

# A Vision for Child Health Information Systems: Developing Child Health Information Systems to Meet Medical Care and Public Health Needs

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In both the medical care and public health arenas, a variety of information systems have been developed to serve providers and program managers. In general, these systems have not been designed to share information with other information systems and provide comprehensive information about a child's health status to the information user. A number of initiatives are underway to develop integrated information systems. In December 2003, All Kids Count hosted an invitational conference "Developing Child Health Information Systems to Meet Medical Care and Public Health Needs." Through a series of plenary presentations and breakout discussion groups, participants developed a series of recommendations about governance, economic issues, information infrastructure, and uses of information from integrated child health information systems (CHIS). Common threads in the recommendations were: (1) 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 the National Health Information Infrastructure and the Public Health Information Network, (2) the need to develop the business and policy cases for integrated CHIS, (3) the need to develop agreement on standards for collecting and transferring information, and (4) the need to get the word out about the importance of integrating separate CHIS to improve health and health services.

**KEY WORDS:** child health, electronic medical record, information systems

Along with the development of new preventive and therapeutic interventions in health, there have been ma-

ior developments in information technology and the information systems that support public health and medical care. In the clinical arena, one of the most exciting developments has been the continuing evolution of electronic medical records, which are now in use in a number of practice settings, both inpatient and outpatient. Many of these information systems are capable of bringing together information from a variety of different sources, including nursing, pharmacy, laboratory, radiology, and physician notes. Some of the sources themselves have dedicated information systems to meet their individual needs (eg, pharmacy, laboratory). In general, these systems have not been designed to handle other facets of health care, such as reporting notifiable diseases to health departments or providing information directly to the patient.

In the public health arena, information systems have typically been designed to serve individual program needs (eg, surveillance, tuberculosis prevention and control), often in response to requirements of federal funding agencies. A single federal agency may fund several state/local programs, each of which has its own required information system for providing information

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to the national level and each of which differs from the others, requiring that state/local health department workers who are involved in a number of programs learn a variety of different ways of entering and summarizing information.

Beginning in the 1980s, increasing attention in the public health arena has been paid to the desirability of making the various systems congruent with one another and possibly even standardizing the way information is captured and transmitted. At the Centers for Disease Control and Prevention (CDC), a 1995 study reported that integrated information and surveillance systems "can join fragments of information by combining or linking together the data systems that hold such information. What holds these systems together are uniform data standards, communications networks, and policy-level agreements regarding confidentiality, data access, sharing, and reduction of the burden of collecting data."<sup>1</sup> The National Electronic Disease surveillance system (NEDSS) project is a direct outgrowth of the recommendations in that report as is the current Public Health Information Network (PHIN) initiative.

In the area of childhood immunizations, a revolutionary approach was undertaken to serve both medical care and public health needs by developing population-based immunization registries that gathered information from all providers of immunizations (whether private and public) and consolidated the information so any provider could, at a glance, determine the complete immunization history of a child.<sup>2</sup> Although practice-based registries had been used for some years, this was the first attempt to capture information from all sources, private and public, and was particularly useful since more than 25% of US children receive immunizations from more than one provider before they are 3 years of age. Registries can also generate reminder/recall notices, official immunization records, and assess the immunization coverage in a given area or practice. All Kids Count was privileged to participate in supporting the development of immunization registries, which have advanced further than other information systems seeking to bridge the public/private divide.<sup>3</sup> Currently, more than 40% of US children have at least two immunization doses recorded in a population-based registry.<sup>4</sup>

Considerable effort has gone in to defining functional standards for registries<sup>5</sup> and agreement has been reached that HL7 packaging will be used for transferring information.<sup>6</sup> A certification process for registries is being developed.<sup>7</sup> Although registries have proven their worth and are well advanced, very few are capable of communicating with other health information systems. Most are not yet capable of exchanging information with other registries and few are integrated with information systems serving other program areas.

