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# *Proceedings*

## A Vision for Child Health Information Systems

Developing Child Health Information Systems to Meet Medical Care  
and Public Health Needs

Emory Conference Center | Atlanta, Georgia | December 3-4, 2003

**All Kids Count**



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All Kids Count is a National Technical Assistance Center supported by  
The Robert Wood Johnson Foundation.

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*“This nation is making a tremendous transition as we move from isolated programs using isolated information systems to an enterprise that integrates surveillance, research, and service delivery. We need to ensure that all kids receive routine preventive services. We need to protect kids by detecting threats to their health and intervening quickly. And we need to support parents by creating a service delivery system that supports them with information when they need it and in a form they can understand and use.”*

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Dave Ross  
Executive Director  
Public Health Informatics Institute

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This report was prepared by Alan Hinman with assistance from Terry Hastings, John Kiely, Lorrie Alvin, and Patricia Richmond.



# ABSTRACT

All Kids Count, a program funded by The Robert Wood Johnson Foundation, hosted *Developing Child Health Information Systems to Meet Medical Care and Public Health Needs*, an invitational conference convened in Atlanta, Georgia, December 3-4, 2003. The conference was co-sponsored by a number of governmental and non-governmental organizations (see Acknowledgements). Approximately 100 public health stakeholders representing 55 organizations participated in the meeting with the goal of delivering feasible recommendations that can be carried out.

Conference participants reviewed national initiatives and other factors influencing the development of child health information systems infrastructure. They developed concrete recommendations - reflecting the input of stakeholders - for the development of actions to take now and over the next three to five years. The conference attendees also enlisted stakeholders in communicating, supporting, and implementing the recommendations.



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**Meeting sponsors:** All Kids Count/Public Health Informatics Institute (AKC/PHII), American Immunization Registry Association (AIRA), Alliance of Community Health Plans (AHCP), Association for Health Center Affiliated Health Plans (AHCAHP), Agency for Healthcare Research and Quality (AHRQ), American Academy of Pediatrics (AAP), Association of Maternal and Child Health Programs (AMCHP), Association of State and Territorial Health Officials (ASTHO), Centers for Disease Control and Prevention (CDC), Commonwealth Fund, Family Voices, Health Resources and Services Administration (HRSA), March of Dimes, National Association of County and City Health Officials (NACCHO), National Association of School Nurses (NASN), National Health Information Infrastructure (NHII), National Initiative for Children's Healthcare Quality (NICHQ), U.S. Department of Agriculture Food and Nutrition Service (USDA/FNS).

**External planning committee members:** Claire Broome (CDC), Cia Byrnes (AHCP), Jennifer Cernoch (Family Voices), Ed Gotlieb (AAP), Bob Kambic (NHII), Mike Kogan (HRSA), Linda Murphy (Centers for Medicare and Medicaid Services), Lisa Ruben (AHCAHP), Richard Scoville (NICHQ), Rick Shiffman (Yale University), Scott Young (AHRQ), Scott Williams (Utah Department of Health), Amy Zimmerman (Rhode Island Department of Health). AKC planning committee members were Lorrie Alvin, Sherry Bolden, Terry Hastings, Alan Hinman, Carol McPhillips-Tangum, Patricia Richmond, Dave Ross, Kris Saarlal, Ellen Wild. Patricia Richmond was overall Conference Coordinator.

**Plenary session presenters and panel members:** Claire Broome, MD; Jennifer Cernoch, PhD; Rick Friedman, MBA; Ed Gotlieb, MD; Stephen Lawless, MD; Allan Lieberthal, MD; Marie Mann, MD; David Ross, ScD; Kristin Saarlal, MPH; Rick Shiffman, MD; William Yasnoff, MD; Scott Young, MD; and Amy Zimmerman, MPH.

# ACRONYMS AND ABBREVIATIONS

## *Organizations and Associations*

**AAHP** / American Association of Health Plans

**AAP** / American Academy of Pediatrics

**ABP** / American Board of Pediatrics

**AFEHCT** / Association For Electronic Health Care Transactions

**AHCAHP** / Association for Health Center Affiliated Health Plans

**ACHP** / Alliance of Community Health Plans

**AHRQ** / Agency for Healthcare Research and Quality

**AIRA** / American Immunization Registry Association

**AKC** / All Kids Count

**AMIA** / American Medical Informatics Association

**APHA** / American Public Health Association

**APHL** / Association of Public Health Laboratories

**AMCHP** / Association of Maternal and Child Health Programs

**ASPH** / Association of Schools of Public Health

**ASTHO** / Association of State and Territorial Health Officials

**CDC** / Centers for Disease Control and Prevention

**CMS** / Centers for Medicare and Medicaid Services

**CSTE** / Council of State and Territorial Epidemiologists

**DHHS** / Department of Health and Human Services

**FACCT** / Foundation for Accountability

**GSB** / Genetic Services Branch

**HRSA** / Health Resources and Services Administration

**IOM** / Institute of Medicine

**IHS** / Indian Health Service

**JCAHO** / Joint Commission on Accreditation of Health Organizations

**MCHB** / Maternal and Child Health Bureau

**NACCHO** / National Association of County and City Health Officials

**NAPCI** / National Alliance for Primary Care Informatics

**NAPHIT** / National Association of Public Health Information Technology

**NASN** / National Association of School Nurses

**NASMD** / National Association of State Medicaid Directors

**NCVHS** / National Committee on Vital and Health Statistics  
**NCQA** / National Council on Quality Assurance

**NHII** / National Health Information Infrastructure  
**NICHQ** / National Initiative for Children’s Healthcare Quality

