

In Our Own Words:

Using Family Stories to Teach Family Centered Care

Many colleagues shared their ideas and experiences in the development of this Guide. We especially want to acknowledge and thank the following family members and professionals who provided insight, encouragement and their own very personal stories, which guided our efforts all along the way.

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Welcome to Participating Families:

Welcome to the Family Faculty program at Dartmouth Hitchcock. This is such an exciting time to be teaching future physicians about family centered care. Many teaching hospitals are now actively seeking consumer feedback about the kinds of services that best meet patient and family needs. We can share our perspective, as consumers of health care services, and know we will be heard.

As parents of children with special health needs, we have a wealth of experience. We know what a difference it makes when our children receive excellent care. We know how it feels to be really listened to, to have our questions thoroughly answered, to have our doctors care about how things are at home and whether we're getting enough sleep and how our kids are doing at school. On the other hand, most of us have also experienced the flip side of the coin. We know what doesn't work. We know what makes us feel worse, rather than better.

As Family Faculty, you will be sharing what you've learned as the recipients of great, good, poor, or indifferent care. When parents lend their voices to the process of medical education, they are ensuring other families will have more positive experiences in the future. Pediatric residents will now learn family centered care directly from families. They will see your child in the community, come to your home, and observe a typical day at school. When they begin their own community pediatric practices they will draw upon the wisdom of your words and the power of your stories to guide them in their work.

Thank you for joining us in this important endeavor.

Sincerely,

Nancy DiVenere
Executive Director,
Parent to Parent of Vermont

THE PURPOSE OF THIS HANDBOOK IS TO:

- Support the overarching goal of increasing pediatric residents' ability to care for children with chronic conditions.
- Provide a framework for families to share their knowledge and expertise in caring for their child with special needs.
- Help families organize their stories around central themes.
- Prepare families for their role as members of family faculty programs

HOW FAMILIES WILL USE THE HANDBOOK

- This handbook identifies eight skill areas essential to the practice of family centered care. Families will use the handbook as a guide, as they draw upon examples from their own lives, to illustrate how these skills can best be practiced.
- Participating families will attend orientation sessions to practice sharing their stories and to develop strategies for teaching the 8 skills to residents.
- Families will teach family centered care in a variety of ways, including: home visits, parent panel presentations, small group discussions, and school and community visits.

The Narrative-Based Family Faculty Curriculum: Using Story-Telling to Teach Family Centered Care

"Their story, yours, mine- it's what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn from them."¹

Everyone has a story to tell. Our stories reveal how we think about ourselves, how we define and give meaning to our experiences and how information is selectively passed on from one generation to the next. Our stories are shaped by what we pay attention to. And what we pay attention to is influenced by gender, age, culture, family history, values, and expectations for the future.

The American Association of Medical Colleges, in their 1998 learning objectives for medical student education, underscores the need to recognize a patient's individual experience.

"In all of [a student's] interactions with patients, they must seek to understand the meaning of the patients' stories in the context of the patient's beliefs, and family and cultural values."¹

In keeping with the AAMC's emphasis on a patient's "individual experience" the Family Faculty Curriculum offers parents a basic framework for teaching family centered care to pediatric residents. It is organized around the central principal of story-telling, a language common to families everywhere.

Physicians, too, are familiar with story-telling. Many physician-patient interactions begin with a description of the patient's experience: the "story" of the illness. Before a treatment strategy can be developed, the physician must first understand the meaning of the symptoms in the greater context of the patient's life.

By inviting pediatric residents into their homes and their communities families will begin to teach the kinds of lessons that can't be learned in a hospital or out-patient setting. Within the hospital the emphasis is on the illness. In the home and community the emphasis is on living life to the fullest.

Pediatricians who develop skills in the areas outlined here will dramatically improve the quality of life for children with chronic conditions and their families.

¹ Coles, Robert, *The Call of Stories: Teaching and the Moral Imagination*, pg 30

¹ AAMC: Learning Objectives for Medical Student Education: Guidelines for Medical Schools, 1998

WHY FAMILY FACULTY?

As high frequency users of health care, families of children with chronic conditions are uniquely qualified to teach medical students and residents how to design and deliver services for children and families.

This is true for the following reasons:

- Over time, families acquire knowledge and expertise in managing their child's care. By serving as Family Faculty parents are able to demonstrate these skills and model collaborative partnerships with physicians.
- Parents are experts at balancing a child's physical needs with the larger social, emotional and spiritual aspects that add richness and meaning to life. Parents can help others see the child first and the illness second.
- Families of children with chronic conditions have a wealth of experience as consumers of health care services. They know what works. They know what they need. They can describe what is and is not helpful. They are passionately committed to the cause.

WHAT DO PATIENTS AND FAMILIES WANT?

