

# THE FINANCIAL BURDEN OF AUTISM SPECTRUM DISORDER

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## Introduction and Background

- The prevalence of Autism Spectrum Disorder (ASD) is growing yearly with one in eight children receiving an ASD diagnosis, and rates are predicted to increase.
- Many children with ASD have other comorbid disorders causing an increased dependence on the health care system.
- Several studies have shown that total health care expenditures for children with ASD were higher than for other disorders.
- Although we know children with ASD spend more on health care services, there is little evidence examining the financial impact these families experience compared to families of children with other special health care needs (CSHCN).
- This study examines how health system and coverage inadequacies impact families of children with ASD compared to families of CSHCN.

## Methods

### Participants

- Data from the 2009-2010 National Survey of Children with Special Health Care Needs was used for this study.
- Participants 0-17 years of age with a physical or mental health diagnosis were included in the study.

### Analysis

- Three main outcome variables were included in the analysis including: the families out-of-pocket health care costs, parents perceived adequacy of health insurance, and parent's job stability and transferability ("job lock").
- Analysis of Variance (ANOVA) and Chi-square tests were used to compare the frequency of outcome variables between groups.
- Complex sampling methodology within SPSS statistical software was used for all analysis.

## Demographics

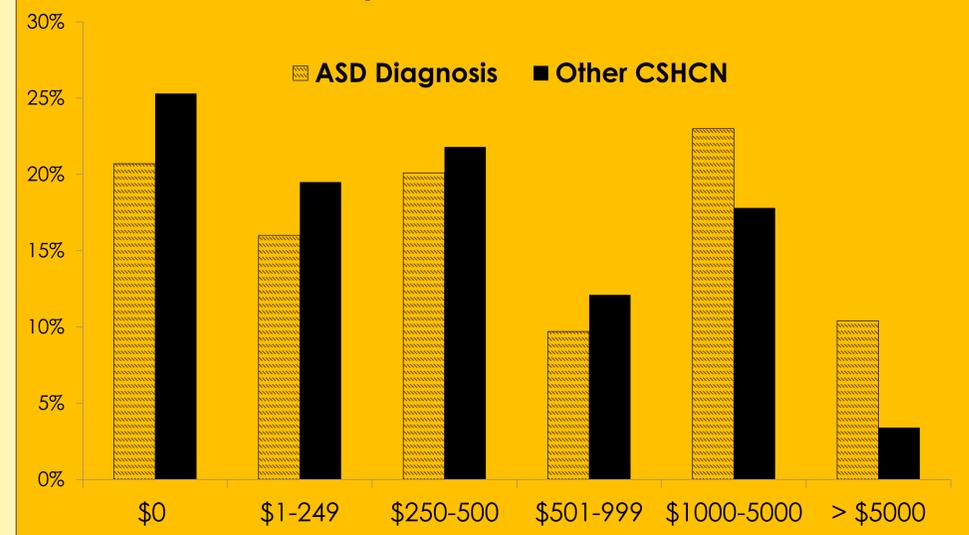
	ASD	Other SHCN
Age (mean)*	9.77	10.35
Gender (male)*	80.6%	57.8%
Race*		
White	62.7%	59.4%
African American	10.4%	16.3%
Hispanic	16.4%	16.7%
Other	10.6%	7.6%
Parents Highest Level of Education*		
Less than High School	7.8%	11.1%
High School Graduate	16.0%	20.3%
More than High School	76.2%	68.7%
Poverty Level		
>100%	18.9%	22.0%
100-199%	21.7%	21.8%
200-399%	31.7%	28.5%
<400%	27.7%	27.8%

