IMPROVING HEALTH OUTCOMES FOR CHILDREN IN FOSTER CARE:

The Role of
Electronic Record Systems

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Foreword

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A Message From
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Information and Communications Technology (ICT) is reshaping the health care system in the United States, and the pace of change is accelerating. Tremendous public and private efforts are underway to promote the timely exchange of accurate health information to improve health outcomes at the individual and population levels. Yet, as this electronic revolution gathers momentum, there has been little public discussion about how ICT tools could improve health care for and the health of America's 74 million children.

Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems 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 children.

This report summarizes how ICT tools could benefit one particularly vulnerable group of children: the 800,000 children who spend time in foster care each year. A number of programs and services are available to meet these children's complex needs, yet children in foster care tend to have worse health status, higher average health costs, and less access to needed health services than other children.

While the use of ICT is still in its early stages, a small number of states and cities around the country are using electronic record systems to improve the coordination and delivery of health care and other services to children in foster care. This report provides an overview of these efforts, highlights the lessons learned from them, and offers recommendations on how to promote promising approaches so that all children in foster care can benefit.

This information and these recommendations are designed to take advantage of a unique opportunity.

In 2009, a new president and Congress will be forging ahead on important policies, including the reauthorization of the Child Abuse Prevention and Treatment Act, which provides grants to states to improve their child protection system, including money for research, pilots, and other activities related to the prevention and treatment of child abuse or neglect. In addition, federal and state policy leaders alike will continue to struggle with escalating public program expenditures, particularly in health programs. By focusing on the use of ICT tools to improve outcomes for children in foster care, policy leaders can not only better meet the needs of a particularly vulnerable and costly population, they can also incubate robust and scalable solutions in a manageably sized population to allow proven approaches to be expanded over time.

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 the most vulnerable children.

Introduction

Children in foster care have greater health care needs than other children. These needs are not being met due in part to insufficient information about these children and a lack of care coordination. An Electronic Record System (ERS)[i] can be a powerful tool for facilitating better collection, storage, sharing, and analysis of health information. Investments in such systems to integrate information about and for children in foster care would likely yield significant returns, including improved outcomes for children and more efficient use of current spending to meet their needs. Yet, such solutions have not been widely deployed to better meet the needs of the approximately 800,000 children in foster care annually across the nation.[1]

The Children's Partnership developed this issue brief to provide policy leaders with information about the ways ERSs, when applied appropriately, can benefit children in foster care and the systems that serve them. The brief focuses primarily on health care and outcomes, where the needs and solutions are clearest and where most early efforts have begun. Specifically, the brief examines the need for improved information collection and sharing in the provision of health care services to children in foster care; provides an overview of the ways in which ERSs can be and are being used to improve health outcomes for children in foster care; highlights early evidence of the impacts of these efforts; outlines lessons learned from these efforts about system development, capacity, privacy issues, and funding streams; and highlights strategies to expand the use of ERSs to greater numbers of children living in foster care.

Children in Foster Care

The term *foster care* commonly refers to all out-of-home placements for children who cannot remain with their birth parents. Children may be placed with nonrelative foster families, with relatives, in a therapeutic or treatment foster care home, or in some form of congregate care, such as an institution or a group home. Nearly half of all children in foster care live with nonrelative foster families, and about one-quarter reside with relatives. The remaining quarter live in group homes, institutions, or supervised independent living settings.[2]

Over the course of each year approximately 800,000 children in the United States spend time in foster care.[3] Due to exits and entries throughout the year, the number of children in foster care at a given point in time each year is approximately 500,000.[4] The majority of children in foster care (60 percent) enter in response to a report of child abuse or neglect that is provided to a state's child welfare system by a doctor, teacher, police officer, or other source.[5] Approximately 300,000 of the 500,000 children in foster care in 2006 stayed in foster care for a year or more.

Children in foster care are more likely to come from communities of color than other children in the United States. Forty percent of children in foster care in 2006 were White, non-Hispanic; 32 percent were Black, non-Hispanic; and 19 percent were Hispanic.[6] African-American children are more likely than White children to be in foster care and tend to stay in foster care longer as well.[7]

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[i] An Electronic Record System (ERS) is an electronic record of information about an individual that can be created, gathered, managed, and consulted by authorized people, and includes the networks, computers, hardware, software applications, and other technologies that make this record possible.

Facts at a Glance

Children served in foster care in FFY 2007	783,000[8]
Children in foster care on September 30, 2007	496,000[9]
Average age of children in foster care in FFY 2006	9.8 years[10]
Average length of stay of children in foster care in FFY 2006	28.3 months[11]
Average placement changes per year	1-2[12]
Annual total federal and state spending on children in foster care	$10 billion[13]
Total Medicaid expenditures on children in foster care in FFY 2001	$3.8 billion[14]
Average per-child Medicaid expenditures for all enrolled nondisabled children in FFY 2001	$1,315[15]
Average per-child Medicaid expenditures for all enrolled nondisabled children in foster care in FFY 2001	$4,336[16]
Children in foster care who have chronic medical problems	50 percent[17]
Cases reviewed by the U.S. Department of Health and Human Services (2005) in which child welfare agencies failed to provide adequate services to children in foster care	Over 30 percent[18]

How Foster Children Receive Care

The foster care system is not a single system, but a combination of overlapping and interacting agencies and programs—including health, education, social welfare, and juvenile justice—that provide services and support to children and their families. Each agency relies on the others to provide the information and resources necessary to meet the complex needs of children in foster care.

