President's Choice

Care Coordination for Children With Complex Special Health Care Needs: The Value of the Advanced Practice Nurse's Enhanced Scope of Knowledge and Practice

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ABSTRACT

Efficiency and effectiveness of care coordination depends on a match between the needs of the population and the skills, scope of practice, and intensity of services provided by the care coordinator. Existing literature that addresses the relevance of the advanced practice nurse (APN) role as a fit for coordination of care for children with special health care needs (SHCN) is limited. The objective of this article is to describe the value of the APN's enhanced scope of knowledge and practice for relationship-based care coordination in health care homes that serve children with complex SHCN. The TeleFamilies project is provided as an example of the integration of an APN care coordinator in a health care home for children with SHCN. J Pediatr Health Care. (2013) *27*, 293-303.

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Approximately 14% of all children who are younger than 18 years have a special health care need (SHCN), which is defined as having a chronic physical, developmental, behavioral, or emotional condition and requiring more services than typical children (U.S. Department of Health & Human Services, 2008). The number of children in the United States with SHCN has increased dramatically in the past four decades (Burns et al., 2010). Because of the higher need for and use of health care services, the costs per capita of health care for children with SHCN are nearly three times higher than for children in the general population (Grupp-Phelan, Lozano, & Fishman, 2001; Newacheck & Kim, 2005). In a study of more than 46,000 children enrolled in a state health plan, Neff, Sharp, Muldoon, Graham, and Myers (2004) found that children with one or more chronic conditions accounted for more than 45% of all pediatric charges.

CHILDREN WITH COMPLEX SHCN

A subset of children with SHCN has unique needs because of the complexity of their conditions. Cohen et al. (2011) termed this subgroup *children with medical complexity* and proposed a definitional framework with four domains based on a systematic review of chronic disease of childhood. In their framework, children with medical complexity have (a) characteristic patterns of family-identified health care service needs; (b) lifelong chronic conditions that are severe and/or associated with medical fragility; (c) functional limitations that may be severe, requiring assistance from technology; and (d) high utilization of health resources, such as hospitalizations and/or the involvement of multiple subspecialists (Cohen et al., 2011).

Children with complex SHCN are a rapidly growing group of health care consumers (Tennant, Pearce, Bythell, & Rankin, 2010; Wise, Huffman, & Brat, 2007). These children are more likely to need health services and have a significantly higher financial impact on families in terms of days missed from work and school as a result of illness and health care encounters (Nageswaran, Silver, & Stein, 2008). Compared with other children, children who have functional limitations have the highest needs for outpatient and emergency care. Also, their health conditions place significantly greater demands on their families' time and finances, and medical expenditures for children with SHCN are two to three times higher than those of children without functional limitations. The increasing numbers of children with SHCN and the complexity of their conditions, in particular, have significant implications for utilization of public and private health resources (Perrin, Bloom, & Gortmaker, 2007).

COORDINATED CARE

Health care providers face challenges related to the management of health and service needs of children with complex SHCN. Among these challenges is coordination of care. The Institute of Medicine has identified care coordination as one of its 20 national priorities for improving the quality of health care and a primary area for performance measurement following the landmark publication *Crossing the Quality Chasm: A New Health System for the 21st Century* (National Research Council, 2001). The Affordable Care Act (ACA) recognizes the value of coordinated care as essential for the optimal delivery of health care in the United States (Orszag & Emanuel, 2010). Specifically, Section 2717 of the ACA requires that experts in health care quality and stakeholders *"shall develop…health care provider reimbursement structures that improve health outcomes through activities such as effective case management, care coordination, [and] chronic disease management"* (Office of the Legislative Council, U.S. House of Representatives, 2010, p.19). The ACA further recommends rewarding quality with market-based incentives through a payment structure that provides incentives for care coordination and directs systems to include a *nurse care coordinator* on the health team.

Care coordination is a key component of the health care home (medical home) model of care. The pediatric health care home is a model of care that promotes holistic care of children and their families and provides management of both acute and chronic issues, and is a model in which each family has an ongoing relationship with a health care professional (National Association of Pediatric Nurse Practitioners [NAPNAP], 2009). The concept of a medical home for children with SHCN is not new; the term first appeared in a book published by the American Academy of Pediatrics (AAP) in the 1960s, in which the Council on Pediatrics noted a concern about "duplication and gaps in services that occur as a result of lack of communication and coordination" (AAP, 1967, p. 78; Sia et al., 2004). The medical home concept evolved and gained recognition nationally during the next four decades, with policy statements from professional organizations including the AAP (2002) and NAPNAP (2009) supporting a comprehensive, coordinated model of care with families at the center.

Coordinated care is a vital component of the health care home approach (Palfrey, 2009), but this coordination requires an investment of dedicated time and resources to develop, implement, and evaluate the processes and activities that constitute comprehensive, coordinated, and compassionate care (Safriet, 2011). It also is important to distinguish between care