An important, practical, approach to integrating child health information systems has been undertaken by the Genetic Services Branch, Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA/MCHB). Since 1998, HRSA/MCHB has undertaken a series of grant initiatives to facilitate, among other things, the development of integrated child health information systems to include newborn screening systems. As a starting point, four programmatic areas were selected—newborn dried blood-spot (NDBS) screening for inherited and congenital disorders, early hearing detection and intervention (EHDI), immunizations, and vital registration. These 4 were selected because they are recommended for all infants/children, they are carried out (or begin) in the newborn period, they are time-sensitive (delay in carrying them out can lead to adverse outcome), and they are primarily delivered in the private sector but have a strong public sector component (eg, public health agencies, federally qualified health centers). Additionally, they are mandated in most or all states.

In the clinical care area, attention has been paid to the special requirements for electronic medical record systems in pediatrics.<sup>8</sup> Some of the important data needed in pediatric records that may not appear in adult electronic medical records include growth data, age-based normal ranges, information on dosage of medications, and immunizations. The topic was further explored in a 2000 meeting on Information Technology in Children's Health Care, which also outlined major research needs.<sup>9</sup>

Several national initiatives are currently underway that have major implications for the development of integrated child health information systems. These include the National Health Information Infrastructure (NHII) initiative, which addresses all aspects of health information systems (including clinical medicine and public health), and CDC's Public Health Information Network (PHIN) initiative, which addresses the public health component of NHII.<sup>10,11</sup> In addition, the Center for Medicare and Medicaid Services' Medicaid Information Technology Architecture (MITA) initiative addresses information systems for the nation's largest payor of health care.<sup>12</sup>

The various initiatives in both the clinical and public health arenas have similar objectives but are proceeding, to a certain extent, independent of one another. The time seemed ripe for those working in these activities to discuss commonalities and, if possible, agree to work together to enhance the probabilities of success of all the endeavors.

To foster development of a shared vision of integrated child health information systems (CHIS) and an action plan to develop them, All Kids Count hosted an invitational conference "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 nongovernmental organizations.\* The objectives of the conference were to: (1) review national initiatives and other factors influencing the development of child health information systems infrastructure, (2) develop concrete recommendations, reflecting the input of stakeholders, for the development of immediate actions and actions for the next 3–5 years, and (3) enlist stakeholders in communicating, supporting, and implementing the recommendations.

An external planning committee developed the agenda for the meeting, 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 plenaries 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 and made recommendations for immediate actions and actions for the next 3–5 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 end user in a simple yet comprehensive format so that he/she can readily take all appropriate actions. Integra-

tion does not imply a specific technical model. Authorized end users of the information may be clinical care providers, public health officials, or patients/families.

In the keynote presentation, Dr. Rick Shiffman (Yale University Center for Medical Informatics) provided a conceptual framework for considering integrated child health information systems.<sup>13</sup> He was followed by presentations summarizing important national initiatives including the National Health Information Infrastructure (NHII), the Public Health Information Network (PHIN), the Medicaid Information Technology Architecture (MITA) initiative, activities of the Genetic Services Branch (Division of Services for Children with Special Healthcare Needs, Maternal and Child Health Bureau, Health Resources and Services Administration [HRSA/MCHB]),<sup>14</sup> and activities of the Agency for Healthcare Research and Quality (AHRQ). Dr. David Ross (All Kids Count/Public Health Informatics Institute [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. 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 the systems contain accurate information and are interoperable, and to resolve the thorny issue of who pays for the systems.

The last set of plenary presentations included a brief summary of the history of All Kids Count and the lessons learned from its 12 years of activities<sup>3</sup> and case studies describing: the health impact of immunization registries in Michigan, the use of a comprehensive electronic health record in the Indian Health Service, and the utility of electronic medical records in ambulatory pediatric practice.

The plenary presentations are summarized in proceedings of the conference, which are available at [http://www.allkidscount.org/pdfs/VisionConfproceedings\\_30mar2004.pdf](http://www.allkidscount.org/pdfs/VisionConfproceedings_30mar2004.pdf).

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\*\*External planning committee members were: 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 Saarlus, Ellen Wild. Patricia Richmond was overall Conference Coordinator.

Participants then went into a series of breakout sessions addressing 4 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. It should also be noted 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 actual implementation of a program. Governance, the purview of this workgroup, includes the following activities: (1) defining functional outcomes, (2) creating accountability, (3) setting priorities, (4) making major policy decisions, and (5) overseeing finances.

