



# **ELECTRONIC INFORMATION EXCHANGE FOR CHILDREN IN FOSTER CARE:**

## **A Roadmap to Improved Outcomes**

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## FOREWORD

*A Message from Wendy Lazarus & Laurie Lipper  
Founders and Co-Presidents, The Children's Partnership*

The need for efficient and effective coordination of care to adequately serve children living in foster care is broadly acknowledged by experts in the field. Increasingly, those who provide services and care for these children are exploring the use of information technology to enable better coordination of care through electronically sharing information. As outlined in a previous report by The Children's Partnership entitled *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems*, electronic systems that enable providers to share care information have resulted in measurably improved health outcomes for children living in foster care. That report and this follow-up piece, *Electronic Information Exchange for Children in Foster Care: A Roadmap to Improved Outcomes*, are published as part of The Children's Partnership's E-Health Program. Our mission is to undertake research, build demonstrations in local communities, and promote public and private policies and practices that harness information and communications technology to improve the health of America's 74 million children.

This document provides an overall strategy and actionable steps that California leaders can take to improve the lives of the 75,000 children living in foster care in California. Beginning with an overview of how the electronic exchange of information can improve care coordination and outcomes for children in foster care, this report lays out two practical models for a system that facilitates information-sharing between providers caring for foster youth. It concludes with a set of achievable steps California leaders can take to develop and implement this innovation.

Unique circumstances—political, legislative, and technology developments—make this an ideal time for California to put these reforms for children in place. The American Recovery and Reinvestment Act of 2009 provides funding specifically to implement information technology that improves coordination and continuity of care. In addition, the federal Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351) specifically mandates interagency information-sharing for the purposes of assisting governmental entities in fulfilling their duties to protect and provide adequate services to children in the child welfare system. And, over the last few years, there has been a dramatic increase in information technology infrastructure as well as rapid development of new technology, increased interest in data integration and data-driven decision making, and the emergence of models that make the electronic collection, storage, and sharing of information possible, efficient, and affordable. Moreover, the lessons learned from developing such Electronic Record Systems (ERSs) for foster youth will provide an important opportunity to incubate ideas that can form the basis for ERSs for all children and families as well as save taxpayer money.

A handful of states and localities have developed electronic systems for children in foster care, but none in locations as large and complex as California and none at this time of unprecedented opportunity around this issue. Early meetings on this agenda across state agencies, as well as across local, state, and federal levels of government, have positioned California to become a leader in this arena over the next few years. California has a rare opportunity to lead the effort to improve coordination of care and health outcomes for children living in foster care and take advantage of the fact that all the necessary pieces are available and falling into place. We hope this Roadmap can serve as a resource and catalyst. The Children's Partnership looks forward to working with leaders in the public and private sectors to apply these findings and, as a result, improve the lives of tens of thousands of children living in foster care in California and eventually in other states.

## OVERVIEW

Children living in foster care in California have complex and intensified care needs and receive services from a fragmented system of providers.<sup>1</sup> This population receives inadequate and costly care, and sometimes faces tragic outcomes, because providers are unable to sufficiently coordinate care and services. Electronic exchange of key information about this mobile, high-needs population of children can facilitate greater coordination of care between providers, which can significantly improve outcomes.

Recent legislation and technology developments have created an environment conducive to implementing a system for electronically sharing information about children living in foster care. These developments make it an opportune moment to improve outcomes for these children by using information technology to increase coordination of care.

The Children's Partnership (TCP), with funding from the California HealthCare Foundation and working closely with state agencies, has examined the potential for California to improve outcomes for children in foster care in the state by developing and implementing a system—referred to in this document as the California Electronic Data System (CEDs)<sup>2</sup>—that would allow for the electronic exchange of information about these children in order to improve coordination of care.

This Roadmap is built on the findings of a brief published by TCP in January 2009 entitled "Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems (ERSs)," which provided policy leaders and key stakeholders with information about the ways ERSs, when applied appropriately, can benefit children in foster care and the systems that serve them. This document summarizes our research and provides actionable steps for California state policy leaders and stakeholders to take to encourage the development of CEDs.

This Roadmap reviews the challenges of providing necessary and coordinated care to children living in foster care in California and summarizes how information technology and the electronic exchange of information can be used as a powerful tool to improve the sharing of information, coordination of care, and provision of services to these children. The Roadmap suggests alternate models for the design of CEDs and considers the technological, financial, and political opportunities that exist for moving this effort forward.

Finally, the Roadmap provides recommendations for concrete steps that the State and other key stakeholders can take toward the development of an electronic system of information-sharing to improve outcomes for children living in foster care in California.

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<sup>1</sup>For the purpose of this document, the term "providers" refers to individuals that are responsible for ensuring the safety and well-being of children living in foster care, including caseworkers, juvenile court judges, attorneys, foster caretakers, public health nurses, educators, and physical, mental and dental health care professionals.

<sup>2</sup>The California Electronic Data System (CEDs) would be a collection of networks, computers, hardware, software applications, and other technologies that facilitate the sharing of data in an efficient and secure manner for the purposes of allowing authorized users to have access to a more comprehensive set of information about an individual, in order to enhance coordination of care and delivery of services.

## METHODOLOGY

This Roadmap was developed through nine months of research and analysis based on a literature review; interviews with multiple experts and stakeholders; and an analysis of available data, data sets, policies, and technology.

The interviewees included an array of state and local experts in the foster care population and in information and communications technology (ICT) solutions; philanthropic leaders focused on youth in foster care and/or technology; and state and local officials from the many programs that serve children in foster care, including representatives from such sectors as social services, health, mental health, justice, and education.

We drew from the lessons learned in other states and localities that have developed systems for information-sharing for children in foster care. Finally, we coordinated with the California Child Welfare Council (CWC)<sup>3</sup> and built upon its research and recommendations.<sup>i</sup>

## CURRENT OUTCOMES FOR CHILDREN IN FOSTER CARE IN CALIFORNIA

More than 75,000 children are living in foster care in California.<sup>ii</sup> As is the case nationally, these children have greater, more complex needs than other children and account for a disproportionate share of state expenditures.<sup>iii</sup>

- **Nearly half of all children living in foster care in California suffer from chronic illnesses,<sup>iv</sup> and children in foster care are three to six times more likely than those in the general population to have significant psychological or behavioral problems.<sup>v</sup>**

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<sup>3</sup> The Child Welfare Council (CWC) was established as part of AB 2216, The Child Welfare Leadership and Performance Accountability Act of 2006. The responsibilities of the CWC include: to increase collaboration and coordination between county agencies, state agencies, federal agencies and the courts; to develop data and information-sharing agreements and protocols for the exchange of information; to develop case plans for youth sixteen years or older and describe programs and services to assist them in independent living.

- A disproportionate number of children in foster care suffer academically, with poor test scores, low high-school completion rates, and low levels of qualification for and participation in post-secondary education.<sup>vi</sup>
- Children who grow up in foster care are at greater risk of becoming involved in the criminal justice system, compared to their peers with nonfoster care status.<sup>vii</sup>

Few children living in foster care receive adequate services.<sup>viii,4</sup> The costly and inadequate care delivered to children in foster care is due, in part, to placement instability, combined with limited coordination among a wide variety of siloed public services.

**On average, children placed in foster care in California experience two to three changes in foster homes each year.<sup>ix</sup>** Placement changes are often accompanied by changes in physical health, mental health, and educational service providers. This exacerbates the problem of incomplete information about a child that is spread across many different sites.

As indicated above, providers often operate in a fragmented system where communication and information-sharing is limited.<sup>x</sup> The existing system for sharing information about a child in foster care is, to a large extent, based on the passing of duplicate paper forms among providers. This system is inefficient and rarely works as intended. Often, providers do not receive forms in a timely manner. When they do, the forms are missing crucial information about these children.

For example, when a child enters the foster care system in California, a caseworker opens a case file in the Child Welfare Services/Case Management System (CWS/CMS)<sup>5</sup> in order to manage the case plan and other information about the child.<sup>xi</sup>

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<sup>4</sup>Please refer to Appendix A for a list of services available to children living in foster care in California.

<sup>5</sup>The Child Welfare Services/Case Management System (CWS/CMS) is California's Statewide Automated Child Welfare Information System (SACWIS). The CWS/CMS assists caseworkers by storing information about each dependent child and automating many administrative functions, including generating and managing forms. This report will further discuss CWS/CMS in a later section.

A key component of the case file is the Health and Education Passport (HEP), which is intended to supply caseworkers, foster caretakers, and individuals involved in the health and education of the children with essential information about the health and educational status of the child.<sup>xii</sup> Caseworkers are often unable to collect complete health and education information, and caretakers and providers often don't receive HEPs or the forms required to keep the HEP complete and accurate.<sup>xiii</sup> The result is that providers do not have the information necessary to provide children living in foster care with services that adequately ensure their well-being.<sup>xiv</sup>

## Lives at Stake

In October 2002 a four-month-old girl was placed in a short-term housing facility for children moving into foster care. The infant had a history of reflux: severe spitting up. Doctors at the facility recommended giving her small, frequent feedings and keeping her upright for 20 minutes after eating.

Eight days later, the baby was transferred to an experienced foster parent. The first day in her new home, shortly after being put down for a nap, she was found facedown and still. When picked up, she spewed vomit.

The baby was immediately rushed to the hospital, where she was pronounced dead. It is still unclear whether the child died due to choking from a reflux episode, or sudden infant death syndrome. The foster parent says that no one told her the child had reflux or special feeding needs. The facility counters that the information was provided.

Concerns about inadequate information-sharing, and the potentially harmful outcomes that can result, arise frequently in the effort to meet the needs of children in foster care. An electronic record system that includes basic health information about a child living in foster care, and is accessible to her caregivers, can improve health outcomes and save lives.

Source: Greg Moran, "Information Exchange Essential in Placement Transfers," *San Diego Union-Tribune*, 28 Oct. 2008 (<http://obituaries.signonsandiego.com/news/metro/20081028-9999-lz1n28infor.html>).

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 overprescription of powerful psychotropic medications, misdiagnoses, and medical errors and omissions.<sup>xv</sup> According to Children's Action Network, "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."<sup>xvi</sup>

Educators often have little or no information on prior test scores, credits earned, or classes taken by children living in foster care, nor do they have transcripts.<sup>xvii</sup> This results in incorrect grade and class placements, failure to provide needed and/or timely assistance, and repeated or missed coursework or entire grade levels.<sup>xviii</sup>

With responsibility shared among multiple providers, recent legislation has emphasized communication and information-sharing as critical means to improving outcomes for children living in foster care. The federal Keeping Children and Families Safe Act of 2003 and the Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351) both mandate interagency information-sharing for the purposes of assisting governmental entities in fulfilling their duties to protect and provide services to children in the child welfare system.<sup>xix</sup>

In California, Welfare and Institutions Code 16010 and Assembly Bill 490 (Chapter 862, Statutes of 2003) require information-sharing among governmental agencies in order to fulfill federal mandates and facilitate decision-making and the provision of services for the purpose of improving outcomes.<sup>xx,6</sup>

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<sup>6</sup>Please refer to Appendix B for a list of mandates related to the collection, recording, and sharing of information for the purpose of coordinating care and ensuring positive outcomes for children living in foster care.

