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The future of child welfare will look toward children's health: the case of the Kentucky Health Information Data Sharing (KHIDS) project

Matthew T. Walton ^{a,b}, Kailyn L. Conner ^{a,b}, and Jake A. Mackie^{a,b}

^aOffice of Health Data and Analytics, Division of Analytics, Kentucky Cabinet for Health and Family Services, Frankfort, KY, USA; ^bUniversity of Kentucky, Lexington, KY, USA

ABSTRACT

The child welfare field in the United States aspires to encompass more than child protection and to move toward the promotion of child and family wellness. Scholars and practitioners have long observed that child wellbeing has been the most elusive of the three-part mandate of the Adoption and Safe Families Act. In response, child welfare agencies have increasingly been asking themselves hard questions and testing new approaches to meet the needs of families. This commentary argues that current developments suggest a future where child welfare workers' activity in the field actively promotes the health of children and is recognized as an asset to pediatricians and healthcare systems. An example is offered to support this prediction in the form of the Kentucky Health Information Data Sharing (KHIDS) project. KHIDS involved an operational linkage between Kentucky's child welfare information system and its health information exchange to allow child welfare professionals access to information that allows them to more efficiently perform their duties – especially those related to monitoring health care services for children in out of home care. The KHIDS project is a positive sign of things to come for the future of the field.

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We can only see a short distance ahead, but we can see plenty there that needs to be done.

-Alan Turing

Introduction

Children placed in out of home care often experience more severe health problems than other children (Szilagyi, Rosen, Rubin, & Zlotnik, 2015; Turney & Wildeman, 2016), and consequently have higher utilization of health services compared to the general pediatric population (Florence, Brown, Fang, & Thompson, 2013; Knight, McDuffie, Gifford, & Zorc, 2016). Tragically, one study estimates that the mortality rate among children in foster care is significantly higher than the general child population (Chaiyachati, Wood, Mitra, & Chaiyachati, 2020).

CONTACT Matthew T. Walton  Matthew.walton@ky.gov  Office of Health Data and Analytics, Division of Analytics, Kentucky Cabinet for Health and Family Services, 275 E Main Street, Frankfort, KY 40261

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When healthcare providers can deliver the right care for these children, it benefits both their health and their experience with the child welfare system (Rubin et al., 2004; Vimpani, Boland, Barr, & Marshall, 2011; Zlotnik, Wilson, Scribano, Wood, & Noonan, 2015). Innovations in data science, computing technology, and healthcare analytics offer tools that will animate the child welfare field's emphasis on child well-being ([Kentucky Revised Statutes \(KRS\) Section 620.230 - Case permanency plans](#)). Specifically, these tools will sit at two intersections: (1) between the work humans do and the work machines do; and (2) between the healthcare and social services systems. These advances are likely to continue in the future, and the access to families that child welfare workers possess will enable new technological tools to create a reality where workers' contact with vulnerable families is viewed as an asset to inform healthcare services to children.

Technological innovations also raise new ethical and legal questions. Collaborations between legal, information technology, and human services professionals are necessary to allow the field to transcend the barriers that currently stand in the way of realizing a more integrated way to serve children. This commentary presents an example of a recent project in Kentucky to defend this position and offers a discussion of new policies that suggest this future is already taking shape.

Pediatrics and child welfare: powerful allies

When children with serious healthcare needs are placed in out of home care, they exist at a nexus point between systems. This phenomenon is so common that it has spawned special language within states to orient their programming, such as “medically complex” or “medically fragile” (Williams, Seltzer, & Boss, 2017). Seltzer, Henderson, and Boss (2016) estimate that 5–10% of the total foster care population, or 20,000 to 40,000 children each year, are in foster care due to medical complexity.

Providing adequate care to these children requires coordination and information sharing. Foster parents must be equipped to get children to physician offices, child welfare professionals must complete extra monitoring, and healthcare providers are required to share sensitive clinical information (Risley-Curtiss & Stites, 2007). While each of these parties share a common mission in promoting the wellbeing of children, their efforts to coordinate are often frustrated by forces outside their control (Greiner et al., 2019).

