

RESEARCH HIGHLIGHT-1

Advocating for Care Coordination

Strickland, B., McPherson, M., Weissman, G. vanDyck, P., Zhihuan, J.H., & Newacheck, P. (2004). Access to the medical home: Results of the national survey of children with special health care needs. *Pediatrics*, 113, 1485-1492.

BOTTOM LINE

Parents shared their experiences about their child's access to a medical home. Then researchers used the five defining characteristics of the medical home model in analyzing the data. The five characteristics are:

- Having a usual place of care
- Having a personal doctor or nurse
- Getting referrals to specialty care
- Receiving care coordination services
- Receiving services characterized by family-centered care (extent to which services recognize families as the primary decision-maker, consider the needs of all family members, and build on family strengths)

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Making a Sustainable Difference in Quality of Life



ACTION STEPS

- In reading the findings of this study, compare your own situation with the information presented in order to determine how satisfied you are with your child's access to a medical home:
 - ◆ Does your child have a usual place for receiving medical care?
 - ◆ Does your child have a personal doctor or nurse?
 - ◆ Are you able to get referrals for specialty care for your child?
 - ◆ To what extent do you consider the care coordination services that your child receives as adequate?
 - ◆ To what extent are you satisfied that your child's pediatrician recognizes you as the primary decision-maker, builds on your child's strengths, and considers the needs of your child.
- Given the responses to the questions above, consider to what extent you are satisfied with your child's access to a medical home and what extent you believe that this situation needs improvement.
- Consider ways to use this information to advocate for improvements in medical home access for your child.
- Consider ways to use this information to highlight the inequities in the health care system and to advocate for change at local, state, and national levels.

INTRODUCTION

Children and their families need access to reliable, comprehensive medical care. Comprehensive care is essential for children with special health needs.

The medical home philosophy, defined by the American Academy of Pediatrics, is characterized as “continuous and comprehensive primary pediatric care from infancy through young adulthood, with availability 24 hours a day, 7 days a week, from a pediatrician or physician whom families trust” (p. 1486).

The Maternal Child Health Bureau (MCHB) is a staunch supporter of the medical home philosophy. In conjunction with the Healthy People 2010 objectives, MCHB describes a larger system of care as encompassing the following principles:

- Families and providers as partners
- Access to comprehensive care
- Adequate sources of financing for services
- Early and continuous screening for special health care needs, followed by receipt of services

- Easily organized community services
- Services and supports for transition to adult health care, work, and independence

METHOD

- Researchers interviewed at least 750 families per state whose children had been identified by the National Center for Health Statistics as having a special need.

KEY FINDINGS

- About 90 percent of the children had access to a usual source of care. However, as the level of poverty increased, the usual source of care decreased. Similarly, lower percentages of Hispanic (85%) and African American (88%) children had a usual source of care, as compared to White children (92%).
- Most of the children in this survey had a personal doctor or nurse; however, 11% did not. Again, as poverty increased, fewer families reported that their child had a personal doctor or nurse. More children of families of different ethnicities also did not have a personal doctor or nurse as compared to children in European families.
- Overall, about 22% of families reported having difficulty getting referrals for specialty care. This percentage increased by poverty level. A similar trend was also reported across different ethnicities.
- Receipt of care coordination services was most problematic. Of those families who reported needing care coordination, only about 40% reported that these services were adequate. Eighteen percent reported not receiving care coordination when needed.
- Overall, about 67% of parents reported receiving family-centered care from their child's physician. With respect to poverty status, only 50% of poor families felt that they received family-centered care as compared to 75% of non-poor families. Similarly, lower percentages of family-centered care varied by ethnicity.

RELATED PUBLICATIONS

Gupta, V. B., O'Connor, K. G., & Quezada-Gomez, C. (2004). Care coordination services in pediatric practices. *Pediatrics*, 113(5 Suppl), 1517-1521.

Krauss, M. W., Wells, N., Gulley, S., & Anderson, B. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children's Services: Social Policy, Research, and Practice*, 4(4), 165-187.

Pfefferle, S. G., Gittel, J. H., Hodgkin, D., & Ritter, G. (2006). Pediatrician coordination of care for children with mental illnesses. *Medical Care*, 44(12), 1085-1091.

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