

FROM SILOS TO LINKAGES:

Improving Outcomes for Vulnerable Youth Through the Wise Use of Information Technology

By

Stefanie Gluckman

with **Ashley Phelps**



May 2011

FROM SILOS TO LINKAGES: Improving Outcomes for Vulnerable Youth Through the Wise Use of Information Technology

Table of Contents

Overview	Page 1
Relevant Policy Developments: A Uniquely Opportune Moment	Page 3
Progress and Current Efforts in California	Page 4
Highest Priorities for Policy Change	Page 5
Moving Forward	Page 8
Acknowledgments	Page 9
Appendices	
Appendix A — Further Information on Policy Developments and Initiatives	Page 10
Appendix B — A Model for Reform: The Indian Employment, Training and Related Services Demonstration Act of 1992	Page 12

Foreword

California is poised to make great progress and has an unprecedented opportunity to leverage the tremendous potential of information technology to improve health and wellness outcomes for vulnerable populations, particularly children and youth living in foster care. The rapid development of state information systems and federal incentives through the American Recovery and Reinvestment Act (ARRA) and Affordable Care Act have created an environment in which it is possible to transform the delivery of care by linking systems, programs, and providers, enabling decision-makers to have the information necessary to treat the whole child.

From Silos to Linkages: Improving Outcomes for Vulnerable Youth Through the Wise Use of Information Technology is 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 Issue Brief builds on two previous reports, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* and *Electronic Information Exchange for Children in Foster Care: A Roadmap to Improved Outcomes*. These previous reports summarize how information technology tools can benefit a particularly vulnerable population, and outline an overall vision and actionable steps that California leaders can take to facilitate electronic information exchange to improve care coordination and thereby improve outcomes for children in foster care. This Issue Brief discusses the importance of care coordination, highlights some current efforts at the state and local level to enable appropriate electronic information exchange, and identifies priority policy issues that, if resolved, will facilitate California's creation of a more effective system of care for youth.

With California's current budget crisis and realignment efforts, now more than ever is the time to make use of innovative solutions to improve the efficiency and effectiveness of our state and local programs that serve children and those who care for them. We hope the information and recommendations presented here build the base of engagement and move California to action. The Children's Partnership looks forward to continuing to work with stakeholders and leaders in the public and private sectors to implement these recommendations and improve the lives of hundreds of thousands of children in California through the wise use of information technology.

— **Wendy Lazarus and Laurie Lipper**
Founders and Co-Presidents
The Children's Partnership

Preface

The following hypothetical scenario illustrates how the reform called for in this report—creation of an electronic system of information exchange—could facilitate improved outcomes for vulnerable youth, such as children and youth living in foster care, by enabling more informed decision-making and more effective care coordination.

Kelly is a seven-year-old child who has just moved from a group home to a foster home in a California County. She has previously been diagnosed with asthma and is allergic to corticosteroids, the commonly used anti-inflammatory drug for persistent asthma.

Kelly is currently experiencing coughing, shortness of breath, and tightness in her chest consistent with an asthma attack. Unfortunately, Kelly did not have any medication with her when she moved to her foster home. Her new foster parents take her to a clinic affiliated with the County Medical Center, where they see Dr. Sanders.

Upon learning that Kelly is in foster care, Dr. Sanders conducts a search in a Web-based electronic system by entering Kelly's identifying information, including name and date of birth. The system indicates on a secure Web-based browser that there is health information about Kelly in a few databases connected to the system.

Dr. Sanders selects which records he wants to see, and the electronic system generates a summary record of all of Kelly's information that the provider is qualified to access. This summary record is printable to both PDF and paper, so Dr. Sanders can incorporate information to the clinic's electronic health record for Kelly, enabling Kelly's information to be securely shared via statewide health information exchange.

From this summary record, Dr. Sanders sees information about Kelly's asthma diagnosis and past treatment, noting that she cannot take corticosteroids, and is able to prescribe alternate medication that will control Kelly's condition, but avoid the painful rash she suffers when taking corticosteroids. Dr. Sanders also notices that Kelly is allergic to peanuts and strawberries, which is critically important information for her new foster parents.

At the end of the visit, Dr. Sanders provides Kelly's foster parents with a printed summary of information from the visit as well as important and appropriate information from the summary record, reminding them to discuss this information during the next visit with Kelly's caseworker.

Use of this electronic system enhances Dr. Sanders' ability to provide Kelly with quality health care. It also provides important information that will help Kelly's foster parents keep her safe and healthy while she is in their care.

Overview

This once in a generation opportunity to link systems will be lost if we do not act in creative, bold, and forward looking ways.

— Daniel Stein
Managing Partner & Co-Founder
Stewards of Change, Inc.

California is poised to make great progress in care coordination for vulnerable youth. This Issue Brief, written by The Children's Partnership with funding from the Sierra Health Foundation, summarizes key efforts that are currently underway in California to improve outcomes for children in foster care through the use of information technology. The brief also addresses how these efforts can be leveraged to allow California to move toward an environment of interoperable systems that will allow for efficient and effective care coordination.

