



Electronic Information Exchange: Elements that Matter for Children in Foster Care

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Summary

Electronic information exchange has the potential to improve care coordination for children, particularly those who have complex health and social needs such as children in foster care. This primer lays out the case for investing in systems that enable such exchange, reviews existing efforts underway in states and communities, identifies specific elements that serve this population most effectively, and discusses issues that need to be addressed and steps that can be taken to make the most of this opportunity.

Introduction

Young people in foster care have greater, more complex health care needs than other children and account for a disproportionate share of public health spending. Yet, despite this level of spending, most children in foster care receive less than the recommended care. This inadequate care is due, in part, to a lack of coordination across health, education, and other caregivers for children in foster care, who move often between families, placements, and schools.

The careful use of cross-agency and cross-sector electronic information exchange has the potential to transform a fractured system by enabling real-time coordination between the multiple health care and other caretakers of children in foster care. This report will focus on the benefits of electronic health records, which can connect information across a multidisciplinary team of caregivers to coordinate care, and personal health records, which place control over health information and documents in the hands of the consumer. Both must be supported by sophisticated information technology (IT) systems on the back-end. While these tools are generally designed to include only health-related information, our vision would extend the record for children and youth in foster care beyond the health silo to include other important information that assists a caregiver in meeting a child's needs, such as education and dependency court information.

This primer will help advocates and other stakeholders understand:

- How electronic information sharing can lead to better health outcomes for foster youth, improve their lives, and potentially save dollars at the same time;

- The benefits of using advances made possible through technology to create an electronic record of care for these children; and
- Some strategies for making this happen.

The Unique Needs of Children and Youth in Foster Care

Children in foster care are vulnerable in many ways and experience a substantially higher prevalence of physical, developmental, and mental health conditions and poor outcomes.¹ Adding to these challenges, they often move around from home to placement, and placement to placement. In these transitions, their care and life experiences can easily become fragmented, exacerbating and sometimes cause physical and mental health issues.² Children in foster care are three to six times more likely than those in the general population to have significant psychological or behavioral problems.³ They are also more likely to suffer from a range of acute and chronic physical health problems.⁴ And, significant numbers experience frequent upper respiratory infections, dermatologic disorders, dental caries, and malnutrition.⁵

Part of the higher prevalence of mental and behavioral health conditions in foster children can be attributed to trauma associated with dysfunctional family settings, acute reactions to the trauma of being placed in foster care, and being separated from their families. For many of these children, this trauma occurs at an early age. Of the children who enter foster care for the first time, roughly 55 percent are age 5 or younger⁶ and one-quarter of them have three or more chronic conditions.⁷ Additionally, 80 percent of foster children assessed by a clinician had at least one psychiatric diagnosis,⁸ with the most common diagnoses being disruptive behavior disorders (41 percent), affective disorders (32 percent), anxiety disorders (20 percent), adjustment disorders (13 percent), and learning disorders (12 percent).⁹ As a result, these children require more specialized services and account for a disproportionate share of state expenditures. Adding to the mix of challenges that foster youth face is the exponentially higher rate at which they are prescribed psychotropic medicines. Studies show that children in foster care are prescribed psychotropic drugs at rates 2.7 to 4.5 times higher than nonfoster children in Medicaid.¹⁰

Academically, children in foster care perform at a notably lower level than their nonfoster care peers and require more special education services. Children and youth in foster care are 2.5 to 3.5 times more likely to receive special education services than their nonfoster peers.¹¹ These children have poor test scores, poor school attendance, low high school completion rates, and low levels of qualification for and participation in post-secondary education.¹² Part of the reason for their lower performance is the greater mobility in their lives.¹³ These moves can result in the loss of school records and other important documents that then delays enrollment in the new school, causing gaps in the learning process. For example, children placed in foster care in California average two to three changes in foster homes each year and, therefore, frequently change schools and even school districts. Understandably, children who change schools frequently make less academic progress than their peers.¹⁴

The effects of this instability in home and services experienced by foster children during childhood continue as they age and results in disproportionate use of state funds and services as they enter adulthood.

