

**A Report on the Feasibility
of Establishing the Health Portion of**

CHEER

**(Child Health and Education Electronic Record)
for Los Angeles County Foster Youth**

April 2005

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Executive Summary

The Child Health and Education Electronic Record (CHEER) is a proposed automated system for exchanging records and information for children in Los Angeles County's foster care system. This report is the result of a research and planning project conducted by the Children's Action Network with funding from The California Endowment. The intent of the project is to document the most critical issues and challenges in collecting data and developing an electronic system, and propose concrete recommendations and solutions.

An electronic records system is an essential tool for medical and social service providers to better serve the foster care population. With such a system, foster children will have greater protection against dangerous practices that result from an absence of medical histories. For the first time, doctors will have a reliable and consistent source for those histories, aiding them in the diagnosis and treatment of illness and reducing errors and omissions. Caregivers will be better informed about the health needs of children in their care. Caseworkers and public health nurses will be able to develop and follow through on health case management plans for foster children.

Research conducted for this study consisted of over 70 interviews with potential stakeholders and users: caregivers, emancipated foster youth, medical providers, social service and public health workers, and other experts and advocates. An extensive literature review of materials from a range of sources aided in providing detailed information and in shaping our findings and recommendations. Additionally, we examined analogous systems and efforts in other areas of California and the U.S., as well as in related programmatic areas, to glean lessons learned and assess their potential as solutions for Los Angeles County.

Our research highlighted the following major problems inherent in the current process of tracking health care information for foster children.

Key Findings

1. Inadequate medical records for children in foster care contribute to a number of dangerous—and in some instances life-threatening—practices, including multiple immunizations, the over-prescription of powerful psychotropic medications, misdiagnoses, and medical errors and omissions.
2. The provision of adequate health care to foster children is severely hampered by the lack of reliable historical patient information, in large part because information contained in Los Angeles County's current Health and Education Passport (the collection of paper forms provided to caregivers) is, for most children, incomplete or not current.
3. Practices for recording and collecting data for foster children are not standardized.

4. Caregivers report that they lack both sufficient training in collecting and maintaining health records and forms, and information regarding those records' importance to child health and case management.
5. Medical providers are reluctant to adopt a system that increases their already high workload or that of their staff, particularly if the system serves only a small percentage of their patients.
6. The mandated Child Welfare System/Case Management System (CWS/CMS) used in California does not generally provide accurate, complete, or timely health information.
7. State Medi-Cal information systems may provide some useful historical medical data.
8. Memoranda of Understanding, consent forms, and court orders may be sufficient to satisfy state and Federal confidentiality restrictions and permit data and record-sharing.
9. A number of disparate systems collect piecemeal health and medical data on children in the Los Angeles County foster care population, resulting in poor coordination of services, duplicative efforts, and large information gaps.

Solution

The solution is an Internet-based universal electronic medical record for Los Angeles County foster children: CHEER. This record will accept data from numerous sources and permit authorized sharing from a single, monitored source. It will greatly facilitate the coordinated collection and use of health and, ultimately, education information.

With its links to Medi-Cal—through which many children receive services long before they enter the child welfare system—CHEER will make it possible to obtain a complete medical and health care history on many, if not most, foster children. This will dramatically improve the ability of medical personnel to accurately diagnose and treat foster children, a significant breakthrough.

The system envisioned will create standardized procedures for caregivers, medical providers, and social service workers to enable the collection of health data into a centralized system. It will act as a conduit, feeding information to authorized recipients through a secure electronic portal and acting as a dynamic, real-time (or close to it) record of each child's medical history.

The primary benefits of CHEER will be:

- Improved quality and consistency of health care
- Possible reductions in health care costs
- Improved access to information
- More complete historical data enabling better diagnoses and treatment
- Improved tracking and management

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- Expedited permanency planning for foster children
- Enhanced oversight, accountability, and outcome measurement

CHEER will utilize the Department of Children and Family Services' HUBs—hospitals or clinics that will coordinate health services for foster children and serve as medical entry points for all children entering foster care—as the primary points for data collection. CHEER will be the mechanism for the maintenance of medical records at HUBs and for those providing services to foster children served by HUBs. The CHEER model is viable for Los Angeles County and a pilot can be developed and implemented in a nine-month time period at a reasonable cost.

Introduction

Project Description and Goals

CHEER, the Child Health and Education Electronic Record, is a proposed automated system that can securely exchange information on children in Los Angeles County's foster care system between authorized users—health care providers, schools, foster parents, and caseworkers. Current processes rely on paper records and obsolete computer systems that often contain inaccurate and out-of-date information. Health providers cannot access medical histories and prescription data, and educators have little or no information on prior test scores, credits earned, classes taken, or transcripts.

The Children's Action Network (CAN), a Los Angeles-based nonprofit, is the CHEER project coordinator. With funding from The California Endowment, CAN spearheaded this effort to document the major issues and challenges in developing an electronic system, assess which solutions might be feasible for Los Angeles County, and develop practical recommendations for moving forward.

Such an electronic information system is not a new concept, though it has not as yet been successfully implemented in Los Angeles County. Now, however, the requisite technologies exist and are relatively inexpensive, and policymakers have initiated efforts to digitize and automate many administrative and data management functions of government, the educational system, and health care. Several years of intense advocacy on the Federal, state and county levels have built political support for the concept.

The system envisioned will, when fully realized, create standardized procedures for caregivers, medical providers, educators, and social service workers to enable the collection of health and education data into a centralized system. This system will act as a conduit, feeding information to authorized recipients through a secure electronic portal and acting as a dynamic, real-time (or close to it) record of each child's medical history.

The potential benefits of such a system are enormous. Doctors will be able to more effectively diagnose and treat children in foster care. Caregivers will be better informed about the health needs of those in their care and will be relieved of the burden of handling paper forms. Caseworkers will have a single, reliable source of health and school information for children in their caseload, reducing the amount of time spent searching for and obtaining records.

Foster children will be shielded from some of the dangerous practices that result from the absence of medical histories, such as multiple immunizations, the over-prescription of powerful psychotropic medications, and misdiagnoses. The expense of providing health care to this population will decrease. Child mobility may be reduced as foster parents, relative caregivers, and group homes are better able to address each child's individual health care needs.

While this may be a compelling vision, there are serious challenges to developing and maintaining such a system. These include technological hurdles, policy changes, creating

incentives for participation, identifying funding sources, and instituting standardized procedures for accessing and providing health care to foster children. The solution is not easy, but the system can no longer afford not to act.

Background and History

Providing medical services to foster children is a daunting challenge. Nearly half of California's foster children suffer from chronic illnesses such as asthma, diabetes, or serious visual and auditory problems; almost as many require ongoing medical treatment. Foster children are three to six times more likely than those in the general population to have significant psychological or behavioral problems. Because they are in the protective care of the state, these children rely on public health services. But a combination of complex systems, uncoordinated services, bureaucratic red tape, and an absence of basic medical records has resulted in few foster children receiving adequate care.

California's inability to provide adequate health care to its foster care population has been cited in reports conducted by the Little Hoover Commission and the Institute for Research on Women and Families. The California Performance Review, a government assessment and reorganization plan commissioned by Governor Schwarzenegger, placed the failure to provide sufficient health and mental health services at the top of its list of problems in the foster care system.

Though these issues are common to most—if not all—of California's counties, nowhere is the impact more severe than in Los Angeles County, home to almost half of the state's children in out-of-home care (33,787 in 2002). There are frequent reports of children receiving multiple immunizations, improperly prescribed or harmfully interacting medications and psychotropic drugs, misdiagnosis of illnesses and a multitude of other medical errors and omissions. An independent analysis of Los Angeles County's foster care system by Kaplan and Associates in 2002 specifically identified data collection and data-sharing as a barrier to providing quality health care.

The existing system for exchanging medical records and information is based on the passing of duplicate paper forms among caregivers, caseworkers, county departments, health care providers, and public health nurses. The records should ultimately be entered into the state's child welfare data system (CWS/CMS), printed on paper as part of Los Angeles County's Health and Education Passport (HEP), and given to caregivers. This inefficient process rarely works as designed.

Social workers and caregivers have repeatedly stated that health information on foster children is essentially nonexistent at the time of placement. Records generated while the child is in foster care are often inaccurate and lack essential information. HEPs are infrequently updated and new ones are seldom generated and sent to caregivers, who are then unable to give medical providers needed information.

Doctors often have no reliable birth or immunization records, don't know who has previously treated the child, and have no facts about current and past diagnoses, treatments, or prescriptions.

Legislation passed in 2001 (AB 427) allowed Los Angeles County to pilot an electronic passport program for possible statewide expansion. Because the pilot would have utilized state and Federal funds, its implementation was contingent on approval from the Federal Administration for Children and Families (ACF), which administers the Statewide Automated Child Welfare Information Systems program that helps fund CWS/CMS. In a July 2002 letter, the ACF outlined a host of reasons for not approving the project, most of which were specific to planning documents outlining how the AB 427 pilot would be created, implemented, and maintained and would not be applicable to other proposals.

Many advocates, health and education providers, and individuals within county departments continued to seek out solutions.

Current Landscape

Electronic Medical Records

In 2004, recognizing the potential to significantly reduce medical error, provide modernized health services, and increase efficiency in health care—possibly lowering costs—the Federal government established the Office of the National Coordinator for Health Information Technology (ONCHIT) within the Department of Health and Human Services. The goal of ONCHIT is to develop an infrastructure for electronic medical records (EMRs) or electronic health records (EHRs) within ten years.

The work of ONCHIT is supported by several years of developments in the growing field of health care information management. Numerous private sector companies, including large health care insurers, are developing electronic patient records systems, joined by a number of information technology companies. Unfortunately, many of these efforts have resulted in failed or abandoned systems, at the expense of billions of dollars. Though some large commercial solutions do exist, experts estimate that it will be five to fifteen years before there is wide scale adoption of EMRs.

Despite the large number of available commercial EMR applications, the rate of adoption in private medical offices has been slow, with providers citing a lack of capital and unknown cost benefits as barriers. The pace is likely to accelerate once sufficient pressures from insurers, market forces, and government incentives are in place.

Additionally, there is much confusion regarding what constitutes an EMR. Though various attributes have been proposed, there is at present no definitive set and no certification process. ONCHIT has appointed a certification commission that will announce the process and standards in 2005.

HELIX

Two years ago, the Service Integration Branch (SIB) of Los Angeles County's Chief Administrative Office began developing the Health and Education Local Information eXchange, or HELIX. The HELIX system was intended to give providers the ability to exchange records and data in XML (Extensible Markup Language, a standard format that can be read by most commercial applications). HELIX was to initially focus on educational data, though the capability to transmit health data would also exist.

CHEER and HELIX will have shared goals and complementary functions. CHEER will provide a means of collecting information from providers and assembling it in a centralized system, while HELIX will act as an information broker, allowing providers and the county to request and exchange records.

A Request For Proposals (RFP) to implement HELIX was issued in 2004 and negotiations were begun with the vendor. However, legal barriers emerged with respect to confidentiality and the project is on hold pending satisfactory solutions.

Social Services

To improve overall health care for children entering the system, the Department of Children and Family Services (DCFS) has developed a medical HUB system, which is described in detail in DCFS Medical HUBs beginning on page 30. There will be six HUBs that will serve as common medical entry points for children entering the child welfare system. Each will develop a network of providers committed to serving this population and addressing their particular medical needs.

Methodology

The research conducted for this report by the CHEER Project Team included interviews with stakeholders and reviews of model systems that could provide insight into possible approaches as well as lessons learned.

We began with a belief that a functional description of CHEER would emerge through understanding the oft-neglected “human element”—i.e., the flow and use of information, the needs and capabilities of stakeholders, and how users might interact with an electronic system. This approach allowed us to devise solutions that make use of existing resources while addressing key systemic problems. These solutions then served as the basis for the technological model. Adhering to the truism that “the perfect is the enemy of the good,” we sought to achieve the greatest amount of benefit for foster youth and their caregivers while offering attainable and practical answers.

Interviews

The first phase of our research consisted of a series of over 70 interviews and focus group meetings to determine where problems occur in the existing systems, and how an electronic system could be designed to address these issues. Our team identified a core group of key contacts, many of whom provided referrals to others in the community. Participants included representatives of Los Angeles County departments and agencies, health care professionals, foster parents, current and former foster youth, attorneys, educators, and information technology experts. A detailed list of interviewees is provided in Appendix A: Interviews and Meetings Conducted beginning on page 49.

Meetings with advocates and nonprofit organizations served the additional purpose of building a network of groups interested in the promotion and development of an electronic passport or in associated issues. These included representatives of the Alliance for Children’s Rights, the Children’s Law Center, the Children’s Partnership, the Association

of Community Human Service Agencies, the Children’s Planning Council, the American Academy of Pediatrics, United Friends of the Children, and Health-e-LA.

Models

In an effort to learn from and perhaps build on efforts in other regions within California and across the U.S., we reviewed systems providing similar services, appraising their technologies and their governance and organizational structures, gauging their effectiveness, and assessing what aspects might be applicable to a solution for Los Angeles County. While none of the models was capable of meeting the specific needs of the county’s child welfare system and foster care population, all offered lessons to help guide the development of CHEER.

We initially sought out programs that share health data or records for foster children among public and private providers and government agencies. Few systems met these criteria. Our search then broadened to include those serving other populations but providing similar functionality. These are detailed in Related Models and Lessons Learned beginning on page 23.

Literature Review

We conducted an extensive review of literature on electronic passports, child and foster care health, and other related issues concurrently with the interview and model review processes. Sources ranged from official government reports to independent research and reports, professional journals, trade and online publications, and newspaper and magazine articles. For a full bibliography, consult Appendix B: Materials Reviewed beginning on page 53.

Challenges and Issues

At the outset of our research, we identified a set of challenges and issues that must be addressed to develop and implement an effective electronic passport system:

1. What are the current processes for collecting, inputting, and storing health information for foster children?
2. How do providers, caregivers, and social service workers interact and contribute to these processes?
3. What are their strengths and weaknesses?
4. What are the effects of the current processes on the foster care population?
5. Who are the stakeholders and users of the proposed system?
6. How do stakeholders currently access records and information?
7. What kinds of solutions or technologies for providing access are feasible and acceptable to stakeholders?

8. What sorts of incentives are in place for health care providers to participate in CHEER?
9. What are the optimal means, times, and locations for gathering and inputting data?
10. What qualifications or training level should data entry personnel have?
11. How can the design of the system minimize organizational resistance?
12. What other sources of information exist? How can these be integrated to increase efficiency and reduce workloads?
13. What data elements are essential to meeting the information needs of stakeholders?
14. Which pieces of data, if included, would have the greatest impact on improving service?
15. What are the privacy and confidentiality issues? How do they affect CHEER's ability to provide data to different groups of users?
16. What key county, state, and Federal policies affect the creation of an electronic system?

These issues directed the course of our interview and information-gathering processes. Additionally, numerous other lines of inquiry emerged from the interviews. The list changed throughout the course of our research, as we weighed responses and our questions became more specific. The responses to these questions, included in our findings, constitute the functional basis of the CHEER model.