## **INFORMATION TECHNOLOGY: A TOOL TO DRIVE IMPROVED OUTCOMES**

Electronic information exchange is an efficient way to meet federal and state mandates to coordinate services and improve outcomes for children living in foster care. A variety of states and localities throughout the nation have developed Electronic Record Systems (ERSs) to collect, store, share, and analyze information about children living in foster care.

**Early findings from these efforts indicate that the information management and coordination of care enabled by the ERSs results in improved preventative care, decreased hospital stays, improved clinical conditions, and decreased cost of care.** (For a full report on this topic, see *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems*.<sup>xxi</sup>)

Recent policy and technology developments have created an unprecedented opportunity to move forward with reforms for children in foster care through this type of effort. Federal legislation, particularly the American Recovery and Reinvestment Act of 2009 (ARRA), provides significant new information technology funding and policy direction. The health information technology (HIT) provisions of the ARRA focus on the “meaningful use”<sup>7</sup> of HIT to improve health outcomes, particularly through better coordination and continuity of health care.

Consistent with this emphasis on care improvement through better information-sharing, the federal Fostering Connections to Success and Increasing Adoptions Act of 2008, as mentioned above, mandates interagency information-sharing for the

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<sup>7</sup>As described in ARRA, a meaningful electronic health record (EHR) user must use a certified EHR technology that allows for electronic prescribing, electronic exchange of health information to improve the quality of health care, and reporting of clinical quality and other measures as selected by the Secretary of HHS. Rules on “meaningful use” will be defined by the Department of Health and Human Services by the end of 2009. For more information, visit [http://healthit.hhs.gov/portal/server.pt?open=512&objID=1325&parentname=CommunityPage&parentid=6&mode=2&in\\_hi\\_userid=10741&cached=true](http://healthit.hhs.gov/portal/server.pt?open=512&objID=1325&parentname=CommunityPage&parentid=6&mode=2&in_hi_userid=10741&cached=true).

purposes of assisting governmental entities in fulfilling their duties to protect and provide adequate services to children in the child welfare system.

At the state level, the California Child Welfare Council is working to improve outcomes for children in foster care by developing data-sharing agreements and protocols to increase coordination between the various agencies and courts that serve these children. Additionally, California has taken a number of steps to further the development and implementation of information technology infrastructure and has demonstrated increased interest in data integration and data-driven decision-making in the past few years, facilitating the electronic collection, storage, and sharing of information.

For example, California is currently building and redesigning some of the largest state social service and health data systems, making it a key moment to ensure that these new systems are designed and implemented to fulfill federal and state mandates regarding information-sharing related to children in foster care and to provide the best outcomes for these high-needs children.

“Duplication of efforts occurs when communication lines do not exist, are poorly set up and/or break down. However, increasing collaboration not only among government agencies, but also, community organizations and the sharing of information, co-location of staff, all would decrease the potential for duplication.”

— Los Angeles County  
Department of Children and Family Services

Source: California Health and Human Services Agency, *Child Welfare Council Draft Recommendation Public Comment* (July 2009) (<http://www.chhs.ca.gov/INITIATIVES/CACHILDWELFARE/COUNCIL/Pages/default.aspx>).

## A MODEL FOR ELECTRONIC INFORMATION-SHARING

In order to take advantage of these new developments, California should create an electronic system for sharing information, referred to in this document as the California Electronic Data System (CEDS). Described below are the key elements of the system design for CEDS. This system should be designed to meet the following objectives:

- Give providers access to a more comprehensive base of information about a child;<sup>8</sup>
- Facilitate communication among providers for the purposes of coordination of care and delivery of services;
- Afford caretakers and older youth in foster care access to information; and
- Provide youth in foster care with a record of conditions and services received as they prepare for permanency or emancipation.

The system models below also have the capacity to facilitate education through resource materials, monitoring of service utilization, and networking and communication for providers and youth. In order to be helpful to providers and youth, CEDS needs to be easy to access and use.

Privacy and security are key components of any electronic system for information exchange. The proposed models for CEDS address security by utilizing, at minimum, user identifications (IDs) and passwords to restrict access of the system to authorized individuals. Built into each user ID will be individualized security clearance, which will dictate the amount of information that is accessible to each user. CEDS will include additional security measures as deemed necessary by technology and privacy experts.<sup>9</sup>

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<sup>8</sup> Data collection and sharing through CEDS could also allow for population level analysis about the needs and service utilization of children living in foster care; however, this use of CEDS is outside the scope of this Roadmap.

<sup>9</sup> The California Privacy and Security Advisory Board (CalPSAB), a private/public advisory board that develops recommendations for privacy and security policies for California Health Information

## Functional Components

Table 1 outlines a list of core functional capabilities for CEDS, as well as a list of optional functional capabilities that should be considered. The functional components listed below can be achieved through various architectural designs, which are described in the following section.

Some of the functions listed in Table 1—including controlling access to information—would need to be built directly into CEDS. Other functions—including providing reminders and alerts—may already exist in other electronic systems used by providers (e.g., electronic health records). In such cases, CEDS need not duplicate functionality, but instead facilitate information-sharing to support the functionality of existing systems.

Finally, CEDS would be built in coordination with other efforts to facilitate information exchange, such as California's current effort to advance statewide health information exchange (HIE).<sup>10</sup>

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Exchange, is currently assessing the appropriate level of authentication to require for electronically exchanging health information. The recommendations of CalPSAB will inform the level of security measures that should be built into CEDS.

<sup>10</sup> Health information exchange (HIE) is a process of electronically sharing patient-centric clinical data among separate healthcare systems. The purpose of HIE is to facilitate real-time access to and retrieval of healthcare information in order to enhance clinical decision-making and to efficiently and effectively provide better healthcare. Statewide HIE in California will require the development and implementation of statewide technical architecture that enables electronic information-sharing between health care providers.

[Source: Agency for Healthcare Research and Quality; California Health & Human Services Agency]



**TABLE 1. FUNCTIONAL CAPABILITIES OF THE CALIFORNIA ELECTRONIC DATA SYSTEM (CEDS)**

<b>CORE FUNCTIONS</b>	
<b>FUNCTION</b>	<b>DESCRIPTION</b>
Control Access to Information	User IDs and passwords will control who has access to the system and what information each user can retrieve.
Monitor and Record System Usage	CEDS will contain an audit trail, which will monitor the effectiveness of user IDs and passwords in limiting access to information. The audit trail will contain information about which users have accessed the system, the time and date of system usage, and what information was viewed.
Retrieve and Display Information	By logging on to CEDS, a provider or youth will initiate a request for information about a particular child. CEDS will automatically retrieve information from connected databases and present the information in a record template. CEDS will display the origin and date of each data element, which will resolve issues of duplicate data (e.g., different addresses). CEDS will also include data quality tools, which will resolve issues of different data formatting that may exist in the various connected systems.
Store Data and Provide Longitudinal Record	Depending on the architectural design, CEDS will store or collect information about the child from various sources, tracking data over multiple points in time. This will allow users to have a record of the child's history of conditions and services received, which will be particularly useful for a child/youth preparing for permanency or emancipation. This function is also useful for tracking a child's movements in foster care placement and location, as well as identifying the most recent services received and current providers.
Provide Reminders and Alerts	CEDS will provide alerts to users, as appropriate, based on their role in the child's care. Alerts include, but are not limited to, gaps in care (related to both preventative care and current treatments), interacting medications, and upcoming or missed appointments and court dates. The user will receive these reminders and alerts either when they log on (either by pop-up windows or using colors/bolded text to indicate the alert) or via automated e-mails.
Enable Provider Communication for Case Coordination	Providers will be able to communicate to coordinate care either by using a messaging tool built into CEDS or by accessing contact information made available through CEDS.

**TABLE 1. CONTINUED**

OPTIONAL FUNCTIONS	
FUNCTION	DESCRIPTION
Generate Forms and Reports	After logging on, users would be able to initiate automatic form generation using information available within CEDS.
Facilitate Initial Case Plan and Referrals	By linking to other databases, CEDS would collect historical information about the child (data that were gathered prior to entering the foster care system), which will be useful in developing the initial case plan and ensuring appropriate referrals to services and providers.
Provide Decision Support	CEDS would provide access to decision support tools and medical guidelines available in the connected systems in order to assist with decision-making.
Support Social Media	CEDS would allow users to communicate through messaging and chat rooms. This function will be particularly useful for foster caretakers and youth living in foster care.
Provide Resource Materials and Interactive Media Tools for Educational Purposes	CEDS would support interactive media tools, such as games and quizzes, to educate about disease management and assist with decision-making. CEDS would contain links to various resource materials, such as training materials for foster caretakers, educational materials about various conditions and treatments, and course catalogues for academic planning.
List Directory of Services and Care Providers	CEDS would contain a directory of providers and services available, organized by location and category. The directory would link to Web sites containing additional information for users.
Facilitate Program Evaluation and Management	CEDS would allow specific users to monitor what services have been offered and delivered and how the child is progressing through the foster care system.

### System Design

Following are two Web-based models for CEDS that address the aforementioned capabilities. These models are meant to serve as the starting point for conceptualizing CEDS. One key distinction between these models relates to the storage of data. Much of the data that will be accessed through CEDS is already collected and stored in state-level department databases or is accessible through state-level portals/hubs/networks. In the first model, data are accessed through a hub, which does not store data. Rather it is designed to simply allow for the passing through of data. In the second model, data are accessed through a warehouse, which will store data that has been pulled from existing databases. This

issue of how data are stored is significant because institutional ownership of data<sup>11</sup> has been cited as a barrier to data-sharing.<sup>xxii</sup> Further, additional security concerns exist when data are stored in a warehouse as opposed to simply passing through a hub. Both of these designs require beginning a new endeavor, which necessitates addressing funding, timing, and implementation.

<sup>11</sup>"Data ownership refers to both the possession of and responsibility for information; ownership implies power as well as control." Ownership of data is a barrier because information-sharing requires an entity to relinquish control over data, which represents a loss of power for that entity. Additionally, unclear policies increase apprehension about data-sharing. [Source: Responsible Conduct of Research, Northern Illinois University ([http://ori.dhhs.gov/education/products/n\\_illinois\\_u/datamanagement/dotopic.html](http://ori.dhhs.gov/education/products/n_illinois_u/datamanagement/dotopic.html)).