Federal Programs

There are two major federal sources of child welfare[ii] funding: Titles IV-E and IV-B of the Social Security Act. Title IV-E is a permanently authorized and open-ended entitlement program that guarantees federal reimbursement to states for a portion of the cost of maintaining an eligible child in foster care. Specifically, states may claim a federal reimbursement on behalf of every income-eligible child they place in a licensed foster home or institution. In State Fiscal Year (SFY) 2004, state and federal Title IV-E program spending totaled more than $5.8 billion.[19] Title IV-B provides less money but more flexible funding that can be used by states for a broad array of child welfare services. Unlike Title IV-E, this funding is not an open-ended entitlement, but rather a mixture of capped entitlement dollars and discretionary funding that is subject to the annual appropriations process.[20] In SFY 2004, states spent $639 million in total Title IV-B funds.[21]

Additionally, in SFY 2004, states spent at least $4.8 billion each year in nondedicated funds from federal sources including Temporary Assistance for Needy Families,[iii] and Social Services Block Grants.[iv, 22]

[ii] The term “child welfare” is used to describe a set of government and private services designed to protect children and encourage family stability. These typically include investigation of alleged child abuse, foster care, adoption services, and services aimed at supporting at-risk families so they can remain intact.

[iii] Temporary Assistance for Needy Families is the United States federal assistance program. It began on July 1, 1997 and succeeded the Aid to Families with Dependent Children program, providing cash assistance to impoverished American families with dependent children through the United States Department of Health and Human Services.

[iv] Title XX of the Social Security Act, also referred to as the Social Services Block Grant, is a capped entitlement program. Block grant funds are given to states to help them achieve a wide range of social policy goals, which include preventing child abuse, increasing the availability of child care, and providing community-based care for the elderly and disabled.

All children in foster care are also eligible for Medicaid, a federal entitlement program administered by the states that provides health and long-term care coverage for low-income individuals. State and federal Medicaid spending for children in foster care totaled approximately $3.8 billion in FFY 2001.[23]

State Programs

Child welfare policies and practices vary from state to state but are generally overseen by each state's Department of Social Services or Human Services. Each state determines its own definition of maltreatment (based on federal regulations) and its own level of investment in child welfare services. The way in which child welfare organizations are administered also varies across states. In some states, the child welfare system is administered at the state level and, in others, it is administered at the county level. In every state, the courts play an important role in foster care from the initial decision to remove a child from their home, to the development of a permanency plan, to the decision to return a child to his or her home or to terminate parental rights and make the child available for adoption.[24]

Health Care Needs of Children in Foster Care

Children in foster care have greater health care needs than other children. Compared with children from the same socioeconomic background, children entering foster care have much higher rates of serious emotional and behavioral problems, chronic physical disabilities, birth defects, and developmental delays.[25] Approximately 12.8 percent of children in the U.S. population have special health care needs.[v, 26] In comparison, 50 percent of children in foster care have been estimated to have chronic health conditions, such as asthma, repeated ear infections, other respiratory problems, severe allergies, epilepsy, and skin disease.[27] Many children in foster care also have behavioral, emotional, and developmental problems, such as learning disabilities, emotional disturbances, or speech impediments. When such concerns are taken into consideration, the estimated proportion of children in foster care with special health care needs rises to more than 80 percent.[28]

Consistent with these complex health care needs, children in foster care account for a disproportionate share of health care spending. Virtually all children in foster care are eligible for Medicaid.[vi, 29] Children in foster care represent 3.7 percent of all nondisabled children enrolled in Medicaid, but 12.3 percent of all Medicaid spending on nondisabled children. On average, Medicaid spending in federal fiscal year 2001 was $4,336 per enrolled, nondisabled foster child, compared to $1,315 per enrolled, nondisabled child.[30] However, there is more significant variation in average Medicaid expenditures across states for children in foster care than other children.[31]

Despite disproportionately high health care expenditures, children in foster care experience serious unmet health care needs. The U.S. Department of Health and Human Services (HHS), in reviewing all states' child welfare systems, established a performance goal of having children receive services to meet their physical and mental health needs in 90 percent of cases reviewed.[vii] In the most recent comprehensive review available,

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[v] The term "special health care" needs follows the Maternal and Child Health Bureau definition of children "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type and amount beyond that required by children generally."