\* Indicated statistical significance between groups,  $p > .05$

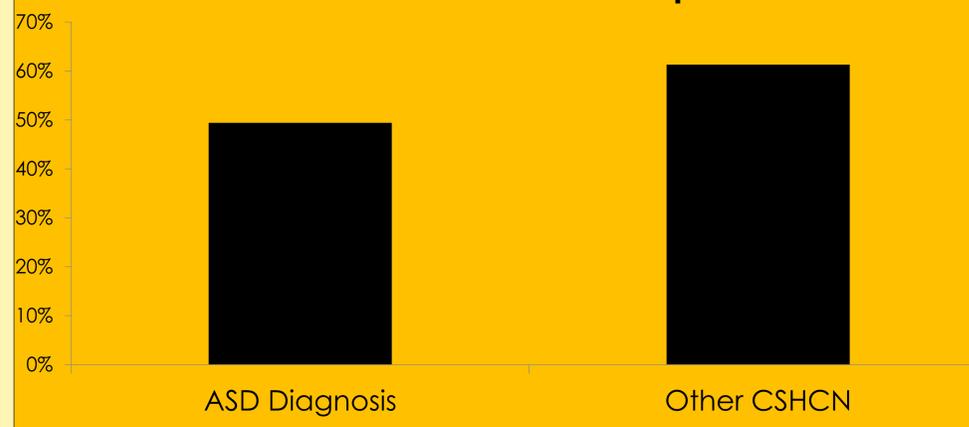
## Demographics Continued

	ASD	Other SHCN
Family Structure		
Two Parent Household	70.1%	66.0%
Single Mother	22.2%	26.1%
Other	7.7%	7.9%
Type of Insurance*		
Private	44.5%	51.8%
Public	32.7%	34.4%
Both Private and Public	17.1%	7.0%
Other Comprehensive Health Insurance	3.0%	3.2%
Uninsured	2.7%	3.6%
Activity Limitation*		
Daily activities never affected	6.1%	36.5%
Daily activities mod. affected sometimes	25.2%	40.2%
Daily activities consistently affected, often	68.7%	23.4%

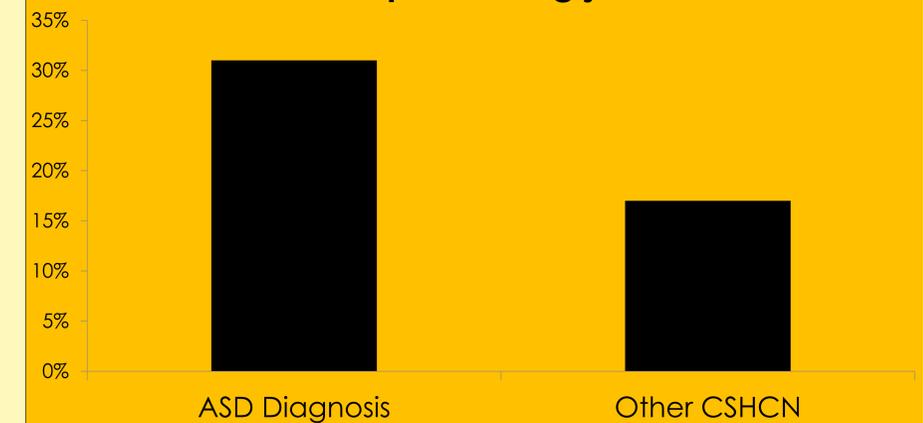
## Out-of-pocket health care costs\*



## Health insurance is adequate\*



## Parent experiencing job lock\*



## Results

### Summary

- Children with ASD were more severely impacted by their disability than other CSHCN.
- Families of children with ASD experienced more financial and employment hardships across the board.

### Out-of-Pocket Costs

- Over three times as many families with children with ASD paid over \$5000 in out-of-pocket costs annually compared to families with CSHCN
- Significantly more families who had children with ASD paid over \$1000 in out-of-pocket costs than families with CSHCN

### Adequacy of Health Insurance

- Adequacy of health insurance was evaluated by seeing if the parents or caregivers felt that their insurance covered the services needed, had reasonable costs, and that the child's health insurance allowed the child to see the health care provider that they needed.
- Half of the children with ASD had inadequate health insurance coverage compared to 39% of those with CSHCN.

### Job Lock

- Families with ASD reported job lock (31%), almost twice as often as for those with CSHCN (17%).

## Conclusion

- Families of children with ASD face significant financial stress.
- This study identified a significant disparity in financial and work related impact for families of children with ASD compared to those with CSHCN.
- Although many families of children with ASD felt their health insurance wasn't sufficient they reported being unable to leave their current job due to fear of even less adequate insurance.
- Further research is needed to better understand this disparity and how to use this information to improve access to affordable health care.