Status of Children in Foster Care

There are over 60,000 children living in foster care in California.^a

- Approximately half of children in foster care in California experience two to three changes in placement each year.^b
- Children in foster care are three to six times more likely than those in the general population to have significant psychological or behavioral problems.^c
- Nearly half of all children living in foster care suffer from chronic health conditions, such as asthma, repeated ear infections, and skin disease.^d
- In a 2009 survey, approximately 24 percent of foster care cases reviewed did not demonstrate the provision of adequate services to address the children's health needs.^e

Providers in the System of Care

Individuals responsible for ensuring the safety and well-being of children living in foster care include caseworkers, foster parents, program administrators, juvenile court judges, attorneys, public health nurses, school administrators, teachers, educational liaisons, probation officers, school-based health care and developmental service providers, and physical, mental and dental health care professionals.

Finally, this issue brief identifies priority policy issues that, if resolved, will facilitate California achieving this goal, and offers suggestions for moving forward toward resolving these issues.

Vulnerable youth, particularly children living in foster care, have complex health and care needs, and their outcomes depend on treatment and care from providers¹ in a variety of sectors, including health, child welfare, juvenile justice, and education. Despite the fact that a disproportionate amount of public dollars is spent on these children, they rarely receive adequate treatment because providers do not have efficient access to critical information about them.

Experts in the field broadly acknowledge the need for efficient and effective cross-sector care coordination to serve these children effectively and prepare them for transitioning to emancipation and adulthood. Electronic exchange of key information about this mobile, high-needs population of children across multiple providers can facilitate care coordination, inform decision-making, allow providers to spend more time focused on the specific needs of each child, and improve outcomes.²

California has the potential to develop a technology environment that will enable data about a child's health and care needs to be appropriately gathered, organized, and shared.³

Insufficient Information Can Lead to Dangerous Practices

Inadequate medical records for children in foster care contribute to a number of dangerous—and, in some instances, life-threatening—practices, including multiple immunizations, the over-prescription of powerful psychotropic medications, misdiagnoses, and medical errors and omissions.^f

The goal is to link state- and county-level electronic systems—while maintaining essential privacy protections and meeting security standards—such that each caregiver can have an understanding of the whole child—both at a single point in time and over time—leading to better decisions and more coordinated services.

Such a system-of-systems will also afford older youth the opportunity to have more efficient access to their own information, which will empower them to play a role in their own care and better prepare them as they transition to adulthood.

This innovative use of information technology can dramatically change the foster care environment in California, improving both caregiver effectiveness and the lives of at-risk children. It will also provide California with the opportunity to lead the way toward the development of similar models of care improvement for children living in foster care in other states and nationwide. Further, once evaluated and refined, this model can benefit populations of vulnerable children beyond those in foster care.

The State of California is in the process of newly designing and/or redesigning many of its data systems in sectors that touch the lives of vulnerable youth. This is an important juncture when these large systems can either be built with the architecture to be interoperable, to link across sectors, and to facilitate sharing of information and care coordination, or they can continue to be built in silos and perpetuate the fragmentation of programs and services that has been so damaging to our youth.

“We have found that there are sometimes barriers to information access, as the foster parent may not be privy to or have all of the medical and social information that is vital to providing complete medical care to the child. Additional time outside of the visit is often needed to access the necessary information to medically manage the child. A system of electronic information-sharing, if well thought out (both in terms of the type of information contained and the selection of users for access) could significantly improve care.”

*—Dr. Michelle Laba,
who practices pediatrics, is affiliated with
Ventura County Medical Center,
and treats many children in foster care.*

Early Results from Other Localities

Results from the few state and local efforts across the country that have implemented electronic information exchange for children in foster care indicate that greater real-time access to a more comprehensive base of information about a child enhances care-related decision-making and improves diagnosis, treatment, and, ultimately, outcomes for these vulnerable children.

For example, in Milwaukee, the number of youth in residential programs declined from 364 to 140 per day, psychiatric hospitalizations declined by 80 percent, and the cost of care per child dropped from \$5,000 per month to less than \$3,300 after implementation of the electronic information exchange system.^g

Relevant Policy Developments: A Uniquely Opportune Moment

In order to achieve this goal of linked systems, California needs the technology infrastructure and policy and practice environment that will enable caregivers to share information electronically and have a holistic view of each child. Fortunately, there are a number of recent policy developments, financial opportunities, and technology initiatives in the health and human services sectors that can help support this goal (listed below; see Appendix A for additional information).

This push for greater care coordination and program integration is coming from the highest levels of government. Seizing this moment will improve the lives of some of California's most underserved and at-risk children, while placing California at the forefront, nationally, in using information technology (IT) to benefit children living in foster care.

- The **Fostering Connections to Success and Increasing Adoptions Act of 2008** mandates 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.⁴
- The **American Recovery and Reinvestment Act of 2009** and the **Health Information Technology for Economic and Clinical Health (HITECH) Act** provide financial incentives to implement health information exchange (HIE) and the meaningful use of health information technology to improve health outcomes, particularly through better coordination and continuity of care.⁵

In California, **Cal eConnect** serves as the governance entity for establishing statewide electronic HIE in order to improve the quality, safety, and efficiency of health care for all Californians.

