



# Engaging Foster Youth and Foster Parents in Electronic Records Initiatives

## LESSONS LEARNED

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# Introduction

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More than 400,000 children and youth are in foster care in the United States. Most have experienced trauma that will have a lifelong impact on their physical and mental health, educational attainment, and prospects for self-sufficiency and success. Numerous studies have shown that children and youth in foster care have much higher rates of chronic health conditions, developmental delays, learning disorders, and behavioral health issues than non-foster children of similar backgrounds.<sup>1</sup>

Once in foster care, this population of vulnerable minors is likely to experience frequent changes in homes and, as a result, disruptions in health care and gaps in personal records, such as medical records, birth certificates, and school transcripts.<sup>2</sup> Such disruptions contribute to poor health and education outcomes.<sup>3</sup>

Recognizing the potential of electronic record systems to help address the problem of fragmented health care and incomplete health records, The Children's Partnership launched an initiative in 2009 to promote electronic care coordination in foster care through two

county-level pilots developed over five years.\* These county initiatives tested innovative approaches to developing and disseminating electronic record systems for foster youth and foster parents. The projects had two main goals: to support exchange of critical health care-related information among members of the care team (including foster parents) and to provide youth with tools that allow them to manage their own records and lives. In addition to these California pilots, several other forward-looking communities across the country have experimented with “consumer-facing” electronic record initiatives—meaning they connect directly with youth in foster care and/or foster parents (the “consumers” in this dynamic).

This brief catalogs, to our knowledge, all consumer-facing foster care electronic records initiatives, describes lessons learned, and highlights promising strategies and practices to help guide future efforts to promote the direct connection of foster youth and foster parents to critical health and other care-related information.

\*For more information, refer to [childrenspartnership.org/cademonstrationprojects](http://childrenspartnership.org/cademonstrationprojects).

# Background

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Communities around the country are exploring ways to improve services for children and youth in foster care; to integrate data about these vulnerable youth from across sectors and systems (health, mental health, education, child welfare, and others); and to engage foster parents and foster youth more effectively in planning, coordination of care, and decision-making. One approach to achieving these goals is the use of electronic information exchange and related electronic records to knit together the continuum of care and make sure that timely, organized, complete information is available when services are being delivered. Such information can contribute to more appropriate care and reduce the impact of disruptions that children and youth routinely experience in foster care. Some of these initiatives are designed to improve the case management systems used by child welfare staff, others focus on informing and exchanging information with health providers or appropriate school staff, and a few have taken the approach of engaging directly with foster parents and/or foster youth. Other efforts are designed to meet the needs of all these groups. However, while each of these efforts holds the promise to improve the lives and outcomes of children and youth in foster care, more research is needed to better understand how such foster care electronic records initiatives can realize their full potential.

A number of initiatives that engage foster parents<sup>\*</sup> and/or foster youth directly through electronic records hold strong promise for ensuring critical information is in the hands of families in foster care. These “consumer-facing” initiatives, which take a number of forms, are unique in that they can build a network of care that centers on the child. Some collect information through electronic questionnaires from foster parents and/or foster youth to inform care planning; some provide health and education data through an electronic record to foster parents and/or youth such that they can use it to help their care team know what they need; some allow youth to organize, store, and share their own important documents; and others combine some or all of these options. Other variations exist as well. For instance, some link the consumer-facing tool with useful data systems that populate the tool with data, while others rely on the foster parent or youth to input relevant data and documents.

This brief highlights the progress of several electronic consumer-facing initiatives, identifies lessons that can be applied to initiatives going forward, brings in relevant research from broader health information technology efforts to inform future efforts, and provides some important guideposts to ensure that these future efforts have their intended impact.

<sup>\*</sup>In this brief, the term “foster parent” refers to all non-congregate substitute caregivers who take care of a foster child in a family-like setting, which includes foster and kin caregivers as well as other home-based family caregivers.

## Summary Description of the Consumer-Facing Foster Care Electronic Records Initiatives Discussed in this Brief

| Name of Tool                             | Foster Health Link  | FosterEd   | Follow My Child  |
|--|---|--|--|
| <b>Lead Organization(s)</b>              | Ventura County Human Services Agency, Ventura, CA   | National Center for Youth Law, Oakland, CA   | Our Kids of Miami-Dade/Monroe, Inc., Miami, Florida  |
| <b>Description of Tool</b>               | Foster Health Link (FHL) is an electronic, mobile-accessible version of the Health and Education Passport, which was previously in paper format. FHL was developed for use by foster parents. It integrates data from the child welfare and health services data systems and makes it available through an online portal. It also connects users to an online information resource, the Network of Care, which helps them understand the information in the record. | FosterEd uses an electronic communications platform to allow education teams to share information and documents, communicate, set goals, and conduct education planning for children and youth in foster care. The tool allows biological parents, foster parents, and youth to engage as a member of this education team. The most prominent feature of the tool is a message feed, akin to Facebook, and the tool links to some relevant data systems based on location, such as the child welfare case management system in Indiana and a foster care education database in California. | Follow My Child provided foster parents, physicians, and nurse case managers with electronic portal access to aggregated data from school, child welfare, and health records. Caseworkers used the system to send encrypted email reminders to foster parents of court appointments and health visits as well as notifications when a child missed school. |
| <b>Dates of Operation &amp; Location</b> | July 2015–Present<br>Ventura County, California   | 2009–Present<br>In place in Indiana; Pima County, Arizona; New Mexico; and counties in California (Santa Cruz, Santa Clara, and Los Angeles)   | 2012–2014<br>Miami-Dade/Monroe County, Florida   |
| <b>Data Shared</b>                       | Child welfare, health services data   | School records and education team planning documents   | Primary health and school records; select information from court records   |
| <b>Users</b>                             | Foster parents  | Foster children/youth, foster parents, biological parents, educational champions, and social workers   | Foster parents, physicians, nurse case managers  |
| <b>Website</b>                           | <a href="http://fostervckids.org/fhl">http://fostervckids.org/fhl</a>   | N/A  | N/A  |
| <b>Funding</b>                           | Planning supported with limited foundation and federal Health Information Technology for Economic and Clinical Health Act (HITECH) funding; development supported by county funds   | Private foundation funding as well as federal Department of Health & Human Services and California Department of Education funding   | Private foundation funding   |