[vi] Though virtually all children in foster care are eligible for Medicaid, many face gaps in coverage while in placements due to complex and burdensome enrollment procedures. See: Shwartz, Sonya and Glascock, Melanie; *Improving Access to Health Coverage for Transitional Youth*, National Academy for State Health Policy, July 2008, www.nashp.org/Files/transitional_youth.pdf

[vii] HHS Child and Family Service Reviews, mandated by Congress in 1994, evaluate how well state child welfare agencies are meeting established national standards. States are assessed on a broad range of systemic, family, and child outcome measures to determine how well they are meeting the goals of promoting safety, permanency, and well-being for children in foster care. States that do not meet federal standards are required to submit performance improvement plans to HHS, mapping out how they plan to address their deficiencies.

HHS found only one state in substantial compliance with this goal. State results varied from 51 percent to 92 percent, with the median result of 69 percent. Thus, half of the states failed to provide adequate physical and mental health services in more than 30 percent of the cases reviewed.[32] Furthermore, a special study conducted by the U.S. General Accounting Office found that 12 percent of young children (36 months of age or younger) in foster care had received no routine health care; 34 percent had not received any immunizations; 32 percent had at least some identified health needs that were not met; and fewer than 10 percent had been tested for HIV, even though more than three-quarters of the children were at high risk of infection.[33]

The costly, yet inadequate, care delivered to children in foster care is due in part to placement instability, combined with limited coordination and information-sharing between service providers. On average, children placed in foster care experience 1-2 changes in foster homes per year.[34] Placement changes are usually accompanied by changes in physicians and other health care providers. These placement changes, along with the multiple providers likely involved in caring for the complex health needs of children in foster care regardless of placement changes, leads to incomplete health information that is spread across many different sites. As a result, children in foster care frequently receive incomplete and/or duplicate immunizations, and they lack proper ongoing primary care, including both acute care and periodic assessments of their health development and emotional status.[35]

Why ERSs for Children in Foster Care Should Be a Priority

To date, very little of the significant public and private sector attention to electronic medical records, personal health records, and similar Electronic Record System solutions has focused on meeting the needs of the foster care population. Yet there are many indications that prioritizing such advancements for this population would result in significant gains not only for children in foster care, but for the systems that serve them and other children and families.

- As many as 80 percent of children in foster care have chronic conditions, and evidence suggests they have serious unmet health care needs. Their complex care needs often require the involvement of many different providers in separate care settings, and those providers are likely to change over time as children move from placement to placement. ERSs designed to capture and share information from multiple sources about these children's needs and treatments—and to provide relevant anticipatory guidance, decision support, and reminders to the evolving care team about those needs and treatments—would support better health care delivery and outcomes for these children.
- Medicaid spending is more than three times higher for children in foster care than other children. As noted above, some of this spending goes toward duplicative, unnecessary care. Documented inadequacies in preventive and primary care likely also contribute to unnecessary spending on more acute or emergency care that could have been avoided. Therefore, the improvements in care delivery and outcomes that an ERS supports would likely also result in better use of taxpayers' health dollars.
- ERSs can be used as a way to assess, not just address, the needs of children in foster care. ERSs not only facilitate the storage and sharing of information for the coordination of care for individuals in foster care, but also facilitate the collection of data about the foster care population as a whole that can be analyzed to give new information about the changing health status and needs of this group. This data can also be used to evaluate outcomes of specific programs and services. Thus, ERSs can assist in planning and managing foster care programs, further helping to improve outcomes and ensure that limited public dollars are put to best use.
- Improving services and outcomes for children in foster care can lead to improvements for all children and families and the systems that serve them. Due to the complex needs of children in foster care, developing, testing, and implementing

systems to serve their needs can provide a strong foundation from which to expand to other populations. The technologies developed and lessons learned from these early efforts, as well as the improvements in service delivery and cost-efficiencies gained from them, should be readily translatable to other efforts.

Promising ERS Efforts in States and Local Communities

A small number of states and local communities around the country are on the leading edge of capturing the benefits of Electronic Record Systems for children in foster care. These efforts are in their early stages, but they are providing promising evidence of success and valuable lessons learned to help others move forward. These systems are consistent with and build upon the concept of earlier paper-based medical passports, which sought to capture and maintain key pieces of information about foster children in a single file.[36] But the electronic systems offer the promise of much greater information capture, easier information-sharing among a broader spectrum of the child's care team through networked systems, and enhanced functionality to translate the information into better care and outcomes.

Because the current ERS efforts are in their early stages, many focus on capturing and sharing a relatively small array of information with a relatively small array of individuals that participate in the child's care. Most focus primarily on health information due to the clear health needs of this population and promise of improved cost-effectiveness for the substantial health spending on this population. However, leaders of these efforts recognize the additional benefits that could be realized from additional information for improved coordination among child welfare agencies, schools, the courts, nonmedical service providers, and other caregivers. The systems have generally been designed with the intent of allowing greater scope and functionality over time as the technology continues to evolve and members of the care team become more comfortable with coordinated technology solutions.