**PHIN** / Public Health Information Network

**SPR** / Society for Pediatric Research

**RWJF** / The Robert Wood Johnson Foundation

**USDA/FNS** / U.S. Department of Agriculture Food and Nutrition Service

**WEDI** / Workgroup on Electronic Data Interchange

### *Programs and Other Abbreviations*

**AFIX** / Assessment, Feedback, Incentive, Exchange

**ARCH** / Automated Record for Child Health

**CHIS** / Child Health Information Systems

**CSHCN** / Children with Special Health Care Needs

**EHR** / Electronic Health Record

**EMR** / Electronic Medical Record

**HL7** / Health Level Seven, an ANSI-accredited standards developing organization

**HEDIS** / Health Plan Employer Data and Information Set

**HIPAA** / Health Insurance Portability and Accountability Act

**HIT** / Health Information Technology

**LOINC** / Logical Observation Identifiers Names and Codes

**L/RHII** / Local/Regional Health Information Infrastructure

**MCIR** / Michigan Childhood Immunization Registry

**MITA** / Medicaid Information Technology Architecture

**NBS** / Newborn Screening System

**NEDSS** / National Electronic Disease Surveillance System

**RPMS** / Resource and Patient Management System

**SCHIP** / State Children’s Health Insurance Program

**SNOMED** / Systematized Nomenclature of Medicine

**WIC** / Women, Infants, and Children



# INTRODUCTION

Since its inception in 1992, All Kids Count has fostered development of information systems to help improve health and health care of children. With support from The Robert Wood Johnson Foundation, All Kids Count coordinated development of immunization registries in state/local health departments through two phases. The first phase (1992-1997) provided grants to encourage innovation in development of registries. The second phase (1998-2000) provided grants for implementation of registries.

In its current phase (2000-2004), All Kids Count provides technical assistance to promote integration of child health information systems, focusing primarily on immunization registries, newborn dried blood spot screening, newborn hearing screening, and vital registration. This work is quite similar to, and complements, initiatives developed by the Genetic Services Branch (Division of Services for Children with Special Healthcare Needs, Maternal and Child Health Bureau, Health Resources and Services Administration). It also complements other national initiatives that promote information systems standards, such as the National Health Information Infrastructure and the Public Health Information Network.

The convergence of all these initiatives made it particularly appropriate to convene a meeting to address practical issues in developing integrated child health information systems. All Kids Count was pleased to serve as host, along with 18 co-sponsors, for this Conference on Developing Child Health Information Systems to Meet Medical Care and Public Health Needs. The conference brought together 100 participants representing 55 different agencies for two days of discussion and development of recommendations for actions in the immediate future. One indication of the timeliness of the meeting was the observation by one of the participants that, despite their shared focus on children and information systems, many of the participants had never met before.

These proceedings summarize the presentations, conclusions, and recommendations developed at the Conference.



# OVERVIEW

All Kids Count, a program funded by The Robert Wood Johnson Foundation (RWJF), hosted an invitational conference titled *Developing Child Health Information Systems to Meet Medical Care and Public Health Needs* in Atlanta, Georgia, December 3-4, 2003. The conference was co-sponsored by a number of governmental and non-governmental organizations (see Acknowledgements). The objectives of the conference were to:

- Review national initiatives and other factors influencing the development of child health information systems infrastructure
- Develop concrete recommendations, reflecting the input of stakeholders, for the development of:
  - Immediate actions.
  - Actions for the next three to five years.
- Enlist stakeholders in communicating, supporting, and implementing the recommendations.

**NOTE:** The conclusions and recommendations of the conference summarized in this report are those of conference participants and do not represent the official views of the sponsors. The conclusions and recommendations have not been officially endorsed by any of the sponsoring agencies/organizations.

An external planning committee developed the agenda for the meeting (Attachment 1), the roster of speakers, and the invitation list for participants. The conference began with an initial set of plenary presentations that established context for the development of the action agenda, including presentations on national initiatives relevant to developing child health information systems. The plenary sessions were followed by a series of breakout sessions in which participants considered in detail specific aspects of integrating child health information systems. Approximately 100 persons participated in the meeting (Attachment 2) and made recommendations for immediate actions and actions for the next three to five years.

For the purposes of the meeting, integrated child health information systems (CHIS) were defined as those that provide a range of information to the user in a simple yet comprehensive format so that he/she can readily take all appropriate actions. Integration does not imply a specific technical model. Authorized users of the information may be clinical care providers, public health officials, or patients and their families.



# PLENARY PRESENTATIONS

In the keynote presentation, **Dr. Rick Shiffman** (Yale University) provided a conceptual framework for considering integrated child health information systems, taking into account the perspectives of the child and the child's health care provider, the public health system, and information technology. Children of different ages have different needs; providers and sites of care differ from those most commonly encountered in the adult population, ranging from highly specialized providers to allied health care personnel and care delivered in settings varying from children's hospitals to schools. The nature of the care ranges from acute illnesses to health maintenance to new morbidities such as obesity. The public health system is involved in screening, prevention, environmental hazards, infectious diseases, and health care provision (e.g., Medicaid, State Children's Health Insurance Program [SCHIP]). Children's health care and public health also overlap with information technology, which has traditional categories of bioinformatics, clinical informatics, and public health informatics. Information technology can be used for decision support, to identify errors, and to provide guidelines for management. Electronic health records for children have special requirements, such as growth monitoring and drug-dosing algorithms, as well as unique privacy issues. Standards remain to be developed and accepted in many areas of information technology. The technology also promotes an array of possibilities for communication.

Dr. Shiffman made these key points:

- The three areas have often existed independently.
- It is essential that they work together in the areas of overlap.
- One-size solutions won't work.

**Dr. William Yasnoff** (Department of Health and Human Services [DHHS]) described the National Health Information Infrastructure (NHII) as the key to the future of health care. The health care system faces many challenges, including the fact that medical error rates are too high, quality of care is inconsistent, research results are not rapidly used, costs are escalating and new technologies continue to drive up costs, the demographics of baby boomers will greatly increase demand, and the capacity for early detection of bioterrorism is minimal. All of these problems can be solved, or at least improved, through efficient use of information technology.

NHII represents a comprehensive knowledge-based network of interoperable systems capable of providing information for sound decisions about health when and where needed ("anywhere, anytime health care information"). NHII is **not** a central database of medical records. It includes technologies, practices, relationships, laws, and standards and applications (e.g., communication networks, message and content standards, computer applications, and confidentiality protections). Individual provider Electronic Medical Record (EMR) systems are only the building blocks; they are not NHII. NHII will enable linkage between medical care and public health that can make a complete medical record with test and x-ray results always available (thereby eliminating unnecessary repeat studies), and provide decision support (with guidelines and research results). Quality and payment

information will be derived from the record of care rather than from separate reporting systems. Consumers will have access to their own records.