| Name of Tool                  | My JumpVault   | HealthShack  | Girls Health Screen   |
|-------------------------------|--|--|---|
| Lead Organization(s)          | Five Points Technology Group and Big Bend Community-Based Care, Bradenton, Florida   | AltruIT, a subsidiary of Aspiranet, Sacramento, CA   | National Girls Health and Justice Institute (NGHJI), Los Angeles, CA  |
| Description of Tool           | My JumpVault is a secure, mobile-friendly, web-based system that allows youth, caseworkers, and caregivers direct access to vital case information. Originally developed to provide users with access to health records populated from the Medicaid managed care program, Sunshine Care, as well as the Child Welfare Data System, it has since been enhanced to permit users to view and upload records and information. The implementation of this tool is configured by the community foster care agency. | HealthShack is a personal health record designed specifically for—and in partnership with—youth in foster care or facing homelessness. Youth can upload and store life documents and accomplishments such as school transcripts, identification, and housing history, which can later be downloaded and shared when they are needed. | The Girls Health Screen is an electronic self-report questionnaire—available in iPad and web formats—that girls complete when they enter juvenile detention. The tool allows youth to identify health, mental health, and community needs. The questionnaire takes less than 15 minutes to complete and triggers follow-up services from facility medical and mental health staff. The information from the questionnaire is transmitted to the county and enters the health record that is developed as part of incarceration. It triggers enrollment or pre-enrollment in health insurance before release and follows the youth when they leave custody, often for foster care. |
| Dates of Operation & Location | 2015–Present<br>Being customized and deployed across Florida by community-based foster care agencies that contract with the State to provide foster care services.   | 2009–Present<br>Deployed at community-based organizations in Sacramento, California  | The effort began in 2012 in paper form. It went electronic in 2013. Beginning June/July 2016, it will screen all girls entering the Los Angeles County juvenile justice system. It has also been piloted in Stockton and San Joaquin, California.   |
| Data Shared                   | Social security cards, court documents, birthday pictures, birthday cards, report cards, and other life documents as well as primary health and behavioral health data   | On their own, or with help from an enrollment assister, youth upload their own records such as medical records, birth certificates, and school transcripts.  | Primary health, mental health   |
| Users                         | Foster youth, foster parents, case managers  | Foster youth (age 16 and older)  | Incarcerated youth,* health providers and mental health providers at juvenile justice facilities  |
| Website                       | <a href="http://www.myjumpvault.org">http://www.myjumpvault.org</a>  | <a href="http://www.healthshack.info">http://www.healthshack.info</a>  | <a href="http://www.girlshealthandjustice.org/programs/girls-health-screen">http://www.girlshealthandjustice.org/programs/girls-health-screen</a>   |
| Funding                       | State funding  | Funded by private foundations and Aspiranet, the foster care agency of which AltruIT is a subsidiary   | Initial funding from foundations; implementation funding from implementing counties   |

\*While Girls Health Screen focuses on incarcerated youth, it is included in this brief because there is significant overlap between the juvenile justice-involved and foster care populations and the tool has a unique manner of interfacing directly with youth that is relevant for other foster care initiatives.

