Information Sharing to Improve Health for Children in Foster Care

Population Health Sciences

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As pediatric residents in Philadelphia, we provide care to many children in the foster system. According to the U.S. Department of Health and Human Services, between 400,000-500,000 children were in foster care in the U.S. on any given day in 2016. A 2018 report put the number in Philadelphia at around 6,000.

The social hardships and upheaval inherent within the lives of youth who experience foster care would be enough to merit our attention, but research demonstrates that nearly half of children in the child welfare system have special health care needs, over twice the rate of the general population. Moreover, nearly 90 percent of children in foster care require a referral to a specialty medical provider (e.g., a gastroenterologist), and of those who do, one-quarter require *three or more* referrals to specialty providers. In addition to physical ailments, nearly two-thirds of children in foster care have mental and behavioral health problems and one-quarter of adolescents suffer from Post-Traumatic Stress Disorder (PTSD). As a result, the American Academy of Pediatrics (AAP) has classified children in foster care as a population with special health care needs.

Because of the potential complexity of their medical needs, children in the foster system require well-coordinated health care. Unfortunately, they face significant barriers—fragmented care and incomplete or unavailable health information are nearly universal challenges. Recent data shows that around 40 percent of children in foster care relocate within six months of placement, and that teenagers often have multiple relocations during that same period. Fragmented health care results not only from these geographic moves within a region, but also from insurance regulations limiting access to certain providers and from communication breakdowns at multiple levels. These breakdowns in communication can occur at several critical points, such as removal from a home, during court hearings or medical checkups and/or at the time of placement. Gaps in medical data and communication harm children, with a 2015 survey finding that caregivers ranked incomplete medical and placement histories as one of the primary causes of children receiving inadequate medical care.

In just our first years of training, we have cared for children hospitalized with respiratory failure after being placed in a new home without their asthma medication. We have struggled alongside a foster parent to piece together a newly placed child's medical and social history. And in our observation of placement hearings within the Philadelphia legal system, we witnessed the challenges of confirming diagnoses and medications for children in foster care.

Investment in data-sharing technology to facilitate communication between the child welfare and health care systems is one way to tackle these challenges. With improved data transfer, doctors can better care for children in the foster system and caseworkers remain informed of basic, yet vital, health information like current allergies and medication needs. While 2008 federal legislation, the *Fostering Connections to Success and Increasing Adoptions Act,* requires that states develop systems for health coordination for children in foster care, there are few statewide electronic data-sharing systems to date. Fortunately, there is innovation in the sector—for example, researchers at Cincinnati Children's are addressing this problem through The IDENTITY (Integrated Data Environment to eNhance ouTcomes in cusTody Youth) project, building a web portal that establishes an information exchange data hub between the state welfare database and the Cincinnati Children's electronic health record (EHR). Researchers hope the portal will improve the processes of receiving medical consent, scheduling, billing and identifying associated health risks in the clinical setting. They also note that allergies, medication lists and upcoming appointments are shared back to state welfare caseworkers to keep them apprised of the medical needs of children in their care. Should this project succeed within Cincinnati Children's, it has the potential to be scaled to the state and national levels.

Through a unified effort among child welfare agencies, medical and legal professionals, health insurance agencies, policymakers, and information technology and EMR providers, we can make a similar investment in the health and well-being of children in the Philadelphia foster care system. An electronic data-sharing system connecting EHRs and the state welfare database has the potential to fill gaps in care and provide the timely, medically necessary and life-saving care that children in our foster system, locally and nationally, both need and deserve.

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