Compounding the challenges they face, many youth aging out of the foster care system are on their own without the support most young people have from family, and they often lose contact with available services and supports as well as important records.¹⁵ These youth usually do not have families that provide financial support as they transition into adulthood, pursue a college degree, or attend vocational school. Some ultimately return to the care of the state as adults, either through the public welfare, criminal justice, or other systems.¹⁶ During their early adult years, they are much more likely than their peers to forego higher education, describe their general health as fair or poor, or become homeless. As many as 40 percent of the homeless youth population are foster care youth and, by age 24, 37 percent of foster care alumni have experienced homelessness or “couch surfed.”¹⁷

The Promise of Electronic Information Exchange for This Vulnerable Population

In general, care coordination has been shown to support the healthy development of children through improved screening, referrals, and follow-up while also maximizing efficiencies in care delivery.¹⁸ As it does for children broadly, care coordination has been shown to improve care for children in foster care¹⁹ and is even more important and challenging because of their disproportionately high level of health and behavioral health needs and their experience with frequent disruption through changes of caregiver and living situation.²⁰

Currently, health and education records for foster children are captured in a Health and Education Passport. However, this record generally is shared only in paper form. As such, it is a challenge to ensure that it contains the most current information and is available when care providers need it to help make informed care decisions.²¹ As has been noted by the Bipartisan Policy Center, “[w]ithout robust health information exchange it will be difficult, if not impossible, to develop and spread several common attributes of high performance [health care], including those related to care coordination, clinical decision support, shared decision-making among the patient and the care team, and measurement of outcomes to support accountability and improvement.”²²

A growing body of evidence indicates that it is the use of robust *electronic* information exchange that holds the greatest promise for achieving such high performance, including care coordination. When electronic information exchange is used to enable coordination, it has had the following positive impact for broader populations: improved quality,²³ improved preventive health,²⁴ reduced laboratory testing,²⁵ and reduced prescription errors,²⁶ among other successes.²⁷ When electronic care coordination is applied to uniquely underserved populations that experience fragmented care and have disproportionately high levels of chronic conditions that require added attention, such as children and youth in foster care, it is arguable that the potential for positive outcomes is even more pronounced than for the population as a whole.

One Child’s Experience

A Texas grandmother had responsibility for her granddaughter who had been prescribed an ADHD medication, was in special education classes, was very depressed, and was sometimes bullied at school. This grandmother said that despite the medication, the girl couldn’t focus and was not listening to her. Her electronic Health Passport records showed visits to the emergency room for ear problems. So, the health plan referred the grandmother to a specialist to check out the child’s hearing, where they learned that she was 75 percent deaf in both ears due to trauma caused by abuse. Until this point, the grandmother had not considered that her granddaughter could be suffering from a hearing impairment. According to the grandmother, once fitted for hearing aides, the girl exclaimed, “Grandma, I didn’t know that when you walk, you can hear footsteps!” Able to hear, the girl’s focus in school improved, she was taken off the ADHD medication, and she moved into a regular classroom.

Models from the Field: Electronic Information Exchange Being Used to Improve Care Coordination and Outcomes for Children in Foster Care

While the use of electronic information exchange to facilitate care coordination for children and youth in foster care is in its infancy, a smattering of such projects can be found. Early results from these efforts are already demonstrating their value.

First, positive results have been demonstrated by a number of projects specifically aimed at addressing the need to share *health information* across the silos of health care providers to coordinate health and mental health care for children and youth in foster care.

Wraparound Milwaukee: Most mature of these projects is Wraparound Milwaukee, a unique managed care program serving over 1,000 children and adolescents up to age 24 with serious emotional and mental health needs and their families. The majority of children and youth served are referred through child welfare and juvenile justice, with the remainder being families who self-refer or are referred through the school system. Wraparound Milwaukee has a network of child psychiatrists that maintain regular contact with the primary care provider, particularly those whose care is coordinated by federally qualified health centers. The program uses electronic records to integrate medical and behavioral health information, including that related to medications use.

Since Wraparound was initiated, it has seen:

- A reduction in residential treatment for child welfare and juvenile justice youth from 375 to under 80 youth per day;
- A reduction in psychiatric inpatient bed days from 5,000 to 500 for enrolled youth; and
- A drop in juvenile placements from Milwaukee County in state corrections from over 300 to 120 youth, resulting in the governor closing two of the three juvenile correctional facilities.

