

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 coordina-

tion, 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 sys-

tem 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 coordina-

tor, 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 addition, 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 meas-

urement, 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.

Center for Innovation in Health Information Systems

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

The Center for Innovation in Health Information Systems (Center for Innovation) is committed to improving the health and well-being of individuals and communities, especially children, through strategic application and management of health information and its underlying systems and technologies. All Kids Count is a program the Center for Innovation.

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.