

Most kids with special healthcare needs still aren't receiving 'patient-centered medical home' care

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The "patient-centered medical home" (PCMH) approach is an important tool for providing coordinated care for the millions of American children with special healthcare needs. But most of these special-needs children don't have access to care consistent with the PCMH approach, reports a study in the October issue of *Medical Care*.

Despite extensive efforts over more than a decade, more than two-thirds of [children](#) with special healthcare needs aren't receiving "PCMH-concordant" [care](#), according to the study by Mónica Pérez-Jolles, Ph.D., of University of Southern California and Kathleen C. Thomas, Ph.D., MPH, of University of North Carolina at Chapel Hill. Inequities in PCMH-concordant care are more common in certain subgroups, including children with higher functional impairment.

More Progress Needed in Providing PCMH Care for Kids with Special Needs

Children with special healthcare needs are those with "a diagnosis of mental illness and/or the presence of a chronic physical or developmental condition that requires a higher use and range of health services compared to the general population." [A national survey](#) estimated that about 15 percent of children have special healthcare needs, and that 23 percent of US families have at least one child with special needs.

Because of their complex needs for healthcare and other services, these children are at risk for fragmented care or duplication of services. The PCMH approach—focused on delivering care that is accessible, family-centered, coordinated, comprehensive, culturally competent, compassionate, and high-quality—is an important part of efforts to improve outcomes for children with special healthcare needs.

In 2002, the American Academy of Pediatrics issued a statement [endorsing the PCMH approach for children with special healthcare needs](#), stating that "every child deserves a medical home." Drs. Pérez-Jolles and Thomas write, "This study sought to elucidate how much progress have we made on that promise."

Using nationally representative data (the Medical Expenditures Panel Survey) from 2003 to 2013, the researchers analyzed parent/caregiver experience concordant with PCMH care. The survey included data relevant to four PCMH characteristics: accessible, family-centered, comprehensive, and compassionate care. The authors examined the implementation of PCMH-concordant care overall and across the PCMH characteristics measured.

The findings suggested that only 31 percent of children with special healthcare needs were receiving PCMH-concordant care, based on a composite score consisting of total average scores across all four characteristics. On analysis of individual characteristics, more than 80 percent of children experienced care that was comprehensive and compassionate, while about 60 percent received accessible and patient-centered care.

About 87 percent of children with special healthcare needs had at least moderate functional impairment. These children were less likely to experience PCMH-concordant care—especially those with a high level of functional impairment. Several other characteristics were also linked

to lower levels of PCMH-concordant care, including non-white race/ethnicity, lower parental education, low household income, living in a home where English is a second language, and being uninsured or on public health coverage. There were also significant differences by metropolitan area and region.

"Overall, our results showed that just under a third of children with special healthcare needs reported experiencing PCMH-concordant care and there was high variation across components," Drs. Pérez-Jolles and Thomas write. "Thus, despite strong support for this care model, we still have a long way to go to reach 'every child' ...with implementation of [PCMH care].

The researchers conclude: "Despite increased parent perception of care that is concordant with medical home care over time, disparities remain among high-need children with special healthcare needs." The authors believe their findings may be useful in tracking special-needs children at higher risk of [healthcare](#) inequities, and in tailoring PCMH care to meet the unique needs of these subgroups.

More information: "Disparities in Self-reported Access to Patient-centered Medical Home Care for Children With Special Health Care Needs" [journals.lww.com/lww-medicalca ... px?PRID=MC PR 091418](https://journals.lww.com/lww-medicalca...px?PRID=MC_PR_091418)

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