- The **Patient Protection and Affordable Care Act of 2010** devotes substantial resources for testing and implementing

medical homes,⁶ which are enhanced models of primary health care that focus on comprehensive and coordinated patient and family-centered care.⁷

- The federal Administration for Children and Families (ACF) is in the process of redesigning the requirements for **Statewide Automated Child Welfare Information Systems (SACWIS)**,⁸ providing the opportunity to develop policy to allow, require, and facilitate information-sharing.⁹

Concurrently, California is redesigning its SACWIS, to be called **CWS/Web**, to be a system that will afford appropriate levels of access to information for various providers involved in the lives of children in foster care, including foster families.

- Through the federal **Medicaid Information Technology Architecture (MITA)** Initiative, the Centers for Medicare and Medicaid Services (CMS) are providing enhanced federal funding for targeted improvements in program automation, standardization, and interoperability for state Medicaid Management Information Systems (MMIS).¹⁰
- The judicial branch of California is developing the **California Court Case Management System (CCMS)**, which will be a unified case management system for all 58 superior courts and will connect the courts with city, county, and state justice partners, giving Californians an “unprecedented level of access to their courts.”¹¹
- A **memo** from the federal **Office of Management and Budget** to heads of Executive Departments and Agencies, signed **November 3, 2010**, encourages sharing data between Federal agencies “for purposes of supporting important Administration initiatives, informing public policy decisions, and improving program implementation while simultaneously embracing responsible stewardship.”¹²
- Signed by President Obama in January 2011, **Executive Order 13563** requires greater coordination across agencies at all

levels of government as well as an analysis of existing rules and requirements, with the intent of establishing an environment that supports efforts to modernize and integrate program delivery.¹³

Progress and Current Efforts in California

Several efforts are moving California closer to the goal of improving outcomes for children living in foster care through the use of information technology. Described below are a few such efforts, which are leveraging policy and financial opportunities, demonstrating interagency and cross-sector information-sharing, and strengthening information exchange capacity (see Appendix A).

Leveraging Funding and Infrastructure for Health Information Exchange

Coordination of services for vulnerable and underserved populations is a priority in California's Health Information Exchange Strategic and Operational Plans, which are part of a Cooperative Agreement with the federal government to access funding for health information exchange (HIE) activities under the American Recovery and Reinvestment Act. In these plans, the California Health and Human Services Agency (CHHS) has directed departments and programs to "help develop, promote and ensure the consistent policies and interoperable systems necessary to support federal meaningful use criteria, and to ensure more effective and efficient service delivery and program outcomes."¹⁴

As such, the Health Information Technology Division of CHHS, in partnership with California Department of Social Services (CDSS) and Department of Health Care Services (DHCS), has developed a model use case focused on immunization data for children in foster care to assess how HIE can improve service delivery and care provided to these children and improve their outcomes.

Additionally, California included the goal to enhance care coordination across sectors in California's State Medicaid Health Information Technology Plan (SMHP), which is the agreement between the federal Centers for Medicare and Medicaid Services (CMS) and CHHS regarding the planning and implementation of the Medicaid electronic health record (EHR) incentive program under the HITECH Act.

In order to benefit vulnerable populations like children in foster care, California's SMHP proposes leveraging Medicaid EHR incentive program funding to demonstrate how electronic information-sharing between clinical and nonclinical caregivers can lead to better outcomes for patients, as well as support and encourage meaningful use of EHR technology. As a starting point, California has requested funding for such a demonstration in Ventura County.

Ventura County Pilot to Demonstrate Information Exchange

Working in partnership since 2009, and with the support of the Verizon Foundation, the Health Care and Human Services Agencies in Ventura County, The Children's Partnership, and Believe Health, LLC have developed a pilot of electronic information exchange between caseworkers and health providers in the Ventura County system, with the plan to launch the 22-month effort in late summer of 2011.

The electronic system will link existing data systems used by caseworkers and health providers to generate summary records of health needs and conditions for each of the 700 children living in foster care, which can be shared with foster parents, in order to enhance care-related decision-making. The electronic system will also include a "youth portal" that will allow older youth to access their own information.

The system will be designed with the architecture to eventually include information exchange across agencies and services beyond health and child welfare, including education, juvenile justice, and other sectors and caregivers that deliver services to

these vulnerable children and youth. The architecture will also be designed to eventually help enroll these children in relevant programs for which they are eligible.

Beyond changing the way that Ventura County caseworkers and health providers work together and deliver services, this pilot will have a broad impact on the health and human services fields, as it will develop policy and technology models that will be useful across the state and nationwide.

The California Health and Human Services Agency considers this pilot effort in Ventura County a strategic priority and critically important for guiding the use of information technology to benefit vulnerable populations in California, which is why it was included in California's State Medicaid Health Information Technology Plan.

California Child Welfare Council Data Linkages Committee

Representatives from CHHS, CDSS, and DHCS participate in meetings as part of the California Child Welfare Council (CWC)¹⁵ Data Linkages and Information Sharing Committee, which is made up of representatives from various state and county level agencies, the courts, and stakeholders in the advocacy and philanthropic communities.

The purpose of this committee is to address data integration and information-sharing barriers that exist between different governmental and nongovernmental entities maintaining data necessary to best serve the needs of children in foster care.

