Study examines autism law, financial burdens

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While the causes of autism continue to be debated and bandied about, real families who have children with autism spectrum disorders are left to struggle with expensive health care needs. These costs can be devastating - but they can also be markedly different if the family lives in Massachusetts or Maine.

Advocates in many states have lobbied for legislation to force private insurers to offer autism services at the same levels as other covered services. A new study by Susan Parish, the Nancy Lurie Marks Professor of Disability Policy at the Heller School for Social Policy and Management, looks at the effectiveness of these so-called parity laws in reducing families' financial burdens. It was published in the journal *Intellectual and Development Disabilities*.

According to the National Conference of State Legislators, parity, as it relates to mental health and substance abuse, prohibits insurers or health care service plans from discriminating between coverage offered for mental illness, serious mental illness, substance abuse, and other physical disorders and diseases. In short, parity requires insurers to provide the same level of benefits for mental illness, serious mental illness or substance abuse as for other physical disorders and diseases. These benefits include visit limits, deductibles, copayments, and lifetime and annual limits.

"We found that families who live in states that have passed parity legislation spent considerably less for their children with autism than

families living in states without such legislation," Parish says.

The study examined data from the National Survey of Children with Special Health Care Needs, which includes a group of more than 2,000 children with autism living across the United States.

Data revealed that more than one-third of the families reported spending more than three percent of their gross annual incomes on services for their children with autism.

"Families raising children with autism incur exceptionally high out-of-pocket costs. These costs pay for things that insurance doesn't fully cover, like therapies and behavior management interventions," says Parish. "These services are often critically important to the well-being and development of children with autism."

Where families live really matters, Parish concluded. Families living in states that had enacted so-called parity legislation had much lower financial burden than families who lived in states without such legislative protections.

Data found that 60 percent of families in Massachusetts, Missouri, and Utah had out-of-pocket in excess of $500 annually. By comparison, 27 percent of Maine families spent above $500 annually. At the time the survey was collected, in 2005, Massachusetts, Missouri and Utah did not have parity legislation, but Maine did. Furthermore, these findings were robust. Even after controlling for a host of characteristics including severity of the child's impairment, family income, and state wealth, families' financial burden was much less if they lived in states that had passed parity legislation.

According to the advocacy group Autism Speaks, 30 states currently have enacted some form of legislation.

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