

Key Elements for Successful Integrated Health Information Systems: Lessons From the States

Ellen L. Wild, Terry M. Hastings, Ruth Gubernick, David A. Ross, and S. Nicole Fehrenbach

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The Genetic Services Branch, Maternal and Child Health Bureau of the Health Services and Resources Administration has provided funding to state health departments to integrate their newborn dried blood-spot screening programs with other early child health information systems since 1999. In 2001, All Kids Count conducted site visits to these grantees to identify and describe best practices in planning, developing, and implementing their integration projects. The site visits were organized around 9 key elements considered critical to the success of an information systems integration project: leadership, project governance, project management, stakeholder involvement, organizational and technical strategy, technical support and coordination, financial support and management, policy support and evaluation. Best practices for each of the key elements and 5 lessons learned were documented in *Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Sourcebook for Planning and Development*. The lessons learned are overarching conclusions that agencies should consider when planning and implementing integrated information systems. This article briefly describes the key elements, their best practices as implemented by states, and the lessons learned.

KEY WORDS: child, information systems, newborn dried blood-spot screening, newborn screening, public health informatics, systems integration

Newborn dried blood-spot screening, a public health activity that has been conducted for the past 3 decades, is universally accepted because of its profound impact on the health of newborns. However, new issues and challenges related to newborn screening programs and providing care to children with special health care

needs are now emerging because of recent trends in diagnostic capability, technology, society, and the health care system.

To address these challenges, the American Academy of Pediatrics (AAP), at the request of the Health Services and Resources Administration (HRSA), convened the National Task Force on Newborn Screening (Task Force) to outline a national agenda for strengthening state newborn screening programs. The report, published in August 2000, included 4 recommendations, the first of which was a recommendation for action to develop public health infrastructure and integrate newborn screening systems with the health care delivery system.¹ The report also called for a national process to share and promote best practices in information integration models.

In response to the Task Force report, the Genetic Services Branch, Maternal and Child Health

The authors thank the teams from each of the SPRANS grantee states that All Kids Count visited to identify and document best practices in the integration of newborn dried blood-spot screening systems with other early child health information systems. The seven states visited were: Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah. The teams interviewed at each of these sites provided invaluable information on the planning, development, and implementation of their integrated child health information systems. The authors also thank the Genetic Services Branch, Maternal Child Health Bureau of the Health Services and Research Administration for their support on this project.

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Corresponding author: Ellen L. Wild, MPH, All Kids Count, Public Health Informatics Institute, Task Force for Child Survival and Development, 750 Commerce Drive, Suite 400, Decatur, GA 30030 (e-mail: ewild@phii.org)

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Ellen L. Wild, MPH, is Director of Programs, All Kids Count, Public Health Informatics Institute, Task Force for Child Survival and Development, Decatur, Georgia.

Terry M. Hastings, MA, is Communications Director, All Kids Count, Public Health Informatics Institute, Task Force for Child Survival and Development, Decatur, Georgia.

Ruth Gubernick, MPH, is a Public Health Consultant, Cherry Hill, New Jersey.

David A. Ross, ScD, is Director, All Kids Count, Public Health Informatics Institute, Task Force for Child Survival and Development, Decatur, Georgia.

S. Nicole Fehrenbach, MPP, is a Senior Research and Evaluation Associate, All Kids Count, Public Health Informatics Institute, Task Force for Child Survival and Development, Decatur, Georgia.

Bureau (MCHB) of HRSA contracted with All Kids Count/Public Health Informatics Institute to identify and describe best practices in integrating newborn screening information with other early childhood health information and their supporting systems among 7 of their Special Projects of Regional and National Significance (SPRANS) planning grantees. By the end of 2000, SPRANS grants had been awarded to 17 states to assist them in developing state genetics plans and integrated data collection and services systems.

All Kids Count reviewed grant application proposals from the 17 grantees to determine which states were in the process of planning, developing, or implementing an integration initiative. Seven states were chosen for 2-day site visits: Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah.

All Kids Count organized site visits around 9 key elements considered critical to the success of an information systems integration project. The key elements are not technical; rather they are cross-cutting organizational considerations that are critical to success for an integration project, regardless of its scope or focus (see Box 1).

The site visits focused on identifying and understanding what factors, from the grantees' perspective, were important for the planning and implementation of integration efforts within their states. Findings from

BOX 1 ● Nine key elements and best practices

1. *Leadership*—Project has an executive sponsor and a champion.
2. *Project governance*—Project is guided by a steering committee representing all key stakeholders and uses outside facilitators.
3. *Project management*—Formalized management strategies and methodologies are used. Project has adequate and appropriate staffing.
4. *Stakeholder involvement*—There is frequent interaction and high quality communication with stakeholders.
5. *Organizational and technical strategy*—Strategy is based on local issues, aligned with national efforts, customer-focused, developed through a legitimate process, and based on business processes.
6. *Technical support and coordination*—Centralized within the health department with technical staff working closely with program staff. Uses business analysts to coordinate between technical and program staff.
7. *Financial support and management*—Funding is adequate, derived from multiple sources and managed by an oversight committee.
8. *Policy support*—Legislation, regulation and policy foster, or are neutral, to the integration of information systems.
9. *Evaluation*—Regularly performs qualitative and/or quantitative monitoring or evaluation.

