

Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems

A Sourcebook for Planning and Development

All Kids Count



Public Health
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**Published by All Kids Count
Public Health Informatics Institute
750 Commerce Drive, Suite 400
Decatur, GA 30030
(800) 874.4338**

This report was supported in part by All Kids Count, a National Technical Assistance Center supported by The Robert Wood Johnson Foundation, and the Health Resources and Services Administration's (HRSA) Bureau of Maternal and Child Health, Division of Services for Children with Special Health Care Needs, Genetics Services Branch.

The contents of this report are solely the responsibility of the authors and do not necessarily represent the official view of the supporting funding agencies.

June 2003

The *Integration Sourcebook* is available in its entirety at www.phii.org

Acronyms

AAP	American Academy of Pediatrics
ACM	Association for Computing Machinery
ALERT	Oregon's Immunization Registry
AMCHP	Association of Maternal and Child Health Programs
BDAC	Birth Defects Advisory Committee
BPCTS	Michigan's Provider Tracking System
CCC	CHARM Core Council
CDC	Centers for Disease Control and Prevention
CDPHE	Colorado Department of Public Health and Environment
CFHS	Community and Family Health Services
CHARM	Child Health Advanced Record Management
CHEC	Child Health Evaluation and Care (Utah's version of EPSDT)
CHIME	Center for Health Information Management and Evaluation
CHIP	Child Health Insurance Program
CHIRP	Clinic Health Information Records for Patients
CIO	Chief Information Officer
CSHCN	Children with Special Health Care Needs
DHHS	Department of Health and Human Services
DISC	Data Integration Steering Committee
EBC	Electronic Birth Certificate
EHDI	Early Hearing Detection and Intervention Program
EPSDT	Early Periodic Screening, Diagnosis and Treatment
FamilyNet	Oregon's child health information system integration project
FCM	Family and Child Module
FTE	Full-time Equivalent
GOT	Grant Oversight Team
GPRA	Government Performance Results Act
GSB	Genetic Services Branch
HAN	Health Alert Network
HRSA	Health Resources and Services Administration
IBIS	Indicator-Based Information System
IDPH	Iowa Department of Public Health
INPHO	Information Network for Public Health Officials

Acronyms

(continued)

IS	Information Systems
IT	Information Technology
JAD	Joint Application Development
KIDSNET	Rhode Island's child health information system integration project
MCHB	Maternal and Child Health Bureau
MCIR	Michigan Childhood Immunization Registry
MDCH	Michigan Department of Community Health
MIHAS	Maternal and Infant Health Advocacy Services
MIS	Michigan Information Systems
MPHI	Michigan Public Health Institute
N-CHARM	Newborn Child Health Advanced Record Management
NTFNS	National Task Force on Newborn Screening
NEDSS	National Electronic Disease Surveillance System
OBRA	Omnibus Budget Reconciliation Act
OCP	Oregon Children's Plan
OFH	Office of Family Health
OHD	Oregon Health Department
OIS	Office of Information Services
PMO	Project Management Office
PRAMS	Pregnancy Risk Assessment and Monitoring System
QA	Quality Assurance
RIDOH	Rhode Island Department of Health
SEMHA	Southeast Michigan Health Association
SIGMOD	Special Interest Group on the Management of Data
SPRANS	Special Projects of Regional and National Significance
SSDI	State Systems Development Initiative
SWOT	Strength, Weaknesses, Opportunities and Threats
TDT	Technical Development Thread
Title V	Title V of the Social Security Act
UCI	Unique Client Identifier
UDOH	Utah Department of Health
USIIS	Utah Statewide Immunization Information System
WIC	Women, Infants and Children

Contents

1	Executive Summary
4	Introduction
8	I. Key Elements for Integration of Public Health Programs and Their Information Systems
10	II. Best Practices in Implementing Key Elements of Information Systems Integration
	III. Case Studies
42	Utah: Institutionalizing an Integration Project
52	Missouri: From Fragmentation to Integration
63	IV. Lessons Learned
67	Appendix A: Project Briefs
85	Appendix B: CHARM Stakeholders
86	Appendix C: Genetics and Health Information Technology Resources
96	Bibliography

**“Improved coordination and integration
of information systems is needed.”**

-Taskforce for Newborn Screening, 2000

Executive Summary

Newborn metabolic (heelstick) screening is a public health activity that has been conducted for the past three decades and 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 healthcare 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 to outline a national agenda for strengthening state newborn screening programs. The report, published in August 2000, includes four recommendations, the first of which is a recommendation for action to develop public health infrastructure and integrate newborn screening systems with the health care delivery system. The report also calls for a national process to share and promote best practices in information integration models.

In response to the National Task Force on Newborn Screening report, All Kids Count partnered with the Genetic Services Branch, Maternal and Child Health Bureau (GSB/MCHB) of HRSA, to identify and describe best practices in integrating newborn screening information with other early childhood health information and their supporting systems among seven of their Special Projects of Regional and National Significance, or SPRANS, planning grantees. By the end of 2000, SPRANS grants were 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 a two-day site visit: Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah.

All Kids Count organized the two-day site visits around nine key elements considered critical to the success of an information systems integration project. The key elements are not technical but rather are cross-cutting organizational considerations that are critical to success for an integration project, regardless of its scope or focus.

The nine key elements are:

- **Leadership.** The project has an executive sponsor, a high level official who advocates for the project, and a champion, someone who is willing to devote a significant effort to see the project succeed.
- **Project Governance.** 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.
- **Project Management.** The project has formalized management strategies and project management methodologies designed to assure consistent communications, accountability, and resource constraints.
- **Stakeholder Involvement.** Frequent communication with stakeholders and involvement of stakeholders in the integration project throughout the life cycle of the project contributes to its success and credibility.
- **Organizational and Technical Strategy.** The project has a strategy that takes into consideration local issues such as funding, the political environment, organizational structure, the strengths of the organization, and stakeholder beliefs and values.
- **Technical Support and Coordination.** Technical information systems support and coordination is organized centrally to assure consistent support and a robust infrastructure capable of maintaining and complying with standards.
- **Financial Support and Management.** The project is adequately funded and has multiple funding sources.
- **Policy Support.** Rules, regulations, legislation, and policy advisory or policymaking bodies are supportive or are at least neutral to the integration of health information systems.
- **Evaluation.** The project has some form of qualitative and/or quantitative monitoring or evaluation that is performed regularly.

The site visits focused on identifying and understanding what factors, from the grantees' perspective, were important for planning and implementation of the integration effort within their states. Site visits were structured to gather consistent information across sites, yet allow flexibility in dealing with the unique nature of each grantee.

This *Sourcebook* contains a description of each of the key elements and what are considered best practices in their implementation. It

gives examples of best practices of the elements as demonstrated by five of the seven SPRANS grantee states visited: Colorado, Iowa, Michigan, Oregon, and Rhode Island. Through in-depth case studies of the two remaining states, Utah and Missouri, it describes how the key elements were implemented through two very different approaches.

The *Sourcebook* also presents five lessons learned – over-arching conclusions that states and government agencies should bear in mind as they consider implementing health information systems integration projects.

The lessons learned are:

- **Data Are for Sharing.** Public health agencies that create an environment where data and information are considered assets to be shared among programs are more likely to succeed in developing integrated information systems.
- **Listen Up.** Communication is critical when developing an integration system. This means communicating with all stakeholders, listening carefully to their concerns and needs, and actively working to gain feedback from stakeholders throughout the integration project's development and implementation.
- **Change Is Hard.** Implementing integrated information systems within an organization means changing the way people do their jobs. This can potentially be very threatening. The natural tendency of people is to hold on to the status quo.

Employing change management strategies to mitigate this challenge increases the likelihood of successfully implementing an integration project.

- **Let Public Health Program Needs Drive Technology.** Project goals, objectives, functionality, and needs must be identified before searching for technology solutions. When program managers become enamored with technical solutions before developing a requirements document, the end result may be a system that does not meet program goals.
- **Stay the Course.** Adoption of new technology is slow. Health departments, funding agencies, program and IT staff, and other stakeholders should recognize that they need to be committed for the long haul and that patience is required to realize the vision of integration.

Along with the key elements, best practices, and lessons learned, this *Sourcebook* contains relevant bibliography and resources for information systems program managers engaged in planning, developing, or implementing an integrated child health information system.

Introduction

EACH YEAR, 4 million U.S. infants are screened to detect genetic conditions that threaten their lives and long-term health. Newborn metabolic (heelstick) screening is a public health activity that has been conducted for the past three decades and 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 healthcare needs are now emerging because of recent trends in diagnostic capability, technology, society, and the healthcare system.

Among them:

- a revolution in biotechnology, dramatically increasing the number of tests that can be performed;
- an explosion of new information technology, making it possible to provide comprehensive, integrated information to a child's medical home;
- an increase in population mobility. Families relocate, change employers and insurers, and change healthcare providers with increasing frequency, resulting in records scattered among different providers, offices, and clinics, and even across states;
- increasing numbers of children who are uninsured or underinsured. Children and families often lack coverage for or access to specific services;
- new and growing partnerships between private sector and public sector healthcare organizations and providers;
- pressures to contain costs, even in the face of new tests and treatments that offer promise; and
- ethical, legal and social questions associated with all of these changes, including the need to balance the population's health with individuals' rights and to assure families that their privacy is fully protected.

Recognizing these challenges will have a significant impact on newborn screening programs, at the request of the Health Resources and Services Administration (HRSA), the American Academy of Pediatrics (AAP) convened a National Task Force on Newborn Screening, representing a broad base of perspectives. The August 2000 report from the Task Force outlines a national agenda for strengthening state newborn screening programs (Task Force, 2000).

The report includes four key recommendations, the first of which was a recommendation for action to develop the public health infrastructure and integrate newborn screening systems with the healthcare delivery system. The report stresses the importance of placing newborn screening programs within adequate public health infrastructure, which includes collaboration of federal agencies; development of standards; appropriate evaluation and monitoring of program performance; informed and involved health professionals and the public; and coordination and integration of program activities including information and services, through public-private, federal-state, and intrastate partnerships.

The report lists programs with information that logically can be integrated: those that screen infants for other health and developmental risks (prenatal screening and follow-up, newborn hearing screening, WIC, outreach, case management and home visiting programs); programs for infants with or at risk for special healthcare needs (high risk infant follow-up programs, early intervention programs, and state genetics services

programs; and registry and data programs that include infants (vital records, immunization registries, birth defects).

But it goes on to say:

Publicly funded infant and child health programs often operate independently of one another. The resulting duplication of effort can increase costs, burden families and healthcare professionals, and create redundancy in data management systems.

Improved coordination and integration of information systems is needed.

Addressing the challenges associated with integrating information and information systems, the report suggests two strategies: assess the status of state newborn screening systems, including information on the capacity to manage and integrate information at each state of the system, and more broadly, the relationships among newborn screening program, especially immunization registries; and support program integration models.

In accordance with these strategies to develop the public health infrastructure that will improve service delivery to children within a medical home, the report specifically notes the need for a national process to share and promote best practices in information integration models.

In October 2001, All Kids Count partnered with the Genetic Services Branch, Maternal and Child Health Bureau (GSB/MCHB) of HRSA, to identify and describe best practices leading to the integration of newborn metabolic screening programs with other public health programs and their information systems. Because of its previous experience,

All Kids Count was uniquely qualified for this work. The All Kids Count Program, funded by the Robert Wood Johnson Foundation since 1992, had spent eight years assisting state and local health departments in developing and implementing immunization registries. In 2000, All Kids Count broadened its focus to address integration of immunization registries with other early childhood health information systems, including newborn metabolic and hearing screening systems.

