State Insurance Parity Legislation Reduces Financial Burden of Families with Children with Autism



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#### **Overview**

Many private health insurance plans exclude or limit autism-related services (e.g. diagnostic or behavioral support). Advocates have succeeded in having states enact legislation that requires insurance reform to better include autism-related services. This reform has taken shape in either mandated coverage, requiring private insurers to provide mandated coverage of certain autism-related services up to a prescribed limit, or parity laws requiring insurers to provide autism coverage equitable to coverage for individuals with other health needs. We examined the impact of states' insurance reforms on the financial burden of families with children with autism and found that families in states with mandated coverage were 28% less likely to have out-of-pocket expenses exceeding \$500. Families living in states with parity legislation were 29% less likely to have out-of-pocket expenses over \$500. This study provides initial evidence that state parity legislation that requires private insurers to cover autism reduces families' financial burden.

Children with autism have increased and complex health care and ancillary needs compared to other children <sup>1, 2, 3, 4</sup>. These increased needs are often expensive both to the public <sup>1, 5, 4</sup> and private <sup>6</sup> insurance systems. In addition, compared to families with children with other types of disabilities or health conditions, families of children with autism faced disproportionately higher costs for care <sup>7, 8, 9, 3, 10</sup>.

Many private insurers exclude autism or autism-related care from their coverage <sup>11</sup>. Autism advocates have pushed for state legislation that mandates coverage of health care and ancillary services for children with autism <sup>12</sup>. As of September 2012, 43 states had enacted some form of insurance reform. These reforms have taken different forms. Parity laws require private insurers to provide coverage for autism-related needs equal to coverage provided for other kinds of needs. In addition to parity laws, some states have passed legislative mandates requiring coverage of certain types of services used by children with autism up to prescribed limits.

We examined the impact of these mandated reform laws on the financial burden of families with children with autism, using data from the 2005-2006 National Survey of Children with Special Health Care Needs.

### **Findings**

Among all families of children with autism, 78% reported some health care expenditures for their child in the past year. Among those reporting out-of-pocket costs, 21% reported costs ranging from \$1-\$249, 24% reported costs between \$250 -\$500, and 55% reported costs exceeding \$500 for the year.

Families living in states with parity legislation were 29% less likely to have out-of-pocket costs exceeding \$500. Families living in states with mandated coverage of specific autism services were 28% less likely to have costs exceeding \$500. These results persisted after we controlled for a host of state, family, and child characteristics. Table 1 shows the percentage of families in each state with any spending, and annual spending of \$200-\$500 or >\$500 as well as state rankings.

Table 1

	Type of		Relative	
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State	2005	% of Families	Income	Rank
Massachusetts	None	60	3	1
Utah	None	60	1	2
Missouri	None	60	2	3
Maryland	None	59	2	4
Delaware	None	56	0	5
Connecticut	None	56	1	6
Illinois	None	55	5	7
Michigan	None	53	3	8
New Jersey	None	53	5	9
New Mexico	None	51	0	10
Iowa	Other	51	1	11
Minnesota	None	51	2	12
Ohio	None	51	2	13
North Carolina	None	49	3	14
Hawaii	None	47	0	15
West Virginia	None	47	1	16
Nevada	None	47	1	17
Montana	None	46	0	18
Virginia	Parity	45	2	19
New				
Hampshire	Parity	44	1	20
Arkansas	None	44	1	21
Florida	None	43	5	22
Wisconsin	None	43	1	23
Oregon	None	43	1	24
South Carolina	None	42	1	25
Vermont	None	42	0	26
North Dakota	None	41	0	27
Alaska	None	41	0	28
Indiana	Other	39	3	29
Tennessee	Other	39	1	30

# **Table 1**Continued

Oklahoma	None	39	0	31
Louisiana	None	37	2	32
Washington	None	37	2	33
California	Parity	37	10	34
Idaho	None	36	0	35
South Dakota	None	36	0	36
Kansas	Other	36	1	37
Arizona	None	36	2	38
Nebraska	None	36	0	39
Kentucky	Other	35	1	40
Wyoming	None	34	0	41
Colorado	None	33	2	42
New York	None	32	5	43
Dist Col	None	31	0	44
Pennsylvania	None	29	6	45
Alabama	None	29	2	46
Georgia	None	29	4	47
Texas	None	29	11	48
Maine	Parity	27	1	49
Mississippi	None	25	1	50
Rhode Island	None	18	1	51

### **Summary & Recommendations**

There is significant state-level variability in the amount of financial burden experienced by families with children with autism, even after we controlled for state, individual and family characteristics. Families living in states without legislative mandates had significantly higher out-of-pocket costs as compared to families living in states with mandates. While we cannot infer causality from our study, these findings provide early evidence of the potential impact of state insurance parity laws on families with children with autism. Policymakers should consider such mandates and other potential initiatives that may reduce families' financial burden.

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### References

- 1. Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatric and Adolescent Medicine*, 161, 343-349.
- 2. Gurney, J. G., McPheeters, M. L., & Davis, M. M. (2006). Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Archives of Pediatric and Adolescent Medicine*, 160, 825-830.
- 3. Kogan, M. D., Strickland, B. B., Blumberg, S. J., Sing, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122*, e1149-e1158.
- Mandell, D. S., Cao, J., Ittenbach, R., & Pinto-Martin, J. (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*, 36, 475-485.
- 5. Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation*, 41, 329-339.
- 6. Leslie, D. L., & Martin, A., (2007). Health care expenditures associated with autism spectrum disorders. *Archives of Pediatric and Adolescent Medicine*, 161, 350-355.
- 7. Fujiura, G. T., Roccoforte, J. A., & Braddock, D. (1994). Costs of family care for adults with mental retardation and related developmental disabilities. *American Journal of Mental Retardation*, 99, 250-261.
- 8. Jarbrink, K. (2007). The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*, 11, 453-463.
- 9. Jarbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *Journal of Autism Developmental Disorders*, 33, 395-402.
- 10. Wang, L., & Leslie, D. L. (2010). Health care expenditure for children with autism spectrum disorders in Medicaid. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49, 1165-1171.
- 11. Peele, P. B., Lave, J. R., & Kelleher, K. J. (2002). Exclusions and limitations in children's behavioral health care coverage. *Psychiatric Services*, *53*, 591-594.
- 12. Autism Speaks. (2007). Arguments in support of private insurance coverage of autism-related services. Available at <a href="http://dhhs.nv.gov/autism/TaskForce/2008/ATF\_Report\_08/Appendix%20E.pdf">http://dhhs.nv.gov/autism/TaskForce/2008/ATF\_Report\_08/Appendix%20E.pdf</a>