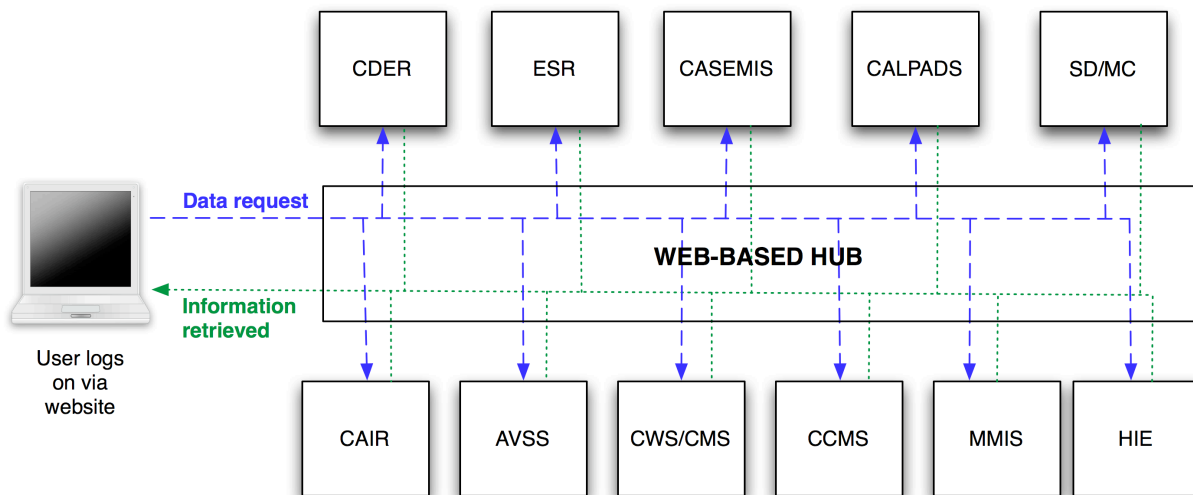
## Model #1: Web-Based Hub

### Technical Design of Hub

The Web-based hub would be built on Service-Oriented Architecture (SOA),<sup>12</sup> contain an Enterprise Service Bus (ESB),<sup>13</sup> and interface with several existing databases that contain relevant information about children living in foster care.<sup>14</sup> The hub would also contain a Data Dictionary and an audit trail.<sup>15</sup> The purpose of the Data Dictionary is to work with the ESB to allow interoperability and flow of information among systems. The purpose of the audit trail is to monitor the effectiveness of user IDs and passwords in limiting access to information.

(See Appendix E for definition and description of terms and acronyms used in model above.)

### Model #1: Web-Based Hub



<sup>12</sup>Service-Oriented Architecture (SOA) is “an application architecture within which business functions and selected technical functions can be invoked using documented interfaces.” [Source: Centers for Medicare & Medicaid Services]

<sup>13</sup>Services built on a SOA platform communicate and interoperate using an Enterprise Service Bus (ESB), which manages messages, data format, and service coordination. [Source: Centers for Medicare & Medicaid Services]

<sup>14</sup>Please refer to the glossary at the end of this document for descriptions of databases.

<sup>15</sup>A Data Dictionary is a collection of information about data elements, including the meaning, format, usage, and relationships to other data elements [Source: IBM Dictionary of Computing]. An audit trail contains information about which users have logged-on, when they log on, and what information they have accessed [Source: Webopedia].

### Accessing and Using the Hub

Using a pre-assigned user ID and password, both providers and youth (“user”) would log on to the hub via a Web site.

Once connected to the hub, the user could indicate which child’s record is of interest for the purpose of querying or requesting updated information. Using the ESB, this request would be sent through the hub to all connected databases. Data about the indicated child would flow back from connected databases, through the hub, to autopopulate a record template and forms that exist on the hub Web site.

Data flowing back through the hub would be limited based on the security clearance—which is built into the user ID and password—of the requesting user. In other words, each user’s record template and forms would only be autopopulated as factors including privacy laws, user preferences, data use agreements, and security allow.

Some providers may not need to access the hub through the Web site, but could instead access updated information through a system that is connected to the hub (e.g., caseworkers using CWS/CMS).

### Benefits and Limitations of Hub Design

A benefit of hub architecture is that it facilitates information-sharing without requiring data to be moved to a central location, allowing organizations to maintain ownership of data. This is significant because ownership of data has been cited as a contributing factor to the current lack of data-sharing among systems.<sup>xxiii</sup> This is also significant as it alleviates some concern over the security of data. However, as hub architecture does not store data, this design may also limit the ability to generate a historical record of health conditions and services received depending on the capabilities and practices of the connected databases. Another limitation of a system design that does not store data is the missed opportunity for population-level analyses.

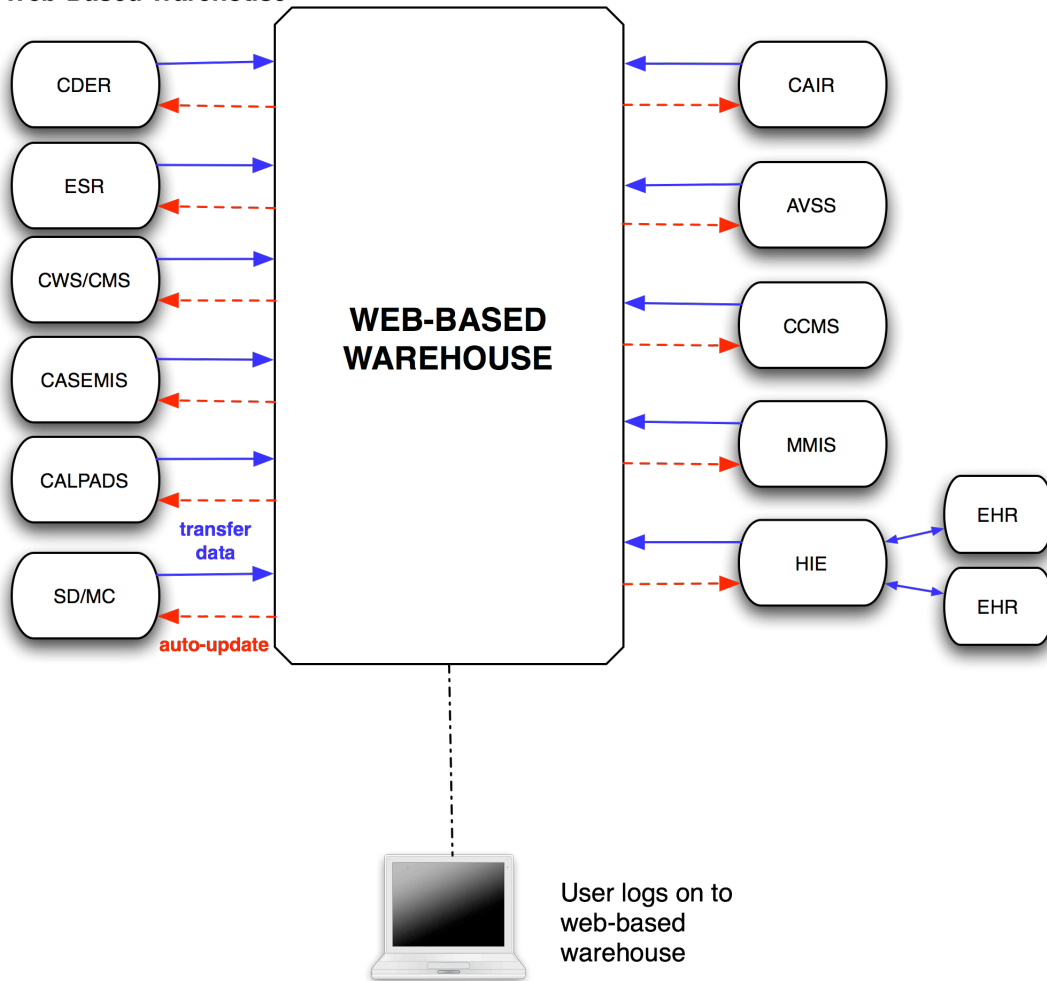
### **Model #2: Web-Based Warehouse**

#### Technical Design of Web-Based Warehouse

The Web-based warehouse would be built on SOA and contain an ESB, which would allow information to be updated in connected databases, as appropriate, when data are entered or modified anywhere in the system. As with Model #1, this warehouse would contain a Data Dictionary and an audit trail.

(See Appendix E for definition and description of terms and acronyms used in model above.)

### **Model #2: Web-Based Warehouse**



### Accessing and Using the Warehouse

Using a pre-assigned user ID and password, a provider or youth (“user”) would log on to the warehouse via a Web site.

Once connected to CEDS, the user could indicate which child’s record is of interest. The record would be generated using information residing in the warehouse, which would be continuously populated as new information is entered into the connected databases. The amount of information within each record that would be accessible to the user would be based on security clearance, which would be built into the user ID and password.

The user would be able to generate forms based on the information accessible. Users would not be able to manually input information into the warehouse, but would need to input new or additional information through the database from which the data originated. As with the hub model, some users may not need to access the warehouse through a Web site, but could receive updated information through the previously existing system.

### Benefits and Limitations of Warehouse Design

A benefit of the warehouse design is that it allows for the generation of longitudinal records as information is transferred and stored in the warehouse. However, this architecture does not allow for organizations to maintain ownership of data as information is transferred and stored in the warehouse. This architecture also raises the issue of how and when information should be expunged from the warehouse when youth transition out of the system.

### **Hybrid System**

**In order to achieve all of the functional components mentioned in Table 1, it would be necessary to develop a hybrid of the hub and warehouse designs.** This is because some components—such as locating data about a child—are better suited for the hub model, while others—such as longitudinal records and allowing for population level analysis—are better suited for the warehouse model.

### **CEDS Users and Informational Needs**

Regardless of which architecture model and what functionalities the State chooses to implement, CEDS will address the informational needs of youth living in foster care and their providers. Who will have access to CEDS and what their informational needs are will be carefully determined by the State working with a large group of stakeholders, including CEDS users. As a starting point, this discussion includes access to CEDS for individuals who are responsible for ensuring the safety and well-being of children in foster care, including caseworkers, juvenile court judges, attorneys, foster caretakers, public health nurses, educational service providers, and physical, mental and dental health care providers, as well as perhaps older children living in foster care.<sup>16</sup>

The key issues to consider in terms of youth having access to the system will be what information is appropriate to include, their ability to understand the information, anxiety they may have about sharing information, and the appropriate age for gaining access. As the goal is to provide youth with information that will assist them in being successful in life, it will be important to provide instructions or guidance on how to use and interpret the information. The age for informed consent in health care<sup>17</sup> may be a starting point for considering the appropriate age for youth access to this system.

