



Improving Care Coordination for California's Children and Youth in Foster Care Using Integrated Personal Health Records:

A Strategic Plan of Action

Introduction

In 2011, the State of California established an “audacious goal” to provide an electronic personal health record (PHR) to every child and youth in foster care that would enable information sharing and linkages across data systems, providers, and agencies that serve them. In 2012, the California Health eQuality (CheQ) program awarded a small planning grant to The Children’s Partnership to pull together stakeholders, review the research and current initiatives, and develop a Strategic Plan to help California policymakers, funders, public officials, and advocates chart a path forward to implement this “audacious goal.”

This report highlights the Strategic Plan and the progress made since it was completed in 2013. Consistent with the Plan’s recommendations, a variety of public and private partners, including The Children’s Partnership, have been implementing two county demonstration projects to test two models for providing an electronic personal health record to children and youth in foster care, measure the impact of the PHR on their lives, and generate lessons learned for scaling the model to other counties and/or statewide. Additionally, The Children’s Partnership is convening a variety of stakeholders to brainstorm ideas for incorporating a link to a PHR into California’s new Child Welfare Services data system (CWS/NS), now under design. In the near future, The Children’s Partnership will initiate a learning community of counties currently engaged in electronic information exchange to share lessons learned and best practices for implementing a PHR for children and youth in foster care.

Visit our [website](#) for more information on [partners and stakeholders](#) consulted in developing the [Strategic Plan](#), the planning process, or to get the current status of these [demonstration projects](#).

Why This Matters

There are more than 60,000 children¹ in foster care in California, including over 13,000 transition age youth.² As is the case nationally, these children tend to have greater, more complex health care needs than other children and account for a disproportionate share of Medi-Cal expenditures. Despite this level of spending, most children in foster care receive less health care than what’s recommended. The lack of adequate care is due, in part, to California’s highly fragmented, decentralized system of programs and services for children in foster care.

As a result, health status and outcomes for these children and youth are worse than for their peers and are well-documented, including the following:

- Children in foster care are more than twice as likely as other children to say they are in “not good” or “poor” health and nearly four times as likely to have a disability.³
- Almost half of children between the ages of 6 and 11 in foster care, and 40% of children between the ages of 12 and 14, have a clinical level of behavioral or emotional problems.⁴
- Girls in foster care are twice as likely to report having had a sexually transmitted infection and two and a half times more likely to have had a child by age 19.⁵

Please see [Electronic Information Exchange: Elements That Matter for Children in Foster Care](#) for more information about the health and well-being challenges facing this vulnerable population.

Improving Outcomes

Evidence from early efforts around the country suggests that electronic information exchange can help providers coordinate care for children and youth in foster care through better information sharing and, thereby, help ensure that appropriate, cost-effective services are delivered. At the same time, consumer-facing electronic records (personal health records and patient portals) have been recognized as an important step to engage consumers and empower them to make better health decisions for their children and themselves. Electronic records can be critical for older foster youth, since they otherwise often lack basic information about their own health history and the health records and life documents that are important as they establish independence. Today, we face an extraordinary opportunity to improve the lives and health status of children and youth in foster care through the innovative use of information technology and electronic records.

The Strategic Plan developed by The Children's Partnership and our [partners](#) aims to make the most of that opportunity by developing such exchange and records in a manner that engages foster parents and youth directly, while also supporting greater coordination of care among professional caregiving teams.

Please see [Electronic Information Exchange: Elements That Matter for Children in Foster Care](#) for more information about efforts in the field and the evidence base for this approach, as identified in the [Annotated Bibliography](#) produced by the California Research Bureau for this planning process.

Key Elements for Success

The strategic planning process identified the following major elements for success in any effort to create electronic information exchange and records for the population of children and youth in foster care:

- **Coordinate with Related State and Federal Initiatives.** Disconnected county-level projects cannot support a statewide strategy without involvement and policy support at the state level. Failure to coordinate county-level IT efforts could result in new IT silos and duplicative systems development, which ultimately would result in less effective use of technology to transform service delivery. Instead, when coordinated, state and federal initiatives can undergird county efforts by building the necessary interoperability between data systems and across agencies and caregivers that serve this population, including health providers, caseworkers, schools, and courts, among others. In California, the statewide strategy must be incorporated into the development of the new Child Welfare Services data system (CWS/NS), anticipated to be completed by 2018, and efforts are underway to achieve systems interoperability across the Health and Human Services Agency.
- **Develop Local Champions.** Ultimately, in California, efforts must meet the needs of county child welfare agencies and support their efforts to improve services for children and youth in their charge. As such, county champions are essential, both within child welfare and among other relevant agencies and decisionmaking bodies. In addition, local community partners can help support the project and guide it in the best direction. Once partners are on board, projects should be driven by designated county staff. Strong governance practices will also be required to ensure that the many issues regarding sharing of government-held information and services and the use of technology across agencies are thoughtfully addressed.
- **Develop Interfaces with Other Systems.** In order to develop a robust electronic record that is easy for foster parents and youth to use, it must be

linked with available data systems to ensure that it is automatically populated with data. This would reduce the administrative burden required to keep it up-to-date and position it to function as a node of communication among providers, caregivers, foster parents, and youth.

