



FAMILY/PROFESSIONAL PARTNERSHIPS

WHAT ARE PARTNERSHIPS?

A partnership is a relationship between individuals or groups that is characterized by mutual cooperation and responsibility for the achievement of a specified goal. Partnerships have been used as successful models in many disciplines. In health care, evidence has shown that strong doctor-patient relationships improve patient and family health outcomes¹. Key to such partnerships are the following principles²:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

WHY ARE FAMILY/PROFESSIONAL PARTNERSHIPS IMPORTANT IN HEALTH CARE?

Families lived experience makes them uniquely qualified to partner not only on the individual level with the care of their own child, but to also partner at the systems level shaping policies that improve health and outcomes for all CYSHCN. As primary caregivers, families are deeply affected by issues such as care fragmentation that results from lack of communication on the individual level, and ineffective and outdated health care policies and practices on the systems level. Evidence indicates that family/professional partnership at the individual level improves care coordination and health outcomes. Furthermore, meaningful family at the systems and other levels can be a powerful catalyst for reducing system fragmentation, removing barriers to health care and improving the quality of health care.

Effective partnership is the foundation of family-centered care, as families and providers work together in the best interest of the child and the family. Just as meaningful family/professional partnership at the individual level involves a shared, family-centered approach to providing care, meaningful partnership at the systems level integrates the importance and value of basing policies, programs, and services on the lived experiences of families who navigate fragmentation and these barriers daily for their CYSHCN.

HOW DO FAMILIES PARTNER WITH PROFESSIONALS TO IMPROVE CARE FOR CYSHCN?

Partnering with a child's provider: As their child's most consistent caregiver, families know their child with SHCN in ways that no one else can, and have the most vested interest in ensuring that their child's health care needs are met. Family input when something is wrong or how a treatment or medication is working is essential to the providers who treat CYSHCN. Communication is critical to developing a partnership with a child's provider.

Partnering with health plans: The financing of health care for many children with special health care needs is provided by managed care plans, which by definition, control access to services and programs. Many children with special healthcare needs are served by both private health insurance and public programs such as



Medicaid. Just as you do with your child's provider, you can help health insurance plans to understand what works well and what doesn't with their programs and policies. Many health insurance providers work with family advisors to learn more about the populations they serve.

Partnering with Title V: There is a federally-funded Title V Program in each state that provides services to enhance the health of women and children, including children/youth with special healthcare needs. State Title V programs are required to partner with families to ensure that family perspectives and lived



experience/expertise help to guide these programs. Families in these partnership roles are critical to helping our government understand family needs in caring for our children with special health care needs.

Partnering with Programs and Agencies: Many stakeholder groups contribute to the setting of policies that affect children/youth with special health care needs. Families often become involved with a broad spectrum of programs and agencies, filling roles from volunteer, to staff, to appointed advisory board members.



Partnering with other family leaders: In advocating for their child, many parents have learned the importance and value of speaking out for larger systems change. Advocacy groups, whether disability-specific or broader (such as Family Voices), arose because a few individuals wanted a better life for their child and believed they could make a difference. By joining your voice with others, your message and potential impact is stronger.

SOURCES

1. [American Academy of Pediatrics, Committee on Hospital Care: Policy statement: Family-Centered Care and the Pediatrician's Role Pediatrics, Vol. 112, No. 3, September 2003](#)
2. [Maternal and Child Health Bureau: Family-Centered Care](#)