Findings

The Current Process

- 1. The existing paper-based process for collecting health information for foster children is inadequate.*
- 2. Much of the information collected resides in caseworker files and is not entered into Los Angeles County's child welfare data system (CWS/CMS) and, therefore, does not appear in the Health and Education Passport.*
- 3. Caregivers often do not receive a printed Health and Education Passport, the passport binder, or other essential documents, records, and forms.*
- 4. Health and Education Passports, when available, are generally incomplete or not current and are unreliable sources of information.*
- 5. The provision of adequate health care to foster children is hampered by the lack of reliable patient information.*

The movement of health records for foster children in Los Angeles County currently relies on a labyrinthine network of hand-to-hand exchanges of duplicate paper forms. Those interviewed unanimously agree that this system is an ineffective means of passing, storing, and providing critical information. At each point in the network, those responsible for completing the form (or a portion of it) place blame on others for the fact that records are rarely properly completed or do not arrive at their intended destination in a timely fashion.

When children enter the foster care system, a file is opened for them in CWS/CMS. This contains an electronic version of the Health and Education Passport (HEP), which should then be printed and placed in the “black binder” in which copies of all the child’s records and information are collected, and which is given to the caregiver. Caregivers and caseworkers alike agree that in almost all instances, no information is available at the time of a child’s first placement.

At the time caseworkers are required to provide caregivers with the black binder, it should contain a placement packet with preliminary information available on the child. It should also include medical care consent and authorization forms, the child’s Medi-Cal card, the HEP, blank DCFS 561 health examination forms, and a 709 form, which is designed to alert foster caregivers to immediate and urgent issues, and summarize the case plan. The 709 is often absent or contains little more than the caseworker’s signature. (An updated HEP should be issued to caregivers within 30 days.)

In practice, binders are frequently not given to caregivers at the time of placement and often contain little essential information. Some caregivers reported waiting more than a

year to receive their binder. Others have received them, but were never sent updated forms or HEPs.

An informal survey conducted in 2004 by the Association of Community Human Service Agencies (ACHSA) found that only 15 percent of the 145 children placed with the 23 surveyed group homes and foster family agencies had a Health and Education Passport. Caregivers had black binders for only 15 percent of the children, Medi-Cal cards for 43 percent, and immunization records for 35 percent. These figures dropped from 2003; the number of binders is 35 percent less, while the number of passports is 19 percent less.

This is an obvious issue for children entering the system with existing medical, behavioral, and psychological conditions. One caregiver reported receiving a toddler who came with a prescription but no instructions for medication or information on the child's condition. Another child was put into a placement with a cast on his arm, but no information regarding why it was there, what doctor had put it on, or when it was supposed to come off.

Caregivers are required to have children examined by a doctor within 45 days of placement. Doctors providing these exams to foster children usually do so without the benefit of a medical history or information on existing conditions and current treatments. Unfortunately, for most children in foster care, this is usually the first of many instances where the lack of records results in inadequate care.

As one doctor stated, "I cannot imagine a worse set-up than a client with no information." Another remarked, "It's like treating a patient with a paper bag over my head."

Forms and Data

- 1. The flow of health information through the foster care system contains numerous gaps and no clear means of accountability.*
- 2. Caregivers lack information and training in the importance of collecting and maintaining health records and forms.*
- 3. Forms do not resemble those commonly used in hospitals and doctors' offices and lack key medical information deemed critical to providing proper health services. Because the forms appear vague, health care providers do not feel compelled to provide detailed medical information.*
- 4. Medical providers are frequently unaware of the importance of the health visit log forms, which are currently the sole source of medical information on foster children.*

Interview subjects unanimously agreed that the means of passing health records and data through the foster care system simply does not work. No clear means exists to verify what information passes through the system and what is absent. Caregivers, caseworkers, and medical providers all work independently to gather information which, when

Findings

obtained, is not shared. Responsibility for maintaining records is diffuse and shifts among caregivers, caseworkers, health care providers, and other departments serving the child.

As Figure 1 illustrates, the system is based on a series of transactions that “should” occur. In reality, each node in the diagram is an opportunity for information to become lost or for inaccurate information to be recorded.

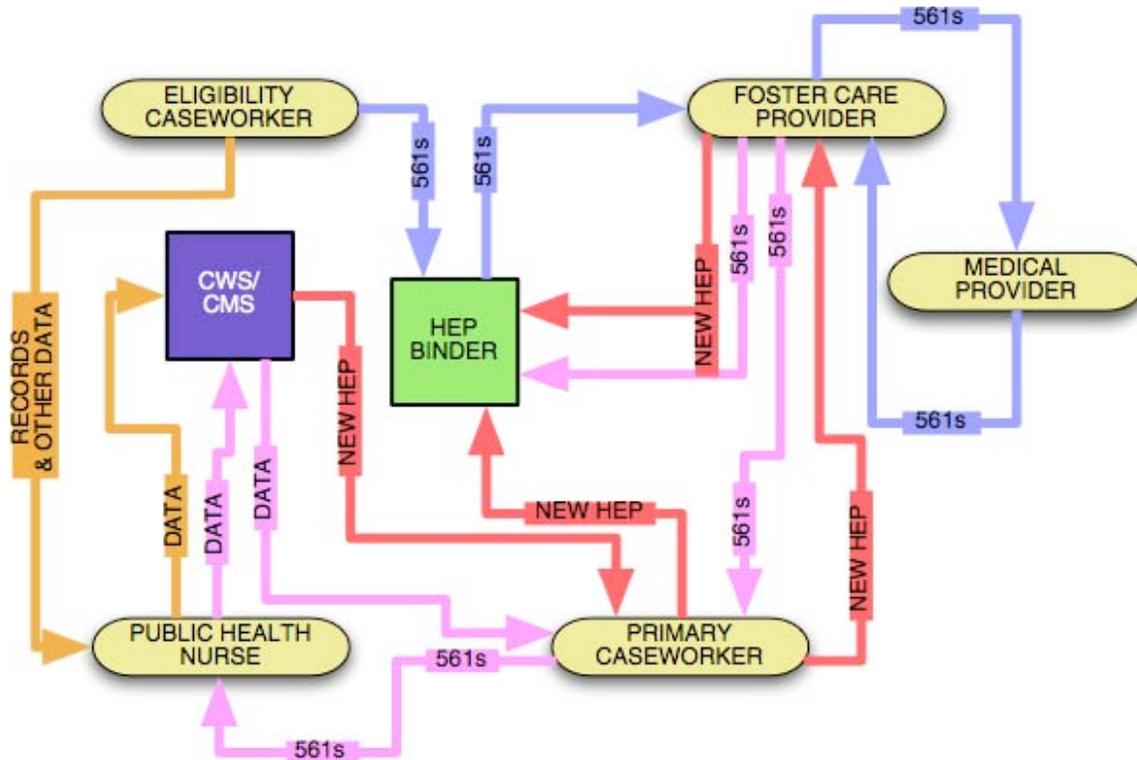


Figure 1. Simplified flow of health data for foster children in Los Angeles County

DCFS eligibility caseworkers initiate the flow of health information for foster children by providing caregivers with blank 561 forms for recording medical, dental, and psychological visits.

- Caregivers bring copies of the appropriate 561 to each provider visit.
- The doctor or provider completes the form and returns it to the caregiver.
- A duplicate is placed in the child’s binder.
- The 561 is handed to the case-carrying caseworker at the time of the next home visit.
- The caseworker passes the form to a Department of Health Services public health nurse (PHN), who verifies the information and enters it into CWS/CMS.
- The caseworker generates a new HEP when significant changes are made, or on a regular basis.
- The HEP is either sent to the caregiver or delivered in person.
- Blank 561s are given to caregivers at each caseworker visit.

Findings

While caseworkers usually do provide 561 forms at the time of placement, caregivers are not always educated in their use and their importance. In the 2004 ACHSA survey, only 17 percent of caregivers had a copy of the DCFS instructions for medical records procedures. As a result, 561 forms are not always presented to doctors at the time of a medical visit, in which case the exam is just “lost.” When they are presented, it’s often at the end of a visit, when the provider has little time to complete them. The forms themselves are ambiguous, so doctors don’t feel the need to provide detailed accounts of the visit. Many of the medical providers interviewed noted that the forms do not resemble those in use by doctors’ offices and hospitals and that they are poorly organized. Medical providers are also not informed of the forms’ importance as the sole source of medical information on the foster child.

Following a medical visit, caregivers place the completed form in the child’s binder and must remember to pass a copy to the caseworker at the time of the next visit. Forms may be misplaced, incorrectly completed, or simply not given to the caseworker. By the time a PHN receives the form, months may have passed.

Public health nurses also rely on PM160 forms, which are records of the child’s CHDP’s well-child exams that are used primarily as claim forms for Medi-Cal reimbursement. (Child Health and Disability Prevention is a state-funded program administered locally by the Department of Health Services.) A CHDP exam should occur within 45 days of placement and thereafter on a regular basis, less frequently as the child ages. PM160 forms are not used for medical visits resulting from illness, emergency, or other reasons.

Providers are required to submit copies to the state for claims processing, to the CHDP program, and to caregivers. Records for foster children are sorted from those sent to CHDP and sent to PHNs at the Department of Children and Family Services. The PHN is then responsible for verifying and following up on the information on the forms. (Nurses report that they spend almost half their time calling doctors’ offices to verify ambiguous or incomplete information.) The record is then entered into CWS/CMS. In many instances, clerical workers with limited medical training are responsible for the data entry.

The time span between the examination and data entry into CWS/CMS is generally between two to four months. Some PHNs reported much longer delays—sometimes more than a year—because medical providers have up to one year to submit forms for reimbursements.

One major weakness of the current system of passing forms from hand to hand is the number of intermediate steps and exchanges before data is received by those capable of verifying and following through on information. This practice results in a cycle of “bad data in, bad data out” that creates the impression that the system itself is sufficiently faulty so that individuals are absolved from the responsibility of providing high-quality, complete data.

Mobility

The most frequently cited barrier to well-maintained health records is child mobility. Stable, long-term placements and infrequent changes in health care providers result in better information and records.

As of 2000, children in foster care in Los Angeles County experienced an average of 2.4 placements each year. Though this number has declined, there is unanimous agreement that the high rate of mobility among foster children is a leading contributor to poor record maintenance.

Several caregivers and advocates stated that when children are in stable placements, records are often well maintained. This is particularly true in group homes or where caregivers have established relationships with medical providers. These records, however, are often kept by the provider or caregiver separately from the HEP and binder.

Children in the foster care system are often moved with little notice or time for gathering clothing and personal possessions. As such, the binder often doesn't follow the child to the next placement. Records maintained by doctors or kept separate from the HEP are also not passed on, as caregivers are frequently unaware of the new placement location. Any progress made during a placement, then, is usually eradicated when the child moves. Changes in placement are often also accompanied by a change in medical providers serving the child.

Low Priority Given to Health Issues and Records

Health care for foster children does not receive the same priority from caseworkers as placement, behavioral issues, and education. There is little oversight and accountability to ensure that health issues are dealt with.

When suspected instances of child abuse or neglect are referred to the Department of Children and Family Services (DCFS) for investigation, the chief concern is the safety and well-being of the child. Caseworkers reported—and several caregivers and service providers confirmed—that low priority is given to health issues; most emphasis is put on placement. One caseworker stated that, “It’s on the back burner . . . except for putting the kids on psychotropics, you don’t hear about it too much.”

Supervising caseworkers stated that some of the records and information sent to DCFS workers by caregivers and medical providers do not make it into CWS/CMS (and therefore the Health and Education Passport), but instead remain in caseworkers’ paper files. Workers are sometimes reluctant to give records to PHNs for entry because of the possibility of not having them returned. And because turnover rates for the PHNs are high, one supervisor stated that most caseworkers are unaware of which PHN is currently assigned to their caseload.

Supervisors also stated that a technical glitch prevents some caseworkers from outputting new Health and Education Passports. Unlike other forms in CWS/CMS, the HEP is not

dynamic, but is generated as a Microsoft Word document with all the data automatically populated. Caseworkers cannot generate a new HEP unless the current one has been deleted.

Numerous explanations exist for the low priority given to maintaining health information; most often cited are the large caseloads carried by workers. Providing basic services, dealing with emergencies, filing court reports, and numerous other tasks are given precedence over what is perceived as a time-consuming administrative function. Though supervising caseworkers receive statistical reports on each worker's output, they stated that there is little they can do to motivate workers faced with more important tasks. Supervisors added that improvement is unlikely given current caseloads and the existing systems of collecting and inputting records.

Manual Data Input

- 1. Individuals tasked with the manual entry of data must have sufficient training in medical issues and terminology as well as technical skills.*
- 2. Most medical providers agreed that PHNs are ill-suited for doing this type of data entry, and identified medical technicians and nursing attendants as possible personnel for this duty.*

One question that emerged from the interview process was what qualifications are necessary for processing and entering health data into an electronic system. Both the Department of Children and Family Services and the Department of Health Services utilize public health nurses (PHNs) for this task, but the hours needed to verify and track down records leave little time for PHNs to assess the information collected and engage in health case management, as they are also required to do. While PHNs may be overqualified for data entry tasks, trained data entry personnel who also do input for DCFS have the opposite problem: insufficient training in medical terminology and practices. They are much less likely to notice errors, inconsistencies, or patterns that may be indicative of chronic health issues.

While some professionals interviewed disagreed about the specific level of training needed to enter data into an electronic passport system, most agreed that public health nurses are a poor fit for this task. Other criteria identified focused on a combination of technical and medical training. Though some amount of training will be necessary to implement any new system, many in the medical field already possess these skills, such as nursing attendants and medical assistants.

Data Sources

CWS/CMS

- 1. CWS/CMS, the primary information system for DCFS and the child welfare system, is the first—and earliest—possible source of data.*

- 2. CWS/CMS is an unreliable source of accurate, complete, and timely health information.*
- 3. Confidentiality rules may prevent the use of CWS/CMS as a source of health data for an outside system.*

The first collection of data for children entering foster care is CWS/CMS, the chief case management and information system in use by DCFS. It contains current and archival information on children who have been in the child welfare system or whose families have been investigated. Unfortunately, the quality and completeness of its health data is lacking. Medical providers and public health nurses also indicated that the data elements in CWS/CMS (information the system is capable of collecting, whether or not any actual data is present) are insufficient for providing adequate medical services.

CWS/CMS may be, however, the most consistent and reliable source for identification and demographic information for foster children. In addition, it is possible to create an automated interface between it and outside systems, which DCFS has done with ITRACK, an incident-reporting system used by foster family agencies and group homes.

Medical Providers

- 1. The large number of medical providers offering services to foster children prevents the standardization of practices for recording and collecting data.*
- 2. Medical providers may be unwilling to adopt a system that places an increased work burden on them or their staff, particularly if the system serves only a small percentage of their patients.*
- 3. Though perceived as an inevitability, few electronic medical records systems are in use. Billing and practice-management systems rarely contain sufficient health information.*
- 4. The lack of electronic records necessitates the manual entry of data obtained from medical providers.*
- 5. The use of new technologies such as PDAs and tablet PCs is likely to hinder the acceptance of a system by medical providers. Adoption of such technologies is unlikely to occur unless they benefit all patients, not just foster children, and are cost-efficient.*
- 6. Few substantial incentives exist for the medical community to adopt practices or systems that serve the foster care population.*

The second point at which health information is collected is at the time of a medical exam or visit. Collecting data at this level presents numerous challenges.

