

# The Near-Term Future for Child Health Information Systems

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The developmental process in children offers an opportunity to influence their health and well-being as adults. The information infrastructure of the future needs to support the multiple partners responsible for providing elements of the health protection and health care of children. In this partnership, public health plays simultaneously a supportive role and a leadership role. Five tasks need to guide near-term information systems thinking with respect to establishing a basis for building electronic linkages among various child health programs. First, the nation's vital records system must be reengineered to ensure that this key information asset can be integrated into other child health information systems. Second, through an appropriate governance structure, the key stakeholders in child health should endorse standards and requirements that define a longitudinal health record for children. Third, public health agencies should develop a thorough business case/value proposition that drives mutually developed and mutually endorsed requirements for the integration of presently fragmented systems. Fourth, public health should take the lead in ensuring that parents have convenient access to information that can support the coordination of their child's care and development. And fifth, provider groups and public health agencies should join research networks to study how information supports positive changes to children's health.

**KEY WORD:** child health information systems

A significant body of research points to the importance of the early childhood developmental process on adult health and "suggests that the developmental process in childhood offers a significant but time-limited opportunity for health promotion and disease prevention."<sup>1</sup> This window of health opportunity in-

cludes maximizing the delivery of preventive health services beginning at birth but also extends to coordination of social support services and educational services, especially for children identified as at risk for a number of conditions and needs. Over the past 30 years, the United States has established comprehensive screening for heritable and other congenital disorders through newborn dried blood-spot screening programs extant in every state. Additionally, almost all states now screen newborns for sensorineural hearing loss (SNHL), because an estimated 5,000 infants (1–2 per 1,000 newborns) are born in the United States with moderate, severe, or profound bilateral SNHL.<sup>2</sup> With screening information and well coordinated programs, SNHL should not impede a child's chances to learn and progress at a normal rate. Today, we expect that life threatening or life altering conditions will be detected in the first days of life and appropriate care will be instituted to prevent adverse consequences of these conditions. Vaccine protection also begins at or near birth with the administration of the first dose of hepatitis B vaccine, usually administered in the hospital.

In addition to providing scheduled preventive services, such as regular immunizations and screenings for lead poisoning, vision, hearing, developmental disabilities, genetic disorders, etc., the public health system

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is challenged to inform parents and policy makers about the impact that lifestyles have on their children's health and to explain how these choices will impact their health when they become adults. For example, using the power of information, public health can help citizens understand the threat posed by obesity and how physical activity is linked to community planning, recreation facilities, parks, and sidewalks. The medical community is challenged with reacting to the increasing rates of chronic conditions in children, conditions that were once only seen in adults. New information systems and linkages among the systems of health partners are needed to document improvements in child health services, offer parental access to information and informal resources and inform policy makers in a more timely manner.

### ● Our Children Today

Understanding the role emerging information technologies (ie, standards that structure data, standards that facilitate data exchange, visual display technologies, etc.) should play in child health requires an understanding of the health care system that seeks to benefit children and the social context in which they are developing. Children under age 18 represented about 25% of the population in 2001, a population that is becoming more ethnically and culturally diverse (64% of US children were White, non-Hispanic; 16% were Hispanic; 15% were African American, non-Hispanic; 4% were Asian/Pacific Islander; and 1% was American Indian/Alaska Native.) While the poverty rate for children has leveled off and remains stable, economic security remains a major challenge for a large segment of the nation's children.<sup>3</sup> The percentage of children covered by health insurance has increased, in large part due to the implementation of Medicaid expansions and State Children's Health Insurance Programs (SCHIP) throughout the country. Medicaid has played and will continue to play a major role in supporting health coverage and health improvements for children. Several demographic and social trends indicate positive improvements that will positively impact the health of children. Key among them are:

- In 2000, the poverty rate for children living with family members was 16%, a decrease from a high of 22% in 1993.
- Birth rates for unmarried teenagers have dropped since 1994, while increases in rates for women in their 20s and older have slowed. In 2001, the overall birth rate was 44 births per 1,000 unmarried women ages 15–44.

- Since 1995, the percentage of children living with two married parents has remained stable around 70%, ending a decades long downward trend.
- The proportion of children ages 3 to 5 enrolled in preprimary education rose from 42% in 1990 to 61% in 2000.

