
Quotes from Parents

“Sharing my story gave a context for my first committee meeting and made me feel valued, relaxed and confident. The first meeting set the tone for the whole year.”

“The amount of input the Family Advisory Network has been asked to give is very positive.”

“The give and take at the committee meetings between professionals and parents has been very positive.”

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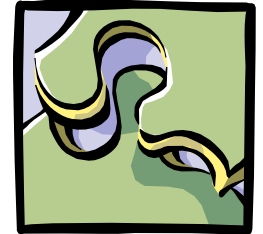
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Practical Tips:

Involving Family Consultants in Program and Policy Development



Washington Family Advisory Network

Washington State Department of Health
Children with Special Health Care Needs Program

Washington Integrated Services Enhancement (WISE) Grant Partners:
OSPI, DSHS, DCTED, DOH

Acknowledgments

This document reflects the thinking and comments of the Family Advisory Network of the Washington Integrated Services Enhancement (WISE) Grant, as well as many state Parent to Parent Coordinators and Medical Home Leadership Network parents. Thank you for sharing your expertise on WISE Grant committees, and for contributing your thoughts and experiences to create this document.

Thank you also to veteran parent leaders from the Washington Family to Family Network, which includes statewide family support organizations such as Family Voices of Washington, Washington State Fathers Network, Washington Parent to Parent, Children's Hospital & Regional Medical Center parent support programs, Ethnic Outreach Coordinators, Infant Toddler Early Intervention, the Family Leadership Team of the State Interagency Coordinating Council, Medical Home Leadership Network, Washington Parents are Vital in Education (PAVE), and Statewide Action for Family Empowerment of Washington (SAFEWA).

Leslie Carroll, Former Chair
Family Advisory Network

Outcomes

- ◆ Broad range of diverse input is received from new and veteran families.
- ◆ Policy and program recommendations reflect needs of real families of children with special needs.
- ◆ Meaningful relationships are created between families and professionals.
- ◆ Parents and professionals work from a common ground.
- ◆ Services are designed in a family centered, culturally appropriate manner.
- ◆ Parent advisors and professionals grow in their roles as consultants and partners.



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- ◆ Pick parents up at the airport or arrange to carpool together.
 - ◆ Go over agendas with parents in advance and debrief after meetings.
 - ◆ Involve parents in evaluation of projects and process all along the way.
 - ◆ Validate parents' experiences; listen and incorporate their ideas.

Remember: it takes time to mentor and build partnerships.



Washington's

Family Advisory Network

The Family Advisory Network (FAN) is a group of parents of children with special health care needs (CSHCN) who are working on policy issues to improve health care for children with special needs. The group was recruited through efforts led by the Washington Department of Health Children with Special Health Care Needs Program and the Washington Family to Family Network.

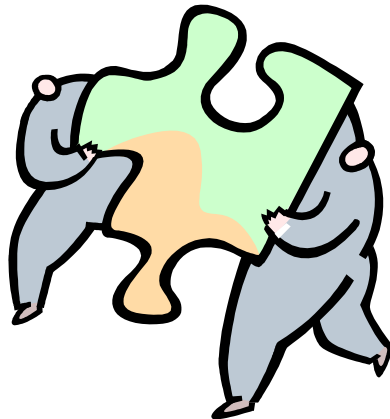
As families and professionals seek to integrate services for children with special health care needs, Family Advisory Network parents have envisioned



ways to improve and increase family involvement in policy. Many of these ideas are found in “Practical Tips for Involving Family Consultants in Program and Policy Development.”

How Do You Start?

- ◆ Involve families from the very beginning of a project...at the first planning meeting!
- ◆ Develop or work with an existing family advisory board to recruit diverse families.
- ◆ Recruit new families from a wide range of cultures, geographic areas, children's ages, and diagnoses.
- ◆ Use a range of communication and teaching strategies (interpreters, sign language, visual learning tools, and adult learning strategies).
- ◆ Develop meeting agendas that include protected time for sharing family stories and building family-professional partnerships.
- ◆ Mentor both parents and professionals in their partnership roles.
- ◆ Select meeting times that work for fathers, too.
- ◆ Compensate parents for their time.



What Works?

- ◆ Provide well planned orientations and ongoing leadership trainings.
- ◆ Present parents with the “Big Picture” of project, goals, and partners.
- ◆ Teach parents how to tell their family story to a range of audiences.
- ◆ Model sharing family stories in meetings.
- ◆ Orient and train professionals to work effectively with family consultants.
- ◆ Give “take home tools” for family consultants to use at meetings and in their communities. *For example: colorful drawings of their family story and their role in the “Big Picture.”*
- ◆ Do a dress rehearsal of potential scenarios of what could go wrong for first-time family consultants. *For example: What do I do if no-one listens to me? What if I start to cry? What if I get angry?**
- ◆ Establish mentor-match programs between veteran and new family consultants.
- ◆ Train and support mentors.
- ◆ Create opportunities for families to network and learn from one another.

*Contact us for examples.