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<sup>16</sup>This list is not meant to be exhaustive. Additional providers, such as biological parents, play essential roles in the health and well-being of children living in foster care. Such providers have not been included at this time, as their contribution of and access to information have specific privacy implications that must be considered.

<sup>17</sup>Informed consent in health care is a process of communication between a physician and patient that results in the patient authorizing a specific medical intervention. In general, informed consent in health care must be given by someone with appropriate legal authority, which, excluding other factors, most states confer at 18 years of age. There are a number of exceptions to the age rule, allowing minors to give informed consent based on specific legal status (e.g., emancipated minor) or based on specific health care services (e.g., pregnancy-related care). [Sources: American Medical Association (<http://www.ama-assn.org>); Abigail English, et al., “Legal Basis of Consent for Health Care and Vaccinations for Adolescents,” *Pediatrics*, Vol 121, Supplement 1 (2008): S85-S87.]

## CHART 1. INDIVIDUALS WHO WILL USE CEDS



Providers play specific roles in the provision of care for children living in foster care, and thus have specific information needs when it comes to decision-making that impacts the child's well-being. Through informational interviews with experts and stakeholders, we identified some of the informational needs of providers that would use CEDS, which allowed the development of a core set of data elements that could collectively meet the needs of all providers and youth.<sup>18</sup> Presented in Table 2, these data elements span seven data element categories, including general, demographic, social services, health, mental health, education, and justice information.

As illustrated in Table 2, some data elements—such as contact information for the child and caseworker—are needed by all individuals that have access to the system. However, other data

elements are only needed by specific individuals, and access to the information should be restricted to ensure privacy and security.<sup>19</sup>

Using Table 2 as a starting point, the specific informational needs of providers and the amount of information they should be able to access through CEDS should be carefully determined. Another option would be to begin with a core set of data, consisting of information that is currently mandated to be shared at the state and federal level. This data set is presented in Appendix C.

The record template of CEDS would contain space for all of the data elements listed in Table 2. However, as previously described, the record template would only be populated with the information that is appropriate and accessible to each individual provider and youth.

<sup>18</sup>This list of core data elements was created by combining the input of each expert interviewee. Once created, the list was distributed to all of the contributors for comments.

<sup>19</sup>One strategy for ensuring the protection of confidential information would be phased implementation where smaller pools of users (e.g. caseworkers, public health nurses) are allowed access to CEDS. Implementing CEDS in phases would make it possible to monitor the effectiveness of security protocols.

**TABLE 2. CORE DATA ELEMENTS AND INFORMATIONAL NEEDS OF PROVIDERS AND YOUTH IN FOSTER CARE**

DATA ELEMENTS	INFORMATIONAL NEEDS OF PROVIDERS AND YOUTH
<p><b>1. GENERAL INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Name</li> <li>b. State</li> <li>c. Record Number</li> <li>d. Child's Contact Information</li> <li>e. Child's Social Security Number</li> <li>f. Child's Primary Language</li> <li>g. Child's Placement Setting<sup>20</sup></li> <li>h. Principal Caretaker Information</li> </ul>	<p><b>CASEWORKER</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-c</li> <li>• Social Services Information a-c</li> <li>• Health Information a-k</li> <li>• Mental Health Information a-c</li> <li>• Education Information a-i</li> <li>• Justice Information a-e</li> </ul>
<p><b>2. DEMOGRAPHIC INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Date of Birth</li> <li>b. Sex</li> <li>c. Birth record</li> </ul>	<p><b>PUBLIC HEALTH NURSE</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-b</li> <li>• Social Services Information a</li> <li>• Health Information a, e, g and h</li> <li>• Mental Health Information a and c</li> </ul>
<p><b>3. SOCIAL SERVICES INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Name and Contact Information for Caseworker</li> <li>b. Date of Discharge from Foster Care</li> <li>c. Reason for Discharge from Foster Care</li> </ul>	<p><b>PHYSICAL HEALTH PROVIDER</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-b</li> <li>• Health Information a-k</li> <li>• Mental Health Information a and c, (as relevant to physical health and treatment plan)</li> </ul>
<p><b>4. HEALTH INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Names and Contact Information for each Health and Dental Provider</li> <li>b. Medicaid Service Claims</li> <li>c. Lab Results</li> <li>d. Record of each Visit with Physician, Including Diagnosis</li> <li>e. Record of each Visit with Allied Health Including P.T., O.T., and Nutrition</li> <li>f. Identification of Child's Current and Previous Medical, Surgical, and Developmental Problems</li> <li>g. Allergy Information</li> <li>h. Immunization Records</li> <li>i. Pharmacy Claims (Current Medications)</li> <li>j. Plan of Care</li> <li>k. Medicaid ID Number</li> <li>l. Medicaid Eligibility Information</li> </ul>	<p><b>MENTAL HEALTH PROVIDER</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-b</li> <li>• Health Information a, e, and h, (as relevant to mental health and treatment plan)</li> <li>• Mental Health Information a-c</li> </ul> <p><b>DENTAL HEALTH PROVIDER</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-b</li> <li>• Health Information a, e, f, g, h and j, (as relevant to dental health and treatment plan)</li> </ul>

<sup>20</sup>"Placement setting" refers to the living arrangement for a child living in foster care, which can be pre-adoptive home, foster family home (relative), foster family home (nonrelative), group home, institutions, supervised independent living, runaway, and trial home visit. These terms are all defined in Appendix A to 45 CFR 1355.54.

**TABLE 2 CONTINUED**

DATA ELEMENTS	INFORMATIONAL NEEDS OF PROVIDERS AND YOUTH
<p><b>5. MENTAL HEALTH INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Names and Contact Information for each Mental Health Provider</li> <li>b. Record of Relevant Mental Health History</li> <li>c. Known Mental Health Condition and Medications</li> </ul>	<p><b>EDUCATIONAL SERVICES PROVIDER</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-c</li> <li>• Social Services Information a</li> <li>• Health Information e, f, g and h (as relevant to conditions and medication that need to be treated/administered in school setting)</li> <li>• Education Information a-i</li> </ul>
<p><b>6. EDUCATION INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Names and Contact Information for Education Providers</li> <li>b. Transcripts (School Record)</li> <li>c. Previous and Current Individualized Education Program (IEP)</li> <li>d. Grade Level Performance</li> <li>e. Attendance Record</li> <li>f. Special Education</li> <li>g. Noted GATE</li> <li>h. School of Origin</li> <li>i. Schools Attended</li> </ul>	<p><b>FOSTER CARETAKER</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-b</li> <li>• Social Services Information a</li> <li>• Access to Health, Mental Health and Education Information (to be defined by experts and stakeholders)</li> <li>• Justice Information a</li> </ul> <p><b>ATTORNEY</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-b</li> <li>• Social Services Information a</li> <li>• Access to Health, Mental Health and Education Information (to be defined by experts and stakeholders)</li> <li>• Justice Information a-e</li> </ul>
<p><b>7. JUSTICE INFORMATION</b></p> <ul style="list-style-type: none"> <li>a. Name and Contact Information for Primary Attorney</li> <li>b. Court Data and Reminders</li> <li>c. Case Plan</li> <li>d. Case Management</li> <li>e. Case Initiation</li> </ul>	<p><b>JUDGE/COURTS</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-c</li> <li>• Social Services Information a-c</li> <li>• Health Information a-k</li> <li>• Mental Health Information a-c</li> <li>• Education Information a-i</li> <li>• Justice Information a-e</li> </ul> <p><b>YOUTH IN FOSTER CARE/EMANCIPATED YOUTH</b></p> <ul style="list-style-type: none"> <li>• General Information a-h</li> <li>• Demographic Information a-c</li> <li>• Social Services Information a-c</li> <li>• Health Information a-k</li> <li>• Mental Health Information a-c</li> <li>• Education Information a-i</li> <li>• Justice Information a</li> </ul>



## Location of Existing Data<sup>21</sup>

Much of the data listed in Table 2 is currently collected by county-level service providers—such as a social worker, physician, or teacher—and is submitted to a state-level department for reporting and/or reimbursement purposes.<sup>22</sup> The California agencies that receive and store this data are the Department of Social Services, Department of Mental Health, Department of Health Care Services, Department of Education, Department of Public Health, Department of Developmental Services, and the Administrative Office of the Courts.

Table 3 provides a brief look at what data resides at the state level, how it is collected, and where it is stored. The left column lists the databases that would be connected to CEDS. As noted in the table, some of these databases are operational, some are currently in the redesign phase, and some are in the design and implementation phase.

At this point, most information that is reported to and stored in state databases is not accessible for retrieval by individual providers.<sup>23</sup> For example, without access to existing information about educational status, children may be placed in the wrong grade level or class setting, or may suffer gaps in treatment for existing conditions that are treated in the school setting.

Linking the databases listed in Table 3 through the proposed electronic system would allow such providers to have access to necessary information, reducing the incidence of duplication of services and gaps in treatments. Additionally, linking existing databases to facilitate autocollection and autoupdate of information could reduce data entry and collection workload for providers.

“Children and families benefit from a data linkage system. Without such a system, there are limited resources to determine what agencies/ departments a family is currently, or was previously, served by. This limitation may negatively impact an agency or department’s ability to best serve a family.”

— Los Angeles County  
Department of Children and Family Services

Source: California Health and Human Services Agency, *Child Welfare Council Draft Recommendation Public Comment* (July 2009) (<http://www.chhs.ca.gov/INITIATIVES/CACHILDWELFARE/COUNCIL/Pages/default.aspx>).

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<sup>21</sup> More information about existing databases and systems can be found in G.S. Goodman et al. *California Department of Social Services and Child Welfare Council Data Linkages Project*. Center for Public Policy Research, University of California, Davis: 2009.

<sup>22</sup> Information that is not currently stored at the state level includes Individualized Education Program (IEP) reports and lab results. Individualized Education Program (IEP) reports are stored with the teacher and school district providing services, and may or may not be in electronic form. Lab results are stored in a patient’s individual health record, which may or may not be electronic. Implementation of Health Information Exchange in California will allow for the sharing of more health information.

<sup>23</sup> The exceptions are CWS/CMS (accessible to caseworkers), CAIR (accessible to physicians), and, once implemented, CALPADS (accessible to schools) and CCMS (accessible to court officials).