BOX 2 ● Lessons learned

- Data are for sharing.
- Listen up!
- Change is hard.
- Let public health program needs drive technology.
- Stay the course.

the site visits were analyzed and documented in the *Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Sourcebook for Planning and Development* (available at <http://www.phii.org>).

The Sourcebook contains a description of each of the key elements and examples of what are considered best practices (or “pretty darned good” practices) in their implementation. All Kids Count defines “best practices” as practices (or characteristics) that contributed to the success of the integration project. The best practices described in the Sourcebook were based on the grantees observations and information synthesized from the site visits.

The Sourcebook also presents 5 lessons learned, overarching conclusions that states and government agencies should bear in mind as they consider implementing health information systems integration projects (see Box 2).

This article briefly describes each of the key elements and provides examples of best practices as demonstrated by states' integration projects (Boxes 3–11). It also describes the lessons learned that other states could use to guide the development and implementation of their integrated child health information systems.

BOX 3 ● Best practices in leadership

Project has an executive sponsor who:

- encourages a culture that values information
- creates an environment that fosters innovation
- encourages information-driven decision-making
- educates legislature on importance of data and value of information systems
- supports sharing costs of system across programs and with insurers

Project has a champion who:

- educates and garners support of senior management and program managers
- secures funding for the project
- promotes flexibility in blending program resources to support integration

BOX 4 ● Best practices in project governance

The project governance/steering committee:

- represents all stakeholder groups
- prioritizes staff work on the project
- expedites processes to keep the initiative on track
- addresses issues of concern to all programs
- addresses high level issues and reviews regular project reports

● Implementing Key Elements of Information Systems Integration

Element 1: leadership

An integrated information systems project has an executive sponsor and, ideally, a champion. They may be the same person. The executive sponsor is a high-level official who works for the institutionalization of the project, is a good communicator, and has political awareness and influential contacts. The champion has a passion for the project, the respect of other staff and executive management, access to senior leadership, and is willing to devote a significant effort to see the project succeed.

In Rhode Island, Dr. Patricia Nolan, director of the Rhode Island Department of Health (RIDOH), serves as the executive sponsor for KIDSNET, the state's child

BOX 5 ● Best practices in project management

Project has formalized management strategies that:

- uses a chartering process to clearly identify business needs, key partners, roles, and responsibilities of all participants, expectations and limits, decision-making process, timeline, and probable costs
- ensures the project will be implemented within the agreed and documented time, cost, and scope
- verifies that the project can produce the desired solution and identifies barriers
- provides risk management and quality assurance—throughout the life of the project
- establishes standard processes for sign-offs and change requests
- generates a formal paper-trail that indicates what specifically has been agreed to and what has not
- ensures that the system requirements are properly defined, users will find the solution acceptable, and deployment of the new system is feasible

Ensures adequate and appropriate staffing by:

- hiring staff through creative mechanisms, such as nonprofit organizations
- training program staff in technology to blend public health experience with technical competence

BOX 6 ● Best practices in stakeholder communication and involvement

Project stakeholder communication and involvement:

- is focused on the customer
- is frequent and of high quality
- emphasizes development of strong interpersonal relationships that allow for customer feedback
- ensures good communication with programs through the business analyst role
- ensures private providers participate in developing the integrated system

health information systems integration project. She believes it is her role to “shelter people [who take risks in programs] from criticism,” and to allow them “to think out of the box,” while she sets boundaries on risk-taking.

Dr. William Hollinshead, medical director of the Division of Family Health and creator of the KIDSNET concept and project, has been a constant within the department for over 15 years, and through his leadership, has helped KIDSNET flourish. He has enlisted 4 successive health officers as executive sponsors of the project.

In Missouri, Garland Land is viewed as both the executive sponsor and the champion of Missouri's integration project, the Missouri Health Strategic Architectures and Information Cooperative project (MOH-SAIC). Land is the director of the Center for Health Information Management and Evaluation (CHIME), a centralized unit of all information technology staff and high-level data analysis staff.

Land's position within the Missouri Department of Health and Senior Services (MODHSS) allows him

BOX 7 ● Best practices in organizational and technical strategies

Project's organizational strategy:

- articulates the organizational goals and objectives of integrating child health information systems
- clearly identifies the problem that the integrated system is anticipated to solve
- documents stakeholder and program needs to be met through the integration of child health information systems
- documents the business/program needs that drive the integration project

Project's technical strategy:

- is aligned with the organizational strategy, goals, and objectives
- plans for flexibility, technical evolution, and expansion
- maps the technical solution to the specific program's needs
- supports and complies with national or state standards for technical applications and data

BOX 8 ● Best practices in technical support and coordination

Project's technical support and coordination:

- uses a standardized approach to information systems development and management
- uses standardized definitions, processes, checkpoints, and deliverables
- establishes a process for current projects to learn from previous efforts to prevent re-inventing the wheel
- ensures that program needs are understood by technical staff and that technical solutions are understood and accepted by program staff
- includes an IT project director with project management authority and a program coordinator who identifies the system functionality
- has a project director with authority to direct the activities of all participants, including the program coordinator and program staff

to participate in center/division director meetings, providing him with access to top-level management through regularly held meetings. In these meetings, Land has been kept informed of up-coming grants and opportunities for using and funding MOHSAIC. Land uses these "opportunities" to discuss how MOHSAIC might help new or expanding programs.