This issue brief highlights six promising ERS efforts: statewide initiatives in Texas, Tennessee, Kansas, and Arizona, and local initiatives in Milwaukee and Sacramento. These six efforts were selected because they all contemplate some form of ERS (some include solely medical information, some include a broader array of information) to serve at least a portion of the highly mobile and vulnerable foster care population. While other localities have experimented with technology solutions, such as creating electronic medical passports, the efforts profiled in this brief are notable for the breadth of the information capture and sharing they are attempting to accomplish and for their innovative approaches of deploying and using the technology solutions. Program leaders in each of these localities were interviewed at length about the systems.

The efforts profiled here were planned and implemented by two general types of entities: state or county health and human service departments and nonprofit organizations that provide services to children in foster care. In most cases, the planning and implementation entities contracted with a private technology developer to work with them to create an ERS. These efforts were funded through a variety of sources, including Medicaid grants, state general fund dollars, federal grant money from the Center for Mental Health Services, and grants from private foundations. (See Table 1, *A Summary of ERSs* for details.)

These initiatives are developing or utilizing ERSs to store and share health information for children in foster care. These ERSs enable data about a child's health care, status, and needs to be gathered, organized, retained, and shared—despite frequent changes in placements and physicians—such that updated information is available regularly to people who are involved in the care of the child. These systems enable data regarding a variety of aspects of a child's health and care—including immunizations, allergies, mental health, and chronic conditions such as asthma and diabetes—to be accessed electronically by those currently involved in the care of the child as well as transferred directly to a new foster family, new physicians, and new caseworkers when children change placements. The data that populate an ERS can be made accessible in full or in part to those involved in a child's care depending on the sensitivity of the information. In some of the ERSs, alerts can notify caseworkers and other caregivers of when screenings, immunizations, or other medical or judicial appointments need to take place.

Elements of Existing ERSs for Children in Foster Care

Table 1 includes detailed information about each of the programs examined for this issue brief. Each of the six ERSs for children in foster care has been developed differently, but there are many commonalities.

- *Data Included*. Most of the ERSs examined here focus primarily on collection and distribution of health care information. The information about a child that populates each electronic record comes, in most cases, from medical service claims, pharmacy claims, and lab data. The records also contain basic health information about each child including allergies, immunizations, provider contact information, and birth date. In many of the systems, additional information can be input by medical providers and/or caseworkers.
- *Access*. In the majority of ERSs, medical providers and child welfare caseworkers have access to at least a portion of the information in the record. In some systems, access is also extended to the children in foster care, the foster families, or an even broader group of people involved in the child's care, such as school representatives or those involved in the justice system.
- *Additional Functions*. Most of the ERSs that have been developed not only store data but also provide messages or alerts to users—such as caseworkers, providers, or families—that include relevant reminders about a child's needs or warnings of gaps in care or medication interactions.

See Table 1 below for a summary of the major features of each of the profiled ERSs.

Table 1: Summary of ERSs

	Texas	Milwaukee, WI	Tennessee	Kansas	Sacramento, CA	Arizona
Name	Health Passport	Wraparound Milwaukee	Shared Health Clinical Health Record	Electronic Medical Record	FollowMe	Medical History Portal
Population Served	Children in the care or custody of the Department of Family and Protective Services (DFPS), including but not limited to children in foster care	Seriously emotionally disturbed children (those at risk of being placed in a psychiatric hospital or residential center), over a third of whom are children in foster care	The Medicaid population as a whole, with a special program focusing on children in foster care	Children in foster care	Homeless Youth, one-third of whom are youth in the process of emancipation from foster care	Children in foster care
Funding Source	✓ Medicaid Transformation Grant ✓ Appropriation from Legislature	✓ Child Welfare Department ✓ Grant from Center for Mental Health Services	✓ State and federal funding for TennCare, the state's managed care program for Medicaid-eligible and otherwise-uninsured individuals	Grants from: ✓ The Health Care Foundation of Greater Kansas City ✓ REACH Healthcare Foundation ✓ Prime Health Foundation	✓ Sierra Health Foundation	✓ Medicaid Management Information System funds
Who Can Access Information	✓ Health care providers (including dental) ✓ Child's medical consenter ✓ DFPS staff ✓ Caseworker	✓ Health care providers ✓ Caseworker ✓ Youth ✓ Education provider and after school coordinator ✓ Judges in juvenile justice system	✓ Health care providers ✓ In new release, caseworker and foster child	✓ Health care providers ✓ Caseworker	✓ Youth have control over who can access	✓ Health care providers ✓ Caseworker
Sources of Information	✓ Providers can input data manually ✓ Automated sharing of Medicaid claims data	✓ Case managers ✓ Moving toward input directly from providers	✓ Automated sharing of Medicaid claims data ✓ In new release, caseworker	✓ Caseworker ✓ Providers	✓ Providers and caseworkers with the permission of youth	✓ Caseworker ✓ Possibly family (not yet determined) ✓ Automated sharing of Medicaid claims data

