

Addressing Parent Employment as an Essential Issue in Child Health

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In this issue of *Pediatrics*, Foster et al¹ address the often unseen and pressing reality of the economic impact that having a child with special health care needs (CSHCN) has on families. Using data from the 2016–2017 National Survey of Children's Health, the authors specifically address foregone family employment (FFE) and lost earnings.

The numbers reported are sobering: FFE occurs in 14.5% of employed families of CSHCNs and skyrockets to 40.9% for those who have children with intellectual disability, seeming to correlate to the number of hours families raising CSHCNs must dedicate to caring for their child. Viewed through an equity lens, the authors' findings become even more pointed. Those who have public insurance, are of Hispanic ethnicity, or whose children are younger, have functional limitations, or medical complexity seem particularly vulnerable.

We know from the existing literature, well referenced by the authors, that social determinants of health (SDOHs), including family income, can directly impact health outcomes for a child.^{2,3} The estimated annual household loss of \$18 000 among families caring for CSHCNs calculated by Foster et al¹ may affect family stability in ways that resonate beyond the specific day-to-day care of the child affected, driving additional key concerns such as food insecurity and access to shelter, increasing the risk of negative health outcomes. The national aggregate

lost income is staggering, estimated at \$9 to \$19 billion annually. However, the consequences of FFE are not confined to loss of income.⁴ They include decreased contributions to Social Security, lack of access to private health insurance, reduced asset acquisition, and opportunity costs related to career advancement. Because women are more likely than men to leave work to care for a CSHCN, they experience these negative impacts disproportionately. The numbers and trends Foster et al¹ identify should spark further discussion about how our health care system can both better identify those families raising CSHCNs at risk for economic strain and, by extension, better support them.⁵

The study has important implications for public policy and practice change. Strategies for policy makers may include the following⁶:

- increasing funding for home- and community-based services, such as respite, transportation, home modifications, and home health care;
- enhancing paid family leave;
- improving access to skilled child home health aides and pediatric home nursing by increasing the workforce through increased reimbursement, paid training, continuing education, and unionization;
- removing a driver of FFE by implementing the Family Opportunity Act, which allows families whose income is <300% of the

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- federal poverty level to buy-in to Medicaid for their children with disabilities (including the expansive Early and Periodic Screening, Diagnostic and Treatment child health benefit);
- supporting caregivers in upcoming hot topics for the Biden administration policy priorities;
 - reimbursing for telehealth beyond the pandemic period and thereby reducing work interruptions for caregivers;
 - supporting enhanced reimbursement and other incentives such as paid training that increase access to safe and disability-inclusive child care settings; and
 - incentivizing employers in offering flextime, work-from-home options, job sharing, and other accommodations.

Although policy change must be prioritized, health care providers can also address FFE from a boots-on-the-ground perspective within local practice constructs and communities.⁷⁻¹⁰ Some families may be reluctant to declare or seek help. This may be because of perceived or actual discrimination. At the level of individual patient care, the study's findings suggest that providers consider each of the following:

- standardize SDOH screening, including employment and/or FFE, routinely in pediatric care and particularly for those families who have CSHCNs;
- pair SDOH screening with outcome measures to foster quality improvement and care coordination in practice settings;
- expand practice hours to include evenings and weekends to better accommodate working parents;
- improve parent awareness of public programs such as Head

Start and earned income tax credit;

- work with local agencies such as Family-to-Family Health Information Centers to establish access to information, resources, and system navigation for CSHCNs and their families;
- address potential discrimination through medicolegal partnerships; and
- provide letters of medical necessity for families to share with their employers, explaining what workplace accommodations are required to maintain employment and reduce turnover costs.

Foster et al¹ have shined a light on an important, often overlooked stressor for families of CSHCNs. Even if providers screen diligently for SDOHs, only half of the current SDOH tools include FFE,¹¹ further reflecting the invisible threat of FFE and calling for modification to existing tools. If we can improve our capacity to identify FFE in families caring for CSHCNs and implement the policy and practice recommendations outlined above, it is possible to imagine positive downstream effects on parent and child health, quality of life, wellness, functional outcomes, and even decreased health care system burdens as children are cared for more effectively in their communities and caregivers are able to work.

ABBREVIATIONS

CSHCN: child with special health care needs

FFE: foregone family employment

SDOH: social determinant of health

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