**TABLE 3. LOCATION OF RELEVANT EXISTING DATA**

<b>DATABASE [DEPARTMENT]</b>	<b>RELEVANT DATA ELEMENTS</b>	<b>HOW DATA ARE COLLECTED</b>
<b>Operational Databases</b>		
Client Development Evaluation Report System (CDER) and Early Start Report System (ESR) [Department of Developmental Services]	Name, address, demographic information, date of evaluation, developmental status, diagnosis and related medication	Providers report information to the Department of Developmental Services via ESR (for active service recipients under age three years) and CDER (for active service recipients over age three years).
California Special Education Management Information System (CASEMIS) [Department of Education]	Name, address, demographic information, referral date, services received, provider	Teachers or school-based service providers submit information to the school district. The school district reports information to the Department of Education via CASEMIS.
Short-Doyle/Medi-Cal (SD/MC) [Department of Health Care Services]	Name, address, demographic information, date service received, service provided, diagnosis, provider	Providers submit claims information to county mental health plans, substance abuse treatment programs, or behavioral health programs. County-based programs and direct providers submit claims to the Department of Mental Health (DMH) through the Information Technology Web server (ITWS) maintained by the Department of Mental Health. DMH passes on the claims to Department of Health Care Services (DHCS) for processing through the Short-Doyle/Medi-Cal (SD/MC) system.
California Immunization Registry (CAIR) [Department of Public Health]	Immunization records	Providers submit immunization data and records to regional registry via Web. Work is underway to link nine regional registries for information-sharing purposes.
Automated Vital Statistics System (AVSS) [Department of Public Health]	Birth records	Hospitals and local registration districts enter data to automate birth certificates and other public health records.
<b>Operational Databases Undergoing Redesign</b>		
Child Welfare Services/Case Management System (CWS/CMS) [Department of Social Services]	Name, address, demographic information, caretaker information, identified developmental issues, immunization record, health provider information, diagnosis and observed conditions, past and current treatments, education provider information, grade level performance, school record	Social workers and public health nurses enter information in CWS/CMS at the county level. Health and education information is gathered through the transfer of forms from caseworker to foster caretaker to provider. The CWS/Web system (currently in design phase) will allow for greater information-sharing through interoperability with other data systems.
Medicaid Management Information System (MMIS) [Department of Health Care Services]	Name, address, demographic information, Medicaid eligibility, date service/meds/DME received, service provided, diagnoses, providers	Providers submit claims to Department of Health Care Services via MMIS.

**TABLE 3 CONTINUED**

DATABASE [DEPARTMENT]	RELEVANT DATA ELEMENTS	HOW DATA ARE COLLECTED
<b>Databases in Design and Implementation Phases</b>		
California Longitudinal Pupil Achievement System (CALPADS)  [Department of Education]	Name, address, demographics, program participation, grade level, enrollment and attendance, course enrollment and completion, teacher assignment	Teachers and schools submit information to the school district. Districts report information to Department of Education via one of several existing systems. Implementation of CALPADS will create longitudinal record of information about child within one system.
California Case Management System (CCMS)  [Administrative Office of the Courts]	Name and contact information of primary attorney, court data and reminders, case initiation, case plan, case management	Court data collection and management is currently administered at the local level. The implementation of CCMS will allow for court officials to capture information from criminal, civil, and juvenile courts in a single system.

**Addressing Confidentiality Laws**

The issue of privacy must be carefully addressed in developing a system that facilitates the electronic exchange of information about children living in foster care. Confidentiality provisions exist in both federal and state laws to protect the rights of children and their families to maintain the privacy of information contained in records, subject to limited exceptions.<sup>24</sup> Government departments and agencies working with children in foster care are often reluctant to exchange information due to concerns of noncompliance with confidentiality laws and to avoid the risk of jeopardizing the privacy rights of children and their families.<sup>xxiv</sup>

However, while confidentiality provisions contain protections against the unfettered access to information, they generally allow for the electronic exchange of information for improved coordination of care and health oversight of children receiving child welfare services. Other stakeholders, including the California Administrative Office of the Courts and the California Privacy and Security Advisory Board, are currently doing work related to privacy protections and electronic information-sharing.

It is especially important in moving forward with this effort that special attention be given to the issue of privacy as children in foster care have unique and varied privacy concerns. Misused or inaccurate information can have implications for the child’s education, court proceedings, ability to obtain health insurance in the future, and family relationships. Appropriate privacy protections will guard against those risks and take into account concerns about particularly sensitive information—such as mental, reproductive, and sexual health information—as well as the varying rights of parties to give consent to information-sharing or otherwise have access to and control over information.

It is crucial in moving forward that a special commitment is made to take the time to draw on what is known in this area, and to further define and clarify privacy issues in terms of both policy and practice where necessary.

**OPPORTUNITIES FOR DEVELOPING CEDS**

Developing a system for electronically sharing information to improve the coordination of care for children living in foster care could increase efficiency and reduce program costs at the state and local levels.<sup>25</sup> Additionally, development and

<sup>24</sup> Please refer to Appendix D for brief descriptions of federal and state laws related to health and educational information.

<sup>25</sup> Please see: Stefanie Gluckman with Terri Shaw, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* (Santa Monica, CA: The Children’s Partnership, 2009).

implementation of CEDS is aligned with current technology and policy trends. The State can improve coordination of care for children living in foster care by leveraging the current technological, political, and financial opportunities to facilitate the development of CEDS.

### Technology Opportunities

There are three technology initiatives in California that represent assets that can be leveraged in the development of CEDS: (1) the development of statewide health information exchange (HIE); (2) the modernization of California's Medicaid Management Information System (MMIS); and (3) the redesign of the Child Welfare Services/Case Management System (CWS/CMS). These initiatives are based on technology that allows information to be shared in an efficient and secure manner.

Leveraging these efforts and implementing them in a way that enables systems to exchange information will facilitate the creation of a system that is adaptable and can, therefore, have long-term utility for stakeholders in the foster care system. Aligning technology initiatives is a significant way the State can contribute to the development of CEDS.

#### Health Information Exchange

Health Information Exchange is a process of electronically sharing patient centric clinical data among separate healthcare systems.<sup>26</sup>

Implementation of HIE in California will enable greater availability of health information about children living in foster care, as health providers will have the ability to share information housed in electronic health records. Adoption of HIE has been part of California's health reform strategy since Governor Arnold Schwarzenegger signed Executive Order S-06-07 in March 2007, which

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<sup>26</sup> The purpose of HIE is to facilitate real-time access to and retrieval of healthcare information in order to enhance clinical decision-making and to efficiently and effectively provide better healthcare. Statewide HIE in California will require the development and implementation of statewide technical architecture that enables electronic information-sharing between health care providers. [Source: Agency for Healthcare Research and Quality; California Health & Human Services Agency]

called for the advancement of such technology to increase quality and accountability and strengthen transparency in the health care sector.<sup>xxv</sup>

California received an opportunity to accelerate the implementation of HIE with the passage of the American Recovery and Reinvestment Act (ARRA) in February 2009, specifically the portion of the act that provides for grants, incentives, and loans for providers to implement and meaningfully use health information technology (HIT), known as the Health Information Technology for Economic and Clinical Health Act (HITECH). California has recently finalized an HIT & HIE strategic plan and is applying for HIE implementation funding under section 3013 of ARRA.<sup>xxvi</sup>

California's HIE initiative represents an asset for this project for two reasons. First, as stated above, implementation of HIE in California will enable greater availability of health information about children living in foster care, as health providers will have the ability to share information housed in electronic health records. Once statewide HIE is operational, CEDS could connect to health care providers through HIE. Second, the process of implementing statewide HIE will yield important lessons that can inform the development of CEDS, including issues related to governance, privacy and security, and brokering data-exchange among new and legacy data systems.

#### Medicaid Management Information System

In 2002, the federal Centers for Medicare and Medicaid launched the Medicaid Information Technology Architecture (MITA) Initiative in an effort to modernize and improve the efficiency of states' Medicaid Management Information System (MMIS)<sup>27</sup> through enhanced federal funding for targeted improvements in program automation, standardization, and interoperability.<sup>xxvii</sup> Through

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<sup>27</sup> Medicaid Management Information Systems are automated claims and information retrieval systems. With the enactment of Public Law 92-603 in 1972, the Centers for Medicare and Medicaid Services (CMS) began requiring State Medicaid programs to implement and utilize an MMIS in order to standardize federal reporting and facilitate accurate claims adjudication.

MITA, each MMIS will be based on nationally accepted technical standards related to interoperability, allowing for interface with other data systems to facilitate: the validation of eligibility; review of utilization data; authorization of payments; and completion of other administrative tasks.<sup>xxviii</sup> States are encouraged to adopt service-oriented architecture (SOA) in order to achieve MITA enterprise architecture principles.<sup>xxix</sup>

California is in the process of developing a MITA Transition Plan. California's transition to MITA represents an asset for the development of CEDS, as the adoption of SOA will require the development of data architecture and governance standards, which would also be necessary for CEDS. Additionally, implementation of MITA interoperability standards could allow California's MMIS to be connected to CEDS, which would supply important information for providers in the foster care system.

#### Child Welfare Services/Case Management System (CWS/CMS)

The Child Welfare Services/Case Management System (CWS/CMS) is California's State Automated Child Welfare Information System (SACWIS).<sup>28</sup> California is currently in the process of redesigning CWS/CMS in order to improve functionality and meet federal interoperability requirements. The new system, called CWS/Web, will be Web-based,<sup>29</sup> have a simplified data entry process, include interfaces with other state systems that contain relevant data related to children living in foster care, and expand access to the system beyond caseworkers.<sup>xxx</sup> It has not yet been defined who will have access to CWS/Web; however, one of the purposes of making

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<sup>28</sup> As the State's SACWIS, CWS/CMS is meant to be California's comprehensive automated case management tool that meets the administrative and case management needs of the State's caseworkers. Additionally, states that accept federal funding for a SACWIS are expected to implement a system that meets several functional requirements, including bidirectional interfaces with the state's Temporary Assistance for Needy Families (TANF), Medicaid, and Child Support systems. [Source: 45 CFR 1355.53(a) and 45 CFR 1355.53(b)(2)]

<sup>29</sup> Currently, CWS/CMS is a personal computer (PC)-based Windows™ application.

the new system Web-based is to allow additional providers to have access to specific information.<sup>30</sup> CWS/Web is scheduled to be implemented in 2014.

The timing of this redesign process represents an asset for the development of CEDS in two ways. First, given the goals of making it interoperable with other systems and accessible to a broader range of individuals, CWS/Web could potentially serve as CEDS. Utilizing CWS/Web would provide an operating system, funding, and a maintenance structure for the data exchange system. If it turns out that a new, independent system must be created to meet the previously described information-sharing and technology interests, CWS/Web would still be an important contributor of information to CEDS.