There are four domains of NHII: personal/consumer, clinical, public health/community, and research/policy. NHII will monitor and protect public health, improve patient safety, improve quality of care, effectively share decision support, and lead to better understanding of health care costs and better-informed health care consumers.

Overwhelming support for the concepts of NHII has been manifested since 1991, including from Institute of Medicine (IOM) reports, the National Research Council, and the National Committee on Vital and Health Statistics. Among the reasons why NHII has not already been done are that: health care information is very complex and therefore information systems are expensive and difficult to build, health care is highly fragmented, organizational and change management issues relating to information systems are difficult to manage in the clinical environment, and it is difficult to generate the capital needed for investment in information systems. Fragmentary and isolated elements of NHII exist but there is uneven distribution, a lack of coordination, minimal interoperability, and many one-of-a-kind systems, leading to much duplicative work.

Accelerating NHII progress entails disseminating information about NHII (its vision, activities, and lessons learned), collaboration with stakeholders, convening a national meeting, developing standards (e.g., HL7, Systematized Nomenclature of Medicine [SNOMED], Logical Observation Identifiers Names and Codes [LOINC]), funding demonstration projects (\$50 million in FY 2004 Agency for Healthcare Research and Quality [AHRQ] budget), and evaluation of NHII benefits and policy options. A national meeting was held June 30 - July 2, 2003 in Washington with more than 500 attendees representing all stakeholders. It resulted in recommendations in four areas:

- Management - governance, education, shared resources, metrics
- Enablers - financial incentives standards, legal issues
- Implementation strategy - demonstration projects, architecture, identifiers
- Targeted domains - consumer health, research.

The current approach to NHII is to develop Local/Regional Health Information Infrastructures (L/RHIIs), and expand them to cover the nation. NHII will result when L/RHIIs are connected.

In summary, health care is in crisis and NHII is needed for safety and efficiency by providing “anywhere, anytime” health care information, decision support, and communication. Most elements of NHII already exist somewhere. HHS is working to accelerate the process. The IOM Committee on Data Standards for Patient Safety said, “The committee believes that establishing [NHII] should be the highest priority for all health care stakeholders.”

**Dr. Claire Broome** (Centers for Disease Control and Prevention [CDC]) described how the Public Health Information Network’s (PHIN) standards and tools can accelerate integrated child health information systems. PHIN supports information system needs of public health

partners - health departments, public health laboratories, field investigation teams, hospitals/health plans, ambulatory care facilities, the pharmaceutical stockpile, non-clinical sources of information, law enforcement and first responders, and the public. PHIN functions include detection and monitoring, analysis, information resources and knowledge management, alerting and communications, and response. PHIN utilizes national standards such as those endorsed by the National Committee on Vital and Health Statistics (NCVHS). PHIN technical specifications are available at [www.cdc.gov/phin](http://www.cdc.gov/phin). In moving from the conceptual to the real, each health care delivery setting will have a different stage of electronic records implementation and each state/jurisdiction will have specific plans on which systems to integrate and what funding streams are available. The central concept of PHIN is implementation of standards-based interoperable systems to maximize reuse of tools and leverage resources, make efficient use of technical expertise, and plan for extensibility. For example, in an integrated child health information system, the PHIN messaging components could support integration of laboratory results of newborn metabolic screening tests.

The Public Health and Social Services Emergency Fund of 2002 provided \$1 billion for state and local public health preparedness capacity. CDC and HRSA stipulate in grant guidance the use of PHIN standards for information technology investments (available at [www.cdc.gov](http://www.cdc.gov)). The second round of preparedness funding in September 2003 provided an additional \$498 million in HRSA grants and \$870 million in CDC grants to states. All 50 states have been funded for continuous Internet connectivity to counties and surveillance planning. CDC has also developed specific tools to assist states in implementing PHIN. For example, the PHIN Messaging System software provides industry standards-based secure encrypted transport for inter-institutional messaging. A beta release of PHIN Vocabulary Services is scheduled to go out in December 2003; this supports maintenance and versioning of standard controlled vocabularies. Laptop deployable systems exist for case management, contact tracing, specimen and results management, and vaccination and prophylaxis management. Technical assistance resources are available for public health partners.

Surveillance and disease monitoring is a core component of PHIN implemented by the National Electronic Disease Surveillance System (NEDSS). Twenty-six states/jurisdictions are developing local systems that are NEDSS-compatible; an additional 31 jurisdictions are deploying the NEDSS Base system, a surveillance application developed by CDC and partners. In addition to surveillance functionality, participation in NEDSS engages state health departments in addressing rigorous information security tools and practices, which provide privacy protections required by the Health Insurance Portability and Accountability Act (HIPAA).

**Mr. Rick Friedman** (Centers for Medicare and Medicaid Services [CMS]) described the Medicaid Information Technology Architecture (MITA) Initiative. Through the MITA project, CMS' goal is to provide states with a conceptual architecture that will serve as a framework for improved system development and data exchange within and among states, federal agencies, and other health care partners. MITA is:

- a **plan** to make improved use of the Internet and emerging technologies, facilitate interoperability among trading partners, and improve data exchanges between trading partners.

- an **architecture** in which models and standards are defined and recommended solutions are offered.
- a **framework** whose models can be adapted to state needs; guidelines for adaptations offer choices.
- a collaborative **process** in which states participate to develop additional detail; a change management process governs changes.

MITA's mission is to establish a national framework of enabling technologies and processes that support improved program administration for the Medicaid enterprise.

Its goals are to:

- Provide performance measurement for accountability and planning.
- Provide data that are timely, accurate, usable, and easily accessible in order to support analysis and decision making for health care management and program administration.
- Promote an enterprise view that supports enabling technologies aligned with Medicaid business processes and technologies.
- Develop seamless and integrated systems that effectively communicate to achieve common Medicaid goals through interoperability and common standards.
- Promote an environment that supports flexibility, adaptability and rapid response to changes in programs and technology.
- Reduce duplication of costs to collect data already available elsewhere that can be used to more effectively administer the program.