| Name of Tool                             | Texas STAR Health Passport   | TAY Assistant  | Ratemyfosterhome.com   |
|--|--|--|--|
| <b>Lead Organization(s)</b>              | Texas Health and Human Services Commission (HHSC); Superior Health Plan, Austin, Texas   | iFoster, Truckee, CA   | Foster Skills, Inc., Boston, MA  |
| <b>Description of Tool</b>               | Health Passport is a statewide mobile-enabled electronic health record that provides foster parents, health providers, and caseworkers with Medicaid claims-based health information for children in foster care, all of whom are served by a single managed care organization (Superior Health Plan). All basic health information is made available to foster parents, except behavioral health information. If the foster child was previously insured through CHIP or Medicaid, then two years of health history is available in the record when the child enters care. When the child is reunified with his/her biological parent, the Health Passport is printed and provided to biological parent(s). | TAY (Transition-Age Youth) Assistant is embedded in an electronic resource (iFoster) that links foster youth to extensive services and resources based on their preferences, including free computers and job support. Among other activities, TAY Assistant allows youth to upload, store, retrieve, and share documents in a secure, encrypted, HIPAA-compliant Digital Locker. The tool is mobile accessible. | Ratemyfosterhome.com is a hybrid (mobile and web) application that supports child welfare agency efforts to improve foster home quality. The tool helps social workers diagnose behavioral, emotional, communication breakdowns, etc., by collecting real-time information on foster home conditions from foster parents and foster youth. |
| <b>Dates of Operation &amp; Location</b> | 2008–Present   | September 2014–Present<br>In use in Los Angeles County’s transition to independent living process; available to foster youth statewide.  | 2015–Present<br>Being piloted in Boston, MA  |
| <b>Data Shared</b>                       | Primary health, mental health, health screenings and assessments, demographics, lab results, immunizations, and case planning documents  | Health records, school documents, and life records   | Foster home conditions   |
| <b>Users</b>                             | Foster parents, health care providers, caseworkers   | Foster youth   | Foster children and youth (age 10 and over, in MA), foster parents, social workers   |
| <b>Website</b>                           | <a href="https://www.fostercaretx.com/for-providers/health-passport.html">https://www.fostercaretx.com/for-providers/health-passport.html</a>  | <a href="https://www.ifoster.org/iFoster-Locker.aspx">https://www.ifoster.org/iFoster-Locker.aspx</a>  | <a href="http://www.ratemyfosterhome.com/">http://www.ratemyfosterhome.com/</a>  |
| <b>Funding</b>                           | Developed with a federal Medicaid Transformation Grant; ongoing support from Superior Health Plan and Texas HHSC   | Private foundation funding   | Private foundation funding   |

# Lessons Learned

**Consumer-facing electronic records initiatives, in the foster care environment and more broadly, provide the following lessons for success:**

- 1. Build upon strong, committed leadership.**
- 2. Know your target audiences and involve them in the design, implementation, and improvement processes.**
- 3. Cultivate trust in the tool and the process.**
- 4. Design to demonstrate value.**
- 5. Understand the evolving landscape.**

## **1. Build upon strong, committed leadership.**

Projects featured in this brief used a variety of operational and leadership models: agency-driven teams, private-public collaborations, as well as vendor-driven teams that partnered with community-based organizations. Regardless of the different approaches, all projects recognized the importance of perseverance and strong leadership. Developing foster care electronic records initiatives and seeing these efforts through to success can take years, and success requires significant commitment on the part of the project team, project leadership, and project partners. Cross-sector data sharing, in particular, requires building relationships that take time to develop and nurture, as does planning an initiative in a manner that meets the needs of the children in foster care and the larger team that supports them.<sup>4</sup> Furthermore, where an initiative requires a significant change in culture on the part of government, service providers, and/or consumers—as is true of most cross-sector data sharing and consumer-facing electronic initiatives—it takes time and pressure from leadership to make that shift.<sup>5</sup> In fact, more innovative initiatives typically require the greatest commitment from leadership.

To see this extensive process through, the program staff interviewed for this brief spoke about the need for a strong leader who maintains momentum in the face of heavy workloads, competing priorities, and

challenges encountered along the way. For example, Ventura County Foster Health Link took years from the first planning meeting until launch. In the early phases, the project team, led by the Ventura County Human Services Agency, put extensive time into developing cross-sector relationships and community partnerships, securing financial support, conducting an environmental scan, and defining the scope of the project. When a base level of project funding was eventually received, the County felt comfortable allocating significant staff time to do the deeper dive planning, and the project moved forward swiftly thereafter. At that stage, the project benefited greatly from having a dedicated project manager from both the child welfare and technology agencies, a committee of social workers and public health nurses to address workflow and business processes, as well as strong support from the director at the lead agency. As a county priority, the project was able to overcome some significant hurdles. For example, when early staff adoption was slower than expected, leadership required staff to use Foster Health Link as part of an internal accountability process that included reporting utilization to supervisors. This coordinated response rapidly boosted use, reflecting the critical role of leadership engagement.

Likewise, Girls Health Screen has required persistence on the part of the lead organization and its founder

in the face of funding and technology challenges. The effort was also developed over many years, which included a prolonged validation stage—a step taken to establish credibility and demonstrate the value to potential agency partners whose buy-in and commitment were needed to help the project gain traction. Initially

developed with foundation funding, the tool has more recently secured funding from government partners interested in deploying it. Over time, Girls Health Screen has been able to scale up as it gains supporters among agency leaders and government officials.