Focus group participants in a 1998 study conducted by the American Association of Medical Colleges “*spoke at length about their desire for more personal attention from their physician, and the need to be treated like a person, not just another case. Both men and women put characteristics such as ‘caring, compassionate, being a good listener, and having a good bedside manner’*”² at the top of their lists. Clearly, the physician who practices family centered care displays such qualities.

As families share their stories with pediatric residents their experiences become part of the educational process. While some medical schools rely on surrogate patients or computer simulations to promote the development of interpersonal and diagnostic skills, family faculty bring their real life experiences.

These experiences are not staged and there is no script. The resident is not responsible for providing any clinical care. Thus, he or she can focus exclusively on the interpersonal skills and the specialized knowledge families of children with chronic conditions find most valuable in a physician.

² Neeley, McInturff, & Cohen, 1998, p.9.

HOW RESIDENCY TRAINING WORKS:

PL I: The First Year

After completing 4 years of medical school, these new graduates have earned the title of M.D. They are here to begin a "pediatric residency", a three-year program which will prepare them to become Board Certified in Pediatrics.

First-year residents are also known as "interns". (The terms are used interchangeably.) They have less responsibility than the more experienced residents. Many interns find themselves doing "the work no one else wants to do": gathering test results, ordering lab tests, documenting charts. Often they don't have as much contact with patients and families as they had hoped they would. Interns rotate from one area of the hospital to another, usually for 4 weeks at a time. Just when they are getting used to one place, it's time to move on to another.

Your intern will make two home visits this year. Each intern will visit during the month when he/she is placed in the community practice rotation and during the behavior and development rotation.

Before each home visit, interns meet individually with project staff. During these meetings we cover various aspects of a family centered approach to care— communication, collaboration, forming partnerships with families, sibling issues, etc. Following that meeting, the resident visits the family and then meets one more time with project staff.

HOW RESIDENCY TRAINING WORKS: (continued)

PL 2: The Second Year

The "PL 2" residents have a year of training behind them! They are no longer called "interns". They are now "pediatric residents" for the remainder of their training.

During the PL 2 year you will again meet twice with your resident. The focus of their training expands a bit to include school, community and specialty care settings. Their visits with you will occur when they are placed at _____. These months have been selected because residents typically have more flexibility in their schedule during these times.

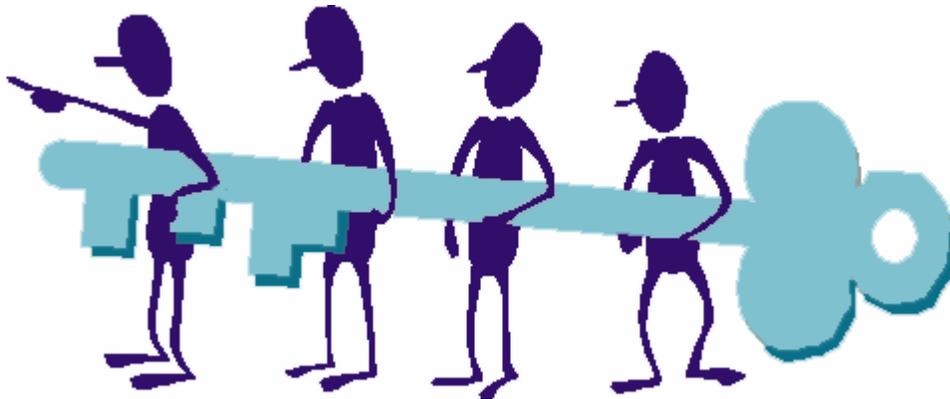
The residents will be expected to visit your child's school or daycare in order to gain a better understanding of what things are like for kids in the community. You might invite them to watch a soccer game, or other extra curricular activity your child enjoys! They may attend a Care Conference or IEP/IFSP meeting if you think that would be helpful and if you have such a meeting scheduled during the month of your resident's visit.

PL 3: The Third Year

Third year residents are responsible for teaching, as well as for providing clinical care within the hospital. They are also beginning to look for jobs, or making plans to continue their training as a pediatric sub-specialist.

Please use the margins and other spaces in this booklet to jot down your personal notes. As you read, you may be reminded of family experiences to share with your resident.

PRACTICAL TIPS FOR FAMILIES:



WHAT CAN YOU EXPECT?

The First Home Visit:

"At first, it felt a bit awkward. I wasn't sure what to expect. Was this supposed to be a social visit? Was it more formal than that?"

Many parents look forward to the opportunity to share what they've learned with a pediatric resident. But, while they're waiting for the resident to arrive for the first home visit, they realize they're entering into an unfamiliar situation. They're not sure what to expect.