One of the committee's current priorities is to develop a template for a Memorandum of Understanding (MOU) for interagency information-sharing within and between counties. This is being developed by CDSS. Once established, this template MOU will greatly facilitate the appropriate exchange of information to benefit children in foster care.

Cross-Agency Meetings to Strengthen Information Exchange Capacity

In early 2010, The Children's Partnership began convening regular meetings with high-level state officials in the Health Information Technology Division of CHHS, CDSS, and DHCS on the topic of electronic information exchange for children in foster care.

The purpose of these meetings is to coordinate the policy and technical standards development of Medi-Cal, Child Welfare, and statewide HIE electronic data systems, and to provide a forum for addressing relevant policy issues across departments. These meetings are also used to discuss and develop piloting efforts, such as the immunization data use case and the Ventura County pilot. These meetings not only strengthen state information exchange capacity, but also reinforce California's commitment to interdepartmental coordination.

Highest Priorities for Policy Change

While these promising efforts are bringing California closer to the goal of an integrated system that supports the complex needs of children in foster care, there remain obstacles to comprehensive care coordination and information-sharing. Our work to date has identified several high priority policy changes that would go a long way toward facilitating a more effective system of care.

Integrating Federal Funding Sources

California leaders ought to work with relevant federal agencies to clarify how federal funding streams can be integrated and used by states to develop linkages to allow for cross-system information-sharing for the purpose of care coordination.

In order to achieve efficient and effective information exchange, data systems that are being newly designed or redesigned in the variety of sectors that impact children in foster care must be built with the architecture to be interoperable.

Though legislation, particularly the Fostering Connections to Success and Increasing Adoptions Act of 2008, mandates information-sharing across sectors for the purpose of care coordination, no single sector or single agency is independently able to bear the entire burden of financing the development of the system linkages required to enable this information-sharing. Nor does one agency have the capacity to be solely burdened with the reporting requirements.

These issues of system costs and reporting requirements have slowed movement toward this goal of electronic information-sharing through systems that are linked. Currently there is no explicit policy authorizing cost allocations that would enable multiple agencies to share in the cost and reporting requirements of developing such linkages.

In order to take advantage of existing technology concepts and capabilities such as Enterprise Architecture and interoperability, the federal government could allow more flexibility for a state's cost allocation and reporting methodology, which would enable states to integrate funding streams.

Relevant federal agencies ought to collectively clarify how federal funding streams can be used by states to develop the linkages to support appropriate electronic information-sharing for the purpose of care coordination. Relevant agencies include, but are not limited to, the Children's Bureau, the Centers for Medicare and Medicaid Services (CMS), the Center for Consumer Information and Insurance Oversight (CCIIO), the Office of the National Coordinator for Health Information Technology (ONC), the Office of Management and Budget (OMB), and the Department of Education (DOE).

There is a strong precedent for statutory language allowing for integrated funding for the provision of coordinated services across agencies. In 1992, the federal government created a successful demonstration project, (Public Law 102-477, the Indian Employment, Training, and Related Services Demonstration Act) to improve the provision of client-focused

services by allowing for the combining of funding silos across agencies and programs. (See Appendix B.)

This Act allows federally recognized tribes and Alaska Native entities to consolidate funding streams from multiple agencies into a single plan with a single budget and a single reporting system. Lisa Rieger, General Counsel of the Cook Inlet Tribal Council, says that inception of Public Law (P.L.) 102-477 has led, in Alaska, to significantly integrated and improved client services, and has reduced administrative burdens and maximized federal dollars where they are most needed.

*"The success and importance of the 477 program to participating tribes and tribal organizations cannot be overstated."*¹⁶

— Lisa Rieger
General Counsel
Cook Inlet Tribal Council

Using P.L. 102-477 as a model, federal agencies could authorize states and counties to weave together relevant federal funding streams as they develop the linkages to support appropriate electronic, cross-systems information-sharing.

Privacy and Confidentiality

California leaders ought to work with state and federal officials to resolve outstanding issues related to privacy and confidentiality rules and regulations as they apply to electronic information exchange for children in foster care.

"Data is like wealth – it's a treasure, it's like gold – but it's sensitive. We have to make sure the right data is in the right hands at the right time, but no longer than necessary."

— Lillie Coney
Associate Director
Electronic Privacy Center (EPIC)

It is especially important in moving forward with this effort that special attention be given to the issue of privacy and confidentiality, as

children in foster care have unique and varied privacy concerns. Misused information can have implications for a child's access to services. Appropriate privacy protections will guard against those risks and take into account concerns about particularly sensitive information—such as mental health, reproductive, and drug treatment information—as well as the varying rights of parties to give consent to information-sharing or otherwise have access to and control over information.

Privacy and security are key components of any electronic system for information exchange. The models for electronic information exchange will 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. The system of electronic information exchange will include additional security measures as deemed necessary by technology and privacy experts.

A number of federal and state laws address the sharing of health, human service, and education data. The California Administrative Office of the Courts has examined these state and federal laws and has written a series of issue briefs detailing the laws that pertain to information-sharing for children living in foster care. (To access these briefs, visit <http://courts.ca.gov/7871.htm>.)