## 2. Know your target audiences and involve them in the design, implementation, and improvement processes.

Across all projects examined, one lesson clearly stands out: the importance of soliciting input from the intended users of the technology tools from the earliest planning to later implementation stages. Following principles of “user-centered” design is a best practice for any consumer-focused technology project but is especially important when developing resources for vulnerable populations, like children and youth in foster care and/or their caregivers.<sup>6</sup> These groups face unique barriers, including limited access to technology, financial constraints, and health literacy issues that may hamper adoption and use, if not adequately addressed.<sup>7</sup> Further, these populations have very unique needs that can only be understood by listening and learning from them. Involving potential user groups early in the conceptual design process can help ensure that the tool developed is actually needed and desired by the intended users. For example, Foster Skills decided to develop Rate My Foster Home in direct response to a need expressed by stakeholders in the foster care community, including former foster youth. This type of user-centered approach helps guarantee that there will be uptake of the final product, especially if such feedback also informs the requirement specification, design, and testing process.<sup>8</sup>

Early partnership with the intended user can prevent glitches, low adoption, and design flaws that are harder to fix once the project is more fully formed. For example, several projects included in this brief discovered technology use barriers that hampered adoption by the target audience. These included discomfort with writing and posting comments online, limited use of email, and lack of access to computers and the Internet. One potential pitfall, for instance, is an over-reliance on email communication to authenticate eligible users. Use of email as a mode of communication is increasingly limited among those under age 30, a fact that could potentially inhibit uptake.<sup>9</sup> Such insights are important to glean early in the process so that the design of tools, especially their format, better

fits with the intended users’ existing patterns of technology use and preferred modes of communication.

Investing in early engagement with the target population can also help with appropriate language choice and framing. Another project, Girls Health Screen, solicited input from over 6,000 girls and women across the country before the tool was launched. This allowed the design team and staff to be versed in the language that the target audience used and preferred. “Because the kids feel so invisible, even having a name that appeals directly to them (‘girls,’ ‘boys’) helps get them interested and using it. They want to feel that the tool is for them,” noted Leslie Acoca, President of the National Girls Health and Justice Institute, the organization that developed Girls Health Screen. Likewise, HealthShack, the personal record for transition-age foster youth, was named after an actual shack at Wind Youth Services in Sacramento, where youth receive advice and other basic services. This naming approach grounded the resource in familiar language already used by intended users.

### Personalization/Tailoring

Research shows that consumer health applications that are tailored to user types and that include personalization have the most impact.<sup>10</sup> Indeed, generic design that fails to acknowledge the uniqueness of users (individual or categories of them) will have more limited impact, but such tailoring—for example, a display of information that is unique to their specific health needs (i.e., diabetes management) or personal preferences—is surprisingly rare.

The reasons for the less-tailored record are many. Allowing multiple user types to access information is often a laudable goal of consumer-focused electronic records in the foster care space. Data and information housed in electronic record systems are especially useful when they are shared with all parties involved in the child’s or youth’s life—for example, caseworkers, foster parents, biological parents, or the broader

care team. Creating a tool that can facilitate coordination and knowledge-sharing among these parties is highly desirable. However, tailoring to each of these audiences can be cost prohibitive.<sup>11</sup> The complexity and expense are magnified when access to data populated into the record requires different permissions for each user type.

Yet, the less-expensive, one-size fits all approach rarely succeeds. For example, a physician and foster youth will have very different needs as far as design and communication. Follow My Child in Florida, an electronic health passport tool, was intended to provide education and health data to physicians, case-workers, and foster parents. The record was designed to provide the same data in the same format to all of these users. However, the passport was primarily used by physicians, and the project leaders hypothesize that the information in the passport required more context and explanation, as well as a narrower selection of data, to have been of greater use to foster parents.

### Usability

Usability (the ability of users to navigate the tool's interface and support services) is key to the adoption and use of personal health records.<sup>12</sup> When users cannot make sense of the interface or require assistance to figure out how to use the site, they often abandon it and rarely return. High bounce rates, or a high percentage of single-page visits in which the user leaves the site from the landing page, could indicate usability flaws.

Low utilization of key features may also suggest a cumbersome design. Records that rely upon a manual, multi-step process for uploading and retrieving documents (and the forethought to have assembled such documents before logging in) are more likely to face barriers to use. In contrast, where a record is auto-populated with available data, the tool is easier for consumers (and others) to use. For instance, My JumpVault, Ventura County Foster Health Link, and Texas STAR Health Passport contain a pre-populated health record without any action required from the foster parent, providing value from the first time it is accessed.

Web-based tools are easiest to use when they have a consistent design and navigation structure across

pages and elements. In addition to being auto-populated, data should be easy to interpret and integrated into one place rather than scattered across different sites that require mastery of multiple design and navigation interfaces. Intuitive, consistent design and navigation reduces the “cognitive burden” on the user—or the amount of mental effort required—and helps foster a favorable experience.

Getting usability right requires early and ongoing user feedback, ideally through formal testing during the development stages but also after implementation to ensure that the optimal anticipated design approach is actually “usable” from the user's perspective.

Further, ongoing monitoring is essential, both to understand how the tool is being used and to improve it. For example, iFoster used an iterative design process that nimbly responded to feedback from foster youth in an ongoing way. iFoster originally designed its secure record-keeping feature to require a passcode (or PIN) to be entered for each document that was uploaded. But during the testing phase, youth reported that this process was cumbersome. Therefore, the protocol was changed and the design of the site modified. Modifications allowed for greater security on the backend of the system and an invisible hand-off to an encrypted server to permit an easier, single passcode at log-in without compromising security. In another example, Texas STAR Health Passport maintains a steering committee and holds periodic stakeholder meetings to capture feedback from stakeholders, including health providers and other users, about how Health Passport is functioning. Using input from these entities, the tool has undergone significant modification since its initial launch, including adding mobile capability.