Land is also considered the champion of MOHSAIC. He believes that "you must have a champion—someone who will invest his or her career in the project." When MODHSS started the integration initiative, many people within the department were convinced it would fail and left the organization. Land believed in the project and stood by MOHSAIC. The implementation of MOHSAIC has now attracted national attention and is frequently cited as a successful integration endeavor.

Element 2: project governance

The project is guided by a governance/steering committee representing all key stakeholders. The com-

BOX 9 ● Best practices in financial support and management

Project's financial support and management strategy:

- pursues grant and other opportunities to support the integrated system, in alignment with the organizational and technical strategies
- creates a network allocation scheme that distributes the costs of network software, hardware, technicians, help-desk staff, and trainers among users
- expands the range of grant-seeking programs to include the information management unit to apply for grant funding
- leverages existing grant funds to obtain new grants by building upon the infrastructure and demonstrating its potential for additional uses

BOX 10 ● Best practices in policy support

Policies influencing the project:

- include recommendations regarding integration of information systems, data sharing among agencies, privacy and security, data standardization, and issuance of common identifiers to guide departments' efforts
- propose a comprehensive approach for improving the health and well-being of children and makes it a priority with the state or local jurisdiction

mittee develops the integration strategy, based on clearly defined business processes. Outside facilitators are used to assist the committee in making objective decisions.

A *governance committee* provides a forum for the integration project to develop and maintain communication and support from key stakeholder groups throughout the project's lifecycle. A governance committee may be called various names including "steering committee," "management committee," or other.

In Michigan, the Administrative Steering Committee is the governance committee for the integration effort. The administrators of bureaus and divisions within the Michigan Department of Community Health (MDCH) participate on the committee, as well as representatives from all the programs involved in the integration project.

The Administrative Steering Committee addresses a wide variety of issues of concern to all representatives and their programs. For example, when concerns about security surfaced, the committee recommended bringing in an outside consultant to conduct a security audit, set up a training curriculum, and develop a data sharing process. Data quality issues were addressed through a collaborative decision about edits, update frequency, and utilization of data.

In Oregon, the FamilyNet Steering Committee guides the integration project. The committee comprises managers from all of the Office of Family Health

BOX 11 ● Best practices in evaluation

Project's evaluation strategy:

- incorporates qualitative and quantitative evaluation
- has a written evaluation plan with process-oriented and outcome measures
- assigns evaluation responsibility to an individual
- builds on pre-existing indicators, including Title V performance measures and HEDIS measures
- uses focus groups with families, providers, and office managers to identify stakeholder values

(OFH) programs with modules in FamilyNet and the project directors from the Office of Information Services (OIS). As new modules are added, representatives of the programs become members, and as modules are completed, they become less active. The committee facilitator is the OIS manager in charge of all application development for Health Services, including OFH and Medicaid. The committee's chair is the project's executive sponsor.

The Oregon Department of Human Services staff believes that use of an outside facilitator, over time, saves the programs money because a well-facilitated meeting runs more efficiently and requires less time.

Element 3: project management

The project has formalized management strategies and project management methodologies designed to ensure consistent communications, accountability, and awareness of resource constraints. The project has adequate and appropriate staff with the right skill sets to achieve project goals.

Management of an information systems integration project requires competencies in technology, economics, and human relations. Integration efforts are built, deployed, maintained, and operated by large teams of managers, programmers, analysts, quality assurance personnel, trainers, and others. Personnel from multiple programs and multiple external stakeholders are potential users of the system, once deployed. As a result, information system integration projects encounter numerous political and organizational challenges because of shifts in power through changes in access to information, involvement of a range of personnel, and varied expectations.

The success of an integration project is highly correlated with investment in appropriate human resources. Information technology staff and program staff are only two parts of the equation; equally important is the role of "business analyst"—an individual with the project management and communication skills who can provide a link between information technology and programs. Public health information technology projects include a range of interested parties, including families, users, program staff, managers, and technical personnel. Each stakeholder has different perspectives, terminology, and expectations. The important role of the business analyst is to bridge the gaps that exist in communication and comprehension among the disparate but critical project team members.

Formalized management strategies

The success of an integration project is dependent upon teamwork and communicating within the constraints of time, scope, and cost. Oregon's FamilyNet project em-

ployed a "project initiation" (chartering) process recommended by the Project Management Office to "get people on the same page." Carrying out the first of their roles and responsibilities, the information technology (IT) and program staff work together on project initiation. They explain the business need in a product description; identify a program area executive sponsor to garner support, executive approval, and resources; write an executive summary for senior management; and document management approval, project plans, and team roles and responsibilities in a project charter.

In Iowa, a formalized project methodology provides a logical flow of activities, and ensures quality communication and appropriate use of personnel/resources. All IT projects use a 4-step methodology: definition and analysis; design; develop; and deploy. A business analyst serves as the liaison between the programs, or "customers," and the IT department. Clear paths of authority are delineated, and the entire process is codified through rigorous documentation.

The project is organized formally with communication procedures and expectations articulated. For example, through a standardized sign-off and change request process, project key stakeholders and users must agree that each task has been completed before moving to the next. This process formally outlines what specifically has and has not been agreed to.