There are some outstanding issues regarding electronic information exchange for children living in foster care that, if resolved, would facilitate the creation of a system of information exchange. Some of these resolutions could come from a clarification in the law, some from developing tools or mechanisms explicitly tuned for the electronic exchange of information for children in foster care (such as consent or release forms or court orders), and some through educating and training directed at providers about the current rules and regulations around information-sharing.

Some California stakeholders are currently taking steps to address certain privacy issues related to sharing personal information for children living in foster care.

Over the past year, pursuant to recommendations of the Blue Ribbon Commission, the Administrative Office of the Courts (AOC), in partnership with the Child Welfare Council (CWC), held several meetings with county counsel and child welfare directors to hear about issues they faced regarding information-sharing and privacy and confidentiality for children in foster care. Stakeholders consistently advocated for the creation of a standardized consent form for the release of health and mental health information as well as for the creation of a consent form for the release of education information for use by public and private providers statewide. These Judicial Council forms are currently out for public comment. For more information, visit <http://www.courts.ca.gov/policyadmin-invitationstocomment.htm>.

In addition, the stakeholders flagged issues of access to confidential information in child welfare records. The AOC and CWC are developing another legal brief on access to juvenile case file records, both in the social service files and in the court files, with special attention to confidentiality and evidentiary privilege. They are also holding further stakeholder meetings, which may result in recommended legislation.

In some instances, these unresolved issues in the area of privacy and confidentiality have created a fear around information-sharing, despite the fact that in many cases the information-sharing is sorely needed to improve outcomes for and sometimes even to save lives of children. Over the years, concern about liability has created a culture of withholding information, even information that is clearly permissible and mandated to be shared amongst providers. Providers are afraid to make mistakes and risk liability.

The federal government has recently demonstrated interest in addressing these issues. This is exemplified by Executive Order 13563 and the associated February 2011 Presidential Memo, which orders greater administrative flexibility and the elimination of barriers, as federal, state, local, and tribal governments are required to coordinate care, share information, and work across agencies to realize efficiencies and improved program outcomes. The time is therefore ripe for California state leaders and stakeholders to work with the federal government for resolution of these privacy issues.

The privacy and confidentiality issues needing resolution through clarification of law, the development of new tools, and education and training, include, but are not limited to:

- What parties can consent to the release of information in the case of a child living in foster care?
- What is the difference between confidentiality and evidentiary privilege in the case of electronic information exchange for children in foster care?
- What happens when shareable data cannot be separated on a single electronic record from protected data?
- Who holds the right to opt in or opt out of a system of information-sharing upon a child entering the foster care system?
- Who has the ability to re-disclose information that has been shared about a child in foster care?

Clarification and guidance as well as the development of tools, education and trainings around these and related issues could significantly ease providers' fears about sharing data and facilitate the building of linkages between systems to enable the electronic exchange of information for children in foster care.

Moving Forward

In order to move away from the provision of services in silos toward achieving more highly coordinated care for vulnerable youth, California state leaders and other stakeholders can build on the tremendous momentum now underway. A high priority is to identify key obstacles and opportunities to facilitate interoperability and articulate them to the players that can make change. These players are more open to changes that will facilitate linkages and information-sharing than ever before and it is crucial to seize this important opportunity.

California stands at an important juncture when it can build its large information technology systems with the architecture to be interoperable, to link to other sectors, and to facilitate sharing of information and care coordination. Alternatively, California can build these systems in silos and perpetuate the fragmentation of programs and services that has been so damaging to our youth.

California state and local leaders have exhibited extraordinary leadership and vision over the past year that has enabled great progress toward making electronic information exchange for children in foster care a reality. The Children's Partnership looks forward to moving these promising reform efforts forward with our local, state, federal, and philanthropic partners and taking this unique opportunity to build linkages across programs and systems to facilitate efficient and effective care for so many of our most vulnerable youth.

Acknowledgments

This Issue Brief and its recommendations are the result of extensive conversations with leaders in the health care, health information technology, child welfare, and justice fields. The author would like to thank the following individuals:

Lisa Ashton, Health Sciences Assistant Clinical Professor, UCSF School of Pharmacy and Office of Health Information Technology, California Department of Health Care Services; **Lynda Bowman**, Volunteer-Private Sector; **Debbie Campora**, Project Manager, CWS/Web Project, California Office of Systems Integration; **Holly Cole**, Director, Government & External Affairs, Verizon California; **Gwendolyn Doebbert**, Consultant to California Deputy Secretary for Health Information Technology, California Health and Human Services Agency; **Carladenise Edwards**, President and CEO, Cal eConnect; **Jonah Frohlich**, former Deputy Secretary, Health Information Technology, California Health and Human Services Agency; **Kevin Gaines**, Assistant Deputy Director, Children & Family Services Division, California Department of Social Services; **Bob Gonzalez**, Director, Ventura County Health Care Agency; **Rebecca Gudeman**, Senior Attorney, National Center for Youth Law; **Chet Hewitt**, President and CEO, Sierra Health Foundation; **Sidney Hollar**, Attorney, Center for Families, Children and the Courts, Administrative Office of the Courts; **Michelle Laba**, Ventura County Medical Center; **Diane Littlefield**, Director of Program Investments, Sierra Health Foundation; **Carrie Miller**, Acting Manager, Service Integration Branch, Chief Executive Office, Los Angeles County; **Kiki Nocella**, CEO, Believe Health, LLC; **Kim Ortiz**, former Chief, Office of Health Information Technology, California Department of Health Care Services; **Mike Powers**, County Executive Officer, Ventura County; **Raul Ramirez**, Chief, Office of Health Information Technology, California Department of Health Care Services; **Paula Rockwell**, Program Manager, CWS/Web Project, California Department of Social Services; **Greg Rose**, Deputy Director, Children