The following tips were compiled by several parents who have recently completed first-time home visits with their resident:

- 🔑 Expect to feel a bit awkward at the beginning. Don't worry, this will pass. Remember, this is a new experience for the resident, too. He or she probably feels even more awkward than you do.
- 🔑 Prior to the visit, you might want to spend a few minutes thinking about how you will begin. Part of your objective is to develop a relationship with the resident. You can do this through casual conversation about hobbies, family, pets, and by asking questions about the resident's own family, his or her interests, etc.
- 🔑 Some parents like to give the resident an idea of what to expect. For instance, if you have invited him or her to share a meal with your family, you might say, *"I thought we could talk a bit before dinner, then sit down and eat. After dinner we'll have some more time before the kids go to bed at 8:30."* A typical home visit lasts between 2 and 3 hours. Some have been as long as 4hrs. It's really up to you. You can play it by ear, or you can be more specific about how much time you have available that day.
- 🔑 Expect the unexpected. The first time the resident comes to visit, younger children (and even adolescents) can sometimes behave in unexpected ways. One mother described the first visit this way:
"As soon as he walked in the door my 4 year old became very shy. She wouldn't even come in the room. Usually she is so outgoing and friendly."

Another parent felt thrown off balance when her teenage daughter decided to use that opportunity to argue with her about why she couldn't go to the mall with friends on a school night.

Another mother described the following:

"While I was speaking with the resident my 5 year old walked over to the cupboard and got out a box of croutons. She then turned on the TV, sat down in front of it and started eating the croutons out of the box. I wanted to say, this isn't what we usually do. She doesn't watch TV during the day and she doesn't eat croutons in the morning."

Relax!

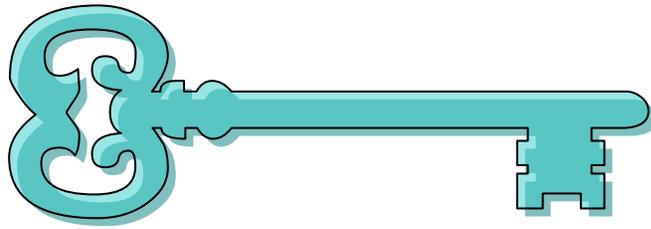
The resident is not there to evaluate you or your parenting. In each of the above situations, the visits turned out to be very enjoyable experiences.

Parent Panel Presentations, Case Conferences and Grand Rounds

- Some families may chose to participate as members of parent panels or speak individually to a group of residents about a specific topic. Speaking in front of an audience can be intimidating and not everyone will be comfortable in this role. Again, parents who have been through this have some tips to share with those of you new to public speaking.
- Try to observe other parents in this role before you, yourself, agree to participate as a speaker.
- Speak to one of the program coordinators about borrowing one of the video tapes on this topic. These tapes contain practical advice about how to organize what you want to say, how to handle last-minute-jitters, how to connect with your audience and how to deal with unexpected emotions that may arise.
- Talk with other parents who have done this. Find out what their experience was like and what helped them prepare for it.

KEY OBJECTIVES FOR A FAMILY-CENTERED PEDIATRIC RESIDENT





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1. Communication
2. Collaboration
3. Family strengths
4. Effective help-giving
5. Cultural and spiritual beliefs
6. Compassionate behaviors
7. Self-awareness
8. Empathetic support with terminal illness, therapeutic failure, and death

FAMILY CENTERED CARE FOR PEDIATRIC RESIDENTS

Skills

The family centered pediatric resident will demonstrate *skills* in the following areas:

- ☞ Communication
- ☞ Collaboration
- ☞ Identifying and promoting family strengths
- ☞ Effective help-giving
- ☞ Recognizing & respecting cultural and spiritual beliefs regarding health and well-being
- ☞ Compassion
- ☞ Self-awareness
- ☞ Recognizing the limits of medical intervention and maintaining a supportive presence when these limits have been reached

Knowledge

The family centered pediatric resident will demonstrate *knowledge* of the following topics:

- ☞ Public health issues, policies and concerns affecting children with chronic conditions and their families
- ☞ Local, state and national programs, resources and supports for children and families
- ☞ Family systems theory
- ☞ Family expertise in caring for and educating others regarding their child's condition
- ☞ Familiarity with the roles and responsibilities of other health care professionals
- ☞ A child/family perspective on living with a chronic condition
- ☞ How to provide a Medical Home
- ☞ The non-linear model of the grieving process

Goal

1 Pediatric Residents will develop excellent COMMUNICATION SKILLS

OBJECTIVES FOR THE RESIDENT:

- 1.1 Expressive skills including: gathering information, breaking bad news, giving information in ways parents can understand, effective use of non-verbal responses.
- 1.2 Receptive skills, including: listening, attending to body language, hearing “what is not said”, appropriate use of silence.
- 1.3 Ability to recognize and respond to feelings

METHODS THAT YOU CAN USE:

your family narratives
home visits
parent panel presentations
case conferences
observations
readings

1 Pediatric Residents will develop excellent COMMUNICATION SKILLS

HOW DO FAMILIES TEACH COMMUNICATION?

Your Personal Notes:

Most parents agree; communication is everything. If a physician can't communicate well, everything else that he or she *can* do pales in comparison.