All Kids Count was asked by GSB/MCHB to identify and describe best practices in integration among seven of their SPRANS planning grantees. SPRANS grants were awarded to states to assist them in developing state genetics plans and integrated data collection and service systems for the purpose of enhancing early intervention services. By 2000, grants had been awarded to 17 states: Alaska, Arizona, Colorado, Hawaii, Indiana, Iowa, Kentucky, Massachusetts, Michigan, Mississippi, Missouri, Oklahoma, Oregon, Rhode Island, Texas, Utah, and Wisconsin. All Kids Count reviewed the proposals from these grantees to determine which states were in the process of planning, developing, or implementing an integration initiative. Seven states were chosen for two-day site visits: Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah.

All Kids Count organized the two-day site visits around nine key elements considered critical to the success of an information systems integration project. The key elements are not technical but rather are cross-cutting organi-

zational considerations that are critical to success of an integrated project, regardless of its scope or focus.

The nine key elements are:

- leadership;
- project governance;
- project management;
- stakeholder involvement;
- organizational and technical strategy;
- technical support and coordination;
- financial support and management;
- policy support; and
- evaluation

All Kids Count staff identified these elements through review of health information systems management literature and by drawing from their experience over the last decade.

The site visits were focused on identifying and understanding what factors, from the grantees' perspective, were important for planning and implementation of the integration effort underway within their states. Site visits were structured to gather consistent information across sites, yet allow flexibility in dealing with the unique nature of each grantee.

The seven sites offered a wide range of experiences. One had more than a decade of experience at developing a state-wide integrated information system to support many public health systems. Others are in the very early stages of their work and have not yet

formulated a master plan for future integration efforts. Yet despite the variability of the sites, the key elements critical to success proved valid across all.

This *Sourcebook* contains a description of each of the key elements and what are considered best practices in their implementation. It gives examples of best practices of each of the elements as demonstrated by five of the seven SPRANS grantee states visited: Colorado, Iowa, Michigan, Oregon, and Rhode Island. Through in-depth case studies of the two remaining states, Utah and Missouri, it describes how the key elements were implemented through two very different approaches. And, it presents five lessons learned – over-arching conclusions that we believe states and government agencies should bear in mind as they consider implementing health information systems integration projects.

This *Sourcebook* provides guidance to other states in planning, developing, and implementing the integration of their newborn screening systems with other early childhood health programs and their information systems.

I. Key Elements for Integration of Public Health Programs and Their Information Systems

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.

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.

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. The project has adequate and appropriate staff with the right skill sets to achieve project goals.

4. Stakeholder Involvement

Best Practices: Frequent and high quality communication with stakeholders and stakeholder involvement in the integration project contributes 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.

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 based on business processes.

6. Technical Support and Coordination

Best Practices: Technical information systems support and coordination is organized centrally to assure consistent technical support and a robust infrastructure capable of maintaining and complying with standards governing public health and healthcare systems. Technical staff works closely with the program staff in order to understand their objectives and business processes. Technical coordination involves translating programmatic needs to technical staff. A new role, business analyst, offers a means of implementing this best practice.

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.

8. Policy Support

Best Practices: Rules, regulations, legislation, and policy advisory or policy-making bodies support or are neutral to integration of health information systems and programs.

9. Evaluation

Best Practices: The project has some form of qualitative and/or quantitative monitoring or evaluation that is performed regularly. The measures can be developed internally or adapted from other sources.

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 break down 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 systems 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 in 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 appropriate 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 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 project subcommittees.

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 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 a steering committee to deal 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.

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.

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:

Formalized Management Strategies

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 documents, 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

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 MDCH 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 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. 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, do.” 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

metabolic 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 Head Start recently requested access to KIDSNET, the agency was informed as to which programs were involved in KIDSNET. Head Start 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 Head Start 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, thereby improving 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 previous 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 program-specific activities. However, when funding a new system that integrates disparate databases, public health departments often 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, federal grants to 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

integration 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 infrastructure 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 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 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 integration projects 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 frequently 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).

III Case Studies

UTAH: Institutionalizing an Integration Project

The elements of leadership, a strong understanding of stakeholder needs and the business needs of health department customers, and strong organizational management in developing an integrated system combined in Utah to make CHARM, the health information programs and systems integration initiative, part of the fabric of the Utah Department of Health. UDOH took a modular approach to integrating systems, beginning with a core of programs and leveraging funding and incremental successes to achieve a long-term vision for a state-wide integrated system.

Utah was one of the pioneering states for newborn hearing screening for high-risk infants, as far back as the 1970s. When this type of screening failed to identify half of the children with sensorineural hearing loss, the Utah Department of Health (UDOH) began to promote universal newborn hearing screening, and by 1996, over half of Utah newborns were being screened through the voluntary efforts of several hospitals. In 1998, Utah passed legislation to have newborns in all Utah hospitals screened for hearing loss before discharge. Follow-up of the families whose infants failed hearing screening presented similar problems as those experienced through UDOH's newborn blood screening program. The need for integration of all newborn public health data was recognized.

In late 1999, UDOH began the Child Health Advanced Records Management (CHARM), initiative to address the need for integrated child health information. A charter was developed stating the purpose of CHARM:

“to create a virtual health profile for every child and to allow real-time data sharing across health-care programs and partners. CHARM will provide immediate access to information that is stored in program-specific databases to track and monitor screening results, immunization status, referrals, follow-ups, assessment, treatment, and outcomes for children and their families. The integrated system will reduce or avoid redundant data entry, increase

accountability, and reduce the fragmentation of data and healthcare services.” (Utah Data Integration Plan, 2002, p61).

An examination of how CHARM was developed in Utah provides a case study of many best practices in implementing a health information system integration project. The planning and implementation of CHARM is examined here in light of each of the nine Key Elements.

Leadership

The Utah Department of Health Data Integration Initiative began formally in 1997, when executive management of UDOH, including Scott Williams, MD, now Deputy Director in charge of clinical components at UDOH, and at the time, Director of the Division of Community and Family Health Services, realized that multiple, independent program-centered processes and systems wouldn't yield population-based data and would never bring together a picture of the whole child. On the contrary, data silos promoted redundancy and insulation in the collection and use of data, a limited view of clients' needs, and an inability to provide coordinated care.

The realization that a “holistic” approach was needed translated into a formalized UDOH information systems (IS) vision with four strategies: identify and support an accountable individual to assure achievement of the IS Vision, objectives and strategies; establish processes to develop, implement and monitor data standards and to integrate information

systems; identify major stakeholders and develop a process for their participation in achieving the Vision; and create an analytic network to facilitate converting data into useful information.

The IS Vision also called for three major outcomes: public health data to be complete, uniform, and accurate; stakeholders to be satisfied with the availability and usefulness of public health data; and public health data to be entered only once, and to be readily retrievable by all authorized people.

It soon became apparent that to move this vision for integrated systems forward and to fulfill the first strategy (complete, uniform and accurate public health data), a dedicated chief information officer was needed to lead and implement a clear, department-wide integrative vision. With support from Dr. Williams, the executive director brought on Rhoda Nicholas as chief information systems officer (CIO), reporting directly to the executive director, not the IT department.

Nicholas understood and advised the executive level that integration is not simply about integrating systems: it's about integrating programs and the people that operate them. Without buy-in from programs, no one will use the integrated system. The level of Nicholas' position within the organization is key to the project's success.

Barry Nangle, PhD, director of the Office of Vital Records and Statistics, and George Delavan, MD, director of the Division of Community and Family Health Services, also embraced the integration vision. Dr. Delavan is now seen as the sponsor of the project

because most of the programs being integrated are within in his division, along with programs supported by Title V. His role is to keep focus on the vision while also managing expectations and understanding of realities, such as funding, which can adversely affect the project.

Today, data and system integration is a “level 4” issue in UDOH – one of less than a dozen issues given this highest priority rating, and is closely watched by the UDOH director.

The data integration initiative is just one part of a larger vision of the way UDOH does business. In mid-1999, UDOH adopted a guiding business principle of “customer centricity.” The executive team, program, and IT representatives were challenged to do business according to this principle. By the end of 1999, UDOH had five strategic initiatives underway, supported by programmatic and IT staff: CHARM (Child Health Advanced Records Management, the child health data integration initiative); financial information; human resources management information; Indicator-Based Information System for Public Health (IBIS-PH); and department-wide data warehouse (expanded beyond Medicaid).

Governance

In June 2000, UDOH started a CHARM Core Council (CCC) comprising program managers from Newborn Metabolic Screening, Newborn Hearing, Immunization, Early Intervention, Birth Defects, and Vital Records. Other programs that have participated or participate

occasionally include EPSDT, WIC, and Lead Screening. Utah State University, the technical partner on the project, is also a council member. Dr. Delavan chairs the Council; Barry Nangle of Vital Records and Statistics is co-chair.

The mission of CCC, which meets bi-monthly, is to make content and policy decisions regarding CHARM scope, goals and objectives, programmatic integration sequence, issues about data access and authorization, privacy and confidentiality, and client consent. CCC also has defined the functional requirements for CHARM.

Through time and prioritization discussions, the group determined that a first set of programs would be integrated (Birth Registration, Newborn Metabolic Screening, and Newborn Hearing Screening), quickly followed by another two (Utah Statewide Immunization Information System or USIIS, and Early Intervention). Then new programs would be added in a phased approach. CCC became smaller and more focused on the programs currently being integrated.

A second committee that has a significant role in guiding CHARM is the Grant Oversight Team (GOT). Their charge is the financial needs of the initiative (see Funding).

Management

The UDOH approach to managing CHARM has resulted in a tightly integrated plan with a high degree of accountability. Due to its complex nature, CHARM has been organized into three phases: Needs Assessment,

Planning, and Implementation. The phases cover the time span from fourth quarter 1999, when the UDOH Data Integration Vision was formulated, through third quarter 2004, when the web version of CHARM is rolled out, and beyond.

Each phase is managed slightly differently depending on the needs of that phase. Phases 2 and 3 are planned and managed as a program under which interrelated projects are coordinated around identified “threads” or themes. The threads are translated into projects with goals and objectives. Each thread has its own team with a project coordinator. The program manager oversees project coordinators to ensure their activities are in line with the overall goals and objectives of CHARM. The program manager also manages the timeline and resources for CHARM and meets on a regular basis with each of the project coordinators.

Needs Assessment: This first phase, discussed below under Stakeholder Involvement, produced the information on which the Planning Phase was built.

Planning Phase: The planning process began with a review of the needs assessment findings and identification of the “threads” or themes, which then became projects, each with a project coordinator and team:

- Communication and Marketing
- Data-related Rules, Policies and Procedures
- Data Quality
- Organizational Change

- Technical Development
- Participating Program Technical Development
- Program Management

Much of the planning process took place at a two-day meeting of moderated focus groups that included staff from the programs participating in the CHARM, IT representatives, parents and parent advocacy groups, partners from Utah State University, the CFHS division director, members of the Data Integration Initiative team, and observers. Building on rough plans already developed for one thread, Technical Development, the groups then developed draft plans for all threads. Finally, the group revised, refined, and reconciled plans for all threads into a cohesive planning document.

Each thread/project has specified objectives. Activities, timelines, responsible parties, and deliverables were identified for each objective.

The planning process also yielded Vision and Mission statements, a SWOT (strengths, weaknesses, opportunities and threats) analysis, and a list of “critical success factors” without which the initiative would not achieve its goals, may not be adopted, or may even fail. Stated Principles and Values guide the work of the team during the planning definition and realization of the solution.

Assumptions and Constraints, Risks, and Financial Sources also were identified in the planning process.

Implementation Phase: The phased integration strategy, developed in the planning

process and already underway, is discussed under “Integration Strategy.”