Table 1: Summary of ERSs Continued

	Texas	Milwaukee, WI	Tennessee	Kansas	Sacramento, CA	Arizona
Information Included	✓ Child's name, birthdate, address of record, and Medicaid ID number ✓ Name and address of each of the child's physicians and health care providers ✓ Medical service and pharmacy claims data ✓ A record of each visit to a physician or other health care provider, including diagnosis ✓ Identification of the child's known health problems ✓ Information on prescriptions ✓ Allergy information ✓ Immunization records	✓ Name and address of physicians ✓ Date of last and next visit ✓ Eligibility information ✓ Plan of care ✓ Crisis plan ✓ Progress notes by case managers ✓ Claims data ✓ Moving toward detailed physical and pharmaceutical data	✓ Claims data ✓ Pharmacy data ✓ Lab data ✓ Allergy information ✓ Immunization records ✓ Diagnoses ✓ Providers child has seen (including in emergency room)	✓ Court documents ✓ Birth records ✓ Complete medical history ✓ All paper records of doctor visits	✓ Youth decide what information is included in their record. Will be advised to include things like birth certificate, immunization records, medications, and allergies	✓ Diagnosis code ✓ Service code ✓ Name of provider and contact information ✓ In future, will include lab results
Privacy Protections	✓ Information is password-protected ✓ When emancipated, child receives the Health Passport information	✓ Information is password-protected ✓ Use one release of information form across all agencies	✓ Information is password-protected ✓ Some information blocked from certain users, such as information tied to psychosis or substance abuse	✓ Information is password-protected ✓ When emancipated, child receives the electronic medical record information	✓ Information is password-protected ✓ Access to and input of information controlled by youth	✓ Information is password-protected
Alerts	Yes: System indicates when medications have been prescribed that have a negative interaction	No: However, caseworker receives one-page monthly report, including information contained in the ERS that must be reviewed for gaps in care	Yes (to be implemented in the future): System will send physicians and case workers alerts if there are gaps in a child's care	No	No	Yes: Will start with a wide variety of reminders and see which ones are useful and needed and if any need to be added
Implementation Date	April 2008	June 1999	October 2007	January 2007	May 2008	Not yet determined

Early Evidence of Impacts

The ERS efforts profiled in this brief are in their early stages, not a great deal of documentation exists about their impacts. The strong expectation is and initial evidence indicates that ERSs facilitate information-sharing and coordination of care among service providers, improving health outcomes and decreasing the cost of health care.

Improved Outcomes

Early findings indicate that the information storage, sharing, and coordination of care that is facilitated by ERSs result in improved preventive care, decreased hospital stays, and improved clinical conditions. Milwaukee, through its Wraparound Milwaukee program (a program that serves seriously emotionally disturbed children[viii] in the welfare and/or juvenile justice system, many of whom are children in foster care), uses an ERS to track, manage, and coordinate care. Since Milwaukee introduced the Wraparound model, the number of youth in residential programs has declined from 364 to 140 per day and psychiatric hospitalizations have declined by 80 percent.[37] Program officials attribute this reduction to the ability to provide an array of coordinated and individualized services—facilitated by their ERS—to those they serve.[38] Wraparound Milwaukee also saw a variety of improvements in clinical conditions of the children it serves.[39] Other localities across the nation with ERSs for children in foster care have not yet completed evaluations, but initial anecdotal evidence indicates that service providers are seeing positive results in the areas of preventive care, emergency care, and psychiatric care as a result of ERSs.[40]

Decreased Cost of Care

Early evidence from localities that have developed ERSs indicates that increased information-sharing and coordination of care decreases the cost of care. Cost containment is important, as states disburse about $10 billion dollars a year in federal and state funds to meet the needs of children placed in foster care. There is early evidence of ERSs facilitating increased prevention, decreasing expensive avoidable illnesses and hospital stays, and reducing inefficiencies such as duplicate immunizations. These improvements in health outcomes for children in foster care also decrease costs.

In the Wraparound Milwaukee system, the cost of care per child dropped from $5,000 per month to less than $3,300 due to improved coordination of care, which resulted in improved health outcomes and less necessity for residential and psychiatric hospital care.[41] Other states that have implemented ERSs also report cost-savings to the health care system. In Tennessee, according to studies done by their ERS developer, use of the ERS resulted in an 18 percent cost avoidance driven by a reduction in pharmacy, ancillary (lab, imaging, etc.), and facility (hospital charges, inpatient, outpatient, etc.) costs.[ix, 42] Texas expects that their ERS, the Electronic Health Passport system, will result in cost-savings due to more efficient service delivery and better management of costly prescription drugs. Arizona believes that an ERS will help eliminate duplicate services and that the improvement in health status of children in foster care resulting from an ERS will significantly reduce costs.

