Children's Hospital of Philadelphia
PolicyLab

Working While Caring for Children With Complex Medical Needs

Family & Community Health

Date Posted:

Nov 13, 2018
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Anyone who has worked with kids and their families, or who is a parent themselves, has seen plainly that children do better when their caregivers do better. Although social determinants of health—factors such as education, housing and transportation—have become increasingly recognized as critical components of health care, there is still a lot we do not know about how we can support families within the pediatric health care system. One such area we wanted to explore was caregiver employment.

Through our combined work supporting some of our community health worker teams, facilitating a positive parenting intervention in primary care, speaking with families through qualitative research studies and examining policies that impact families, we have often seen caregivers' employment and work-related needs intersect with children's health care. There are some very clear examples, like the mom who runs into the parenting group 30 minutes late each week because her boss requires her to work late. But we've also noticed the indirect examples of this connection: the grandfather who had to go back to work after retiring in order to pay for his grandchild's care; the mom who was afraid to be honest with her supervisor about her child's health needs for fear of losing her job; and the parent who confided that her own mental health was suffering from the stress of working demanding hours to pay the bills and caring for her child's complex medical needs.

At Children's Hospital of Philadelphia (CHOP), we are lucky to have social workers and community health workers who can help support our families, yet brief appointments and limited time with patients only give us a glimpse of what families are experiencing day-to-day. Given its clear impact on caregivers and their children, families' employment needs are something we want to learn more about—so to take a closer look, we're turning to the experts: caregivers.

The caregiver balancing act

Better understanding employment needs directly from families is something that can impact the care we provide, as well as the policies that support employees and employers. Parents with sick children are protected by a federal law called the Family Medical Leave Act (FMLA), which provides them with up to 12 weeks of unpaid leave from their job per year. While this law gives parents the flexibility to take leave from work when their child's medical conditions call for it, they are not paid for the time they take.

We know that finances are a balancing act for many working families, even when everyone is healthy; foregoing pay is simply not an option. But when a child gets sick, parents may be left with little choice. This can be particularly concerning for parents of children with complex medical needs who may need to devote more time off to be with their child during hospitalizations, attend doctor's visits, seek specialty services and provide overall care and support for their child. And for many families who have just one working parent, the financial strain can be even more acute. Financial stability for families is vital to children's health, so if we want parents to be empowered to care for their children without fear of losing a paycheck, the first step is to learn from them about their experience with the current policies and how they can be strengthened.

Next steps to inform employment policy and practice

As our team started thinking more about the financial and occupational struggles of caregivers of children with complex medical needs, it was clear that we had more questions than answers: How are they coping with their child's illness financially and emotionally? To what extent are their jobs being impacted? What do caregivers understand about FMLA policies? How do they feel about using FMLA? If they aren't currently employed, but have a desire to work and are able, how does that impact their decisions? Where do they need more support? What resources have they identified on their own?

We needed to have a more fully-developed understanding of the diversity of parent and caregiver experiences. So based on our questions, we worked in partnership with a care coordination team at the CHOP Karabots Pediatric Care Center to develop interview questions for caregivers of children with complex medical needs. This fall, with support from Clinical Futures, we reached out to caregivers of children with complex or chronic medical issues who visit Karabots Pediatric Care Center and plan to interview 20 of them to hear about their experiences juggling a job with care for their child, and how those experiences may affect family financial stability. Once we know more about how families of children with medical complexity make decisions and prioritize their time and energy, it can generate new ideas for ways to support families' financial stability while caring for sick children.

We are happy to say that we have been strategic in developing this project to impact current practice, inform future research and, ultimately, influence policy change. We look forward to sharing the results with you in the coming months as we continue to explore new ways to provide better care and support for the whole family.

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