Stakeholder Involvement

UDOH recognizes that all major stakeholder groups must ultimately have input into the development of CHARM. For the purposes of this initiative, “stakeholders” were defined as anyone who can impact the success of CHARM or anyone impacted by the initiative. A list of stakeholders was generated to ensure involvement from each group (see Appendix B).

Formal stakeholder input was sought through a comprehensive needs assessment process. Focus groups were conducted by an outside contractor. Participants included UDOH managers from programs that currently have child health data sets; parents of children with special healthcare needs; and representatives from family and other community advocacy groups.

The needs assessment surfaced three major findings:

- parents and families have a strong need to have their voices heard throughout the data integration process, and parents have concerns that mishandling of data may negatively impact insurance costs and healthcare access;
- UDOH must make participation by providers (in CHARM) very easy and attractive if they are to share data; and
- program staff was interested and supportive, but desired training and support

Different priorities have been given to the stakeholder groups, depending on the phase being worked on. However, throughout each of the phases, the program business needs are constantly being addressed with the stakeholders.

Parent input was sought early on, stemming from ongoing relationships between the UDOH and community groups, and will continue throughout the project.

Private providers’ input will be sought close to the time when CHARM becomes web-enabled in order to allow for their access. UDOH plans on engaging providers in CHARM through the USIIS Oversight Committee. The Committee consists of representatives from insurance plans (plans that fund USIIS), private providers, and public health. UDOH is expecting to use this committee to solicit feedback on CHARM from private physicians.

Organizational and Technical Strategies

The strategy for integrating child health programs and their information systems in Utah is driven by the vision, 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 – is the most appropriate integration strategy.

The incremental approach offers several advantages:

- UDOH will demonstrate the viability of the approach to potential stakeholder groups through multiple prototypes. This allows feedback and a chance to incorporate feedback during development, rather than after the fact;
- it allows programs to be added easily, at the pace of the program, while allowing participating programs to maintain their independence; and
- programs will retain stewardship and responsibility for their data.

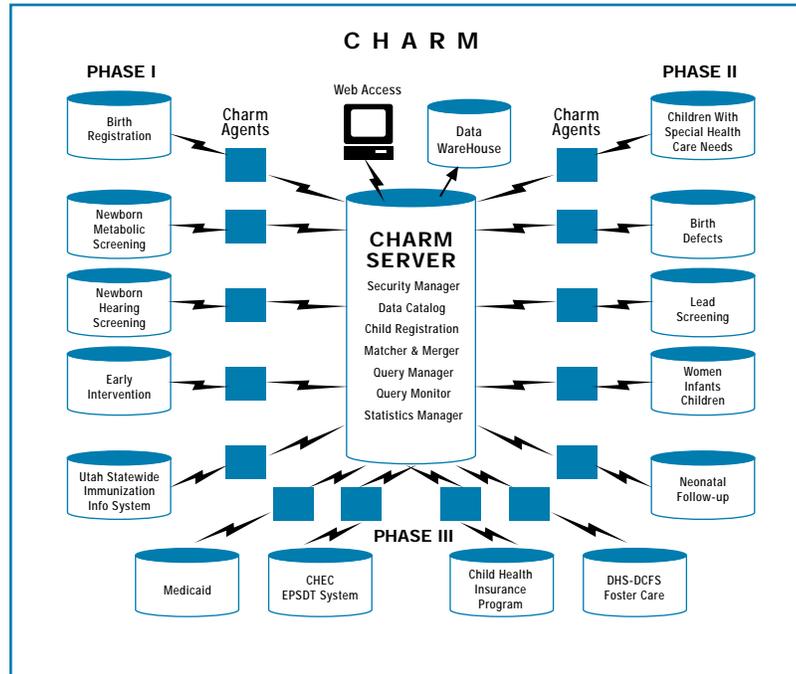
It also allows UDOH to take both an opportunistic and systematic approach to integration, assessing each system/program to be integrated based on several criteria:

- accordance with the CHARM Vision – integrating the system leads to the vision of a comprehensive child health profile;
- appropriate technology – the technology of the current system is appropriate and ready for integrating;
- availability of funding – the program has funding to support integration;
- willingness of the program – the program is open to integration; and
- political rationale – there is political support for integrating the program.

CHARM will develop and/or acquire a core collection of software components to build an integration infrastructure, or “hub.” The hub

will serve different roles, depending on the needs of the programs: broker, dispatcher, traffic cop, conflict manager, and policy enforcer. Each participating program will have its own “agent” or adapter and front-end to plug in to the CHARM hub. The agents and “front-ends” will help the programs translate and format their communications as well as define and manage the rules under which they are operating and sharing data.

FIGURE 1: Architectural Overview of Child Health Advanced Records Management (CHARM)



The CHARM project is structured in three main Programmatic Integration (PI) releases. The focus of the integration project for the last year has been on the first PI release integrating programs that serve the universe of children born in Utah: Birth Registration, Newborn Metabolic Screening, Newborn Hearing Screening, Immunization Registry, and Early Intervention. A subset of these programs, Birth Registration, Newborn Metabolic Screening, and Newborn Hearing Screening, have also been the focus of additional integration through the use of a shared number UDOH has informally referred to this integration subset as “NCharm,” for Newborn CHARM. The annual birth cohort is approximately 47,000.

This key group of stakeholders knew that they needed each other’s current data to identify the same group of children – children who were falling through the cracks, not getting screened. Funded by an SSDI (State Systems Development Initiative) grant, NCHARM created a linkage among the three programs by using the number from the newborn screening “kit” (on labels) as the birth record number and thus as a common identifier in all three systems. The process was piloted

in two hospitals and 97.5% of the newborns were found in all three systems. The system will be rolled out statewide, funded by a 2002 HRSA implementation grant.

The second PI release includes programs targeted for later integration into the hub: Children with Special Health Care Needs; Birth Defects Network; Lead Screening; Women Infants & Children (WIC); and Neonatal Follow-up Program.

The third PI release will include Medicaid; Child Health Evaluation and Care or CHEC (Utah Version of EPSDT); Child Health Insurance Program (CHIP); and DHS/DCFS – SAFE (Health Services for Children in Foster Care).

In addition to the PI releases, there will be several “enabling” releases, such as the Integration Infrastructure, Web Access, Content Enhancement, Extended Integration and Data Warehouse releases. After the Web Access release, providers can be hooked into the CHARM system to get data from across the participating programs to help them provide better care to their patients.

The Extended Integration release looks at connecting with the National Electronic Data Surveillance System (NEDSS). The final release of CHARM – the Data Warehouse release – will send information from CHARM to the UDOH Data Warehouse. CHARM will prove to be a rich source of integrated data. The Data Warehouse, developed and funded by the state Medicaid program, will serve as a repository for historical and statistical data, and will allow for longitudinal studies, analysis, research,

reporting, and policy development. UDOH’s Indicator Based Information System for Public Health (IBIS-PH) will be able to access the data for measures and reporting.

Technical Support and Coordination

In 2000, when UDOH started the development of CHARM, the technical staff providing support for the integrated information initiative was not centralized. Technical staff was hired by the programs and was program-specific. The funding for the staff came from the programs, and they reported to program people. UDOH had to be creative in pulling together an IT team for CHARM. They created a CHARM Technical Program Manager position and partnered with Utah State University to contract for graduate students as members of its technical team, called the Technical Development Thread (TDT) team. The TDT team is responsible for developing the core infrastructure of CHARM. Once this has been developed and they begin to build the linkages with the various programs, it is expected that the technical staff from those programs will join and become members of the TDT team.

Recently, UDOH has restructured their technical support by going through a centralization effort. However, as of yet, the restructuring has not been implemented, and the TDT team approach is still in place.

In looking to the future, CHARM anticipates following the path of the immunization registry (USIIS), which has been developed and supported by the Immunization Program, but

now uses the web-hosting services of the State Division of Information Technology Services (ITS). The primary impetus for moving USIIS to the state ITS was to be able to provide users with 24/7 support and coverage, and better funding support. ITS houses the servers, Unix administrators and low-level support people; public health staff are on-call to answer questions that ITS cannot answer. ITS negotiates enterprise licensing fees for common applications, which reduces the operating costs to state agencies that use their services.

The relationship appears to be working smoothly. If CHARM were to follow the same path, the UDOH would develop CHARM and the state ITS would host it, providing 24/7 support. This becomes especially important when CHARM releases its web-enabled components and access to CHARM is allowed by outside users.

There is no formal statewide IT strategic plan to go across all Utah state departments. Discussions are held among departments on issues of joint concern. Courts and Public Safety are two departments that also are integrating systems. UDOH believes that CHARM's integration architecture can be applied to other state agencies that have a need to integrate information across several inter-agency programs.

Funding

Sustaining funding is one of the biggest challenges facing Utah's Data Integration Initiative, and like most integration projects,

creativity and coordination are required if it is to move forward.

The Grant Oversight Team (GOT) addresses issues related to the financial needs of CHARM. The team comprises the principal investigators and budget coordinators for all grants that have a data integration component and are pursuing similar or complementary purposes. The team meets monthly to coordinate and optimize funding streams, and to assure grant accountability. As more programs/systems are integrated, its membership will expand. Chair of GOT is Dr. Delavan, director of the CFHS Division, and the executive sponsor of the initiative.

Currently, the project is supported principally by grants from federal agencies:

- CDC Early Hearing and Detection Intervention (EHDI) (5 years/\$233K for technology personnel);
- HRSA Genetic Services and Data Integration Planning Grant (2 years/\$75K for data integration needs assessment and planning);
- HRSA State Systems Development Initiative (SSDI) (\$89,900K for NCHARM);
- HRSA MCH Block Grant (\$35K - one time) for .5 FTE programmer position;
- All Kids Count Program, Robert Wood Johnson Foundation, (\$52K).

UDOH would like to make a "business case" for the project in order to answer, "Why is CHARM a priority?" However, it is difficult to build a cost benefit equation for an

integrated newborn screening system because it is based on societal benefits – benefits for a child and his/her family. UDOH is conducting an economic study on newborn hearing and will do the same for newborn metabolic screening to determine if the kit fee covers the cost of services.

UDOH continues to look for additional sources of funding or ways to minimize costs to complete the initial release of CHARM while planning for the long-term deployment and maintenance. It is following the relationship between USIIS and the state ITS with an eye to chartering CHARM as an enterprise project to facilitate its support by ITS.

The partnership with Utah State University has allowed UDOH to maximize its funding for technology development. They are able to get high caliber technical skills at a very low cost. UDOH hires graduate students who have finished their course work.

Because of its public nature, IBIS-PH challenges each UDOH program to do business in an “indicator-based way.” Program managers are working with IBIS staff to determine which measures should be included and how data will be reported. Title V measures are used for newborn metabolic screening, and staff are working with CDC to refine newborn hearing measures.

Evaluation

UDOH’s Indicator Based Information System for Public Health (IBIS-PH) is a web-based system that presents data and information on pre-defined indicators of health and well-being in Utah. The information is presented in a variety of ways, including tables and multiple graphs, and provides information on the public health context, which is necessary for interpretation. How is Utah doing compared to the rest of the U.S.? Which local, state or national public health initiatives address this indicator?

Missouri: From Fragmentation to Integration

The Missouri Department of Health and Senior Services (MODHSS) has built a highly integrated health information system over the last 10 years that has brought cohesion to the state's multitude of public health programs. While the technology strategy implemented in Missouri may not lend itself to most states, their clear vision, leadership, and organizational approaches are a model for many other states to follow.

In 1992, health data in Missouri came from 67 different categorical state databases serving over 100 autonomous local public health agencies, all of which collected data different ways. Together they comprised a robust store of data, but there were no central inventories of what systems existed or what data were being collected. There was no single technical architecture, no hardware or software standards, no LAN or Internet access at the local health departments, and the system was replete with redundancy. Garland Land, director of the Center for Health Information Management and Evaluation (CHIME) for MODHSS recalls, "We had data, but no information. We could not tell you the health status of Missouri. We were burying ourselves in data." The system had developed piecemeal over the years, in part because of the categorical nature of federal funding that resulted in information systems that did not support the health needs of the department's clients in a coordinated fashion.

