

# Families' Financial Burden of Raising Children with Autism: Association with State Medicaid Spending



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## Overview

There is a robust association between state Medicaid spending for children with disabilities and financial burdens incurred by families raising children with autism, whose care is exceptionally costly. Families living in states with more generous Medicaid programs, measured in per capita spending for disabled children, report reduced health care costs incurred in caring for their children with autism. Overall, 78% of families with a child with autism had health care expenditures for their child for the prior 12 months. Among these families, 54% reported expenditures over \$500, with 34% spending over 3% of their total household income. Families living in states with higher per capita Medicaid spending for disabled children were significantly *less likely* to report having annual expenditures greater than \$500 or exceeding 3% of total household income for their children with autism. To strengthen family efforts to secure adequate health care for their vulnerable children with autism, states should consider expanding their Medicaid spending for children with disabilities.

Children with autism need a wide range of health care services including medical, behavioral, and other specialized therapies. The costs of these services are often not fully covered by health insurance, and families incur high out-of-pocket costs to meet the needs of their child's care needs. Typical private behavioral health coverage for children often excludes autism altogether.<sup>1-4</sup> Medicaid therefore provides important coverage for these families.<sup>4-7</sup>

Greater financial burden is associated with parental work loss and other negative outcomes for families of special needs children.<sup>7-8</sup> Children with autism have greater problems accessing care, have unmet need for care and their parents have significantly higher financial burden than families whose children have other special health care needs.<sup>9</sup>

This *Lurie Institute for Disability Policy Brief* reports findings from an analysis of data from the 2005-06 National Survey of Children with Special Health Care Needs. We examined the relationship between state per capita Medicaid spending for disabled children and the out-of-pocket expenses incurred by families raising children with autism.

## Out-of-pocket Spending by Families Raising Children with Autism

- 78% reported having some out-of-pocket financial expenditures related to the health care of their child, beyond insurance co-pays, deductibles and co-insurance.
- 54% of these families had annual out-of-pocket spending of more than \$500.
- 34% of these families had annual out-of-pocket spending that exceeded 3% of their total household income.

## State Medicaid and family spending for children with Autism

- Controlling for child, family and state characteristics (including severity of the child's condition, health insurance, race, ethnicity, and income), for every \$100 of state per capita Medicaid spending, families of children with autism who had out of pocket spending had 60% lower odds of having out-of-pocket costs over \$500, and 42% lower odds of having out-of-pocket spending above 3% of their total household income.

### Summary & Recommendations

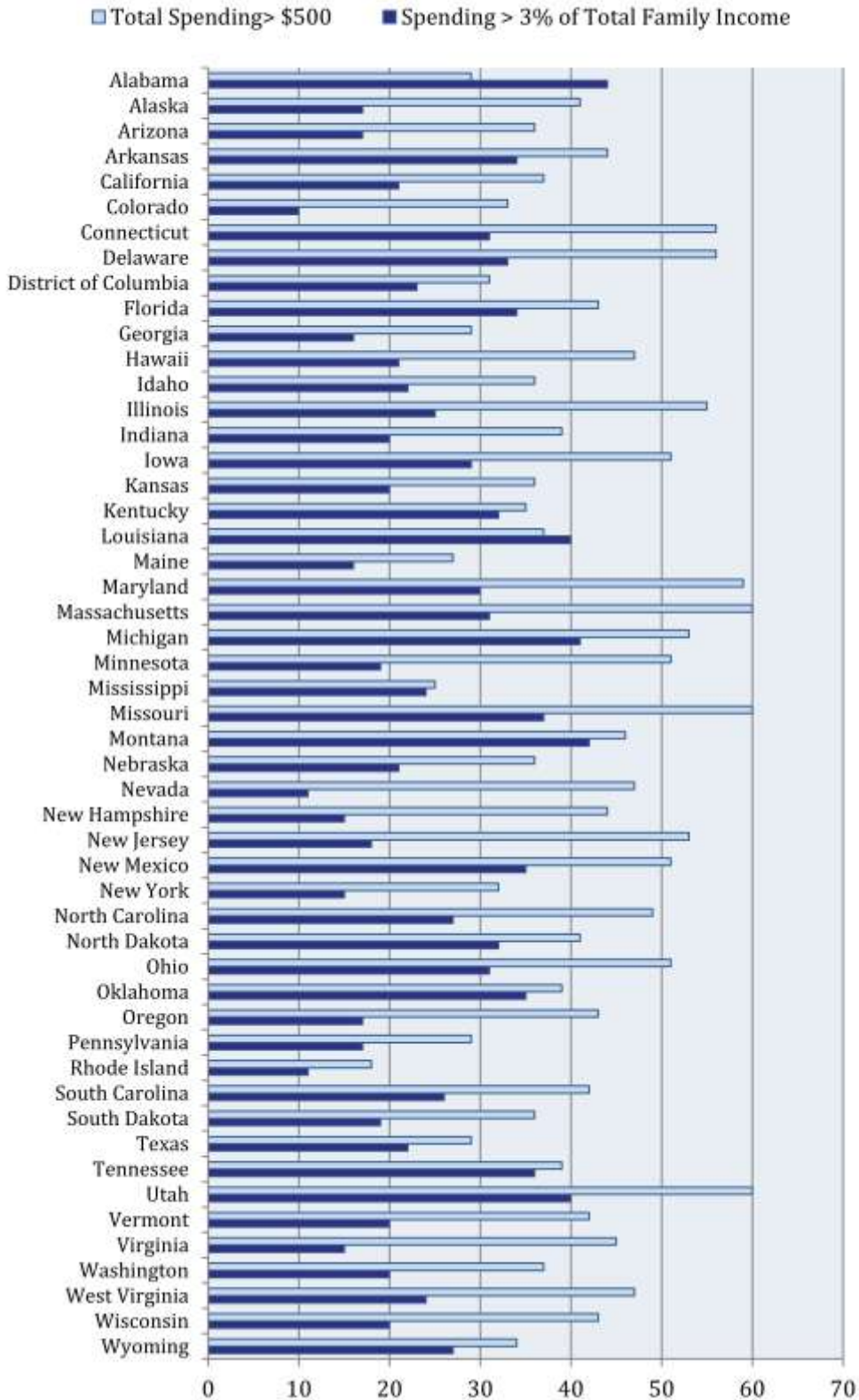
Families have exceptionally high out-of-pocket spending for their children with autism – more than one-third of families that had any out-of-pocket expenses spent *more than 3% of their total household income* for their child's health care costs, above and beyond co-pays, co-insurance and deductibles. There is a robust relationship between state Medicaid spending and the expenses families incur. Even after controlling for family and child characteristics, families living in states with more generous Medicaid spending have markedly lower expenditures for their children with autism than families living in less generous states.

The current situation for families of children with autism is likely to worsen as states take action to cut their Medicaid spending. Since families raising children with disabilities face elevated levels of material hardship and deprivation,<sup>10</sup> which likely have a deleterious effect on the children's well-being, policymakers should consider ways to strengthen Medicaid and to reduce the financial burdens these families incur to care for their children with autism.

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### Percentage of Families Raising Children with Autism with High Financial Burden, by State



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