

## II. Best Practices in Implementing Key Elements of Information Systems Integration

### Element 1: Leadership

***Best Practices: A project has an executive sponsor and, ideally, also a champion. They may be the same person. The executive sponsor is a high level official who works for the institutionalization of the project, creates a work environment that fosters risk-taking and innovation, 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 higher-ups, access to senior leadership, and is willing to devote a significant effort to see the project succeed.***

Leadership for a health systems integration project ideally involves two key roles: executive sponsor and champion. When both are present and actively involved, projects are most likely to succeed. The same person may serve both roles, or there may be more than one person in each role.

The executive sponsor has four key functions: to legitimize goals and use of resources; to provide access to resources and/or discussion about resources; to resolve cross-organizational disputes and breakdown barriers to cooperation; and to establish practices that reinforce use of information as a public health tool.

While both the executive sponsor and the champion embrace the vision of the project, the executive sponsor has the more “official” role in promoting the project internally and externally. In addition to the functions noted above, he/she creates a work environment that fosters risk-taking and innovation. Placed high enough in the organization, he/she wields influence and has influential contacts that can be called upon. The sponsor knows, however, when to keep a low profile and when to ride on the wave of a politically favorable environment.

The executive sponsor may be a political appointee, or may occupy a position that is impacted by changing political appointments, and thus may not have longevity.

Consequently, the champion may be the more important role of the two because it is constant. The key functions of this role are to promote the vision for integrated information systems; to educate and

build support for the initiative with key audiences; to pursue funding and other resources; and to develop policy and procedures that support the initiative.

Key characteristics of the champion are longevity with the department, passion for the problem, respect of colleagues, strong relationships with and access to senior leaders, and influence with peers. The champion frequently brings the executive sponsor on board and educates the sponsor. It may be advantageous for the champion to be a physician because it can increase his/her credibility with private sector providers. The champion is passionate about the cause and often is willing to devote his/her career to the cause.

### Examples:

***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 health information systems integration project. In her seven years as a state health official, Dr. Nolan has created an environment in which innovation is possible. She believes it is her role to "shelter people [who take risks in programs] from the criticism," and to allow them "to think out of the box," while she sets boundaries on risk-taking.

Dr. Nolan encourages a culture within RIDOH that values information and decision-making that is information-driven. She also promotes the idea that "information is a product, not a possession" – that the department's health information is a tool to enhance programmatic efforts.

Dr. Nolan serves as a conduit to other child services within Rhode Island. She is a member of the Rhode Island "Children's Cabinet," a program supported by state statute, as well as executive order, which serves as a forum for connecting departmental directors across agencies to streamline services to children. The goal of the Children's Cabinet is to develop integrated child services system for Rhode Island state agencies that will achieve improved preventive programs for children and families and better use of resources. Their vision is "All children will enter kindergarten ready to learn and leave school ready to lead productive lives." The Children's Cabinet has made integration of programs the norm in Rhode Island.

As a promoter of information-driven decision-making, Dr. Nolan educates the legislature as necessary about the importance of data and the value of information systems to assist in tracking individual, as well as aggregate, data. She has openly supported sharing the costs associated with large information systems across programs and with insurers. She also has recently educated the legislature about increasing newborn screening regulatory fees as another method for spreading the costs of the information systems development, tracking, and follow-up necessary to assure preventive services for all children.

Dr. Nolan supports close informal and formal communication across the spectrum of health department staff. She is in frequent contact with KIDSNET staff, is copied on project emails as needed, and uses conversations in the hallway to seek information on projects underway. She facilitates communication

through the executive committee structure by meeting with the committee as a whole, as well as with individual members.

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 educated four health officers on the vision of KIDSNET, enlisted them as executive sponsors of the project, and garnered their support for KIDSNET as a RIDOH priority. The consistency of this support has earned him the role of “champion.”

Hollinshead’s vision of KIDSNET, written into a plan in 1980, grew from his experience as a pediatrician trying to provide services to children with special healthcare needs. Most of that plan has been realized.

In addition to advocating for KIDSNET with new directors of the RIDOH, Dr. Hollinshead also encourages other influential health department staff, such as Dr. Peter Simon, assistant medical director, Division of Family Health, to be active advocates, especially with outside organizations, including funding agencies (see also Element 7: Financial Support and Management). Dr. Simon is a pediatrician who, in addition to his full-time role at the RIDOH, still practices pediatrics at community health center clinics and as an attending physician at local teaching hospitals. He is an active member and past president of the Rhode Island Chapter of the American Academy of Pediatrics (AAP), serves on an Institute of Medicine board that is looking at the future of measuring child

health, is a national leader on issues related to children with special healthcare needs, and is well respected and trusted by his peers, both in Rhode Island and nationally. His active involvement in pediatric healthcare issues has enabled him to be very effective in educating providers about KIDSNET and enlisting their support for the project.

Drs. Hollinshead and Simon have also been creative in finding funding for the project. For example, as medical director for the Division of Family Health, which includes well-funded programs such as the immunization program and other maternal-child programs that are not as well funded, Dr. Hollinshead has been able to promote flexibility in blending program resources and has supported data and program integration. He has successfully secured funding from private sector insurance companies by demonstrating the cost-effectiveness of KIDSNET.

Both Drs. Hollinshead and Simon are well known and active nationally in promoting maternal and child health policy agendas. They frequently serve on committees for the Association of Maternal and Child Health Programs (AMCHP), for Title V efforts, and for AAP. These activities enable them both to learn about funding initiatives and promote the need for others to support child health integration efforts that can lead to family-centered systems of care.

As pediatricians, Drs. Hollinshead and Simon have more connections and influence with the provider community in Rhode Island than would non-physicians. Peer-to-peer communication is recognized as the most effective kind of communication when promoting a

new idea or practice.

***In Oregon,*** Donalda Dodson, Oregon's Title V director and administrator of the Office of Family Health (OFH) in the Department of Human Services (DHS), serves as both the executive sponsor and the champion of the FamilyNet data integration project. Within the organization, she sits at a high enough level of management to assure that the project gets the attention and support that it needs. She is involved as chair of the FamilyNet Steering Committee and will "take the fight to the top" when needed to move issues forward. She has a good working relationship with both program and information technology staff, whom she treats as a "partners."

As the executive sponsor, Dodson has been successful leveraging an external initiative sponsored by Oregon's governor, the Oregon Children's Plan (OCP), which in turn has helped push forward integration within the Health Department. The integration initiative within DHS had been started before OCP and Dodson took the time to educate the OCP "people" – to show them how to use the FamilyNet integration project to move OCP forward. She also spent much time and energy educating policymakers about the confidentiality and security of FamilyNet, so they would support the project (see also Element 8: Policy Support).