The key steps in MITA's evolution are to: develop the architecture framework; manage communication; provide state planning guidelines; and implement processes. MITA portfolios (groupings of projects around a common goal) are: interoperability, data management, adaptability and flexibility, data sharing coordination, security, business area improvement, and performance measurement. Future state requests for CMS funding should include data sharing, reusable components, modularity, open architecture, standards, security, and collaboration.

**Dr. Marie Mann** (Health Resources and Services Administration [HRSA]) described the activities of the Genetic Services Branch (GSB), Maternal and Child Health Bureau (MCHB) with newborn screening systems and state program and information integration. The components of the newborn screening system (NBS) are education, screening, follow-up, diagnosis, management, and evaluation. The 2000 report of the Newborn Screening Task Force concluded that "improved coordination and integration of information systems is needed." An Integrated NBS Service Systems Initiative seeks to integrate NBS and genetic services into existing state and territory systems of care, networks of services and supports with linkages to the community-based system of care. To facilitate the development of public health infrastructure that allows for such an integration, HRSA is seeking to enhance and expand newborn screening programs and improve linkages between NBS programs, the state and community systems of care for children with special health care needs (CSHCN).

Beginning in 1999, GSB/HRSA has awarded planning grants to 22 states to develop plans for integration of NBS and genetic services. Implementation grants have subsequently been awarded to 11 states (most of which had had planning grants). In 2003, five additional states received grants under a joint program of GSB and MCHB's Office of Data and Information Management to implement data integration and program linkage.

GSB has also supported All Kids Count/Public Health Informatics Institute (AKC/PHII) in development of the *Sourcebook for Planning and Development for Integration of Newborn Screening and Genetic Services Systems with Other Maternal and Child Health Systems*. The Sourcebook outlines key elements of integrated information systems and enunciates five important lessons learned in working to integrate child health information systems:

- Data are for sharing.
- Communication is critical.
- Change is hard.
- Let public health needs drive technology.
- Stay the course.

A planning and assessment tool was also developed, featuring a self-assessment guide. The Sourcebook and the Self-Assessment Guide are available at <http://genes-r-us.uthscsa.edu> and [www.phii.org](http://www.phii.org).

Finally, GSB has supported AKC/PHII in developing a framework for integrating child health information systems serving newborn dried blood spot screening, early hearing detection and intervention, immunization, and vital records registration. The framework articulates the need for integration, presents collaboratively developed core functions for the integrated systems and the child health profile, and identifies strategies for sustained support for integration.

**Dr. Scott Young** (Agency for Healthcare Research and Quality [AHRQ]) described AHRQ's activities in assessing the role of health information technology (HIT) in improving health care quality and safety. AHRQ has a research portfolio related to the development, evaluation, and diffusion of HIT in clinical settings, with emphasis on the role of HIT in patient safety. Specific components in building the evidence base for HIT include, but are not limited to, electronic health records, clinical decision support, electronic prescribing, use of hand-held devices, and consumer use of the Internet. A total of \$60 million in HIT grants/contracts is proposed for Fiscal Year 2004: \$26 million to implement proven technologies in small and rural communities where HIT penetration has been low; \$24 million for developing, implementing, and evaluating the use of new and innovative technologies to improve patient safety and quality of care in diverse health care settings; and \$10 million for clinical data standards and interoperability. In the future, AHRQ intends to continue to demonstrate the value of HIT in improving quality and safety in diverse clinical settings, build on its previous investments, and expand collaboration with public and private partners.

**Dr. David Ross** (AKC/PHII) described the current efforts moving from individual program information systems to integrated systems as being akin to moving from a sack race, in which

participants set their own course and speed, to a three-legged race, in which participants must work in harmony in order to achieve their individual and shared goals.

A panel of stakeholders representing parents, pediatricians, health plans, hospitals, and public health presented their perspectives on what an integrated child health information system would do, and what the first step toward achieving it should be.<sup>1</sup> Common themes were the importance of having all stakeholders involved in the development of the systems, meeting the needs of the systems' users, protecting against misuse of information, and demonstrating the usefulness of systems.

In a discussion of concerns about integrated child health information systems, stakeholders agreed that these systems have the potential to return benefits to families, providers, health insurers and public health. Much work remains to be done, however, to ensure that the systems contain accurate information and are interoperable, and to resolve the thorny issue of who pays for the systems.

**Ms. Kristin Saarlax** (AKC/PHII) described the lessons learned from the All Kids Count experience. AKC is a program that has been funded by the Robert Wood Johnson Foundation (RWJF) since 1992. In its first Phase (1992-1997) it oversaw 24 planning and early implementation grants to develop immunization registries. In Phase 2 (1998-2000) it oversaw 16 implementation grants to advance immunization registries to fully operational status. In the current, final, phase (2000-2004) it is promoting the development of integrated preventive health information systems for children. The Public Health Informatics Institute was established in 2001 with RWJF support; AKC is now part of the Institute.

The primary goals of the current phase of AKC are to develop an action agenda for integrated child health information systems (CHIS), and to develop resources and tools to assist public health agencies in the development of integrated CHIS. Integrated CHIS are needed because many children do not receive all preventive or therapeutic services in a timely manner, failure to receive one type of service is correlated with failure to receive other services, many public health programs focus on the same target population without coordination of services and outreach, and there is a need for population-based information that can better identify at-risk children and target programs and services to their needs. The goal of integrated CHIS is to provide all appropriate information to patients/families, providers, and programs. The basic premise is that complete, accurate, and timely information will lead to improved service delivery and health outcomes for children. In this context, integration means providing a range of information to the user in a simple, comprehensive format so that he/she can readily take all indicated actions. Integration relates to the end user, not to the background machinery.

Four areas have been chosen as the first targets for integration – immunizations, newborn dried blood spot screening, early hearing detection and intervention, and vital records registration. These areas were chosen because they are: recommended for all

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<sup>1</sup>Stakeholders on the panel were Dr. Edward Gotlieb (practicing pediatrician), Ms. Jennifer Cernoch (Family Voices), Dr. Allan Lieberthal (Kaiser Permanente), Dr. Stephen Lawless (Nemours Foundation), and Ms. Amy Zimmerman (Rhode Island Department of Health).

infants/children, carried out or begin in the newborn period, time-sensitive, primarily delivered in the private sector but have strong public sector component, and are mandated in most or all states.