Early Lessons in Developing ERSs for Children in Foster Care

As localities have developed ERSs as a tool to improve outcomes for children in foster care, early lessons have emerged regarding funding, stakeholder involvement, provider participation, privacy concerns, and system scope.

Funding

One of the most significant challenges in pursing ERS initiatives is obtaining necessary funding. Upfront costs can be large, even where the technology may ultimately lead to significant cost-savings. Obtaining sustainable funding can

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[viii] Defined as children who are or are at risk of being placed in a psychiatric hospital or residential treatment center.

[ix] This evidence comes from a controlled study that was done in a general practice environment. The results of this study are expected to transfer to the subset population of children.

present an even greater hurdle. Localities have identified a variety of federal, state, and local funding streams to finance the development of ERSs for children in foster care.

Medicaid

ERS-related activities that serve children in foster care may be eligible for Medicaid funding. For example, Tennessee's state Medicaid program has invested both state funds and federal matching funds in a public/private ICT initiative called Shared Community Health Record, which allows its Medicaid program—and, therefore, children living in foster care—to participate in an ERS.

Localities have also funded a portion of the initial costs of ERSs with funds that come from Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)[x] services. EPSDT funds are available to support a wider array of medically necessary services than may be covered through a Medicaid state plan as well as to support the documentation of those services. The portion of the money that is provided for documentation purposes can be used to store notes electronically in a record for children in foster care.

Localities are also exploring requesting prior approval for Medicaid Management Information Systems (MMIS)[xi] funds at an enhanced match through an Advanced Planning Document in order to support ERSs in the long term. Some uses of ERSs for children in foster care, such as using electronic data in the provision of services, may receive a standard Medicaid administrative match of 50 percent (depending upon each state's individual vision of electronic health and the overarching plan of the state agency).

Other Federal Sources

Federal grant programs may offer funding alternatives. For example, Milwaukee received federal funds through a grant from the Center for Mental Health Services within the Substance Abuse and Mental Health Services Administration to develop and implement its ERS. The Texas Electronic Health Passport was initiated through a one-time appropriation of $500,000 from the Texas Legislature and later was awarded a $4 million Medicaid Transformation Grant[xii] from the Centers for Medicare and Medicaid Services.

Private Sources

Private sources of funding are available for the development of ERSs as well. Foundations have provided significant funding to help states deploy health information technology. For example, in Kansas, KVC Behavioral Healthcare Inc., the private organization that contracts with the state to provide foster care for 3,000 children in Kansas, set up an ERS to provide a "medical home" for children in their care. KVC's start-up was funded by a grant from three foundations: The Health Care Foundation of Greater Kansas City, REACH Health Care Foundation, and Prime Health Foundation. In addition to direct funding, private partners can also help states obtain the money needed to secure federal matching funds.

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[x] EPSDT is Medicaid's comprehensive and preventive child health program for individuals under the age of 21. Enacted in 1967, it requires states to provide periodic screening, vision, dental, and hearing services as well as any medically necessary health care service listed in Section 1905(a) of the Social Security Act, even when the service is not available under the State's Medicaid plan to the rest of the Medicaid population.

[xi] In October 1972, Public Law 92-603 was enacted in which Section 235 provided for 90 percent Federal financial participation (FFP) for design, development, or installation, and 75 percent FFP for operation of state mechanized claims processing and information retrieval systems approved by the Secretary. For Medicaid purposes, the mechanized claims processing and information retrieval system is known as the Medicaid Management Information Systems (MMIS). In general, where the funds are being used to support the state information system, it will fall within the purview of MMIS, whereas it will generally be classified as a standard Medicaid administrative expenditure (at 50 percent FFP) when the funds are helping administrators and providers use the data and provide the services.

[xii] Section 6081 of the Deficit Reduction Act of 2005 authorized $150 million in federal grants to States for the adoption of innovative methods to improve effectiveness and efficiency in providing medical assistance under Medicaid. In its first set of grants (FY 2007), HHS awarded $98 million to 26 states; in the second set of grants (FY 2008), it awarded $52 million to 16 states and Puerto Rico. Only Texas used its grant to support the development of a foster care health record.

Other Innovative Approaches

Once developed and implemented, an ERS may be able to generate funding. For example, Wraparound Milwaukee is licensing its system and charging fees for its use, working with counties that function similarly and for whom its tested software is a logical fit.

Stakeholder Involvement and Leadership

The ERS development process can take a long time and requires complex negotiations regarding roles and responsibilities of the various stakeholders. Localities reported that involving representatives of the various child welfare agencies, clinicians, caseworkers, other service providers, and child advocates in the planning from the early stages helps to ensure that the ERS meets the needs of its users as well as children in foster care. A cooperative development structure helps to build trust and buy-in.