As champion, Dodson has invested her career in the FamilyNet project and rallied her staff to take on the challenges as well. Dodson has a management style that is open to others' ideas "even if they don't sound appropri-

ate at first." She encourages people to bring innovative ideas forward and supports and defends the risk-takers. Dodson believes in the Oregonian notion that "you can bring together many diverse folks and work it out to get consensus." She says, "A 'top down' style of leadership would never fly in Oregon. Open communication is key."

## Element 2: Project Governance

***Best Practices: The project is guided by a steering committee representing all key stakeholders. The steering committee 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. Called variously "steering committee," "management committee," or other names, the committees fall into two main types. The governance committee for a large project – one that is well established or is integrating many programs at one time – is more likely to have a greater number of internal stakeholders, (e.g., representatives of the programs that are being integrated) than external stakeholders. A project that is just beginning or that is integrating just a few programs or integrating programs incrementally is more likely to have equal representation by internal and external stakeholder groups, (e.g., programs and parents and genetics advisory boards). Project vendors may also be members of the governance committee.

Both types of governance committees need to be working, hands-on groups of people who understand the project and can translate it to their constituencies. To be relevant and useful, members of the governance committee need practical work assignments that contribute to the project's goals. The external

members of a governance committee may contribute most during the conceptual phase of the project, but must be kept involved throughout the lifecycle because they function as the liaison to the external stakeholder groups.

Meetings of the governance committee must be held frequently in order for them to address both strategic and operational issues.

Outside facilitators help to forge consensus, both inter-program and intra-program. Emotions can run high in governance meetings as programs voice their needs and concerns. Having a neutral, third party that is experienced in project management to convene and moderate such a session enables all parties to be heard, issues aired, and common ground established.

### Examples:

#### ***Governance Committee***

***In Michigan***, the Administrative Steering Committee has wide representation from all the programs involved in the integration project. Meeting every two weeks, its goal is to address issues of concern to all programs, while cutting through red tape and assisting the vendor in meeting their deliverables on time.

The administrators of bureaus and divisions within the Michigan Department of Community Health (MDCH) participate on the Steering Committee. They include Women, Infants and Children (WIC), Vital Records, Epidemiology, Family and Community Health programs (MCH), Medicaid Quality Assurance and the Information Systems, among others.

The Medicaid deputy director chairs the steering committee.

Representatives of the vendor, Bull, also are valuable members of this committee because the company has staff experienced in project management. In addition, because payment for their work is tied to deliverables, they have an incentive to keep the project on track. The Steering Committee reviews with Bull the decisions made at each step of implementation of the work plan and the recommendations from all subcommittees to the project.

The 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 joint decision about edits, update frequency, and utilization of data. Similarly, a review of the project plan enabled the committee to resolve issues regarding deliverables, completion, review of functionality, acceptance, and implementation.

Because they are distinct and separate from staff, the Administrative Steering Committee can prioritize the work of the staff and expedite processes as necessary to keep the initiative on its established timetable. They met every two weeks during the first 18 months of the project and currently meet monthly.

***In Oregon***, several steering committees oversee the multi-agency, multi-program integra-

tion project that is part of the Oregon's Children Plan (OCP) (see also Element 8: Policy Support). Coordination among the various committees is ensured by representation across committees.

The FamilyNet integration project is guided by the FamilyNet Steering Committee, which meets twice a month to address high level issues as well as regular reports on progress. This committee comprises managers from all of the Office of Family Health (OFH) programs with modules in FamilyNet and the project directors from the Office of Information Services (OIS) who are working on active modules. The current participants include Nutrition (WIC program), Perinatal and Child Health programs in the Family and Child module, Immunization Program, and the ALERT Immunization Registry. The MCH Data Systems coordinator and the Health Services Information Technology coordinator also serve on this committee. 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, Donalda Dodson.

Each module also has its own steering committee that deals with the actual building of that module and has frontline program personnel and IT staff working together.

The FamilyNet Steering Committee's members also participate in a new OCP Policy Group, which determines business policy for OCP. The Policy Group was formed when leg-

isolation transferred responsibility for the OCP data system to three agencies (including Department of Health Services, which previously had sole responsibility). The FamilyNet Steering Committee retains its development responsibility for FamilyNet and shares responsibility for Family and Child Module development with a new committee, the Early Childhood Data System Steering Committee, because that module is both part of FamilyNet and the core of the multi-agency data system. The facilitator and executive sponsor of the Family Net Steering Committee also sit on that committee.

**In Iowa**, where the integration of systems is in its beginning stages, the integration project seeks guidance from three different advisory committees, each with a different focus.

The Birth Defects Advisory Committee (BDAC) advises the Iowa Department of Public Health (IDPH) on genetic issues and the genetics programs within the state. It also makes policy and procedure recommendations. It was instrumental in the development of the State Genetics Plan, and its recommendations are the backbone of the Iowa Genetics Implementation Grant. Although the BDAC provides input and support for the overall goals of the Genetics Implementation Grant, it is not involved in the direct oversight of the integration activities within the grant.

Its membership comprises 23 stakeholder groups, representing a wide variety of concerns and viewpoints: public health, clinical medicine and nursing, legal and ethical, parents and consumers, insurance, and social

work. Parents are voting members and also serve on subcommittees to ensure that the committee drives the agenda of the community and families (*see also Element 4: Stakeholder Involvement, for more on parent involvement in the BDAC*).

The policy decisions from BDAC impact program responsibilities and activities. The effort to integrate newborn metabolic screening with other public health programs must take into account the needs of the programs to ensure that their requirements are met. Through BDAC, a range of internal and external stakeholders who will experience direct and indirect effects of the integration project are able to articulate their expectations and needs from genetics programs and provide input into the process.

Committee members are appointed for three years by the director of the IDPH; an individual can serve for two full terms unless given a waiver. BDAC meets quarterly, and the Genetics Implementation Grant activities are discussed at each meeting.

In contrast, the Electronic Birth Certificate (EBC) Steering Committee is narrowly focused on the design and development of the Web-based birth/fetal death certificate reporting and data management system. Its membership reflects the technical focus of the group: Project manager, bureau chiefs from Vital Records and Information management, the state coordinator for Genetic Services, the newborn hearing screening coordinator, the grant program planner, vital records staff, and information management staff. As a working committee, EBC modifies technical specifications, solves problems, and main-

tains communication with external stakeholders, such as hospitals, to ensure that concerns about the new system can be identified and addressed throughout the integration effort.