These objectives refer to some very general categories of communication skills. Expressive skills can be thought of as "things we do and say." Depending on the situation, a well-timed hug can be a very effective communication strategy. In this case, words aren't really necessary. In other instances, the doctor who is able to look you in the eye and say, "*Tell me what you're really worried about*" is probably very skilled at gathering information.

You may be wondering what to focus on and how to illustrate some of the above objectives. Often, families can simply share a story about something they experienced and how it affected them. Be as specific as you can.

For example, most parents have very detailed memories related to their child's diagnosis. In fact, many parents say they will never forget the tone of voice, the look in someone's eyes or the words that were used to describe their child's condition. Frequently, the stories about a child's diagnosis highlight a number of communication issues.

The following questions may help you describe your own family's experience:

- *How did you first learn of your child's condition?*
- *Who told you?*
- *Who else was with you at the time?*
- *Did you have the opportunity to ask questions?*
- *How did you feel?*
- *Were your feelings acknowledged?*
- *What helped? What could have been done differently?*
- *Did you understand what was being said?*

Goal

2 Pediatric residents will be skilled in developing and maintaining **COLLABORATIVE** relationships with parents, sub-specialists, related service providers and others in the community.

OBJECTIVES FOR THE RESIDENT:

- 1.1 Understand the characteristics of effective parent-physician partnerships
- 1.2 Recognize possible barriers to working in partnership
- 1.3 Develop strategies that enable all parents to contribute to the collaborative process
- 1.4 Demonstrate flexibility
- 1.5 Allow for reciprocity and mutual support
- 1.6 Remain non-judgmental

METHODS THAT YOU CAN USE:

your family narratives
home visits
care conferences
community visits (IEP meetings, school observations)
readings

2 Pediatric residents will be skilled in developing and maintaining COLLABORATIVE relationships with parents, sub-specialists, related service providers and others in the community.

HOW WILL FAMILIES TEACH COLLABORATION?

Your Personal Notes:

Although families of children with chronic illness often rely on the expertise of a myriad of professionals, families are the ultimate experts on their children.

Parents have a unique and valuable perspective, acquired over time, based on countless experiences in a variety of settings. They have a holistic understanding of their child that goes far beyond the details of the diagnosis. While professionals come and go; a parent is there for the long haul and his or her knowledge, insight and intuition are essential to an effective plan of care.

In addition to this broad-based understanding of "who a child is" and what makes her tick, a parent also possess a very detailed and specific body of knowledge about a child's medical condition. Over time, many parents have become experts at managing complex medical needs in the home and in the community. Furthermore, as long-term and frequent consumers of health care services, parents are a wealth of information regarding the design and delivery of those services.

Think about all of the different relationships you have with people who care for your child.

☞ What makes them work?

☞ What specific things have physicians said to you or your child that indicates he or she values your opinion?

One Neonatologist begins her meetings with parents by asking, *"How do you think things are going?"*

Another pediatrician told a parent of a newly diagnosed baby, *"I don't know a lot about this condition. But I can find out about it. We'll go over the information together and eventually you'll know more about this than just about anyone."*

These kinds of comments set the stage for collaborative relationships.

Your Personal Notes:

Now, think about those interactions with physicians, or other health professionals that haven't gone so well.

🔑 *Why not? What could have been done or said differently...*

🔑 *What steps did you take to try to improve the situation?*

🔑 *Why is collaboration so important?*

The best way to teach residents collaborative skills is to provide opportunities for them to observe others using these skills effectively.

Can you invite the resident to join you at a care conference or school meeting? Try to find time after the meeting to talk about how it went.

What was the purpose of the meeting?

What was the pediatrician's role?

What was your role, as the parent?

What decisions were made and how were things decided?

Your Personal Notes:

Goal

3 Pediatric residents will be skilled in identifying and promoting FAMILY STRENGTHS

OBJECTIVES FOR THE RESIDENT:

- 1.5 Create opportunities for families to demonstrate things they do well.
- 1.6 Help family members learn new skills, or acquire additional resources, in response to family-defined needs
- 1.7 Offer interventions that are congruent with family strengths
- 1.8 Help other members of the health care team recognize family strengths
- 1.9 Encourage family members to utilize “natural”, informal and community based supports

METHODS THAT YOU CAN USE:

family narratives
care conferences
case presentations
home visits
community visits

3 Pediatric residents will be skilled in identifying and promoting FAMILY STRENGTHS

HOW DO FAMILIES TEACH RESIDENTS TO RECOGNIZE STRENGTHS?

Your Personal Notes:

Often, families are so busy they don't really stop to think about all the things they do well. Prior to speaking about this topic with the pediatric resident, you might want to reflect upon what you like about the way your family does things. Ask other family members, too. "Family strengths" come in all shapes and sizes. They can be as simple as reading bedtime stories together, following routines, or playing in the park.