In response, the Missouri Department of Health, now called Missouri Department of Health and Senior Services (MODHSS) created the Missouri Health Strategic Architectures and Information Cooperative project (MOHSAIC). MOHSAIC is a single network system that houses the data and services needs for almost all the programs in MODHSS. MODHSS has built the core system and integrated program systems one by one over the past 10 years.

Leadership

Leadership in Missouri has taken several different forms and senior management has been involved in the overall conceptualization of

MOHSAIC from the beginning. In the early 1990s, it became clear to the department director and MODHSS management that to reach their Year 2000 goals, an integrated system was needed and so, in 1991, they created the OIS (Office of Information Systems) Steering Committee to address these and other information system issues. After a false start with the wrong consultant, the department engaged a new consultant who was a skilled facilitator and an initial project to create an Information Strategy Plan (ISP) was implemented. They called the project MOHSAIC. Development of the ISP required the commitment of 80-90% of six senior managers' time to participate in high-level Joint Application Development (JAD) sessions for a period of 14 weeks. All divisions of MODHSS were represented on the team and the project emerged as a leadership initiative.

A decision was made shortly after starting MOHSAIC to centralize all information technology staff and high-level data analysis staff into one unit, CHIME, with a director, Garland Land, who reports to the director of MODHSS. Land is viewed as both the executive sponsor and the champion of the integration project, MOHSAIC. In his role as executive sponsor, Land has sought and secured funding for the project, and educated senior management, the director and deputy director of MODHSS on the need for the project, thereby institutionalizing MOHSAIC within MODHSS.

As director of CHIME, Land participates in MODHSS Center/Division Director meetings. This provides him with access to top-level management through regularly held meetings.

It is in these meetings that Land has been kept informed of new projects and up-coming grants and opportunities for using and funding MOHSAIC. Land uses these "opportunities" to discuss how MOHSAIC might help new or expanding programs. He does not require participation of programs in MOHSAIC. Instead, when a program has funding, he sells the program manager on the benefit of participating in MOHSAIC and then convinces them that they should pay for it.

In order to be effective, Land must be politically astute. He has learned when and how to "pick his battles" in order to move the integration initiative forward. In some cases, it became apparent to him that insisting a program integrate its system into MOHSAIC would have jeopardized future working relationships and hence stalled the integration project. For example, the initial funding for the Information Network for Public Health Officials (INPHO) funding received by Missouri was redirected from MOHSAIC to build a separate immunization registry. Land decided it was more important to build the relationship with the Immunization Program staff. He was able to gain the immunization staff's confidence in his ability and later convinced the staff that they would be better served if the system were part of MOHSAIC. He has the wisdom to know how far to push issues.

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." MOHSAIC has been fortunate to have two such people, Land and Nancy Hoffman, the MOHSAIC program

manager. Hoffman, a public health nurse, serves an important translation role within MOHSAIC. She has been instrumental in connecting the IT professionals with the real world of public health. She also has been able to help the public health managers understand how MOHSAIC can assist them. When MODHSS started the integration initiative, many people within the department were convinced it would fail and left the organization; only few remained to start the initiative. Both Land and Hoffman believed in the project, stood by it, and staked their careers on MOHSAIC.

Land believes that organizational perceptions of MODHSS were important factors in MOHSAIC's success. The last two health directors said they "want this to be a Department of Health, not a collection of programs. We work for one Governor" – a statement of executive commitment to a re-organized, unified department. Land credits MOHSAIC with stimulating much of the reorganization because high-level people were able to see how programs could work together.

As both the executive sponsor and champion, Land has been aggressive about making those he considered national stakeholders aware that Missouri was a center of innovation. He got his message out by presenting at national meetings, serving on national committees and being available to advise other states' information systems projects. His vision, commitment, and competency were recognized by funding agencies. Missouri was awarded one of the largest CDC INPHO project grants.

Leadership of MODHSS continues to be very supportive of the initiative. They understand that the department is building an information system and that system is only valuable if programs use it. They have learned to value information, which makes them value and support the IT systems that produce the information. It is widely held in MODHSS that "information might be considered the second most valuable resource of the department – second only to its employees."

The state health officers who served during most of the early MOHSAIC development period wanted data to support decisions and recognized that MOHSAIC was a rich source of health information. Their support for MOHSAIC helped to ensure its continued success.

Project Governance

The governance of Missouri's integration project has been transformed over time. Information engineering (IE) methodology was used to guide Phase 1 of the MOHSAIC project. With this methodology, users are involved in all stages of the process. The initial stages focus on high-level goals and involve the department's senior management, while the later stages analyze more detailed information and involve lower level program staff.

The initial internal steering committee of the OIS, represented by the high-level senior management from all of the divisions of the MODHSS, worked closely with an outside consultant who was well versed in IE and who facilitated high-level JAD sessions over a

14-week period. They assessed all of the information systems in the department, then identified all the functions performed by the department and the data needed to perform these functions. These team members defined each data element and process to ensure clear communication with future workgroups and program developers. The end result was a long-range plan for information systems development that transcended program/organizational boundaries.

A second team was formed consisting of representatives from a rural health department, a city health department, a large metropolitan health department, and one manager from the original team. The same consultant facilitated a review of the functions performed by the local public health agencies and the data needed to perform these functions. The ISP developed by this group was identical to that of the first ISP with the exception of a few activity definitions. The definitions were expanded and the two plans were consolidated to create a single plan that addressed the information needs for public health in Missouri. The final plan “integrated the critical success factors, strategic issues and information and technical needs necessary for the department and local public health agencies to achieve their goals” (Land, et. al, 2002, p. 620).

Over time, this steering committee became less important as MOHSAIC moved from being a new concept – when it was important to get buy-in and involvement from many high-level partners and stakeholders – to being an integral part of the department’s day-to-day work.

Currently, MOHSAIC has an Information Advisory Committee consisting of Division/Center directors or their deputies. Their discussions focus on financial issues (how to pay for being part of the network) rather than policy issues. Land and Hoffman also have scheduled meetings with the program directors to provide status updates on projects and to establish priorities for ongoing and planned projects. The combination of these meetings works well to address cross-program issues. For example, with the governance infrastructure of MOHSAIC in place, managing bioterrorism-related activities, which involve multiple programs, has been much easier than if MODHSS did not have MOHSAIC.

Project Management

MODHSS uses a formalized project information systems management methodology that establishes specific goals and plans and then determines the resources needed to bring a program into MOHSAIC. Land, Hoffman and their staff work with the program staff much like consultants work with clients. They provide estimates of cost and help develop the complete program plans. When undertaking the design and development of system module components, a carefully selected CHIME liaison is assigned to work directly with the program staff, bringing together both sides of the team.

CHIME had a huge turnover in technical staff during the first few years of the Center because the state’s salaries for IT staff were far below the national average and because of

the uncertainty of success in implementing MOHSAIC with the limited funding that was available. As a result of this staffing problem, MOHSAIC leadership has learned to seek flexible and creative ways to cultivate new staff with the right skill sets. For example, they developed a strategy to provide IT training to selected public health staff within the agency that had an interest and had demonstrated some ability in information technology. They trained program staff in technology, rather than hiring technical staff and teaching them public health skills. They found that having staff who understood the programs' needs greatly reduced communication barriers. Their knowledge of public health and their understanding of the users' needs created better and more user-friendly applications.

As another strategy to increase technical staff, MOHSAIC leadership hired outside contractors who were familiar with the MOHSAIC software. This initially was more costly, but the contractors worked closely with CHIME staff, and some eventually became state employees.

Much of MOHSAIC's success can be attributed to CHIME's customer-centric management approach that is directed to returning value to the customers (programs) they serve. Because Land is the director of the Vital Records Program, in addition to being director of CHIME, he has the opportunity to provide services to himself as a customer, and he is able to see how good (or bad) those services are as a "program person."

Land believes there is "no sense requiring something if I can't help them." He didn't expect all MODHSS programs to buy into the concept of a highly integrated information system such as MOHSAIC from the beginning. He has kept a long-term view to creating the integrated system, working with programs to assure linkage with MOHSAIC whenever possible and providing technical assistance to them. Gradually, over time fewer and fewer programs have chosen to develop their own systems. When a program's timeline is too short for a MOHSAIC response, CHIME staff consults with the program and look to a future time when they can bring the application into the fold. An example of this is the Newborn Metabolic Screening Program and Newborn Hearing Program, which had decided to use the Neometrics system for its lab data, test results, and case management. By modifying the birth data system, which is the hub for MOHSAIC, they were able to bring these data into MOHSAIC. In order to do this, they needed to convince the Newborn Metabolic Screening Program staff and then they had to convince the Newborn Hearing Program's Advisory Board.

Land believes in being humble. "Don't toot your horn and always admit your mistakes. This makes it easier for your customers to tell you that you have problems." He works to develop strong interpersonal relationships because it creates a comfort zone that allows for customer feedback. Strong relationships build trust and that trust comes from delivering on promises.

Stakeholder Involvement

The methodology (Information Engineering) used by MODHSS for the initial planning process formally involved high level internal stakeholders from the beginning. The process later involved program level staff and additional stakeholders representing local public health agencies in Missouri.

Informally, Land and Hoffman actively seek feedback from programs by walking around and talking with staff. They rely on their established web of interpersonal relationships and meet with the division and program managers regularly to keep apprised of their needs and concerns. Having a communication strategy is essential to keeping stakeholders involved in such a complex information systems implementation. They have used several communication approaches over time, including newsletters explaining MOHSAIC to the department, project management meetings, Friday Fax (originally, a fax to all county health departments and now sent by e-mail and renamed Friday Facts), large presentations, and an advisory group of information representatives.

Buy-in and involvement from external stakeholders is seen as a progressive process. The MOHSAIC strategy is to work with hospitals first and then reach out to the individual providers in the community. Program staff has a good partnership with the Missouri Hospital Association (MHA) and has been working closely with the newborn nursery and ICU staff from all of the hospitals. They have done one-day trainings to OB/Nursery and laboratory staff about MOHSAIC to

inform them about newborn hearing and metabolic screening information.

Physicians received information about MOHSAIC, newborn hearing, and metabolic screening through newsletters and professional organizations. Providers currently are able to access MOHSAIC through the web for immunization information. MODHSS is planning on expanding access to the private sector for metabolic screening, newborn hearing and lead result information within the next year and is currently reaching out to the provider community directly to seek their input.

Integration Strategy

MODHSS 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.