The workgroup 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. The focus should initially be on integrating child health modules within the context of general health information systems, although overall child services including education, 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; capabilities of present and emerging technology should not. Clear accountability mechanisms must be part of the governance.

Strategies over the next 3–5 years should include approaching major sponsor(s) 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 identified or es-

tablished. This coalition should define the scope of the effort, including functional system requirements and accountability mechanisms. It should leverage existing successful initiatives such as PHIN and NHII.

Potential representatives of the various perspectives are listed in the proceedings of the conference cited previously.

As steps for the next year, the workgroup 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 (eg, NHII, PHIN, by September 2004), and then join or become an advisor to that initiative (by December 2004).

In years 2–5, the workgroup recommended that the stakeholders governance body should continue 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 workgroup were: what an integrated CHIS is, what it will cost, who will pay, who will benefit, and how it is valued. Current knowledge around the costs, benefits, implications, and outcomes of integrated CHIS is extremely limited. Funding is limited, fragmented, in silos (categorical), and unstable. During the next 3–5 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 diversity of stakeholders. In the longer term, CHIS should be considered part of the infrastructure for child health and part of the cost of doing business 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 current barriers and challenges include the lack of an agreed definition for integrated CHIS and the silo nature of the health care system, 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, even 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, a Hill-Burton type act 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 would probably require OMB clearance to implement, must have clear language and specifications of what needs to be included in grant applications. To accomplish this common guidance, a letter or report should be provided to the secretary specifying 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 (eg, President's New Freedom Initiative, Health and Wellness Program, the E-government initiative, the Data Action initiative, and the Healthy People 2010 goals). The letter could be drafted by AKC/PHII then reviewed and endorsed by stakeholders (including attendees at this meeting as well as others). In addition to the Secretary of DHHS, other recipients could include the Secretaries of Education and Agriculture, as well as 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

Some immediate strategies to pursue for sustainability 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 that require 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 be an important factor. 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 strategy suggested for incentives was to develop a surcharge of one mil per transaction on e-commerce transactions under HIPAA. This could generate a fund that could provide grants to sustain or improve CHIS infrastructure. Some benefits of this approach are that it would require use of data transaction standards in order 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.

General immediate actions were to define integrated CHIS and to develop and market the business/quality/policy/value case. During the next 3–5 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: (1) nodes create places in which electronic child health data are captured and processed, (2) arcs develop the physical infrastructure and processes for communicating among nodes, (3) unique identifiers support establishment of a national system for tracking individual and aggregate health care needs and outcomes, and (4) data and messaging standards incorporate child health, public health, and bi-directionality into communications standards.

The key approaches advocated were 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 the formation of information infrastructure to support the CHIS vision. This should be accomplished by collaborative efforts of entities such as NHII, PHIN, CMS, CDC, HRSA, eHealth Initiative, AKC/PHII, HL7, Public Health Data Standards Consortium, vendors, and subject matter experts. The requirements should be completed within 3 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 a summary of this conference (eg, *Journal of Public Health Management and Practice* supplement), 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; includes a check digit; is established prior to birth; and 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.

## ● 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 (eg, reminders/recalls), assessing population needs and compliance with recommendations and mandates, monitoring the use of services, quality improvement, and evaluating programs and health outcomes.

Change management, technology, data quality, privacy and confidentiality, and structural/legal issues were identified as the primary areas of concern.

### 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

Actions recommended were to 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 previous Information Infrastructure section) and ensuring that feedback loop mechanisms are incorporated into the system to ensure 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

It was recommended that suggestions for any needed modifications to the AAP statement on electronic medical records to accommodate privacy and confidentiality issues for children and adolescents 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 should be set.

## ● Conclusions and Recommendations

There are many efforts 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 infrastructure, and uses of information. Common threads in the recommendations were: (1) 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, (2) the need to develop the business and policy cases for integrated CHIS, (3) the need to develop agreement on standards for collecting and transferring information, and (4) the need to get the word out about the importance of integrating separate CHIS to improve health and health services.

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