Executive Summary

The full report Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems is published as part of TCP’s E-Health Program and is available at www.childrenspartnership.org/reports/fostercare.

Approximately 800,000 U.S. children spend time in foster care each year. These children have greater health care needs than other children and account for a disproportionate share of public spending on children’s health care. Nevertheless, children in foster care experience serious unmet health care needs. This is due, in part, to placement instability combined with limited coordination and information-sharing between service providers. Electronic Record Systems (ERSs) are a powerful tool to aid in collecting, storing, sharing, and analyzing health information. Early evidence from a small number of pioneering communities across the nation using ERSs for children in foster care suggests ERSs can result in significant improvements in health care delivery and health outcomes. However, to date, very little of the significant public and private sector attention to health information technology has focused on meeting the needs of children in foster care.

Lives at Stake

In October 2002 a four-month-old girl was placed in a short-term housing facility for children moving into foster care. The infant had a history of reflux—severe spitting up. Doctors at the facility recommended giving her small, frequent feedings and keeping her upright for 20 minutes after eating. Eight days later, the baby was transferred to an experienced foster parent. The first day in her new home, shortly after being put down for a nap, she was found facedown and still. When picked up, she spewed vomit. The baby was immediately rushed to the hospital, where she was pronounced dead. It is still unclear whether the child died due to choking from a reflux episode, or sudden infant death syndrome. The foster parent says that no one told her the child had reflux or special feeding needs. The facility counters that the information was provided.

Concerns about inadequate information-sharing, and the potentially harmful outcomes that can result, arise frequently in the effort to meet the needs of children in foster care. An electronic record system that includes basic health information about a child living in foster care, and is accessible to her caregivers, can improve health outcomes and save lives.
In 2009, President Obama and a new Congress are forging ahead on important policies regarding children’s health care and health information technology. These efforts include the reauthorization of the Child Abuse Prevention and Treatment Act, which provides grants to states to improve their child protection systems; implementation of the Fostering Connections to Success and Increasing Adoptions Act of 2008, which requires health care coordination for children in foster care; and the promotion of health information technology legislation and comprehensive health care reform. By focusing on the use of ERSs to improve outcomes for children in foster care, policy leaders can more effectively meet the needs of a particularly vulnerable population, make more efficient use of limited taxpayer dollars, and incubate scalable health information technology solutions in a manageably-sized, high-needs population.

### Serious Unmet Health Care Needs Due to Lack of Information Management

Up to eighty percent (80%) of children in foster care have chronic conditions and/or behavioral, emotional, and developmental concerns. That rate is more than four times the rate (13.9%) of all children in the U.S. population with special health care needs.¹,² Consistent with their health needs, children in foster care account for a disproportionate share of health care spending. Virtually all children in foster care are eligible for Medicaid. Medicaid spending in the most recent year for which data are available was more than three times higher for children in foster care than for other children, and totaled $3.8 billion.³ Yet, the health needs of children in foster care often go unmet. In its review of all states’ child welfare systems, the U.S. Department of Health and Human Services found half of the states failed to provide adequate physical and mental health services in more than 30 percent of the cases reviewed.⁴

Children in foster care receive inadequate health care due, in part, to placement instability combined with limited coordination and information-sharing between service providers. On average, children placed in foster care experience one to two changes in foster homes per year.⁵ Placement changes are usually accompanied by changes in physicians and other health care providers, resulting in incomplete health information that is spread across many different sites. In turn, children in foster care frequently receive incomplete and/or duplicate immunizations and lack proper ongoing primary care, including regular assessments of their healthy development and emotional status, along with needed treatment.

An ERS can be a powerful tool to more effectively collect, store, share, and analyze health information. As a result, ERSs can improve the health of children in foster care and more efficiently use the dollars spent to meet their needs.

### Promising ERS Efforts Help Manage Information and Meet Health Care Needs

**Improving Health Outcomes for Children in Foster Care:** The Role of Electronic Record Systems, highlights six promising ERS efforts: statewide initiatives in Texas, Tennessee, Kansas, and Arizona; and local initiatives in Milwaukee and Sacramento. The ERSs enable a variety of health care data—such as identification of providers, medical service and pharmacy claims, and diagnoses—to be collected, stored, and accessed electronically by the child’s caregivers, which include health care providers and caseworkers. This information can also be transferred immediately to new care providers when a child changes placements. Most ERSs currently focus primarily on health information. However, leaders of these efforts recognize the benefits that could come from broadening the information management to include child welfare agencies, schools, the courts, nonmedical service providers, and other caregivers, provided that appropriate privacy safeguards are built in.

The ERSs have generally been designed with the intent of allowing greater scope and functionality over time. Early findings indicate that the information management enabled by ERSs results in improved preventive care, decreased hospital stays, improved clinical conditions, and decreased cost of care. For example, in Milwaukee, the number of youth in residential programs has declined from 364 to 140 per day, psychiatric hospitalizations have declined by 80 percent, and the cost of care per child dropped from $5,000 per month to less than $3,300.⁶ Children in foster care also experienced a variety of improvements in clinical conditions.⁷ Program officials attribute these improvements to the ability to provide an array of coordinated and individualized services—facilitated by their ERS—to those they serve.⁸ Initial anecdotal evidence from other localities indicates positive results in preventive care, emergency care, psychiatric care, and cost savings as a result of ERSs.⁹

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¹ The Maternal and Child Health Bureau defines children with special health care needs as 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.”
An Opportunity to Move Forward: Role of Local, State, and Federal Leaders

As localities have developed ERSs, early lessons have emerged regarding funding, stakeholder involvement, provider participation, privacy concerns, and system scope. Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems highlights these lessons, and offers recommendations about how to promote promising approaches so that all children in foster care can benefit.

Local leaders can move forward by expanding the focus and functionality of existing ERS efforts, and pursuing efforts in additional locations, to reach more children in foster care more effectively. Further research and evaluation of these efforts would help guide further development and deployment.

Strong state leadership can be critical to the successful development and deployment of ERSs. For example, a clear articulation of the need for and benefits of this investment can help overcome the resistance to change that often arises in technology efforts. State leaders can also engage key stakeholders—including foundations, corporations, and private sector innovators—to fund and help promote the development of ERSs.

At the federal level, in addition to making a case for investment and enlisting stakeholders, policy leaders can secure funding and provide other incentives and assistance to support ERS efforts. More specifically, grants or an enhanced Medicaid matching rate could be directed toward the development and use of ERSs.

Careful attention to privacy concerns is essential in all ERS efforts, especially for children, whether at the local, state, or federal levels.

Conclusion

Rarely has there been a technology tool so well-suited to address such serious needs among particularly vulnerable children. It is an ideal time for a new administration and new Congress to seize this opportunity and provide the leadership and incentives to support states and localities that are interested in efficient, forward-looking strategies. Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems provides leaders for children with a vision and concrete ideas for turning these opportunities into results for children in foster care.
E-Health Resources:

Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems (2008) [http://www.childrenspartnership.org/reports/fostercare]


Meeting the Health Care Needs of California’s Children: The Role of Telemedicine, 2nd Ed. (2008) [http://www.childrenspartnership.org/reports/telemedicine]

Meeting the Needs of California’s Children in Schools and Child Care: Telemedicine Can Help (2007) [http://www.childrenspartnership.org/schoolstelemedicine]


Digital Opportunity Research and Resources:

“Digital Opportunity for America’s Youth: State Fact Sheets” (March 2008)

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

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

Since 1993, The Children’s Partnership, a national nonprofit child advocacy organization, has worked to ensure that all children—especially those at risk of being left behind—have the opportunity 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.

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