not timely and is incomplete or fragmented. For example, newborn screening data reported to the National Newborn Screening and Genetics Resource Center[1] indicate that, in 2000, there were 3009 newborns with positive screening results for hyperphenylalaninemia in the 50 states, District of Columbia, Puerto Rico, and the Virgin Islands. Of these, 112 were lost to follow-up. Of the 2897 who were followed up, 274 were found to have classical phenylketonuria (PKU) or a clinically significant variant. Thus, approximately 1 significant diagnosis was made for every 11 newborns with positive screen results for PKU who were followed up. If that same rate held true for the 112 newborns who screened positive for PKU and were not followed up, 10 cases might have been missed. The information available to state health officials and clinicians is insufficient for us to know with certainty that these infants were never followed up nor diagnosed. A comparable calculation on data reported for congenital hypothyroidism indicates that, potentially, 52 cases might have been missed in 2000. Of the 1086 cases with known intervals between birth and initiation of therapy, 40% received therapy more than 14 days after birth, a suboptimal interval.

In addition, a survey of primary care pediatricians by Desposito et al. found that fewer than half received notification of positive newborn screening results within 2 weeks, and 4.5% never received them. Perhaps even more disconcerting, 26% of primary care pediatricians never received negative screening results.[2] Thus, no news may be interpreted as good news, but one cannot be sure.

Lack of timely and complete information has led both to missed opportunities to immunize some children and overimmunization of others.[3] Use of registries has been demonstrated to increase immunization levels and to increase timeliness of administration of vaccines.[4] Registries have also been shown to be save costs.[5,6]

To prevent health problems and health care problems arising as a result of a lack of timely, accurate, and complete information and to reinforce the importance of a medical home (primary health care that is accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally effective) for children that contains all information about the child,[7] the Health Resources and Services Administration (HRSA) and All Kids Count (AKC) have worked over the past several years to improve and integrate child health information systems. First, since 1999, the Genetic Services Branch of the Division of Services for Children with Special Health Needs in the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA/MCHB) has been supporting efforts to develop a child health profile that would capture accurate information from a variety of programs in a timely manner, support decision-making at the point of services, and support public health program needs. Bringing together information from a variety of sources into an integrated information system should facilitate assessment and prompt provision of appropriate services. Making comprehensive information readily available to authorized users will also facilitate entry into a community-based system of services for all children and their families, with the medical home at the center.[8] To date, 25 state public health programs have received funding through HRSA/MCHB Title V Special Projects of Regional and National Significance (SPRANS) grant support to improve the coordination and integration of newborn screening and genetic service systems with other maternal and child health systems. HRSA/MCHB has also supported the development of the key elements, principles, and core functions for child health integrated information systems.

Second, from 1992 to 2000, The Robert Wood Johnson Foundation (RWJF) provided support to AKC (now a part of the Public Health Informatics Institute, also supported by RWJF) to stimulate development of immunization registries in the United States. As registries became more functional, the focus of All Kids Count shifted (2000–2004) to fostering the development of integrated child health information systems.[9] AKC's goal was to work with stakeholders (families, health care providers, public health programs) to develop a vision and action agenda for child health information systems that meet medical care and public health needs and to develop resources and tools that assist public health agencies in developing information systems that help ensure timely delivery of child health services and follow-up.

Since 2001, HRSA/MCHB and AKC have coordinated their efforts, and HRSA/MCHB has provided additional financial support to AKC. The efforts have initially focused on integrating information systems dealing with vital registration, newborn dried blood spot screening, early hearing detection and intervention, and immunization. These 4 program areas were chosen because they share several important characteristics: they are recommended for all infants and children; they are carried out or begin in the newborn period; they are time sensitive—delay can lead to unfavorable outcomes; they are primarily delivered in the private sector but have a strong public sector component; and they are mandated in most if not all states.

