

CONNECTIONS™

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

Integrated Child Health Information Systems Community of Practice

UP CLOSE IN RHODE ISLAND

The Connections community of practice on integrated child health information systems met in Providence, Rhode Island, in October for a close-up look at Rhode Island's KIDSNET. The meeting was highlighted by panel discussions of internal and external stakeholders.

The Utah Department of Health will host the next Connections site visit, March 24-27. Highlights will include an award from All Kids Count to Utah Governor Mike Leavitt and First Lady Jackie Leavitt for their dedication to improving the health of children through application of information technology, and a demonstration of the Utah integration project, Child Health Advanced Records Management (CHARM).

FOR RHODE ISLAND'S KIDSNET, STAKEHOLDERS COME FIRST

The developers of KIDSNET, Rhode Island's integrated child health information system, have had a vision since 1992: a computerized public health information management and follow-up system that would track children's preventive health services, link primary care providers to the health department, promote sharing of information between providers, and promote comprehensive contacts with family.

Thanks to the leadership of the Rhode Island Department of Health (RIDOH) and a state-level policy supporting integrated child services, KIDSNET is realizing the vision. But just as important in attaining that vision is the support of KIDSNET stakeholders, both internal and external. Without it, KIDSNET understands, the vision will remain just that.

KIDSNET, which is part of the Division of Family Health, integrates information about Immunizations, Newborn Developmental Risk, Metabolic Screening, Newborn Hearing Assessment, Childhood Lead Poisoning, Vital Records, WIC,

Early Intervention, and Home Visiting. Because all children's health services are provided in the private sector, KIDSNET relies on 150 provider sites in Rhode Island to submit immunization information. In return, the system generates well child reminders and recall letters for lead screening to families, feedback reports for providers on lead screening and immunizations, and information for the home visiting program.

Current users of the system's information include health department staff, health care providers, Head Start agencies, and home visiting agencies. Access to information has been requested by school nurses, managed care organizations, audiologists, and community-based organizations.

Recognizing that the ultimate goal of KIDSNET is to promote sharing of health information among all the stakeholders in KIDSNET (RIDOH programs, providers, and families), KIDSNET has focused on improving communication with stakeholder groups. A provider recruitment and retention effort, guided by ongoing feedback from providers and practice management staff, has achieved significant results. In 2000, 43% of children with immunizations were being tracked by KIDSNET and 25% of practice sites

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WHAT IS STAKEHOLDER COMMUNICATION?

Frequent and quality communication with stakeholders and stakeholder involvement in the integration project contribute to its credibility and effectiveness. Stakeholder communication and involvement can influence the perception, reception, and ultimately, the success, of the project.

From the Integration Sourcebook, prepared by The Center for Innovation in Health Information Systems for the Genetics Services Branch, Maternal and Child Health Bureau, Health Resources and Services Administration.

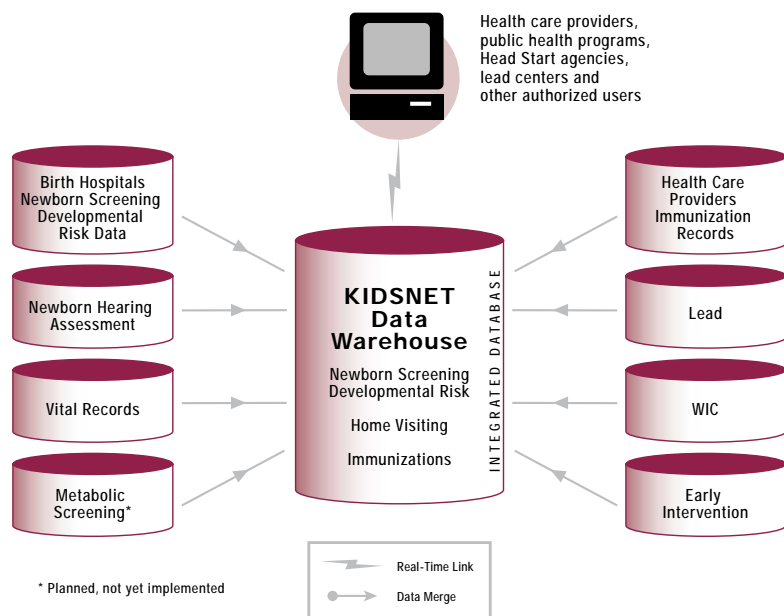
Draft Report at <http://genes-r-us.uthscsa.edu/resources/HRSAMeeting2002/resources.htm>

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participated. These percentages increased to 71% and 50% respectively in 2002. A provider relations manager, focus groups, and surveys ensure ongoing, two-way communications with providers and their staffs.

In addition, research to assess families' awareness of newborn screening programs, their information needs, and the best methods for informing families has guided communications between KIDSNET and families. Focus groups with diverse groups of parents from throughout the state showed that parents were overwhelmed with information and paperwork in the hospital; awareness

Rhode Island KIDSNET



of newborn screening and other tests was low; and they had many unanswered questions about newborn testing. KIDSNET also found that parents were unaware of test results; they wanted information in the prenatal period; language barriers in the hospitals were a problem; and access and privacy concerns about KIDSNET needed to be addressed. As a result, KIDSNET is reviewing its communication materials and methods and will be making revisions to address families' needs and recently, changes to confidentiality standards