There are also opportunities to solicit feedback after a launch of a product. Feedback can be gleaned from users through “human” technical support and educational outreach. However, too often, projects do not have the capacity to provide such services due to limited funds. Therefore, building this support into an overall budget is critical, given that research clearly shows that low-income, vulnerable users often require personalized assistance to acquire the skills to use online record systems.<sup>13</sup>

### 3. Cultivate trust in the tool and the process.

Protecting consumer privacy and building trust among partners, especially consumers, are essential steps in the development of an electronic records initiative.<sup>14</sup> Privacy and trust issues become especially salient when an initiative seeks to share or link data sources with government agencies. Addressing this challenge was a pivotal issue for all of the projects reviewed for this brief. For example, Follow My Child invested significant time drafting agreements in order to fully comply with the Health Insurance Portability and Accountability Act (HIPAA) and other relevant privacy laws so that it could obtain health data from Florida's Department of Child and Family Services. As a result of this upfront investment, Follow My Child was able to obtain and share valuable information with foster parents and build a stronger relationship with the state agency. Importantly, by developing a tool that allowed for greater transparency of information and authentic relationships with foster parents, the project team was able to cultivate trust with the end user, which ultimately enhanced adoption.

An important purpose of electronic records initiatives is to increase the availability of appropriate data to caregivers and consumers to support health care decisions. With more data available, foster care-focused record tools allow more visibility into the foster child/

youth's health history. But first they must ensure that policies are in place and information security networks are well-maintained in order to prevent unauthorized access to data. One way to approach data access is through a "role-based" permissions framework so that access mirrors each user's existing authorizations related to paper records. This approach, used by Ventura County, helps to ensure that privacy protections are upheld and appropriate access granted according to each individual's role. Another way to ensure that access is properly regulated is to set hierarchies around the datasets that determine how the data flows. This strategy was adopted by Community Based Care of Central Florida, which utilizes My JumpVault.

Such attention to privacy has an added benefit: trust in the privacy of personal data is directly correlated to consumers' trust in and ultimate use of an electronic record.<sup>15</sup> For example, iFoster's TAY Assistant uses security, encryption, and HIPAA-compliant formats for its electronic record feature—safety measures that allow youth to be comfortable uploading, storing, retrieving, and sharing documents. Importantly, TAY Assistant places control of the electronic record fully in the hands of the youth, which builds significant trust and supports the tool's ability to comply with privacy rules.

### 4. Design to demonstrate value.

To be successful and sustainable, consumer-focused foster care electronic record initiatives must be integrated into service provider and agency workflow<sup>16</sup>—ideally reducing, rather than adding to, workload—and be easily integrated into consumers' lives.<sup>17</sup> To get the leadership commitment required for a successful effort, such tools should provide some benefit to the child welfare agency at the same time that they impact the child and/or foster parent. This benefit can include reduced administrative burdens, such as streamlining the process for gathering critical information and reducing the administrative support required when youth transition to independence. For instance, in using My JumpVault, Florida foster care agencies are streamlining workflow around the tool and using it to reduce duplicate data entry. When a foster parent calls a social worker to obtain a school report, they are referred to the tool to obtain the report directly. When a foster parent performs certain required tasks, they

report the activities directly into My JumpVault, which is then available to the case manager for oversight. This direct access reduces the administrative burden on the social worker and increases a foster parent's ability to function independently. It is also helpful because such workflow drives greater use of the tool, which in turn contributes to its value. Another example is found in iFoster's TAY Assistant, which was developed to meet a program need identified by Los Angeles County's Department of Children and Family Services. In particular, as a youth transitions to independence, California law requires counties to offer ongoing supports like job training and to provide youth with a number of documents (such as birth certificates and other records) needed to manage their own affairs going forward.<sup>18</sup> Independent living program staff were concerned that the youth were not ready to take charge of the documents and that this often results in additional work for staff as youth lose and re-request

the materials. TAY Assistant's Digital Locker was created as a solution to this administrative challenge, and TAY Assistant was further developed to help strengthen ongoing communication between youth and their caseworkers about available resources and independent living support services, as required by state law.

While there will always be an up-front expense to deploying an information technology (IT) initiative, such efforts should be developed in a manner that reduces costs in the longer term, whether through reduced administrative expense, reduced use of the emergency room, or other improved outcomes. Evidence of cost

savings is the strongest way to ensure sustainability. However, in addition to having quantifiable program goals such as cost savings, the value of these projects can be demonstrated through clearly articulated goals that are less measurable. For instance, Girls Health Screen has the quantifiable goal of reducing recidivism, which in turn provides cost savings, but the initiative is significantly strengthened by its goal of empowering girls by giving them a voice in their own care. On an ongoing basis, electronic foster care records initiatives must be evaluated against both their measurable and less measurable goals and modified as necessary to improve the results.