AKC proposed a systematic approach to development of integrated child health information systems that includes first defining the business case (or value proposition) for how information systems can improve child health outcomes and developing a shared vision among stakeholders and plan of action on how to move forward in a collaborative way. Next, an analysis of functional, business, and workflow processes will enable requirements to be developed that meet the needs of the users whether they are clinicians, public health agencies, health plans, or consumers. Additionally, a comprehensive evaluation plan that will provide data on costs, costs savings, and changes in quality of care and outcomes is necessary so that supporters of integrated systems will be able to demonstrate a return on their investment. Throughout the development process, a communication plan is essential to educate stakeholders on progress and to document and disseminate best practices.[10]

Selected activities were undertaken by AKC and HRSA to implement a strategy for integrated child health information systems. Additionally, 1 state (Utah) provides an example of integration efforts. We present a brief summary of future activities.

KEY ELEMENTS FOR SUCCESSFUL INTEGRATION OF CHILD HEALTH INFORMATION SYSTEMS

The documentation of best practices among states was initiated when AKC, with support from HRSA/MCHB, conducted site visits in 2001/2002 to newborn screening programs in 7 states that had received Title V SPRANS development grants: Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah. The purpose of the visits was to identify and describe best practices in planning, developing, and implementing integration projects. Nine key elements were considered critical to the success of integrating information systems: leadership, governance, management, stakeholder involvement, policy support, organizational and technical strategies, technical support and coordination, financial support and management, and evaluation.

The site visits focused on identifying and understanding the factors that were important for the planning and implementation of integration efforts. Findings were analyzed and presented in a sourcebook for planning and development[11]; a condensed version has been published.[12] The Sourcebook contains a description of each of the key elements and examples of what are considered best (or "pretty darned good") practices, as well as presenting case studies of mature and emerging projects. The Sourcebook also presents 5 lessons learned that states should keep in mind as they integrate health information systems:

- Data are for sharing. When data and information are considered assets to be shared among programs, integration efforts are likely to succeed. Information systems gain in value as the information they contain is shared more widely among authorized users.
- Listen up! Communicating with all stakeholders, listening carefully to their concerns and needs, and actively working to gain feedback through the project's development and implementation are essential to enssure that systems meet stakeholder needs and expectations.
- Change is hard. Change management strategies can help mitigate the challenges posed by the integration project.
- Let public health program needs drive technology. Project goals, objectives, functionality, and needs must be identified before searching for technology solutions. Technology must serve the public health program's goals and ends, rather than the reverse.
- Stay the course. Integration of information systems is a long-term process and requires long-term commitment.

As a companion to the Sourcebook, a planning and assessment tool was developed to help program managers and key stakeholders characterize their strategic vision, assess organizational readiness, determine where they stand in the project life cycle, and question data integration needs and strategies.[13,14]

PRINCIPLES AND CORE FUNCTIONS FOR INTEGRATED CHILD HEALTH INFORMATION SYSTEMS

In May 2003, AKC, with support from HRSA/MCHB, convened a workgroup to propose a set of core functions of integrated child health information systems—activities an integrated system must be capable of performing. The workgroup reviewed existing programmatic standards, guidelines, and recommendations for the 4 program areas under consideration. They also reviewed the 12 previously established functional standards for immunization registries and discussed how these core functions would have to be modified or expanded to meet the standards, guidelines, and recommendations of the other program areas. They developed a set of 19 basic principles underlying integrated child health information systems serving these 4 program areas, 22 core functions, and 8 desirable functions.[15]

The principles and core functions have been widely distributed and discussed in public health circles. Clarification of principles and core functions that were not clear to everyone is currently underway. The principles and core functions have formed the basis for an important next step: the development of performance indicators to assess how well integrated information systems are carrying out the core functions. It is important to keep in mind that the principles and functions refer to integrated systems and that individual program information systems may have additional functionality. They do not speak to system architecture, data elements, or software. They are the basis for *what* the functions are, not *how* the functions are to be achieved.