❖ Challenge 1: Too many providers

Caregivers seeking medical services for foster children have a disparate array of providers to choose from. DCFS currently suggests that caregivers use CHDP for their initial

and periodic medical exams, and any physician or clinic accepting Medi-Cal is an option. Many caregivers reported that they paid for the exams required within the first 45 days of placement out of their own pockets because they had not yet received Medi-Cal cards. Though caregivers frequently reported difficulties in locating doctors to provide service, thousands exist in Los Angeles County, but there is little standardization in how and when they collect information and what is collected. Though the CHDP program has specific criteria for its exams, these are seldom followed outside the program.

❖ **Challenge 2: “Increased burden” on providers for a small population**

Throughout the interview process, medical providers stated that they were unlikely to adopt any system or process that placed an increased burden on them and their offices. The threshold varied, but in general this meant the collection of significantly increased amounts of data, any disruption of current work and office procedures, and the addition of time-consuming tasks such as form filling and data entry.

❖ **Challenge 3: Few electronic systems**

Most doctors and policymakers agree that the eventual widespread use of electronic health information systems is inevitable, though their existence now is a rarity. Major hospital systems have yet to adopt or implement platforms for patient records, and few medical offices use electronic record-keeping or practice-management software. Much of what does exist is for billing and reimbursement purposes and varies both in functionality and in any ability to import and export patient data via interfaces with an Internet-based data system.

❖ **Challenge 4: Introducing new technologies**

In recent years, computer hardware has become both portable and capable of wirelessly accessing networks or the Internet. Many forward-thinking doctors and other experts have suggested use of PDAs or tablet PCs as a possible means of electronically entering patient data, and some medical students and hospital interns are required to use these devices. The use of these technologies in health care settings is becoming more commonplace, particularly when they are tailored to specific programs or functions.

❖ **Challenge 5: Incentives**

At the beginning of the research process, we hoped that many of these challenges might be overcome through providing various incentives to medical providers. Few such incentives exist, however, to bring private providers into CHEER. Medical providers are paid for services to foster children by Medi-Cal, usually through a fee-for-service rate or, less often, through Medi-Cal managed care. In either instance, reimbursements to the providers are so low (\$18 for a standard examination) that even the promise of faster reimbursements has little effect. More direct financial incentives, however, may have an impact. Illinois’ HealthWorks program pays doctors in their statewide provider network \$15 for initiating and completing their paper-based passport record for each child’s initial medical assessment. Providers interviewed stated that as little as \$5 per visit might be sufficient.

Some providers interviewed did mention qualitative incentives, but these alone are unlikely to spur widespread buy-in of CHEER. All doctors interviewed expressed that

they want as much information as possible before seeing a patient, even if they also expressed limits on what they'd be willing to do to collect and transmit this information.

Medi-Cal

The state Medi-Cal information systems may provide some useful historical medical data.

The capture of data from Medi-Cal reimbursement claims requires addressing time lags between the rendering of services and the availability of information (sometimes a year or more), the limited information available, and the costs of implementing a data capture.

Many caregivers reported delays in the issuance of Medi-Cal cards for foster children and frequent problems with using Medi-Cal to pay for services. Some medical expenses—most commonly initial exams—are paid for out of pocket. When this happens, no claim forms are generated, and no medically significant record of the visit exists outside the provider's office.

Sharing with Other Systems

- 1. A number of disparate systems collect health and medical data on portions of the Los Angeles County foster care population.*
- 2. These systems are not interoperable and have no means of exchanging information.*
- 3. These systems represent a lack of coordination that results in duplicative efforts and large gaps in information.*

A number of county agencies and services collect records on foster children, yet little information is shared among them. Individuals in several departments may input the same child information into a variety of unconnected systems, which translates to a greater chance of errors and conflicting data. A summary of other county systems collecting health and education information for foster children is included in Appendix C: Related Los Angeles County Efforts beginning on page 59.

Information sharing between systems is, at present, almost nonexistent. One reason for this is the development of many information systems with varied technologies and adherence to data standards, and different degrees of interoperability. Another involves possible confidentiality and privacy issues (discussed in Confidentiality beginning on page 21). The most likely cause, though, has been a lack of coordination between services. Programs are developed by departments, and are often isolated from other efforts within the county or state. Each often believes another is responsible for various aspects of a foster child's well-being.

The Los Angeles County Office of Education's Foster Youth Services (FYS) program maintains one system that in many ways exemplifies the problems and challenges of all the disparate efforts to collect health information for foster children. FYS serves a relatively small percentage of the county's foster care population—approximately 4,000 children who reside in around 220 group homes. While the chief objective of the program

is to provide educational services, it also includes medical information in a data system developed to track client information.

FYS educational community workers gather information for the system, often devoting large amounts of time to locating and entering birth records and medical histories and working with group homes to maintain ongoing medical records. This involves interviewing the children, building a relationship with the group home, and often calling or visiting doctors, hospitals, schools, or previous placements. Though labor-intensive, the FYS system reportedly works well—that is, as long as the foster child stays in one place.

However, because there are no connections between the FYS data system and DCFS or CWS/CMS, this information never makes it into a passport. (FYS had offered DCFS access to the data system, but the offer was declined.) FYS receives no notification when children are moved to another placement, so data is usually rendered worthless unless the child is moved to another participating group home. Some foster children are placed only intermittently in participating homes, creating gaps in records. More often, mobility means children drop out of the system and don't reappear.

Information Needs of Stakeholders

Each group of stakeholders has distinct information needs. DCFS and medical providers have the greatest needs, while education and other county departments need specific items.

Department of Children and Family Services (DCFS)

DCFS collects and utilizes the largest volume of information on foster children, but relies on a single resource for management of that information, CWS/CMS. Use of CWS/CMS is governed by the state's Department of Social Services and the Federal Administration for Children and Families (part of the Department of Human Services). It is mandatory and tied to funding.

As the individuals responsible for case planning and management and overseeing the well-being of children in care, DCFS caseworkers have the greatest information needs—all health and medical data except for items protected by confidentiality laws such as psychiatric case notes.

Public health nurses in the Health Care Program for Children in Foster Care are technically part of the county's Department of Health Services but work in DCFS offices and are charged with entering data into CWS/CMS. They also need access to all medical visit logs and reports from examinations.

Additionally, for the purposes of follow-up and accountability, DCFS workers should have information on any referrals, treatments, and further visits scheduled or required.

Foster Caregivers

Foster caregivers are charged with obtaining health care for those in placement. Their first need is information on any existing or chronic medical conditions, particularly those

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that may need immediate medical attention. Additionally, as previously noted, caregivers should be apprised of any behavioral or psychological issues.

For ongoing medical care and treatment, caregivers should have access to a collected medical history and all information about psychotropic drugs and other treatments and medications. Caregivers themselves frequently admitted that they were not well informed when dealing with doctors and administering medications.

Medical Providers

While most doctors said they wanted any and all information available on a child, they also admitted this was unrealistic. Most weight was given to medical histories, past services and treatments, prescriptions, and medications. Information needs to be incorporated into a limited set of data elements with immunization records being essential. Additional suggestions ranged from blood tests to information on allergies and more thorough physical exams.

One point of agreement was that any new forms for recording visits should, unlike the 561s, bear a resemblance to forms currently in use and be more detailed and specific as to what information is needed. The electronic, online versions of records must adhere to the same criteria.

Foster Youth

Foster youth over a certain age, and emancipated foster youth, should be able to access their complete CHEER records, including medical history, exams, medications, and treatments. They should receive all medical records at the time of emancipation, but many have difficulty obtaining them or aren't aware of their right to obtain them. Furthermore, what's most often available to them is the incomplete set of records contained in the black binder.

Education

While recent legislation permits foster children to be enrolled in school without first being immunized, they must undergo immunization within a certain period of time. These records are the primary need of those in education. Any other information provided to schools must be limited and made available only to school medical or nursing staff, unless proper consent is given. Additional information that may be provided to schools includes children's illnesses or treatments that need to be administered during the day (insulin shots, asthma inhalers, severe allergies, etc.).

Other County Departments and Services

A number of county departments and agencies provide services to foster children besides DCFS. The needs of the Department of Mental Health are limited to behavioral, emotional, and psychological information, and data on any medical conditions that influence mental health. Because of the risk of over-medication, and of prescribing drugs with health-endangering interactions, mental health providers need much better records on prescriptions and, in particular, psychotropic drugs.

The Department of Health Services (DHS), which is creating a county immunization registry, has an immediate need for immunization data. Medical providers in DHS programs such as CHDP also need to be able to access the same information as other providers.

The Juvenile Dependency Court is the ultimate authority in providing care for foster children. Its Medical Services Unit needs access to records of prescriptions and medications, since the court grants medical consent rights and approves all major medical procedures and psychotropic prescriptions. As such, court officials need access to a child's complete record, including medical history, treatments, and prescriptions.

Confidentiality Issues

- 1. Many state laws are more prohibitive than Federal laws, but contain provisions for consent and disclosure that may enable record sharing.*
- 2. Memoranda of Understanding, consent forms, and court orders may be sufficient to satisfy state and Federal confidentiality restrictions and permit data and record sharing.*
- 3. More significant barriers are the fractured system of oversight for children in foster care, combined with ambiguities and conflicts in confidentiality laws and how they're perceived and applied.*
- 4. Further study is needed into how to navigate confidentiality requirements and how these apply to the California foster care population.*

The Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) was enacted to protect the confidentiality of medical records and information transmitted through electronic means. While HIPAA is the most often-cited issue affecting an electronic health passport system, it is in many ways the least restrictive of confidentiality laws, since it grants broad exceptions for information used for treatment services (the provision or management of services by one or more provider, including coordination or management with a third party, consultation between providers, referrals to other providers) and disclosures made with the consent of the patient or patient's representative. As one legal expert stated, "If HIPAA were the only concern, it wouldn't be a problem."

HIPAA grants states the right to enact and enforce laws providing greater protections, and California boasts over a dozen of these, each of which with its own protections, ambiguities, and exceptions. Some provide special protections (or permissions) for foster care and other public services. Others protect special populations such as the developmentally disabled.

Fortunately, all confidentiality laws share one important feature: the ability for patients or clients to waive confidentiality rights or to give consent to providers to share information.

Findings

Consent can even be restricted to specific information shared for limited purposes (such as an integrated electronic medical record or within a service team).

However, the criteria for providing consent differs among laws. For children in the foster care system, it is uncertain just who holds the rights to provide consent. While caregivers can provide consent for most medical procedures, the county's presiding Juvenile Court judge, Michael Nash, admitted that their ability to consent to release or share records is "not really clear," and the rights of group home representatives are even more unclear. One foster care attorney suggested, as a child's legal representatives, they hold the rights to consent to the disclosure of protected information, and frequently exercise this power.

Most research in the area of confidentiality and integrating social services indicates that restrictions can be overcome through the use of Memoranda of Understanding and consent forms. These agreements among stakeholders specify and place restrictions on who can access which information, how the information is to be utilized, and what formal processes are in place. Consent forms allow legal representatives to waive foster children's rights to privacy and permit information sharing for specific purposes.

Another option for navigating the maze of confidentiality requirements is the use of court orders. In 2000, Judge Terry Friedman, who then presided over the county's Juvenile Court, signed a blanket order waiving confidentiality for children served by the Los Angeles County Office of Education's Foster Youth Services, and directing DCFS to verify and maintain information on all affected foster youth. In San Diego County, a court order permits the disclosure of otherwise protected information about children needing assessment prior to their detention. Judge Nash agreed that the use of court orders to waive confidentiality or permit record sharing for foster children may be possible, but requires further study.

Research does not exist that is specific to the foster care population, the state of California, or electronic records systems. As the push for electronic medical records gathers momentum, many governments and private providers will seek to clarify and test the boundaries of these laws. Because of their unique legal status as (mostly) minors in the care of the state, special attention must be given to how these laws affect foster children.

Related Models and Lessons Learned

Western Governors' Association Health Passport Project

Inspired by the success of a demonstration of the use of smart cards for electronic benefits transfers in Wyoming, the Western Governors' Association initiated a project to evaluate whether the technology could be applied to storing health data as well as delivering benefits for aid recipients in the Women, Infants and Children (WIC) program. The Health Passport Project (HPP) began in 1997 and was rolled out in three locations from 1999 through 2001: Cheyenne, Wyoming; Bismarck, North Dakota; and Reno, Nevada. The goals of the project were to improve the efficiency of services, to improve quality through better coordination and integrating patient data, and to provide clients with a measure of control over their own records.

The basic process for using the cards was similar in each test location. Upon arrival at a medical provider's office, clients inserted their (or their child's) smart card into a reader and entered a PIN code. Patient data then downloaded to the office's computer and a medical form printed for doctors to complete. At the end of the visit, the information from the form was entered into the computer and synchronized with an offsite, centralized server. The data on the smart cards was updated in the office or automatically the next time the card was placed into a reader at any location.

Alternate processes allowed providers to enter data after visits or store data on office PCs until all information (test results, etc.) was available. Additionally, clients were able to access their own information at kiosks placed in service locations.

The HPP was hampered by delays in development. The unique challenges presented at each demonstration site—which differed in the available features of the smart cards and service environments in which they were accepted—intensified the project's difficulties and complexities.

Reno, with the largest client population, had the fewest participating partner programs. The HPP was primarily used here for electronic benefits transfer rather than health information purposes (and is now the basis of the state's EBT system). Cheyenne, which had been using a smart card-based EBT system for several years prior to HPP, had several partners, including a regional public health department and a large, private pediatrics clinic. In Bismarck, the cards were used to determine eligibility for benefits and in some small health care environments. Bismarck was the only site not to utilize the EBT function.

Only two private medical providers participated in the program, in part because of the lack of incentives and the need to implement two systems (one HPP, one not) in each office.

Because of the delayed implementation, the evaluation period for the program was shortened to less than a year for most functions and applications. The Urban Institute and MAXIMUS, who were retained to evaluate the program, were unable to make definitive

claims about the HPP's effectiveness. They did recognize that the system was implemented and functioned as planned, that clients were better able to manage family records, and that users and clients expressed a high level of satisfaction with the system.

Lessons Learned

1. A vision of integrating information for multiple programs must be emphasized from the beginning and reinforced among stakeholders.
2. Technological solutions must be accompanied by a consideration of human needs and processes. Comprehension should be built through user participation and buy-in at each stage
3. Additional work or expense required to operate a new system must be matched by benefits to users or sufficient incentives for use.
4. Incremental implementation has numerous benefits. Seek simple solutions with the greatest benefits, then expand.
5. Formal agreements and business processes should be standardized across programs and locations.

