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Integrated Child Health Information Systems Community of Practice

FINAL CONNECTIONS MEETING: COMMON GROUND AND A NEW BEGINNING

The final meeting of the All Kids Count Connections community of practice (CoP) on integration of child health information systems was held in March in Atlanta, bringing closure to a two-year experience in sharing best practices and growing knowledge in the field. The Connections members attending the meeting updated their colleagues on their progress and explored ways that they can continue the experience outside the sponsorship of All Kids Count.

FINAL MEETING HIGHLIGHTS BENEFITS OF SHARED LEARNING

“Diversity within commonality.” That’s how Alan Hinman, MD, MPH, Principal Investigator of All Kids Count, summarized the All Kids Count Connections community of practice (CoP) at its final meeting. Although **Connections** members differ in size, scope, programs being integrated, laws and policy, funding, and other contextual factors, they found through the peer-to-peer sharing of **Connections** that the issues they face are more similar than dissimilar as they strive to meet their common goal of improving the health and health care of children through integration of health information systems.

The 11 agencies participating in the three-year **Connections** experience agree that the major barriers to integrating systems are not strictly technical. Integration projects must navigate complex matters of data security and confidentiality. Consolidation of duplicate and fragmented records is necessary to maintain data quality and accuracy—no small task.

Integration has impacts on all levels of an organization, and change must be effectively managed. Integration projects require strong, committed executive leadership, yet cannot rely solely upon individual sponsors, who may move on. Excellent communication among project managers, IT specialists, and external vendors is required to avoid errors, unmet expectations, and scope creep. And on top of these immediate challenges, integration projects at state and local agencies must stay abreast of emerging national health IT initiatives.

Connections members shared their solutions to these common challenges at the Atlanta meeting:

- CalOptima, the Medicaid managed care organization for Orange County, Calif., has implemented its Login Information Network for Kids (LINK) at eight provider sites. With feedback from the pilot sites, CalOptima has enhanced LINK and developed a marketing plan. CalOptima now faces serious funding issues, however, and the project currently lacks

“The community of ideas works!”

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Connections members found common ground with colleagues sharing in the experience.

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executive sponsorship, dedicated IT support, and other official resource allocation. Nevertheless, CalOptima's active participation in the **Connections** CoP has provided knowledge of "what is possible" and heightened awareness of integration challenges and solutions.

■ Iowa has demonstrated the importance of the role of the business analyst and parental involvement in the integration of its newborn metabolic screening, newborn hearing screening, birth registration, and birth defects surveillance systems. The Department of Public Health is addressing its biggest challenge: state technical and business policy development to allow integration. **Connections** gave its Iowa members a comfortable setting for problem solving and the confidence to move forward.

■ The involvement of the Kansas Integrated Public Health System (KIPHS) in **Connections** shed new light on the complexities of collaborative system development efforts as KIPHS staff attempted to work with a childhood lead poisoning prevention coalition. Through their work on another **Connections** project, KIPHS members also learned that understanding data and their sources is essential to integrating systems and using system data. They demonstrated to the group the importance of standard data definitions to successful data exchange.

■ Maine's Integrated Public Health Information System (IPHS) has a project charter and management team in place. The project has developed risk management strategies to mitigate uncertain leadership and priorities, organizational changes, and difficulty defining project scope, communicating with key stakeholders, and gaining consensus.

■ Michigan is building on the positive reputation of its Michigan Childhood Immunization Registry (MCIR) to support integration with additional programs. While the Department of Community Health struggles with a lack of consensus about the rationale for integrating child health data, the success of the MCIR has brought many stakeholders to the table. Information from **Connections** site visits has been instrumental in proving the integration concept to Michigan's executive leadership.

■ Missouri's project continues to add programs and data sources to the system despite shifts in departmental priorities, leadership and technology, and diminished flexible funding. Missouri's **Connections** members maintain that the insights and peer support they gained from the CoP has bolstered their efforts.

■ New York City is adding adult client systems to its integrated information system, heralding its evolution from Master Child Index to Master Client Index (MCI). The project has reduced duplicate records in the MCI from 30 percent to less than 10 percent, making data more complete and usable. NYC's participation in **Connections** helped justify the need for integration to stakeholders, and **Connections** peers provided important support for the MCI project.

■ **Connections** members from Oregon joined in the final meeting by telephone when state travel restrictions prevented them from being physically present. Oregon's FamilyNet continues to revise its

strategic plan and its system modules, accommodating changing circumstances with a commitment to continuous improvement. FamilyNet has an innovative family-centric “lock and key” security approach that assures appropriate system access by authorized family members. **Connections** allowed Oregon to share ideas with counterparts in other states, demonstrating that, as Sherry Spence said, “The community of ideas works.”