ALL KIDS COUNT SURVEY OF STATE AND LOCAL INTEGRATION EFFORTS

As a prerequisite for developing a business case on integration, AKC conducted a telephone survey of the current status of integration of child health information systems in mid 2003.[16] The survey included 23 state or large metropolitan health departments that had been identified as integrating child health information systems. They were identified as a result of being members of the All Kids Count Connections Community of Practice,[17] receiving SPRANS grants from HRSA/MCHB, having reported information sharing between programs on the 2000 Immunization Registry Annual Report carried out by the Centers for Disease Control and Prevention/National Immunization Program, or having reported information sharing on a survey by the American Immunization Registry Association's Programmatic Registry Operations Workgroup. Eighteen of the 23 reported current or future integration activities. Of these 18, 12 were currently integrating, or planned to integrate, all 4 of the programmatic areas that HRSA/MCHB and AKC had identified as core programs—vital registration, newborn dried blood spot screening, early hearing detection and intervention, and immunization. A variety of programs overall were targeted for integration by at least 6 of the 18 respondents, including: immunization registry (17 programs), WIC (16 programs), newborn dried blood spot screening (15 programs), early hearing detection and intervention (15 programs), vital registration (13 programs), lead screening (10 programs), programs for children with special health care needs (8 programs), public health patient billing systems (6 programs), birth defects surveillance (6 programs), and early intervention (6 programs). These findings suggest that integration of child health information systems is an essential part of many health departments' strategies to improve coordination and delivery of care.

DEVELOPING A COMMON VISION FOR CHILD HEALTH INFORMATION SYSTEMS TO MEET MEDICAL CARE AND PUBLIC HEALTH NEEDS

Efforts to develop a common vision for child health information systems began with a conference December 3–4, 2003 (Developing Child Health Information Systems to Meet Medical Care and Public Health Needs).[18] The purpose of the conference, hosted by All Kids Count (with 16 cosponsors), was to review national initiatives and other factors influencing the development of child health information systems infrastructure; to develop concrete recommendations, reflecting the input of stakeholders, for the development of immediate actions and actions for the next 3–5 years; and to enlist stakeholders in communicating, supporting, and implementing the recommendations.

The vision of the conference was to improve children's health and health services through the timely provision of accurate and comprehensive information. Participants at the conference developed recommendations for action steps in 4 areas: governance, information infrastructure, economics, and information use. A detailed summary of the meeting has been published.[19] The complete recommendations and plenary presentations are also available.[18]

There were several common threads in the recommendations, including the need to develop a national coalition of stakeholders to promote integration of child health information systems within the context of ongoing initiatives, such as the National Health Information Infrastructure and the Public Health Information Network; the need to develop the business and policy cases for integrated child health information systems; the need to develop agreement on standards for collecting and transferring information; and the need to get the word out about the importance of integrating separate child health information systems to improve health and health services.

CHILD HEALTH ADVANCED RECORDS MANAGEMENT: THE UTAH EXPERIENCE

The Utah Department of Health's (UDOH) child health data integration effort is administered as the Child Health Advanced Records Management (CHARM) Program.[20] CHARM provides real-time access to information that is stored in specific databases to track and monitor child health status, such as screening results, immunization status, referrals, follow-ups, assessment, treatment, and outcomes for children. To do this, the integrated data system has been woven into the existing organizational culture.

UDOH programs have historically developed independent systems for collecting information. This necessitated duplicate data entry that hindered agency operations, consumed program resources, and degraded data quality. CHARM is designed to provide information in a more timely, complete, and accurate manner. CHARM integration employs a variety of functions designed to reduce duplicate data entry, to provide updated information, and to support coordinated service delivery.

Although the CHARM effort covers managerial, political, and information technology issues, its focal point is the development of a secure distributed middleware solution. This solution allows any health program that wants to participate to do so with minimal impact upon the program's existing information systems. CHARM is taking a modular approach to integrating systems, beginning with a core of programs and leveraging funding and incremental successes to achieve a long-term vision for a statewide integrated system.

The CHARM information system is designed to combine child health information from several programs. CHARM is not intended to replace existing UDOH databases, and instead will be the "brain" of the integrated data system, acting as an electronic broker, dispatcher, traffic cop, conflict manager, and integration policy enforcer. The participating programs will be fitted with their own front-end "agent" to plug in to the CHARM infrastructure. Each program will continue to manage its own data and specify what parts are to be shared and with whom they can be shared. This arrangement will ensure that participating programs retain stewardship of their own data.

Interviews with health program managers focused on identifying data they collected that might be of interest to other programs and data from other programs that could be used in their own program. These interviews identified a substantial number of specific data elements that could be practically shared across programs to enhance services to children.