## 5. Understand the evolving landscape.

For long-term sustainability, initiatives must understand and adapt to the evolving policy, funding, and technology landscape, as well as changing needs of the target population. Successful electronic record initiatives employ ongoing monitoring and iterative improvement while also taking the long view to ensure that the tools and related business processes evolve to line up with changing policy requirements, new ways to use technology, and funding opportunities.\* Initiatives that are developed as part of a statewide plan are at an advantage when it comes to achieving scale and sustainability not only because they have broader reach, but also because they have an easier time accessing potentially significant amounts of federal funding. This was the case in Texas, which initially developed STAR Health Passport using a federal Medicaid Transformation Grant (a 2007 grant offered to promote innovation in Medicaid programs). My JumpVault also benefited from being a state initiative, with the state legislature providing funding to the child welfare agency in 2013 to procure a personal health record system for Florida's foster youth. With State backing, foster care agencies were given access to a core template that is interoperable with state health and child welfare databases, which they could then modify to suit agency practices. In contrast, Follow My Child was developed and deployed within one foster care agency, making it difficult to build data linkages with state systems, and, ultimately, the project failed to scale statewide. In fact, without stable and ongoing funding or significant policy directives that

propel a project forward, initiatives often struggle to gain traction.

In addition to understanding the policy landscape, to accurately assess opportunities, it is imperative to monitor ongoing innovative developments in the IT sector that would benefit foster care coordination, along with gathering up-to-date research and data on the particular health needs and concerns of foster youth. The National Center for Youth Law, creator of FosterEd, noted the importance of having an in-house, expert IT team in order to design and quickly modify electronic tools, as needed. Having an IT expert on staff enables an initiative to move forward by identifying project needs irrespective of the available technologies, rather than having the available technology define where the project goes. Additionally, Foster Skills, Inc., creator of Rate My Foster Home, emphasizes the need for adept technical staff as well as staff in-house who have expertise and knowledge in child welfare policy to respond to the evolving landscape.

The Texas Health and Human Services Commission Health Plan echoes the importance and value of having immediate access to IT support and expertise for its Texas STAR Health Passport. As the Passport's system provider, Superior Health Plan manages the Passport's system support, technology updates, and functionality. With that capacity, the Passport receives routine system checks and was recently upgraded to have a more streamlined user interface, which is attracting more consumer usage.

\*For information about the federal policy environment, see <https://www.healthit.gov/sites/default/files/pdf/individual-access-06-03-2012.pdf>.

# A Critical Appraisal & the Path Forward

To ensure that foster care electronic records initiatives achieve their fullest potential, the following efforts are required:

1. Further insight is needed on how best to engage consumers through electronic records.
2. Initiatives should increase and improve communication across the care team.
3. User-centered design and testing must be more rigorous.
4. Evaluation and ongoing, iterative improvement should be strengthened.
5. Privacy challenges are real but not insurmountable.
6. Federal and state support are needed.

## 1. Further insight is needed on how best to engage consumers through electronic records.

Consumer engagement in health care is of great potential value,<sup>19</sup> but there is limited evidence about how information technology supports that end.<sup>20</sup> This dearth of evidence is mirrored in the foster care environment where the aim is to engage youth and foster parents in education, health, and wellness. Yet, it is critically important that we identify how to make the most of the opportunity that IT offers. The projects presented in this brief are on the cutting edge, applying a new set of tools in a challenging, fragmented environment with consumers who often lack resources and support systems. These projects indicate a number of promising approaches to the use of youth- and family-facing electronic records. However, evidence for how to successfully engage foster youth and foster parents in the adoption and utilization of such systems is still lacking, and account creation/usage trends for most programs profiled for this brief indicate that most tools have yet to see robust enrollment or a documented impact in terms of health or other outcomes. The table on the following page shows consumer account creation/use over the time periods for which data were available.

Evidence from the broader health IT environment<sup>25</sup> should be leveraged to promote effective consumer engagement in the foster care environment, as well. Behavior change is hard in all contexts, which is certainly true in the foster care environment. Foster care agencies struggle, in general, to get foster youth to engage with enrichment opportunities, let alone with their own health and records. As a result, the lure of a new technology must speak to the needs that foster youth, themselves, prioritize. For example, iFoster is successful in attracting youth to an electronic platform with its array of resources, like free computers, from which they then are more likely to use the attached Digital Locker to manage their documents. Rate My Foster Home appeals to a child's desire to have a voice—which is often missing in their foster care experience. It is important to note that there is value in offering youth an opportunity to be involved in planning their own lives and controlling their documents. Thus, even where utilization is low, the effort may still serve an important project goal.

| Project                    | Account Creation/Use by Foster Parents/Youths*  |
|----------------------------|---|
| Follow My Child            | Piloted with 150 families. At least 29 families of 58 studied in a six-month evaluation in 2012 signed in at least once.  |
| FosterEd                   | 228 youth were served in Santa Cruz between Jan. 2013 and Dec. 2014. <sup>21</sup><br>748 foster children were served in Marion County, Indiana, between 2009 and 2012. <sup>22</sup><br>Data not available for other locations.                          |
| Foster Health Link         | 68 foster parents created accounts from July 2015 to present.   |
| Girls Health Screen        | Approx. 400 in long-term locked facilities have used the tool in Los Angeles County since the pilot began in 2012.<br>Another 350 girls in San Joaquin County detention have used the tool between 2015 and 2016.<br>Data not available for Stockton, CA. |
| HealthShack                | Approx. 850 foster youth since 2009.  |
| My JumpVault               | 47 caregivers, group homes, and teens had active accounts in April 2016 at the agency interviewed for this brief, Community Based Care of Central Florida.<br>Statewide data not available.   |
| RateMyFosterHome.com       | Data not available.   |
| TAY Assistant              | Approx. 4,300 youth from 2014 to present.   |
| Texas STAR Health Passport | 363 active foster parent accounts in Nov. 2015.   |