For example:

6 year-old Daniel was born with Down Syndrome. He learned some sign language in kindergarten to help with his expressive language skills. Daniel's 4 older brothers and sisters learned sign language, too. They all signed the words they knew together at home. It wasn't a formal intervention, lasting 30 minutes per day, five days per week. Signing became "just something they did because it was fun". In this case, Daniel's older siblings can be considered a family strength.

Sometimes families need to draw upon strengths they don't even know they have. Or, they need to learn to do things they never imagined they could do.

When Nora's daughter was born with a cleft palate it was difficult to feed her. She couldn't breast feed and bottle-feeding was very slow and inefficient. Nora was frustrated. She had no time to play with her other children because she was spending all her time feeding the new baby. Despite her efforts, the baby wasn't gaining weight. Finally, she told her pediatrician they needed to try something else. She didn't know exactly what she needed but she knew things weren't working as they were.

The pediatrician began to teach Nora how to feed the baby with an "n.g. tube" that very day. He assumed she would be able to do it and because he acted like it was possible Nora was able to envision herself succeeding.

Goal

4 Pediatric residents will have EFFECTIVE-HELPING skills

OBJECTIVES FOR THE RESIDENT:

- 1.1 Ability to offer help in a way that is most likely to be accepted
- 1.2 Ability to offer help that will be most effective
- 1.3 Ability to offer help that will have lasting benefits
- 1.4 Interpersonal traits and attributes that positively affect the helping process

METHODS THAT YOU CAN USE:

readings
case conferences
parent panel presentations
discussions with practicing community pediatricians

4 Pediatric residents will have EFFECTIVE-HELPING skills

Effective helping is closely related to collaboration. Professionals who collaborate well with parents are probably skilled at offering help that is likely to be accepted, is effective and has lasting benefit. (See tips on Effective Helping)

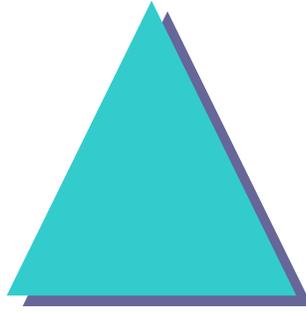
HOW DO FAMILIES TEACH ABOUT HELPING SKILLS?

Your Personal Notes:

It is important for service providers to remember that every minute a parent spends focusing on the recommendations of one professional or another takes time away from something else. "Helpers" who are *less effective* prescribe interventions for parents to carry out. *Effective* helpers ask parents what their concerns and priorities are and approach them together.

One mother describes how a nurse practitioner admonished her for not devoting sufficient time to her son's dental hygiene. The nurse practitioner's focus was on the individual child. Thus, brushing and flossing were appropriate concerns. However, this boy's mother was juggling services, therapies, and appointments for one child, while trying to carve out time in the day for the typical things all families enjoy. At the moment, a peaceful bedtime routine for each of her children was a higher priority than a nightly struggle with dental hygiene.

The following pages describe "Effective Helping" in more detail. As you read these pages, please jot down examples of ways others have offered you or your family help. What was the difference between help that was truly helpful and help that was not?



The Effective Helping Triangle is one way to illustrate the varied components of help-giving. For example, the left side of the triangle: **Technical Quality**, refers to the professional training and hands-on skills people rely on to do their work. Standard medical training ensures that residents have a great deal of "technical expertise". They know how to draw blood and put in chest tubes and do LP's. For the most part, they are comfortable in this role.