A third advisory committee, the Data Integration Steering Committee (DISC), focuses on system changes for data linkage and integration. The committee provides a forum for MCH data partners to collaborate. Membership includes representatives from the Iowa Newborn Metabolic Screening Program, the State Center for Health Statistics, WIC, Child Health Specialty Clinics, Department of Human Services/Medical Services Division, Iowa Birth Defects Registry, and Bureau of Nutrition. The Title V director, the Vital Records bureau chief, and the IDPH Chief Information Officer (CIO) serve on the committee. The DISC is able to negotiate departmental and cross-agency policies and procedures that reflect common needs, organizational changes, and emerging expectations in data linkage and integration. The goals and objectives of the integration project can be consistent across the programs involved in current and future integration efforts as well as the external agencies impacted by the integration.

The three advisory committees in Iowa reflect different intentions but critical elements. BDAC develops and debates genetics policies for the State, while EBC and DISC concentrate on the technical issues associated with integration of public health programs and directly influence the implementation of technical processes. Each committee has a for-

malized process to impact the integration of newborn metabolic screening with other public health programs. Collectively, the three committees ensure communication with critical stakeholders and project teams such that significant information can flow among the groups, thereby increasing the likelihood of a successful effort.

#### ***Outside Facilitators:***

***Oregon's*** Office of Family Health uses outside facilitators (the OIS manager) to make meetings more efficient, enabling them to get at the heart of matters and make decisions, while avoiding conflict because it de-personalizes participants' input and helps avoid or identify turf issues.

All partners may contribute to the cost of an outside facilitator, or they may choose someone from the state's Personnel Development Department to facilitate the meeting. OHD staff believes that over time, facilitators save the programs money because a facilitated meeting runs more efficiently and requires less time.

***Michigan*** Department of Community Health (MDCH) uses staff from its vendor, Bull, to facilitate meetings. Their Joint Application and Development (JAD) sessions were attended by all programs with a stake in creating a data sharing process for MDCH. The sessions were run by a Bull staffer who previously was a state of Michigan employee. Because she was somewhat familiar with Michigan programs as well as data, she served as a good translator between the program and technical staff.

### Element 3: Project Management

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

#### Formalized Management Strategies

With growing recognition that fully one third of IT projects are failures, government agencies are increasingly requiring that tools for project management be used in the development of IT products.

Management of an information systems integration project is a challenging art. It requires a combination of technology competency, 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. The technical experience required to envision and implement an information system project is significant. 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.

Given these complexities, it is not surprising that numerous information systems projects

fail to meet expectations. A 1994 study of more than 8,000 large private sector and government information system development projects found that 31.1% of the projects were total failures (The Standish Group, 1995). A later study estimated that 70-80% of complex IT projects fail to deliver their promise on some level, such as extreme cost overruns, significant time delays, or project cancellation (Stonebraker, 1998).

The Association for Computing Machinery (ACM) concluded that project management is part of the answer to overcoming these formidable challenges. Project management reflects an effort by an organization to function effectively within certain environmental and situational constraints. Pete Kitch and William Yasnoff recently identified seven important project management techniques that maximize the probability of successfully developing and deploying a public health information system (Kitch and Yasnoff, 2002, p176):

- start with clear goals supported by management;
- be sure adequate time and resources are available;
- involve users throughout the process;
- use education and planning as change management tools;
- use proven methods and technology;
- minimize increments of change; and
- use behavior modification.

## Examples:

**In Oregon**, state law requires projects costing more than \$300,000 (and recommends for all others) to use a clearly defined project management approach. The primary purpose of this approach is to increase the likelihood that the organization will produce a workable solution for the specified business issue within the agreed and documented time, cost, and scope constraints. Secondary purposes, very important in achieving the primary one, are to verify that the project can produce the desired solution—that the project should be done at all—and to identify risks or barriers to project success with appropriate monitoring and contingency plans. The Project Management Office (PMO) within the Office of Information Services (OIS), Department of Human Services (DHS), offers a variety of management tools that are available online (<http://pmo.hr.state.or.us>).

In addition, Oregon State projects costing \$500,000 or more are mandated by State law to have a quality assurance contractor assign a risk management consultant, independent of the software vendor, to the project. The consultants participate in the JAD sessions, assessing risks and developing mitigation strategies at the start of the project, and continue to monitor risks and risk management throughout the life of the project. This creates a high level of accountability.

Sherry Spence of Oregon's FamilyNet data system (FamilyNet) notes that integration projects are not about IT, but about teamwork and communicating within the constraints of time, scope, and cost. FamilyNet's

Family and Child Module (FCM) employed the "project initiation" process recommended by the PMO to "get people on the same page." This process, sometimes called "chartering" (the name of the last step in the process), focuses on starting the project off by clearly identifying business needs, key partners, roles and responsibilities of all actors, expectations and limits, decision-making processes, timeline, and probable costs. Carrying out the first of their roles and responsibilities, the 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.

Identifying the business needs in the product description, a clear statement of high-level requirements, is the first step. Family and Child Module (FCM) staff and partners developed this document in a two-day planning meeting facilitated by FamilyNet's WIC module project director. This intensive work was possible because, for more than a year before that meeting, Spence facilitated monthly meetings with partners and key stakeholders from the three different state agencies who would use the system. At these meetings, participants identified shared goal, mission, vision, objectives, and requirements. The investment of the up-front time was worthwhile to establish buy-in, develop relationships, establish concept consensus, and agree on shared vision. The project initiation docu-

ments, which were based on this work, have been used many times by all parties.

“Payback has been very high,” says Spence. While Spence facilitated the monthly meetings as the program coordinator, the executive sponsor (and Oregon’s Title V director), Donalda Dodson, arranged for a different facilitator to lead the critical two-day meeting so Spence could be an active participant. The facilitator, Barbara Woods, was well grounded in the necessary FamilyNet background from her role as WIC module director, yet able to approach the task with the necessary impartiality.

With the project description complete, the next project initiation steps establish the project and document the expectations on which planning will be based. The initial champion for the project works with upper management to identify the executive sponsor – someone placed highly enough to assure that the project will get the attention and support it needs. In this example, Donalda Dodson was the obvious choice because of her commitment to and executive sponsorship of FamilyNet as a whole. The project team then develops an executive summary and a project charter, which the executive sponsor takes to a review team – the information technology department, the public health program, and department executives – for approval. On approval, the project team identified in the charter can begin developing the detailed project plan. As Spence says, “Project initiation is like getting ready to paint your house. You spend months and months scraping down to the good stuff, repairing and patching, sanding, and priming.

