

## **Racial and Ethnic Disparities in Family Burden and the Access, Service Utilization, and Quality of Health Care for Children with Autism**

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### **Project Abstract**

Numerous US policy objectives call for research and interventions to reduce racial/ethnic health care disparities. However, few studies have addressed this important issue for children in general, and no studies have examined the extent or correlates of racial/ethnic health care disparities for children with autism and other developmental disabilities. Although research has established that Black and Hispanic children are less likely to be diagnosed than White children, and Hispanic children are diagnosed at a significantly later age than their White counterparts, little other evidence exists about the extent of racial/ethnic health care disparities in this population.

Therefore, this study has four aims: (1) To identify the extent and correlates of racial and ethnic disparities in health care access, health care quality and health service utilization of Black and Hispanic children with autism and other developmental disabilities; (2) To examine differences in the health care access, health care quality, and health service utilization of Hispanic children with autism and other developmental disabilities by one dimension of acculturation, parental primary language. Parents whose primary language is Spanish are less likely to be acculturated to US conceptualizations of disability and the US health service system; (3) To identify the extent and correlates of racial and ethnic family burden disparities of Black and Hispanic children with autism and other developmental disabilities; and (4) To examine differences in the family burden of Hispanic children with autism and other developmental disabilities by parental primary language. The four major outcomes include: (a) **family burden**, measured as absolute out-of-pocket spending, spending relative to family income, whether parents stopped or reduced work to care for the child, and parents' need for mental health services; (b) **health care access**, measured by insurance coverage, continuity of coverage, adequacy of coverage, having a usual care provider; (c) **health care service utilization**, measured by number of visits, receipt of preventive care, timely receipt of needed care, referrals to specialty care, receipt of specialty needed care; and (d) **health care quality**, measured as receipt of care within a medical home, parental satisfaction with care, culturally competent care, and receipt of professional care coordination. The study will specifically determine whether patterns of racial/ethnic disparities persist after controlling for socioeconomic status, severity of impairment, and health insurance status. Identifying the correlates of racial/ethnic health care disparities is imperative as a first step in developing interventions that effectively promote optimal development of vulnerable children with autism. Using existing data from the 2005-06 wave of the National Survey of Children with Special Health Care Needs, we will conduct bivariate and multivariate logistic regression analyses. Models will be estimated with appropriate weighting and variance adjustment. The results of the study will be published in four papers, presented at two scientific or policy meetings, and disseminated via at least two fact sheets.

Key words: Access to Health Care, Children with Special Health Needs, Autism, Developmental Disabilities, Families, Health Care Quality, Health Care Utilization.