## 2. Initiatives should increase and improve communication across the care team.

A major goal of electronic information exchange is to improve communication across a care team through the exchange of actionable data. In the broader electronic health records context, where this issue has been heavily studied, consumers have expressed a desire for such tools to support secure, direct communication with their health care providers through secure email and other means.<sup>24</sup> However, foster care electronic record systems have not leveraged this opportunity fully, if they have undertaken it at all.

FosterEd is tackling this challenge, trying to use electronic tools to tap into existing channels of communication in order to enhance teamwork. Other projects, such as Girls Health Screen and Rate My Foster Home, allow youth to communicate their needs directly with their care team through a questionnaire. Moving forward, all foster care electronic records initiatives should build in an opportunity for communication, at least one-way but ideally multi-directional, between foster parents, foster youth, and the larger care team.

## 3. User-centered design and testing must be more rigorous.

Across all projects reviewed, the importance of robust user involvement in the design process was one of the

most important lessons learned. Adoption of the recommendations outlined in this brief—user interviews,

\*Except where otherwise indicated, these statistics were provided by personal communication from each program in Spring 2016.

usability testing, tailoring, iterative design, and ongoing adjustment and support—would greatly benefit future efforts. Even projects developed with the best intentions and most talented IT team will not be successful if the intended users do not see the value or

cannot navigate the design. Up-front investments in usability testing and meaningful partnership with users in all phases of the design are essential to achieving the most important goal—to create an actual positive impact for children and youth in foster care.

## 4. Evaluation and ongoing, iterative improvement should be strengthened.

Most initiatives reviewed in this brief, limited by staff and resources, have not engaged in formal evaluations of the effort. This is understandable, given the costs associated with a rigorous evaluation. As a result, there are limited data related to outcomes and spotty information about what is working and what is not. Without such knowledge, improvements and modifications may not achieve their intended effect. When initiatives actively and routinely seek feedback from users—as is the case in Texas’s STAR Health Passport and TAY Assistant—they have made significant enhancements

over the years and have achieved greater success incorporating the tool into the services being offered. Funding is required for all phases of an effort—development, implementation, evaluation, improvement, and ongoing maintenance. When a project faces resource limitations, it is less likely to evaluate and take effective steps to improve a tool. At the same time, it is also less likely to have invested in the up-front development and testing that reduces the need for enhancements. This combination significantly limits the ultimate impact of an effort.

## 5. Privacy challenges are real but not insurmountable.

Often, concerns about whether it is possible to meet privacy laws and expectations can seem so daunting that they derail an effort before it even gets started. However, the initiatives explored in this brief show that a balance can be achieved that allows for appropriate information sharing while, at the same time, protecting privacy. One successful strategy for getting a project off the ground is to confine electronic information sharing to information that is already being shared in paper form and holding off on inclusion of additional information and functionality until a future point at which the system has built up trust and demonstrated value. This approach was taken in Ventura County Foster Health Link, which used the

initial phase of the electronic record to provide a more complete, timely version of the data that were already being provided to foster parents in a paper “Health and Education Passport” that summarizes essential information about the child. Other projects, such as iFoster and HealthShack, meet privacy expectations by putting youth fully in charge of their own record, including the sharing of information and documents. As systems capabilities are further developed to facilitate appropriate treatment of data, such as through data tagging and segmentation, they should be leveraged to further enhance the ability of these projects to achieve their goals.<sup>25</sup>

## 6. Federal and state support are needed.

While the projects discussed in this brief have demonstrated that great innovation is possible through community-based, private, and public-private projects, it is clear that an electronic records initiative requires substantial federal or state support to achieve its intended impact and grow to scale. As states move forward in the development of new Comprehensive Child Welfare Information Systems that meet federal expectations of interoperability and reach, an ideal opportunity exists to develop such systems to reach members

of the wider care team, as well as foster parents and youth, with new tools and usable information. Federal and state support can help by ensuring projects develop as part of a larger, statewide vision, sharing best practices and reusable assets wherever possible and not re-inventing the wheel with each new initiative. In the end, such planning will lead to more cost-effective solutions that achieve the best outcomes for children and youth in foster care.

The Children’s Partnership is a California-based nonprofit children’s advocacy organization committed to improving the lives of children where they live, learn, and play. Our mission is to better the health and well-being of underserved children through strong community partnerships, forward-looking research, and informed policy. We build meaningful partnerships with communities and decision-makers to provide a powerful voice for children and champion programs and policies that break down barriers to advancement. Since 1993, TCP has been a leading voice for children and a critical resource for communities across California, working every day to provide all children with the resources and opportunities they need to thrive.