Adequate and appropriate staffing

In Michigan, a "standing" hiring freeze prevents the Michigan Department of Community Health (MDCH) from hiring from civil service. To meet staffing needs, MDCH instead hires staff through two of many not-for-profit organizations that are developing in states across the country to assist state public health departments in their efforts. The administrative fees for using such organizations range from 5%–10%.

In Missouri, technical staff turnover during the first few years of the integration project caused leadership to seek flexible and creative ways to cultivate new staff with the right skill sets, including training program staff in technology. They found that having staff members who understood the programs' needs greatly reduced communication barriers, and it was easier to train program staff on technology than to train technical staff on programs.

Element 4: stakeholder communication and involvement

Frequent and quality communication with stakeholders and stakeholder involvement in the integration project contribute to its credibility and effectiveness. Stakeholder communication and involvement can

influence the perception, reception, and ultimately, the success, of the project. In addition to the programs that are being integrated, important stakeholder groups include providers, parents, other organizations, government sectors, and insurers, including Medicaid. “Stakeholder involvement” means seeking their input throughout the life cycle of the project, establishing mutual goals, and providing a feedback loop from stakeholders back to the project.

One of the first steps in any information systems project is stakeholder identification to determine who will be affected by the project, indirectly or directly, positively or negatively. Often interested parties may be able to influence the outcome of the project either because they can contribute knowledge and ideas or because they have political influence.

Channels for communicating often and well with stakeholders must be developed and used to ensure that stakeholders are kept up to date with project progress, as well as barriers, and ensure customer input and feedback.

In Iowa, Greg Fay, Chief, Bureau of Information Management, and CIO for Public Health, says the IT division did not always see programs as “customers.” But with the realization that the department does not have “sticks” and “carrots” to use to bring different programs together around common program needs, IT, 4 years ago, began to change the way it interacted with customers to become more “customer-centric.”

The Bureau of Information Management relies on the position of a business analyst to ensure good communication with programs. The official job description for this position hints at the communication skills required: “project initiation, customer business process review” and “consulting with end-users.” Fay, however, identifies the key skill for the position as “listening.” Business analyst Jennifer Hollingsworth agrees. “Let me hear what *you* have to say,” she tells customers. “I will make sure the tech people build it to meet your needs.”

Garland Land in Missouri believes that being humble creates an environment that encourages feedback from users. “Don’t toot your horn, and always admit your mistakes. This makes it easier for your customers to tell you that you have problems.” Strong relationships build trust and that trust comes from delivering on promises and being open about failures.

In Colorado, where the American Academy of Pediatrics (AAP) holds considerable influence, the integration project team recognized that to be successful, the integration project must have buy-in and participation from a key stakeholder group: private providers. Dr. William Letson, MCH epidemiologist and co-principal investigator on the Early Hearing Detection and Intervention (EHDI) grant, provides the connecting link between the health department and private providers.

The involvement of providers in the Colorado integration project has won the support of significant pediatric leaders in the state. Dr. Peter Lane, formerly at the University of Colorado Health Sciences Center/Children’s Hospital, understands that the integrated system, Clinic Health Information Records for Patients (CHIRP), will provide higher quality information than what is available through the Children’s Hospital clinical management system. He said, “This is the best example I know of how the public health department is helping us rather than us helping them. . . We would never have had the money to do it ourselves.” He recognizes the potential of CHIRP to help all children with special needs.

Element 5: organizational and technical strategies

There is no single best strategy for an integration project. An integration strategy should take into consideration local issues such as funding, the political environment, organizational structure, the strengths of the organization, and stakeholder beliefs and values. The strategy should be customer-focused, developed through a legitimate process involving stakeholders, and be based on well-defined business processes.

Creating integrated public health information system presents an immediate information architectural challenge that has organizational implications. The technical approaches include a centralized database solution, an intelligent middleware solution, a data warehouse solution, or a combination of these.

The classic *centralized, integrated database* requires a large-scale data model to ensure that the data needs of every departmental user are properly supported. The *middleware* approach routes a request or query for information through a software module that can determine where specific data reside. The final solution is the *warehouse* solution. This solution establishes a separate database (referred to as the warehouse) into which specific data from discrete departmental systems are copied, frequently for historic or analytic purposes.

These 3 technical approaches have different organizational implications. The centralized approach presents the most challenge to the organization because the participating programs must adapt to a new system as their system is integrated into a single platform. This requires a high level of program participation in the design and implementation of the information system. The middleware approach is less burdensome as the design does not necessitate changing how separate child health programs manage their activities. Instead, participating programs maintain their independence and share their data through an “agent” or adapter to plug into the integration infrastructure. The data warehouse approach offers similar flexibility but does require that

departments contributing data to the warehouse participate in deciding which data elements flow into the warehouse.

Which strategy an organization chooses to implement will depend on how robust their current program systems are, budget constraints, and organizational structure.