It takes forever, and everyone gets tired of the thought of it. But when you take that time to prepare, the painting is a snap, the house looks great, and the paint job lasts.”

***In Iowa***, a formalized project methodology provides a logical flow of activities and use of personnel/resources to ensure that the system requirements are properly defined, that the solution is acceptable to users, and that the new system can be feasibly deployed. The information technology department employs a business analyst to serve as the liaison between the programs, or “customers,” and the information technology department is charged with implementing the methodology. (See Example, Iowa, below for a description of the business analyst role.)

Drawing upon her previous experience in the private information technology sector, Jennifer Hollingsworth, business analyst, uses a four-step methodology: Definition & Analysis, Design, Develop, and Deploy.

The Project Definition & Analysis phase consists of five major tasks: organize the project; review the current environment; define future requirements; develop a conceptual model; and develop an implementation plan.

Each of these tasks has a series of subtasks. For example, within Organize Project, the subtasks include confirming project roles, scope, and objectives, finalizing the project team, establishing the schedule, and communicating with the project participants.

The project is organized formally with communication procedures and expectations articulated. Hollingsworth has established a

standard process for project implementation, which includes sign-offs and change requests. For example, prior to moving from one major task to another major task, the project key stakeholders and users must agree that the previous task has been completed. This process generates a formal paper trail that indicates what specifically has and has not been agreed to.

Through formal and informal processes, Hollingsworth cultivates a cohesive, highly functional and supportive team in order to better accomplish the integration effort. The “business” (e.g., public health program personnel) and the technical personnel meet routinely to discuss, plan, and solve problems. In addition, to encourage a more collegial atmosphere and to help build the necessary social capital for increasing the likelihood of success, Hollingsworth brings treats to meetings and encourages social interaction outside the office. As a result, the IT staff began to trust her intentions to successfully manage the integration project between the Newborn Metabolic Screening program and Vital Records.

### **Adequate and Appropriate Staffing.**

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 that can provide a link between information technology and programs. Experience has shown that interdisciplinary

teams on information technology projects in public health 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.

All the SPRANS grant integration projects visited believed that they could use more qualified, trained staff, and some developed creative ways to overcome the barrier.

### **Examples:**

*In Iowa*, the role of business analyst requires a variety of skills. As the liaison between information technology and programs, this person must be knowledgeable about project methodology, information technology, and programs needs. In addition, the business analyst role requires the ability to facilitate team communication. In Iowa, the CIO made the explicit decision to hire a business analyst to work intimately with program and information technology personnel to increase the likelihood that the needs of the program were explored, clearly understood, and translated into requirements that the technical personnel could take action on.

The job description for a senior business analyst includes the following attributes:

- taking the lead on project management for information technology system development, including project initiation, business process review, requirements development,

budget development, project staffing, application development, product testing, system delivery, and documentation;

- defining program needs related to changes in and compliance with federal regulations, state codes, and program policies;
- managing the technical change process as new systems resources are developed and phased-in to normal operations;
- evaluating business needs and consulting with end-users;
- ensuring development complies with technical and business standards and that the health program's requirements are met;
- managing contracts related to application development and evaluating potential contractors; and
- acquiring management approval and communicating with all affected parties.

The activities related to the job requirements include holding regular, frequent meetings with programs; issuing regular project progress reports to programs and management; and documenting decisions, standards, and discussion items. Recognizing that one of the challenges to the successful completion of information technology efforts is the lack of technical understanding by program personnel, Iowa's CIO physically located the business analyst with the program personnel in order to increase communication and build good rapport. Informally, the business analyst makes sure she spends time talking with and listening to program and technical personnel. Solid, positive interpersonal relations

enhance the ability of teams to work together and help overcome gaps in understanding and jargon barriers.

***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 the Michigan Public Health Institute (MPHI) or the Southeast Michigan Health Association (SEMHA), 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% to 10%.

MPHI is the more autonomous organization of the two and has more of its own infrastructure and employees doing projects for the MDCH. SEMHA hires the selected individual as a contractor or as a SEMHA employee, with benefits. Either way, the project management is retained by the MDCH program that is funding the position.

For this SPRANS implementation grant, for example, several positions such as the administrative assistant, the Genetic Resource Center coordinator, the newborn screening quality assurance position, the newborn screening nurse coordinator, the parent consultants, and an epidemiologist have been contracted through SEMHA. This allows MDCH to hire and bring qualified people on board quickly. MDCH does the recruiting, advertising, and interviewing. The contract is then set up through SEMHA. The contractors invoice SEMHA and MCDH signs off invoices

every two weeks. MDCH has master agreements with SEMHA and MPHI, and job descriptions for anticipated positions are written into these agreements. The agreements correspond with the state's fiscal year, while the grants do not. This system works fairly well, but MDCH has to be careful to include any upcoming positions in the master agreement or wait until a quarterly amendment to the agreement can be filed.

Similarly, because the *Rhode Island* Department of Health lacks FTEs, it has been contracting for many services supporting KIDSNET and “borrows” staff from various programs to work on pieces of the KIDSNET project. Amy Zimmerman, chief, Office of Children's Preventive Services, notes that, most recently it has been easier to get funding than it is to get permanent staff positions filled. Contracting can work well when it is difficult to hire the people with the right skill sets or when there is a short-term specific project. Contracting out for whole full-time equivalents (FTEs), although not ideal, is also preferable to “borrowing” multiple staff on a part-time basis from other programs because the training, management, and quality control needed to oversee borrowed staff is enormous.

## Element 4: Stakeholder Communication and Involvement

***Best Practices: 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 to them.***

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. It is important to be comprehensive and thorough in identifying the groups and understanding their interest or “stake” in the project. In addition to those directly affected by the project, there are often other interested parties who 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. Because communication is a two-way process, channels must not only deliver messages, but also ensure customer input and

feedback.

Stakeholders need to have varying degrees of input, depending on the impact of the project on them, at strategic points throughout the lifecycle of the project.

### Examples:

***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 four years ago began to change the way it interacted with customers to become more “customer-centric.”

The Bureau of Information Management places high value on communication with customers. It relies on the position of business analyst to ensure good communication with programs (see also Element 3: Project Management). The official job description for this position hints at the communication skills required (“project initiation, customer business process review” and “consulting with end-users,” but Fay 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.”