■ Rhode Island’s KIDSNET system allows an integrated presentation of data across multiple public health programs. The system continues to be marketed and rolled out to new user groups within and outside the Department of Health; 92 provider sites currently use KIDSNET. Rhode Island’s participation in the CoP linked them with a strong peer network, funded specific developments within KIDSNET, highlighted the state’s progress, and helped drive a new department-wide informatics initiative.

■ The Child Health Advanced Records Management (CHARM) system in Utah exemplifies a phased approach to integration. It uses “translator” agents to integrate data from individual programs, presenting integrated front-end information without changing the back-end systems. Loss to follow-up has been a major challenge for Utah child health programs, and CHARM has provided the opportunity for outreach by generating immunization reminders for parents requesting birth certificates for their children. This in turn has indicated areas for improvement to the system’s immunization data. A benefit of **Connections** for Utah has been the so-called “visibility paradox”—the spotlight of membership has motivated success.

While **Connections** members diverge in the strategies, resources, and technical approaches they use to manage their many challenges, they find common ground with their colleagues sharing in the **Connections** experience. The CoP allowed them to learn from and with one another, and to participate in candid discussions in which they shared their mistakes, failures, and frustrations without fear of judgment or repercussions. Out of this “safe haven” atmosphere of mutual trust and respect emerged good friendships, good practices, and solutions that worked.



MARCH 2004 FINAL MEETING ATTENDEES

Representatives of 9 of the 11 organizations that comprise the **Connections** Integrated Child Health Information Systems community of practice attended the March final meeting in Atlanta. Oregon Department of Human Services dialed in.

CalOptima (Medicaid managed care for Orange County, CA)

Iowa Department of Public Health

Kansas Integrated Public Health System

Maine Bureau of Health

Michigan Department of Community Health

Missouri Department of Health and Senior Services

New York City Department of Health

Rhode Island Department of Health

Utah Department of Health

Oregon Department of Human Services

Also attending were representatives from the following:

Genetic Services Branch, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA)

Early Hearing Detection and Intervention Team, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC)

Immunization Registry Support Branch, Division of Immunization Services, National Immunization Program, Centers for Disease Control and Prevention (CDC)

National Health Information Infrastructure, Department of Health and Human Services (DHHS)

Center for Quality Improvement and Patient Safety, Agency for Healthcare Research and Quality (AHRQ)

GROUP COLLABORATIONS

All Kids Count funded two group projects to demonstrate the value of collaboration by multiple agencies.

De-duplication Technology and Practices

This project examined de-duplication software and approaches, performed limited testing and technical analysis of a number of products, and compared the products' effectiveness, underlying approach to de-duplication, cost and other factors. Although the study did not yield a single "best product," it provides a framework to examine alternatives and trade-offs to consider when choosing de-duplication products and strategies to meet integration project requirements. Seven Connections member sites participated in this study.

PDA-based Interface

This project developed a PDA application that interfaces with an immunization registry to provide both an alternative data entry tool and a clinical support tool. Developed through a collaboration of six **Connections** member sites, the application accommodates the needs of a diverse set of registries with a minimum of customization.

Reports on both projects are included in *Creating a Roadmap—Volume Two*. They can be found online at www.allkidscount.org.

ROAD MAP TO INTEGRATION

A compilation of practical experience about integrating child health information systems is now available from All Kids Count.

All Kids Count recently published *Creating a Road Map: Sharing Knowledge About Integrating Child Health Information Systems—Volume Two*, a collection of project reports by members of **Connections**. *Creating a Road Map—Volume Two* contains reports by five individual agencies, covering a range of integration topics, including data entry and use, data quality, and the sharing and exchange of data among multiple information systems. Two group projects also report on their collaborative efforts in de-duplication technology and a PDA-based interface to immunization registries.

The first volume, published in 2003, presents reports from nine agencies and includes detailed information about partnership with the private provider community, ensuring privacy and confidentiality, and using billing data, among other topics.

Full text of both volumes, including appendices, can be found at www.allkidscount.org.

THE VALUE OF CONNECTIONS

Through sharing of best practices and knowledge, communities of practice (CoPs) are intended to benefit their members' mutual projects, their organizations, and the members themselves, both professionally and personally. After three years of facilitating the **Connections** CoP, All Kids Count wanted to better understand the learning community's value to its members, and how the value might be increased.

Silver Creek Associates, an agency with expertise in evaluating CoPs, conducted the evaluation through a series of facilitated individual interviews, group interviews, and a Web-based survey. They interviewed 26 **Connections** members, and 28 members responded to the Web-based survey. Interviews included members that had been highly involved in **Connections**, as well as those that had been only peripherally involved.