Missouri was the first state health department to conceive of one totally integrated system, and the strategy that was developed for the MOHSAIC project has been well documented. The Information Strategy Plan (ISP) consists of 3 architectures: information, business systems, and technical. The information architecture shows the relationship between the functions performed and the data. The business systems architecture details this relationship into business areas and the business systems from which information systems were developed. The technical architecture establishes the necessary hardware and software to support these systems. The ISP also provides the architectures for a statewide information network to link public and private healthcare providers electronically.²

Missouri chose this integration strategy because the political, technical, and organizational environments were favorable to a single system approach. Politically, legislators and the director of MODHSS were asking for information on the health of Missourians that required bringing together information from across health pro-

grams. Concerns over privacy and confidentiality were minimal because MOHSAIC began as an internal system with controlled access.

Utah took the middleware approach to integration. Their strategy for integrating child health programs and their information systems is driven by the Utah Department of Health (UDOH) vision, the business needs of the programs, stakeholder concerns, and availability of funding. Taking these drivers into consideration, UDOH decided during its planning process that a phased/incremental approach, as opposed to the “Big Bang” approach—in which multiple programs are integrated at one time—was the most appropriate integration strategy.

The middleware approach allows UDOH to take both an opportunistic and systematic approach to integration, assessing each system/program to be integrated based on several criteria: (1) concordance with the CHARM Vision—integrating the systems leads to the vision of a comprehensive child health profile, (2) appropriate technology—the technology of the current system is appropriate and ready for integrating, (3) availability of funding—the program has funding to support integration, (4) willingness of the program—the program is open to integration, and (5) political rationale—there is political support for integrating the program. UDOH has found this approach to be highly flexible and advantageous. Programs can be

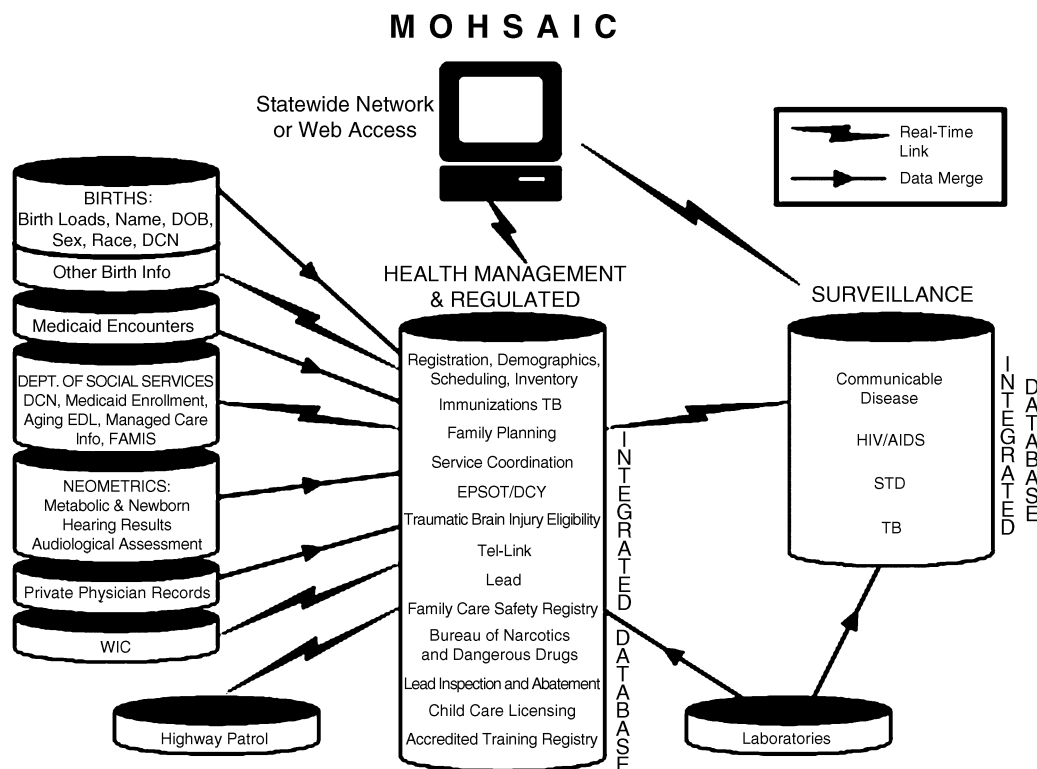


FIGURE 1. The Missouri Health Strategic Architectures and Information Cooperative project (MOHSAIC).