Other trends that affect overall child health are less positive. For example,

- In 2001, more than a third of US households with children had either physically inadequate housing, crowded housing, or housing that cost more than 30% of the household income.
- Data from 2001 paint a mixed picture of children covered by health insurance (government 26%, private 68%). On the one hand we witnessed an all-time high of all children covered, yet the proportion of children covered by private health insurance dropped slightly.
- Nearly one-quarter of children and adolescents did not have an annual preventive health care visit at the recommended ages.<sup>4</sup>
- Fifteen percent of children and teens ages 6 to 19 are overweight and another 15% are at risk of becoming overweight—triple the rate of only 20 years ago.<sup>5</sup>

The health of our children results from the interplay of social, economic, and disease phenomena. The consequences of being uninsured are that the uninsured receive less preventive care, are diagnosed at more advanced stages of illness, receive less therapeutic care, and are 30–50% more likely to be hospitalized for an avoidable condition. Health insurance provides access to care, which reduces mortality rates on the order of 10–15%. Children in poor health miss more school days and have lower cognitive development. Poor health in childhood leads to lower wages and lower labor force participation.<sup>6</sup> These data indicate that children remain at risk and need a coordinated approach to child health. Information technology cannot ameliorate problems of access, but it can be used to ensure that opportunities for preventive health services are not missed, can improve care coordination, and can make available information in ways that will stimulate policy action and empower parents.

Looking to the near term, future improvements in health status will derive in part from improvements in the way in which children interact with their home, school, and physical and social environments. New child health information systems must acknowledge this interplay of forces and systems within community systems of care—the health care system, school system, environmental protection system, city planning, public safety—and find effective ways of combining/linking

data to result in information that focuses action and coordinates those responsible for improving child health outcomes.

### ● Possibilities in the Near-Term Future

Coordinated attention to the health and developmental needs of children, at least beginning at birth, requires a longitudinal approach to development and health maintenance. Coordinating information about a child throughout the preschool years has been a vexing problem. Recent innovations in information technology have created opportunities to rethink the approach and to reset an expectation about the role information should play in improving child health and development. Most observers of technology today would agree that technological limitations are no longer the barrier. The major barriers to information that improves the health of children are related to the absence of an accepted approach to governance. That is, we lack a social understanding of the potential benefits of shared information, an acceptable means to finance a new information infrastructure, agreement on standards, and a governance approach that mediates the interests of the multiple stakeholders that have legitimate interests in collecting, managing, and using individual and aggregated data on children. Given the significant role Medicaid programs play in health system development and in child health in particular, Medicaid must play an important role in promoting clear goals and systems development. Medicaid, public health, and the rest of the medical care sector must ensure their efforts are in alignment.

In 1926, C.E.A. Winslow described the field of public health as “the science and art of preventing disease, prolonging life, and promoting physical and mental health and efficiency through organized community efforts, for the sanitation of the environment, the control of community infections, the education of the individual in the principles of personal hygiene, the organization of medical and nursing service for the early diagnosis and treatment of disease and the development of social machinery that will ensure to every individual in the community the standard of living adequate for the maintenance of health.”<sup>7,8</sup>

Almost a century later, Winslow’s definition serves as an instructive guide for thinking about the future of the information infrastructure needed to serve child health, development, and well-being. Investments made in information systems in the name of improving child health should advance longevity; inform policy makers and the community at large about environmental threats to a child’s health; ensure that every

child is protected from infectious diseases preventable through timely administration of vaccines; maintain a web of surveillance for emerging infectious diseases; ensure that newborns are screened for conditions that can, if treated and managed properly, result in normal, productive lives. Most importantly, new child health information systems must show policy makers and the public the extent to which every community is producing “a standard of living adequate for health and well-being”—a concept central to the Universal Declaration of Human Rights.<sup>9</sup> Child health information and its supporting infrastructure will be judged by what every community knows about the threats to health of their children, how timely that knowledge is, and what is done to act upon that knowledge.