Meanwhile, recidivism rates for delinquent youth have fallen below 15 percent and child permanency has been around 85 percent. Clinical scores on the Child Behavior Checklist continue to show improved functioning at home, in school, and in the community for enrolled youth. In the future, Wraparound Milwaukee will be working with the state's new six-county medical home pilot for children in foster care.²⁸

Texas STAR Health Program: The most extensive example of an Internet-based health record being used for this particularly vulnerable population of children is Texas's Health Passport for the STAR Health Program. In Texas, a single managed care organization, Superior Health Plan, serves about 30,000 children and youth in foster care. The program administers the electronic Health Passport, which is largely populated by Medicaid claims and pharmacy data, with more limited input by providers. The effort was launched in 2008²⁹ and since that time the program has realized the following results for children in foster care:

- The portion of well-child visits completed within 90 days has risen from 42 percent to 75 percent;
- The number of psychiatric admissions has decreased 79 percent and the length of psychiatric inpatient stays has decreased 40 percent; and
- The use of psychotropic medication has decreased by 20 percent overall, class polypharmacy has dropped by 30 percent, and children taking five or more medications concurrently has been reduced by 43 percent.

Furthermore, extensive anecdotal evidence attests to the benefits of this record.³⁰

HealthWorks of Illinois: The state of Illinois has created an electronic health summary for children in foster care called the Health Passport, which supports a network of providers who coordinate and provide care for the population as part of a dedicated health system for children in foster care called HealthWorks of Illinois. The Health Passport is automatically populated by Medicaid claims data, which gives providers access to

critical information about the child upon their entering care since approximately 70 percent of children entering foster care were previously served by Medicaid.³¹

UPMC for You: Allegheny County, Pennsylvania has deployed a targeted effort to assess and meet the medical and behavioral health needs of children entering foster care. The program, operated by UPMC for You, Inc., uses an electronic health record to keep child welfare workers in the loop and facilitate their ability to coordinate health care. The results of the effort are clear: the coordination, facilitated through the use of the record, led to a 48 percent increase in children receiving their annual well-child visit and a 25 percent increase in those receiving the recommended annual dental visit.³²

Importantly, steps are also being taken to go *beyond health information* in creating an integrated electronic record for children in foster care.

Foster Youth Student Information System: San Diego County, California has developed the secure, web-based Foster Youth Student Information System, which regularly receives information directly from schools, Child Welfare Services, courts, and probation departments, as well as information from the Health and Education Passport. This information is made available, in a timely manner, to authorized users including school staff, social workers, and supervising adults who are legally responsible for promoting the educational success of the child. Having access to this timely data allows caregivers to respond quickly to these children's needs.³³

Follow My Child: In Florida's Dade and Monroe Counties, a prototype comprehensive electronic care record for children and youth is being tested among participating foster families that receive services through the lead agency for community-based care, Our Kids of Miami-Dade and Monroe, Inc.. Relevant information from a number of entities (local school system, juvenile justice, court administrator, and state child welfare, Medicaid, and education agencies) flows into a data warehouse, where it is merged and used to populate the record called "Follow My Child." This enhanced electronic passport is available to case workers and foster parents. As this prototype is being rolled out, participating foster parents are accessing the record frequently. The effort has been funded in a large part through cost savings being realized through the impact of better care coordination and improved family retention efforts, which is then poured into the technology development.³⁴

Guideposts: Making Sure these Exchange Efforts Achieve their Goal

The Children's Partnership has identified four guideposts to govern any electronic information exchange effort for children:

- To *connect* children and youth to doctors, caregivers, and services while ensuring their care is tailored to meet their individual needs;
- To *inform* families with individualized tools that help them understand their children's health needs, assess their options, and make knowledgeable choices;
- To *empower* children and youth, supported by their parents and guardians, to actively and effectively participate in their own health care; and
- To *protect* children and youth through appropriate privacy and security policies and through the more effective use of available information.³⁵

These guideposts expand upon the goals the Institute of Medicine identifies for the use of electronic records systems: improved safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.³⁶ Of course,

for health IT to improve outcomes for children and youth, it must be developed to engage them and their caregivers and address their unique needs, while also being meaningfully used by providers.