and Family Services Division, California Department of Social Services; **Will Sanson**, Senior Business Applications Analyst, Center for Families, Children and the Courts, Administrative Office of the Courts; **Christine Schmoeckel**, Senior Policy Analyst to California Deputy Secretary for Health Information Technology, California Health and Human Services Agency; **Linette Scott**, Deputy Director, Health Information and Strategic Planning, California Department of Public Health and Interim California Deputy Secretary for Health Information Technology; **Cynthia Solomon**, President, FollowMe; **Daniel Stein**, Managing Partner, Stewards of Change; **John Wagner**, Director, California Department of Social Services; **Chris Wu**, Supervising Attorney, Center for Families, Children and the Courts, Administrative Office of the Courts; and **Barry Zimmerman**, Director, Ventura County Human Services Agency.

This Issue Brief was written by Stefanie Gluckman with Ashley Phelps, Wendy Lazarus, Laurie Lipper, Terri Shaw, and Beth Morrow provided strategic input throughout this project.

The author expresses gratitude to Carrie Spencer and Karen Anthony for their editorial assistance. The Children's Partnership thanks Sierra Health Foundation for their support of this work.

APPENDIX A

Further Information on Policy Developments and Initiatives

Highlighted Policy Developments, Financial Opportunities, Technology Initiatives, and Current Efforts

For additional information about highlighted policy developments, financial opportunities, technology initiatives, and current efforts, visit:

Fostering Connections to Success and Increasing Adoptions Act of 2008

<http://www.fosteringconnections.org/>

Health Information Technology for Economic and Clinical Health (HITECH) Act and Funding Opportunities

http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__hitech_and_funding_opportunities/1310

Cal eConnect

<http://www.caleconnect.org/>

Patient Protection and Affordable Care Act of 2010

<http://www.healthcare.gov/law/introduction/index.html>

Statewide Automated Child Welfare Information Systems (SACWIS)

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

California CWS/Web

http://www.hwcws.cahwnet.gov/projects/CWS_WEB.asp

Medicaid Information Technology Architecture (MITA)

<https://www.cms.gov/MedicaidInfoTechArch/>

California Court Case Management System (CCMS)

<http://www.courts.ca.gov/partners/ccms.htm>

November 3, 2010 Memo from Office of Management and Budget

<http://www.whitehouse.gov/sites/default/files/omb/memoranda/2011/m11-02.pdf>

Executive Order 13563 and Presidential Memorandum on Administrative Flexibility

<http://www.gpo.gov/fdsys/pkg/FR-2011-01-21/pdf/2011-1385.pdf>

<http://www.whitehouse.gov/the-press-office/2011/02/28/presidential-memorandum-administrative-flexibility>

California's Health Information Exchange Strategic and Operational Plans

<http://www.ehealth.ca.gov/eHealthPlan/tabid/72/Default.aspx>

California's State Medicaid Health Information Technology Plan

<http://www.dhcs.ca.gov/Pages/DHCSOHIT.aspx>

Ventura County Pilot to Demonstrate Information Exchange

<http://www.childrenspartnership.org>

California Child Welfare Council

<http://www.chhs.ca.gov/initiatives/CACChildWelfareCouncil/Pages/default.aspx>

Cross-Agency Meetings to Strengthen Information Exchange Capacity

<http://www.childrenspartnership.org>

Administrative Office of the Courts Briefings on Sharing Information About Children in Foster Care

<http://courts.ca.gov/7871.htm>

Related Efforts

For information about related efforts, visit:

Assembly Bill 278 Demonstration Projects are demonstrations to test privacy and security standards for health information exchange in California.

<http://www.ohi.ca.gov/calohi/>

Health Shack is a Personal Health Record (PHR) and information system that provides a safe place for California's system based youth—including the homeless and those aging out of foster care—to keep their health records and other important documents.

<http://www.healthshack.info/>

San Diego County Office of Education Foster Youth-Student Information System (FY-SIS) is a secured, Web-based system designed specifically to store health, education, and placement information for wards and dependents of San Diego County. <http://www.sdcoe.net/ssp/support/fys/?loc=fysis&m=4>

National Information Exchange Model (NIEM) is a logic data model, or common vocabulary, of terms that is mutually agreed upon through a rich governance process of practitioners at all levels of government and private industry. It is designed to develop, disseminate, and support enterprise-wide information exchange standards and processes that can enable effective cross-department information-sharing. Several California data systems are or will be NIEM conformant. According to the 2010 Federal CIO Council report on adoption and use of NIEM, 22 federal agencies and 4 Lines of Business have been able to identify business driven cross-domain information exchange opportunities.