The State should ensure that HIE, MMIS, and CWS/Web are implemented in such a way that facilitates the sharing of information among these three systems, regardless of whether these systems are leveraged for the development and implementation of CEDS.

“Sharing data is key to making sure that youth don't slip through the cracks of a complicated and giant system.”

— K. Gelardi,  
California Youth Connection

Source: California Health and Human Services Agency, *Child Welfare Council Draft Recommendation Public Comment* (July 2009) (<http://www.chhs.ca.gov/INITIATIVES/CACHILDWELFARE/COUNCIL/Pages/default.aspx>).

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<sup>30</sup> In 2010, the California Department of Social Services will hire a contractor to facilitate a Stakeholder Management Group, which will decide who should have access to CWS/Web.

## Funding Opportunities

Independent of whether any of the above-mentioned technology assets are leveraged, the State can utilize several funding streams to develop CEDS. The funding opportunities are both governmental and nongovernmental, and can contribute to the design, implementation, and/or sustainability of systems that electronically collect, store, and exchange information. Briefly described below are potential federal, state, and nongovernmental funding sources, including sources previously used by localities across the nation for electronic record systems for children in foster care.<sup>31</sup>

### Funding that Supports Other Systems

It may be possible for the State to leverage funding for CEDS from some of the data systems that ultimately connect to CEDS, such as HIE, MMIS, and CWS/Web. A large portion of the start-up capital for California's HIE will come from HITECH funds, including grants and 90 percent federal match for costs to administer Medicaid EHR incentive payments.<sup>xxxix</sup> Implementation of MITA in California comes with 90 percent federal financial participation (FFP) during the design, development, or installation process, and 75 percent FFP to support operation of California's MMIS.<sup>xxxix</sup> Finally, as California's new SACWIS, CWS/Web will be eligible for 75 percent FFP for the design and implementation phases and 50 percent FFP annually for maintenance of the system.<sup>xxxix</sup>

### Federal Sources

There are a variety of potential funding sources at the federal level, which can be pursued to fund a portion or the entirety of the development, implementation, and maintenance of CEDS. First, applications can be made to the Children's Bureau in the Administration for Children and Families for either a Discretionary Grant or a Title IV-E Child

Welfare Waiver Demonstration,<sup>32</sup> which allows states to use federal funds for innovative approaches to deliver child welfare services.<sup>xxxiv</sup>

Second, California receives block grants from the Administration for Children and Families for the Independent Living Program, which could be used, in part, to coordinate the exchange of information that would be useful for foster youth preparing for emancipation.<sup>33</sup> Two options that have been successfully utilized to implement electronic record systems in other localities in the United States come from Medicaid funding for the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services,<sup>34</sup> and grants from the Center for Mental Health Services within the Substance Abuse and Mental Health Services Administration.<sup>35</sup>

Another potential funding source is the American Recovery and Reinvestment Act of 2009, which created and directed the HIT Policy Committee to make recommendations regarding "technologies that address the needs of children and other

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<sup>32</sup> Per section 1130 of the Social Security Act, the Secretary of the Department of Health and Human Services has the authority to grant states flexibility in their use of Federal Title IV-E foster care funds, in order to support projects that represent innovation approaches for promoting safety, permanency, and well-being for children in the child protection and foster care systems. [Source: Children's Bureau, *Summary of the Title IV-E Child Welfare Waiver Demonstrations* (June 2008) ([http://www.acf.hhs.gov/programs/cb/programs\\_fund/cwwaiver/2008/summary\\_demo2008.htm](http://www.acf.hhs.gov/programs/cb/programs_fund/cwwaiver/2008/summary_demo2008.htm))]

<sup>33</sup> The Independent Living Program, authorized by the Foster Care Independence Act of 1999 (P.L. 106-169), provides training, services, and programs to assist foster youth in achieving self-sufficiency prior to and after emancipating from the foster care system. [Source: California Department of Social Services]

<sup>34</sup> EPSDT is Medicaid's comprehensive and preventive child health program for individuals under the age of 21. Under EPSDT, Medicaid funding is available to support a wide array of medically necessary services, as well as to support the documentations of those services. As explained in a report by S. Gluckman, the portion of the money for documentation purposes can be used to store notes electronically. [Source: Stefanie Gluckman with Terri Shaw, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* (Santa Monica, CA: The Children's Partnership, 2009)]

<sup>35</sup> For more information, please see: Stefanie Gluckman with Terri Shaw, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* (Santa Monica, CA: The Children's Partnership, 2009).

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<sup>31</sup> For more information about previously used funding sources, please see: Stefanie Gluckman with Terri Shaw, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* (Santa Monica, CA: The Children's Partnership, 2009).

vulnerable populations.”<sup>xxxv</sup> Finally, as the current federal health reform debate has emphasized the importance of health information technology, it is possible that the final bill will include an opportunity to garner funding for the creation and implementation of a system to exchange information about children living in foster care.

### State Sources

There are two potential funding sources at the California level that can be pursued for CEDS. The first is through the Department of Mental Health, which is making funds from the Mental Health Services Act available to counties for the implementation and/or improvement of health information technology, with the long-term goal of developing an Integrated Information Systems Infrastructure, where all counties can access and exchange information.<sup>xxxvi</sup> Second, it may be possible to secure funding through Legislative Appropriation of the State’s general fund. Finally, agency could include funding for this in their state budget proposal.

### Nongovernmental Sources

There are three potential nongovernmental sources of funding, which have all been successfully used by other localities to implement electronic records for children living in foster care. These sources are grants from private foundations, financing from corporate partners, and funds generated from licensing system software to other localities and states.<sup>36</sup>

### **Political Opportunities**

As mentioned at the beginning of this Roadmap, political factors that make this a key moment for developing and implementing CEDS are the passage of federal Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351) and the convening of the California Child Welfare Council. Specifically, the mandate in P.L. 110-351 that the State or Tribal agency responsible

<sup>36</sup>For more information, please see: Stefanie Gluckman with Terri Shaw, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* (Santa Monica, CA: The Children’s Partnership, 2009).

for foster care services must work with the State Medicaid agency to develop a plan for ongoing oversight and coordination of health care services for children in foster care, including how medical information for these children will be updated and shared,<sup>xxxvii</sup> provides a political impetus for developing CEDS.<sup>37</sup>

These technology, financial, and political opportunities create an environment conducive to implementing an electronic system for sharing information about children living in foster care in California. Key steps for moving this project forward are described below.

“The sharing of the data allows agencies to better address each individual’s needs and provide a customized service plan. It is a cost-saving effort providing less paperwork, more client-focused consultations, and increased client satisfaction.”

— Los Angeles  
Department of Children and Family Services

Source: California Health and Human Services Agency, *Child Welfare Council Draft Recommendation Public Comment* (July 2009) (<http://www.chhs.ca.gov/INITIATIVES/CACHILDWELFARECOUNCIL/Pages/default.aspx>).

## **ACTION STEPS FOR MOVING AHEAD**

California has a rare opportunity to lead the effort to improve coordination of care and health outcomes for children living in foster care and take advantage of the fact that all the pieces—technology, financial and political—are available and falling into place to implement CEDS. Following are steps we suggest the State should take to advance the development and implementation of CEDS.

<sup>37</sup> This mandate is outlined in Section 205 of P.L. 110-351. On October 11, 2009, California Senate Bill 597 was chaptered, serving as a first step toward achieving compliance with Section 205 of the P.L. 110-351. This bill mandates that the Department of Social Services work in consultation with physicians, health care experts, and experts in and recipients of child welfare services to develop the plan for ongoing oversight and coordination of care. [Source: California Welfare and Institutions Code §16010.2]

## **Leadership at the Highest Levels of State Government**

Leadership at the highest levels of state government is necessary for the successful development and implementation of CEDS. Strong leadership is critical to facilitate the policy, technology, and behavioral changes and financial commitments needed to accomplish the development and implementation of information exchange. The role of leadership in this area is to clarify, if not amend, policies, including those regarding privacy and security, and to develop and mandate technology standards. Leadership will also entail encouraging, if not requiring, agencies and organizations to share data and utilize electronic systems.

Finally, leaders will be required to seek funding to dedicate to this effort. Funding for this effort may consist of a combination of federal, state, local, and private dollars. An initial show of leadership may include the Governor pledging support for this effort through the development of a white paper or task force or by issuing an executive order. Another step forward would entail one of the relevant state agencies adopting this effort as an official project of their agency by including it in their state budget proposal.

## **Development of a Strategic Plan**

The State should create a strategic plan for the development of CEDS. This strategic plan should outline a phased approach which encompasses three realms of work: (1) connecting existing state-level electronic systems; (2) connecting existing county-level systems, leveraging state systems wherever possible; and (3) developing standards for local pilot efforts that can be replicable.

The initial phase should include development of a system of information-sharing that can happen quickly—a system to exchange a small amount of simple information between two or three state agencies. This will result in immediate benefits to children, and it will unveil lessons for the development of the larger vision and more all-encompassing system of information exchange.

Later phases should focus on the development of CEDS, which has multiple functionalities and shares a relatively large amount of data across multiple agencies. Key elements of the strategic plan are described below. Many of these goals may be best accomplished by a joint effort between relevant state agencies, providers who will use CEDS, and other key stakeholders.

## **Leveraging Existing Opportunities**

It is crucial that California leverage the concurrent development of CWS/Web, MMIS, and HIE to facilitate efficient exchange of information related to children in foster care to support program planning and administration as well as service delivery and care coordination. This work can take place both through stakeholder involvement in official state bodies, such as the California Child Welfare Council and the Underserved and Vulnerable Populations Workgroup with the State's HIE effort, and through convenings held specifically on this topic.

## **Creation of Standards for Information Technology**

The State, working with stakeholders, should develop and/or adapt policy and technical standards to meet the unique needs of the foster care population and the data systems of the agencies that serve them. This will require: working with local, state, and federal leaders to identify gaps in existing standards and proposing solutions to address them; ensuring that standards currently under development support appropriate information exchange for children in foster care; developing model interagency memoranda of understanding, contract language, and similar tools; and creating or adopting data and transactions standards.

## **Clarification of Privacy Laws Related to Data-Sharing for Children in Foster Care**

The State should carefully address the issue of privacy when developing a system for electronic information exchange for children in foster care. Confidentiality provisions regarding information-sharing exist in both federal and state laws to protect the rights of children and families. Specific provisions relating to those children in foster care have not consistently been stipulated in the laws.



The State, working with stakeholders, should examine and further interpret these laws and make clarifications or amendments as necessary. State leaders should continue the work they are currently doing on this with the California Privacy and Security Advisory Board, which is looking at confidentiality provisions in terms of HIE, and the California Administrative Office of the Courts, which is working with the CWC to address how confidentiality provisions apply in the foster care setting.

