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Commentary on “Connecting the Dots: Families and Children with Special Needs in a Rural Community”

Carl Tapia

Baylor College of Medicine, ct692423@bcm.tmc.edu

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Starks et al. discuss an important innovation: an educational series to enhance rural systems of care for children with special needs that is family-centered, coordinated, and effective. Using a structured evaluation training instrument, the group was able to demonstrate that community providers and families benefited from the training and had increased confidence in advocating for children with special health care needs (CSHCN).

Background and policy implications

Although only 20% of CSHCN have been reported to live in rural areas, they experience important disparities in care compared to urban families. For example, CSHCN in rural areas experience more delayed health care, report more unmet needs for services such as dental care and therapy, and families report a greater burden in caring for their children (including providing more care at home and spending more time arranging and providing care for their children) (Skinner & Slifkin, 2007).

Starks et al. describe how "it takes a village" to provide effective health care for children with special needs. Their description seems to be an expanded version of the medical home neighborhood concept. In order for systems of health care to improve the quality of care delivered, demonstrate savings, and engage community providers, the "village" must be willing to share information and collaborate in decision making (Fisher, 2008). The medical neighborhood recognizes that health delivery systems include a large number of health service providers who are jointly responsible for engaging with individual families and providing comprehensive, family-centered care (Pham, 2009). From a policy standpoint, community investments in systems of care have the most impact when aligned with other reform measures that collectively enhance shared accountability across community providers (Fisher ES, 2008), provide an accessible "key" contact to help families navigate the system (often, but not always, the medical home), and help families synthesize disparate sources of information (Pham, 2009). Further, systems of care for children with special needs are complex, and better quality care can be delivered when numerous agencies are empowered to coordinate services to prevent care from falling "through the cracks" (Pham, 2009; Sinsky, 2011). Two well-designed programs, the HomeBase program in South Carolina and the Special Needs Program of Wisconsin, demonstrate that structured programs providing care coordination and enhanced community relationships decrease emergency room visits and hospitalizations (Gordon et al., 2007; Martin et al., 2007).

As Starks et al. argue, caregivers of children with special needs experience a variety of stresses and strains that impact their own health, as well as their ability to provide optimal care for their child. Health policymakers should be mindful that patient experiences of care are as important to measure and prioritize as costs and utilization.

Limitations

Starks et al. did not expand on the role of primary care providers and families within the Clinical Education Complex. The majority of attendees were health care professionals (presumably in social services), and only 11% of attendees were parents. Since primary care teams and families shoulder the greatest responsibility in care coordination and care planning (Pham, 2009), they are vital partners to engage. Second, the sessions mostly focused on specific diagnoses or services. While expanding community capacity to recognize and counsel regarding specific disorders is laudable, cohesive “villages” or medical neighborhoods are more likely to be successful when joint responsibilities among care providers are explicitly agreed upon and care preferences of families are assessed and integrated throughout the medical continuum (Pham, 2009). Future education sessions could focus on topics such as co-management, patient hand-offs, and engaging families in care (Sinsky, 2011). Finally, educational programs can be effective at disseminating information to providers about caring for children with special needs, but knowledge decay after the session is an inherent problem (Spaite et al., 2000). Although utility reactions are predictive of learning, readiness to learn and post-training knowledge are also important factors in training outcomes (Antle, Barbee, & van Zyl, 2008). Evaluating the effectiveness of the conference in promoting knowledge sharing and collaboration within the community would be a powerful tool for sustainability (Collins, Amodeo, & Clay, 2008).

Strengths

Starks et al. add to the literature an evaluation process for use in building a cohesive, holistic medical “village” or neighborhood. Policymakers must provide resources to invest in community infrastructure for shared information and efficient communication, as well as providing each community provider with sufficient financial resources or reimbursement to provide quality care.

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