Racial Disparities in the Quality of Health Care Provider Interactions for Children with Autism and other Developmental Disabilities

December 2014

Sandra Magaña, Susan Parish, Esther Son, Leah Igdalsky

Overview

This study analyzed racial disparities in the quality of interactions with health care providers for children with autism and other developmental disabilities. We analyzed data from the National Survey of Children with Special Health Care Needs. The purpose of this study was to examine whether there was a change in racial and ethnic disparities in the quality of provider relationships among children with autism and other developmental disabilities. We examined changes between 2005-06 and 2009-10.

We found no statistical differences across years, indicating that racial disparities in the quality of health care provider interactions for children with autism and other developmental disabilities were unchanged. Despite ongoing policy discussions about the importance of reducing health care disparities, these findings indicate that more assertive policy measures are warranted.

In 2012, the American Academy of Pediatrics released a policy statement highlighting the importance of integrating patient and family-centered care across all pediatric healthcare settings. High quality provider interactions with parents and patients are core, requisite features of family-centered care. Previous research using the 2005-06 National Survey of Children with Special Health Care Needs found significant racial and ethnic disparities in the quality of provider interactions for children with developmental disabilities. While research on racial and ethnic disparities among children with autism and other developmental disabilities is just emerging, researchers who analyzed this population using the National Survey of Children with Special Health Care Needs found similar disparities.

For this study, children with autism and developmental disabilities (autism/DD) were identified as children whose parents or guardians responded affirmatively to both (1) they were ever told by a health care provider that the child had the condition and (2) the child currently has one of the following conditions: autism, Asperger’s disorder, pervasive developmental disorder, or other autism spectrum disorder, intellectual disabilities or mental retardation, Down syndrome, cerebral palsy, or developmental delay. We focused on White, Black, and Latino children with autism/DD.

We used five indicators of the quality of health care providers’ interactions: (1) provider usually or always listened carefully to the parent; (2) provider usually or always provided needed information; (3) provider usually or always helped parents feel like partner; (4) provider usually or always spent enough time with child; and (5) provider was usually or always sensitive to family’s values and customs. We compared these measures in 2009-10 to those from the 2005-06 survey.
Findings

In both 2005/06 and 2009/10:
- Black and Latino parents of children with autism/DD were significantly less likely than White parents to report their health care provider spent enough time with their child, or was sensitive to the family’s values and customs

In 2005/06:
- Latino parents were significantly less likely to report that their provider gave them needed information

In 2009/10:
- Black parents were significantly less likely to report that their provider listened carefully to them or made them feel like a partner

Summary & Recommendations

To the best of our knowledge, this is the first investigation of changes over time in racial and ethnic disparities in the quality of health care providers’ interactions with parents raising children with autism/DD. Racial and ethnic disparities were evident for four of the five indicators of provider interaction quality in 2009/2010. Importantly, the study found no evidence that disparities declined over time. Policymakers must consider robust and aggressive measures, including payment-linked incentives and penalties for inadequate care, for health care providers in order to effectively address these disparities.
Authors & Acknowledgements


Sandra Magaña, PhD, MSW, Institute on Disability and Human Development, University of Illinois at Chicago; Susan L. Parish, PhD, MSW, Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University; Esther Son, PhD, Department of Social Work, College of Staten Island/CUNY; and Leah Igdalsky, Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University.

References