Strong leadership throughout the development and implementation phases was also said to be beneficial. Programmatic "champions" often helped to drive the process. Many of the localities that developed ERSs attribute their ability to do so to having a state or local government that supported and nurtured this development. For example, in 2005 the Texas Legislature enacted S.B. 6, a comprehensive initiative to reform the state's child protective services division within the Department of Family and Protective Services. The legislation required the development of a comprehensive medical services delivery model for children in foster care. The Texas Healthcare Passport was developed under that authority.[43] TennCare indicated that its use of the Shared Health Clinical Health record was eased by Tennessee's governor, who encouraged the use of technology in health care settings.[44]

Although strong support from governmental leadership can help drive development efforts, one program manager and ERS developer reported that their system was successfully designed, developed, and implemented independently, with little involvement of public officials or other stakeholders.

Utilization by Service Providers

ERSs only facilitate sharing of information, coordination of care, and improved health outcomes if they are utilized by service providers. Much of the data that populates the ERSs comes directly from medical service claims, pharmacy claims, and lab data. More detailed information can be input by providers and would make the record a more useful tool. Providers may resist accessing and inputting information into ERSs due to time, training constraints, and a concern that there is not enough information in the record to be useful. Localities found that, as the ERSs are populated with more data and providers use the systems more routinely, providers recognize the benefits of seeing a child's whole medical history, and provider participation levels increase.

The managed care contracting process has enabled localities to require and/or offer incentives to providers to input and view data in ERSs. In the Tennessee model, all 9,000 children in foster care are in the same managed care organization. An exclusive set of providers sees the children in foster care at an enhanced reimbursement rate. The doctors are instructed to use (view) the system of electronic records. At last measurement, 63 percent of these doctors had actually viewed records.[45]

Privacy: Legal Boundaries and Control of Information

To deliver high-quality care, caregivers need access to accurate and complete information about children in foster care. Children and those who care for them are more likely to share such information with health care providers and other members of the care team if they are confident that the information will be treated confidentially, maintained accurately, and used appropriately to improve the child's care.

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 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 biological or foster parents, caseworkers, and adolescents to give consent for information-sharing or otherwise have access to and control over information.

A complex array of privacy laws apply to electronic records for children in foster care, depending on the nature and sources of the information the records contain. At the federal level, relevant laws may include the Health Insurance Portability and Accountability Act (HIPAA),[xiii] which regulates the use and disclosure of protected health information, and the Family Educational Rights and Privacy Act (FERPA),[xiv] which regulates education records. State laws vary, but may include specific protections for certain sensitive information, such as information relating to mental health or HIV/AIDS, or information held by specific programs, such as Medicaid.

As a state or community explores opportunities for developing electronic record systems for children in foster care, there are at least three interrelated components to consider in establishing appropriate privacy protections for the systems. The *first* component is policy development. Relevant privacy laws must be identified and their implications, including the potential need for legislative or regulatory clarification, analyzed. Policy issues must be resolved in a manner that optimizes the potential benefits of sharing information about children in foster care between welfare agencies, service providers, and other entities while guarding against the risks of harm due to potential misuse of this sensitive information. Engaging stakeholders, including advocates for children in foster care, throughout the systems development process can help to achieve this balance.

The *second* component is the development of tools for carrying out the desired privacy policies. Data sharing agreements and business process changes will likely be required among the various entitities participating in the electronic records systems. In addition, the system architecture will have embedded privacy and security measures. For example, all systems that have been reviewed in this issue brief are password-protected and are designed to comply with HIPAA and state privacy and security laws. Most systems have additional protections for particularly sensitive information and can limit the information that is viewable depending upon who is accessing the information.

The *third* component is specific consideration of the role of youth in foster care in contributing to and controlling the information in the electronic record system. The ERS being developed by the Wind Youth Services Center in Sacramento, California provides foster youth with heightened privacy controls. This center serves homeless and vulnerable youth, who, on average, are 16 years old, and many of whom have been recently emancipated from foster care or are in the process of emancipation. In this ERS, the youth will determine what information is entered into their electronic record (though it will be entered by providers), who is authorized to view the information, and what portion of the record those authorized can view. The youth will receive training about the ERS, including how it is intended to be used, what information is appropriate to include and why, and how to access and allow others to access their record. In emergency situations, when a youth is unable to grant permission to a provider to view a record (e.g., if the youth is unconscious), the caseworker will be able to override the password protection and view portions of the record. The program's intention is to protect the privacy of the youth and empower them with control over their own information.

Scoping the Effort Appropriately

Many localities want to collect and share a broad amount of information among health care providers, behavioral and mental health professionals, caseworkers, educational specialists, juvenile justice officials, and others involved in the care of a child in foster care. However, multiple concerns have arisen,

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[xiii] Public Law 104-191 Sections 261-264; 45 CFR Part 160 and Part 164, subparts A and E.

[xiv] 20 U.S.C. Section 1232g; 34 CFR Part 99.

including the complexity of resolving important design and implementation decisions across actors, heightened privacy concerns, difficulties in coordinating and connecting agencies, challenges in maintaining the system over time, and the practicalities of training so many diverse participants at once. While the scope of information collected and the number and types of participants in the ERSs profiled in this brief vary, most localities have opted for a narrow initial approach with the intention of broadening the scope of information and actors over time. The systems have been designed with this goal in mind (see Table 1 for details).