All participants in the study, without exception, reported gaining significant and tangible benefits from the **Connections** experience. The members reported that All Kids Count created a community of safety, where members felt comfortable sharing their failures as well as their successes. **Connections** deepened their professional commitment to the vision of integration and inspired them with new possibilities. The group's visits to other members' sites were reported to be the most significant aspect of the members' experience with **Connections**. The listserv and on-line communications tool were less fruitful activities.

All Kids Count plans to build on the **Connections** experience in the future. "**Connections** has advanced our knowledge about integration of child health information systems, and our understanding of the value of shared learning and collaborative work," said Ellen Wild, program director. "It has greatly influenced how our organization will assist health organizations as we go forward."

A VISION FOR CHILD HEALTH INFORMATION SYSTEMS

Representatives of 55 organizations and government agencies met in Atlanta in December 2004 to recommend next steps for development of child health information systems that meet medical care and public health needs. The diverse group of stakeholders, convened by All Kids Count, identified actions that should be taken immediately and in the next three to five years to integrate the information about the health care that a child receives, from the moment he or she is born, in a simple yet comprehensive format so that the end user (parents, families, health professionals, insurers and policymakers) can take all appropriate actions.

Meeting participants worked in groups for two days to forge recommendations in the areas of governance, economic issues, information infrastructure, and data use.

Proceedings of the meeting, along with slides of the presentations and the workgroup recommendations, are posted on the All Kids Count web site, www.allkidscount.org. In addition, the meeting summary and other information about integration of child health information systems will be published in the professional literature in 2005.

The Institute has received funding from The Robert Wood Johnson Foundation to facilitate implementation of the recommendations (see *New Funding*).

ALL KIDS COUNT: WHAT WE'VE LEARNED

From 1991 through 2004, All Kids Count, supported by The Robert Wood Johnson Foundation, worked to improve child health and the delivery of immunizations and preventive services through the development of health information systems. Over the years, All Kids Count worked directly with 38 state and local health agencies through its grant program and **Connections**, its community of practice.

While the agencies that were directly involved in All Kids Count made significant progress, much was also learned that is applicable to other public health and medical informatics initiatives.

The history of All Kids Count, its milestones, and the top 10 lessons learned from the program will be published in the peer review literature later this year. Notes lead author Kristin Saarlal, MPH, deputy director of All Kids Count, "It's not easy to distill 13 years of learning into 10 lessons – there were so many significant developments and realizations in All Kids Count." Lessons relate to stakeholders, the complexity of the effort, understanding users' needs, standards, collaboration, change, communications, information use, and bold planning and incremental development.

Look for the Supplement to the *Journal of Public Health Management and Practice* in November 2004. The supplement also will include numerous other articles by public health practitioners and leaders in child health information systems.

NEW FUNDING FOR CHILD HEALTH INFORMATION SYSTEMS INTEGRATION

Two new grants to the Public Health Informatics Institute add to its portfolio of work on child health information systems.

The Robert Wood Johnson Foundation has funded the Public Health Informatics Institute to facilitate collaborative public health informatics projects over the next two years. One project supported by this grant follows up on the recommendation from the December meeting (see story this page) for the Institute to convene a coalition of stakeholders to advance the movement to integrate child health information systems.

Funding from the Health Resources and Services Administration will support a community of practice for Genetic Services Branch Implementation Grantees. The CoP will assist them in developing and implementing integrated newborn dried blood spot screening programs and their information systems with other early child health programs, their information systems, and the health care delivery system.

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.

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The Sound Of CONNECTIONS

FUTURE CONNECTIONS

Throughout the final **Connections** meeting, facilitators from the Public Health Informatics Institute commented that the gathering was not meant to put closure on the community of practice and everything that All Kids Count has accomplished over the last 10 years.

"We look at this as a new beginning," Kristin Saarlas, Institute deputy director, told the community of practice participants. "We're handing off the torch in hope that you will find ways to carry on the **Connections** mission."

Thus the final **Connections** meeting became the first in a series of brainstorming sessions that have continued by teleconference and e-mail. Although the Institute no longer facilitates the meetings, it remains actively involved as a consultant and participant.

Next step suggestions include:

- Investigate involvement in the Institute's project (funded by The Robert Wood Johnson Foundation)

to develop a coalition to spearhead the effort to integrate child health information systems.

- Look for opportunities for involvement and collaboration in national public health informatics initiatives (PHIN/NEDSS), NHII and local health information initiatives, patient safety and clinical improvement initiatives, and local health and child health programs sponsored by CDC and HRSA.
- Discuss identified issues in a quarterly conference call.
- Continue occasional site visits, funded by CDC or HRSA conference support grants.
- Find a home base or organization to sponsor the **Connections** group.

Participants pledged that **Connections** will continue to bring public health practitioners together to develop and exchange best practices in an atmosphere of trust, confidence, and support, and to advocate for successful models for moving integration forward.