Today, we understand that optimum child health results from a partnership among parents/guardians, their physicians, nurses, and other health care providers representing a medical home, and a coordinated public health and health care system, including financing. Future information infrastructure must support and strengthen this partnership. The business case for future investment in information technologies in the child health arena derives from how it supports and guides the partners whose joint actions will improve the health of children. Each partner has special needs that must be met by new information systems. But, the interaction of partners is equally important. The information needed to support coordinated interaction will become an important aspect of near term activity. Before establishing a general framework for measuring child health information systems, we must first understand the view of each partner.

### ● Parental View

Parents want to know how their child’s development conforms with normative milestones and may need accessible information that assists their understanding of their child’s progress. For children with special health care needs, parents express a strong desire for efficient access to information about disorders and access to information that assists in the coordination of care. Parents also want an information infrastructure that supports the coordination of care through a medical home, ensuring accurate information is available to the array of providers required to support their child.

For children without special health care needs, parents share the desire for a medical home that coordinates care and offers supporting information, as needed. All parents expect that providers know important information, such as immunization status, and are

prepared to provide the right preventive treatment at the right time in their child's development.

Parents share the same concern for privacy and confidentiality in dealing with their children's health information as they do with their own. In the future, we should assume that parents will become more active consumers, pressing for longitudinal health records and appropriate access to health information. Thus, information technologies should be judged on the degree to which they support education about health promotion and disease prevention, improve coordination of care, and make care more accessible.

### ● Provider View

In November 2002, the Institute of Medicine issued a report stating the "the American health care system is confronting a crisis. The health care delivery system is incapable of meeting the present, let alone the future, needs of the American public."<sup>10</sup> During the past decade healthcare providers have confronted the fact that care is delivered within a very complex system and that the complexity of the system breeds mistakes, can cause suboptimal care, and harm people.<sup>10-13</sup> The combination of escalating costs,<sup>14</sup> skyrocketing insurance premiums, costly administrative burdens and inefficiencies, and growth in the elderly population create a version of the perfect storm in health care<sup>15</sup> and threaten a shaky health care system for children.

The American Academy of Pediatrics medical home initiative<sup>16</sup> stresses accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care for children. In addition, the National Health Information Infrastructure (NHII) and the Connecting for Health initiatives reflect national attention to the complex problem of improving care while constraining costs.<sup>17,18</sup> The NHII argues for an infrastructure that produces on-demand information as a step towards resolving pervasive information deficits and inefficient administrative systems.

To participate fully in this solution, the pediatric provider needs cost-effective information tools that offer a longitudinal health record, chart developmental milestones, and present a complete and up-to-date picture of every child's preventive health services, such as immunization history and screening results. To be of maximum use, the electronic health record (EHR) must support the unique needs of the pediatric population, link to other information systems, and integrate information from other provider organizations as well as from public health programs. In effect, we will judge the EHR in child health by how well the record arms providers and parents with information that maximizes each child's developmental trajectory and supports the

elements of the medical home. Core public health programs, such as newborn screening and immunization, stand to benefit also and will judge the EHR on the basis that it meshes seamlessly with their systems and facilitates more effective population assessments and case management.

### ● Public Health View

Public health agencies influence community understanding of the threats to child health, manage programs that create community-level protection against disease and promote health, and in some cases provide aspects of primary care. In the future, we should expect that all communities will strive to achieve five basic goals for their children. They need to ensure that children are safe; healthy; nurtured in a stable, caring environment; succeeding in school; and supported by an effective interaction of supporting programs and systems.

From the community's perspective, future child health information systems should be judged on how well they support these goals, monitor progress towards these goals, and show where and how interventions are needed. Public health agencies play an important role in ensuring community interests are met. Community interests will be best served by increasing access to data that can be analyzed by and for community groups in a manner that allows them to urge policy action in areas that threaten their children's health.

Public health has adopted an enterprise view of its information system needs,<sup>19-21</sup> which means it has adopted an information architecture based upon standards for coding and communicating data. The Public Health Information Network (PHIN) vision will drive future child health information systems development within public health. At least two important consequences should result. First, a standards-based architecture within public health should enable a joining of public health data needs with the needs and wants of other health care partners. Disease surveillance, health promotion interventions, and preventive health services can improve by creating a more seamless linkage between public health and health care delivery systems.<sup>22,23</sup> It should be noted, however, that the PHIN architecture is a necessary but not sufficient step to accomplishing this linkage. Significant attention must be paid to implementation success factors, such as organizational readiness and willingness to change. Second, parents/guardians will be better served because their children will receive the right services at the right time and they will be more readily guided to informational resources they need to assist their child's development.