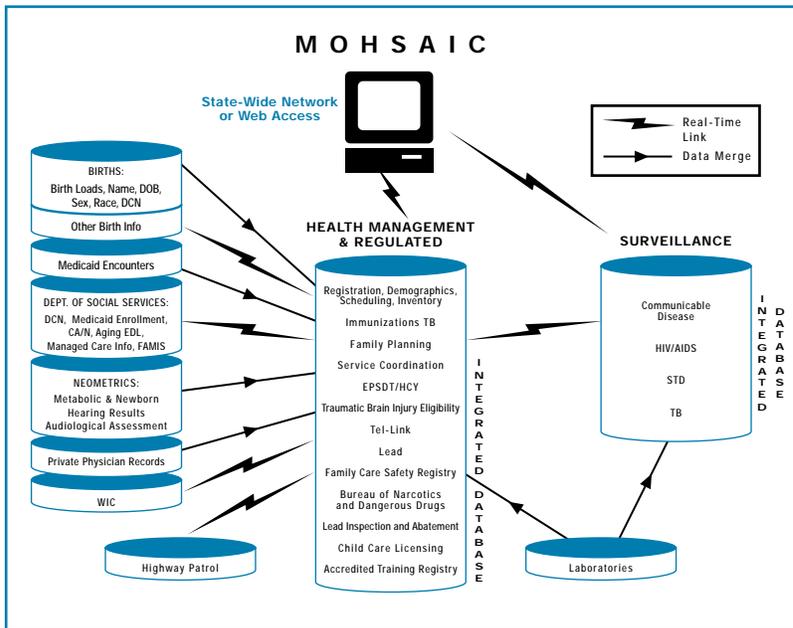
As part of the ISP development, both MODHSS and the local health agency teams identified requirements for the integrated system. These included:

- a set of standards would be used to capture all data;
- all data would be included in a single integrated system;
- one technical platform would be used;
- records would be client centered to allow a holistic view of client versus episodic or single service information;

- the system would support data sharing among public health agencies and staff;
- the system would support the capture of demographic and other client information one time to reduce the amount of redundant information that must be entered and stored; and
- the system would be designed for MODHSS and the local public health agencies that are independent of MODHSS (Land, et al, 2002, p. 620).

The ISP consisted of three architectures: information, business systems, and technical. The information architecture showed the relationship between the functions performed and the data. The business systems architecture detailed this relationship into business areas and the business systems from which information systems are developed. The technical architecture established the necessary hardware and software to support these systems. These architectures were broadly designed and formed the framework to guide the systems development. The ISP also provided the architectures for a statewide information network to link public and private healthcare providers electronically (Land, et al, 2002, p. 620).

FIGURE 2: Architectural Overview of Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC)



The plan also identified similar processes that occur with all types of clients, such as registration, scheduling, inventory, and program specific information. Development of these generic processes supports the grouping of similar programs by component and allows the integration of client data. It was determined that 80% of the functions performed by the department and local public health agencies was related to Clients and Services. A team of information system staff was initiated to support this “person” client, the Health Management component. The Health Management application formed the basic infrastructure to support the statewide immunization registry and will include all public health services, such as a web-based birth certificate, newborn metabolic screening, and hearing screening. A second team developed and implemented the surveillance component that supports the mandated reports of communicable diseases. A third team focused on supporting regulatory “clients,” programs that support the licensing and certification functions performed by the department.

MODHSS 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 programs. Concerns over privacy and keeping data confidential were less of an issue, especially since MOHSAIC began as an internal system. Putting all program systems into a single system, as long as access could be controlled, did not raise the same level of concern as one might see in other states.

Technically, MODHSS could not support the myriad of systems they had developed with their current technical staff. Creating one system allowed them to train their technical staff more easily and efficiently. Pulling the technical team into one centralized division also allowed greater technical support and created an organization that would be conducive to a single-system strategy.

Technical Support and Coordination

MODHSS believes that technical organization needs to be centralized within the organization to be successful. “There must be one network, one set of standards, one e-mail, etc., for an agency to be able to communicate and exchange data efficiently,” says Land. The creation of CHIME, which centralized all information technology staff and the high-level data analysis staff in one unit to serve all programs in MODHSS, was critical to the success of MOHSAIC.

CHIME has a depth of technical expertise that sets the standard for technology in MODHSS. The technical competency of the staff is very high. The Center has provided multiple training opportunities for staff,

which has allowed them to learn and stay with current with technology. Recently, however, they have had to deal with reduced training opportunities and stagnant salaries. This negative impact is, fortunately, offset by the supportive work environment MODHSS provides to staff.

CHIME management has learned the importance of supporting the maintenance of the MOHSAIC infrastructure. Emphasis on MOHSAIC has moved from development work to system maintenance and data management. It took a while to recognize the need for infrastructure support, as the focus had been more on development. The people in the “backroom” are easily overlooked. However, it eventually became apparent that if the staffing infrastructure wasn’t properly maintained, the whole system could halt. Land came to believe, “They’re the people that keep the engine for the big ship moving.” It is important to educate leadership about the need and cost of maintenance in technology systems at the beginning of a project.

Financial Support and Management

Although MODHSS was quick to accept the proposed ISP technical architecture, it was slow to implement the plan because of funding issues. To address this issue, the department agreed in 1994 to a network allocation scheme that would charge each network user an annual network fee. The total annual cost of the network, including network software, network hardware, network technicians, help desk staff and trainers, were divided by the total number of users to determine the annual

user fee. CHIME also gathered all Microsoft licenses that existed throughout the department and applied them to upgrades. The annual network fee has remained in the range of \$1800-\$2300 per user since the inception of the network (Land, et al, 2002, p. 622). These strategies, however, addressed only MODHSS local area network (LAN) and significant funding was needed for the other functions of MOHSAIC.

Funding for the installation of a wide area network (WAN) that connects remote department sites and local public health agencies was provided by the CDC's initial Information Network for Public Health Officials (INPHO 1) grant and a \$750,000 general revenue appropriation. To support the ongoing cost of the WAN, a WAN allocation scheme was developed that allocated the cost to the programs using the WAN (i.e., WIC, Vital Records, Immunization), based on the volume of transactions generated by their application. A CDC Health Alert Network (HAN) grant provided funds for MODHSS to increase functionality to the local public health agencies over the WAN.

Although finding funding for the network was challenging, the real challenge lay in funding the development of the integrated public health information system. 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, MOHSAIC is unique in that MODHSS' information management unit, CHIME, applied for and acquired the majority of the development funds rather than the programs

directly. It was the vision, the well-conceived plan, and the leadership continuity that allowed Land and his team to be thoughtful and aggressive about applying for these large grants. Those programs that saw this arrangement as an opportunity to obtain the system they needed but otherwise could not afford eagerly participated as partners with CHIME and have greatly benefited.

Early in the development of MOHSAIC, MODHSS negotiated an agreement with the state's Medicaid program. The agreement provided matching funds for development of components of MOHSAIC that directly benefited the Medicaid program. MODHSS was also able to acquire an on-going state general revenue appropriation for MOHSAIC development that was used for the Medicaid match. MODHSS then received a second INPHO grant that was used to develop additional components of MOHSAIC. Over the past 10 years, MOHSAIC has been developed and maintained using 12 federal and state funding sources totaling \$24 million. Federal funds were used to support 72% of the costs to develop MOHSAIC.

Policy Support

MODHSS does not have the legislative barriers to integration experienced by many other state health departments. For example, the Newborn Hearing Screening law indicates that the state can share data with a child's provider without informed consent. The current genetic screening legislation is older, however, and says that the state cannot share metabolic screening data with providers

without informed consent. Informed consent is now being collected at the time of the metabolic screen. The MCH program maintains these consent forms.

Leadership of MODHSS believes the department is ready for the impact of the Health Information Portability and Accountability Act (HIPAA), which can restrict sharing of health information, because they have chosen to use the national standards required by HIPAA whenever possible. They also have the advantage of not having a billing system as part of MOHSAIC, which exempts them from certain aspects of HIPAA. They have developed a HIPAA brochure to answer any questions providers might have around sharing information with MODHSS.

Evaluation

MODHSS uses data for evaluative purposes. They analyze and use data and regularly feed it back to the programs and local health agencies. For example, county-level immunization data is provided to the local health agencies to show them how well they are performing compared to the rest of the state in getting providers involved in submitting data. MODHSS also uses continuous quality improvement (CQI) to focus on process, such as looking at better access to services and better treatment in the medical home.

Lessons Learned

1. Data Are for Sharing.

The categorical manner in which state health department information systems have been developed historically has had considerable influence on current practices in health information access and sharing. Programs know there is added value in sharing data among programs, but to do so requires major re-engineering of information systems, their organizations, and the way program and IT staff do their jobs – changes that people and programs tend to resist.

In addition, there are other barriers to sharing health information: concerns that the funding that provided the data may not support sharing them; concerns that sharing data with another program may threaten a program's authority; and concerns that the wrong people may see the data or the data may be misused.

Health departments, however, are increasingly recognizing the value of sharing information not only among multiple programs, but also private sector providers, policymakers, 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." The Rhode Island view is that information is 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, policymakers – begin to realize the value that sharing information brings, their perspectives will shift.

2. 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. And in Rhode Island, communications skills are critical to the role of the provider relations coordinator, who actively and frequently sought feedback from the providers using the system.

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.

Who delivers that message also is important. A group of people is much more likely to “hear” a message when it is delivered by someone who shares their own beliefs and experiences. For example, in several states, champions for integration projects are physicians who can communicate effectively with providers. Similarly, IT staff relates best to other IT staff, and program staff to other program staff.

3. 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.”

Diffusion of Innovation in Health Care (May 2002). Ihealth Reports, Institute for the Future

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.

Within a health department that is integrating information systems, different roles (e.g., executive sponsor, manager, IT and program staff) will experience different kinds of change – operational, strategic, cultural, and even political change – each with its own set of challenges.

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.

The natural tendency of people is to hold on to the status quo, and the introduction of a new or changed information system can be threatening. 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.

4. Let Public Health Program Needs Drive Technology.

All too often, information systems are developed with the latest, most advanced technol-

ogy 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.

Because they involve more than one public health program, integrated information system initiatives are highly complex projects. When the information technology managers of these projects work collaboratively with public health program managers to guide or assist in the formulation of the rationale for the new integrated system (e.g., the business case), there is a logical linkage to program outcomes and service to the end users. But when these managers turn over their responsibility for goals, outcomes, and performance metrics of the new system to technology, the result is systems that users will not use and that fail to meet important program goals. Strong direction from the managers of integrated systems projects in the development of system specifications is essential to successful integration efforts.

5. Stay the Course.

The study of technology adoption has taught that not only is change hard (Lesson #3), 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 toward a comprehensive child health record that supports a range of program services for 10 years.

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*, noted, "Getting a new idea adopted, even when it has obvious advantages, is often very difficult."

Appendix A

PROJECT BRIEF

COLORADO

Project Name: Newborn Evaluation, Screening, and Tracking (NEST)

Organization Responsible: Colorado Department of Public Health and Environment (CDPHE)

Geographic Area Covered: State of Colorado

Annual Birth Cohort: 67,000

Scope of Project:

The universal newborn metabolic screening (NBMS) and newborn hearing screening (NBHS) clinical databases are to be interfaced with an existing electronic platform called the Integrated Registration and Information System (IRIS) that has a case management module for client information from the Early Periodic Screening, Diagnosis and Treatment program and the Health Care Program for Children with Special Needs (HCP). The system is also being designed to have the capacity to integrate with a web-based immunization registry that is under development in Colorado and other clinical and surveillance databases.

Detailed clinical databases have been designed for sickle cell disease, the inherited metabolic diseases screened for in Colorado (PKU, galactosemia, and biotinidase deficiency) and the newborn hearing screening data, which are initially populated with hospital data provided to Colorado's electronic birth certificate. Colorado also screens for cystic fibrosis. Processes that will bring that data into the central platform and allow it and other data-

bases to interface with IRIS are being designed.

Sources of Funding:

HRSA SPRANS grant

CDC Early Hearing Detection and Intervention (EHDI) grant

History:

Data integration will both create major efficiencies and allow extended follow-up and tracking of infants with diagnosed conditions secondary to screening processes to an extent not possible before. The idea was generated at a Maternal Child Health Bureau meeting on integrating newborn screening with the medical home concept and its application to children with special healthcare needs. When the CDC grant was announced, some formal planning for the concepts noted above had been done, and CDPHE applied for funding accordingly. The state of Colorado provides very little state monies for such projects or for public health infrastructure, so the opportunity to use federal funds to design and build such a system was very attractive.

Executive Leadership and Organizational Endorsement:

The executive director of CDPHE provided permission for grant application and has continued to do so in each grant year.

