



SHARED RESPONSIBILITIES

Tools for Improving Quality of Care for
Children with Special Health Care Needs

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Best Practices

Pediatric Alliance for Coordinated Care: A Medical Home Demonstration Project

The Pediatric Alliance for Coordinated Care (PACC) is a medical home demonstration project initiated in 1997, through the Division of General Pediatrics at Children's Hospital in Boston. Operating in six community-based pediatric sites in Massachusetts and serving 150 children with special health care needs, the PACC project has been conducting a study of a coordinated approach to primary care that includes specialized supports and training for physicians, nurses and families. The project has been investigating the impact of this package of medical home services on health outcomes, service utilization and family and provider satisfaction caring for children with special health care needs. Preliminary findings are summarized below.

The main components of the model include:

- Eight hours per week of a *pediatric nurse practitioner* at each office site to provide care coordination services for approximately 25 children.
- Support to parents from a *local parent consultant* who was a mother of a child with special needs enrolled in the same pediatric practice *or* living in the same community.
- An *individualized health plan* that includes a written summary of a child's individual assessments, service needs and providers.
- *Continuing medical education* (CME) classes for physicians and nurses.

Findings: Nearly 75% of families reported that the PACC program made it "*much easier or somewhat easier*" to get health care and other services for their child with special needs. Parents reported missing fewer workdays because of their child's health care needs, significant improvements in family satisfaction in getting referrals, appointments, and early medical care for their child, and hospitalizations decreased. Preliminary data from exit interviews with primary care providers confirm high levels of satisfaction with the enhanced pediatric nurse practitioner role, specific benefits to their patients as well as improvements in the day-to-day functioning of their offices. All sites continue to maintain some degree of this valuable nurse practitioner role despite termination of the demonstration project funding. Long-term sustainability will likely require changes in the overall payment structure for these care coordination services.

Publications:

Silva, TJ, Sofis, LA & Palfrey, JS. *Practicing Comprehensive Care: A Physician's Manual for Implementing a Medical Home for Children with Special Health Care Needs*. Boston, MA: Institute for Community Inclusion, Children's Hospital; 2000.

Davidson, EJ, Silva, TJ, Sofis, LA, Ganz, ML & Palfrey, JS. The Doctor's Dilemma: Challenges for the Primary Care Physician Caring for the Child With Special Health Care Needs. *Ambulatory Pediatrics*. 2002;2:218-223.

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