To be fully successful in their child health role, public health agencies need to build systems that link or integrate information, in effect to adopt the perspective of the whole child within a whole community,” supported within the context of the medical home. They need to link information in ways that elicit better understanding of community health dynamics.<sup>24</sup> Adopting the “whole child within a whole community” view requires that public health agencies should convey in their public use of information an understanding of demographic, business, housing, community planning, and lifestyle trends that influence child health.<sup>21</sup> In their secure, role-based, confidential systems designed to support families, providers, and case managers, they should be capable of assembling (or integrating) all the information they hold on a child into a consolidated health record, including in it every aspect of preventive services information (eg, immunization status), screening results (eg, hearing, metabolic, lead poisoning, etc.), and practice-based knowledge to ensure that opportunities to promote the child’s health and development are not missed. We argue that an explicit goal of the NHII should be to enable this comprehensive, patient-centered record, accessible by the multiple stakeholders for the purpose of fulfilling their respective roles. Public health plays a supportive role in the assembly and communication of this information for some purposes and a primary role for other. Public health must assist child health and development by presenting information that highlights important health problems and also explains the context in which they exist. Public health information in the future needs to do a better job at mobilizing parents and providers in the task of nourishing children’s adult health.

### ● Five Tasks for the Next 3 to 5 Years in Child Health Information Systems

The next few years offer hope that those responsible for shaping new child health information systems will be enabled by new technologies and a new spirit of collaboration. Dougherty and Simpson,<sup>25</sup> in their recent article summarizing a national meeting about measuring the quality of children’s health care, conclude that “the highest-priority recommendation for national action was to create the requisite information technology (IT) infrastructure for quality measurement in children’s health care and across all health care sectors.” This represents a major challenge, one that can only be addressed by through vigorous leadership by public health in forging and supporting alliances that focus attention on child health, active partnerships with Medicaid programs, and continuous attention to build-

ing a standardized electronic infrastructure. Among the steps we can take in the near term, 5 significant tasks need attention:

1. **Reengineer vital records**—The United States should complete the task of reengineering the vital records system. Birth and death records underpin many statistics that track changes in child health status. Reengineering the birth system will allow it to populate screening systems and immunization systems, thereby closing the quality feedback loop. Timely knowledge that a child was born is the only efficient and timely way to begin the longitudinal health record. Increased attention and funding to this hidden national treasure is essential.
2. **Agree on standards**—Through a governance structure acceptable to all,<sup>26</sup> the key stakeholders in child health—parents, providers, payers, environmental and public health agencies—should discuss and eventually endorse standards and requirements that define a longitudinal health record for children. Child-centered information accessible to providers at an affordable price should be accomplished before the end of this decade.
3. **Develop a policy and business case**—Public health agencies should develop a thorough business and policy case (value proposition) that drives mutually developed and mutually endorsed requirements for the integration of presently fragmented systems. Working from the same set of blueprints will eventually ensure that every state public health agency can view a whole child within a whole community.
4. **Develop means for patient and family access to information**—Public health should take the lead in ensuring that parents, especially those of children with special health care needs, have logical and convenient access to information that can support the coordination of care and development. Measuring this capability should be factored into Title V grants and other grants that support maternal and child health information.
5. **Document improvements in health and health services**—Provider groups and public health should join research networks to study how information leads to changes in children’s health.<sup>27</sup> These health services research networks should model practices and approaches that successfully highlight some of today’s difficult problems, like the rise in childhood obesity, asthma, and other chronic diseases. Understanding how to make community data visible and a stimulant to action will change our children’s health for the better.

Achieving these 5 tasks will improve the health of children because they will focus our attention on how well services are delivered, provide expanded

information for families, chart a course for the integration of public health's child health information systems, establish a widely adopted norm for a longitudinal health record that begins at birth, and strengthen the nation's vital records system. Focused attention to the information needs associated with child health and development will help to ensure that every child has a healthy start and every community possesses the information it needs to support the health of children.

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