

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 screen 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 or CHARM, the initiative that would 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 the UDOH does business. In mid-1999, UDOH adopted a guiding business principle of “customer centrality.” 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 Record 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

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 managed and 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 integra-

tion 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:

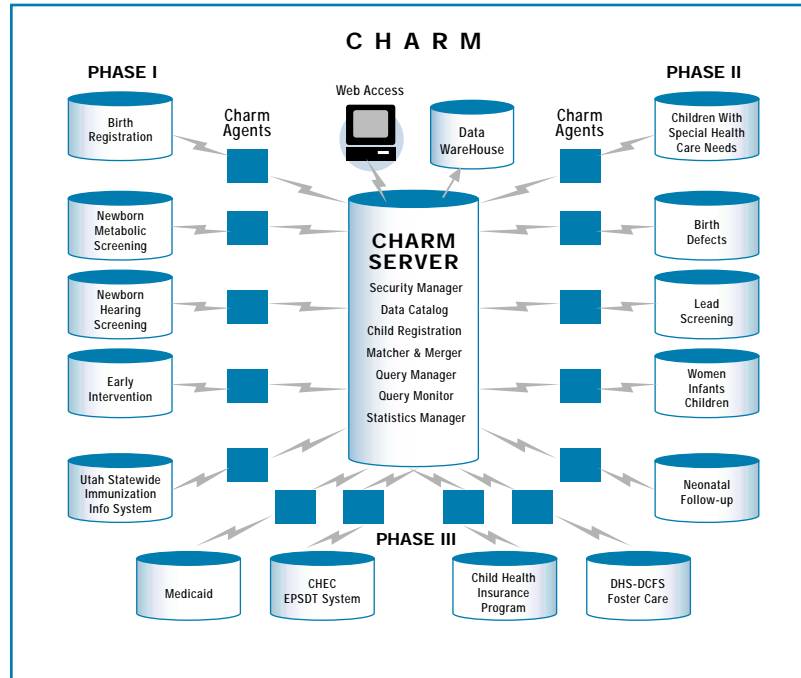
- UDOH will demonstrate the viability of the approach to potential stakeholder groups through multiple prototypes. This allows feedback and a chance to incorporate feedback during development, rather than after the fact;
- it allows programs to be added easily, at the pace of the program, while allowing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

ment. 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 inte-

grated 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.

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.? What local, state or national public health initiatives address this indicator?

Because of its public nature, IBIS-PH chal-

lenges 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.

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 meet-

ings. It is in these meetings that Land has been kept informed of new projects and upcoming 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 system. 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

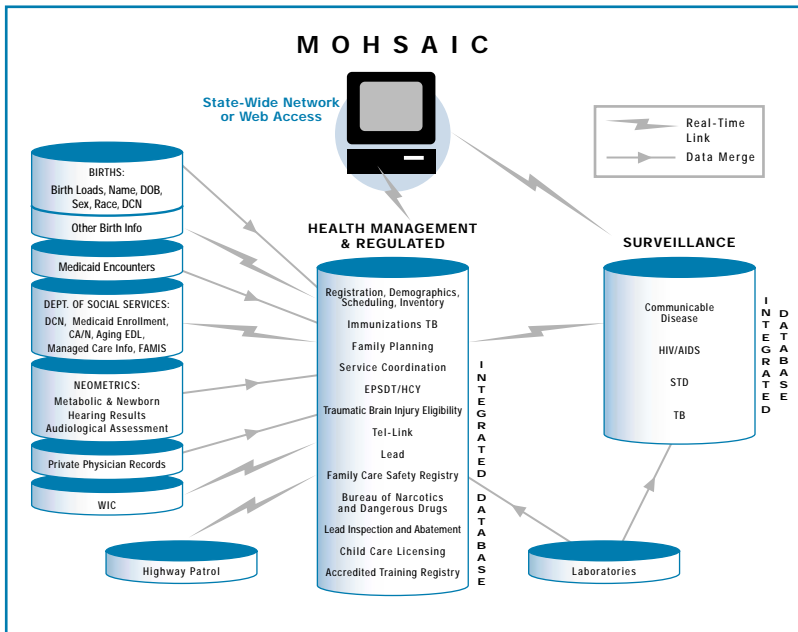
MODHSS was the first state health department to conceive of one totally integrated system and the strategy that was developed for the MOHSAIC project has been well documented.

- As part of the process when developing the ISP, both MODHSS and the local health agency teams identified a number of 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 the area that supported 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 with-

out 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.