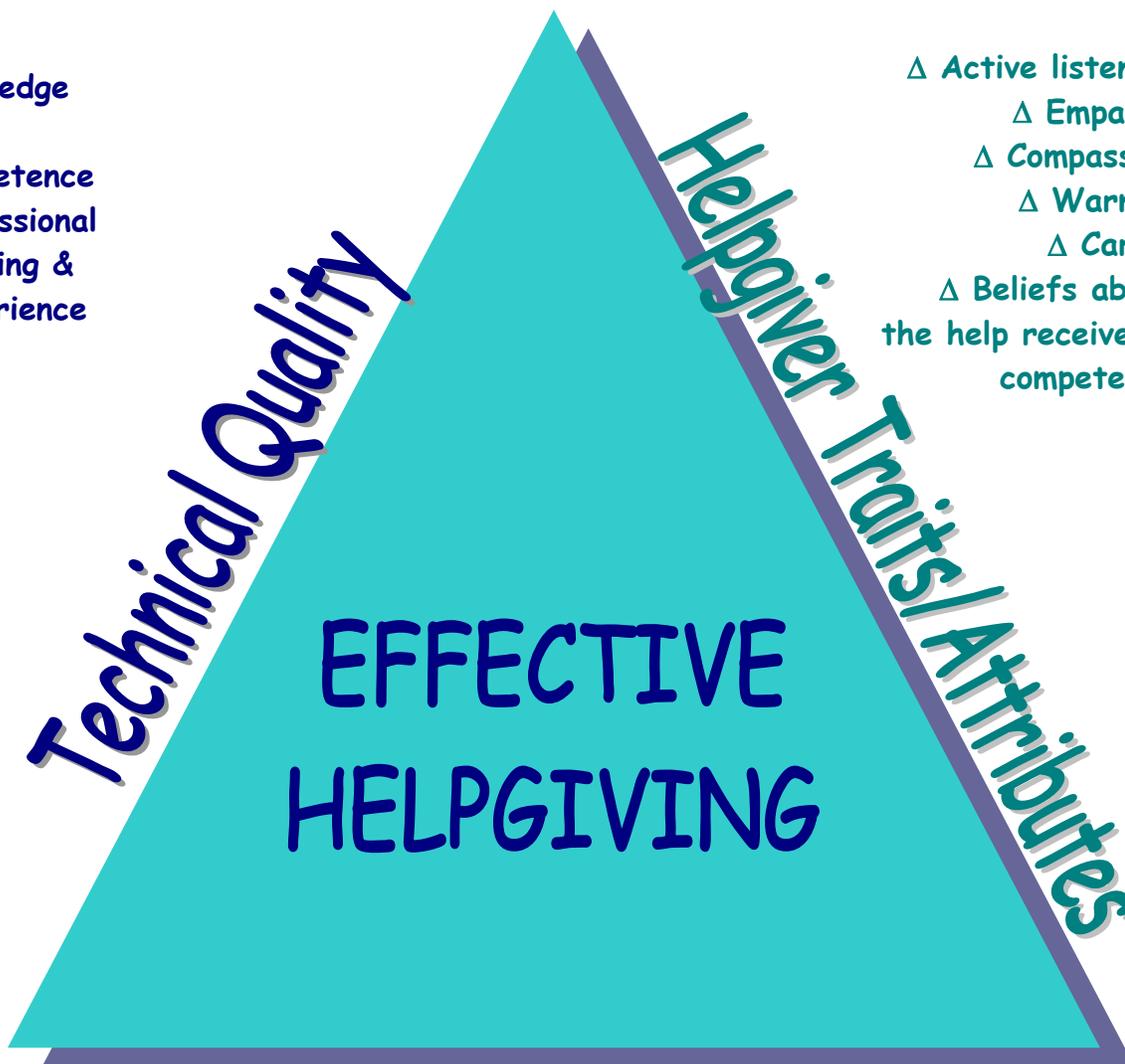
The right side of the triangle describes the interpersonal skills and attitudes that make the practice of the technical skills effective. This includes such qualities as empathy, compassion and warmth. As one parent said, *"I need to know how much you care, before I care how much you know."* Often, there is little formal training around the acquisition of these essential behaviors. Family stories are a particularly effective method of illustrating the kinds of interpersonal traits families value most in their physicians.

Finally, the helping process should include the opportunity for shared decision-making. Regular opportunities for discussion, reflection and sharing information must be part of the process.

Three Components of Effective Helpgiving Practices

- △ Knowledge
- △ Skills
- △ Competence
- △ Professional training & experience

- △ Active listening
- △ Empathy
- △ Compassion
- △ Warmth
- △ Caring
- △ Beliefs about the help receiver's competence



Participatory Involvement

- △ Shared decision-making
- △ Opportunities for discussion
- △ Information for making choices
- △ Collaboration around common interests and concerns

Adapted by Parent to Parent, with permission from Dunst, C.J. and Trivette, C. M. Empowerment, Effective Helpgiving Practices and Family Centered Care. Pediatric Nursing, July-August 1996. Pgs. 334-7.

Effective Help-Giving ³

In the words of Carl Dunst and his colleagues, "*Help isn't helpful unless you think you need it.*"⁴ There is both an art and a skill to offering professional help that is congruent with family-defined needs.

Help is most **useful** if:

- It conveys caring, warmth and encouragement

Help is more likely to be **accepted** if:

- It is in response to needs identified by the help-seeker.
- The responsibility for meeting needs and solving problems is shared

Help is more **effective** if:

- It is clear to the recipient that he or she has the right to accept or decline the help
- There is no implication that there is "something wrong" with the individual because he/she needs help
- It is in response to the individual's view of his/her problem or need
- Help-seekers are encouraged to use personal support networks (informal supports) rather than rely solely on professional support services.
- The help is acceptable to everyone involved

Help will be more **beneficial** if:

- People are encouraged to acquire the knowledge and skills that will help them help themselves
- People experience immediate success in solving a problem or meeting a need
- If the individual experiences improvement in his/her situation and feels responsible for it

³ Adapted from the work of Dunst, Trivette and Deal, 1988

⁴ *ibid*

Your Personal Notes:

Goal

5 Pediatric residents will recognize and respect a family's CULTURAL AND SPIRITUAL BELIEFS regarding health and well-being.