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## Endnotes

<sup>1</sup> Jan McCarthy, *Meeting the Health Care Needs of Children in the Foster Care System* (Washington: Georgetown University Child Development Center, 2002).

<sup>2</sup> Mark D. Simms, Howard Dubowitz, Moira A. Szilagyi, “Health Care Needs of Children in the Foster Care System,” *Pediatrics* 106(3) (2000), accessed April 18, 2016, [pediatrics.aappublications.org/content/106/Supplement\\_3/909.full](http://pediatrics.aappublications.org/content/106/Supplement_3/909.full).

<sup>3</sup> The Children’s Partnership, “Top Reasons Why Electronic Care Coordination Can Help Children and Youth in Foster Care Beat the Odds” (November 2014).

<sup>4</sup> Richard C. Antonelli, Jeanne W. McAllister, and Jill Popp, *Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework* (Washington: The Commonwealth Fund, May 2009).

<sup>5</sup> Jane E. Fountain, *Building an Enterprise Government* (Washington: Partnership for Public Service, March 2016).

<sup>6</sup> Smitha Pushpangadan and Charlotte Seckman, “Consumer Perspective on Personal Health Records: A Review of the Literature” *Online Journal of Nursing Informatics* 19(1) (2015).

<sup>7</sup> N. Archer et al., “Personal Health Records: A Scoping Review,” *Journal of the American Medical Informatics Association* 18(4) (2011): 515-22.

<sup>8</sup> Ibid.

<sup>9</sup> Matt Richtel, “E-Mail’s Big Demographic Split,” *New York Times*, December 21, 2010, accessed May 4, 2016, [bits.blogs.nytimes.com/2010/12/21/e-mails-big-demographic-split/?\\_r=0](http://bits.blogs.nytimes.com/2010/12/21/e-mails-big-demographic-split/?_r=0).

<sup>10</sup> N. Archer et al., “Personal Health Records: A Scoping Review,” *Journal of the American Medical Informatics Association* 18(4) (2011): 515-522; A. Ant Ozol et al., “Usability and Perceived Usefulness of Personal Health Records for Preventive Health Care: A Case Study Focusing on Patients’ and Primary Care Providers’ Perspectives,” *Applied Ergonomics* 45(3) (2014): 613-28.

<sup>11</sup> Clare Tobin Lence and Corey Capozza, “Health Information in Bits and Bytes: Considerations and Challenges of Digital Health Communication,” in *Meeting Health Information Needs Outside of Healthcare*, eds. Catherine Arnott Smith and Alla Keselman (Waltham: Chandos Publishing, 2015): 291-319.

<sup>12</sup> N. Archer et al., “Personal Health Records: A Scoping Review,” *Journal of the American Medical Informatics Association* 18(4) (2011): 515-22; K. Keshavjee et

al., “Best Practices in EMR Implementation: A Systematic Review,” *AMIA Annual Symposium Proceedings* 2006 (2006): 982.

<sup>15</sup> Ibid.

<sup>14</sup> Agency for Healthcare Research and Quality, *Designing Consumer Health IT: A Guide for Developers and Systems Designers* (Washington: US Department of Health and Human Services, 2012), 11-13.

<sup>15</sup> The Office of the National Coordinator for Health Information Technology, *Guide to Privacy and Security of Electronic Health Information v.2* (Washington: Department of Health and Human Services, April 2015), 8.

<sup>16</sup> Institute of Medicine, *Health IT and Patient Safety: Building Safer Systems for Better Care* (Washington: The National Academies Press, 2011).

<sup>17</sup> Taya Irizarry, Annette DeVito Dabbs, and Christine R. Curran, “Patient Portals and Patient Engagement: A State of the Science Review,” *JMIR* 17(6) (2015).

<sup>18</sup> The Children’s Partnership, “Supporting California Counties in Transitioning Foster Youth to Independence: How Electronic Record Systems Can Help Serve the Goals of AB 12” (November 2015).

<sup>19</sup> Lygeia Ricciardi et al., “A National Action Plan to Support Consumer Engagement via E-Health,” *Health Affairs* 32(2) (2013): 376-384.

<sup>20</sup> Marsha Gold, Mynti Hossain, and Amy Mangum, “Consumer Engagement in Health IT: Distinguishing Rhetoric from Reality,” *eGEMS* 3(1) (2015): 1190.

<sup>21</sup> Jennifer Laird, *FosterEd Santa Cruz County: Year 2 Evaluation* (Berkeley: RTI International, 2015).

<sup>22</sup> Stephanie Yoder, *FosterEd: Indiana* (Oakland: FosterEd, 2013).

<sup>23</sup> See, for example: Karandeep Singh et al., *Developing a Framework for Evaluating the Patient Engagement, Quality, and Safety of Mobile Health Applications* (Washington: The Commonwealth Fund, 2016).

<sup>24</sup> National Partnership for Women & Families, *Engaging Patients and Families: How Consumers Value and Use Health IT* (December 2014) 34-35.

<sup>25</sup> President’s Council of Advisors on Science and Technology, *Report to the President: Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward* (December 2010): 51-52.



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