What is needed to move ahead are a shared vision and plan of action; agreement on core functions; definition and pilot testing of performance indicators; documentation and dissemination of best practices; studies that provide data on costs, cost savings, and changes in outcomes; and education/advocacy of stakeholders in public and private sectors.

**Mr. Bob Swanson** (Michigan Department of Community Health) described how the Michigan Childhood Immunization Registry (MCIR) is protecting Michigan's children. The purpose of MCIR is to improve levels of protection against vaccine-preventable diseases; provide a single site for a child's complete immunization record; provide a complete record for HEDIS (Health Plan Employer Data and Information Set) and AFIX (Assessment, Feedback, Incentive, exchange); and simplify "each visit" individual assessments.

In 1991 and 1994, Michigan had the lowest immunization levels of any state in the country. In 1997, legislation was passed (PA 540) establishing the legal basis for MCIR, and in 1998 a fully functional registry was put into production. In 1999, a vaccine inventory module was added to MCIR and in 2000 a reminder/recall module was released. By 2000, 100 percent of public health clinics were reporting to MCIR. In 2002 MCIR was integrated with WIC (Women, Infants, and Children) and Medicaid data systems, and in 2003, providers began accessing MCIR via the Web.

In developing MCIR, a centralized approach was taken to software development and database management but a regional approach was taken to marketing, implementation, and maintenance. Public-private partnerships were essential in both development and implementation. MCIR is population based, being populated from electronic birth records within two weeks of birth. There are now 2.8 million children in MCIR with more than 32 million shot records. Some 2,000 users access MCIR every day, and 1,932 provider offices submitted immunization data to MCIR in 2002. At the national level, 44% of children <6 years of age are enrolled in state registries with two or more doses of vaccine recorded; in Michigan, the figure is 86%.

MCIR provides individual assessment of immunization status at the time of a visit. It also provides assessment of immunization coverage in individual providers' offices and population assessments. Between January 2001 and October 2003 there has been a dramatic increase in the percentage of 19-35 month old children who are series-complete. Increases have been seen in all regions in the state. MCIR also provides sub-population assessments. For example, MCIR has demonstrated that children enrolled in WIC have coverage levels about 10% higher than community levels. MCIR has also provided data that significantly increase HEDIS compliance levels. Whereas 42% and 61% of Michigan children 19-35 months old were series-complete in 1991 and 1994, respectively, series-complete status (for a more complex series) was 81.6% in 2002.

**Dr. Scott Hamstra** (Indian Health Service [IHS]) described the IHS RPMS (Resource and Patient Management System). To illustrate the power and practical usefulness, he described a case study of a 15-year-old Native American male who presents to clinic for care of his diabetes and asthma. At registration, the business office clerk updates his demographic and billing information and confirms the appointment (in the scheduling system package). The nurse assesses previous measurements (e.g., blood pressure, peak flow) and adds current values, reviews health care maintenance reminders (e.g., immunizations) and health factors (e.g., smoking) based on national, age, and gender specific recommendations, and carries out previously ordered physician instructions (e.g., draw blood for Hemoglobin A1c) from the appointment system. Via computer, the provider reviews the current problem list and plan and updates them as well as refilling or changing medications. The health summary also includes past medical history, family history, and social history, all of which the provider can quickly update electronically. Lab tests are ordered and results sent electronically with immediate alert to the provider, who then signs off electronically. Lab results can be graphed to monitor trends and printed for patient education. The immunization module assesses and forecasts vaccines due and the nurse administers and electronically documents all aspects of the vaccines given. The pharmacy module gives provider warnings about allergies, drug interactions, etc. There is specific case management software for asthma and diabetes. If additional issues are reported that require subspecialty providers or specialty exams or tests that are not available at the primary care IHS facility, an electronic referral is completed. The system also provides quality management reports and community/public health information via local data searches. A portion of the local data is exported for inclusion in IHS' national dataset.

**Dr. Bill Adams** (Boston University) described the experience of an academic medical center in developing a child health information system. Boston Medical Center (BMC) Pediatrics has more than 30,000 annual visits from predominantly poor, publicly insured patients representing diverse ethnicities. The CHIS has evolved through four phases: repository building, real-time data entry, EMR-based primary care, and population-based primary care. Repository building began in 1994 with flat file transfer of laboratory and immunization data, which could be linked. This was useful for research and form printing for WIC, school, etc. Real-time data entry began in 1996 with hearing and vision screening, followed by immunization. In 1998 the Automated Record for Child Health (ARCH) was implemented, representing a comprehensive pediatric primary care electronic health record (EHR). ARCH enabled point of care entry in the medication room (previously it had required a dedicated data entry) and improved data quality and completeness. Nurse feedback was extremely positive. ARCH is based on evidence-based structured encounter forms and users are encouraged to provide entries as structured data. Information in ARCH includes problem-specific histories, problems, medications, development, risk assessment, growth monitoring, immunizations, vital signs and physical exam, anticipatory guidance, and WIC and school forms.

Use of ARCH resulted in significant improvements in including information about elimination, sleep, and discipline in the interim history. It also resulted in significant increases in risk assessment regarding smoking in the home, lead risk factors, tuberculosis risk factors, domestic violence, WIC enrollment, childproofing, guns at home, and dental care. Significant improvements were also seen in guidance on sleep position, poison center,

the importance of reading, and dental care advice. Six of seven clinicians queried “strongly agreed” that use of ARCH increases completeness, reminds them to do things they might forget, and improves the quality of guidance. Six of seven “agreed” or “strongly agreed” that ARCH was easy to use and that it improves overall quality of care. Six of seven strongly agreed that they would recommend ARCH to other practices. From the family perspective, there were significant improvements in clinicians discussing guidance topics and providing printed material on guidance topics.

BMC is now migrating to “Logician” which provides a comprehensive EHR for both adult and pediatric care. The pediatric templates build on ARCH content but include expanded disease management modules and establish interfaces for most laboratory and X-ray results. Logician is a generic design Oracle database with 200+ tables and high granularity.