<http://www.niem.gov/>

www.niem.gov/pdf/AssessmentReport.pdf

APPENDIX B

A Model for Reform: The Indian Employment, Training and Related Services Demonstration Act of 1992

Public Law 102-477 is the Indian Employment, Training and Related Services Demonstration Act of 1992. This Act is unique among federal legislation in that it allows federally recognized Tribes and Alaska Native entities to consolidate funding streams (“formula-funded federal grants funds”) that are employment- and training-related into a single plan with a single budget and a single reporting system. These are called “477 plans” or “477 programs.” This Act allows entities to minimize administrative redundancy by merging reporting requirements, while still adhering to government accountability standards.

All the funds involved in an entity's "477 plan” are those which the entity would otherwise receive under the authority of the individual programs it chooses to consolidate in its "477" plan. The lead federal agency for this interdepartmental demonstration is the Department of the Interior (DOI), Office of Indian Energy & Economic Development. Formula-funded programs in the Bureau of Indian Affairs, the Department of Labor, the Department of Health and Human Services, and the Department of Education are involved.

In 2009, the Office of Management and Budget released A-133 Circular compliance guidance that requires tribes and tribal organizations to track each funding stream under 477 separately and retroactively.

Statutory Language (from Public Law 102-477)

United States Code Title 25 Chapter 36 Section 3403. Integration of services authorized.

The Secretary of the Interior, in cooperation with the appropriate Secretary of Labor, Secretary of Health and Human Services, or Secretary of Education, shall, upon the receipt of a plan acceptable to the Secretary of the Interior submitted by an Indian tribal government, authorize the tribal government to coordinate, in accordance with such plan, its federally funded employment, training, and related services programs in a manner that integrates the program services involved into a single, coordinated, comprehensive program and reduces administrative costs by consolidating administrative functions.

Other Resources from The Children's Partnership

Available at www.childrenspartnership.org

Digital Opportunity Resources

The School2Home Program: A Public-Private Initiative to Close the Technology Gap for California's Middle School Families (2009, in partnership with the California Emerging Technology Fund)

Information Technology Making a Difference in Children's Lives: An Issue Brief for Leaders for Children (2008)

Digital Opportunity for America's Youth: State Fact Sheets (2008)

The State of Youth and Technology in Children's Advocacy: A Survey of Children's Organizations Across the Nation (2007)

Helping Our Children With Disabilities Succeed: What's Broadband Got To Do With It? (2007)

Helping Our Children Succeed: What's Broadband Got To Do With It? 2nd Edition (2007)

Measuring Digital Opportunity for America's Children: Where We Stand and Where We Go From Here (2005)

Parents' Guides and Child Safety on the Internet

A Parent's Guide to Online Kids: 101, PowerPoint Presentation (2006)

The Parents' Guide to the Information Superhighway: Rules and Tools for Families Online, 2nd Edition (1998)

E-Health Resources

Explaining Health Reform: Eligibility and Enrollment Processes for Medicaid, CHIP, and Subsidies in the Exchanges (2010, in partnership with the Kaiser Commission on Medicaid and the Uninsured)

Electronic Information Exchange for Children in Foster Care: A Roadmap to Improved Outcomes (2010)

School-Based Telehealth: An Innovative Approach to Meet the Health Care Needs of California Children (2009)

Technology-Enabled Innovations for Improving Children's Health (2009)

E-Health Snapshot: Federal Support for Health Information Technology in Medicaid - Key Provisions in the American Recovery and Reinvestment Act (2009, in partnership with the Kaiser Commission on Medicaid and the Uninsured)

How Technology Can Help an Express Lane Eligibility Effort (2009)

Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems (Full Report, 2008; Executive Summary, 2009)

Children's Health Information Technology Action Plan: Priorities for Federal Action to Modernize Health Care for Children through Health Information Technology (2008)

E-Health Snapshot: A Look at Emerging Health Information Technology for Children in Medicaid and SCHIP Programs (2008, in partnership with the Kaiser Commission on Medicaid and the Uninsured)

Meeting the Health Care Needs of California's Children: The Role of Telemedicine, 2nd Edition (2008)

E-Health Snapshot: Harnessing Technology to Improve Medicaid and SCHIP Enrollment and Retention Practices (2007, in partnership with the Kaiser Commission on Medicaid and the Uninsured))

About The Children's Partnership

Since 1993, The Children's Partnership (TCP), a national, nonprofit organization, has worked to ensure that all children—especially those at risk of being left behind—have the resources and the opportunities they need to grow up healthy and lead productive lives. Consistent with that mission, we have educated the public and policy-makers about how technology can measurably improve children's lives. We have also worked at the state and national levels to enact policies and build programs that extend digital opportunity to all children.

Santa Monica, CA Office

1351 3rd St. Promenade
Suite 206
Santa Monica, CA 90401
t: 310.260.1220
f: 310.260.1921

Washington, DC Office

2000 P Street, NW
Suite 330
Washington, DC 20036
t: 202.429.0033
f: 202.429.0974

E-Mail: frontdoor@childrenspartnership.org

Web: <http://www.childrenspartnership.org>

End Notes

¹ “Providers” refers to individuals responsible for ensuring the safety and well-being of children living in foster care, including caseworkers, foster parents, program administrators, juvenile court judges, attorneys, probation officers, public health nurses, school administrators, teachers, educational liaisons, school-based health care and developmental service providers, and physical, mental and dental health care professionals.

