

# Issue Brief

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## Teaching Families to Fish: How to Support Families as Care Coordinators

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### Background

A perennial paradox seems to exist in how families of children with special health care needs view the role of care coordinator. On the one hand, families often report feeling overwhelmed trying to navigate the complex, fragmented systems on which they and their children depend, and they are eager for health plans to provide more and better care coordination services. On the other hand, these families also consistently assert that they need and want to be their children's principal care coordinator.

Ensuring that a child with a complex chronic condition receives all the recommended care and treatments in a timely, efficient and coordinated fashion is a daunting task for even the most capable families. Honoring families' centrality as their children's principal care coordinator while moderating their burden can be achieved by defining care coordination as a shared task and offering services and training to families so that their coordinating skills and capacities are enhanced.

The American Academy of Pediatrics (AAP) endorsed "family-centered care coordination" in a 2005 policy statement.<sup>i</sup> In the statement it is

clear that the family is to play a central role in developing a care plan to guide care coordination for their child, and that families should be linked to services for their child and themselves. Although the AAP states that families are better able to coordinate care when they are "given opportunities to further develop their skills and strengths," it is less clear that "family-centered care coordination" is intended to systematically provide education and supportive interventions to increase parents' skills and confidence as their child's principal care coordinator.<sup>ii</sup>

### Recommendations

What would care coordination services look like if they were purposely designed to support families' role as the principal care coordinator? First, a care coordination needs assessment would be undertaken to assist families, their providers and community care partners in determining immediate needs and the services that should be in place.<sup>ii</sup> The family then would be offered an array of tools to improve their ability to coordinate their child's care and to partner with the care team, including:

- Designation of a specific staff member or professional to serve as the central contact point for the family and members of the care team

- Engagement in collaborative goal setting with the care team and the family
- Training of health care providers to be teachers and partners in care
- Establishment of planned visits with all members of the care team to discuss a pre-determined agenda
- Teaching and use of the five core self-management skills of problem solving, decision making, resource utilization, forming a patient-provider partnership and taking action
- Use of peer or mentor families to help families learn to navigate the systems of care for CSHCN
- Development of easy-to-use databases of community services available at a centralized location and updated regularly
- Joint development of a written care plan that all essential members of the team, including the family, are able to access and update, and

- Use of mechanisms to promote and streamline communication among members of the care team, including group visits, communication technologies such as video-conferencing and mobile applications, and shared access to medical records.

## Conclusion

To rephrase the old aphorism about fishing, if you coordinate care for a family, things may go well for a while; if you teach a family how to coordinate care, things can go well for a lifetime. If we truly want care coordination services to be family-centered, we must teach families, and, as they mature, their children, the skills to successfully serve as principal care coordinators over the life course, and provide tools to support them in this role.

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<sup>i</sup> The American Academy of Pediatrics, Council on Children with Disabilities. Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics*. 2005; 116(5):1238-1244

<sup>ii</sup> Lorig, K.R. and Holman, H.R. (2003). Self-Management Education: History, Definition, Outcomes and Mechanisms. *Annals of Behavioral Medicine*, 26(1), P. 1-7.

**ABOUT THE FOUNDATION:** The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health care through leadership and direct investment. The Foundation is a public charity, founded in 1997.

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