- **Start with What Is Achievable.** The ultimate vision is to create a comprehensive, integrated record of care for these children and youth. However, to ensure the greatest likelihood of success, projects can start by providing foster parents and youth with an electronic Health & Education Passport in electronic rather than paper form. At a later stage, these records can be expanded to include more extensive health, education, and other data (such as probation) as standards that make such data more easily exchanged are developed and data agreements are reached. Importantly, the PHR format allows foster parents and youth to add important information and documents to the record to build up its content as they choose.
- **Address Privacy Challenges.** Given how beneficial information sharing can be for children and youth in foster care, it is not acceptable to allow privacy challenges to stall efforts that can benefit so many. Rather, projects should take a careful approach to selecting data and deciding who can see it, attempt to get appropriate authorizations up front, and leverage technology to provide data segmentation and privacy preference management capabilities. As necessary, it may be important to clarify the rules surrounding information sharing to promote the best interests of these children and youth. Transparency and user control can help promote trust, which will then promote use of these tools to fullest effect.

Visit our [website](#) for [resources](#) that can help tackle this challenge.

- **Maximize Usability.** Ultimately, as with all electronic records, if the PHR is not meaningfully used, it will not transform care. To ensure greatest use, county efforts must get stakeholder and user input into the design of the PHR and provide ongoing user training and support. Similarly, the record must easily be incorporated into caregivers' work flow and their communications with foster families. The goal should be to incorporate the review and updating of data in the PHR into the standard policies and procedures for child welfare staff, who can then support its use by foster parents, older foster youth, and caregivers.

Visit our [website](#) for [key features and functions](#) identified through this strategic planning process.

- **Identify Sustainable Funding.** Developing sustainable funding requires a creative blend of public and private funds. But, ultimately, counties should recognize the value of these tools to their program and budgets as well as their responsibility to these children and youth and incorporate the development and maintenance of such record systems into their child welfare budgets. In fact, this investment could lead to a cost savings and help counties meet obligations under state law through the Fostering Connections Act (AB 12), among other mandates.

A Plan of Action

The strategic planning process included the development of a Plan of Action to implement the "audacious goal" in two phases: (1) demonstration projects to establish best practices and further develop the key elements for success; and (2) statewide rollout, coordinated with the implementation of the CWS/NS, after completion of the demonstration projects.

Phase One: Demonstration Projects in Multiple Counties

Phase One of the Plan of Action is the demonstration phase, which is intended to develop an evidence base for what advances care coordination, engages consumers *and* care providers, and improves outcomes for children and youth in foster care. The demonstration phase is moving forward as follows.

1. Demonstration projects have been launched in two counties, Ventura and Sacramento, in pursuit of this Plan of Action. Using different models and vendors, both counties are developing and deploying electronic records of care for some or all of their children and youth in foster care. Reflecting the findings of the strategic planning process, these demonstration projects include the following key elements:

- **Consumer-Facing.** While much can be gained through the use of a simple electronic health record or case management system that enables a caseworker to access more complete records, the use of a consumer-facing tool is the recommended approach. It has greater potential to help foster children in some significant ways, including the opportunity it provides for engaging foster parents and older youth in their own care, for addressing elements of the privacy challenge by placing control with the consumer, and for ensuring that the record can follow the child into adulthood.
- **Linked.** In order to be most user-friendly, consumer-facing electronic records should be linked to available electronic data sources so that information prepopulates some or all of the record. Demonstration projects will work to develop the relationships and interoperability that are required to allow for a linked record.
- **Reflect Community Input.** Consumer-facing tools must be developed with early input—and ongoing feedback—from targeted users to ensure that they meet their unique needs and provide real value for those users. Each demonstration project has engaged key stakeholders to provide early input and will seek ongoing feedback.
- **Provide Training and Support.** To ensure that an electronic record is meaningfully used, its users must understand how and why to do so and must trust the tool. Each demonstration project has plans, or has begun, to provide initial and ongoing training and hands-on assistance to support optimal use of the tool.

For current information about the status of these two demonstration projects, please see our [website](#).

- 2. Demonstration projects are following a 12-to-18-month implementation timeframe.**
- 3. Demonstration projects will benefit from an intercounty learning community,** where counties and project stakeholders can discuss issues, challenges, and solutions and provide input into the development of state policy recommendations. The Children's Partnership will be launching this learning community shortly.
- 4. Demonstration projects will be evaluated through qualitative and quantitative measures,** including user feedback, health status questionnaires, and objective health outcomes data. Efforts will be made to identify which elements of the demonstration projects have the greatest positive impact.

