Do gaps in data negatively impact children with complex medical needs?

What can we learn from this study?

About 10% of the nearly 400,000 children in foster care in the United States are considered medically complex. Children with medical complexity are defined as those with high healthcare needs, at least one chronic condition that is severe and associated with fragility, functional limitations, and high healthcare utilization. Yet information is sparse about services provided to children with medical complexity who are in the child welfare system. Studies show that children with medical complexity who are in foster care are less likely to achieve permanency, tend to remain in out-of-home care longer, and are more likely to be in congregate placements. This study provides insight into what the child welfare system currently is doing to support these children, and what might be done to improve services and outcomes.

Study details:

- **Population:** Child protection agencies in 28 states and two major cities (out of 38 agencies contacted for the study)
- **Data sources:** Survey responses
- **Methodology:** Surveys distributed electronically; descriptive statistical analysis
- **Dates:** Between June and November 2022

What are the critical findings?

This analysis revealed:

- **Child protection agencies lack a standardized definition or reliable way to identify children with medical complexity within their data systems.** Nearly half of the agencies (47%) indicated that they did not have a clear definition. Having a standardized definition is a critical step to improving services.
- **Identifying children with medical complexity within current data systems is challenging.** A majority of the agencies (70%) reported difficulty in identifying and storing information about children with medical complexity due to missing or inconsistent data-recording fields. Adding a required field to identify these children will help improve tracking and assessment of service outcomes.
- **Caseworkers require training to identify children with medical complexity.** About three-quarters of agencies (73%) reported that caseworkers are not adequately trained to identify children with medical complexity. While some agencies rely on medical professionals, specialized training for caseworkers is vital to ensure they can appropriately determine and track children's medical complexities when medical professionals are unavailable to assist.

Why is this important to our work?

Placement and permanency outcomes among children in foster care with medical complexities are generally poorer than their peers in foster care who do not have medical complexities. To enhance services and improve outcomes for these children, there is a need to develop a standardized approach to defining, identifying, and tracking children with medical complexity within child protection agencies, including cross-collaboration with medical providers and other relevant stakeholders. Once children with medical complexity are adequately identified in the system, future research can collect population-level data and provide recommendations for best practices and policies.

This summary synthesizes the findings from a single research report. To learn more, see: What are key research gaps in the child welfare field? and What are key principles child protection agencies should follow when providing trauma treatment and healing-centered services?

For additional information, see the article abstract or contact KMResources@casey.org