

Medical care of child with Down syndrome probably not a financial burden for most families

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The first study to analyze the out-of-pocket costs to families for the medical care of children and adolescents with Down syndrome finds that monthly costs - averaged over the first 18 years of life - are less than \$100 a month more than the costs for care of a typically developing child. The report published in *American Journal of Medical Genetics, Part A* also finds that the additional costs are lower when the child is older.

"I think many people will be surprised to learn that parents have few extra medical expenses when raising a child or adolescent with Down [syndrome](#), since [health insurance](#) covers most of the [costs](#)," says Brian Skotko, MD, MPP, co-director of the Massachusetts General Hospital (MGH) Down Syndrome Program and corresponding author of the paper. "After expectant couples receive a [prenatal diagnosis](#) of Down syndrome, many of them search online for information and find the lengthy list of medical conditions that might accompany their child. This can leave them to wonder whether their families will be facing financial hardship; so we wanted to provide them with accurate data reflecting the current situation."

A few previous studies have investigated the lifetime costs to society at large for an individual with Down syndrome - including non-medical costs like special education and long-term care - and were based on data gathered in California in 1988. To get a clearer picture of the additional

costs incurred by families in the current environment, Skotko and colleagues from Harvard University and Analysis Group, Inc., an economics and analytics consulting firm based in Boston, analyzed data from the OptumHealth Reporting and Insights database, which includes insurance claims information for individuals covered by 82 self-insured Fortune 500 companies across the U.S.

From data covering early 1999 to early 2013, the researchers first identified more than 5,000 individuals under the age of 18 who had at least one claim associated with a Down syndrome diagnosis. Then they matched each of them with four other covered individuals of the same age with similar demographic characteristics - resulting in a study group of 5,167 children with Down syndrome and 20,668 matched controls with no diagnosed chromosomal conditions. For purposes of comparison, the groups were divided into age categories: birth to under age 1, age 1 to under 3, age 3 to under 5, age 5 to under 13, and age 13 to under 18. Since data reflected claims paid over 14 years, information on individuals in both groups could appear under several age categories over time.

The difference between the out-of-pocket costs - reflecting things like deductibles, co-payments, inpatient and outpatient care, emergency care, and prescriptions - for the [medical care](#) of children with Down syndrome and costs for typically developing children was greatest during the first year of life, when many children with Down syndrome require surgery to correct heart defects or other complications. The average annual cost difference - which was \$1,907 during that first year - dropped during each higher age category, reaching an annual difference of \$537 for the 13 to 18 age category.

The total average out-of-pocket costs across the first 18 years of life to families of children with Down syndrome were \$18,248 higher - an additional \$1,014 a year or \$84 a month - than those for a typically

developing child. The total average increased costs for all health care expenditures, including those paid by health insurance, for children with Down syndrome over the first 18 years was \$230,000 - \$1,065 a month - with age-category differences ranging from \$80,864 in the first year of life to a difference of \$5,627 a year for the 13 to 18 age category.

The authors note that some out-of-pocket costs such as emergency room visits and prescriptions were actually lower for children with Down syndrome across all age categories. "Many parents have told me that their child with Down syndrome is the least expensive one in their family," says Skotko, who is an assistant professor of Pediatrics at Harvard Medical School. "On the other hand, many obstetricians have mentioned to me that these children end up being very expensive for their families, so I expect the results of our study will surprise many physicians but have many parents nodding their heads."

Skotko adds, "I hope our findings that [children](#) with Down syndrome do not end up incurring large incremental medical expenses for their families provides an additional, helpful piece of information for the complex counseling sessions for parents who have received a prenatal diagnosis of Down syndrome. Parents today have an array of financial planning and investment options - including special needs trusts - so I hope our findings can help families better prepare for their own financial futures."

More information: *American Journal of Medical Genetics, Part A*, [DOI: 10.1002/ajmg.a.38050](https://doi.org/10.1002/ajmg.a.38050)

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