One such frustration stems from the bottlenecks created by a healthcare ecosystem that struggles to share information securely, conveniently, and quickly. The United States has constructed a legal framework to protect the privacy and confidentiality of youth in out of home care. However, these laws also create friction in the sharing of health information to guide medical care

for children. Unintended consequences have arisen and produced time-consuming processes, such as faxing documents (Minor, 2019) or waiting on lengthy hold times during telephone calls (Committee on Children with Disabilities, 1999). These inefficiencies can result in missed appointments, duplication of services, or harm to children's health. While these frustrations may be laborious for children who require care from multiple specialists and complex medical treatment plans, they also stymie the coordination of more routine services for children. When effective information sharing is not present, tracking down health information elements for a single child can add hours of work to a workers' day.

The Kentucky Health Information Data Sharing (KHIDS) project

The child welfare field deserves tools that enable workers to avoid these kinds of tedium. The Kentucky Cabinet for Health and Family Services (CHFS) believed it could build a solution: the Kentucky Health Information Data Sharing (KHIDS) project.

KHIDS was oriented by a central goal: to get useful information into the hands of workers in a way that was safe, secure, and utilitarian. With a Human Services Interoperability Innovations (HSII) grant awarded to the Kentucky Department for Medicaid Services (DMS), CHFS assembled a team of multiple internal agencies to realize this goal. In practice, this resulted in an operational linkage between Kentucky's child welfare information system (known within the state as TWIST) and the state health information exchange (called the Kentucky Health Information Exchange, or KHIE) as a means to reduce burden on the workforce and result in better care coordination for children in out of home care. Health information exchanges are a means of securely sharing clinical data, such as laboratory test values or dictated physician reports, from one healthcare provider to another (Vest & Gamm, 2010).

The KHIDS project began with legal research, identifying a state law that outlines the need for child welfare workers to be provided with healthcare information to facilitate case planning for children in the state's custody (see KRS 620.230). This served as the foundation of an interdepartmental data use agreement. This agreement allows Kentucky's public child welfare department to serve as a named representative for DMS to coordinate medical services for children, which enables the sharing of medical records through KHIE for children in state custody. This framework supports the on-the-ground functionality, granting workers access to KHIE through TWIST using single sign on and application programming interface applications. KHIE also features alert applications available to workers that provide a prompt when a child has a documented, clinically significant event occur, such as an admission to a hospital emergency department or a positive diagnostic test for COVID-19.

Conclusion

Child welfare has evolved from a field that once viewed its central operating principle as a mandate to rescue children into one animated by supporting families. This trend will continue in the future, and future professionals will not only ask “Is this child safe?” but also “Is this child safe and healthy?” Those charged with promoting the health of children will recognize how valuable child welfare workers are to achieving a shared mission. Interoperable tools, like KHIDS, will become commonplace in the future, building bridges between child welfare and healthcare systems.

Much remains to be learned about how to leverage data sharing as a means of helping child welfare workers achieve better health and wellness for children. We grant the sensitivity and caution necessary to harness the power of digital information in ways that conform to the field’s commitment to justice and equity. While it is beyond the scope of this commentary to outline the contours of debate about the proper use of data in child welfare services, we acknowledge the presence of the discourse on this issue, especially as it relates to guarding against the amplification of the historical disenfranchisement of certain groups (for a more thorough treatment, see Kilkenny & Robinson, 2018; Redden, Dencik, & Warne, 2020).

A deliberative process regarding ethics and the appropriate use of administrative data in child welfare settings produces a strong framework for future implementations of innovative ways to serve children and families. The child welfare field should serve as a venue for this debate and equip itself with the necessary training and analytic capacity to contribute to burgeoning applications of data science.

The future landscape of providing health services to children in out of home care is coalescing, and the utilization of data is a centerpiece in these advances. Data sharing initiatives like KHIDS could enable further collaborations between child welfare and healthcare entities. For example, in recent years, states have begun experimenting with new contract mechanisms to provide health insurance coverage for children in out of home care through Medicaid programs (Allen, 2008; Thompson, 2021). Several states, including Kentucky, West Virginia, Georgia, Ohio, Texas, and Wisconsin, have adopted Medicaid policies to incentivize managed care organizations to prioritize better health outcomes for these children.

Children involved with child welfare services have unique needs that require additional attention from their healthcare providers and guardians. By increasing the ability of the child welfare worker to monitor these aspects of a child’s life, the field begins incorporating children’s health to accomplish its goals of safety, permanency, and wellbeing. Harnessing information will be one way that the workers of the future will bring this reality into existence.

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ORCID

Matthew T. Walton  <http://orcid.org/0000-0003-1971-8306>

Kailyn L. Conner  <http://orcid.org/0000-0001-8480-6228>

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