Fay notes, “I rarely talk about technology because I am much more interested in learning about what you, the customer, does.” He says that in recent months, he has been unable to spend time talking with customers

because bioterrorism projects have increased his workload. As a result, he believes he no longer has the depth of understanding of his customers that he used to have; he is concerned that this disconnect could have implications for his ability to be able to interpret needs of his customers and deliver successfully on those. This realization has pushed him to expend extra effort to spend time with his customers in IDPH.

The Bureau of Information Management currently has 27 FTEs and some outside contractual resources that support a “customer base” that includes over 400 internal customers and several thousand external customers, including the customers from the 99 local health departments and private practice healthcare providers. In Iowa’s highly privatized healthcare environment, external customers are distributed among hospitals, private non-profit agencies such as the University of Iowa’s Hygienic Laboratory, which is the central lab for the Newborn Metabolic Screening Program, and the University’s Department of Pediatrics, which contracts with IDPH to provide comprehensive genetic healthcare throughout the state.

A “customer liaison group” – a subset of the Electronic Birth Certificate (EBC) Steering Committee – was established for the integration project to ensure effective communication with internal and external customers. They seek input from customers, provide feedback, and do problem solving at weekly meetings. For example, they perform hospital visits to discuss some of the birth certificate changes, and they bring back concerns and questions to the EBC team, and modifications

to the design of the worksheets and/or system are made with consensus. The group developed a flyer to inform hospital personnel about the new electronic birth registration system; it was then distributed at an annual perinatal conference to nurses and physicians. The maternity unit nurse manager at Methodist Hospital in Des Moines expressed her appreciation for the early communication about the system and the hospital visit. Through further discussions with members of her staff, duplicative data collection efforts by the nurses were discovered and ideas to improve the workflow were shared.

The Birth Defects Advisory Committee (see also Element 2: Governance) also provides opportunities for strong stakeholder involvement by recommending policies and procedures for the Health Department. Members represent many constituencies, including parents. Five members of the BDAC are parents, including the current chair, a lawyer who is also parent of a child with special needs. Parents are selected to participate in the committee because of their great interest and commitment to newborn screening issues such as formula provision for newborns with nutritional imbalances, disorders screened, and health services provision for children with genetic disorders. Many parents were recommended to participate in the committee by healthcare providers.

***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.

Pediatricians and the University of Colorado Health Sciences Center have been involved in several aspects of the project with the result that a number of them recognize its value and are willing to “go to bat” for the project.

Dr. William Letson, MCH epidemiologist and co-principal investigator on the EHDI grant, provides the connecting link between the health department and private providers. He works closely with Dr. James Ledbetter, a community pediatrician, who is medical consultant for the Health Care Program for Children with Special Needs and the Medical Home Initiative. Both are able to advocate for the project because they are intimately involved in its development and understand that it will benefit providers. Letson notes that those staff who are working on integrating programs recognize that “the medical home is the ultimate place for integration,” a value that reflects the AAP medical home initiative.

The involvement of providers in the Colorado integration project has won the support of significant pediatric leaders in the state. Dr. Peter Lane, director of the Sickle Cell Treatment and Research Center, University of Colorado Health Sciences Center/Children’s Hospital [now at Emory University], understands that the integrated system, Clinic Health Information Records for Patients (CHIRP), will provide higher quality information on sickle cell disease 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. It’s a natural because it starts with

newborn screening. It is an excellent example of collaboration. We would never have had the money to do it ourselves.” He recognizes the potential of CHIRP to help all children with special needs.

***In Michigan***, focus groups and key informant interviews were conducted by the project manager and the parent consultant, as part of the needs assessment for the State Genetics Plan. They met with parents of children with special healthcare needs, healthcare providers, local public health staff, educators, and the general public. Many parents were included because of the efforts by the parent consultant to reach out to the parent advocacy groups, and the regional genetics counselors, who asked a random sample of their patients to fill out consumer surveys.

The effort to be comprehensive and inclusive resulted in parent focus groups that were representative of Michigan’s varied geography and demography. They included parents from the Sickle Cell Support Group in urban Detroit, parents of children with special healthcare needs who live on the rural Upper Peninsula, and adults with genetic conditions who live in urban Grand Rapids. Other professional focus groups were held with the in-house Adult Genetics program to get a public health program and administrative perspective, the Expert Working Group on Cancer Genetics (made up of cancer genetic counselors, staff from the MDCH cancer section, a medical geneticist, clinical specialists, and researchers), and the Michigan Association of Genetic Counselors. For additional cultural diversity, a focus group was also held with the Native American University Students from

the University of Michigan.

As a result of the input from all stakeholders, the project team was able to transfer the qualitative data into quantitative survey instruments. The 12 expert work groups, whose membership also included consumers, healthcare providers, researchers, educators and health department staff, used the information from both methods in the final development of the state plan.

Communication with the wide variety of stakeholders helped to assure that the state plan goals and objectives were consistent with identified needs and priorities of real people, communities, and genetic providers as well as other health professionals. This included general agreement that there was a need to find better ways of using existing data sets in order to plan for, monitor, and evaluate newborn screening and genetic services. The process was part of the impetus leading to a new awareness among program staff of the importance of “staying in the loop” on maternal child health data issues and assuring that the newborn screening database was included in the data warehouse when the opportunity became available.

## Element 5: Organizational and Technical Strategies

***Best Practices: There is no single best strategy for an integration project. A strong integration strategy takes into consideration local issues such as funding, the political environment, organizational structure, the strengths of the organization, and stakeholder beliefs and values. The strategy is customer-focused, developed through a legitimate process involving stakeholders, and is based on business processes.***

Creating integrated public health information system presents an immediate information architectural challenge that has organizational implications. Bringing together data from separate programs (e.g., birth data integrated with metabolic screening results integrated with immunization status) requires a technical strategy. The technical approaches usually boil down to a choice between an intelligent middleware solution, a data warehouse solution, or a centralized database solution.

The *middleware* approach routes a request/query for information through a program (often referred to as the middleware layer) that can determine where specific data reside. The middleware manages the requests, finds the data and returns an integrated view of data to the user. The warehouse solution establishes a separate database (referred to as the warehouse) into which specific data from discrete departmental systems (e.g., the immunization registry, metabolic screening results, birth and death

data, etc.) are copied. Users formulate queries with data warehouse tools to extract integrated views of data about these discrete programs. The extent of analysis is determined by the data fields captured within the warehouse. The final solution is the classic centralized, integrated database. The integrated database requires a large-scale data model to assure that the data needs of every departmental user are properly supported. The integrated database requires a comprehensive design, which means that all participating departments be involved in the design of all aspects of the system.