Strategies for Helping More Children in Foster Care Benefit from ERSs

The high burden of illness borne by children in foster care, their serious unmet care needs, and the disproportionate share of Medicaid spending on their behalf provide compelling reasons for continued state and local experimentation with deploying ERSs to support better outcomes. The experience from early efforts provides invaluable lessons and suggests strategies that leaders for children at the local, state, and federal levels can pursue in moving forward.

Local Experimentation and Evaluation

Early evidence from localities on the leading edge of these efforts indicates that the promised benefits of ERSs for the foster care population can be realized. Further experimentation and evaluation in at least the following ways would build on this success:

- *Expand existing efforts.* The efforts profiled in this brief are in their early stages. Most began with a fairly narrowly tailored focus, designed as a platform for further expansion. As they move forward, the scope of information and the functionality included in the systems can be broadened to form more robust records and enable improved service delivery. In addition, the reach of these systems can be expanded beyond the health sector to include the education, social welfare, and/or juvenile justice sectors to coordinate services across all programs that serve children in foster care. Finally, once these ERS systems have been fully developed and implemented, they can be adapted and deployed to address the needs of other underserved populations.
- *Pursue efforts in additional localities.* Compelling health care needs and potential for cost efficiencies exist for foster care populations in every community. As the technology tools developed in early ERS efforts continue to be refined, those lessons learned can be applied in additional communities.
- *Build the evidence base.* More research is needed to determine the effectiveness of these efforts and to identify key factors in maximizing returns for children in foster care and the systems that serve them. This requires building resources for evaluation into these efforts as they move forward and sharing the results with policy leaders and program planners.

State and National Leadership

State and federal leaders can improve outcomes for children in foster care, and realize cost efficiencies, by supporting the development and deployment of Electronic Record Systems. Such support could include at least the following elements:

- *Make a strong case for investment.* By making a strong case for investing in ERSs to help improve outcomes and decrease costs for children in foster care, state and national leaders can help to overcome the resistance to change that often arises in technology efforts, such as institutional and programmatic barriers to collaboration and use of new technologies.
- *Engage stakeholders.* By engaging key stakeholders, state and national leaders can both promote the development of ERS solutions and ensure their success. Foundations and corporations have provided, and can continue to provide, leadership and funding for states and communities to develop ERS solutions. Other key stakeholders—including service providers, advocates, technology experts, and private sector innovators—can also assist in setting the policy goals and

determining the scope of information-sharing and responsibilities.

- *Secure funding.* Funding is required to develop, implement, maintain, and evaluate further local experiments, as described above. Existing initiatives have already identified potential funding sources that could be used as models for additional efforts. However, leadership is required to enhance available funding to stimulate such experimentation and expand the reach of these solutions to more children.

  For example, leaders at the national level could call for reauthorization of the Medicaid Transformation Grants. Medicaid Transformation Grants fund the adoption of innovative methods to improve effectiveness and efficiency in providing medical assistance under Medicaid and have been an important source of funds for technology innovation. However, all grant funds have been obligated. Reauthorizing the grants or creating new grants with similar goals and flexibility would promote further ERS development. Providing an enhanced Medicaid match for the use of coordinated, linked data to serve the foster care population (which currently would receive a standard administrative match of 50 percent) would also promote ERS efforts. Additional funding options may be available at the state level or through private foundations.

- *Address privacy concerns*. As discussed above, successful ERS efforts require careful attention to privacy concerns. Policies and practices should be adopted that optimize the potential benefits of sharing information about children in foster care between welfare agencies, service providers, and other entities while guarding against the risks of harm due to potential misuse of this sensitive information.

Moving Forward

Rarely has there been the emergence of a technology tool that is so well-suited to address such serious needs among our most vulnerable children. Rarely, too, has there been such an ideal window when a new administration and new Congresss can seize this opportunity and provide the leadership and incentives to states that are interested in these cost-saving, forward-looking strategies. The examples in this report provide leaders for children with both the larger vision and some clear direction to develop and implement ERSs to improve health outcomes for children in foster care. As states and the federal government give long overdue attention to strengthening service delivery for children in foster care, now is the time to focus attention on ICT solutions for the population of children in foster care. Children and taxpayers alike will benefit.

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About The Children's Partnership

The Children's Partnership (TCP) is a national, nonprofit organization working 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. The Children's Partnership focuses particular attention on the goals of securing health coverage for uninsured children and ensuring that the opportunities and benefits of digital technology reach all children and families. TCP's newest program, *Defining and Promoting an E-Health Agenda,* aims to harness Information & Communications Technology to improve the health of America's children. For more than a decade, The Children's Partnership has advanced its goals by combining national research with state-based activities that translate analysis into local action.

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End Notes

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