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Understanding and Addressing the Impact of Autism on the Family

Editor's note: Children and adults with autism spectrum disorders (ASDs) have needs that challenge our systems of care. A new study estimates ASDs cost more than \$126 billion each year in the U.S. – an amount that reflects both the costs of providing educational and medical services as well as the costs of *not* intervening early and effectively enough to prevent lifelong disability. This Issue Brief summarizes the implications of childhood autism for parental employment and earnings, and analyzes whether community-based services can reduce costly, psychiatric hospitalizations of children with ASDs.

Autism care is complex, costly, and fragmented

Autism spectrum disorders (ASDs) are a complex set of disorders characterized by impairments in social interaction and communication, often accompanied by repetitive behavior patterns. They manifest in early childhood, by definition by 3 years of age. Children with ASDs can have other psychiatric symptoms, such as anxiety and hyperactivity, and many have self-injurious or aggressive behavior.

- The number of children diagnosed with ASDs is growing. The CDC estimates that among 8-year-olds, 1 in 88 children have ASDs, an increase of 23% since 2006. It is not clear how much of this increase is an actual increase in prevalence, and how much is due to better identification of cases, because of improved awareness and access to care.
- The lifetime costs of autism, including direct and indirect costs, have been recently estimated at \$1.4 million for someone without intellectual disability and \$2.3 million for someone with intellectual disability. Non-medical costs, such as intervention services, special education, child day care, and residential placements for adults account for the largest proportion of costs.
- Recommended interventions for children with ASDs include intensive and prolonged community-based behavior and socialization therapies. Interventions based on principles of applied behavior analysis have improved outcomes for some, though not all, children. Because of the challenging behaviors that children with ASDs often exhibit, they and their families also can benefit from services such as respite and home health care.

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- Autism care is fragmented across health and educational systems, and insurers sometimes exclude these therapies as “non-medical.” States have tried to address financial barriers to autism care through the use of Medicaid home and community-based waivers (nine states) and private insurance mandates (26 states).

Study looks at the economic impact of ASDs on family

To gain a more comprehensive view of the economic impact of ASDs on the family, Mandell and colleagues studied how raising a child with ASD might relate to changes in parental employment. They wanted to know how having a child with ASD might interfere with employment and earnings. They assessed labor force participation and earnings for parents with children with ASDs, compared to parents of children with another health limitation and children with no limitation.

- The researchers used the 2002-2008 Medical Expenditure Panel Survey (MEPS), a nationally representative survey of U.S. households. MEPS collects information on medical conditions, health service use, health status, and health insurance for each member of the household.
- The study included 261 children with ASDs, 2,921 children with another health limitation, and 64,349 children with no health limitation.
- The study analyzed labor market outcomes for mothers and fathers, including employment status, hours of work per week, and annual earnings. The analyses adjusted for other factors that could contribute to differences in income, including parental age, education, race, region, health status, and family size.

Mothers of children with ASDs earn significantly less than other mothers

Mothers and fathers of children with ASDs were older and more educated than other parents. After adjusting for these and other factors, the study found that childhood autism is associated with substantially reduced earnings of mothers.

- Mothers of children with ASDs earn an average of 35% (\$7,189) less than mothers of children with another health limitation, and 56% (\$14,755) less than mothers of children with no health limitation. They are 6% less likely to be employed, and work an average of 7 hours less per week than mothers of children with no health limitation.
 - There were no differences in fathers’ labor market outcomes across the three groups. On average, children with ASDs are 9% less likely to have both parents working than children with no health limitation.
 - Families of children with ASDs work five hours less and earn 21% (\$10,416) less than those of children with another health limitation and 28% (\$17,763) less than those of children with no health limitation.
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Study assesses the interplay of outpatient services and psychiatric hospitalizations

Mandell and colleagues examined whether increased community services are associated with decreased psychiatric hospitalizations for children and young adults with ASDs. Although hospitalization is sometimes warranted, it is often an undesired outcome that may represent a failure to provide appropriate outpatient care.

- The study used national Medicaid claims data from 2003–2004. It included 28,481 Medicaid-enrolled children and young adults aged 5 through 21 who carried a primary diagnosis of ASD.
- The researchers analyzed the risk of hospitalization as a function of the outpatient services used in the previous two months. Outpatient services were categorized into therapeutic services, such as occupational, physical, talk, and family therapies, and respite services, which offer caregiving relief to families through home health aides and personal care assistants.
- Because states vary in their Medicaid policies and the resources available to provide therapy and support to children with ASDs, the researchers included state characteristics, which help adjust for these differences in their analyses. They also adjusted for child characteristics such as age, race/ethnicity, and sex.

Respite care is associated with a decrease in hospitalization, but outpatient therapies are not

The results confirm the importance of respite care for families of children with disabilities, and suggest that it has a role in reducing hospitalizations.

- During the study year, 675 patients (2.4% of the sample) had at least one psychiatric hospitalization. Females were less likely to be hospitalized than males; patients aged 13 to 17, and those in foster care, were more likely to be hospitalized than other children.
- Adjusting for other characteristics, each \$1,000 Medicaid spent on respite care was associated with an 8% decrease in hospitalization.
- Use of therapeutic services, however, was not associated with a lowered risk for hospitalization. This finding is suspect, however, because claims data have no measure of the severity of illness. More severely affected children might have needed more outpatient services and also needed more inpatient services, leading to the erroneous conclusion that more outpatient services are not associated with the use of inpatient services.

POLICY IMPLICATIONS

Raising a child with ASD is fraught with challenges and can place considerable financial and emotional stress on families. These studies provide insight into how this stress affects the labor participation of mothers, and how it might contribute to hospitalizations that could be avoided with respite care.

- These findings underscore the need to design both health care and workplace policies that address the comprehensive burden of ASDs.
- Despite the importance of respite care, these services are not universally available and not always reimbursed. States have options within Medicaid to

POLICY IMPLICATIONS

Continued

ensure the availability of respite and other community-based services, but many have not exercised them.

- The results also indicate the need to examine the characteristics and effectiveness of therapeutic services provided to children with ASDs in the community. Local practitioners often lack experience and training in working with children with ASDs or in using the specific behavioral strategies that have proven effective in studies.

This Issue Brief is based on the following articles: Z. Cidav, S.C. Marcus, D.S. Mandell. Implications of childhood autism for parental employment and earnings. Pediatrics, April 2012, vol. 129, pp. 617-623; D.S. Mandell, M. Xie, K.H. Morales, L. Lawer, M. McCarthy, S.C. Marcus. The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. Archives of Pediatric and Adolescent Medicine, January 2012, vol. 166, pp. 68-73.

*Published by the Leonard Davis Institute of Health Economics, University of Pennsylvania, 3641 Locust Walk, Philadelphia, PA 19104.
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Published by the
Leonard Davis Institute
of Health Economics
University of Pennsylvania

Issue Brief



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