In addition to improving clinical care, some of the robust child health information in both ARCH and Logician was shared with public health agencies. Currently, comprehensive immunization data for all children seen at BMC are regularly transferred to the Boston Immunization Registry. Planning for sharing of data for children with asthma is ongoing. The successful integration of detailed child health information gathered at the clinical point-of-care with public health information systems offers a model for a potentially powerful integrated data system to support and improve child health services.

The reality in the United States is that only 5-10 percent of clinicians use an EHR, with pediatricians having the lowest rate. This contrasts with Australia, Denmark, the Netherlands, Sweden, and United Kingdom, where 53-90 percent of clinicians use electronic medical records. The National Alliance for Primary Care Informatics (NAPCI), which includes a variety of pediatric, family practice, and adult medicine groups, held a summit in November 2000. The vision statement they issued was: “Every primary care provider will use information technology that includes electronic health records with the ability to access and communicate needed clinical information to achieve high quality, safe, and affordable health care.”

### *Breakout sessions*

Participants then went into a series of breakout sessions addressing four aspects of integrated child health information systems: governance, economic issues, information infrastructure, and use of information. Participants stayed in the same breakout group through four sessions. In the first session, they described the major issues facing integrated systems in each of the areas. In the second session, they discussed strategies for action, and in the third, they identified key actors to carry out the strategies. In the fourth breakout session, participants developed recommendations to report back to the entire conference.

Conclusions and principal recommendations in each of the four areas follow. It should be emphasized that the conference focused particularly on **integration** of existing and forthcoming child health information systems (CHIS), not development of new, single-purpose CHIS or a massive, comprehensive CHIS. Also note that CHIS should not be considered in isolation, but rather in the overall context of health information systems.



# GOVERNANCE

The Governance group differentiated between leadership, governance, and management. Leadership involves perpetuating a vision and sustaining support. Management involves implementation of a program. Governance, the purview of this work group, includes these activities:

- Defining functional outcomes.
- Creating accountability.
- Setting priorities.
- Making major policy decisions.
- Overseeing finances.

The work group felt that governance should be national in scope, with local input and implementation. Although government agencies could convene the governance mechanism, the governance should be semi-independent. Initially, the focus should be on integrating child health modules within the context of general health information systems, although overall child services, including education, social services, etc., should be kept in mind. Priority should be given to children with multiple health needs while developing systems that can meet the needs of all children.

Functional requirements should drive the governance agenda; technology should not. Clear accountability mechanisms must be part of the governance.

Strategies over the next three to five years should include approaching major sponsors to spearhead the effort, both in public and private sectors. A governance coalition of stakeholder organizations that represents perspectives of consumers, providers, public health agencies, policy and research bodies, health plans, technical organizations, and payors should be established. This coalition should define the scope of the effort, including functional system requirements and accountability. It should leverage existing successful initiatives such as PHIN and NHII.

Potential **consumer** representatives on the coalition include, among others, Family Voices, March of Dimes, Children's Defense Fund, the national Parent-Teacher's Association, and state child health advocates.

**Providers** could include American Academy of Pediatrics, American Academy of Family Practice, National Association of Children's Hospitals and Research Institutions, pediatric mental health services, nurses, laboratories, pharmacies, and pediatricians with electronic medical record (EMR) experience.

From the **public health** perspective, participants could include the Association of Maternal and Child Health Programs (AMCHP), Public Health Data Standards Consortium, Council of State and Territorial Epidemiologists (CSTE), Association of State and Territorial Health

Officials (ASTHO), National Association of County and City Health Officials (NACCHO), U.S. Department of Health and Human Services (AHRQ, Centers for Disease Control and Prevention [CDC], Centers for Medicare and Medicaid Services [CMS], HRSA), Association of Public Health Laboratories (APHL), and American Public Health Association (APHA).

From the **policy and research** perspective, participants could include the Society for Pediatric Research (SPR), Foundation for Accountability (FACCT), RAND Corporation, Gartner Group, Northrup Grumman, Association of Schools of Public Health (ASPH), AHRQ, National Quality Forum, and American Immunization Registry Association (AIRA).

**Health plan** representation could include American Association of Health Plans (AAHP), Association for Health Center Affiliated Health Plans (AHCAHP), and Alliance of Community Health Plans (ACHP).

**Technical** representation could come from National Association of Public Health Information Technology (NAPHIT), standards development organizations, American Medical Informatics Association (AMIA), PHIN, NHII, vocabulary groups, electronic medical record vendor association, and the federal Chief Information Officer subgroup on infrastructure.

**Payors** could include CMS, National Association of State Medicaid Directors (NASMD), Small Business Administration, Labor, Pacific (or National) Business Group on Health, chambers of commerce, Leapfrog, and other groups concerned with health care quality.

As steps for the next year, the work group recommended and received endorsement of the strategies recommended by participants at the meeting. They also recommended that AKC/PHII coordinate development of a proposal for funding of the governance coalition to be submitted to public or private funding sources (in January 2004) and formation of a steering committee of 15-20 people with representation from stakeholders (by June 2004). It was thought that initial funding could be secured by June 2004 if considerable creativity was exhibited regarding potential funding sources. The stakeholders' governance coalition should subsequently develop a formal proposal to become a part of an existing general health initiative (e.g., NHII, PHIN, by September 2004), and then join or become an advisor to that initiative (by December 2004).

The work group recommended that the stakeholders governance body continue in years 2-5 to perform its core functions: defining functional outcomes, creating accountability, setting priorities, making major policy decisions, and overseeing finances of the coalition.

## ECONOMIC ISSUES

Among the key issues addressed by this work group were: what an integrated CHIS is, what it will cost, who will pay, who will benefit, and how it is valued. Knowledge of the costs, benefits, implications, and outcomes of integrated CHIS is extremely limited. Funding is limited, fragmented, in silos (categorical), and unstable. During the next three to five years a business case must be well developed and marketed to all relevant stakeholders. There should be increased, coordinated federal funding and additional funding reflecting the range of stakeholders. In the longer term, CHIS should be considered part of the infrastructure for child health and part of the cost of serving children's health needs. The possibility of a trust fund for CHIS was discussed, as was the prospect of using regulatory tax incentives as was done with the Hill-Burton Act to construct hospitals.