² For further details, see *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* at <http://www.childrenspartnership.org/reports/fostercare>.

³ For further details, see *Electronic Information Exchange for Children in Foster Care: A Roadmap to Improved Outcomes* at <http://www.childrenspartnership.org/report/roadmap>.

⁴ 42 United States Code §622(b)(15)(iii) (2008).

⁵ *Electronic Health Records and Meaningful Use*. U.S. Department of Health and Human Services, The Office of the National Coordinator for Health Information Technology, 19 May 2011 (http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__meaningful_use_announcement/2996).

⁶ Public Law 111-148 §2703, §3021, §3502, §5405 (2010).

⁷ Ad Hoc Task Force on Definition of the Medical Home, American Academy of Pediatrics, “The Medical Home,” *Pediatrics*, Vol. 90 (1992): 774.

⁸ A state’s SACWIS is an electronic system meant to meet the administrative and case management needs of caseworkers.

⁹ U.S. National Archives and Records Administration, Office of the Federal Register, *Federal Register*, Vol. 75, No. 141 (23 Jul. 2010): 43188-43190.

¹⁰ Medicaid Management Information Systems are automated claims and information retrieval systems. U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, *What is MITA? An Overview*, 19 May 2011 (<https://www.cms.gov/MedicaidInfoTechArch/>).

¹¹ *California Case Management System: A Knowledge Center for the Statewide Case Management System*. Judicial Council of California/Administrative Office of the Courts, 19 May 2011 (<http://www.courts.ca.gov/partners/ccms.htm>).

¹² White House, Office of Management and Budget, *Memorandum on Sharing Data While Protecting Privacy*, M-11-02 (3 Nov. 2010).

¹³ Executive Order No. 13563 (18 Jan. 2011) (<http://www.gpo.gov/fdsys/pkg/FR-2011-01-21/pdf/2011-1385.pdf>); The White House, Office of the Press Secretary, *Presidential Memorandum—Administrative Flexibility* (28 Feb. 2011) (<http://www.whitehouse.gov/the-press-office/2011/02/28/presidential-memorandum-administrative-flexibility>).

¹⁴ California Health and Human Services Agency. *California Health Information Exchange Strategic and Operational Plans* (31 Mar. 2010): O-37.

¹⁵ Established in 2006 as part of The Child Welfare Leadership and Performance Accountability Act of 2006, the CWC is a State advisory body that will “consider recommendations to improve child and youth outcomes through increased collaboration and coordination among the programs, services and processes administered by the multiple agencies and courts that serve children and youth in California’s child welfare system.” The four focus areas of the CWC are: Prevention/Early Intervention; Permanency; Child Development/Successful Youth Transitions and Data Linkage and Information-Sharing.

¹⁶ Lisa Rieger, Vice President and General Counsel of Cook Inlet Tribal Council, “Alaska Native and American Indian Interoperability in Action,” 6th Annual Stewards of Change Conference: From Field to Fed II: Linking Systems to Sustain Interoperability in Challenging Times (New Haven, Connecticut: March 2011). In recent years, tribes have been struggling against the resiloization of programs as federal agencies have had some difficulties in sharing responsibility for monitoring programs. As a result, the true capacity of 477 has not yet been realized, but it is still a promising case study for interoperability facilitated by integrated funding streams.

Boxes

^a B. Needell, et al., *Child Welfare Services Reports for California*, University of California at Berkeley Center for Social Services Research, 8 Mar. 2011 (http://cssr.berkeley.edu/ucb_childwelfare).

^b B. Needell, et al., *Child Welfare Services Reports for California*, University of California at Berkeley Center for Social Services Research, 8 Mar. 2011 (http://cssr.berkeley.edu/ucb_childwelfare).

^c L. Baliver, et al., "The Health of Children in Foster Care," *Social Services Review*, Vol. 73, No. 3 (September 1999): 401; B.T. Zima, et al., "Behavior Problems, Academic Skill Delays and School Failure Among School-Aged Children in Foster Care: Their Relationship to Placement Characteristics," *Journal of Child and Families Studies*, Vol. 9, No. 1 (2000): 98-99.

^d N. Halfon, et al., "Health Status of Children in Foster Care: The Experience of the Center for the Vulnerable Child," *Archives of Pediatrics and Adolescent Medicine*, Vol. 149, No. 4 (April 1995): 386-392.

^e U.S. Department of Health and Human Services, Children's Bureau, "Results of the 2007 and 2008 Child and Family Services Reviews" (PowerPoint Presentation) (Washington, DC: U.S. Department of Health and Human Services, 2009) (<http://www.acf.hhs.gov/programs/cb/cwmonitoring/results/index.htm>).

^f Children's Action Network, *A Report on the Feasibility of Establishing the Health Portion of CHEER for Los Angeles County Foster Youth* (Los Angeles, CA: Children's Action Network, 2005) 1 (<http://www.childrensactionnetwork.org/CHEER.pdf>).

^g For further details, see *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* at <http://www.childrenspartnership.org/reports/fostercare>.