A necessary component to nurture an expanding scope of shareable data over time was the formation of a CHARM Core Council. This group, comprising the program managers, UDOH senior management, and the technical CHARM staff and consultants, was an important mechanism for developing a consensus on what data are to be shared. The Council reviewed prototypes of CHARM system components, participated in legal briefings on the confidentiality of child health data, and, in general, provided input on the potential uses of integrated data in public health programs.

Early in the process, a child health data integration needs assessment was conducted. This provided the opportunity to bring together a large number of stakeholders for focus group discussions of child health data integration issues. Participants included the program managers as well as parents of children receiving services, private health care providers, and child health advocates.

As CHARM gets closer to a web development phase, the Council is working with the data stewards of participating programs to identify data elements to be shared with private providers and how such data will be used. Privacy and confidentiality concerns will be addressed and governed by data sharing and confidentiality agreements between public health and private providers.

Achieving consensus on shareable data under CHARM continues to be a learning process. The outcome of data sharing will ultimately change business processes of those who use child health information systems to deliver services. Although models of shareable data for several programs have been agreed upon, the process will continue to develop and meet changing needs.

UDOH took a modular approach to the integration of child health data beginning with a core of programs to leverage available resources. Like most integration projects, funding is one of the biggest challenges facing the CHARM program. State general funds provide UDOH upper management support as well as information technology infrastructure support. Project coordination and administration continues to be provided by in-kind services through the rest of the UDOH management team.

CHARM development and operations are primarily supported by grants from federal agencies including the Centers for Disease Control and Prevention Early Hearing and Detection Intervention cooperative agreement, the HRSA Genetic Services and Data Integration Planning and Implementation Grants, the HRSA State Systems Development Initiative, and the HRSA MCH Block Grant. The CHARM Governing Board reviews topics related to various financial needs to optimize grant funding streams. The Board includes the principal investigators and budget coordinators for all grants that have a data integration component.

Through a partnership with Utah State University, UDOH maximizes its funding for technology development by contracting supervised computer science graduate students skilled in new technologies as members of its technical development team. This enables CHARM to have access to high-caliber technical skills at low cost. UDOH continues to look for innovative ways to minimize costs and search for additional sources of funding for long-term deployment and maintenance.

The CHARM program has formulated seven goals or "project threads" to effect change. Each thread has its own specific and measurable objectives. The project threads in Utah's data integration plan are technical development (core server middleware); participating program technical development (program interface software); communication and marketing; data-related rules, policies, and procedures; data quality; organizational change; and program management. These threads are being interwoven with the key integration elements identified in the Sourcebook.[11]

Integrating the state's public health care databases will provide immediate access to information that is stored in specific databases to track and monitor health status for children. With CHARM, health-care providers and programs can be alerted about a child's medical needs and assist in the provision of appropriate follow-up and treatment, thus reducing the fragmentation of data and health care services. Utah is well on the way to development of integrated child health information systems with its CHARM project. Although the situation is somewhat different in other states, the challenges faced in Utah are likely the same as those that other states will face.

CONCLUSION

Children's health and health services can be improved by the timely provision of accurate and comprehensive information. Currently, information systems that contain information about children's health services are generally incapable of communicating with other child health information systems. Efforts are underway to integrate child health information systems within the context of the National Health Information Infrastructure. Some of these efforts have included identifying the key elements and best practices in integrating information systems, defining the principles and core functions of an integrated system, and outlining a common vision and action plan for integrated child health information systems. Future activities will include implementing the recommendations from the December 2003 conference, such as assessing the interest in convening a coalition of stakeholders to guide and support child health information systems integration efforts, developing a business case, and further refining and expanding upon the principles and core functions for an integrated child health information system. HRSA/MCHB is also supporting the Public Health Informatics Institute to facilitate a community of practice for state integration projects to collectively develop guidelines and best practices for development of integrated child health information systems. Although understanding of the challenges and benefits of integrated child health information systems has increased, the future is dependent upon a coordinated, sustained effort that ensures these systems meet the collective needs of key stakeholders—families, medical care, public health, and business communities. We believe that improvements in health and in the delivery of health services, combined with a solid business case, will lead health systems (both public and private) to integrate child health information systems. ■

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Contributors

All authors were involved in the planning and presentation of the symposium. A. Hinman took the lead in drafting this article, and each of the other authors contributed significantly to its revision.

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