The prevalence of Autism Spectrum Disorder (ASD) is growing. Over three times as many families are affected. Although we know children with ASD spend more on health care than other CSHCN, many families of children with ASD felt their health insurance wasn’t sufficient to use this information to improve access to affordable health care. Complex sampling methodology within SPSS statistical software was used for all analysis.

### 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: 1. the families out-of-pocket health care costs, 2. parents perceived adequacy of health insurance, and 3. job lock and transferability ("job lock").
- Analysis of Variance (ANOVA) and Chi-square tests were used to compare the frequency of outcome variables between groups.

#### Demographics

- **Age (mean)**: ASD 9.77, Other SHCN 10.35
- **Gender (male)**: ASD 80.6%, Other SHCN 57.8%
- **Race**
  - White: ASD 62.7%, Other SHCN 59.4%
  - African American: ASD 10.4%, Other SHCN 16.3%
  - Hispanic: ASD 16.4%, Other SHCN 16.7%
  - Other: ASD 10.6%, Other SHCN 7.6%
- **Parents Highest Level of Education**
  - Less than High School: ASD 7.8%, Other SHCN 11.1%
  - High School Graduate: ASD 16.0%, Other SHCN 20.3%
  - More than High School: ASD 76.2%, Other SHCN 68.7%
- **Poverty Level**
  - >100%: ASD 18.9%, Other SHCN 22.0%
  - 100-199%: ASD 21.7%, Other SHCN 21.8%
  - 200-399%: ASD 31.7%, Other SHCN 28.5%
  - <400%: ASD 27.3%, Other SHCN 27.8%

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

- **ASD Diagnosis**: $0, $1-249, $250-500, $501-999, $1000-5000, >$5000
- **Other SHCN**: $0, $1-249, $250-500, $501-999, $1000-5000, >$5000

#### Health insurance is adequate

- **ASD Diagnosis**: 25.2%, Other SHCN 36.0%

### 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 OSHCN.

#### Job Lock
- Families with ASD reported job lock (31%), almost twice as often as for those with OSHCN (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 OSHCN.
- 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.

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