OBJECTIVES FOR THE RESIDENT:

- 1.1 Understand that the definition of “family” may differ according to cultural background and individual experience.
- 1.2 Understand how roles, responsibilities and relationships between and among family members may differ according to culture
- 1.3 Use of communication strategies that demonstrate respect and awareness of cultural differences
- 1.4 Sensitivity regarding the ways in which culture governs interactions between physicians, families and their patients.
- 1.5 Understand that “health” and “well being” carry a variety of meanings. In children with chronic conditions, health is not equivalent to the absence of disease.

METHODS THAT YOU CAN USE:

family narratives
readings
home visits

5 Pediatric residents will recognize and respect a family's CULTURAL AND SPIRITUAL BELIEFS regarding health and well-being.

Culture is often something we don't analyze or question. Yet, it shapes many of our daily practices and routines. Our values can be influenced by culture.

Jason is a 10 year-old boy who spent 6 months in the NICU after he was born at 25 weeks gestation. Towards the end of his NICU stay, his parents arranged for a massage therapist to visit Jason every week. They believed massage would help Jason relax, improve his muscle tone and increase his overall sense of well-being. (It was also something they could do to improve his situation.) The doctors and nurses in the NICU didn't think it was appropriate for "outsiders" to "treat" babies in the unit. This incident set the stage for conflict and misunderstanding between Jason's parents and NICU staff.

This story addresses the ways in which "cultural beliefs about health and wellness" can result in misunderstandings between parents and physicians.

HOW DO FAMILIES TEACH ABOUT CULTURE AND SPIRITUAL BELIEFS?

According to the most recent census, VT and NH are among the most homogeneous states in the Country. Yet, even here, the routines of our daily lives, how we celebrate holidays, our relationships with extended family members, who and when we marry, how we spend our leisure time; all vary according to our own family culture.

Simply because many of us share the same ethnic background, doesn't mean we share the same values, or make the same health care decisions about treatment, medication, therapy, surgery and wellness.

Goal

6 Pediatric residents will demonstrate **COMPASSIONATE** behaviors in their interactions with children and families.

OBJECTIVES FOR THE RESIDENT:

- 1.1** Demonstrate empathy through thoughts, words and actions
- 1.2** Spend extra time with families when they need it
- 1.3** Remain comfortable in the presence of emotion- both the family's and your own
- 1.4** Let family members know you are available to answer questions and to listen to their concerns

METHODS THAT YOU CAN USE:

your family narratives

6 Pediatric residents will demonstrate COMPASSIONATE behaviors in their interactions with children and families.

HOW DO FAMILIES TEACH ABOUT COMPASSIONATE BEHAVIORS?

Your Personal Notes:

Compassion is difficult to define. Perhaps compassion is the active expression of respect and empathy. It must be **demonstrated** somehow. Compassion can be conveyed without words. A look or a touch often says a great deal.

Parents have said that compassionate physicians convey respect and understanding for the family's individual experience of a situation. He or she may have given many families bad news. But, for each individual family hearing bad news is devastating. The way in which bad news is delivered can set the stage for all future interactions between these individuals.

For over a year, Kate had been searching for a diagnosis that would explain the increasingly odd behaviors displayed by her four-year-old son Jason. Among other tests and consultations, she was referred to a geneticist by the developmental pediatrician who first confirmed Jason's delays. There was a two month wait for the appointment. Unfortunately, on the morning Kate was scheduled to see him, the doctor was running well behind schedule. Kate was kept waiting with her son in the exam room for close to an hour, during which time her son grew increasingly bored and out-of-control. Though stressed and distracted by Jason's misbehavior, Kate did her best to politely answer the doctor's questions as he sketched in a family medical history and examined her child. Upon concluding the exam, the doctor turned to her abruptly and said, "Well, I see no dysmorphic syndrome." Hearing only another door close, one through which she had hoped to find a name for her son's condition, Kate's eyes filled with tears. Taken aback, the doctor stammered, "but this is meant to be good news." She nodded. "Yes, of course." Without taking a moment to ask about and imagine her situation, the physician could not have known the extent of Kate's frustration or the depth of her fears for her son.

The compassionate physician is able to be present with the family in the "here and now" to share the pain without being overwhelmed by it.

As you tell your story to the resident, try to recall specific examples of compassionate behaviors towards you or your child:

- The hug when you needed one...

- The physician who sat and cried with you...

- The time your child's pediatrician stopped by your child's hospital room twice a day because she thought you might want to talk.

How did it make you feel?

Have you ever experienced what felt like "false" compassion?

What different feelings did that generate?

Your Personal Notes:

Goal

7 Pediatric residents will demonstrate SELF-AWARENESS in recognizing their own values, beliefs, and biases.

OBJECTIVES FOR THE RESIDENT:

- 1.1** Demonstrate a willingness to examine one's own values, beliefs and biases in order to identify how they might impact decision-making with patients and families.
- 1.2** Recognize how values might affect family and physician decisions regarding genetic testing and gene therapy
- 1.3** Identify situations where values might affect public health or educational policy decisions related to programs and services for CSHCN

METHODS THAT YOU CAN USE:

family narratives
readings
community physicians and mentors
community based experiences and discussion with family faculty

Pediatric residents will demonstrate SELF-AWARENESS in recognizing their own values, beliefs, and biases.

