

Study finds racial, ethnic disparities in family-centered care for kids with special health needs

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The concept of family-centered care for children with special health care needs is based on the understanding that a partnership among patients, families and health care professionals is essential to providing quality care.

Components of family-centered care include adequate time spent with the patient, attentive listening, care that is sensitive to the family's values and customs, the provision of necessary information, and helping the family feel like a partner in the child's care.

While previous studies have indicated that racial and <u>ethnic disparities</u> exist in family-centered care, the research has not highlighted specific components associated with such disparities.

Now, a new, nationally representative study by researchers from UCLA and the University of Texas Southwestern Medical Center has found that African American and Latino children with special health care needs, and those who come from households in which the primary language is not English, are less likely to receive family-centered care than are white children and those from households where English is the primary language.

In addition, the study authors found that there were disparities in two critical components of care provided to African American and Latino children and those from households where English is not the primary language: having adequate time with the child's health care provider and receiving care that is sensitive to the family's values and customs. The researchers said that improvements in these components could greatly reduce these disparities for family-centered care.

The findings, which will be published in the June

issue of the journal *Pediatrics*, are currently available online.

This is the first study to demonstrate significant racial/ethnic and language disparities, both in family-centered care overall and in certain components of family-centered care. The study controlled for several factors, including child health, socioeconomics and health care access, among children with special health care needs in the United States.

"We were surprised that these wide disparities persisted, even after controlling for a number of socioeconomic and health factors," said lead author Dr. Tumaini R. Coker, assistant professor of pediatrics at Mattel Children's Hospital UCLA and a natural scientist at the RAND Corp. "Efforts to combat family-centered care disparities for children with special health care needs can focus on two components for which we found important disparities both by race and ethnicity and household primary language: the provider's time and cultural sensitivity."

Researchers used data collected from 2005 through 2006 from the National Survey of Children with Special Health Care Needs and found that, overall, 66 percent of children with special health care needs received family-centered care.

However, significantly smaller proportions of Latino (47 percent), African American (53 percent), multiracial (66 percent) and other race/ethnicity (58 percent) children received family-centered care than did white children (72 percent).

Additionally, when compared with white children, smaller proportions of Latino, African American and other race/ethnicity children who received family-centered care received adequate time with their provider and care that was sensitive to the family's



values and customs. Children with special health care needs from households in which English is not the primary language were also less likely to receive these two care components.

The next stage of research will include testing interventions to improve family-centered care and to reduce these disparities.

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