Family-professional partnerships are one of the six national performance measures identified by the Maternal and Child Health Bureau. These partnerships ensure that a family participates in decision-making with professionals at all levels in their child’s care. Family-centered care honors the strengths, cultures, traditions, and expertise that each person brings to a family-professional partnership. The goal in Washington State is to make families of children and youth with special health care needs partners in the decision-making at all levels to promote satisfaction with the services they receive. In Washington State, 73% of families of children with special health care needs are partners in shared decision-making for their child’s health (Figure 1).

Here’s how we support this performance measure:

**Family Leadership and Support**
- Providing a Family Involvement Coordinator who offers leadership for the inclusion of the family perspective in policy and program development for children and youth with special needs. This position also serves as a resource for promoting high quality, culturally competent, family-centered, and integrated systems of care.
- Contracts with Seattle Children’s Center for Children with Special Needs, Parent to Parent, and Fathers Network provide continuing family leadership training throughout the state.
- Recruiting and financially supporting parents’ attendance at state and local conferences (Seattle Children’s Duncan Seminar, the Infant and Early Childhood Conference, the Washington Autism Advisory Committee and Community Asset Mapping).

**Partnerships**
- Supporting partnerships through contracts such as the University of Washington’s Medical Home Partnerships Project, the Center for Children with Special Needs and family support organizations.
- Developing and maintaining informational websites and resources related to health care services for children with special needs and providers.

**Local Health Departments**
- Funding the CSHCN Coordinators at local health departments to link families to appropriate information, medical homes, and referral services in their local communities.
- Ensuring that coordinated systems of care for families are in place in their local communities.
Family Professional Partnerships

The partnership concept in decision making is crucial because parents and guardians have ultimate responsibility for care giving and overseeing the child’s health care. Partnership is especially important for families with children with special health care needs because they make many decisions regarding primary care, specialty care, and related services.

Existing research suggests that when care is coordinated, comprehensive, accessible, and family-centered, families perceive better access to quality care and more respectful care. A sense of partnership may improve outcomes across a number of important health care measures such as missed school days, access to specialty care, satisfaction with care, and unmet needs for child and family services. These findings suggest that efforts to increase partnerships will have the added effect of improving many other aspects of the family’s experience.

On a broader level, family members, including those from culturally and linguistically diverse communities, must have a meaningful and consistent role in systems development at the state and community levels. Family participation as equal members on interagency teams helps keep discussions open, honest, and focused on those who really matter – children and families.

**Data Sources**


**Endnotes**

The Family-Professional Partnerships National Performance Measure was created by the Maternal and Child Health Bureau (MCHB) and The Child and Adolescent Health Measurement Initiative (CAHMI), together with their partners. The measure uses multiple questions from the 2009-10 NS-CSHCN, and was revised substantially since the 2005-06 NS-CSHCN. The measure is calculated using multiple questions from the NS-CSHCN. In order to meet this measure, the parent must feel that 1) they discuss with providers a range of options to consider for their child’s treatment; 2) they are encouraged to ask questions or raise concerns; 3) it is easy to ask questions or raise concerns; and 4) their health care providers consider and respect what treatment choices the parent feels would be best for child.

**Other Resources:**

Adolescent Health Transition Project [depts.washington.edu/healthtr/](http://depts.washington.edu/healthtr/)
Center for Children with Special Needs [cshcn.org](http://cshcn.org/
Medical Home Partnerships Project [www.medicalhome.org](http://www.medicalhome.org/)
Maternal and Child Health Bureau [mchb.hrsa.gov](http://mchb.hrsa.gov)
Washington State Fathers’ Network [fathersnetwork.org](http://fathersnetwork.org/)
Washington State Parent to Parent [arcwa.org/getsupport/parent_to_parent_p2p_programs/](http://arcwa.org/getsupport/parent_to_parent_p2p_programs/)