### **Develop a Funding Plan**

It is essential for the State to develop a plan for securing funding for the design, implementation, and long-term maintenance and sustainability of CEDS. In order to develop this plan, the State, working with stakeholders, should engage with both governmental and nongovernmental sources in order to gauge what funding is available and appropriate and what steps are required for procurement.

### **Establishment of a System of Governance**

In order to be effective, the State, working with stakeholders, should establish a system of governance to enable decision-making regarding matters having to do with the structure, operation, control, financing, and maintenance of a system of information exchange. These decisions will include: what data will be accessible; who has access to what data; when and how access to the system is granted or revoked; how data will be secured in the system; how the system will be funded; how the system will be designed; and what data standards and data rules will be required and implemented.

### **System Design**

The State should establish a system model for CEDS. This model should include specifications related to system architecture, functional components, data elements, and which existing systems will be connected. This model can serve as a recommendation for the governance body. The governance body will ultimately be responsible for the development and release of a request for proposals, selection of a vendor, and collaboration with the vendor to develop, test, and implement the system.

### **Local Pilot Efforts**

The State should encourage and support the development of local demonstrations where information about children in foster care is electronically exchanged on a county level. These demonstrations are an extremely valuable step toward the development of a statewide system. These local efforts will inform the statewide effort greatly regarding issues of privacy, policy, technology standards, governance, and data rules. It is important that demonstrations have a strong evaluation component to show real outcomes that, if positive, will encourage funders both philanthropic (private and corporate) as well as governmental to fund the scaling of this model to the state level.

The key state roles in local pilot efforts are facilitating the implementation of pilot efforts by authorizing information-sharing, establishing standards so that systems developed in pilot efforts are replicable and interoperable, and allowing local electronic systems to be connected to state-level electronic systems.

### **Implementation of the Strategic Plan**

The final step the State should take is to implement the strategic plan developed for realization of CEDS. The implementation of the strategic plan will take action on multiple levels. Some pieces of the system development may require legislative changes. Other pieces may involve administrative changes coupled with education efforts.

## **THE TIME TO ACT IS NOW**

An electronic system of information exchange for children living in foster care can be a powerful tool for improving the lives of children living in foster care in California. Enhanced access to information and communication between providers facilitates the coordination of care necessary for ensuring the well-being of these children. Recent policy developments, financial opportunities, and technology initiatives have created a uniquely opportune moment for developing such a system in California. Seizing this unique moment in time would have a considerable impact on improving the lives of the 75,000 children in California who are part of this vulnerable population.

## APPENDIX A

<b>PROGRAMS AND SERVICES FOR CHILDREN LIVING IN FOSTER CARE IN CALIFORNIA</b>		
<b>HEALTH</b>		
<b>PROGRAM</b>	<b>SERVICES</b>	<b>OVERSIGHT</b>
Medi-Cal Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program <sup>xxxviii</sup>	Medi-Cal benefits for individuals under 21 years of age, including health, mental health, developmental disability, substance abuse treatment, and health-related social services.	California Department of Health Care Services
Child Health and Disability Prevention (CHDP) Program <sup>xxxix</sup>	Provides complete health assessments: health history; physical examination; developmental, nutritional and dental assessments; vision and hearing tests; tuberculin test; laboratory tests; and immunizations. Also provides health education/anticipatory guidance and referral for any needed diagnosis and treatment. <sup>38</sup>	California Department of Health Care Services
Health Care Program for Children in Foster Care (HCPCFC) <sup>xl</sup>	Public health nurses within county child welfare service agencies and probation departments provide the following services: medical and health care case planning; assistance to caregivers with obtaining timely health assessments and dental examinations; coordination of health services; medical education; and participation in the creation and updating of the Health and Education Passport.	California Department of Health Care Services
<b>EDUCATION</b>		
<b>PROGRAM</b>	<b>SERVICES</b>	<b>OVERSIGHT</b>
Foster Youth Services Program <sup>xli</sup>	Provides instruction, counseling, tutoring, mentoring, vocational training, emancipation services, training for independent living, and other related services.	California Department of Education
Educational Liaisons <sup>xlii</sup>	Responsible for facilitating proper educational placement, enrollment in school, checkout from school, and proper transfer of credits, records and grades.	California Department of Education

<sup>38</sup> This program oversees the screening and follow-up components of the EPSDT program for Medi-Cal eligible children. [CCR, Title 22, Sections 51340 and 51532]

## APPENDIX B

<b>FEDERAL AND STATE MANDATES RELATED TO DATA COLLECTION AND DATA-SHARING IN ORDER TO ENSURE POSITIVE OUTCOMES FOR CHILDREN LIVING IN FOSTER CARE</b>		
<b>FEDERAL</b>		
TITLE	YEAR	RELEVANCE
Social Security Act Amendments of 1994 (P.L. 103-432)	1994	Amended the Social Security Act by authorizing the U.S. Department of Health and Human Services (DHHS) to audit State child and family service programs to ensure compliance with Title IV-B and Title IV-E state plan requirements. <sup>xliii</sup> Such reviews were to be guided by indicators and predictors of welfare receipt. <sup>xliiv</sup>
Adoption and Safe Families Act of 1997 (P.L. 105-89)	1997	Amended Title IV-E of Social Security Act to prioritize child health and safety over family preservation, and required the DHHS to establish outcome measures to guide federal reviews of State Title IV-B and IV-E compliance. <sup>xliv</sup>
Code of Federal Regulations Title 45 Sections 1355.31-37 <sup>xlvi</sup>	2000	Published in 2001, established the current Child and Family Services Review (CFSR) system, which audits State compliance with Titles IV-B and IV-E plans by assessing capacity to ensure positive outcomes in the areas of safety, permanence, and well-being. <sup>xlvii</sup> States must prove conformity with federal standards by using quantitative and qualitative information about children receiving services in the child and family service program. <sup>xlviii</sup>
Keeping Children and Families Safe Act of 2003 (P.L. 108-36)	2003	Amended the Child Abuse Prevention and Treatment Act (CAPTA) to require States to disclose confidential information to any Federal, State, or local governmental entity, if the information will assist the entity in fulfilling its duty to protect a child from abuse and neglect. <sup>xlix</sup>
Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351)	2008	Amended the Social Security Act to require the State or Tribal agency responsible for the Title IV-B plan to work with the State Medicaid agency to develop a plan for ongoing oversight and coordination of health care services for children in foster care, including mental health and dental health needs. <sup>i</sup> Among other requirements, this plan must include details of how medical information for children will be updated and shared, which may include electronic records. <sup>ii</sup>

**APPENDIX B CONTINUED**

<b>CALIFORNIA</b>		
<b>TITLE</b>	<b>YEAR</b>	<b>RELEVANCE</b>
Welfare and Institutions Code Section 16010	1999	Outlines the data elements and sharing requirements of the Health and Education Passport (HEP), which is to include health, mental health, dental health, and educational information about the child living in foster care. <sup>iii</sup> The HEP is to be maintained by the child protective agency, and a copy is to be provided to the caregiver, so that information can be shared with providers as necessary. <sup>iii</sup>
Child Welfare System Improvement and Accountability Act of 2001 (California Assembly Bill 636)	2001	Established and provides legal framework for the California Child and Family Services Review (C-CFSR) process, in order to ensure compliance with the state plan requirements of Title IV-B and federal regulations for the receipt of funds under Title IV-E of the Social Security Act. <sup>iv</sup>
California Assembly Bill 490 (Chapter 862, Statutes of 2003)	2003	Amended California Education Code to authorize the release of educational records of children living in foster care to the county placing agency for the purpose of compliance with WIC § 16010, case management responsibilities required by the Juvenile Court, or to assist with school transfer or enrollment. <sup>iv</sup>
Child Welfare Leadership and Performance Accountability Act of 2006 (California Assembly Bill 2216)	2006	Established the California Child Welfare Council (CWC), an advisory body responsible for improving the collaboration and processes of the various agencies and courts that serve children in the child welfare and foster care systems. Included in the CWC's responsibilities is the development of data and information-sharing agreements and protocols in order to improve outcomes for children living in foster care. <sup>vi</sup>
California Senate Bill 597 (Chapter 339, Statutes of 2009)	2009	Among other provisions, this bill seeks to make changes to California state law to conform to Section 205 of the federal Fostering Connections to Success and Increasing Adoptions Act of 2008. By creating California Welfare and Institutions Code Section 16010.2, this bill mandates the Department of Social Services to work with in consultation with physicians, health care experts, and experts in and recipients of child welfare services to develop the plan for ongoing oversight and coordination of care for children living in foster care. <sup>vii</sup>

## APPENDIX C

<b>DATA ELEMENTS MANDATED BY SACWIS AND WIC</b>
<p>1. General Information/Social Services Information</p> <ul style="list-style-type: none"> <li>• Name***</li> <li>• Record Number*</li> </ul>
<p>2. Demographic Information</p> <ul style="list-style-type: none"> <li>• Date of Birth*</li> <li>• Sex*</li> </ul>
<p>3. Health</p> <ul style="list-style-type: none"> <li>• Names and addresses of each health and dental provider**</li> <li>• Medicaid service claims**</li> <li>• Identification of child's known health problems**</li> <li>• Allergy information**</li> <li>• Immunization records**</li> <li>• Pharmacy claims (current medications)**</li> </ul>
<p>4. Mental Health</p> <ul style="list-style-type: none"> <li>• Names and addresses of each mental health provider**</li> <li>• Record of relevant mental health history**</li> <li>• Known mental health condition and medications**</li> </ul>
<p>5. Education</p> <ul style="list-style-type: none"> <li>• Names and addresses of education providers**</li> <li>• Transcripts (school record)**</li> <li>• Grade level performance**</li> </ul>
<p>*Indicates data elements mandated by State Automated Child Welfare Information System (SACWIS) regulations<sup>lviii</sup>;  **Indicates data elements mandated by California Welfare and Institutions Code (WIC) Section 16010; ***Indicates data elements mandated by both SACWIS regulations and WIC Section 16010.</p>

## APPENDIX D

Legal protections concerning the confidentiality of data and the right to privacy of children and families served by state agencies and private providers are found across various sectors of law. Two key federal laws that must be addressed when developing this system to share information about children living in foster care are the Health Insurance Portability and Accountability Act (HIPAA) and the Family Education Rights and Privacy Act (FERPA). Detailed below are the provisions of HIPAA, FERPA, and related California statutes that inform the discussion about privacy protections for a system that electronically shares information about children living in foster care.