External Endorsement:

The University of Colorado Health Sciences Center is the project's primary clinical partner and source of external endorsement. The Health Sciences Center is benefiting from the

project by having electronic medical charts for patients for diseases identified by newborn metabolic screening.

Significant Challenges:

1. Having the proper technical computer programming skills at the project's disposal. It is difficult to hire people with the types of advanced skills needed in a state system that cannot meet the salary demands of people with such skills.
2. Identifying sources of funds for ongoing maintenance needs beyond grant funding. In the state's current economic climate, this has become more difficult.
3. Development of an understandable informed consent for families whose children's data would be shared with the state.

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PROJECT BRIEF

IOWA

Project Name: Implementation of the State Genetics Plan for Iowa

Organization Responsible: Iowa Department of Public Health (IDPH)

Geographic Area Covered: State of Iowa

Annual Birth Cohort: ~37,500

Scope of Project:

The project will improve linkages between genetic services and the existing systems of care for children with special health needs. It will unify the policy development and program coordination necessary to establish an integrated data repository for IDPH programs serving Iowa's children and their families.

The integrated information repository will be a paperless, Web-based vital records system for registration, certificate issuing, legal modifications, historical information and imaging incorporation that will link with other newborn screening and surveillance systems. Child health programs' access to Iowa Birth Defects Registry aggregate data will be improved, as well as a notification system providing information to parents about Iowa's early intervention and healthcare programs will be implemented. The project will also expand data repository capacity to provide access to WIC, childhood immunization programs, and local healthcare providers.

IDPH Bureau of Information Management is working towards an integrated information system by developing new databases with common data elements, similar layout presentations, standard documentation process, and common data repository for standard look-up tables. The current project development and design is consistent with

those of the department's child health and immunization databases.

Sources of Funding:

HRSA SPRANS grant

Vital Records fee funds

Other federal funds

History:

The current vital records system is antiquated, inefficient, and does not permit linkage with other newborn and child health systems. Senior management and program managers recognized the need for higher quality, timely data for decision-making and program planning, as well as the need to modernize the system, implement new NCHS standards and improve the accessibility, quality, and timeliness of birth certificate data. Previous attempts at modernization were unsuccessful, due to the inability to define and maintain focus on the complex intra-program business requirements. To ensure success of this project, a business plan was developed with collaboration and involvement of all program partners. A four-step methodology is being utilized to organize and complete the electronic birth certificate registration system. These steps are project definition and analysis, design, develop, and deploy. There is a partnership of the business and technical community across all steps. IDPH administrative rules that currently do not permit a centralized information system or the sharing of personally identifiable information between data processing systems of its program are being revised.

Executive Leadership and Organizational Endorsement:

IDPH recognizes and has been responsive to the need for program collaboration and unified data enhancement and integration initiatives. IDPH administration is committed and supportive of the Electronic Birth Certificate Registration Project. In October 2002, the administrators identified the project as the number one priority for the Bureau of Information Management. The Bureau of Information Management, the Bureau of Vital Records, and the Center for Genetics and the Bureau of Family Health Services within the Division of Community Health collaborate as the Electronic Birth Certificate Team. This collaborative practice is now the standard of operation for the development of data systems with IDPH.

External Endorsement:

The National Center for Health Statistics endorses the project.

Significant Challenges:

1. An Information Technology Department (ITD) has been created in Iowa state government to control IT activities across the enterprise, including the acquisition of hardware, software, and contractual resources. ITD has different priorities and a different operations method than IDPH (i.e., decisions based solely on technology), but ITD staff believes they have the ultimate decision-making authority. This relationship causes significant delays in project development.

2. Making sure that all our customers are not forgotten. This project involves multiple public health programs, federal standards and hospital personnel, and the needs of all stakeholders must be balanced.
3. The training of data collection staff at hospitals and making the transition from the existing system to the web-based system and a new data set will involve more than a hundred individuals with different learning styles and needs.
4. Keeping the big picture in mind without letting it blur the scope boundaries. The project must be broken down into manageable/measurable outcomes for reporting victories and assessing progress.

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PROJECT BRIEF

MICHIGAN

Project Name: MDCH Newborn Screening Program

Organization Responsible: Michigan Department of Community Health (MDCH)

Geographic Area Covered: State of Michigan

Annual Birth Cohort: 135,000

Scope of Project:

MDCH has chosen to approach the integration of newborn screening information as a component of a larger state project to build a data warehouse from which appropriate reports can be created.

Agreements have been signed to link Medicaid and Lead data, and a unique identifier will be created to link Vital Records, the Michigan Childhood Immunization Registry (MCIR), WIC, Newborn Metabolic Screening, Michigan's Early Hearing Detection and Intervention (MEHDI), Children with Special Health Care Needs (CSHCN), Pregnancy Risk Assessment and Monitoring (PRAMS), Aging, Provider Tracking System, Maternal and Infant Health Advocacy Services (MIHAS), Mental Health and Substance Abuse). Other state departments also load data, including the Family Independence Agency and Department of Education. The data warehouse will not replace the individual databases, but will load key data elements into a single confidential data warehouse accessible only by approved users.

Sources of Funding:

Medicaid

HRSA SPRANS grant

Family Independence Agency

History:

MDCH has recently undergone reorganization. Public Health,

Medicaid, and Mental Health are now located within the same Department, which has facilitated collaboration. There is a new priority for and dedication to MDCH data and the sharing of information to determine program direction. This commitment has underscored the decision to incorporate MDCH data into the state's data warehouse, initially funded by Medicaid, and focused on linking birth and death records with Medicaid data, the data warehouse project began by adding Medicaid claims data, then encounter data. The next steps will add MDCH data with a phased-in approach.

Executive Leadership and Organizational Endorsement:

Dr. David Johnson, deputy director of MDCH and chief medical executive, is the Executive Sponsor of the data warehouse project. The project also receives support from the relevant divisions and programs within MDCH, the MCH Data Workgroup, an administrative steering committee, the state's Genetics Advisory Committee, and affiliated workgroups and stakeholders.

External Endorsement:

The data warehouse project has strong sponsorship and commitment from Michigan's governor, the Department of Management and Budget, and state legislators.

Significant Challenges:

1. Confidentiality issues and restrictive legislation around data sharing between state departments and MCDH programs.

2. The need for ongoing technical support and system upgrades, and shortage of qualified technical staff.
3. Potential for loss of funding and support with new governor.

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PROJECT BRIEF

MISSOURI

Project Name: Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC)

Organization Responsible: Center for Health Information Management and Evaluation (CHIME), Missouri Department of Health and Senior Services (MODHSS)

Geographic Area Covered: State of Missouri

Annual Birth Cohort: ~75,000

Scope of Project:

MODHSS is developing an integrated public health information system to support all programs and systems that relate to surveillance and/or client services (both healthcare and regulated clients). Common functionality has been identified and grouped together. The application has been developed to support these common functions: registration, scheduling, inventory, disease reporting, etc. All data are being integrated in an Oracle database with each user having the ability to view data based on his/her function and security level. The data are organized around a specific client and his/her relationship to other providers and services.

To date, the following components have been implemented: Surveillance Area (Communicable and Vaccine Preventable Disease and other reportable conditions); Client Health Management Area (Client Registration; Scheduling and Household Management; Inventory Management; Immunizations; TB Skin Testing; Family Planning; Family Care Safety Registry); and Regulated Client Area (Regulated functions for Bureau of Narcotics and Dangerous Drugs; Lead Abatement Inspector Registration).

Components currently in a phase of analysis, design or development include: Surveillance Area (Reporting of STD/HIV cases; Elevated Blood Lead Levels; Electronic reporting of laboratory results); Client

Health Management Area (Service Coordination for Special Health Care Needs and other children; Inquiries and Complaint Tracking; Resource and Referral Services; Blood Lead Level Screenings; Newborn Metabolic and Hearing Screenings and Case Management; Newborn Home Visitation; WIC Registration); and Regulated Client Area (Child Care Licensing). In addition, MOHSAIC staff is completing the necessary infrastructure applications for quality assurance and security activities.

Sources of Funding:

Medicaid

Immunization Program

HAN

Assessment Initiative grant

NEDSS

HRSA SPRANS grant

MCH Block grant

Child Care and Development Block Grant

CDC Early Hearing Detection and Intervention (EHDI) grant

History:

A comprehensive assessment of MODHSS organizational strengths and weaknesses revealed weaknesses in overall strategic use of communications technology. It became clear to the department director that an integrated system was needed to reach Year 2000 goals. Other key factors were the cost and difficulty of maintaining over 60 program-spe-

cific computer systems serving individual health programs. The systems ran on a variety of platforms because there were no hardware or software standards.

In the mid-1990s, the National Immunization Survey ranked Missouri 49th in the nation for two-year-olds who were adequately immunized. Governor Mel Carnahan and legislators agreed to address this issue with a statewide immunization registry. General Revenue funds were appropriated to create the registry and provide access to it to all local public health agencies. The resulting infrastructure and Immunizations and TB skin testing formed the first components of the MOHSAIC integrated system. Subsequent programs have been built on this initial system.

Leadership and Organizational Endorsement:

Critical to the success of MOHSAIC is the support of the director of MODHSS. MOHSAIC was developed under the terms of three directors, each of whom had strong public health backgrounds, understood the importance of information, and showed strong leadership in ensuring that MODHSS operated as a single agency rather than an umbrella agency housing separate categorical programs. They emphasized inter-program cooperation and coordination.

External Endorsement:

MODHSS continues to work closely with the state Medicaid agency and managed care plans to provide HEDIS information.

Significant Challenges:

1. Cuts to State General Revenue dollars for MOHSAIC, which Medicaid will match, could severely limit funds available for maintaining and expanding the system.
2. Private sector provider immunization data are difficult to obtain.
3. USDA approval and funding must be obtained to integrate WIC into MOHSAIC.

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PROJECT BRIEF

OREGON

Project Name: FamilyNet Data System

Organization Responsible: Oregon Department of Human Services (DHS), Health Services, Office of Family Health

Geographic Area Covered: State of Oregon

Annual Birth Cohort: ~45,200

Scope of Project:

FamilyNet is a public sector health data system for local agency use that DHS is developing to integrate and coordinate health assessment and service information about children and families. FamilyNet will help public and private providers coordinate services to children and families and monitor risks, conditions, services and outcomes over time. It will support coordination of services and evaluation of the service delivery system while assuring individual and family confidentiality and data security. The hub is a Client Master that contains demographics and contact information (addresses, family links, telephone numbers, guardian's name). Modules for WIC and public sector immunizations are currently in testing. The ALERT immunization registry participates in FamilyNet by receiving immunization data from the public sector Immunization module. ALERT also has an integration project with WICImm to provide immunization status for WIC clients.

An Early Childhood Services module is in development to support local services to infants, young children, and their families. The first step is to link newborn metabolic and hearing screening data with birth certificate data and use the linked data to populate the database. The next step will be to assure identification, assessment, case

coordination, and referral services that encompass physical and mental health, substance use, and psychological risks to children and families. Future plans include linkage of FamilyNet with private sector immunizations from ALERT, if legislative changes allow linking of ALERT. Most immunizations in Oregon are given in the private sector. Linking ALERT data with other FamilyNet data would give public and private healthcare providers immunization status of their patients who are served by the early childhood system of services and give DHS aggregate, de-identified data for state-level assessment, policy development, and assurance.