Some barriers and challenges include the lack of a consensus definition for integrated CHIS and the health care system's silos, in which single-purpose information systems are developed independently, without overall coordination. Additionally, the costs and benefits of integrated CHIS may well accrue to different entities. The knowledge base regarding the value of integrated CHIS is limited and there are changing political and institutional priorities. Finally, funding sources are ill defined, and in some cases unknown.

Three main areas relating to economic issues were addressed: funding the capital investment in development of integrated CHIS, sustaining integrated CHIS, and providing incentives for new development in CHIS.

### *Capital investment*

Participants recommended several steps to provide financial support for capital investment in integrated CHIS in the short run. An immediate step could be a coordinated federal policy decision to have federal grants require integration of CHIS. Additionally, the business case for integrated CHIS needs to be developed rapidly for the private sector and the policy case for the public sector. The prospect of no-interest loans (through the Small Business Innovative Research program or other mechanism) should be pursued. Private sector involvement through corporate citizenship should also be pursued. In the next 3-5 years, an act modeled after Hill-Burton for health information systems (including CHIS) could be developed.

Achieving the coordination of federal grants would involve a common guidance from the Secretary of DHHS that grant programs relevant to children's health should include support for integrated CHIS. This guidance, which could require OMB clearance, must have clear language and specifications of what needs to be included in grant applications. To accomplish this common guidance, a letter or report could be drafted by AKC/PHII, and then reviewed and endorsed by stakeholders (including attendees at this meeting as well as others). The letter - provided to the Secretary - would specify the need for integrating child health information systems, including the business and policy cases, and emphasizing the potential impact on children's health from integrating CHIS. The central nature of interoperability should be stressed. It should build on current Presidential Initiatives (e.g.,

President's New Freedom Initiative, the E-government initiative, the Data Action initiative, and the Healthy People 2010 goals). In addition to the Secretary of HHS, other recipients could include the Secretaries of Education and Agriculture as well as national legislators.

Participants felt that no- or low-interest loans for health care professionals and providers could be developed based on some of the health plan accounts receivable funds (approximately \$200 billion, according to a 1994 GE report). This approach has been recommended by the National Alliance of Primary Care Informatics (paper published in the Journal of the American Medical Informatics Association). Banks are apparently exploring this funding option at present ([www.mbproject.org](http://www.mbproject.org)). Interoperability of systems would be a requirement for receipt of the loans.

### *Sustainability*

Immediate strategies include development of public-private partnerships where public information systems serve private needs. "Pay for performance" approaches could also be pursued. Additionally, contractual requirements of participation in integrated CHIS could be made for insurance plans.

In the next 3-5 years, strategies to be pursued include developing a user fee (per member per month). Since integrated CHIS should improve the quality of patient care, a Health Plan Employer Data and Information Set (HEDIS) requirement could be developed. This would require developing and pilot testing the indicators through a public-private partnership involving health purchasers (including Medicaid), health plans, providers, and health departments. Use of the indicators would then be recommended to the National Council on Quality Assurance (NCQA) by entities such as AAHP, ACHP, and AAP.

An incentive to employer purchasers of health insurance could be to decrease premiums for those purchasers requiring integrated CHIS. The care coordination made possible by integrated CHIS should be an incentive to consumers (children and parents). Enhanced reimbursement for implementing integrated CHIS could be an incentive to providers. Participation in integrated CHIS could be a criterion for "preferred provider" status. Because child health care is an important factor in parent selection of a provider, use of integrated CHIS by providers could become part of the parents' selection criteria. Efforts should also be made to have the American Board of Pediatrics (ABP) and the Joint Commission on Accreditation of Health Organizations (JCAHO) include integrated CHIS in their criteria for certification/recertification.

### *Incentives for new development*

One new-development strategy is to develop a surcharge of one mil per transaction on e-commerce transactions under HIPAA. This could generate a fund to provide grants to sustain or improve CHIS infrastructure. Some benefits of this approach are that it would require use of data transaction standards to participate and would support maintenance of confidentiality and privacy intentions of HIPAA. Accomplishing this surcharge would require working with the Association for Electronic Health Care Transactions (AFEHCT),

Workgroup on Electronic Data Interchange (WEDI), the E-risk group of large health plans, and the National Business Coalition for Health.

Other prospects for incentives for new development include corporate citizenship and charity. A market analysis of companies engaged in corporate citizenship could identify strategic interests and the business case for integrated CHIS could then be marketed to their governing boards. Foundations, faith-based and community-based organizations, as well as traditional charities, could also be approached.

Immediate actions are to define integrated CHIS and to develop and market the business/quality/policy/value case. During the next three to five years, the functional model of integrated CHIS must be defined, interoperability standards established, and indicators of performance developed.



# INFORMATION INFRASTRUCTURE

The four key issues identified in this area were nodes, arcs, unique identifiers, and data and messaging standards:

- Nodes create places in which electronic child health data are captured and processed.
- Arcs develop the physical infrastructure and processes for communicating among nodes.
- Unique identifiers support establishment of a national system for tracking individual and aggregate health care needs and outcomes.
- Data and messaging standards incorporate child health, public health, and bi-directionality into communications standards.

The key approaches are to spread the word, communicate, and inform to foster understanding and buy-in; involve stakeholders (including subject matter experts) in the process; create new forums; and break down organizational barriers to change.

## *Nodes*

The goal is to create and enhance places to capture and process electronic child health data. The objective is to include the full range of data sources, including electronic health records, laboratories, schools/daycare, mental health, environmental health, and financial institutions. The principal action item is to collaboratively develop standards, business processes, and system requirements to guide vendors in system development. This should be accomplished by collaborative efforts of entities such as NHII, PHIN, CMS, CDC, HRSA, AKC/PHII, HL7, Public Health Data Standards Consortium, vendors, and subject matter experts. The requirements should be completed within three years.

