

National study documents value of family-provided medical care for children

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About half of U.S. children with special health care needs—5.6 million children—receive medical care from uncompensated family members worth billions of dollars, finds a large national study led by Boston Children's Hospital and the University of Southern California (USC).

The study, published online by the journal *Pediatrics* on December 27, is the first to systematically track parents' unpaid time providing care, as well as lost income due to parents taking time off from work.

Compared with a few decades ago, families of children with chronic conditions perform many more medical tasks at home, from maintaining and operating feeding and breathing equipment to administering physical therapy. Home care is becoming more complex as more children with [chronic conditions](#) survive and as hospital stays shorten. The National Survey of Children with Special Health Care Needs (NS-CSHCN), a telephone-based survey, has estimated that 20 percent of households with children have at least one child with [special health care](#) needs.

"If parents did not provide this care at home, children would need to stay in the hospital longer, professionals would need to come to the home, or children might not get the care that their physicians prescribe," says Mark Schuster, MD, PhD, chief of General Pediatrics at Boston Children's Hospital and senior investigator on the study. "Parents want to do everything they can for their children, but it can be a real challenge to juggle their ill child, their other children and sometimes their job."

Valuing home caregivers

The new study analyzed data from the 2009-2010 Survey, and found that the average child with special [health care](#) needs received 5.1 hours of [medical care](#) per week from family members, a total of 1.5 billion hours nationally. This excluded any extra time spent assisting children with activities of daily living. For some conditions, the average was much higher:

- cerebral palsy: 14.4 hours per week
- muscular dystrophy: 13.8 hours per week
- cystic fibrosis: 12.9 hours per week
- intellectual disability 11.2 hours per week
- traumatic brain injury/concussion: 11.9 hours per week

Nearly 12 percent of children in the study received 21 or more hours of family-provided care per week. These children were more likely to be poor or Hispanic or to be under the age of 5.

Lost wages and replacement costs

Family caregivers forego an estimated \$3,200 in earnings per child each year, amounting to \$17.6 billion in lost income nationally, the study found. Hiring health aides to do the same work at typical compensation rates would have cost an estimated \$6,400 annually per child, or \$35.7 billion nationwide. For unskilled, minimum wage help, the figures would be \$2,100 and \$11.9 billion, respectively.

"Children with [chronic health conditions](#) require a significant amount of care, and hiring a home health aide can be prohibitively expensive for a family," says John Romley, PhD, an economist at the USC Leonard D. Schaeffer Center for Health Policy and Economics and lead author of

the study. "To maintain their child's care, families often incur financial and emotional stress from reduced earnings."

The researchers suggest several ways to help family medical providers: paid family leave programs, improving care coordination, providing respite care and home visits by clinicians.

"We need to do a better job of training family caregivers in how to take care of their [children](#) at home, and we need better supports for them," says Schuster, who is also Professor of Pediatrics at Harvard Medical School.

Provided by Children's Hospital Boston

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