Your Personal Notes:

Values, beliefs and biases can shape attitudes and decision-making. Although medical students and residents acquire a great deal of information and technical expertise during their years of training, there is little opportunity for reflection on their beliefs about chronic illness and disability.

Since 1986, Parent to Parent of Vermont has been conducting a series of seminars with third year medical students designed to help them identify their own biases and beliefs regarding chronic conditions in children. Each student is presented with a list of the same four medical conditions. Students are asked to identify which condition would be easiest for them to deal with as a parent and which would be most difficult. To their surprise, the answers vary a great deal. As students discuss their choices they become aware that their decisions were not based on medical knowledge, but rather on their perception of how a particular condition might affect family life and the parent-child relationship. The qualities they value most in that relationship and their beliefs about what's most important in life influence their choices.

HOW CAN FAMILIES TEACH ABOUT A RESIDENT'S SELF-AWARENESS?

As the resident gets to know your child and family they will become more aware of his/her own values and beliefs. Residents will need opportunities to discuss and reflect upon the differences and similarities that may exist.

Goal

8 Pediatric residents will be skilled in providing medical care and empathic support in the presence of terminal illness, therapeutic failure and death.

OBJECTIVES FOR THE RESIDENT:

- 1.1 Involve parents in decision-making
- 1.2 Consider the family's cultural, spiritual and religious beliefs when counseling parents regarding treatment options
- 1.3 Recognize the ways in which impending death affects the family system
- 1.4 Self awareness regarding one's personal response and feelings
- 1.5 Maintain regular contact with family throughout progression of illness and for a period of time after death

8 Pediatric residents will be skilled in providing medical care and empathic support in the presence of terminal illness, therapeutic failure and death.

Your Personal Notes:

"Will did not go easily. His final hours were a desperate no-holds-barred heavy-weight fight with no time limits, no resting between rounds. It was at once the most horrible and the most awe-inspiring experience of my life. I tell you this because I think it's important that everyone know that Will rose above a flood of pain and suffering, through a raging river of morphine and other drugs, asked for his glasses, looked at us and said to Dee and I, "I love you. I'll miss you", then puckered his lips for a kiss. He drifted away from us then, to fight a brutal battle for several hours before taking his last breath as the church bells rang at 9am. Those moments will forever remain the single most profoundly spiritual and beautiful thing that has ever happened to me. I saw life and love and divinity at that moment. It was Will who brought it to us, all of us, everyone he has touched with his short life.

Beginning on June 19th when we arrived at the emergency room in Burlington and continuing at this moment, I have never known such unfathomable pain. Any parent's worst terror is that something might happen to their child. Dee and I have lived with that terror for nearly 2 years- every day, every hour, every minute, awake or asleep, at home or in the hospital, at work or play. The unthinkable happened last Wednesday morning- Independence Day, so perfectly labeled for Will. Since July 4th, I have died with every flood of memories, every dream destroyed, every burst of tears. Heartache and pain have been constant companions."

The above words were written by a father, less than a week after his son's death. Each family is forever changed by the experience of terminal illness. While nothing can mitigate the pain and suffering all families must endure, physicians who remain open and available to the family during this time can be an invaluable source of support and comfort.

Lessons Learned by Brad Friesen, M.D.

A Final Note:

This family faculty handbook is representative of the new opportunities available to families of children with chronic conditions. There is now increased interest in incorporating a family perspective into professional training programs for health care providers. This interest is due, in part, to the efforts of families like you, who have been willing to share their very personal stories in order to improve outcomes for other children and families.

Parents of children with special health needs have long supported and nurtured one another. This holds true whether parents are part of formal parent support organizations, or whether their support comes from casual conversations over coffee with family, friends and neighbors. When parents get the support they need, when they feel well-grounded and knowledgeable about the resources and services in their communities, they are most able to participate effectively in family faculty programs.

But, parents can't do it alone. Successful programs are based on partnerships: Parent to Parent of Vermont has forged close and enduring partnerships with the University of Vermont College of Medicine, the Department of Pediatrics, the Vermont Department of Health and the Vermont Academy of Pediatrics. As a result of those partnerships, there have been significant improvements in the care of children with chronic conditions in Vermont, as well as significant opportunities for parents to participate in the development of programs and policies that impact children with special health needs.

As parents in the Dartmouth-Hitchcock community implement a family faculty program of their own, they too are developing collaborative relationships with the Boyle Community Pediatrics Program, the Department of Pediatrics, Dartmouth Medical School and other member of the health care community. Such efforts are not limited to Vermont and New Hampshire. They are echoed by parents throughout the country as families lend their voices to the development of programs and policies that effect the quality of their lives.