Santa Barbara County Care Data Exchange

In 1998, Santa Barbara County formed what would become one of the country's first systems for electronically exchanging patient information between multiple providers, hospitals, and users. With \$10 million in funding from the California HealthCare Foundation, the county contracted with Care Science, Inc., to create the Santa Barbara County Care Data Exchange.

The purpose of the SBCCDE is to improve the quality of care by making more information readily available, to improve efficiency and create financial benefits for users, and to allow patients access and control over their own information.

The SBCCDE is a provider-oriented system, which allows access to information for specific encounters with patients. Unlike the other models discussed in this report, SBCCDE does not feature a centralized repository for patient information. Instead, it uses a "peer-to-peer" structure. The only patient information contained in the system is an index detailing where each piece of the patient record resides in the various hospital and lab records systems. A request for patient information is routed through the index, which returns a full list of each piece of patient data—much like an online search engine. Providers then select which items they need to access.

This type of structure is possible because fairly well developed systems are already in use in the county's major health centers. The three major hospitals all use sophisticated EMR systems, and Quest (formerly Unilab), where most county lab work is conducted, has its own electronic records system.

The participants in SBCCDE are, as described in the project's Interim Report, ". . . a collaboration of competing, unaligned and semi-aligned organizations." This partnership

results from the mutual benefits of the exchange and the fact that the system utilizes existing information technology (IT) resources without creating significant financial or administrative burdens. Decision-makers and users were engaged early in the development process, and partners were included in the governance model, which provided a sense of common ownership.

At this time, the SBCCDE is undergoing a rigorous testing and certification process. The system is being reviewed for compliance with HIPAA and an independent group is conducting a security audit. Limited user tests are underway to assess functional efficacy. Consumer functions are still in their infancy. SBCCDE is using focus groups and surveys to determine how consumers might utilize the system.

The SBCCDE now operates as a private nonprofit. In addition to the funding from CHCF, they have obtained grants from the Foundation for eHealth Initiatives. The goal is self-sufficiency, but the system must first demonstrate benefits (and cost savings) to participants.

Lessons Learned

1. System design should be guided from the outset by a specific set of requirements intended to deliver the desired benefits.
2. Participation and use by competing stakeholders is the result of shared needs and benefits, the involvement of a trusted private foundation (CHCF), engagement early in development and in governance, and a sense of common ownership.
3. To achieve maximum benefits, the sources of data, users, and specific data elements must be prioritized. Focus should be placed on providing the greatest amount of significant data to those who can best put it to use.
4. Though a fully interoperable system was desirable, SBCCDE concluded that an interim solution—the peer-to-peer exchange—was more feasible and intends to work towards expanded capabilities over time.

San Diego County Health and Education Passport

The purpose of examining San Diego County as a model was to try to identify organizational changes and policies that have proven effective in tracking health records for foster children. Though San Diego has a much smaller foster care population than Los Angeles (approximately 6,000 children in out-of-home placements), the caseloads carried by caseworkers and PHNs do not significantly differ. The processes for collecting and storing health records are similar; PHNs are charged with entering information into CWS/CMS, and a paper HEP is output and sent to caregivers. However, many of the policies and practices in San Diego County suggest a more efficient system of passing information than the one in use in Los Angeles.

San Diego County pioneered the development of the Health and Education Passport and the use of PHNs in child welfare services in 1989. The leadership exhibited by San Diego County exemplifies the high priority given to health issues for foster children and the

Related Models and Lessons Learned

level of collaboration between county departments. These programs were initiated by managers in the Department of Human Services and Department of Social Services (which have since been consolidated) who recognized the special health care needs of foster children.

The CHDP Foster Care Program, in which PHNs were assigned to foster care caseloads, was intended to ensure that the health needs of foster children were properly identified and met in a timely fashion. This became a statewide program in 1999, when the California legislature enacted a bill providing Medicaid funding for PHNs to coordinate health care services. The Health and Education Passport started as a demonstration project at Children's Hospital. A revised version was adopted by the Children's Services Bureau in 1991. This HEP was adopted by CWS/CMS in 1997.

In developing processes for collecting health records, the CHDP Foster Care Program has sought to maximize the utility of CWS/CMS and the available human resources. Here are some of the different policies and practices in use in San Diego:

- PHNs take an active role by participating in developing health care plans for each child and meeting with caseworkers every six months to review plans.
- All data entry into CWS/CMS is conducted by PHNs (unlike Los Angeles, which relies heavily on clerical staff and where caseworkers may enter health information).
- HEP clerks handle many of the administrative tasks for PHNs, freeing them to engage in more important tasks. These clerks have a higher status than other clerical staff.
- CHDP management frequently reinforces the positive roles played by PHNs and HEP clerks.
- The turnover rate for PHNs in San Diego is relatively low.
- Health-visit reports contain more comprehensive information.
- Caregivers receive mail-in envelopes with forms and send them directly to HEP clerks, who distribute them to PHNs.
- New HEPs are generated each time changes are made as well as on a periodic basis. PHNs phone caregivers to answer questions about HEPs.
- Doctors in San Diego send PM160 forms to the Department of Human Services for processing. Those for foster children are sorted and sent to PHNs. The average turnaround time for entering this information into CWS/CMS is one week, a good deal faster than the more than two months required when forms are sent to the state for processing.
- A training program developed by nurses serves more than 600 caseworkers and caregivers annually. This training provides information on common health problems for foster children, community health services, the CHDP Foster Care Program, and the HEP.

Related Models and Lessons Learned

- PHNs have electronic access to the county immunization registry. New HEPs are not sent until immunization information is checked against the registry and updated.
- For emergency visits, child-abuse hotline workers can output and fax a HEP.
- The majority of children entering the San Diego foster care system are initially placed in the Polinsky Children's Center. The Center provides initial medical exams for all children who enter as well as developmental and mental health screenings.

The San Diego system is constantly undergoing assessment and improvement. The San Diego Volunteer Lawyer Program has partnered with Voices for Children in a Foster Youth Health Initiative to determine and advocate for the health needs of foster children. The lack of a comprehensive medical history has been identified as a major component. Research conducted by Voices for Children found that 16 percent of children in their study did not have a HEP. This is still a vast difference from the 85 percent cited in the Los Angeles ACHSA survey. However, 72 percent of the San Diego HEPs were found to be incomplete (there is no comparable data for Los Angeles). Further research indicated that in these instances, immunizations and exams had occurred on time but had not been documented.

The county is also operating the North County Assessment Center, a centralized entry point for all children in that region entering the system. This model is very similar to the HUBs being instituted by DCFS (which are described in DCFS Medical HUBs beginning on page 30).

Lessons Learned

1. Engaging PHNs in more active roles by providing administrative support, increased interaction with caseworkers, and a positive atmosphere can lead to more positive outcomes and help prevent turnover.
2. Training is essential in reinforcing the high priority of health issues among caseworkers and caregivers.
3. A central entry point for children coming into the system provides an opportunity to initiate records and begin data collection.
4. Difficulties in collecting records and data are not unique to Los Angeles, but are more severe here.

Veterans Health Administration VistA

The Veterans Health Administration (VHA) operates the only nationally integrated health system in the country. Charged with providing health services to veterans through VA hospitals and clinics, the VHA faces some of the same tracking and records maintenance challenges as the foster care system—a highly mobile population with unique health needs that must be addressed through a public health system—only on a much greater scale. A single large VA hospital may have a patient base much larger than Los Angeles County's foster care population.

To track patient records and coordinate care across hundreds of locations, the VHA has developed VistA, currently the only nationwide electronic health records system. Much like the open-source software movement that has resulted in popular systems such as Linux, VistA is the result of the decentralized development of hundreds of applications and functions. Over the course of almost 30 years, these pieces have been added to the core product. The Computerized Patient Record System developed in the 1990s integrates all the disparate pieces of VistA a single user interface for accessing and inputting patient data.

VistA is available to the private sector for free through the Freedom of Information Act (which provides the source code). Commercial versions can be purchased from companies such as Medshpere, which has developed its own version of the software with a customized user interface. The VHA has historically provided assistance and support in implementations of VistA either directly or through referrals to contractors. The VHA is also working on VistA Office EHR, a scaled-down version that will be marketed to private physicians and that will include some of the billing, pediatric, and OB/GYN functions absent from the current full version. Some private sector implementations include the DC Department of Health, the Federal Indian Health Service, and several hospital-based pilots in the Louisiana State University System.

Many aspects of VistA are highly desirable for any health records tracking system. The system provides a comprehensive records management system. Some of the functions include electronic prescriptions, bar-code tracking of medications, imaging software to allow access to radiology and X-rays, the ability to store records sent as faxes, interfaces with disease registries, strong reporting functions, and the use of performance measures. A patient-controlled personal record is available online through the Health-e-Vet internet portal.

Despite these advantages, VistA would require extensive customization to be suitable as a basis for CHEER. Because it was developed specifically for use within the VHA, VistA was not designed to be highly interoperable with other systems. VistA is client/server based and therefore requires special installation on each workstation and dedicated connections to a central server. It is not Internet-enabled, which would limit its ability to share data outside clinics and hospitals. This would require private medical providers to install the VistA applications on their offices. The data tables, definitions, and templates in VistA would all need to be customized to match data collections and uses in the foster care setting. Additionally, VistA does not currently limit access to information based on user or group. All providers can access all data in the system.

The additional time and expense incurred altering VistA for use as a records system for foster care may offset its availability as “free” open-source software.

Lessons Learned

1. Successful implementation requires a high level of support from stakeholders, including physicians and frontline users and staff.
2. Extensive outreach must be conducted in order to encourage buy-in, foster common goals, and win over “champions” to support any new system.

DC Kids

In 1999, the District of Columbia's Child and Family Services Agency (CFSA) contracted with DC General Hospital to provide medical examinations and primary care to children in foster care through a program called DC Kids Integrated Delivery System (DC KIDS). DC General then turned to information technology firm CS&O to develop an electronic records tracking system. This system was lauded by many for the quick access it gave medical providers to essential patient records and information. It became the basis for a pilot in Los Angeles County that connected group homes with medical providers.

In 2001, however, DC General was closed as a result of longstanding administrative and financial difficulties. CFSA quickly transferred the program to the Children's National Medical Center on an emergency basis that became permanent two years later. When the transition took place, none of the assets of the previous program were turned over to Children's National. The CS&O passport system fell between the cracks; currently, DC KIDS uses paper records and a limited internal database, which does not contain any medical information. The DC KIDS system currently in place has developed its own processes for tracking records and information, some of which may be beneficial to Los Angeles County.

Lessons Learned

1. The organization and infrastructure of any system must be flexible enough to allow for its transfer and implementation.
2. A centralized location for providing medical care to foster youth benefits the collection and maintenance of records.
3. Although medical records for children in the DC KIDS program is paper-based, case-workers have 24-hour access to information via telephone.
4. The electronic database used by DC KIDS is for scheduling and tracking appointments, which is essential for tracking patient progress.

DCFS Medical HUBs: New Strategies for Providing Health Care

DCFS is in the process of enacting significant changes intended to improve the health care of children in foster care. The basis of these is a system of HUBs, centralized locations that will provide a medical entry point for children entering the child welfare system. The intent is to standardize the processes for accessing health care to foster children and to provide additional services.

These HUBs will reside at six locations and will eventually serve all county foster children. One site, the Community-Based Assessment and Treatment Center at LAC+USC is already operational. Two more are slated to be in operation by July 2005.

The design of the HUB system will help to address several of the challenges facing CHEER. The first of these is by creating a common entry point where the collection of health information can be initiated. Second, it limits the number of doctors providing care to foster children to a select group who will communicate with caseworkers and the HUBs. Third, it creates a standardized process for each child entering the system and provides numerous opportunities for streamlining and refining the flow of records. Finally, state confidentiality laws permit limited record sharing within multidisciplinary teams such as those at the HUBs.

Regional DCFS offices will send children to the HUBs based on the following criteria:

- Any child whose detainment is uncertain
- Any child who has been detained and requires examination
- Any child who has been injured in care
- Any child who has been re-placed
- Any child needing the standard medical exam required within 45 days of placement

These criteria will effectively funnel all new children—and, over time, large numbers of those currently in placement—into the HUBs. Regional Administrators are largely responsible for ensuring that children meeting these criteria are sent to the HUBs, and their incentives to use the system include the need to prevent deaths and severe medical errors/omissions for children in care.

Each HUB will have a co-located caseworker on-site. Following a foster child's examination, the caseworker will work with a Multidisciplinary Assessment Team (MAT) to plan for the child's ongoing health care. The MAT will be composed of physicians, specialists, caseworkers, mental health providers, family members, caregivers, and others engaged in providing services and care for the child. Its composition will change for each client and over time.

The MAT will make recommendations based on the child's exam, history, and health issues. Those who require urgent care or who have severe health problems or chronic illnesses will continue to receive care at the HUB. Some HUBs will also offer mental health

services. The remainder will be referred by the caseworker to area doctors. The doctors will be a discrete set of CHDP providers who meet additional criteria and who have demonstrated an active interest in serving the foster care population. Further criteria are being set by DCFS in cooperation with the Department of Health Services (DHS), which oversees the CHDP program.

By limiting referrals to a vetted list of providers, the HUB system creates a de facto network of providers. These providers will have additional resources available to them, including further training and education, and will be linked to the caseworker through the HUB. Past efforts have demonstrated that when such relationships exist, record keeping improves, provided the child's placement is stable.

DCFS is also providing funding to the HUBs. Since this will be tied to their adherence to certain procedures, it may be a possible incentive for their adoption of CHEER. Separating funding from Medi-Cal reimbursement rates may also permit HUB physicians and staff to dedicate extra time to dealing with foster care-specific issues including additional time spent collecting and assembling records.

One important process lacking at the HUBs is a clear means of collecting patient data and transferring it to the courts and to DCFS. The HUBs have been left with the responsibility of facilitating the flow of data and records through their systems. This is significant because the HUBs, or a similar organizational model, present the best opportunity for improving the flow of information by limiting providers to those partnered with the facility and by creating an enforceable system and accountability.

Several challenges exist to the successful implementation of a HUB system. DCFS anticipates some resistance from caregivers—particularly relative caregivers—who will need to bring children to a location or provider other than their family doctor. Standardized policies for records and data collection, the use of MATs, and criteria for doctors on the provider lists have yet to be developed or enacted. Additionally, the HUB plan does not address the fact that other medical facilities currently serve large numbers of foster children. This is particularly true in Long Beach and Pasadena, which each operates its own health system.

Recommendations: The CHEER Model

The CHEER Vision

The ultimate vision for CHEER is a fully automated system capable of collecting, processing, and providing health records for youth in foster care to authorized users through a secure electronic interface. CHEER will provide comprehensive and reliable medical information in a permanent system unaffected by changes in placement or medical provider. CHEER will be capable of exchanging information with state and county information systems, and will accept input from a variety of resources, thus making it interoperable with electronic medical records in use in hospitals, clinics, and doctors' offices. The administrative burden on DCFS and others charged with health records tracking and maintenance for foster children will be greatly reduced. Caregivers will be able to access meaningful health information for children placed in their homes or facilities. Foster children will be able to access their own records and will have a full medical history when they emancipate.