As detailed above, children and youth in foster care have a unique set of challenges that can be greatly alleviated and addressed through the use of electronic information exchange. Not only can this particularly vulnerable population benefit from the care coordination that information exchange facilitates, as demonstrated through some of the unique efforts underway, these young people can also benefit from the access that electronic records provide to their own critical information and documents as they move through childhood and into adulthood. In the absence of a stable home and a helping hand from parents, the availability of such support can be crucial to foster youth establishing self-sufficiency and being able to manage their complex lives.

To ensure that electronic information exchange improves outcomes for children and youth in foster care and satisfies the recommended guideposts above, systems and resulting records must include the following key design elements:

1. Information exchange must include more than just health information and should connect the array of providers and caregivers that are part of these children's lives (schools, caseworkers, and foster parents), breaking down the silos that currently impede coordination.
2. The power of available technology should be leveraged to the fullest. For example, back-end systems should support robust, bidirectional information exchange and automatically populate appropriate information into a record that follows the child through a continuum of care and over time.
3. Information must be exchanged securely, in a manner that protects privacy and confidentiality, and the tools must support the specific designation of individuals authorized to see specified portions of the record (i.e. granular data segmentation and role-based access), among other protections.
4. Electronic records generated for this population must be able to extract and summarize important information, with history, to tell the story of these children's lives in a manner that helps articulate their needs in the absence of a loving parent who does so.
5. Electronic records should be designed with consumer-facing features, such as patient portals and pre-visit questionnaires, as well as links to available tools that can feed critical information into the record, such as remote monitoring devices.

Steps to Make the Most of this Opportunity

The Role for Governments

Provide Strong Leadership: Because electronic information exchange involves significant up-front planning and investment, it cannot proceed without strong leadership at all levels of government as well as in the philanthropic community. The current paper-based Health and Education Passport was created through federal law in 1989 and was then implemented in states.³⁷ Now, to take that model into electronic form and improve upon it, a similar push should occur at all levels of government, again driven by a national directive.

Create the Conditions for Interoperability: Moving forward requires the development of common standards and protocols – accepted rules and formats – that make it possible to share information across systems. Currently, numerous public/private efforts are underway to develop standards and protocols, often supported by federal agencies and funds, many of which can be leveraged for purposes of electronic

information exchange for vulnerable children. Developing such interoperability is a federal priority and recent efforts, such as the Direct Project enabling secure email messaging, have moved the ball forward.³⁸ Such efforts must continue and be promoted at all levels of government.

Provide Funding That Promotes Coordination: A significant challenge to any systems change is the cost, which is complicated further when a system is being built to cross sectors. And yet, it is that ability to exchange information across jurisdictional boundaries that adds such significant value for children and youth in foster care. Some important steps have been taken in this direction, but more can be done.

- The greatest driver of public technology development is the availability of funding. A number of important federal funding streams, such as for Medicaid Management Information Systems and health IT through the American Recovery and Reinvestment Act, are demanding interoperability in return for enhanced funds.³⁹ Other important gains are being promoted through targeted grant funding, such as the Administration for Children & Families' recent Interoperability Initiative.⁴⁰ Ongoing and targeted federal funding should continue and nudge systems developments to overcome the entrenched boundaries between agencies. States and localities should take advantage of these opportunities.
- The federal government has sent a clear signal that the redesign of child welfare information systems (SACWIS) must facilitate linkages with other agencies. However, final rules regarding SACWIS systems have not been issued, leaving states uncertain as to what is expected of them.⁴¹
- It is important that ongoing funding be made available for projects that benefit multiple agencies and that any process required for allocating the costs not be burdensome. A significant step was taken in this direction through the recent time-limited modification of federal cost allocation rules to promote systems development that allows integration across health and human services programs in the context of health reform implementation.⁴² Such modifications should be made permanent and broadly applicable.
- Beyond funds to support the development of technology, ongoing funding must be available to maintain the systems and support the work of coordination at the state, local, and provider levels. This direction is being taken through support for medical homes and accountable care organizations. However, more can be done to ensure that providers, especially health providers, are compensated for the time it takes to make sure that children in foster care get the services they need.