The organizational implications of these three different technical approaches must be understood. The middleware design provides the most organizational flexibility. It does not necessitate changing how separate child health programs manage their activities. For example, the immunization program can continue to function without change while its data are used by the genetics program, and vice versa. The data warehouse offers similar flexibility but does require that departments contributing data to the warehouse are fully informed and participate in deciding which data elements flow into the warehouse. The centralized approach presents the most challenge to the organization because many programs (e.g., the genetics, immunization, vital records, WIC, etc.) must all participate in the design and operation of the new system. Regardless of the form of technical integration, agreements on data sharing and data use must be developed and agreed upon by all departments involved in the integration project. These agreements must conform to state and federal laws, as well as remain in

keeping with agreements made with specific stakeholders.

### Examples:

Since 1991, the **Rhode Island** Division of Family Health has been working toward its vision of a health information system that tightly integrates all child health programs. Yet to achieve that vision, programs are encouraged to enter into the integration process only when the benefits are clear to them. This “voluntary” approach increases buy-in and support and gains programs’ confidence in sharing data with other programs.

With the long-term vision in mind, KIDSNET staff looks for opportunities: When does a program need to change its business processes and information systems? At that point, programs are open to discussions about integrating with KIDSNET because they realize they need to make business process changes in any case. KIDSNET and the program then negotiate the types of data that the program would like to have in the system, investigate which state laws require data to be entered or restrict entry, and address other program-specific concerns. Programs voluntarily enter into the integration process, which not only increases buy-in and support, but also the program’s comfort level with sharing data with other programs.

The Division of Family Health has integrated eight programs and their systems since 1991. KIDSNET staff is now in the final stages of integrating the ninth program, the newborn metabolic program and its screening results, into the KIDSNET database. When KIDSNET was originally developed, the newborn meta-

bolic screening was managed by the department’s public health laboratory. For a variety of reasons, the laboratory chose not to fully integrate newborn metabolic screening results and tracking functions into KIDSNET. Although KIDSNET staff made numerous efforts to have the screening results integrated, it was not until the management of the entire program was shifted to the Division of Family Health in mid-2000 that significant progress to integrate the data was made.

KIDSNET has most recently been working on integrating the data captured at the hospital: hearing, newborn metabolic, and developmental screening. Because newborns undergo these screens shortly after birth in the hospital, it is logical to link these systems and processes together. These programs will be linked through the use of Genesis®, the vital records system that creates the birth certificate.

Shared access to data is a sensitive issue for programs. When a new program integrates with the KIDSNET system or an outside agency requests access to KIDSNET data, KIDSNET negotiates with them the types of data that can be viewed and by whom. For example, when HeadStart recently requested access to KIDSNET, the agency was informed as to which programs were involved in KIDSNET. HeadStart then sent in a request for access to data from each of the programs that they believed would be useful to their work. Guided by legislation and/or policy and procedures, the programs independently determined whether HeadStart should have access to the data they provided to KIDSNET.

***In Colorado***, the strategy for integrating hearing screening and newborn metabolic screening was guided by a shared vision and recognition of strengths and weaknesses. A core group of individuals within the Family and Community Health Services branch of Colorado Department of Public Health and Environment (CDPHE) shared the vision of a comprehensive health information system that would track infants from birth, through diagnosis to follow up and early intervention. Their goal was to create a child profile that local providers and state health officials could access and to create a “virtual medical home.” The vision was that the integrated system would produce information valuable not only to the private provider community and health officials, but also to those concerned with the welfare of children in the social services and education communities.

The programs that wanted to integrate their systems recognized that funding to do so was scarce and that integration of programs and information systems to support them was not a high priority for department leadership. Their strategy then was to build on the strengths that they did have: an electronic birth certificate already in place, funding to begin with the newborn hearing screening program (EHDI grant), and strong support from key stakeholder groups (the Colorado genetics, birth defects, and provider communities) for integrating these data to support diagnosis and early intervention, as well as the medical home. The core team developing the integrated system believed that once the system was providing useful information, it would gain internal and external support.

In retrospect, the Colorado integration project team believes that, given the constraints under which they must operate, this was a good strategy. Bill Letson, EHDI grant co-principal investigator, stated that it is important to “pick a place to start that can function as a model. Build something that providers can access and find useful. They [providers] can convince legislators that [integrating health information] can be done safely and securely. Families will ultimately discover that it makes their lives a lot easier.”

## 6. Technical Support and Coordination

***Best Practices: IT is centralized within the health department, or within the state, so that programs don't need to develop their own infrastructure, and business processes are standardized. 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.***

The centralization debate has been ongoing in the public and private sector for decades. A tremendous amount of literature exists about the trade-offs between centralization and decentralization.

Years of categorical funding to states have generated data collection systems for individual programs using data definitions and software solutions that seem to best suit the individual programs. But categorical funding for such systems also results in fragmentation – systems that may be unable to communicate with each other. Frequently, technology resources and staff are secured by the programs, which results in technology knowledge being scattered throughout public health departments.

For integration purposes, however, centralization is the optimal mode. Integration, by definition, brings together disparate data systems into one functional entity, either by redesigning the entire system or by linking multiple

sources of data together through software interfaces. The decision to centralize technology staff enables the public health organization to leverage skills and best practices by learning from one another and reduces the specialization that had existed in the past.

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 staff 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 continue their development.

Another creative solution is “matrix-management strategies” – an approach that mixes reporting lines with location. Technology staff report to a chief information officer but reside with program staff. Both of these approaches enable technology staff to stay

connected to programmatic needs and concerns.

### Examples:

**In Iowa**, the Iowa Department of Public Health (IDPH) has its own staff of approximately 27 FTEs to support the more than 100 programs within the department. The Iowa legislature recently created a State Technology Department, overseen by an IT Council, which will look to centralize services and resources, as well as establish enterprise level standards for approximately 30 departments. The IDPH Bureau of IT Management, which provides support to the integration project, interacts with the State Technology Department and with other IT projects within Iowa, such as the State Fiber Optic Network, a governor's alliance to foster public-private partnerships, and a telephone company cooperative – all of which may hold opportunities to benefit IDPH and its programs.

The business processes approach of the Bureau of IT Management 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. The process was initiated in 1999 by Chief Information Officer (CIO) Greg Fay, who was hired by senior management specifically to turn an inefficient and ineffective decentralized system into a centralized, integrated system.

