Families As Teachers

FAMILIES OF CHILDREN with special health care needs have a central role in their child’s life and play a vital role on their child’s health care team. Family expertise and perspective are like no other. Families as Teachers is a well-established training experience that offers pediatric residents and selected masters-level health professionals an opportunity to learn from families. In the comfort and relaxed atmosphere of their homes, families can tell their story, talk candidly about the special challenges they face, and reflect openly and honestly on their experiences with health care professionals. It is through these personal encounters with families that teaching and learning takes place.

How does Families As Teachers Work?
Families as Teachers began in 1996 as a home-based training experience for residents during their developmental pediatric rotation. In this situation, residents are the students and families, the teachers. During the home visit each resident gets a feel for the family’s day-to-day reality—to “walk in their shoes,” at least for a few hours. It is the perfect setting for open conversations about what works and doesn’t work in partnering with health care professionals. Because there is plenty of time and the residents have no clinical responsibilities attached to the experience, they can pursue those questions about which they’ve always been curious. It is a time of lively dialogue that results in an increased sense of mutual respect for one another’s roles and responsibilities, and a better understanding of the special challenges each faces.

In preparation for the visit, families are encouraged to think about what they want to emphasize about their lives and how they can best give residents a glimpse of it during the visit. They are asked to think about the question, “What do you think is important for doctors to know and understand about your children and your family?” Many include the resident in their typical family routines such as the after-school schedule or a family meal. They find these are good ways for the resident to experience many aspects of family life. A typical visit lasts 3-4 hours.

In a follow-up meeting with the Program coordinator, the resident reflects on the experience in a more focused way. Special attention is given to implications for their practice as physicians. These conversations are rich with insights and observations.

Goals
- Enhance understanding of the challenges faced by families who live with special health care needs
- Deepen appreciation for the unique and valuable skills, knowledge and competencies families bring to the health care team
- Gather practical advice/tips on ways to effectively support and partner with families
- Increase understanding of the key principles of family centered care
The Center for Children with Special Needs

Families As Teachers

The success of the program rests solidly on the families themselves. Over 25 families are involved. They represent a wide variety of diagnoses, ages, lifestyles and health care experiences. Everyone has an ongoing relationship with Children’s and is identified by staff as having a balanced perspective on their experience. While each family has their particular perspective to share with the resident, they are also able to articulate the common experiences many families face. Families are positive about their time with the residents. They describe the experience as worthwhile, empowering, and healing. Families are compensated with a $75 honorarium, and while many comment they would participate without compensation, they all appreciate the value it imparts.

As more people became aware of this successful program, Families as Teachers has been extended and adapted to the University of Washington Pediatric Pulmonary Center and the Masters of Social Work students placed at Children’s. As with the residents, these trainees have positively evaluated their experiences.

Comments
From families:
• “Of all the things I’ve done for this hospital, this is the most rewarding. What a great opportunity for personal connection! I’m going to make a difference in the way these doctors view the kids.”
• “Appreciate the opportunity for my child to have a chance to give feedback—roles reversed—we get to be the teachers. Residents were open to hear our input. They were genuinely interested and seemed to have healthy respect for the multiple hats we’re trying to wear here.”

From past residents:
• “There are few opportunities, like this, to visit families without having some medical decisions as an end-point.”
• “I realized how easy it is to forget how much more complex their lives are. . . . I also had the opportunity to see the joy that families with these “survivor” kids experience every day.”

From current residents:
• “I definitely gained a new appreciation for the minute-to-minute, day-to-day struggles these families handle. I also appreciated the joy they experience as well. It’s a wonderful program—a highlight of the rotation.”
• “Parents continue to be the best advocates for their children and the best sources of information about their children. Thank you for reminding me how important it is to listen to parents and directly address their concerns”

It is tempting to collapse key training points into a list of tips and successful techniques; however, it is through the personal encounter with a particular family that powerful insights and lasting impressions are made.

Other Ways that Families Teach at Children’s

• “Do You Know What They Said to Me?”: A parent-authored, parent presented, dramatic approach to exploring the parent/physician relationship.

• Family feedback groups: One-time, focused conversations that solicit family feedback on timely issues and impending decisions. Key staff members attend in a listening role.

• Committee membership: In the course of planning and doing committee business, families share their perspectives in personal ways and offer practical/relevant solutions.

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The Center for Children with Special Needs is a program of Children's Hospital and Regional Medical Center. Formed in 1998, the Center is dedicated to education, policy and research to promote the health of children with special health care needs and their families. Funding for the Families As Teachers Project is provided by the Washington State Department of Health Children with Special Health Care Needs Program and by Children's Hospital and Regional Medical Center in Seattle, Washington.