Phase Two: Statewide Rollout

With evidence from Phase One, including lessons learned and recommendations that reflect the on-the-ground experience, the State will be able to move forward most effectively to make an integrated electronic, consumer-facing record available statewide for all children and youth in foster care, as well as potentially reach other vulnerable populations. A statewide strategy should still allow each county to tailor the content and format of the record to best serve its needs, as long as the system allows for interoperability with other county and state data systems, as appropriate. This statewide approach could scale out one or more of the models pursued in Phase One or determine that it is better to leverage another tool or model, including the new Child Welfare Services data system (CWS/NS) that is in development. The Children's Partnership will work with the new information provided from Phase One to raise the visibility of the issue, promote the adoption of recommended policy changes, and develop commitment among stakeholders to a statewide strategy.

Starting Now to Lay the Foundation

While demonstration projects proceed, a number of activities should continue—and should receive greater attention—to help California prepare for Phase Two of this effort. The six action steps that follow can involve all stakeholders, including county and state officials, partners in the demonstration projects, philanthropy leaders, legal experts, and organizations knowledgeable about children's needs.

- 1. Funding.** Private and public funding sources are needed to develop and fully implement the demonstration projects, as well as to extend the model statewide. To leverage available, generous federal funding sources, proposals must demonstrate coordination of efforts to achieve a statewide solution—an element of planning that should be underway now. However, at the same

time, funding options beyond federal sources should be fully explored, including the state, county, and private sectors. Efforts to identify such funding sources must begin now and be ongoing.

- 2. Coordination.** Similarly, coordination of efforts at the federal, state, and county levels is required to improve coordination of care for this vulnerable population. To this end, collaboration is required throughout the process to ensure that county demonstration projects align with and inform the development of the new Child Welfare Services data system (CWS/NS) and the State's interoperability efforts, among other initiatives currently underway.
- 3. Policy Recommendations.** As the implementation experience unfolds, demonstration projects are identifying policy barriers to electronic information exchange. In addition, other channels, such as the Child Welfare Council's Data Linkage and Information Sharing Committee, have identified barriers. Many of these challenges might be relieved through legislative or administrative change. Work should continue to develop responsive language and policy recommendations, which can be further refined in response to lessons learned as the demonstration projects proceed.
- 4. Model Resources.** Efforts to share information across agencies and providers require significant planning and agreement. Work can begin now to develop model memoranda of understanding, standing orders, and privacy notices that meet the needs of project partners and provide appropriate protection to children and youth. In addition, agencies that are likely to be involved in information exchange can begin discussing goals and develop a process for working through these issues as they arise.

5. **Learning Community.** Foster care data sharing projects should be discussing challenges, successful strategies, and lessons learned – even where the data focus of such efforts is different (e.g., health versus education). The Children’s Partnership is launching an intercounty conversation for this purpose. Those interested in participating should contact [Beth Morrow](#), Director of Health IT Initiatives.
6. **Stakeholder Input.** Now is an appropriate time for the State and counties to gather input into what would most improve their ability to serve this population as well as the features and functions that could make a difference to foster parents and older youth. Such input is essential to ensure that the tools are designed to meet the unique needs of children and youth in foster care, while also fitting into the work flow of caregivers and agencies.

Conclusion

While it is important for counties to be the laboratory for how best to improve the way they deliver services, they cannot and should not work in isolation. County efforts are more likely to succeed if they have the support of state and federal financing, policy, and coordination. While county demonstration projects are a vital first step in learning what works best and in helping counties and state policymakers chart a course forward to improve outcomes for children and youth in foster care, broader funding and state-level policy support are needed to fully realize the opportunity.

Endnotes

¹ Barbara Needell et al., CCWIP Reports, California Child Welfare Indicators Project, Center for Social Services Research, University of California at Berkeley, 2014, accessed June 12, 2014, http://cssr.berkeley.edu/ucb_childwelfare/PIT.aspx.

² Ibid.

³ Sharon Vandivere, Rosemary Chalk, and Kristen Anderson Moore, "Children in Foster Homes: How Are They Faring?" *Child Trends Research Brief*, no. 2003-23 (2003): 2.

⁴ Ibid., 4.

⁵ Heather Boonstra Guttmacher. "Teen Pregnancy Among Young Women in Foster Care: A Primer," *Policy Review* 14, no. 2 (2011): 9.

The Children's Partnership (TCP) is a national, nonprofit child advocacy organization with offices in Santa Monica, CA and Washington DC. We focus particular attention on the goals of ensuring that all children have the health care they need and that the opportunities afforded by computing devices and the Internet benefit all children and families. With input from our advisors, we advance our goals by combining national research with community-based pilot programs. We then develop policy and advocacy agendas to take these demonstrated solutions to scale. For more information about our work, visit <http://www.childrenspartnership.org>.