With the standardization of business processes across applications, all IDPH customers now know what to expect, and those implementing the project can learn from pre-

vious projects without successively re-inventing processes. The approach serves a "translation function," ensuring that program needs are understood by technical staff and technical solutions are understood and accepted by program staff.

An integrated Medicaid database, now in the developmental stages, is the central point of collaboration among IDPH programs. Although IDPH currently lacks the resources to support the development of the integrated system, there is a long-term plan, and as resources become available, they are applied towards a sensible, forward progression of the system. The Bureau of IT Management serves a key role in encouraging programs to contribute data to the integrated system, but because the system has yet to demonstrate its value, this is a difficult task.

Although each agency of state government in Oregon has its own Information Technology (IT) 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." For all things relating to the project, the project director has the authority to direct the activities of all participants, including the program coordinator and program staff. For all business needs and system functionality decisions, the project director and IT staff solicit

input and get direction from the program participants.

Working closely together, this integrated team takes responsibility for project initiation, project planning, data system development, testing, training, and rollout. With individual roles and responsibilities clearly stated in the Project Charter (see also Element 3: Project Management), this cooperative approach enables team members to successfully carry out project planning, implementation, and evaluation.

## 7. Financial Support and Management

***Best Practices: 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.***

In the U.S., federal and state information systems were developed largely independent of one another, each relying on its own financial base. Over time, funding for information systems shifted away from state appropriations to federal categorical program grants, which resulted in an explosion of stand-alone databases frequently containing duplicate information. As public health programs and agencies explore the issue of integrating these stand-alone databases, funding issues remain a challenge.

Categorical funding targets resources to specific public health programs and requires that those dollars support that particular program. However, when funding a new system of integration of disparate databases, public health departments experience difficulty ensuring that dollars are spent on the right program.

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. As a result, the grants given by the federal government to the states to develop integrated information systems are

inadequate. 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.

### **Examples:**

**Rhode Island** has successfully taken advantage of numerous federal and private resources to plan, create, build, sustain, and enhance KIDSNET. This has been in part due to Drs. Hollinshead’s and Simon’s interest and involvement in the Association of Maternal and Child Health Programs (AMCHP), Title V, and CDC initiatives. They not only are both aware of national initiatives and agendas, but they often help to create them. Additionally, the Rhode Island integra-

tion project has been able to successfully leverage existing grant funds to obtain new grants by building upon the KIDSNET infrastructure and demonstrating its potential for additional uses and integration efforts. For example, KIDSNET used immunization grant funds (317 funds) and a Robert Wood Johnson Foundation All Kids Count grant to build the core of KIDSNET, the immunization registry. With this infrastructure in place, they were able to apply for CDC's EHDI grant because they were able to demonstrate the feasibility of integrating newborn hearing screening.

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. Current funding sources include insurance vaccine assessments (for vaccine accountability), CDC Immunization Program, MCH block grant, state systems development grant (SSDI), data utilization and enhancement grant (HRSA), Early Hearing Detection and Intervention (EHDI) grant, the SPRANS grant, and All Kids Count.

The HRSA SPRANS grant emphasized integration of the Newborn Metabolic Screening systems, which fit well with the goals of KIDSNET. Other federal funding, such as SSDI and EHDI grants, can be integrated with this funding because they also focus on integration.

Additional ideas to generate revenue that

could help support the project include incorporating some of the costs associated with data collection and management for the newborn screening programs into the legislated newborn screening fee. In Rhode Island, all hospitals are required to pay the state a newborn metabolic screening fee and a newborn hearing assessment fee for each birth. According to the law, the fees can be based on the cost of operating the programs. This does provide some opportunity to adjust the fee as the cost of the program changes. It is also important to note that although the fees are based on the cost of the program, the funds collected go into the general treasury, and each program is then appropriated its budget for the year.

*Michigan's* newborn screening information integration is a component of a larger state project, funded in its entirety by Medicaid, to build a data warehouse from which appropriate reports can be created. Cost for this vast system has been over \$1 million annually for the last two years, with the third year about to begin. Ultimately, the data warehouse will link data, through the use of a unique client identifier (UCI) from Medicaid claims and encounters, Vital Records, Michigan Early Hearing Detection and Intervention Program, Newborn Metabolic Screening, the Michigan Childhood Immunization Registry (MCIR), and multiple other programs (see Michigan Project Brief, Appendix A, for a complete list of programs being integrated).

Funding from other agencies and specific sources helps to develop specific linkages among programs. For example, Michigan has been creative in its development of data infra-

structure utilizing various grants from HRSA/MCHB (both a planning grant and implementation grant for genetic/newborn screening infrastructure development, SSDI and EHDI), CDC (EHDI, agreements for birth defects surveillance and use of data in public health programs, an oral health surveillance grant and a maternal mortality grant), and the newborn screening fee.

Currently underway are collaborative projects underway to analyze and evaluate program data; add software to the electronic birth certificate to expedite the hospital reporting of early hearing screening results; link birth certificates to metabolic screening and early hearing detection screening reports to identify missing screens; and a variety of projects to improve the quality and completeness of the data in the Birth Defects Registry.

The newborn screening fee, collected on most live births, is determined by the Michigan legislature. These monies fund the state newborn screening laboratory, medical management activities, as well as portions of the genetics program.

## 8. Policy Support

**Best Practices: 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 policymakers about sensitive issues to garner their support.**

State public health agencies operate in the context of the governments that support them, subject to state legislation and regulations, budgetary considerations, political tides, and public sentiment. 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 policymakers 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 policymakers informed about the policies and procedures in place to protect health information.

### Examples:

In **Rhode Island**, the Children's Cabinet was created in 1991 by state law (RI GL42072.5) to address all cross-departmental issues that relate to children's needs and services. Membership comprises state department

directors, including the director of the Rhode Island Department of Health (RIDOH), Dr. Patricia Nolan, and senior departmental policy staff.

The intent of the Children's Cabinet is to foster cooperative state efforts to address the needs of children and families in an integrated and effective way. It addresses long-term issues through a five-year plan, as well as emergent issues. 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.

As executive sponsor for KIDSNET, Dr. Nolan educates Children's Cabinet membership about privacy, confidentiality and security of data in KIDSNET (see also Element 1: Leadership).

**In Oregon**, the legislature passed Senate Bill 555 in 1999. It required state agencies to establish policies for a statewide early childhood system of social supports and to develop a local, coordinated, comprehensive plan that includes children ages 0-8 and their families.