## *Arcs*

The goal is to develop the physical infrastructure and processes for communicating among nodes. The objectives are to increase visibility, engender trust among organizations, support education/training, and create a forum for ongoing discussion. Actions include publishing the proceedings of this conference (e.g., American Journal of Public Health Management and Practice supplement in Nov/Dec 2004), approaching the American Journal of Public Health to propose an issue dedicated to informatics, submitting editorials to pediatric journals, providing articles to professional association newsletters and Web sites, creating a media release directed to health editors, creating an electronic forum for further collaboration among stakeholders, and organizing and funding follow-on meetings. Other actions include creating a template for business agreements (and system business rules) and identifying and bringing together experts in organizational behavior to explore trust issues. Successful efforts should be surveyed to document models. AHRQ was suggested as a potential funding source for some of these activities.

To enhance education and training, public health and pediatric training grants should emphasize informatics and informatics training grants should emphasize child health.

### *Unique identifier*

The goal is to establish a unique national health identifier system. The objectives include ensuring: that the identity is, in fact, unique; that the identifier includes a check digit; that it is established prior to birth; and that there are legal limits on its use (HIPAA-level penalties). The actions include convening a national forum in the current post-bioterrorism, post-HIPAA setting. National experts should be enlisted to clarify risks and benefits. Some attributes include opt out/opt in provisions, independent administration, and a technique for creating the identifier.

### *Data and messaging standards*

The goal is to incorporate child health, public health, and bi-directionality into communications standards. The objective is to improve awareness of the need to incorporate child health and public health data into the standards process to improve interoperability and, therefore, data usefulness. Actions include continued participation of public health and pediatrics at the standards "table." Participants in this meeting should be encouraged to publicize activities and progress of the standards community within their own groups. Pediatricians should be involved with the Public Health Data Standards Consortium and AAP should continue its involvement in HL7. It was also suggested that AKC/PHII consider HL7 membership.

# USE OF INFORMATION

Users of information from integrated CHIS include: parents/families/guardians, physicians/practitioners, public health agencies, health plans, policy makers, health services researchers, schools, and other providers of care. Some of the uses of the information include: diagnostic management, care and outreach coordination (ensuring the right services at the right time), linking children to a medical home, identifying children at risk, assessing patient needs and linking them to resources, empowering families with better information about providers and services, improving continuity of care (prenatal through adolescence), education to families and providers on recommended care and services (e.g., reminders/recalls), assessing population needs and compliance with recommendations and mandates, monitoring the use of services, quality improvement, and evaluating programs and health outcomes.

The primary areas of concern are change management, technology, data quality, privacy and confidentiality, and structural/legal issues.

## *Change management*

This area includes the value case, workflow, time, cultural acceptance, and understanding. Actions proposed include gathering and publishing evidence, testimonials, and case studies that show the value of **integration** of data to families and creating a central repository of this information. It was suggested that AKC/PHII, in collaboration with all key stakeholders (especially families), take the lead and that government agencies might assist with funding. Another action is to use the information to stimulate early use of information in systems as they are developing. It was recommended that forums be provided for sharing stories and experiences in integrating CHIS and that those involved in integrated CHIS get on the agendas of existing meetings to discuss the importance of integrated CHIS. National and state initiatives should be reviewed to ensure that integration of child health information is represented.

## *Technology*

This area includes ease of use and integration into workflow. Actions recommended include ensuring ongoing involvement of the stakeholders and end-users in the development and refinement of the systems - bringing together technology specialists and program people. It will also be necessary to plan for ongoing enhancements, making sure that management and decision makers understand the needs for continuous improvement of the system. Systems should have "push" technology (alerts and notifications) as well as context- and role-based support built in to assist in interpretation of the information included. Easy access mechanisms should also be built in to ensure active use of information at the point of service without technical barriers. The feasibility of developing a community clearinghouse for open source software models should be explored. Development of "plug and play" integration components should be promoted.

## *Data quality*

Recommended actions include a listing and the details (vendors, costs, models, success rates) of matching algorithms in the clearinghouse mentioned above and to encourage the National Library of Medicine and others to fund continued development and evaluation of matching algorithms (name, demographics, and clinical data elements) and strategies for improving data quality overall. Other recommendations include continued investigation on unique identifiers (see Information Infrastructure section above) and ensuring that feedback loop mechanisms are incorporated into the system to ensure that updates and changes to the information in the system are pushed back to the source and to other participants/systems, including families. Clients should be able to participate in data verification at the point of service.

## *Privacy, confidentiality, and structural and legal issues*

Suggestions for any needed modifications to the AAP statement on electronic medical records to accommodate privacy and confidentiality issues for children and adolescents should be submitted promptly as the Academy is embarking on a revision of the statement. The national coalition proposed above (Governance) should analyze HIPAA and other policies/laws to see if they adequately address the unique privacy and confidentiality needs of children and adolescents and, if necessary, suggest modifications. NHII needs to address issues of interstate transfer of information of children and adolescents as well as adults, as children easily move across state boundaries but health records do not.

Each state should have a process that involves families and other stakeholders to address child and adolescent privacy and access issues. Integrated CHIS should have the capability to address any policies/recommendations around controlling access to data (role- and level-based access). Consumer education programs should be developed about integrated CHIS, including value, benefits, uses, and privacy and confidentiality protections.

Finally, a statement should be developed on how consumers are part of the process and can participate in the development of integrated CHIS, not just their use. Realistic expectations for consumer participation should be set.

# CONCLUSIONS AND RECOMMENDATIONS

Many efforts are underway to develop clinical or public health child health information systems but little attention is being paid to integrating the information from those systems. Continuing conscious efforts toward integration are essential. Participants at this conference made specific recommendations about governance, economic issues, information resources, and uses of information. Common threads in the recommendations were:

- Development of a national coalition of stakeholders to promote integration of separate child health information systems within the context of ongoing national initiatives such as NHII and PHIN.
- The need to develop the business and policy cases for integrated CHIS.
- The need to develop agreement on standards for collecting and transferring information.
- The need to get the word out about the importance of integrating separate CHIS to improve health and health services.

**NOTE:** The conclusions and recommendations of the conference summarized in this report are those of conference participants and do not represent the official views of the sponsors. The conclusions and recommendations have not been officially endorsed by any of the sponsoring agencies/organizations.