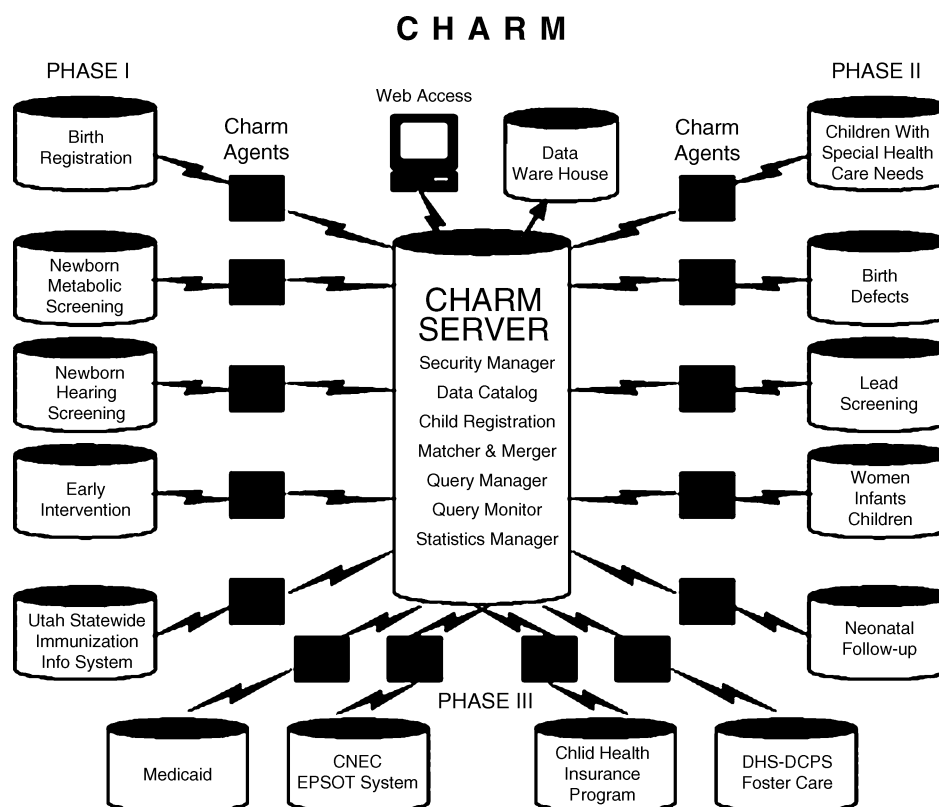


FIGURE 2. The Child Health Advanced Records Management System.

easily added to the integration project, while maintaining independence and stewardship over their own data. Some of the political and organizational challenges can thus be overcome and success repeatedly demonstrated.

Element 6: technical support and coordination

IT is managed centrally within the health department, or within the state, so that programs do not need to develop their own infrastructure or approach to information systems development and management. To be successful, however, IT staff must have a strong service orientation. They must work closely with staff from multiple health department programs in order to understand their objectives and business processes and coordinate among programs to leverage resources.

Frequently, programs secure technology resources and staff, which result in technology knowledge being scattered throughout public health departments. Centralization concentrates decision-making abilities, location, and function and can ease the standardization of hardware and software platforms, data definitions and exchange, and information technology project development. Through such processes, efficiency gains are realized by the organization, and program needs can be better served.

However, effectiveness of the interactions between program and technology staff can be challenged by centralization. One of the leading arguments for decentralization is that placing technology resources with lower level managers enables the managers to take responsibility for their own decisions and can improve performance. A creative solution to this situation, as adopted by some public health departments, is to physically locate a business analyst with the program personnel who are seeking a new technology tool. The business analyst acts as a bridge between the program and technical staff. Such a practice combines centralized and decentralized approaches to ensure good communication while enabling the technology staff to focus on technical development.

Another creative solution is a “matrix-management strategy”—an approach that mixes reporting lines with location. Technology staff reports to a chief information officer but resides with program staff. Both of these approaches enable technology staff to stay connected to programmatic needs and concerns.

The Iowa Department of Public Health (IDPH) has a staff of approximately 27 IT full-time equivalents centrally located in the Bureau of IT Management. The bureau supports more than 100 programs within the department. The bureau takes a business processes approach that brings organization and structure to the

bureau's interaction with IDPH programs. The key element of the approach is "standardization" of definitions, processes, checkpoints, and deliverables.

Although each agency of state government in Oregon has its own Information Technology Office, large IT projects, such as FamilyNet, operate with a collaborative, matrix management approach. The IT project staff report to IT line management, but are housed in the program office and receive their input from program staff. Each project has an IT project director who has project management authority and a program coordinator who has responsibility for identifying—or coordinating the identification of—the system functionality, or "business content." Working closely together, this integrated team takes responsibility for project initiation, project planning, data system development, testing, training, and rollout. Because individual roles and responsibilities are clearly stated in the FamilyNet Project Charter, this cooperative approach enables team members to successfully carry out project planning, implementation, and evaluation.

Element 7: financial support and management

The project funding is adequate and derived from multiple sources. Funding streams are integrated and "creative." Grants management is performed by an oversight committee to ensure accountability and coordinated use.

Inadequate funding plagues information technology development in the public sector. The true costs of information systems are frequently underappreciated by executive management and by political actors who allocate resources. To address this issue, some state health departments have become opportunistic in their pursuit of federal funding to draw financial support from multiple sources, and some have learned how to creatively bundle resources. Integration as an information management strategy to support program and public health goals requires leveraging multiple funding sources to realize the overall vision.

An additional challenge facing states is the downturn in the economy. State budgets are struggling to support basic services, pensions, and employment commitments. During such times, investment in information systems becomes less of a priority unless the need and perceived benefits of continued investment can be clearly articulated. A visible integration effort that responds to the urgent needs of stakeholders—such as families, pediatricians, and care management organizations—is politically advantageous and more readily supported. These efforts have a lower risk of being halted or reduced in scope.

Although Missouri was quick to accept the proposed Information Strategy Plan (ISP) technical architecture,

it was slow to implement the plan because of funding issues. A real challenge lay in funding the development of MOHSAIC. Almost all of the department's funding was program-specific and most funders were not happy with the idea of granting funds for the development of a system that was not program specific. As a result, the information management unit, rather than programs, applied for and acquired the majority of the development funds.