The benefits of this system will be dramatic. Overall health services for foster children will improve, with significant reductions in medical errors resulting from omissions and re-immunizations. Increases in efficiency will save costs from duplicative or unnecessary medical procedures. Caregivers will be able to more effectively meet the needs of children in their care, and improvements in child health will contribute to reducing the number of placements.

The CHEER model addresses current realities while building the foundation for future expansions. As such, some of its features are interim steps, intended to enable the collection and maintenance of information and provide the greatest immediate benefit to foster children.

The time is right to begin developing and piloting a system. The pieces needed to make CHEER work are falling into place, and the necessary technologies are available and cost-effective. DCFS is instituting HUBs, which will provide the structure for obtaining and inputting information and also address the lack of standardization and the unmanageable numbers of medical providers. Electronic medical records are inevitable; waiting for universal adoption will only put CHEER behind the technology curve.

Most importantly, we cannot afford to continue to provide inadequate medical care to foster children.

Challenges

As detailed in the Findings, the collection and management of health care information for children in the Los Angeles County foster care system does not currently occur in a timely, accurate, uniform, or comprehensive manner. The mechanisms used to collect and store this information are inconsistently applied and do not reflect the origin and use of the information. These issues contribute to the difficulty of delivering health care services to youth in care and increase the risk of omissions or errors in services.

The key to realizing improvements in the quality and completeness of foster care health information lies in our ability to leverage technology to enable the originators and holders of health records to more easily and seamlessly record and access information.

The research gathered and presented throughout this report indicates that multiple choke-points exist in the cycle and flow of health care information. These are caused by a number of factors—lack of understanding, lack of time, lack of standards, lack of incentives, the perception that the information is of low priority, cost, complexity, and limitations in current infrastructure capability and capacity.

These factors span the stakeholders and individuals providing care and services to foster children. Figure 2 shows the persons, organizations, and systems involved in the collection, recording, management, and dissemination of the health care information for foster care youth. While this is not a comprehensive list, it clearly illustrates the breadth of participants in the process.

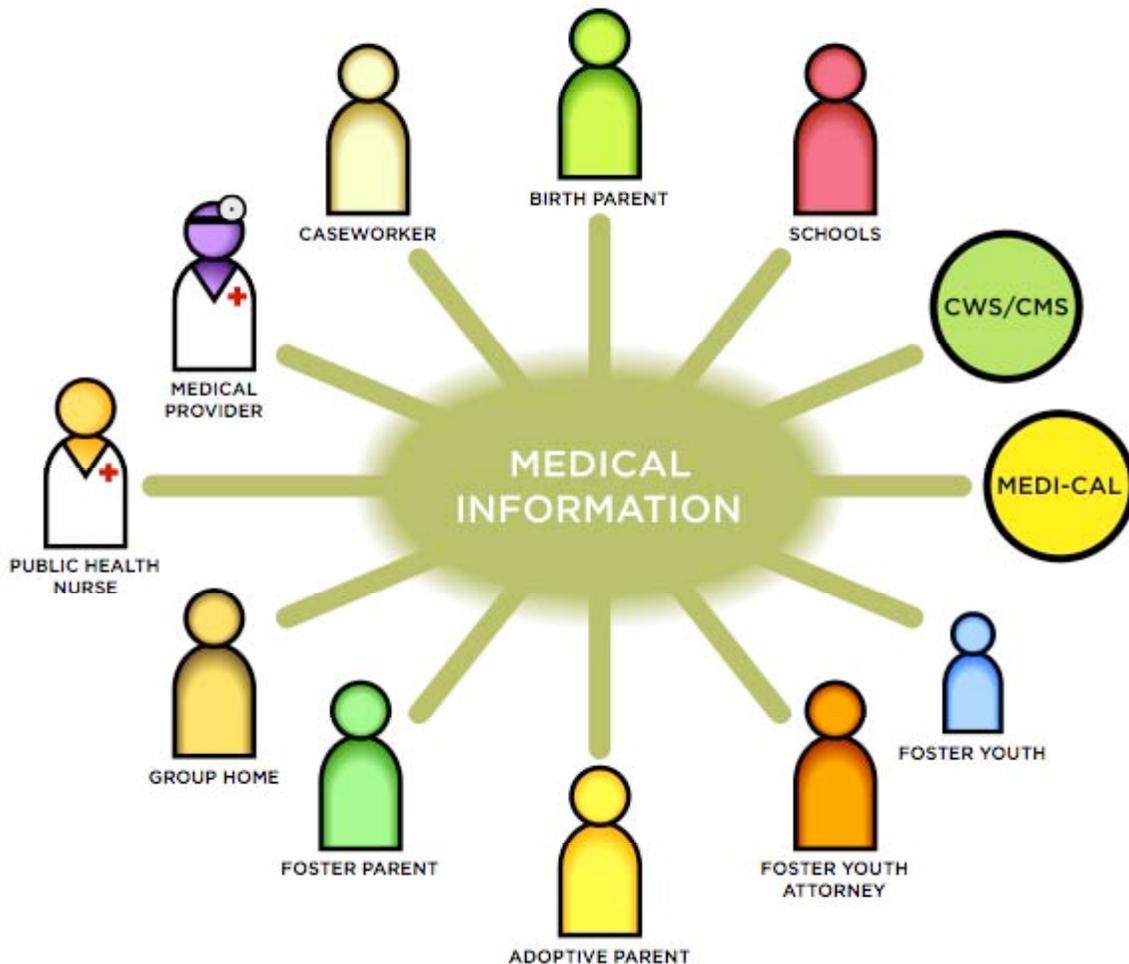


Figure 2. Stakeholders, groups, and systems

Each of the individuals, groups, and systems is driven by their own priorities, which serves to complicate the information collection process and prohibit a solution based on

mandates or demands on individuals who are not under the direct control of the foster care system.

Physicians represent the origination point for the majority of health care information, yet most spend only a small portion of their time working with foster youth. Therefore, any solution that places unreasonable, costly, or time-consuming burdens on medical providers will have little chance of acceptance or of delivering the desired benefits and improvements in service.

Functional and Technical Requirements

❖ Data elements and documents should be standardized and streamlined.

It is essential that the data elements and definitions used by CHEER be closely aligned with those in other systems to facilitate the exchange of records and information. A frequently recurring theme with medical providers we interviewed was also the need for more meaningful information used in assessment and diagnosis. Similarly, caseworkers and medical providers offered numerous suggestions for improving the forms used to record medical visits and the results of examinations.

As part of the pilot phase of CHEER, a series of working groups consisting of medical providers (particularly from the HUBs), caseworkers, and other users will be convened to develop a comprehensive set of data elements and optimized paper and computer forms. These groups will utilize the data elements in CWS/CMS, HELIX, and the Medi-Cal databases, forms used in medical environments, and 561 and PM160 forms as starting points to ensure interoperability.

❖ The CHEER system should be implemented as the health records management system at the DCFS HUBs.

By creating a centralized entry point for the health care of foster children, the DCFS HUBs will act as the physical and organizational structure necessary for the timely and accurate capture of health information and records. However, no common infrastructure currently links the HUBs with other medical providers, DCFS, and other entities in the chain of information. The CHEER system will be capable of bridging the gaps in the flow of information by creating a single conduit for health information that is accessible using technologies already in use in most health care environments.

❖ The collection of health information at the time of service should be automated through the creation of an electronic medical record.

As can be seen in Figure 3, an electronic medical record residing in a central database will provide users with real-time access to a wealth of detail on the foster child.

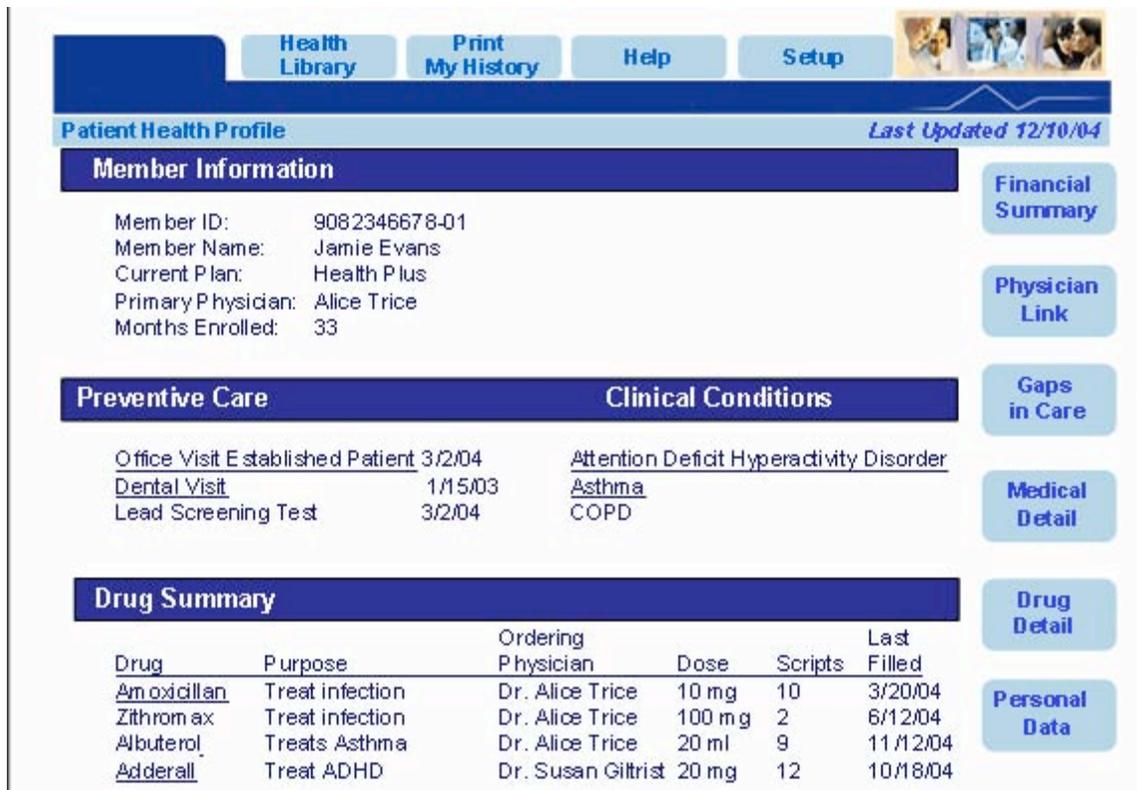


Figure 3. Sample CHEER electronic medical record

With a series of clicks, users can review data on:

- How much money has been spent on the child’s care and for what services
- Who has provided treatment
- Possible gaps in care (a sample of that screen is shown in Figure 4)
- The child’s medical history
- Details of prescriptions and medications
- Age and other personal information for the child

Health Library **Print My History** **Help** **Setup**

Patient Health Profile *Last Updated 12/10/04*

Member ID: 9082346678-01 **Male**
Member Name: Jamie Evans **5 Years of Age**

Primary Preventive Services: Staying Well

Service	Frequency	Last Service	Status
<input checked="" type="checkbox"/> Primary Care Visit	Once per year	3/2/04	Up-to-date
<input type="checkbox"/> Dental Visit	Once per year	1/15/03	Overdue
<input checked="" type="checkbox"/> Lead Screening Test	Once	11/2/02	Up-to-date
<input type="checkbox"/> DTaP Immunization	Once 3-5 yrs	~	Missing
<input type="checkbox"/> MMR Immunization	Once 3-5 yrs	~	Missing

Managing Your Disease

Condition	Service	Frequency	Last Service	Status
<input checked="" type="checkbox"/> Asthma	Rx-Inhaled Steroid	Ongoing	6/12/04	Up-to-date
<input type="checkbox"/> Asthma	Spirometry	Every 1 – 2 yrs	~	Missing

Financial Summary
Physician Link
Gaps in Care
Medical Detail
Drug Detail
Personal Data

Figure 4. "Gaps in care" screen from a sample CHEER electronic medical record

The sample records shown in Figure 3 and Figure 4 were generated from Medi-Cal billing information. Foster youth often have long histories of receiving services provided through Medi-Cal, much of it prior to their entering the child welfare system. CHEER will make it possible for the first time to obtain complete historical medical and health care information on many, if not most, foster children.

Electronic record capability using Medi-Cal information will dramatically improve the ability of medical personnel to accurately diagnose and treat foster children—a significant breakthrough.

❖ **CHEER should accept data input through a variety of means, including e-mail, the Internet, facsimile, and tablet PCs.**

The data collection model should be flexible and extensible enough to accept information from a myriad of sources utilizing a range of automation methods. Figure 5 shows some of the available means for receiving and recording health care information, many of which are being used in the State of California to support other health care systems such as Medi-Cal. The health care provider records information on a paper or electronic health care document, which can then be delivered using a number of methods.

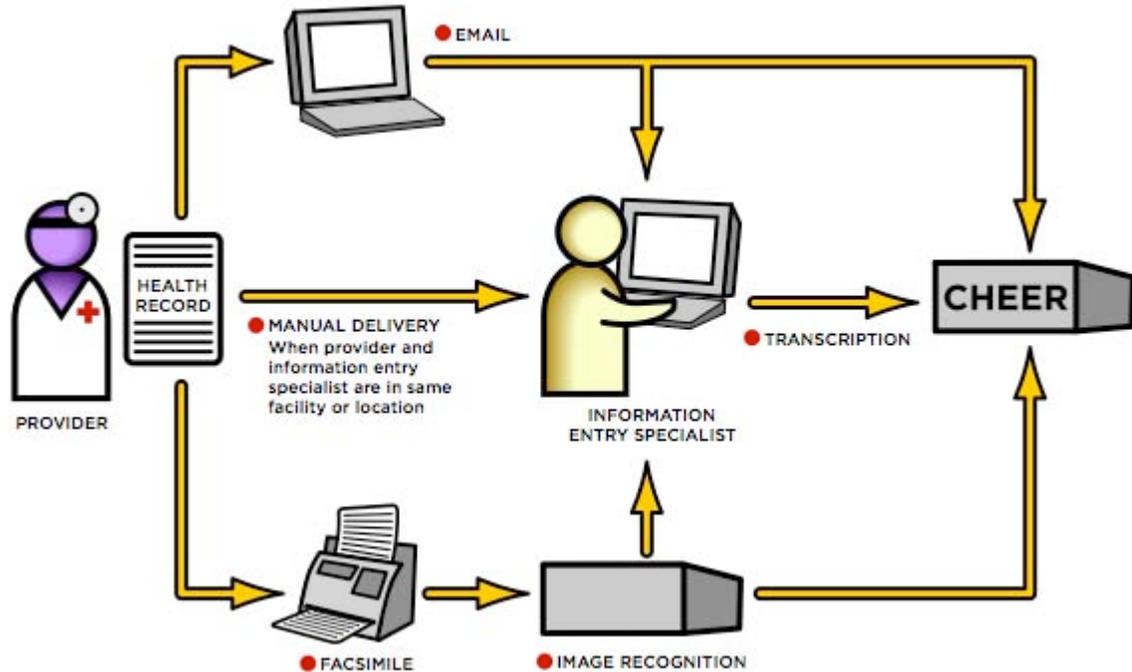


Figure 5. Methods of recording and delivering health information

Optimally, information is electronically recorded at the point of service, then transmitted through secure electronic means such as encrypted e-mail. Enhanced technologies that allow handwriting to be captured and transformed also exist and are in widespread use in government and industry. For example, tablet PCs can display an image of a form and allow it to be completed by “writing” on the screen with a stylus. This method of capturing information has dual benefits. First, the original handwriting is preserved and an image of the form and the handwritten entries, including signatures, can be stored and reproduced. Second, the conversion to an electronic format can be immediate, providing feedback to the originator of the information and allowing any illegible information to be rewritten at its source. This significantly reduces or eliminates the need to transcribe information later, and lessens the potential of transcription errors.