In 2001, the Oregon Legislature passed HB 3659, the Oregon Children's Plan (OCP), which focuses resources on prevention instead of intervention. The intention of the voluntary program is to increase services available to children and families throughout the state; expand the Healthy Start program, with its emphasis on home visiting,

statewide; and continue implementation of the early childhood planning portion of SB 555.

OCP proposes to replace the current fragmented system with a comprehensive approach for helping children. When fully implemented, OCP will screen all Oregon children and provide follow-up support to those families who need and request it. The plan will be available in all 36 counties. The Department of Human Services is leading the effort to link data from existing systems, while preserving confidentiality and data security. This effort is addressed by Oregon's FamilyNet data integration project. The FamilyNet system is an interactive data system that allows real time data entry and use. The Family and Child Module will allow the many participants in the OCP to document and share screening, referral, and service information about children whose families agree to participate. System security will allow parents to determine the level of, and participants in, information sharing. The 2001 Legislature approved a \$60 million budget for OCP. (See [www.hr.state.or.us](http://www.hr.state.or.us) for more information about OCP.)

As executive sponsor for the FamilyNet information systems integration project, Donalda Dodson devotes much of her energy to educating policymakers about the confidentiality and security of FamilyNet. Policymakers, she notes, want integrated systems, but without the assurance that health information in Family Net is confidential and secure, they would be hesitant to support it.

## 9. Evaluation

***Best Practices: 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. Evaluation is most effective when it is seen as an integral component of a project. 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. Evaluations help to determine if the project is achieving its intended purposes.

An evaluation can be formative or summative. A formative evaluation feeds information back to the project and program personnel during the development and implementation to improve the likelihood of success of the project. Summative evaluation, on the other hand, provides information about the effectiveness of the system, once the system is in place. Summative evaluation frequently focuses on outcomes. However, most of the integration efforts are in the planning and development stages. Therefore, formative evaluation is most appropriate to developing integrated systems projects.

Formative evaluation in public health information systems explores several questions: How well do the technical strategies match with program needs? Which information system should be selected and implemented? How much work redesign will be required to implement the system? What expectations does that staff have regarding the new integrated system? and How much will it cost to implement the system? (Lewis, 2002, p242)?

Evaluation of the overall effectiveness of an integration project – Are population health outcomes achieved? – helps to inform policy. Current national standards for newborn metabolic screening programs and other child health programs have been established by Title V of the Social Security Act and Healthy People 2010. Title V measures assess health outcomes, fiscal data, numbers of children served, screening and treatment information, new initiatives, and State priorities. Likewise, the Healthy People 2010 goals seek to improve population health by establishing levels of performance against which programs can be measured. For example, goal 16.20 specifies that States should ensure appropriate newborn bloodspot screening, follow-up testing, and referral to services for all newborns. This includes: ensuring that all newborns are screened at birth for conditions mandated; ensuring that follow-up diagnostic testing for screening positives is performed within an appropriate time period; and ensuring that infants with diagnosed disorders are enrolled in appropriate service interventions within an appropriate time period.

States are using outcome measures for their newborn metabolic screening programs. Outcome measures from integrated newborn screening information systems do not exist for summative evaluation purposes. However, few of the states have a formative evaluation process to proactively examine project development and implementation.

### Examples:

***In Rhode Island***, KIDSNET staff reported that writing an evaluation plan for the HRSA SPRANS grant forced them to think about how to examine KIDSNET. Many of the evaluation measures the staff currently uses to monitor progress tend to be process oriented. KIDSNET staff has begun developing some quantitative measures. They note that they use the 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.

It is interesting to note that despite the need to evaluate the success of the program, KIDSNET is being looked to more and more to be able to provide the data for quantitative monitoring of other programs in Rhode Island including some of the Title V performance measures. KIDSNET staff has also actively participated in the Division of Family Health's Data and Information Group, which is assisting KIDSNET in developing a data usage plan.

Staff also evaluates the success of KIDSNET qualitatively. They have held focus groups with families and with providers and their 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. For example, when it became evident that there was significant reluctance and resistance by providers to participate in KIDSNET, focus groups were held with providers and their office managers to identify their concerns and elicit first-hand information about how the system's value can be increased for its users.

Focus groups also were held prior to changing the notification process for families to be in compliance with confidentiality standards. They helped to identify how families wanted to receive information, when they wanted it, and what kind of information they wanted. Similarly, prior to changing the provider agreement, focus groups were held with providers to obtain feedback on the changes. Although each focus group has a specific intent, general and valuable information and feedback (both pro and con) about KIDSNET is obtained through the focus group process.

KIDSNET staff also receives feedback from a dedicated staff member who visits provider offices regularly and frequently, providing them with continuous anecdotal information. The information gathered is used to make KIDSNET more user-friendly to providers and the information within KIDSNET more valuable. For example, KIDSNET staff learned that providers found the monthly reports they received from KIDSNET overbearing. Providers reported wanting instead "check point" reports. This led to the creation of a 21-month report on immunization and lead testing status of their children. KIDSNET staff recognizes that anecdotal data fre-

quently results in more changes than statistical data, and although they will continue with quantitative evaluations, they believe that listening carefully to stakeholders is equally important.

**In Iowa**, the integration project will be incorporating Title V and Healthy Iowans 2010 performance measures into its processes. Title V of the Social Security Act is one of the largest federal block grant programs intended to improve the health of all women and children. Significant amendments were made to Title V legislation with the introduction of the Omnibus Budget Reconciliation Act (OBRA) 1989 and by the Government Performance Results Act (GPRA) in 1993 to increase accountability in government through performance measures. As mandated by OBRA '89, state data on health status and services are collected and reported to HRSA. In keeping with this initiative, Iowa launched its Healthy Iowans 2010, with similar goals as the Title V performance goals.

***Measures from Healthy Iowans 2010 and Title V include:***

- reduce infant mortality to no more than 5 per 1000 live births and reduce the ratio of black to white infant mortality to no more than 1.0 (Healthy Iowans 2010);
- assure availability of a metabolic newborn screening panel to every infant born in Iowa (Healthy Iowans 2010);
- measure the percentage of newborns in the state with at least one screening for each of PKU, hypothyroidism, galactosemia, and hemoglobinopathies (Title V);
- improve the quality of services to women, children, and families (Healthy Iowans 2010); and
- track the percentage of infants determined to be “at-risk” that are receiving monitoring and follow-up services at 12 months of age (Healthy Iowans 2010).