

CONNECTIONS™

Where public health meets,
exchanges new ideas and
solves public health problems.

Integrated Child Health Information Systems Community of Practice

FINAL CONNECTIONS MEETING SLATED FOR SPRING 2004

The final Connections meeting will be held in Atlanta in early spring 2004, concluding the three-year All Kids Count program to foster integration of child health information systems. The meeting will bring together representatives of the 11 Connections member agencies to share lessons learned from the community of practice and their individual projects and to celebrate the progress they have made.

SHARED VISION FOR CHILD HEALTH UNDERPINS INTEGRATED HEALTH DATA STRATEGY IN UTAH

The leadership of the Utah Department of Health (UDOH), its child health programs, and numerous other stakeholders share a vision for an integrated child health profile that reflects both ethical and organizational imperatives.

From the organizational, or business, perspective, an integrated child health profile holds significant benefits for all its stakeholders, including improved quality and efficiency of care, but most importantly, better health outcomes," said Scott Williams, MD, formerly Deputy Director of UDOH, and since October 2003, Executive Director. "That makes it unquestionably the right thing to do for kids." It is that shared vision that has resulted in the swift progress of Utah's integrated child health information.

The need for integration of all newborn public health data was recognized in the 1990s, when it became clear that "children were at risk of dying because information was not passed along," said

Dr. Williams. A health data integration initiative became one of less than a dozen "priority" issues for UDOH. CHARM (Child Health Advanced Record Management) was formalized in 1999 with the development of a charter.

“Programs asked that we make it easy for them to play.”

UDOH brought on a dedicated chief information officer, Rhoda Nicholas, to lead CHARM. Reporting to the UDOH Executive Director, 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."

From the start, the programs at the core of CHARM — newborn metabolic screening, newborn hearing, immunization, early intervention, birth defects and vital records — comprised the governance body of the initiative. A high degree of structure and accountability characterize the management approach, with CHARM organized into three phases, each with interrelated projects and designated leaders.

continued on page 2



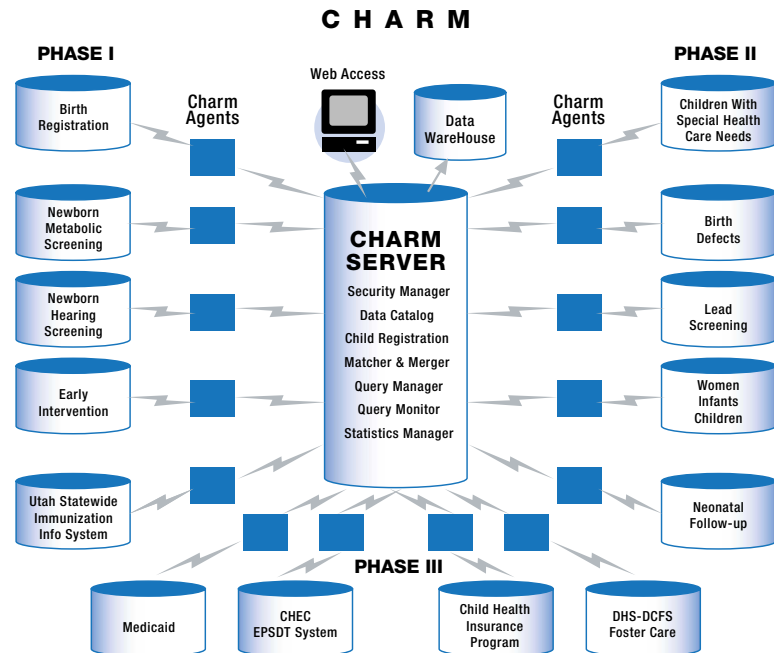
ALL KIDS COUNT RECOGNIZES UTAH GOVERNOR, FIRST LADY

All Kids Count presented Utah Governor Michael Leavitt and First Lady Jacalyn Leavitt with an award for their commitment to improving the health of Utah's children through the application of information technology at the spring Connections meeting in Salt Lake City. For more than a decade, the Leavitts helped to increase child immunization levels by supporting the Utah Statewide Immunization Information System. Their support for technology in government services also provided support for Utah's integrated approach to improving child health.

Note: Michael Leavitt became administrator of the U.S. Environmental Protection Agency in November 2003.

Shared Vision – continued from page 1

Significant stakeholder involvement contributes to CHARM's success. An extensive needs assessment process and ongoing involvement with programs, local health departments, private providers, parents/families, other state agencies, community organizations, grantors and other funding sources, ensures their views are reflected in the system and that it meets their needs.



CHARM's developers chose an architecture and phased incremental approach that enables programs to "join" CHARM easily, while retaining autonomy. Once a program chooses to participate, its data are integrated with other programs' data through a central CHARM server. A program continues to use its own identifiers, identifies the data and services it needs, as well as which data it will offer, and sets up a "broker" to handle its activity with other programs through the integration infrastructure. Core data, elements that identify and define the child, are centrally managed and coordinated by CHARM. Specialized data elements are collected and stored only by a given program/system and shared with other programs through CHARM.

