

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

A Sourcebook for Planning and Development

Prepared by  
the Center for Innovation  
in Health Information Systems



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**Sponsor:**

**Genetic Services Branch**

**Division of Services for Children with Special Needs**

**Maternal and Child Health Bureau**

**Health Resources and Services Administration**

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# 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

|         |  |
|---------|--|
| 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  |

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**“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, the Genetic Services Branch, Maternal and Child Health Bureau (GSB/MCHB) of HRSA contracted with the Center for Innovation in Health Information Systems (Center for Innovation) 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.

The Center for Innovation 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.

The Center for Innovation 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.
- **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.