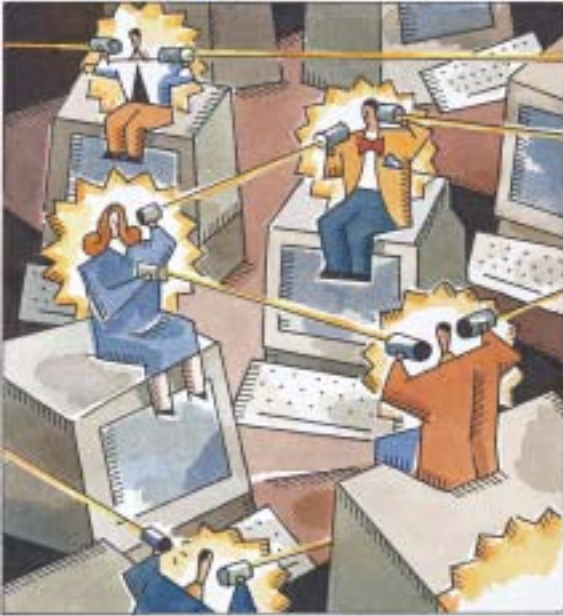
RIDOH's strong emphasis on listening carefully to stakeholders in order to meet their information needs keeps KIDSNET on track. Dr. Nolan is clear: "Information is a product, not a possession. We will be judged on how we share, not how we keep."

ALL KIDS COUNT SURVEY TO CHARACTERIZE STATE OF INTEGRATION

Which states and cities are integrating their health information systems? Which programs are they integrating? How are they doing it? What was the motivation? And perhaps most important, what does it take?

A survey conducted by All Kids Count this spring will answer these questions and more about the state of health information systems integration in the United States and its territories. Nicole Fehrenbach, MPP, senior research associate for All Kids Count, says this survey will provide the most comprehensive picture to date about the extent of child health information systems integration in the United States.

"Integration of disparate databases is perceived to be the next evolutionary step in improving the information infrastructure of the health system. There is a general belief that improved information will result in improved population health," she says.



Fehrenbach continues, "Little is known, however, about the extent of integration activities and what it takes to actually implement an integration project within a public health setting. The results will be used to help us articulate the factors that need to be in place to implement integrated systems that help improve the health of children by ensuring timely delivery of services and follow-up.

"In addition to characterizing, who, what, where, and why," she says, "we will gather information about the challenges health information systems integration projects face, the

factors that facilitate systems integration, and stakeholders and end-users of these systems."

Information will be gathered through telephone interviews with representatives of 25 state, local and private health information systems integration projects. The sites included in the survey were selected from a list of projects that, according to analysis of federal survey results and a review of federal and private foundation grant recipients, are integrating or linking child health information systems. Interviewees may include health program directors, chief information officers, maternal and child health program coordinators, and potentially, information technology personnel.

Fehrenbach expects the results of the survey to be available in summer 2003. A future issue of this newsletter will report on the results.

RESOURCES ON STAKEHOLDER ENGAGEMENT

Tip Sheet – Engaging Community

A tool to help communities improve health and quality of life through community-wide strategic planning.

In *Mobilizing for Action through Planning and Partnerships (MAPP)*, developed by the National Association of County and City Health Officials in cooperation with the Public Health Practice Program Office, Centers for Disease Control and Prevention.

<http://mapp.naccho.org/EngagementTipSheet.asp>

Principles of Community Engagement

Practical guidelines for engaging the public in community decision-making and action for health promotion, health protection, and disease prevention.

Developed by CDC/ATSDR Committee on Community Engagement, Public Health Practice Program Office, Centers for Disease Control and Prevention, 1997

<http://www.cdc.gov/phppo/pce/index.htm>

The Integrated Child Health Information System community of practice is a program of All Kids Count, which is supported by the Robert Wood Johnson Foundation to foster development of integrated child health information systems.

Connections communities of practice bring public health practitioners together to meet, exchange new ideas and solve public health problems. They are a program of the Center for Innovation in Health Information Systems, which is committed to improving the health and well-being of individuals and communities, especially children, through strategic application and management of information technology.

The Center for Innovation is a component of The Task Force for Child Survival and Development.

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

For information, call 404.687.5611

www.centerforinnovation.org
www.allkidscount.org



The Task Force for
Child Survival and Development
750 Commerce Drive, Suite 400
Decatur, GA 30030

Address correction requested

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The Sound Of CONNECTIONS

ALL KIDS COUNT CELEBRATES 10 YEARS WITH PARTNERS

Connections members, former All Kids Count grantees, and many other long-time friends joined with All Kids Count last October to celebrate its tenth anniversary. Almost 400 people gathered at a reception held at the Pennsylvania Academy for the Fine Arts in Philadelphia during the Immunization Registry Conference to recognize the progress of immunization registries and integrated health information systems in the last decade.

Bill Watson, former All Kids Count director, and Dave Ross, All Kids Count's current director, both paid tribute to the tremendous effort and dedication of the public health practitioners who have worked over the years to deliver on the promise of health information systems. They expressed their gratitude to All Kids Count's many partners, grantees, and advisory board members for their leadership and perseverance.

Special thanks was given to The Robert Wood Johnson Foundation for not only initiating All Kids Count in 1992, when the field of public health informatics was in its infancy, but for staying the course and supporting All Kids Count as it moved from implementing immunization registries to fostering development of integrated health information systems. As Dr. Ross noted, developing a health information systems that meet the needs of multiple stakeholders is a highly complex undertaking, requiring vision for how health information systems can help to improve the public's health, the support of leadership, and a commitment to the long haul.

All Kids Count is extremely grateful to be a part of the new frontier of health information systems.