### **Health Insurance Portability and Accountability Act (HIPAA)**

The Health Insurance Portability and Accountability Act (HIPAA) protects the confidentiality of medical records and information transmitted through electronic means.<sup>ix</sup> HIPAA allows covered entities<sup>39</sup> (e.g., providers, health plans, and other insurers) to disclose protected health information under a variety of circumstances.<sup>x</sup> These include the following:

1. Disclosures required by law,<sup>xi</sup> including disclosure to social services and to the court.<sup>lxii</sup>
2. Disclosures to individuals, parents, guardians, and other representatives authorized to act on behalf of the child in making health care decisions.<sup>lxiii, 40</sup>
3. Disclosures to the court pursuant to subpoena or court order.<sup>lxiv</sup>

California state law further defines under what circumstances disclosures of medical information can be made. Per California Health and Safety Code §123100, individuals, parents, guardians, or representatives with authority to make health care decisions for children living in foster care have access to information pertaining to the child's condition and care.<sup>lxv</sup> Per California Civil Code §56.103, social workers, probation officers, or other persons legally authorized with custody or care of a minor are authorized representatives of children living in foster care and can therefore access medical information about the child for the purpose of coordination of health care services.<sup>lxvi</sup> Medical information disclosed to an authorized representative may be further disclosed for purposes of coordinating health care services and the law authorizes the disclosure.<sup>lxvii</sup>

An important limitation to disclosure of medical information is outlined in California Health and Safety Code §123115, which states that representatives do not have access to a child's medical records if the minor has a right to consent to treatment or the provider determines that access to records would have a detrimental effect on the minor's physical or psychological well-being or on the provider's professional relationship.<sup>lxviii</sup>

### **Family Education Rights and Privacy Act (FERPA)**

The Family Education Rights and Privacy Act (FERPA) governs disclosure of personally identifiable information from a student's education records maintained by a school district.<sup>lxix</sup> FERPA permits the disclosure of directory information, which includes a student's identifying information such as name, address, telephone number, date and place of birth, information about fields of study and student activities, and the name of the most recent school attended.<sup>lxx</sup> FERPA allows schools to provide education information without

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<sup>39</sup>For HIPAA descriptions of "covered entities," see <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/index.html>.

<sup>40</sup>HIPAA defers to state law to determine who can act as a representative for a minor. [Source: 45 C.F.R. §164.502(g)(3)]

parental, guardian, or representative consent if pursuant to judicial order or subpoena, provided that parents and the students are notified before the release of information.<sup>lxxi</sup> Additionally, FERPA authorizes release of education records, where authorized by state statute, for juvenile justice cases.<sup>lxxii</sup>

California law allows for release of education information if provided for in a waiver signed by a parent, guardian, or person designated by the court, as detailed in California Education Code §49061.<sup>lxxiii</sup> However, per California Education Code §49076, county-placing agencies such as social services or probation departments are permitted access to a child's records without parental consent or court order.<sup>lxxiv</sup> Additionally, as detailed in California Education Code §49069.3, foster care family agencies are allowed to access grades, transcripts, and individualized education plans (IEP) for students under their care.<sup>lxxv</sup>

As outlined in FERPA, an important limitation to the disclosure of education information is that public notice must be given prior to the release of directory information, giving parents a reasonable time to object to the release of information about the child.<sup>lxxvi</sup> With regard to information other than directory information, FERPA requires signed consent from the child's parent, guardian, or person designated by the court.<sup>lxxvii</sup> These procedural requirements often present problems in the foster care setting, where there is no identified parent or guardian or where the respective roles of parent and guardian remain unclear.

## APPENDIX E

### GLOSSARY OF TERMS

**Audit Trail:** Record within the system that contains information about which users have logged on, when they log on, and what information they have accessed. [Source: Webopedia]

**California Child Welfare Council (CWC):** Established as part of AB 2216, The Child Welfare Leadership and Performance Accountability Act of 2006, the responsibilities of the CWC include: to increase collaboration and coordination between county agencies, state agencies, federal agencies and the courts; to develop data and information-sharing agreements and protocols for the exchange of information; to develop case plans for youth sixteen years or older; and describe programs and services to assist them in independent living.

**Data Dictionary:** A collection of information about data elements, including the meaning, format, usage, and relationships to other data elements. [Source: IBM Dictionary of Computing]

**Data Warehouse:** A repository of electronically stored information.

**Educational Service Providers:** For the purposes of this Roadmap, this term includes school administrators, teachers, educational liaisons, and school-based health care and developmental service providers.

**Enterprise Service Bus (ESB):** The component of Service-Oriented Architecture (SOA) platform that allows services to communicate and interoperate by managing messages, data format, and service coordination. [Source: Centers for Medicare & Medicaid Services]

**Foster Caretakers:** For the purposes of this Roadmap, this term includes foster parents, nonparent relatives serving as principal caretaker, group homes, and institutions.

**Health Information Exchange (HIE):** The electronic movement of health-related information among organizations according to nationally recognized standards. Statewide HIE in California will require the development and implementation of statewide technical architecture that enables electronic information-sharing between health care providers. [Source: Agency for Healthcare Research and Quality]

**Health Information Technology (HIT):** The use of information and communication technology in health care. Health Information Technology can include: electronic health records; personal health records; e-mail communication; clinical alerts and reminders; computerized decision support systems; hand-held devices; and other technologies that store, protect, retrieve, and transfer clinical, administrative, and financial information electronically within health care settings. [Source: Health Resources and Services Administration]

**Hub:** Technology architecture that allows data to be shared between databases, without storing data in a central repository.

**Individualized Education Program (IEP):** A written statement for each child with a disability that is developed, reviewed, and revised in a meeting in accordance with Sec. Sec. 300.320 through 300.324, and that must include: a statement of the child's present levels of academic achievement and functional performance; a statement of measurable benchmarks, short-term objectives and/or annual academic and functional goals; a description of the child's progress and the process through which progress reports will be made; a statement of the special education and related services and supplementary aids and services to be provided to or on behalf of the child; an explanation of the extent, if any, to which the child will not participate with nondisabled children



in the regular class and/or certain activities; and a statement of any individual appropriate accommodations that are necessary to measure the academic achievement and functional performance of the child on State and district-wide assessments. [Source: 34 Code of Federal Regulations §300.320(b)]

**Information and Communications Technology (ICT):** The study, design, development, implementation, support, or management of computer-based information systems, particularly software applications and computer hardware; deals with the use of electronic computers and computer software to convert, store, protect, process, transmit, and securely retrieve information.

**Interoperability:** The ability of systems or components to exchange health information and to use the information that has been exchanged accurately, securely, and verifiably, when and where needed. [Source: University of Kansas Center for Health Informatics]

**Placement Setting:** The living arrangement for a child in foster care, which can be a pre-adoptive home, foster family home (relative), foster family home (nonrelative), group home, institutions, supervised independent living, runaway, and trial home visit. [Source: Appendix A to 45 C.F.R. 1355.54]

**Providers:** For the purpose of this Roadmap, this term refers to individuals that are responsible for ensuring the safety and well-being of children living in foster care, including caseworkers, juvenile court judges, attorneys, foster caretakers, public health nurses, educational service providers, and physical, mental, and dental health care providers. The term “foster caretakers” includes foster parents, nonparent relatives serving as principal caretaker, group homes, and institutions. The term “educational service providers” includes school administrators, teachers, educational liaisons, and school-based health care and developmental service providers.

**Service-Oriented Architecture:** An application architecture within which business functions and selected technical functions can be invoked using documented interfaces. [Source: Centers for Medicare & Medicaid Services]

**Social Media:** The use of software that allows individuals to connect to health information, share knowledge, provide personal support, and collaborate with other users online and while mobile through a variety of Web-based communication tools (including blogs, wikis, podcasts, social networks, instant messaging, video, file-sharing sites, and widgets). [Source: HealthTech/The Children’s Partnership]

**State Automated Child Welfare Information System (SACWIS):** An optional, federally supported, automated data receptacle and case-management tool that is meant to assist social workers and other staff involved in foster care and adoptions with data collection and case management.

**System:** For the purposes of this Roadmap, this term refers to a collection of networks, computers, hardware, software applications, and other technologies that facilitate the sharing of data in an efficient and secure manner for the purposes of allowing authorized users to have access to a more comprehensive set of information about an individual, in order to enhance coordination of care and delivery of services.

**Youth in Foster Care:** For the purposes of this Roadmap, this term refers to children living in foster care that have reached the appropriate age for accessing their record of conditions and services received. The “appropriate age” needs to be determined.

## GLOSSARY OF DATABASES

**Automated Vital Statistics System (AVSS):** Internet-based system used by hospitals, local registration districts, and the California Department of Public Health to produce birth certificates and other public health documents, enabling the storage of birth certificates in electronic databases.

**California Court Case Management System (CCMS):** Currently in the development phase, this system will collect and manage information about civil, small claims, probate, mental health, criminal, traffic, family law, juvenile dependency, and juvenile delinquency cases.

**California Immunization Registry (CAIR):** California's statewide immunization registry network, which ensures the secure, electronic exchange of immunization records. The network consists of nine multicounty regional immunization registries.

**California Longitudinal Pupil Achievement System (CALPADS):** Currently in the development phase, this system will allow for tracking a student's academic performance from K-12 grade.

**California Special Education Management Information System (CASEMIS):** The information reporting and retrieval system for special education in California.

**Child Welfare Services/Case Management System (CWS/CMS):** California's State Automated Child Welfare Information System, which assists caseworkers by storing information about each dependent child and automating many administrative functions, including generating and managing forms.

**Client Development Evaluation Report System (CDER):** Contains diagnostic and evaluation information about Department of Development Services active service recipients who are over the age of three years.

**CWS/Web System:** A Web-based system, in the development phase, which will replace CWS/CMS as California's State Automated Child Welfare Information System. The CWS/Web System will have a simplified data entry process, include interfaces with other state systems that contain relevant data related to children living in foster care, and be accessible to individuals beyond caseworkers. It has not yet been defined who will have access to CWS/Web.

**Early Start Report System (ESR):** Contains diagnostic and evaluation information about Department of Development Services active service recipients who are under the age of three years.

**Medicaid Management Information System (MMIS):** Automated claims and information retrieval system for the state Medicaid program, Medi-Cal.

**Short-Doyle/Medi-Cal (SD/MC):** Department of Health Care Services data system, shared with the Department of Mental Health and Department of Alcohol and Drug programs, used to report behavioral health claims to the Department of Health Care Services for Medi-Cal processing.

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## ENDNOTES

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- <sup>ii</sup> California Blue Ribbon Commission on Children in Foster Care, *Fostering A New Future for California's Children: Ensuring Every Child a Safe, Secure, and Permanent Home* (San Francisco, CA: Judicial Council of California/Administrative Office of the Courts, 2009) 3.
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