



Washington State Medical Home Newsletter

SUMMER 2009

Issue Focus: Increasing Family Involvement



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About half of the 18 active Medical Home Leadership Network (MHLN) teams have one or more parents as part of their county team. Many of the parent participants are Parent to Parent Coordinators and bring not only personal strengths but organizational backing to the teams. Teams speak to the benefits of having parent participation— the energy, good ideas, and motivation that benefit the entire team.

This issue of the Medical Home newsletter looks at tips for parents interested in joining or becoming more active on MHLN teams or other organizations. We also look at resources for MHLN teams or health care organizations looking to increase meaningful parent participation in improving care.

A second companion newsletter focuses on some of the MHLN team family activities, particularly those focusing on family outreach and education around medical home that were discussed on team conference calls earlier this year.

New Web Resources from the Center for Children with Special Needs

The Center for Children with Special Needs at Seattle Children’s Hospital recently launched new web content dedicated to helping parents and caregivers become family advisors and to helping organizations involve families as advisors. Several MHLN parent members helped review the materials and provide input to the family and professional staff members who developed the resources. The materials are practical and well written— we encourage you to take a look! We will offer a conference call this fall with staff from the Center for interested MHLN team members.

Becoming a family advisor: <http://cshcn.org/support-connection/become-family-advisor>

General guidance for becoming a family advisor:

- * Find opportunities to become a family advisor
- * Decide if an opportunity is the right fit for you
- * Consider how much to share about your child and family

Tips to prepare you for a specific family advisor event:

- * Educate others by telling your story
- * Give feedback and share your ideas at meetings

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Tips for Involving Parents in MHLN Teams

By Cynthia Hubert, Parent and Skagit County MHLN Team Lead

Questions that parents may have regarding team involvement:

- * What would my role be? Who are the other members of the team and what are their roles?
- * Will there be other parents involved?
- * What kinds of things would the team be talking about and doing?
- * Can you give me examples of what parents (and the team) have done in the past or projects that you are considering in the future?
- * How much time is involved? Are there meetings? How often will we meet? What happens at the meetings? What days and times? Do I need to be at every meeting or can we talk over the phone?
- * I have a young child; can I bring my child along to meetings? Is there reimbursement for childcare? I need to pay my childcare worker on the spot; how quickly can I be reimbursed?
- * What benefits will there be to my participation?

Strategies to increase parent comfort and maintain involvement in teams:

- * Ensure that one very approachable primary contact talks with the interested parent just before the first team activity to answer questions and make sure the parent feels comfortable with participating.
- * Provide acronym information ahead of time so parent doesn't feel lost in discussions; try to keep the discussion central to the team and avoid "shop talk".
- * Recap meeting with some form of minutes and send out so that those not there feel they are informed and up to date.
- * Send out meeting reminders including brief information of what is planned agenda wise.
- * Form small work group (all parents) for certain projects allowing families to meet and get to know each other and take some ownership while working on something of interest to them. The work group members can be made up of one parent team member and other parents not involved on team, but interested in working on a specific project or two.
- * Make sure that the parent team member feels like they are needed and contributing and reaffirm that is the case with the parent. Get them involved fairly quickly in a project that they can get excited about and see as valuable.

Barriers to parents partnering with PCP's in regard to their own child's medical home:

- * Families not knowing about or having the resources that might assist them in taking a more active involvement in their child's care, such as a care organizer, care plan, and local resource information.
- * Families not knowing the practical "how to" information about how to best use those resources i.e., care organizer, and how their use can result in better care for their child.
- * Families not having a personal connection to Parent to Parent or other resources that might assist them in getting connected to and having questions answered about local resources and "helping parent" mentoring.
- * Families feeling intimidated about making the call to those resources themselves and not knowing what questions to ask or how the resource might be valuable to them and their child.
- * PCP and clinic staff not knowing about the resources the parents have at their disposal enough to reinforce the use of those resources.
- * Lack of written plan for families to take with them, keep a record of and refer to.
- * Cultural barriers that make families less likely to take an active role in their child's care. The same barriers making it less likely that those families will meet with other families and openly discuss their child's special needs and learn from other parents.
- * The parent experiencing special needs themselves, making it more difficult for them to take an active role in their child's care.
- * Communication barriers, not just including language, but even messages and updated information passing between PCP and family.

Resources from the Institute for Family-Centered Care

The national Institute for Family-Centered Care provides leadership to advance the understanding and practice of patient- and family-centered care in hospitals and other health care settings.

They have developed practical tools around both the philosophy and the nuts and bolts of putting patient and family-centered care into action. The Institute is advising the major national health care reform players on how to make sure consumers play a big role.

The Institute has historically worked primarily with pediatric and adult hospitals. This has included work around how to develop family advisory councils and other ways of involving patients and families in meaningful planning and feedback. More recently they have begun to focus on primary care including their recent publication: *Advancing the Practice of Patient- and Family-Centered Ambulatory Care: How to Get Started*. This and other resources are available at: www.familycenteredcare.org/tools/downloads.html

The Institute has other useful tools as well including profiles of health care organizations making a difference. For example the University of WA Medical Center is profiled for their work in this area: www.familycenteredcare.org/profiles/prof-uwmc.html

Profiles of individual parents and patients making a difference can be found too. An interesting one for MHLN teams and clinics is one for [Ashley Peterson, MN](#) a mom of a child with special needs and an active Medical Home Team member from a primary care clinic in Minnesota
www.familycenteredcare.org/advance/pafam.html

The Institute also shares sample job descriptions for family consultants and parent coordinators they have collected www.familycenteredcare.org/tools/position.html

The Listserv for Patient and Family Advisors and Leaders of Advisory Councils is another Institute resource. While the focus is primarily on hospitals, the PFACnetwork listserv is for anyone interested in the work of patient and family advisory councils. This list is not limited to family members or patients. Health care staff welcome. Discussion covers all topics related to starting and sustaining patient and family advisory councils, as well as issues related to promoting family-centered care in a hospital or medical center. The Institute recently developed a webpage limited to listserv members to share documents and tools they are in the process of developing. For more information: <http://mailman.listserve.com/>

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Involving families as advisors:

4 basic steps to guide your work as you involve families in an advising role:

- * Decide what kind of family involvement will work best for your organization
- * Recruit the right people
- * Prepare and facilitate the involvement
- * Follow up and closure

See <http://cshcn.org/support-connection/involve-families-advisors> for more details

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