The department also agreed to a network allocation scheme that would charge each network user an annual fee to include network software, hardware, technicians, help-desk staff, and trainers. Annual costs, based on the number of users, have ranged from \$1800–\$2300 per user since the inception of the network.²

Rhode Island has successfully taken advantage of numerous federal and private resources to plan, create, build, sustain, and enhance KIDSNET. The core investment to develop and implement KIDSNET was approximately \$2.2 million over four years. The cost to maintain KIDSNET is approximately \$700,000 per year. The state supports KIDSNET directly with \$117,000 annually, with the balance of funding for the integration program coming from a variety of other sources, including insurance vaccine assessments, CDC immunization program, MCH block grant, state systems development grants (SSDI), data utilization and enhancement grants (HRSA), the HRSA SPRANS grant, and All Kids Count. The successful procurement of some of these grants has been related to success with earlier grants.

Element 8: policy support

Rules, regulations, legislation, and policy advisory or policy-making bodies support or are at least neutral to integration of health information systems and programs. Executive sponsors educate policy makers about sensitive issues to garner their support.

In recent years, heightened concerns about privacy, confidentiality, and security of health information have been a key factor influencing policy decisions around health information systems. Other key influencers have been concerns about redundant technologies, increasing costs of information technology systems, and perceptions of waste. As policy makers attempt to balance concerns about cost containment and efficiency of government services with concerns about privacy, confidentiality, and security, the executive sponsors must increasingly take on the role of keeping policy makers informed about the policies and procedures in place to protect health information.

In Rhode Island, the Children's Cabinet was created in 1991 by state law to foster cooperative state efforts to address the needs of children and families in an

integrated and effective way. The Cabinet has issued recommendations regarding integration of information systems, data sharing among agencies, privacy and security, data standardization, and issuance of common identifiers to guide departments' efforts. The largest impact this initiative will have on KIDSNET is the development of a unique child ID.

In Oregon, the Department of Human Services is leading the effort to link data from existing systems, while preserving confidentiality and data security. In 1999, legislation required state agencies to establish policies for a statewide early childhood system of social supports for children 0–8 years of age and their families. Additional legislation in 2001 created the Oregon Children's Plan (OCP) that focuses resources on prevention, instead of treatment, by screening all children and providing follow-up support to families that need and request services. A budget of \$60 million accompanied the mandate.

Element 9: evaluation

Qualitative and/or quantitative monitoring or evaluation is performed regularly to systematically assess progress on the integration project. The measures can be developed internally or adapted from other sources.

Evaluation is the systematic collection of information about activities and characteristics of a program to make judgments about its effectiveness and to inform program decisions. Organizationally, evaluation should be assigned to one person with evaluation expertise. The charge of the evaluator is to gather multiple perspectives about the value of the integration during and after the implementation of the project. Ultimately, evaluation helps to inform policy by assessing the effect of integrated child health information systems on population health outcomes.

In Rhode Island, many of the evaluation measures the staff currently uses to monitor KIDSNET progress tend to be process-oriented, measuring record completeness or services received. However, staff has begun developing some quantitative measures to assess health outcome improvements that may be attributable to the existence of KIDSNET. They also use quantitative indicators developed by the All Kids Count program to measure fully operational status of immunization registries and to measure progress of rolling out KIDSNET to private physicians.

Staff also evaluates the success of KIDSNET qualitatively using focus groups with families, providers, and office managers. Focus groups are usually held when there is a lack of progress, when a new idea or initiative is being proposed, or if there is a change in user expectations.

Likewise, Iowa Department of Public Health actively solicited input from its constituency with the implementation of the *Healthy People 2010* measures, and conducted a series of stakeholder meetings to relate the national measures to concerns and values of Iowa residents. The result was the development of *Healthy Iowans 2010*, a series of evaluation measures reflecting the values of the population served by the department of public health. With the implementation of an integrated information system, the project team examined these measures to support an evaluation strategy.

● Lessons Learned

Data are for sharing

Health departments increasingly recognize the value of sharing information not only among multiple programs, but also private sector providers, policy makers, and the public. Dr. Patricia Nolan, director of the Rhode Island Department of Health, aptly stated her department's perspective on sharing health information: "Information is a product, not a possession." Rhode Island views information as a tool to be used to enhance all programmatic efforts.

Similarly, Garland Land, director of Missouri's Center for Health Information Management and Evaluation, says, "The bigger risk to public health is data *not* being used, rather than data being misused."

Yet integrated information systems projects know that data sharing must be voluntary. The extent to which information will be shared must be negotiated with each program, taking into consideration policy (legislation) and users' "need to know."

The integration of health information systems requires changing perspectives about data ownership. This change will come about slowly, as states' policies frequently are a reflection of local values. As the various stakeholders—programs, providers, parents, policy makers—begin to realize the value that sharing information brings, their perspectives will shift.

Listen up!

Communication skills are at the top of the list of skills and knowledge needed by those managing a public health information systems project, say experts. Computer science, information science, public health expertise—all of these also are essential, but without the interpersonal, organizational, and management skills needed to communicate with stakeholders, an information system project's chances of success are considerably diminished.

