Children's Hospital of Philadelphia
PolicyLab

Foster Youth Experience Higher Health Care Utilization & Higher Mortality. How Can Data Help?

Family & Community Health

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Every medical diagnosis is built upon history—the history of current symptoms, past symptoms and, ideally, a complete and detailed medical history. For children in foster care, this information is often minimal, or in some cases completely absent.

A recent case illuminates the very real danger foster children and families can face without these critical details. A foster parent became concerned that a child's low energy was more than sadness as his mood was not improving despite weeks of bonding. Minimal medical history was available, and when child protective services agency workers tried to reach the pediatrician's office, they were told that records could not be provided without a signed release from the biological parent. Eventually, the foster parent took the child to an emergency room where initial bloodwork showed he had a low red blood count. Just prior to his evaluation at Children's Hospital of Philadelphia's Fostering Health Program, additional records were obtained showing the child had a compromised immune system—his lack of energy was likely related to dropping blood cell counts and his low-grade fever instantly became a medical emergency requiring urgent hospitalization.

While this patient's diagnosis was ultimately recognized and he received appropriate medical care, this is just one anecdote of countless others that demonstrates the unique challenges children in foster care encounter and highlights a key issue that deserves attention during National Foster Care Month.

Each year there are approximately 400,000 children in the child welfare system in the United States. Children in foster care represent a critically vulnerable population. Nothing illustrates this more than findings from our recent *JAMA Pediatrics* study, through which we found that children in foster care were 42% more likely to die compared to children in the general population and the difference has increased over time.

Which begs the question, *why?*

While we can say there is a difference, and a significant one, we cannot say what comprises this difference. What are children in foster care dying from? How do those patterns of death compare to children not in foster care? And, more importantly, what can we do to address this concern? Unfortunately, there is much that we do not, and cannot, know about mortality for children in foster care due to a lack of integrated data across agencies and health systems.

The Role of Chronic Health Conditions & Barriers to Care

One potential reason we observed this discrepancy is that children in foster care have high rates of chronic health problems and behavioral health conditions compared to similar children in the general population. As such, they may be at higher risk of mortality due to underlying conditions. Our research has shown that children in foster care utilize health care services and visit the hospital more frequently than children who are not in foster care, and this difference is largely driven by children in foster care who have higher medical complexity.

The American Academy of Pediatrics has identified children in foster care as “children with special health care needs”; as a result, specific guidelines and recommendations exist for their medical evaluations. Despite these recommendations, there are many challenges in addressing their medical and behavioral health needs. For instance, placement into foster care is often done urgently or emergently. As such, physical relocation without adequate health information may result in loss of access to important medications, including inhalers for asthma, or equipment such as eyeglasses. Key details may be lost in communication between the biological caregiver, caseworker, foster caregiver and medical provider.

Placement may also impede continuity of care in a child’s established medical home whether due to physical proximity, insurance barriers or impaired access to prior medical records. Real and perceived issues of consent may also pose a barrier especially in the context of mental health. Furthermore, placement instability within foster care may disrupt access to health care and lead to further fragmentation of care.

A Call for Further Research

There are many challenges and variables that have the potential to impact morbidity and mortality for children in foster care. Disentangling cause, effect and association requires more research. However, research on children in foster care has additional obstacles. For example, electronic health records do not consistently record if a child is in foster care. Data regarding foster care status may be culled from a complex collection of variables including insurance status, social history, and, potentially, diagnosis codes but this complete set of information is not systematically available in large datasets and has multiple limitations.

A separate option to provide a more complete picture of a child’s health and wellness is to link real-time health records with child welfare data. However, this sort of connection is fraught with barriers including appropriate concerns and regulations regarding privacy and release of information. Finally, isolated administrative datasets are limited in their ability to answer cross-disciplinary questions. For example, data describing children in foster care does not contain adequate information to conclude how health may have contributed to mortality, while national mortality data does not contain information about child welfare involvement for decedents. Linking datasets such as these would require unique patient identifiers that are not included in public data.

As we consider next steps to further understand mortality in foster care, we recognize the critical need for gathering additional information through data. Policymakers and researchers must collaborate to leverage existing data through cross-systems integration and to consider alternative approaches for collecting data for children in foster care that may yield helpful information in the future. With more research, we can better understand the factors leading to mortality in order to guide policies and interventions to impact the curve and improve outcomes for this vulnerable population of children.

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