Take Measures to Meet Privacy Expectations: Efforts to coordinate care for these and other populations of children encounter a significant challenge in the web of confusing, and sometimes conflicting, privacy and confidentiality laws. These laws get more complex when applied to adolescents generally, because of their consent rights, and to children in foster care, because of the volume of laws governing the array of providers that serve them. Policymakers at every level – federal, state, local, and agency – need to review and clarify what laws apply, address inconsistencies that inhibit appropriate information exchange, and provide clear direction that promotes appropriate sharing and helps local agencies and providers walk through the decision-making process. Furthermore, the development of common standards and protocols for the technology could greatly advance this cause. Appropriately designed electronic records can protect privacy much more effectively than a binder full of papers and documents that is passed back and forth as a child moves through the foster care system.

The Role for State Advocates

Help Bridge Governance Silos: Federal, state, and local governments all have a role to play in making information exchange happen. State advocates can help connect the dots and help overcome the natural tendency to work in silos by bringing together stakeholders from all levels of government and multiple stakeholder agencies. Convening groups around a common issue or goal, articulating the benefits of

information exchange in creating the desired outcomes, and insisting on coordination as the new norm can often best be done by advocates who are not constrained by existing agency cultural norms.

Educate Policymakers: To make it part of their agenda, policy leaders must understand the value of electronic information exchange for children in foster care. State advocates can put a face on this issue with stories about the tangible impact it has on real children. They can make it clear just how much more efficient and effective an enhanced electronic Health and Education Passport would be than the current paper version. By translating these real stories into a policy agenda, advocates can build support among federal, state, and local leaders who can champion the cause. In particular, combining a strong advocacy agenda for children with a basic understanding of the role of electronic information exchange brings a new and important perspective to policy discussions and decision-making.

Identify Funding Opportunities: As discussed above, numerous federal funding streams can be leveraged for this purpose. Advocates can help get an effort off the ground by identifying funding opportunities and promoting the availability of continuing funds in the future. In addition, advocates can enlist philanthropic organizations to support the effort by building the evidence base, setting the direction, and supporting seed innovations. One possible avenue for making the case for funding is to identify specific high-cost children or programs in which cost savings can reasonably be identified and demonstrated over a relatively short timeframe.

Explore IT Opportunities: States and localities are working on numerous IT projects, some of which might be leveraged to facilitate electronic exchange for children in foster care. For instance, SACWIS redesign, health information exchange development, and horizontal integration as part of health reform can be leveraged to build the infrastructure required for an electronic care record for foster children. Advocates can help connect these efforts. The key is to ensure that the various IT initiatives build in the capacity to connect with one another, so that even if different vendors are used and IT efforts are on different implementation tracks, interoperability of data systems relevant to children in foster care is assured.

Support the Development of Data-Sharing Agreements: To achieve robust electronic information exchange, significant work is required at state and local levels to figure out the terms of information sharing, develop agreements between sharing entities, and establish the vision for how information will flow, among other foundational issues. Advocates have an important role to play in these conversations as representatives of the foster parents' or youth's concerns and can help keep the focus on the benefit of appropriate data exchange, rather than on the issue of data ownership.

Engage Key Stakeholders: Any effort to develop an IT solution to address the unique needs of children and youth in foster care must incorporate their voice into the planning and development of the tool. Advocates can help bring foster youth and foster parents to the table. A diverse and engaged stakeholder community educated on key issues can effectively steer IT efforts to consider and accommodate the unique needs of children in foster care. Without this involvement, these special needs may easily be overlooked.

Conduct Further Study and Evaluation: While it is clear that there is great promise in the use of electronic information exchange to coordinate care for this high-need population, there is still a need to identify what works best and document real impacts for real kids. Advocates can use the lessons learned in the field to help policymakers craft engaging, effective information exchange efforts that transform care for this population and can engage philanthropic institutions to support evaluation, so that there is a strong evidence base as to what works best. Advocates should ask programs to track costs and identify savings, in addition to programmatic and outcome improvement, as this data could make a compelling case for electronic information exchange down the road.

Conclusion

Children and youth in foster care experience immense challenges in their lives. To minimize the negative impacts their difficult life experiences can often have, the many providers and caregivers involved in their care must work in collaboration and foster parents and youth themselves must be more engaged in the process. Electronic information exchange can provide a tremendous boost to such efforts, using modern technology tools to facilitate the very human act of providing care for children and youth in foster care and supporting a healthy transition into independence as adults. States and communities are beginning to take this step, but they need further support and assistance to do so from all levels of government as well as from philanthropists, advocates, and the private sector.



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