This approach also supports multiple types of form input, streamlining information collection for a particular service and also allows the flexibility and extensibility that information collection requires to support a variety of providers, services, and client conditions.

Electronic tablets work especially well in combination with the HUB initiative that DCFS is introducing, since tablets can be supplied to the HUB providers. This does not require providers to learn a computer program or additional staff to process paper documents. When an electronic method such as a tablet is not available or practical, providers can continue to record information on paper documents, which can be transmitted via facsimile to an electronic inbox at one of the HUBs for data entry.

The system could also allow for automated entry from the electronic facsimile image using decoding and recognition functions. A similar practice is in use by the California

Department of Health Services to receive and electronically process Medi-Cal claim forms, and the recognition and accuracy rate exceeds 90 percent. Portions of the document that cannot be electronically decoded are presented to specialists for recognition and entry.

This method of information capture works well within the existing health care infrastructure and allows caregivers to continue to see a family physician or provider of choice. It also works well in circumstances that require specialists or providers not included in the HUB provider network envisioned by DCFS. Both the tablet and image recognition greatly improve the timeliness, accuracy, and completeness of the information collected and reduce the manual labor required to complete the collection process.

A third method is allowing the provider to enter directly information over the Internet through a browser-based service. This will need to be flexible enough to work in a range of environments and be compatible with existing hardware.

The approach of recording information on paper documents and subsequently transcribing information onsite creates the need for additional staff and physical space at the provider location. While feasible at the HUBs, this model does not work well for providers for whom foster care youth represent a small percentage of total clients.

❖ **Existing Medi-Cal and child welfare system data should be used as a starting point for historical medical information.**

In addition to the capture of information at its source, the potential to capture information from existing sources such as CWS/CMS and Medi-Cal is real. These are important repositories of historical data and other information that is not captured during the delivery of service by providers.

A significant number of youths in the foster care population receive Medi-Cal benefits prior to entering the child welfare system (as well as during their tenure there), and records of past medical services covered by Medi-Cal may provide a portion of the child's overall health care history.

As the primary repository of case information for California's foster children, CWS/CMS can also serve as a valuable source of historical and demographic information. There are challenges to the accuracy, timeliness, and completeness of this information, but these are mitigated by focusing on the use of this data as historical background. In order to minimize the effort and cost associated with obtaining data from the CWS/CMS and Medi-Cal systems, a request-based approach should be utilized.

Figure 6 depicts a potential model for this transaction.

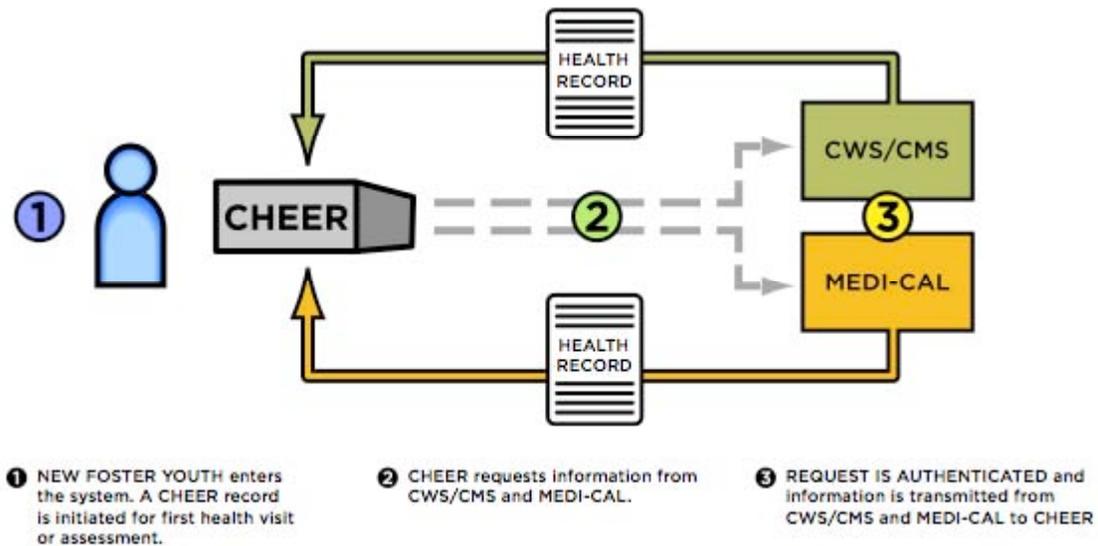


Figure 6. Records request and transmission between CWS/CMS and Medi-Cal.

❖ **CHEER should be scalable, flexible, and extensible.**

While the development of a pilot project—as discussed later in this document—provides the first important step, the CHEER initiative has numerous possibilities for future development. As other sources of information become available (education data through the HELIX project, for example), request-based processing similar to that recommended for the Medi-Cal system can be implemented to enable sharing with CHEER.

❖ **CHEER should be an Internet-based system in order to provide greater access to those who legally can access the information.**

A critical component of the ability to share information between systems is the method and transport technologies utilized; they should not place undue requirements or cost on the agency or individuals responsible for supplying the source information. For example, requiring CWS/CMS to add components or rewrite a large portion of its existing system would significantly reduce the likelihood of success. Similarly, a solution that requires extensive programming would lessen the probability of participation of the Medi-Cal system.

The transport mechanisms should be based on an open technology that is widely available and understood by the systems that are probable data sources. As a data format which has been widely adopted as a standard by the IT industry, XML and its supporting technologies offer a rich, flexible means of encoding and sharing information between sources.

To realize the desired benefits, information in CHEER should be made available in real time to the individuals who require it for analyses and decisions. Figure 7 shows two of the potential methods for providing access and delivering information to a physical location. In the both methods, the caseworker authorizes access to information for a given provider.

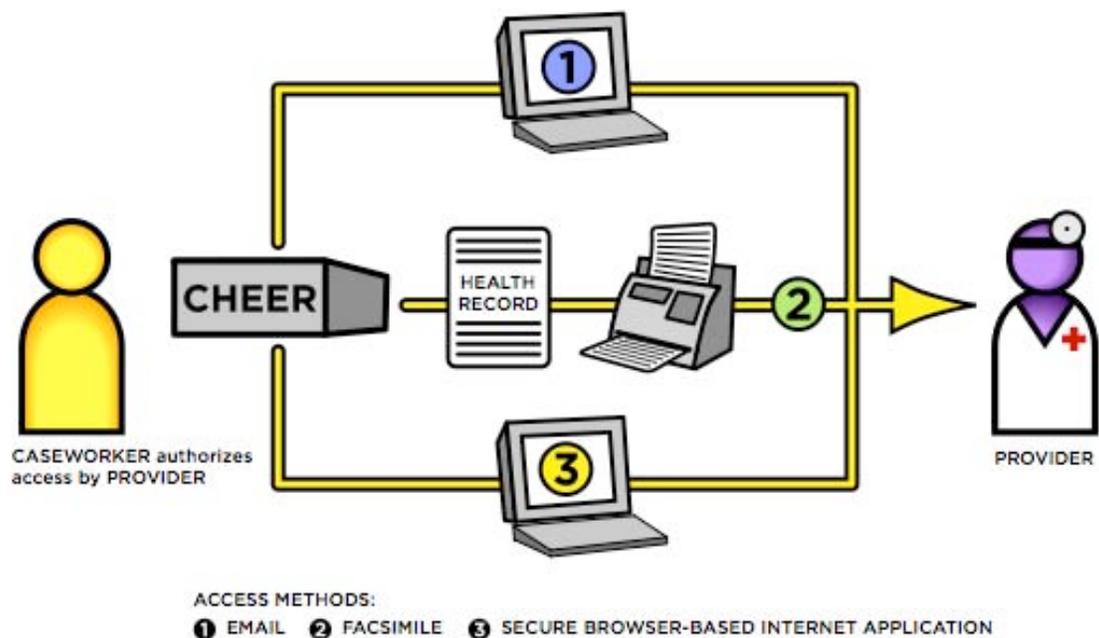


Figure 7. Methods for accessing CHEER information

In the first method, health information is transformed into an electronic health care document. The document is then encrypted and sent to the provider via secure e-mail. The provider is able to decrypt, view, and print the health care document.

In the second method, the health information is transformed into an electronic health care document. The document is sent to the provider via facsimile.

A third method of providing access to health care providers is through the use of a browser-based Internet application similar to the application described in the data collection section starting on page 35.

All methods utilize technologies (facsimile, e-mail, Internet browser) that are nearly universally available, have been industry proven, and are in use in other health care and social services environments for similar purposes.

❖ **Security standards and access policies should be established.**

A key component of CHEER will be a high level of security—both physical and logical—for information during collection, storage, and delivery. Access to information should be limited to authorized and appropriate individuals, and different levels of access will filter the information accessible by various groups of users. The security and access rights for viewing information collected in the system will likely be more politically controversial than technically challenging.

One of the most popular and prevalent Internet security technologies is Secure Socket Layer (SSL). SSL can be utilized with the three methods for accessing information discussed in the previous section, but may not be fully compatible with all Internet browsers.

The system should also:

- Provide a comprehensive audit trail of access to information
- Record and monitor access to information
- Alert appropriate individuals to unauthorized attempts to access information
- Be scalable to support the countywide caseload and transaction volume
- Be flexible and configurable to allow for regulatory, policy, and process changes
- Be standardized for Internet browser compatibility

Operational Description

The following is a step-by-step description of the process for utilizing CHEER. Figure 8 illustrates how a record will move through the CHEER system.

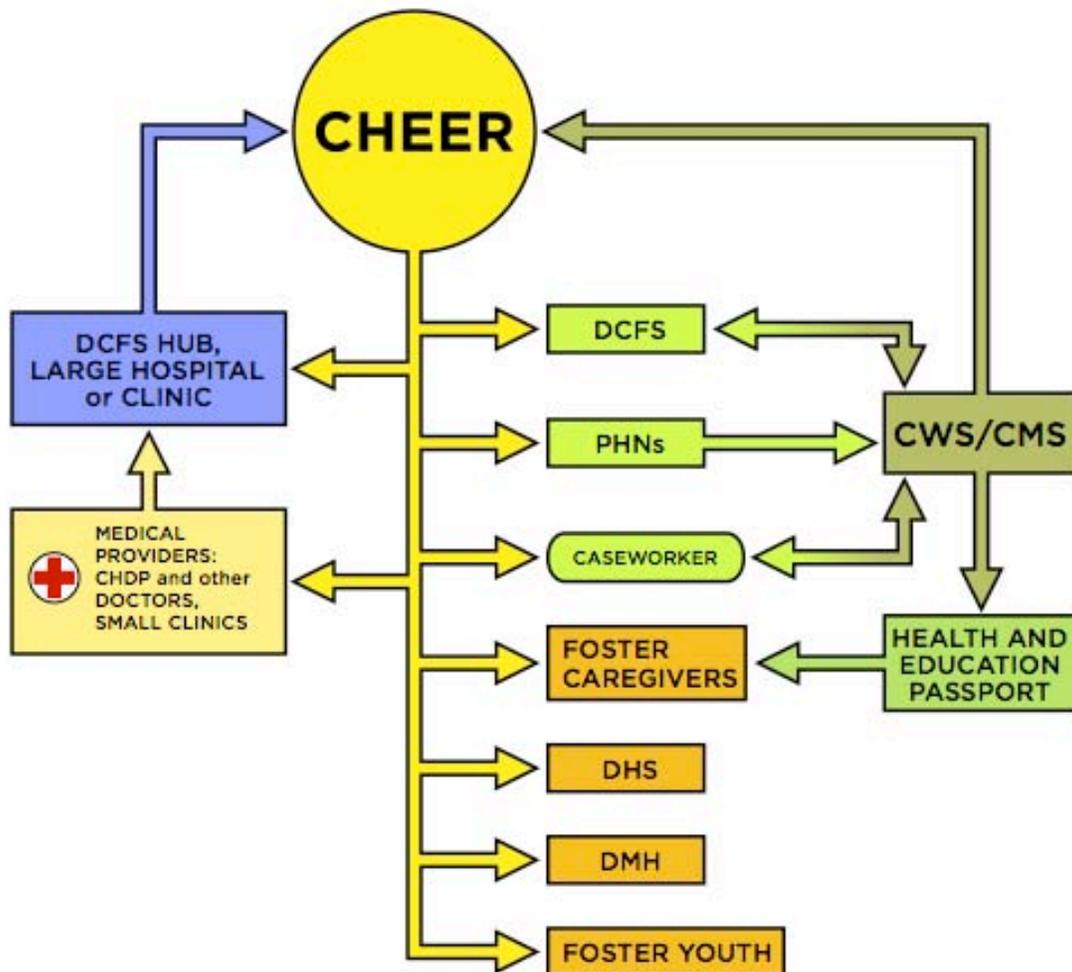


Figure 8. Proposed CHEER dataflow

First HUB visit

1. The child's history, identification, and demographic information is downloaded from CWS/CMS by the onsite caseworker and electronically transferred to CHEER.
2. Additional historical medical information is obtained using Medi-Cal data.
3. CHEER generates the medical visit log forms that are printed and provided to the doctor.
4. The doctor sees the patient and fills out the log form. Information includes CHDP exam record, diagnoses, treatments, prescriptions, and referrals.