The short-term goal for CHARM is to link the birth cohort records (newborn hearing and metabolic screening and birth registration) for all children in Utah. The long-term goal is to integrate the birth cohort systems with immunizations and early intervention, and then expand to other child health related databases.

The UDOH hosted the Connections community of practice on integrated child health information systems in Salt Lake City, UT, in March 2003, for a close-up look at CHARM.

NEW RESOURCES ON INFORMATION SYSTEMS INTEGRATION

Two new resources are available from All Kids Count, Public Health Informatics Institute, to assist public health agencies that are planning or implementing projects to integrate child health information systems.

Integration of Newborn Screening and Genetic Services Systems with Other Maternal Child Health Systems: A Sourcebook for Planning and Development (Integration Sourcebook) was developed by All Kids Count in partnership with the Genetic Services Branch, Maternal and Child Health Bureau, Health Resources and Services Administration.

The **Integration Sourcebook** identifies nine crosscutting organizational elements essential to integrating child health information systems, but also applicable to any information systems project, regardless of its focus or scope. The **Integration Sourcebook** also describes best practices for each element, as demonstrated by health information systems integration projects in Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah. Detailed case studies of the integration projects in Missouri and Utah provide a closer look at the key elements as in those states. The **Integration Sourcebook** also includes high-level lessons learned that are relevant to many different roles in planning and implementing a public health information systems project, including program managers, chief information officers, and public health executives.

Linking Newborn Metabolic Screening Information Systems with Other Early Childhood Healthcare Information Systems: A Project Planning and Assessment Tool, is a companion to the **Integration Sourcebook**. The Planning and Assessment Tool assists public health teams in designing their child health information systems integration projects from planning through early implementation. Its workbook format helps project teams and key stakeholders to understand:

- best practices associated with information systems projects.
- organizational readiness for the information systems project.
- additional strategies required to support successful project planning and implementation.
- accomplishments and action steps.

Ideally, the *Tool* helps project teams assess their organizational readiness and capacity to undertake and sustain a project as complex as integrating public health information systems.

The *Sourcebook* and *Tool* can be downloaded from www.allkidscount.org and www.phii.org.



ACTION AGENDA FOR CHILD HEALTH INFORMATION SYSTEMS

Stakeholders of child health information systems will attend a conference organized by All Kids Count in December to develop an action agenda for development of information systems that meet medical care and public health needs of children. The action agenda will be developed in light of national information infrastructure initiatives and will enlist stakeholders in communicating, supporting, and implementing the recommendations.

Co-sponsors of the conference include: American Immunization Registry Association, Alliance of Community Health Plans, Association for Health Center Affiliated Health Plans, Agency for Health Care Research and Quality, American Academy of Pediatrics, Association of Maternal and Child Health Programs, Association of State and Territorial Health Officials, Centers for Disease Control and Prevention, Commonwealth Fund, Family Voices, Health Resources and Services Administration, March of Dimes, National Association of County and City Health Officials, National Association of School Nurses, National Health Information Infrastructure, National Initiative on Children's Healthcare Quality, USDA-Food and Nutrition Services.

A post-conference report will be disseminated broadly by All Kids Count. Look for more information early next year.

The Integrated Child Health Information Systems community of practice is a program of All Kids Count, a National Technical Assistance Center supported by The Robert Wood Johnson Foundation to foster development of integrated child health information systems.

All Kids Count is a program of the Public Health Informatics Institute, which is dedicated to advancing the ability of public health practitioners to strategically apply and manage health information systems that can improve public health capacity and effectiveness, and ultimately, improve the public's health.

The Public Health Informatics Institute is a component of The Task Force for Child Survival and Development.

Alan R. Hinman, *Principal Investigator*
David A. Ross, *Director*
Kristin N. Saarlus, *Deputy Director*

For information, call 404.687.5611

www.phii.org
www.allkidscount.org

All Kids Count



**The Task Force for
Child Survival and Development**

750 Commerce Drive, Suite 400
Decatur, GA 30030

Address correction requested

CLICK

The Sound Of CONNECTIONS

COLLABORATIONS CLARIFY PROBLEMS, FIND SOLUTIONS

Recognizing the power of collaboration, three **Connections** workgroups have been working to clarify issues or find solutions to problems that are shared by a large number of systems integration projects. **Connections** members identified these problems and issues at the September 2002 meeting held in Rhode Island, and several projects applied for funding from All Kids Count to support their work.

One workgroup is collaborating to document software applications used by **Connections** projects to de-duplicate, merge, or match records. They will evaluate a sample of those products at two levels: against technical documentation provided by the vendor and against CDC test data.

Appropriate use of data is the focus of a second workgroup. Workgroup participants are

categorizing and describing public health data source types, identifying appropriate and inappropriate use of data, and identifying emerging issues associated with data use within integrated public health information systems.

A third workgroup is gathering requirements and specifications and then developing a PDA application for viewing and collecting data from public health information systems. The application will be broadly usable, but for the purposes of this project, will be modified to meet the requirements of three of the workgroup participants.

Solutions and findings from the workgroups will be shared with all **Connections** members and the broader public health community by summer 2004.