Sources of Funding:

CDC Early Hearing Detection and Intervention (EHDI) grant

HRSA SPRANS grant

MCH Block grant

SSDI grant

History:

FamilyNet has been in development since the mid-1990s. In 2000, development of a family public health services module began. The Oregon Children's Plan (OCP) is a 2001 legislative mandate to provide voluntary screening for all pregnant women and new mothers for both medical and psychological risks; to coordinate screening assessment, triage, referral, and services for children and families in each county; and to assure that necessary services are available throughout the state to families who have agreed to participate. This legislation expands the data

system beyond the FamilyNet health services module. The rationale behind FamilyNet is to create a single, cumulative record for each client by tying together module level records. FamilyNet goals include: avoiding redundant data entry by collecting data shared among programs only once; providing timely access to data for both state and local health departments; increasing accountability for state and federal program conditions including program and fiscal assurances; and reducing fragmentation of data and healthcare services available to the public by providing a method to coordinate services among health and social service programs.

Executive Leadership and Organizational Endorsement:

The governor initiated the OCP and supports the development of FamilyNet. The executive sponsor for FamilyNet is Donalda Dodson, Oregon's Title V director and administrator of the Office of Family Health in DHS. Public sector sites have a strong voice with each other and with DHS through the Conference of Local Health Officials. Development partners will participate in system definition, design, testing and implementation. Partners in development of the Early Childhood Services Module include the Oregon Department of Education, the Healthy Start Program, the Oregon Commission on Children and Families, the Child Development and Rehabilitation Center at the Oregon Health Sciences University, and the Conference of Local Health Officials. Within Health Services there is a core team to steer and develop the Early Childhood Services Module of FamilyNet. This includes a project coordinator, project

manager, program technicians, research analyst, database analyst, and database developer.

External Endorsement:

The Oregon Early Childhood Services Module and ALERT registry are both supported by public-private partnerships. The EHDI Steering Committee and the Genetics Planning Steering Committee support and advise FamilyNet Early Childhood Services module development.

Significant Challenges:

1. Identify all existing data sources and potential linkages to create an integrated public health data system.
2. Work collaboratively with state agencies responsible for social, health, and educational services to link data from separate and disparate sources into an Early Childhood Services data system, while ensuring patient confidentiality that is often unique for each source/agency.
3. Focus on incremental progress and identify the local partners needed to develop and maintain an integrated public health data system. Maintain a focus on the ultimate goal: reduce service fragmentation in healthcare, social services, and education for the public.

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PROJECT BRIEF

RHODE ISLAND

Project Name: KIDSNET

Organization Responsible: Rhode Island Department of Health
(RIDOH)

Geographic Area Covered: State of Rhode Island

Annual Birth Cohort: ~ 12,500

Scope of Project:

KIDSNET is designed to integrate data from the following databases and/or programs: Universal Newborn Screening for developmental risk, Immunization, Lead, WIC, Newborn Screening (Heel-stick), Newborn Hearing Screening, Early Intervention, Home Visiting and Risk Response, and Vital Records.

Immunization, Home Visiting and Risk Response, and Universal Newborn Screening for developmental risk are integrated into a single database, KIDSNET. KIDSNET acts as a data warehouse by storing limited information from the Lead, WIC, Newborn Hearing Screening, Early Intervention, and Vital Records databases. Data from the Newborn Screening (Heel-stick) program is not yet integrated but will be data warehoused.

KIDSNET is currently integrating/consolidating the initial data collection process for Vital Records, Newborn Hearing Screening and Universal Newborn Screening for developmental risk through a new Vital Records data system. This will allow the three programs to utilize a single identifier that will minimize data matching and redundant data entry.

Sources of funding:

CDC 317 funds

MCH block grant

State appropriation

Medicaid Match

Vaccine Insurance Assessment
Data Utilization and Enhancement
HRSA SPRANS grant

History:

In the early 1990's, numerous federal and state initiatives led to the establishment of a universal infant/child health tracking system by RIDOH. Nine different infant/toddler programs with tracking and follow-up components were developing separate, automated response, follow-up, and home-visiting services through an integrated data management system.

Leadership and Organizational Endorsement:

KIDSNET receives executive support from the director of RIDOH, Patricia A. Nolan, MD, MPH. The medical and assistant medical directors of Family Health, William H. Hollinshead, MD, MPH, and Peter R. Simon, MD, MPH, provide policy guidance.

External Endorsement:

The Rhode Island Chapter of the American Academy of Pediatrics has supported KIDSNET since its inception. The Academy's newsletter has featured several articles on KIDSNET and encouraged KIDSNET participation in one of its CATCH projects. KIDSNET has also enjoyed the support of Rhode Island's Governor and First Lady through a Hallmark card sent with their signatures to all newborns in the state. Included with these cards is a message informing parents about KIDSNET. In addi-

tion, Senator Jack Reed has been a vocal supporter of KIDSNET and immunization registries and participated as a keynote speaker at the 2000 National Immunization Registry Conference.

Significant Challenges:

1. Integrating/consolidating the initial data collection process for Vital Records, Newborn Hearing Screening, and Universal Newborn Screening for developmental risk through a new Vital Records data system. This will allow the three programs to utilize a single identifier that will minimize data matching and redundant data entry.
2. Improving data quality. Assuring that all data are complete, accurate and timely, paying particular attention to assuring that data are always matched to the correct child.
3. Incorporating data from the Newborn Screening (Heel-stick) program into KIDSNET. This process has presented a number of challenges since the database from which KIDSNET will accept an extract is under separate management in another state.

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PROJECT BRIEF

UTAH

Project Name Child Health Advanced Records Management (CHARM)

Organization Responsible: Office of the Chief Information Systems Officer, Utah Department of Health (UDOH) Geographic Area Covered: State of Utah

Annual Birth Cohort: 47,000

Scope of Project:

CHARM is integrating the state's Birth Registration System, Newborn Hearing Screening, Newborn (heel-stick) Screening, Child Immunizations, Baby Watch and Early Intervention, Birth Defects Network, Children with Special Health Care Needs, WIC, Neonatal Follow-up Program, Medicaid, Child Health Evaluation and Care (Utah's version of Early Periodic Screening and Diagnosis and Treatment, or EPSDT), Child Health Insurance Program, Lead Screening, and DHS/DCFS SAFE - Health Services for Children in Foster Care. CHARM will use middleware to link the operational systems within the programs providing services to a centralized "Child Health Profile" database containing shared data elements.

The architecture for systematically integrating data is in design. However, some of those programs currently share data. Medicaid and child welfare programs are integrated by a common intake process that results in a common identifier. Integration activity over the past year has focused on the three programs that serve the universe of children born in Utah: Birth Registration, Newborn (Heel-Stick) Screening, and Newborn Hearing Screening. The use of a single identifying number for these programs has been demonstrated in a small number of Utah hospitals.

Sources of Funding:

HRSA SPRANS grant

CDC Early Hearing Detection and Intervention (EHDI)

SSDI grant

Utah Department of Health

History:

Several years ago, a now infamous photograph was circulated in meetings of state and local health officials. The picture showed four computers crowded onto a single desk in a rural health clinic, each of which had to be used sequentially to intake a client into the several categorical programs administered for the state by the local health department.

In 1997, UDOH adopted an Information Systems Vision. It called for data to be entered only once, to be complete, uniform and accurate, to be readily available to authorized users, and to meet the users' needs of availability and usefulness. In early 1999, executive leadership of UDOH made an investment in, and a long-term commitment to, systems integration by hiring a CIO with a clear department-wide integrative mission. That summer, UDOH formulated and adopted its first Department-wide business principle calling for a client-centric way of doing business. In fall 1999, a new integrative strategy was formulated during two joint program-IT retreats. This strategy is currently being pursued and CHARM is one of the five strategic initiatives adopted at that time.

Perceived benefits of having different programs working together include enhanced

client satisfaction, improved client services, improved multi-problem response, reduced cost, improved assessment, outcome measurement, information for private providers, and improved monitoring of program coverage.

Executive Leadership and Organizational Endorsement:

Data system integration is a "Level 4" issue in UDOH – one of less than a dozen issues given the highest priority rating, and the issue is closely monitored by the executive director. The deputy director of programs with clinical components has been an early and consistent advocate of integration. UDOH has also formed a CHARM Core Council comprising the managers of the programs targeted for integration. The council is chaired by Dr. George Delavan, director of the Division of Community and Family Health Services, co-chaired by Barry Nangle, director of Vital Records, and takes on such issues as prioritization of program integration, content of the shared data, access and use of the data, etc.

External Endorsement:

Representatives of the IHC, the largest provider of healthcare in Utah, support the ideas and directions of CHARM. The birth-record-number-dissemination pilot recently completed has also been well received in the pilot hospitals. As the design of the CHARM architecture is completed, various groups will be targeted to garner support. One initial target is the USIIS (Utah's immunization registry) Oversight Committee, public/private partners who support USIIS and are instrumental in its success.

Significant Challenges:

1. Funding is, at this point, the most significant challenge.
2. Striking the right balance between safeguarding confidential information and allowing access to it across traditional program and agency boundaries.
3. Building the right partnerships to support the CHARM initiative, short-term and long-term.

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Appendix B

CHARM Stakeholders

A stakeholder is defined as anyone who can impact the success of the CHARM initiative or anyone impacted by the initiative. Stakeholders are identified so that we can take action to assure appropriate involvement from each of them.

- UDOH Executive Leadership
- UDOH Program Managers and Staff involved in Child Health Services
- Local Health Department (LHD) Program Staff involved in Child Health
- Private Providers involved in Child Health
- Parents/Families
- Community-oriented organizations and partners (e.g. IHC, USU)
- Programs tied to child health preventive services – Epidemiology & Surveillance (NEDSS)
- UDOH Data Warehouse project
- Other state agencies:
 - Department of Human Services
 - State Office of Education
 - Department of Administrative Services (state Information Technology Services – ITS)
- Other states (regional efforts)
- Grantors and other funding sources
 - CDC
 - HRSA
 - CMS
 - AKC Connections
 - USIIS Oversight Committee
- Governor, Legislators, state CIO

(Utah Data Integration Plan, 2002, p38).

Appendix C

Genetics and Health Information Technology Resources

Non-profit Organizations

The American Academy of Pediatrics

www.aap.org

The American Academy of Pediatrics (AAP) is a non-profit organization devoted to the medical research and healthcare of persons ranging from infants to young adults. Relevant activities include a genetics compendium of resources such as policy statements, principles and guidelines for early hearing detection and intervention programs, and web links to other genetic organizations. Research findings on genetics can also be found on the website.

Association of State and Territorial Health Officials

<http://www.astho.org>

The Association of State and Territorial Health Officials (ASTHO) is the national non-profit organization in support of state and territorial public health agencies in the U.S. and U.S. Territories. ASTHO members concentrate on public health policy and state-based public health programs for topics such as healthcare access, environmental health, and informatics. The ASTHO Genetics program promotes collaboration between public health policymakers and policymaking organizations, and helps states with integrating genetics into the public health infrastructure. Specific activities include policy forums, a genetics advisory committee, and a genomics toolkit geared towards integrating genomics into public health practices.

Institute for Child Health Policy

<http://www.ichp.edu>

The Institute for Child Health Policy (ICHP) focuses on issues of access, utilization, cost, quality and family involvement in both policy and program development and health services research. They developed a learner-centered interactive CD-ROM called, "Genetics and Your Practice." It is self-paced, multimedia tool designed to help users further their understanding of a wide range of genetic issues. Some projects of ICHP are The Institute

for Leaders in State Title V CSHCN Programs, MCH Interactive Insights, MCN NetLink Plus, and Strategies for Identifying Children with Special Health Care Needs.

Marion Downs National Center

<http://www.colorado.edu/slhs/mdnc/>

The Marion Downs National Center for Infant Hearing (MDNC) is dedicated to pursuing the mission begun by Dr. Downs more than 30 years ago. Early identification and intervention of hearing loss is a basic human right that should be available to all infants who are deaf or hard of hearing.