Among grantees integrating their health information systems, effective communication means identifying stakeholders' concerns and listening carefully to them. In Iowa, for example, grantees emphasized the importance of the role of business analyst, the person who listens to programs and translates their needs to the technical staff. In Oregon, grantees noted the importance of the executive sponsor listening to legislators' concerns about privacy and confidentiality and working to ensure that FamilyNet addressed those concerns.

As these examples demonstrate, even in this age of mass media and Internet communications, personal contact remains the most powerful communication channel. This is especially true when the message is complex, as is the case with integration of health information systems.

Change is hard

"Health care is constantly evolving. Wave after wave of new technologies, insurance models, information systems, regulatory changes, and institutional arrangements buffet the system and the people in it. But people and institutions, for the most part, do not like change. It is painful, difficult and uncertain."⁵

Implementation of an integrated health information system is much more than implementation of hardware and software. Its success is largely dependent on the commitment of public health management, IT staff, and program staff to implementing an information system that will change the way they do their jobs. And although organizations have come to accept the idea that change is inevitable, it's easy for them to forget how hard it can be.

Among grantees integrating their health information systems, those that employed change management strategies to mitigate these challenges—consciously or unconsciously—increased their likelihood of successful project implementation. Strategies include ensuring all stakeholders are "on board" with the project from the beginning; seeking input and feedback throughout the project lifecycle; ensuring staff have the training and resources to do their jobs; and, perhaps most importantly, demonstrating the commitment of leadership to the integration of information systems.

It is up to leadership to recognize the magnitude of change that will result from integration of health information systems and to introduce strategies to increase acceptance.

Let public health program needs drive technology

All too often, information systems are developed with the latest, most advanced technology only to find that

the system does not meet the needs of its users. In health departments, this can easily happen when managers of information system projects that integrate multiple programs do not adequately outline project goals, project design, and information system outcomes before looking at technology solutions. They may also fail to gain participation from key public health program managers in the development of the system specifications. In these cases, technology solutions rather than the needs of the programs drive the system specifications. Technology must serve the public health program's goals and ends, rather than the reverse.

Stay the course

The study of technology adoption has taught that not only is change hard (Lesson #3 stated previously), it is also slow. Most health departments integrating their systems have been pursuing their goal for just a few years. But two states, Rhode Island and Missouri, have been building for 10 years toward a comprehensive child health record that supports a range of program services.

What does that mean for implementation of integrated health information systems, especially given the high failure rate of such projects?

First, health departments considering launching an integrated health information systems project need to think carefully about the critical elements for implementing these systems, as discussed in this report. Leadership, project governance, project management, stakeholder involvement, integration strategy, technical support and coordination, financial support and management, policy support, and evaluation—when best practices are employed in each of these key elements, an integration project's chances for success are improved.

Second, funding agencies and health department leadership should provide opportunities for project management and staff to learn from others who are implementing integrated information systems. Best practices can leapfrog from one project to another in a supportive, collegial environment. Shared experiences can provide project staff with new insights and energy to infuse into their projects.

Third, health departments, funding agencies, program and IT staff, and other stakeholders who share the vision for integration of health information systems should recognize that they need to be committed for the long haul and that patience is required to realize that vision. Everett Rogers, author of the seminal work on adoption of new technologies, *Diffusion of Innovations*,⁶ noted, "Getting a new idea adopted, even when it has obvious advantages, is often very difficult."

● Conclusion

The Sourcebook, printed in February 2003, has been distributed nationally at conferences and through mailings to a variety of stakeholders in the integration of early child health information systems. All Kids Count has received positive informal feedback on the Sourcebook, suggesting that state integration projects have found the 9 key elements and best practices very useful. The stories told within the Sourcebook have provided integration projects with a framework (the 9 key elements), and a sense of connectedness with a larger movement and its associated issues.

The Sourcebook provides state integration projects with a structure to guide the development of their projects. To date, state integration projects have received little direction on how to integrate traditional stand-alone information systems. Federal agencies have funded the development of the systems, but little has been known about what ingredients are needed to make integration projects a success. The Sourcebook not only lays out the critical elements needed for success, it provides clear examples on how other states have applied the 9 key elements.

By reading the Sourcebook, state integration project coordinators begin to realize that they have a lot in common with other states. State integration project coordinators often work in isolation. Just knowing that others are struggling with the same issues and having examples of success can bolster morale and strengthen the case for integration with stakeholders.

In September 2003, All Kids Count produced a companion document to the Sourcebook, an assessment and planning instrument entitled *"Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Tool for Assessment and Planning"* (available at <http://www.phii.org>). Through a series of questions about the 9 key elements, the *Tool for Assessment and Planning* assists state integration project teams in understanding the key elements

for a successful integration project, assessing organizational readiness, and developing a plan of action for moving forward. The two documents go hand-in-hand in providing state integration coordinators with actual practice-based examples of state health departments successfully implementing integrated information systems, as well as a practical check-list style tool to encourage project teams to conduct rigorous self-assessment and engage in productive dialogue. The self-assessment tool is described in the following article of this supplement by Wild and Fehrenbach, "Assessing Organizational Readiness and Capacity for Developing an Integrated Child Health Information System."

We believe that through the sharing of real practices and a provision of useful tools, state health departments will increase their integration projects' likelihood of success.

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