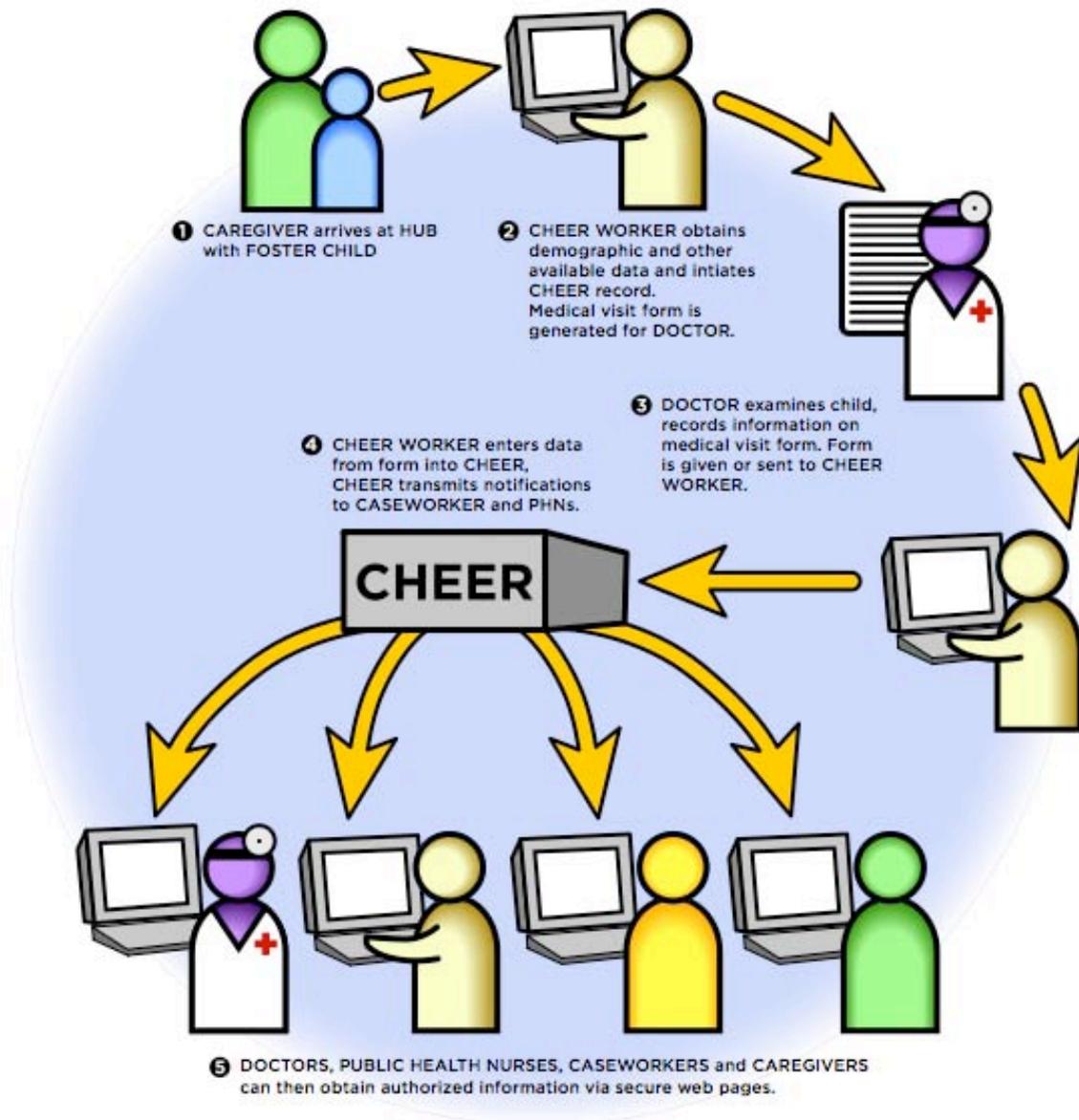


Figure 9. A CHEER record is initiated, entered, and distributed online.

5. The log form is submitted to the CHEER worker at the end of the visit. Information is verified, checked for completeness or errors, and then entered into CHEER. CHEER records are then submitted electronically to the doctor, the billing entity, the caseworker, and the Multidisciplinary Assessment Team (MAT).
6. The MAT conducts an assessment and makes recommendations to the caseworker for a health case plan and referrals. The MAT must also provide a report to the juvenile court within 45 days.
7. The DCFS caseworker makes appropriate referrals based on MAT recommendations. The doctors receiving referrals must be on a HUB provider list.
8. The CHEER worker inputs any referral information. Notifications may be sent or provided to referred doctors, the MAT, caregivers, and/or public health nurses (to alert them of health problems).
9. Visits are scheduled in advance, via CHEER or the caseworker using CHEER. All medical appointments are logged into CHEER for required notifications and follow-ups.
10. The end users (DCFS, other county departments, service and health care providers, caregivers, foster children) then have access to records or limited sets of data (based on confidentiality laws and user agreements) via the secure CHEER website.
11. Access to data (the ability to enter, alter, or output) is determined when users log in to the system using passwords generated by CHEER.

Subsequent Visits to HUB Provider

1. Doctors receive prior notification of a foster child's appointment via CHEER.
2. Records can be viewed and output at time of visit.
3. CHEER automatically populates various fields—including identification, demographic information, etc.—on log forms and then outputs forms for doctors.
4. The doctor sees the patient and fills out the log form. Information includes CHDP exam record, diagnoses, treatments, prescriptions, and referrals.
5. Log forms are submitted to the CHEER worker at the appropriate HUB by doctor's office personnel via fax or, when possible, e-mail or electronic tablets.
6. The CHEER worker verifies and then inputs records and other info (follow-up visits, etc.). Notifications are sent.
7. Visits are scheduled in advance, via CHEER or a caseworker using CHEER. All medical appointments are logged into CHEER for notifications and follow-ups.
8. End users (DCFS, other county departments, service and health care providers, caregivers, foster children) then have access to records or limited sets of data (based on confidentiality laws and user agreements) via secure the CHEER website.

9. Access to data (the ability to enter, alter, or output) is determined when users log in to the system using passwords generated by CHEER.

Visits to Specialists or Other Providers

1. Referrals to health care providers outside the HUB or CHDP list that are entered into CHEER are reviewed and verified by the CHEER worker and the DCFS caseworker at the HUB.
2. Upon verification, CHEER generates a new password for the provider.
3. Instructions for accessing records via CHEER are sent to the provider along with the new password.

Emergency Room and Other Unscheduled Visits

When foster children are taken to emergency rooms or clinics for urgent care or other unscheduled visits, medical personnel will have two ways to obtain records via CHEER.

1. The first method is to call the CHEER worker at the HUB. The CHEER worker can generate a special password for this visit.
2. The second method, available outside business hours for emergencies only, is to call the 24-hour DCFS Child Abuse Hotline. After verifying the request for records, personnel at those locations can access the CHEER system, output an emergency medical history, and fax this to the emergency room.

Organization and Governance

A strong and effective organizational structure is critical to the success of the CHEER system. The structure must be clear, provide levels of accountability, allow for the measuring of outcomes, and be flexible enough to change as the program adjusts in response to outcomes and feedback or expands to other locations. Similarly, the governance of the system must be responsive to input and feedback (particularly in the critical early stages of the program), have a clear understanding of the system's purposes and functions, and be committed to making the system work.

A project manager will oversee and manage CHEER implementation, and a steering committee composed of representatives from stakeholder and advocacy groups will be established. Members should include DCFS caseworkers, public health nurses and information technology staff; representatives from the Department of Health Services, the Department of Mental Health, the Chief Administrative Office's Service Integration Branch, medical providers, each HUB location, foster youth, caregivers, children's attorneys, and other advocates.

From Report to Reality: The Road Map to CHEER

To make the jump from a report to reality will take executive leadership, the coordination of multiple stakeholders, the navigation of government procurement policies, and money. Step one is the development of the health-information part of the system and its pilot. Step two is pilot implementation and operation, and step three is a review of the pilot. Step four is a countywide expansion of the program and the possible inclusion of educational data from other systems. We believe CHEER can serve as the framework for a statewide (and possibly a national) model for improving health care for foster care youth.

During the pilot phase, the collection of and access to information will be improved with the previously described methods, either in conjunction with or as a precursor to the implementation of the DCFS HUB initiative. The capabilities provided during the pilot complement, but are not dependent on, DCFS HUBs.

The pilot's efficacy and outcomes should be measured in a number of dimensions. The first, and most significant, are the benefits affecting the participating segment of the foster care population. Other measures include improvements observed by medical providers, caseworkers, and caregivers who are affected by CHEER, and any changes in their ability to provide services.

To mitigate complexity and risk, the size of the initial population of foster youth and number of staff involved in the pilot will be relatively small. Stakeholder buy-in and participation will be maximized by identifying an office, unit, or individual caseworkers with a particularly strong commitment to the improvement of health care service delivery.

We suggest that the initial scope of the pilot consist of three main activities:

- Re-engineer and streamline the data collection processes and forms in use by medical providers.
- Automate the data collection process as recommended.
- Establish a universal health record for each of Los Angeles County's foster care youth that includes available historical information.

Based on consultations with DCFS, DHS, DMH, and technology vendors, we believe a pilot of this scale and scope could be completed within nine months.

Approach and Timeline

It is optimal to plan, construct, deploy, and monitor the pilot phase in a matter of months so that some of the potential and benefits of the system can be observed before moving forward to countywide deployment of the solution. During the nine-month timeline for the definition, configuration, and validation of the CHEER pilot capabilities, the following activities will be completed:

- Requirements and functionality will be finalized with project stakeholders.
- Focus groups will be conducted to define data elements, improve forms, and streamline and automate the data collection of foster care medical information within the HUBs.
- Tablet PCs will be deployed in two HUBs, using the revised data collection forms.
- A system software solution (platform) will be selected or constructed.
- Interfaces to the CWS/CMS and Medi-Cal systems will be configured and implemented.
- The foster care population to be served by the pilot will be defined.
- A historical health record for the defined population will be established.
- Access policies and procedures will be defined.
- System access within two HUBs will be deployed.
- After three months of use, a review of processes and tools will be conducted to determine the strategies and enhancements required for a countywide rollout.

The following provides a general outline of tasks by month.

❖ **Months 1–3**

- Establish a project plan and governance structure to make required project decisions.
- Finalize the capabilities and requirements of the CHEER pilot.
- Conduct focus groups with stakeholders to define data elements and streamline the data collection process.
- Review and select source document formats.
- Begin to analyze the planned interfaces between CHEER and the CWS/CMS and Medi-Cal systems.
- Identify a software solution that supports the capabilities detailed in the CHEER report.
- Procure the required hardware for CHEER data collection and storage.

❖ **Months 3–5**

- Select or construct the software solution.
- Make contacts with agency staff, including managers, supervisors, and caseworkers, to identify the initial phase population.
- Develop e-forms for the data collection device.
- Develop training materials for pilot participants and schedule training sessions (month 5).

❖ **Month 6**

- Perform field testing.
- Business and technical analysts work with caseworkers and providers to validate the solution and its capabilities.
- Technical and business analysts work with CWS/CMS and Medi-Cal to validate the interfaces with these systems.
- Finalize and prepare the pilot phase population.

- Load test information from CWS/CMS and Medi-Cal into the CHEER system.

❖ Months 7–9

- Deploy and “go live” with CHEER access at two HUBs.
- Project stakeholders work together to monitor and assess the operation and benefits of the system.
- Identify and prioritize improvements and enhancements.
- Project stakeholders begin planning an expansion of the system to other locations and additional capabilities and functions in preparation for full county deployment.

Cost and Staffing

There are two areas of cost for the pilot: staff resources and infrastructure. Based on input from several sources, we anticipate a core team of seven part-time staff will be required to complete the pilot phase. These staff will be supported by project stakeholders, including agency managers, supervisors, and caseworkers. Support and participation from the CWS/CMS and Medi-Cal agencies is also required to realize the full potential of the pilot.

The core staff team should include a project manager, two business analysts, two technical analysts/developers, a technical architect, and an administrative support person.

The system infrastructure is dependent on the hardware and software required to host the solution during the pilot phase. This needs to be scalable to handle the full foster care population, and could be hosted by the Los Angeles County Information Systems or at an external location.

Based on the scope discussed above, the estimated cost of the pilot is between \$1.5 and \$2.0 million. Additional analysis and detail will be required to provide a more definitive cost. The investment in this pilot is largely a one-time up-front expense to establish the necessary infrastructure. We anticipate a fairly nominal cost for the continued operation and maintenance of the system.

Summary

The capabilities of the system during the pilot phase will be focused on the ability to collect and store information and to provide access to the stored information by authorized individuals.

A focus on simplicity is also important, given the complexity of the DCFS HUB initiative and changes in the child welfare system at the state level. Each of these efforts has the potential to affect the CHEER initiative. By keeping the initial phase focused on collection and access to information, the risk of external changes disrupting the CHEER initiative is greatly reduced.

As the potential of the CHEER system and the direction of other initiatives become clear, the capabilities of CHEER will grow to include information management, information

mining, and outcome management. These functions will present the potential for fundamental change in the delivery of services to youth in foster care.

The ability to proactively monitor information will enable caseworkers and foster parents to be alerted of the need for routine health services. Links to care providers will offer the ability to schedule appointments proactively.

The mining of information will enhance the management of health services delivery by identifying trends and predicting case and activity levels. The availability of information collected and stored by CHEER will avoid unnecessary service activity and prevent service errors such as re-immunization.

The long-term potential for CHEER includes improvements in information collection and access for the entire foster care population in Los Angeles County and beyond. Ultimately, CHEER could act as an information broker between disparate systems that collect and store information relevant to youth in foster care and the individuals that have a need for that information. Including linkages to other critical information sources such as education and other human service systems will help achieve a more holistic vision for efficient service delivery.

Appendix A: Interviews and Meetings Conducted

Los Angeles County Departments and Agencies

Department of Children and Family Services

Dr. David Sanders, Director
Lydia Banales, Nurse Manager, Health Care Services
Berisha Black, Emancipation Ombudsman
Donna Fernandez, Administrator, Health Care Services
Joi Russell, Interim Division Chief
Dr. Charles Sophy, Medical Director
Amaryllis Watkins, Division Chief, Special Programs, Medical Placement Unit
Aris Banico, Children's Services Administrator, Specialized and Alternative Services
Division
Mary Velasquez, Public Health Nurse, CHDP, DHS
Leo Yu, Bureau Chief, Information Services
Cecilia Custodio, ITSD
Focus Group: Bill Bedrossian, Lucy Hernandez, Zoe Sariego, Tika Smith

Department of Health Services

Dr. Jonathan Fielding, Director & Health Officer, Public Health Division
Robyn Davis, Regional Manager, Los Angeles Immunization Network
Dr. Joseph Duke, Director, Child Health and Disability Program and Chair, CHDP
Directors and Deputy Directors Group
Dr. Paul Fu, Medical Director for Information Systems. Pediatrician
Nancy Montoya, Nurse Manager, Foster Care Program, Child Health and Disability Prevention, Health Care Program for Children in Foster Care
Kevin Burdett, Public Health Nurse, Pomona
Paula Deng, HCPCFC Public Health Nurse, Pomona
Jeanne Smart, Director, Nurse Family Partnership, Maternal, Child & Adolescent Health Program
Cheri Todoroff, Acting Director, Children's Medical Services

Department of Mental Health

John Hatakeyama, Deputy Director, Children and Family Services Bureau
Sam Chan, District Chief
James Coomes, MH Analyst
Paul McIver, District Chief
Lisa Wicker, District Chief

Chief Administrative Office

Lari Sheehan, Assistant Administrative Officer and Director
Jose Aldana, IT Infrastructure Development
Kathy House
Constance S. Sullivan, Assistant Division Chief
Tuyet Truong, IT Infrastructure Development

Chief Information Office

John McIntire, Associate Chief Information Officer

Probation Department

Ali Farahani, Senior Probation Director

Schools and Education

Los Angeles County Office of Education

Pat Levinson, Coordinator, Interagency Programs, Foster Youth Services

Phil Dawson, Program Administrator

Sheryl Hudson, Data Processing Specialist

Machelle Wolf, Education Community Worker and former foster youth

Los Angeles Unified School District

John DiCecco, Director, Integrated Student Health Partnerships, LAUSD

Karen Maiorca, Director of Nursing, LA County Unified School District

Foster Youth, Caregivers, Advocacy Groups

Dr. Va Lecia Adams, Director, Transitional Living Program, United Friends of the Children

Susan Edelstein, Program Director, TIES for Adoption

Priscilla Charles Carter, Past Vice President, Carson Foster Parents Association and Foster Parent representative to the Children's Planning Council

Wendy Lazarus, Co-Director, The Children's Partnership

Sacha Klein Martin, Child Welfare Policy Director, Association of Community Human Service Agencies; Jenna Valentine, Child Welfare Policy Assistant; presentation and discussion with representatives of 30 member organizations.