National Association of County and City Health Officials

<http://www.naccho.org>

The National Association of County and City Health Officials (NACCHO) is a national non-profit association representing local public health agencies at the city, county, metro, district and tribal levels. NACCHO supports agencies in areas of education, research, collaborations between state and local public health agencies, and provides technical aid. NACCHO's Maternal and Child Health (MCH) Project focuses on the health of women, children, and families. NACCHO serves as an information resource, sponsors workshops on MCH issues, and assists MCH leaders and organizations to successfully implement MCH programs.

National Center for Hearing Assessment and Management

<http://www.infanthearing.org/index.html>

The mission of the National Center for Hearing Assessment and Management (NCHAM) at Utah State University is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

National Initiative for Children's Healthcare Quality

<http://www.nichq.org/>

The National Initiative for Children's Healthcare Quality (NICHQ) seeks to improve the quality of care for children and adolescents. Their mission is to eliminate the gap between what is and what could be in healthcare for all children. NICHQ brings together pediatric primary care practice teams to work together for 9 to 12 months to achieve improvements in health outcomes for children. Current core content expertise includes asthma, pre-

ventative services, attention deficit/hyperactivity disorder (ADHD), foster care, and children with special healthcare needs.

National Society of Genetic Counselors

<http://www.nsgc.org>

The National Society of Genetic Counselors (NSGC) promotes the professional interests of genetic counselors and provides a network for professional communications. Local and national continuing education opportunities and the discussion of issues relevant to human genetics and the genetic counseling profession are an integral part of belonging to NSGC. Their website contains information for consumers about genetic counseling and how to find a genetic counselor. It also contains career information and resources for media.

Parent Resources

Family Village

<http://www.familyvillage.wisc.edu/index.htmlx>

Family Village is a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support. The site includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and more.

Family Voices

<http://www.familyvoices.org>

Family Voices is a national organization representing children with special health care needs (CSHCN). Relevant services and resources include the Bright Futures for Families, a survey of state MCH and CSHCN programs, information to help families deal with health insurers, and a workbook to help families participate with their state Title V grant developments. There is a link to Family Voices groups by each state, and some, if not all, are directly involved in genetics. Oregon's Family Voices chapter, for instance, is working closely with their Title V program on genetics planning.

The Genetic Alliance

<http://www.geneticalliance.org>

The Genetic Alliance (formerly the Alliance for Genetic Support Groups) is an international organization of families, professionals and genetic support organizations that works to improve the quality of life for individuals dealing with a genetic condition. Their site offers disease specific information and resources (including support group information) as well as a "helpline" that provides direct contact to a genetic counselor for more information or to discuss questions and concerns.

Institute for Family Centered Care

<http://www.familycenteredcare.org/>

The Institute for Family Centered Care is a non-profit organization that provides essential leadership to advance the understanding and practice of family-centered care. The Institute serves as a central resource for both family members and members of the healthcare field. This site shares information, facilitates problem solving and promotes dialogue among individuals and organizations working toward family-centered care. Provides leadership and resources to advance the understanding and practice of family-centered care. Leadership training and resources include information on developing and sustaining family advisory councils, involving families as consultants, and encouraging families as active collaborators in their healthcare of their child.

March of Dimes

<http://www.modimes.org>

March of Dimes (MOD) is a non-profit foundation dedicated to the health of babies and promoting interventions that target infant mortality and prevention of birth defects. MOD offers genetics education for healthcare workers to help integrate genetics into their patient services as well as information on birth defects and genetics for the general public. The information resources for the general public include biology of genetics, how genetic counselors can help during pregnancy, contact information and web links to other genetic organizations or resources, and information for specific birth defects and genetic conditions.

The National Organization for Rare Disorders

<http://www.rarediseases.org/>

The National Organization for Rare Disorders (NORD) is a unique non-profit federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Their website is devoted to helping people with rare diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Government Organizations

Centers for Disease Control and Prevention

<http://www.cdc.gov>

The Centers for Disease Control and Prevention (CDC) is the principal federal agency responsible for ensuring public health and safety. Focuses include research as well as application of findings towards interventions such as educational programs and disease prevention and control.

CDC Early Hearing and Detection and Intervention Program

<http://www.cdc.gov/ncbddd/ehdi/>

The CDC EHDI is part of a national effort to promote the early detection of hearing loss, the tracking of infants and children who are deaf or hard of hearing, and the initiation of effective intervention systems. EHDI programs are initiated at the state level with collaboration and support from federal, state and private organizations.

CDC National Center on Birth Defects and Developmental Disabilities

<http://www.cdc.gov/ncbddd/>

The CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD) promotes the health and the potential for a full, productive life for babies, children, and adults. NCBDDD work includes identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities.

CDC National Center for Health Statistics

<http://www.cdc.gov/nchs/>

The National Center for Health Statistics (NCHS) serves as the nation's principal health statistics agency. NCHS compiles statistical information to guide actions and policies to improve the health of people. Data is collected from birth and death records, medical records, interview surveys, and through direct physical exams and laboratory testing. Other resources on their website include an overview of their major data collection activities and findings, web links to additional health information sources, and the opportunity to electronically contact NCHS with specific questions.

CDC National Immunization Program

<http://www.cdc.gov/nip/>

The National Immunization Program (NIP) provides consultation, training, statistical, promotional, educational, epidemiological, and technical services to assist health departments in planning, developing, and implementing immunization programs. NIP assists health departments in developing vaccine information management systems to facilitate processes such as identifying children who need vaccinations, ensuring that all children are immunized at the appropriate age, and assessing vaccination levels in state and local areas. NIP also supervises state and local assignees working on immunization activities.

CDC Office of Genomics and Disease Prevention

<http://www.cdc.gov/genomics/default.htm>

CDC's Office of Genomics and Disease Prevention (OGDP) focuses on the human genome project and integrating research findings into public health programs and policy. Activities of OGDP include development of a model system for collecting, analyzing and disseminating information on genetic tests, prevention research using genetic information to prevent diseases and improve health, and the Human Genome Epidemiology Network, which includes a literature database that can be accessed at <http://www.cdc.gov/genomics/hugenet/default.htm>

Health Resources and Services Administration

www.hrsa.gov

The Health Resources and Services Administration's (HRSA) mission is to improve and expand access to quality healthcare for all. This is done through the elimination of health disparities and barriers to care, assuring

quality of care, and improving public health and healthcare systems. HRSA Preview provides comprehensive information on Grant Funding Opportunities. (Go to Resources, Grants, to access HRSA Preview)

HRSA Information Center

<http://www.ask.hrsa.gov/index.cfm> or 1-888-Ask HRSA.

Publications, resources, and referrals on healthcare services for low-income, uninsured individuals and those with special healthcare needs. It also contains the most recent list of state Maternal and Child Health directors and Children with Special Health Needs directors (some states list genetics contacts).

HRSA Maternal Child Health Bureau

<http://www.mchb.hrsa.gov>

The MCHB mission is to provide national leadership and to work in partnership with states, communities, public-private partners, and families to strengthen the maternal and child health (MCH) infrastructure, assure the availability and use of medical homes, and build knowledge and human resources in order to assure continued improvement in the health, safety, and well-being of the maternal and child health population. The MCH population includes all America's pregnant women, infants, children, adolescents, and their families—including women of reproductive age, fathers, and children with special healthcare needs.

HRSA, Maternal Child Health Bureau, Universal Hearing Screening Program

<http://mchb.hrsa.gov/programs/genetics/hearingscreen.htm>

The HRSA Early Hearing Detection and Intervention (EHDI) program, popularly known as the Universal Newborn Hearing Screening (UNHS), program plays an important role in assisting states develop critical newborn hearing screening, diagnosis, and intervention programs, linking those programs to the baby's medical home, and providing appropriate support for families.

HRSA Maternal Child Bureau, Genetic Services Branch

<http://www.mchb.hrsa.gov>

Background on Mission, History, Initiatives, and links to related agencies and organizations from the Genetic Services Branch (GSB) of the Maternal and Child Health Bureau. From this website, publications and updates

about newborn screening programs, standards, emerging genetic information, and other resources can be found.

National Human Genome Research Institute

<http://www.genome.gov>

The Human Genome Project for the National Institutes of Health (NIH) conducts research to support genomic science worldwide. This international initiative maps and sequences the genes in the human body. Their website contains information on the Human Genome Project, the Ethical, Legal, and Social Implications (ELSI) of the Human Genome Project, and resources on policy, research, grants, media, and more.

Title V: Snapshot

www.mchb.hrsa.gov

(Go to Publications, Title V: Snapshot of Maternal and Child Health 2000)

The Snapshot provides the most comprehensive picture to date of how the Title V Federal-State Partnership works and what is happening in each of the 59 States and jurisdictions. The Snapshot includes Title V Maternal and Child Health Services Block Grant to States program information, a listing of the Special Projects of Regional and National Significance (SPRANS) and other federal MCH grants to each state and jurisdiction.

WIC

<http://www.fns.usda.gov/wic/>

Food, nutrition counseling, and access to health services are provided to low-income women, infants, and children under the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). WIC provides Federal grants to States for supplemental foods, healthcare referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children who are found to be at nutritional risk.

Technical Resources

All Kids Count

<http://www.allkidscount.org/>

All Kids Count is a National Technical Assistance Center funded by The Robert Wood Johnson Foundation to foster development of health information systems that ensure timely delivery of integrated healthcare services and follow-up for children. Integrated child health information systems are systems that consolidate data about the multiple healthcare services a child receives into information useful to the child's medical home provider and to public health authorities.

Integrated Health Information Systems Investment Analysis Guide

www.hrsa.gov/investment.htm

The Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO), the Centers for Disease Control and Prevention (CDC), and the Health Resource and Services Administration (HRSA), endorse the general goal of integrated health information systems and the use of federal categorical grant funds to assist in achieving that end. This document was created to facilitate states' planning and development of integrated health information systems and to foster CDC and HRSA provision of technical assistance and advice, communication among the various programs about state efforts, and coordination as a partner in encouraging and fostering better use of public health data.

National Association of Health Data Organizations (NAHDO)

<http://www.nahdo.org/hidsc/index.htm>

The National Association of Health Data Organizations (NAHDO) is a non-profit membership organization dedicated to strengthening the nation's health information system. NAHDO serves as a broker of expertise for the development and enhancement of statewide and national health information systems. NAHDO brings together a network of state, federal, and private sector technical and policy leaders and consultants to expand health systems development and shape responsible health information policies.

National Newborn Screening and Genetics Resource Center

<http://genes-r-us.uthscsa.edu>

A comprehensive website with information, resources and links in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers and government officials. The Center is a cooperative agreement between the Maternal and Child Health Bureau, Genetic Services Branch, HRSA, and the University of Texas Health Science Center at San Antonio, Department of Pediatrics. The mission of the NNSGRC is to provide a forum for interaction between consumers, healthcare professionals, researchers, organizations, and policy makers in refining and developing public health newborn screening and genetics.

Public Health Informatics Institute

<http://www.phii.org>

The Public Health Informatics Institute (the Institute) is a new, non-profit entity funded by the Robert Wood Johnson Foundation to advance state and local public health agencies' capacity to effectively use information tools to respond to bioterrorism and other public health threats. The Institute fosters collaboration among public health agencies in the conception, design, acquisition, and deployment of software tools. The goal is to eliminate redundant efforts, speed up development process, and reduce costs.

Human Genetics

<http://www.genetics.ucla.edu/home/link.htm>

The UCLA Department of Human Genetics in the School of Medicine maintains a list of organizations, universities, and governments working on describing the functional and complex interactions of multiple genes. The list emphasizes core laboratories specializing in sequencing, genotyping, bioinformatics, and other genome analyses.

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All Kids Count is a National Technical Assistance Center
supported by The Robert Wood Johnson Foundation