

# Research shows impact of caregiving on parents' employment, health

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When it comes to improving the lives of children with genetic conditions, medical research often focuses solely on the children. But there is an equally important population in need of research that a

faculty member at the University of Colorado Department of Medicine is highlighting—the caregivers.

"We need to think very broadly about how to support not just the kids—yes, that matters—but also the people caring for those kids," said Liza Creel, Ph.D., a health services researcher and associate professor in the Division of Health Care Policy and Research. "I want to do work that informs policy to support caregivers and to help families."

Recently, at the CU Department of Medicine's [Research Day](#), Creel presented her research on parents as medical caregivers, specifically looking at how caregiving is associated with their own health and employment.

"The health of these caregivers matters," said Creel, who is also involved in the Adult and Child Center for Outcomes Research and Delivery Science (ACCORDS). "These things are all connected."

## **Caregiving: A valuable but time-consuming role**

Creel said the most recent survey data from 2021 estimates that 3.9% of children in the United States—which is nearly 3 million children—have a genetic condition. This includes inherited [metabolic conditions](#), Down syndrome, blood disorders, and cystic fibrosis. However, capturing a true estimate of the prevalence of genetic conditions is difficult.

"There are many genetic conditions that are not captured in this definition, such as hearing loss," she said. "This likely underestimates the true prevalence, but right now, it's the best that we have."

These conditions are lifelong and require ongoing management and therapeutic interventions, she said. Research has found that children with genetic conditions have increased [health care utilization](#) and are more

likely to have unmet health needs than other children.

"That's attributable to both the complexity of their needs and a very limited specialized workforce in the area of genetic medicine," Creel said.

Caregivers for children with genetic conditions provide a variety of support, such as care coordination of the health care system and insurance navigation, physical support, psychosocial support, navigation of the education system, and other services like transportation.

"Caregiving can be time consuming, and many things that you do as a caregiver have to happen in regular business hours," Creel said. "That suggests that there are potential implications on their participation in the labor market and the amount of time they have to take care of their own health needs."

## **Impact of caregiving on employment, health**

To examine the associations between caregiving for a child with a genetic condition and the caregivers' health status and employment, Creel and her research team conducted a retrospective analysis using combined data from the 2016-2021 National Survey of Children's Health.

Since they had several years of data to analyze, Creel's team decided to also look at the prevalence of children with genetic conditions. They estimated that 4.4% of children in the U.S. have a genetic condition—roughly 0.5% higher than what the 2021 study showed.

Creel said her team measured caregivers' employment by using one specific variable that asked the caregiver, who was the person filling out the survey, if they had left the workforce in the past 12 months due to

caring for a child.

They ultimately found that caregivers for children with genetic conditions had increased odds of leaving the workforce compared to other caregivers. Specifically, 12.6% of caregivers for children with genetic conditions stopped working, as compared to 8.5% of caregivers for children with other special health care needs.

"Overall, among caregivers of all children, 3.7% had left the workforce in the prior year due to caring for a child," Creel said.

The research also found increased odds of leaving the workforce for caregivers of Black children, American Indian children, children who receive care from others at least 10 hours a week, and children who needed care but did not receive it. On the flip side, caregivers with college degrees and those who are married had decreased odds of leaving the workforce.

Caregivers' health status was assessed based on self-reported responses to survey questions about physical and [mental health](#). The data showed caregivers of children with genetic conditions, both mothers and fathers, reported fair or poor physical health and mental health at a higher rate than other caregivers.

For instance, 14% of mothers of a child with a genetic condition reported fair or poor physical health, as compared to 5.9% of mothers of a child who does not have a [genetic condition](#).

"When a caregiver has poor or fair physical or mental health, the likelihood of leaving the workforce doubles," Creel said.

## **Why this research matters**

Understanding the impact of caregiving on employment and caregivers' health matters for a multitude of reasons, Creel said.

In terms of health policy, the Administration for Community Living released a national strategy to support family caregivers in 2022, saying there are financial, physical, and emotional costs to being a caregiver.

"One study estimated that family caregivers lose over \$500 billion in wages every year due to caregiving, and employers experience a financial loss as well," she said.

Understanding the impacts of caregiving is also relevant to [clinical practice](#) in a lot of ways, Creel said. For instance, the health care system focuses on offering clinical interventions and prevention efforts to improve a patient's well-being. However, to achieve this goal, there are a lot of factors and steps.

"There are these enabling resources, like whether a person has health insurance or the financial resources to access the care that they need," she said.

Other factors include caregivers' predisposing characteristics, and their real and perceived need for health care services.

"These things all influence the health behaviors that we perceive in the health system, including their use of services and their application of self-care. Both of which also really matter in terms of health outcomes," she said.

Ultimately, family caregiving is an area of policy, research, and clinical importance, Creel said. Both [children](#) with genetic conditions and their caregivers face substantial medical and care coordination needs. They also potentially face limited access to subspecialty care and other

supports that facilitate access to needed care.

"Policies to support caregivers through respite, specialized childcare, coordination tools, and other resources may allow [caregivers](#) to focus their attention where it is most needed, allowing for a focus on their own health and without needing to leave the workforce," Creel said.

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