Relative caregivers focus group at KEPS Training Class, Pierce College: Zoe Pruitt, Trainer; Carol Bohn, Foster and Kinship Care Education Coordinator; presentation and discussion with eight relative caregivers.

United Friends of the Children, Transitional Living Program Focus Group; group consisted of nine former foster youth, ages 18-20: Percy B., Damion D., Erika N., Christina S., Crystal S., Immanuel S., Milton S., Naevonn S., Christopher V.

Health Care Providers

Dr. Janet Arnold, Medical Director, Community-Based Assessment and Treatment Center, LAC+USC Medical Center

Appendix A: Interviews and Meetings Conducted

Dr. Xylina Bean, Director, Shields for Families Project, Charles Drew University and Associate Director of Neonatology, King/Drew Medical Center

Dr. Kerry English, Director of Child Development, UCLA King/Drew Medical Center. Chair, Foster Care and Adoptions Subcommittee, American Academy of Pediatrics

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Dr. Neal Kaufman, Director of Academic Primary Care Pediatrics, Cedars Sinai Medical Center and Commissioner, First 5 LA

Dr. Olga Mohan, Pediatrician, Professor of Pediatrics and Anesthesiology, Harbor-UCLA Medical Center

Dr. Elisa Nicholas, Executive Director, Children's Clinic, Long Beach Memorial Hospital and Children's Planning Council, Fourth Supervisory District representative; Dr. Maria Chandler, Medical Director, Children's Clinic; Erika Hainey, MSW, Children's Clinic

Susan Rabinovitz, Director, Division of Adolescent Medicine, CHLA; Dr. Marvin Belzer; Dr. Michele Roland; Dr. Curren Warf; Dr. Sara Sherer, Clinical Psychologist

Dr. Barry Zuckerman, Chief of Pediatrics, Boston Medical Center

Dr. Amy Fahrenkopf, Pediatrics, Children's Hospital of Boston

Juvenile Courts, Legal Advocates, Attorneys

Rebecca Gudeman, Attorney, Child & Adolescent Health, National Center for Youth Law; Bill Grimm, Attorney, Adoption, Foster Care, Abuse, Neglect

Janis Spire, Executive Director, Alliance for Children's Rights; Barbara Facher, Social Worker; Lara Holtzman, Senior Staff Attorney

Lisa Mandel, Director, Law Offices of Lisa E. Mandel, A Law Firm of the Children's Law Center of Los Angeles

Judge Michael Nash, Presiding Judge, Juvenile Division, LA County Superior Court

Brandon Nichols, Attorney, Los Angeles County Counsel, Children's Services Division

State of California Representatives

Gail Gronert, Special Assistant to the Speaker of the Assembly

Stan Rosenstein, Deputy Director, Medical Case Services, Medi-Cal

Information Technology, Models

Steven Brown, Veterans Administration Office of Information and Professor of Bioinformatics, Vanderbilt University

Robert Joy, Medicare/Medicaid Business Unit, Thomson-Medstat. Bobbi Coluni, Product Manager. Jeff Robinson.

Dawn Lewis, Program Specialist: Program Development and Quality Assurance (Health & Education Passport), Child Welfare Services, San Diego County Health and Human Services Agency

Sam Karp, Chief Program Officer, California Community Health Care Foundation

Don Knifong, Data Processing Manager II, Information Technology Services Division, California Department of Human Services

Christopher McKinnon, Program Manager, Health Care, Education, Information Technologies, Western Governors' Association

Debbie Neibert-Shanle, HealthWorks Program Coordinator, Illinois Department of Human Services

Judith Quinn, Program Supervisor, Health Care Program for Children in Foster Care, San Diego County

Mike Skinner, Executive Director, Santa Barbara County Care Data Exchange

David Springett, President, Community College Foundation

Jeff Wagner, Deputy Director, Department of Children's Services, Rancho Cucamonga Region, San Bernardino County

Mark Windisch, Senior Advisor, Chief of Staff LA Care Health Plan. Health-e-LA.
Karen Elliott, Manager, HIPAA Program, Privacy Officer, LA Care. Health-e-LA

Marc Wine, Program Manager, OneVA Health Information Technology Sharing, Veteran's Administration Office of Information. Dr. Syed Tirmizi, Medical Informaticist, Health IT Sharing Program.

Dr. Joseph Wright, Medical Director for Advocacy and Medical Affairs, Children's national Medical Center; Franklyn Baker, Director, Community Partnerships; Dr. Greta Todd, Director of Government and External Affairs

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Appendix C: Related Los Angeles County Efforts



	HEALTH	HEALTH + EDUCATION	EDUCATION
LOS ANGELES COUNTY	<p>LA Area E-Health Coalition Coalition consisting of county health agencies, foundations and service providers; funded by Dept. of Health Services, First 5 LA and California Endowment. Objective is to plan and develop patient-controlled, longitudinal health records for all residents of LA Metropolitan Area. Will be convening experts, providers, patients and community leaders to determine protocols and technological interfaces. Also recruiting IT consultants to plan infrastructure.</p>	<p>DCFS "Black Notebook" Health and Education Passport A manual and collection of records given to caregivers in a binder. Includes printed Passport generated by CWS/CMS. Static, paper-based record. Low completion rate.</p>	<p>ISIS LA USD's Integrated School Information System. Five-year implementation began in 2003. ISIS will interface with the state's CSIS system.</p>
	<p>LINK: Los Angeles County Immunization Network LA County Department of Health Services implementation of statewide web-based immunization registry. Los Angeles region includes all of LA County, Long Beach and Pasadena, and Orange County. All county hospitals and clinics will use LINK. The system will be available to other departments on January 1, 2005, though the processes for accessing it have not been defined. Electronic interfaces are possible, but none are currently planned. Participation by medical providers is voluntary. Largest buy in will come from integrating records of hospitals and health systems.</p>	<p>HELIX/Access Manager Web portal for exchanging foster youth records and data between caregivers and service providers. County Chief Administrative Office is the lead agency and will head an interdepartmental steering committee. RFP for building core system and education interface issued 3/1/04. A vendor has been selected, but the contract has not been finalized. In the future, HELIX will be expanded to include health information.</p>	<p>AB490 Requires immediate enrollment of foster youth and prompt transfer of records. Institutes foster youth liaisons in schools.</p> <p>ECC/DCFS Educational Initiative Education Coordinating Council will oversee the educational attainment of LA County foster and probation youth, including implementation of AB 490 and other educational records initiatives.</p>
GAPS IN SERVICE	<p>Private MDs/Dentists/ Specialists Health Clinics Hospitals HMOs CHLA</p>		<p>Private Schools Parochial Schools Non-Public Schools Head Start Universal Preschool</p>

Appendix D: Glossary and Web References

561: Three DCFS forms (561a, 561b, 561c) used to record the results of medical examinations, dental, and mental health visits of children in foster care.

Administration for Children and Families (ACF): Branch of the Federal Department of Health and Human Services that funds state family assistance, child support, and child welfare programs. ACF provides funding to the state for numerous foster care programs and CWS/CMS. <http://www.acf.hhs.gov/>

Association of Community Human Services Agencies (ACHSA): Organization providing support to over 75 foster family agencies and group homes in Los Angeles County.

Caregiver: Licensed foster family, group home, or relative with whom a foster child is placed.

Child and Family Services Administration (CFSA): District of Columbia department that administers its child welfare and foster care programs.

Child Health and Disability Prevention Program (CHDP): Provides public funding for well-child examinations of eligible children, including all youth in foster care. Los Angeles County foster children are required to have at least one CHDP exam per year (depending on age). <http://lapublichealth.org/cms/chdp/>

Child Health and Education Electronic Record (CHEER): Proposed automated system for the exchange of records and information for children in Los Angeles County's foster care system.

Child Welfare System/Case Management System (CWS/CMS): California's State-wide Automated Child Welfare Information System, which has been in use since 1997. All information printed for the Los Angeles County **Health and Education Passport** is stored in CWS/CMS. <http://www.hwcws.cahwnet.gov/>

Children's Action Network (CAN): Los Angeles nonprofit acting as CHEER project coordinator. <http://childrensactionnetwork.org/>

Children's Social Worker (CSW): The primary social worker assigned to a foster child's case.

Department of Children and Family Services (DCFS): Los Angeles County department that administrates the county's foster care program. <http://dcfs.co.la.ca.us/>

Department of Health Services (DHS): Los Angeles County department that operates hospitals and clinics and oversees public health programs. <http://www.ladhs.org/>

District of Columbia Kids Integrated Delivery System (DC KIDS): DC health program for children in foster care. Administered by Children’s National Medical Center. <http://cfsa.dc.gov/cfsa/cwp/view.a.3.q.520670.asp>

Electronic Benefits Transfer (EBT): The use of smart cards with magnetic strips by benefits recipients to access program funds to pay for food and other qualified goods. Similar to using a credit or ATM card.

Electronic Health Records (EHR) or Electronic Medical Records (EMR): These terms are often used interchangeably to refer to an automated longitudinal patient health record. The Health Information and Management Systems Society, a professional advocacy and support group, has proposed standard criteria for EMRs, but these have not been adopted industry-wide. http://www.himss.org/ASP/topics_ehr.asp

Foster Youth Services (FYS): Program under the Los Angeles County Office of Education that provides counseling and support to foster youth in group homes. FYS maintains its own database containing health and education information for children in its program.

Health and Education Local Information eXchange (HELIX): Records exchange being developed by the Service Integration Branch of Los Angeles County’s Chief Administrative Office. An RFP was issued in 2004; though a vendor has been selected, a contract has yet to be awarded because of contractual issues. HELIX will initially focus on education records. <http://cao.co.la.ca.us/sib/imu.htm>

Health and Education Passport (HEP): Printed collection of forms and records generated by CWS/CMS and provided to caregivers by caseworkers. Part of the black binder.

Health Care Program for Children in Foster Care (HCPCFC): State- and county-funded program in which public health nurses are utilized to collect and input health records and information, develop health case management plans for foster youth, and advise and support caseworkers. <http://lapublichealth.org/cms/fostercare/>

Health Insurance Portability and Accountability Act of 1996 (HIPAA): Federal legislation enacted with the intention of protecting the confidentiality of medical records and information transmitted through electronic means.

Health Passport Project (HPP): Smart card–based health records tracking system piloted in 2001–02 by the Western Governors’ Association.

HUB: Centralized locations throughout Los Angeles County that will act as medical “entry points” for children in the foster care system (or for those who need examination prior to their detainment). Each of the six proposed HUBs will utilize

a network of local physicians for the ongoing medical care of foster youth. The HUB system is being created and administered by DCFS.

Information Technology Services Division (ITSD): Technology branch of California's Department of Health Services.

ITRACK: Web-based incident tracking and reporting system for Los Angeles County foster family agencies and group homes. The system can automatically download client information from CWS/CMS and send e-mail alerts to children's social workers.

Los Angeles County Office of Education (LACOE): County agency providing services, training, and support to 81 school districts and education programs for students and adults; operates the county Head Start program. LACOE also runs the Foster Youth Services program. <http://www.lacoe.edu/>

Medi-Cal: California's Medicaid program; state- and Federally-funded medical services for eligible recipients. All foster children in the state are eligible for fee-for-service Medi-Cal. Some are enrolled (by caregivers) in Medi-Cal managed care programs.

Medi-Cal Management Information System/Decision Support System (MIS/DSS) and PCES: The primary data systems used by California to collect (PCES), store, and manage Medi-Cal records and information. <http://www.dhs.ca.gov/mcs/misdss/>

Memorandum of Understanding (MOU): Operational agreement for participation in a program that outlines the roles, responsibilities, and parameters for the use of resources. MOUs are a common means for allowing the sharing of confidential records and information.

Multidisciplinary Assessment Teams (MAT): Groups consisting of caseworkers, medical providers, educators, caregivers, birth parents, and others who interact with a foster child. MATs gather to assist in developing case plans and recommendations for the child. They will be an integral piece of the DCFS HUBs.

Office of the National Coordinator for Health Information Technology (ONCHIT): Branch of the Federal Department of Health and Human Services created by President Bush in 2004. The mission of ONCHIT is "to implement the President's vision for widespread adoption of interoperable electronic health records (EHRs) within 10 years," and to advise the Secretary for Health and Human Services. <http://www.hhs.gov/healthit/>

Passport: Common term used for a paper or computerized collection of health and/or education records for children in foster care.

Personal Digital Assistant (PDA): Handheld computer device such as a Palm Pilot or Pocket PC. PDAs are capable of synchronizing their data with desktop computers and many can wirelessly connect to the Internet or local networks.

PM160: Form used by physicians to request Medi-Cal reimbursement for CHDP examinations.

Public Health Nurse (PHN): Specialized field of nursing dealing with public health issues, including foster care. In Los Angeles County, PHNs are responsible for gathering, verifying, and inputting health records into CWS/CMS and for developing health case management plans for foster youth.

Request for Proposal (RFP): Legally binding document used to describe and set guidelines for a proposed project and to solicit bids from qualified contractors/vendors.

Santa Barbara County Care Data Exchange (SBCUDE): System for exchanging medical records and information between Santa Barbara hospitals, clinics and doctors' offices. Developed by Care Science, Inc. with funding from the California HealthCare Foundation.

http://www.carescience.com/healthcare_providers/cde/care_data_exchange_santa_barbara_cde.shtml

Service Integration Branch (SIB): Branch of Los Angeles County's Chief Administrative Office charged with providing support and assistance to departments providing services to children and families through policy development and the integration of service delivery systems. SIB is administering the HELIX program.

<http://cao.co.la.ca.us/sib/default.htm>

Statewide Automated Child Welfare Information System (SACWIS): ACF-administered program providing matching funds for the creation and operation of child welfare information and case management systems based on compliance with Federal criteria. CWS/CMS is the California SACWIS.

<http://www.acf.hhs.gov/programs/cb/dis/sacwis/about.htm>

Veterans Health Information Systems and Technology Architecture (VistA):

National health information system developed and used by the Veterans Health Administration. VistA is a large suite of applications with a common user interface, the Computerized Patient Records System.

http://www1.va.gov/vista_monograph/

Western Governors' Association (WGA): Organization offering support, policy development, and research services to the governors of 18 western states. The WGA conducted the Health Passport Project in 2001–02. <http://www.westgov.org/>

Women, Infants and Children (WIC): Federally funded program providing food, nutritional services, and health care referrals to eligible low-income women and children under five. <http://www.fns.usda.gov/wic/>

Appendix E: CHEER Team

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