FAMILY-CENTERED CARE FROM THE START: FAMILY FACULTY

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Shane Murchio was a full-term baby, born healthy to his parents, Celina and David, who were 20 years old at the time. At nine months, he became ill with respiratory problems, was diagnosed with RSV, and was hospitalized for three weeks. While there, Shane's parents were told he had suffered a stroke at some point before his hospitalization. A nurse also suggested that he seemed behind developmentally, something Celina and David had also noticed and had asked about during his well-child visits. Because of these multiple concerns, a series of tests were run, and a mass was discovered in Shane's brain. It is this brain tumor that is Shane's primary diagnosis.

A biopsy in Albuquerque indicated the tumor was malignant. But David researched second opinions, found St. Jude's Hospital in Tennessee, and the family raised funds through raffles and other events so that they could travel to St. Jude's. The St. Jude's second opinion? The tumor was not malignant. And thus began a long relationship with and many trips to St. Jude's.

Meanwhile, as a toddler, Shane had RSV several times a year, aspirated frequently, had paralysis of his vocal chords and neck, and was frequently hospitalized. Over the years, his lungs deteriorated, he suffered from sleep apnea, used a nasal canulus, and was ultimately diagnosed with Chronic Obstructive Pulmonary Disease. When Shane was five, it became clear that a tracheotomy was in order. This procedure, which David Murchio can recount in excruciating detail, was awful. The trach dislodged three times after surgery, requiring bagging, more procedures, and incredible pain and fear for Shane and his parents. Finally, after David told the medical team that he would hold the fourth trach in place for 72 hours after the last insertion, it held.

Shane came home from the hospital with a trach, a ventilator, an ambu bag, etc. --- all the equipment that all of you are so familiar with, but which so frightened and intimidated Shane's parents. With medical and emotional support from a remarkable pulmonologist, Niam Bashir, and his team at the University of New Mexico, with periodic respite from family members, the ongoing assistance of New Mexico's Medically Fragile Program, and the absolute devotion and expertise of his parents, Shane is living at home and is in second grade at a regular school. His younger brother, Nathaniel, who is four, is in many ways a big brother who knows what to do when an alarm goes off, is familiar with trach tubes and gauze and heprin, and has helped Shane learn to walk.

The pictures you see behind me tell us that the Murchios are a typical family in many ways, as is Shane a typical boy. But like so many of the families and children you work with every day, their daily lives are regulated by the machines and procedures that keep Shane alive. Thank you, David, Selina, Shane, and Nathaniel, for sharing your story with us.

The Murchios have grounded us. They remind us about why we do this work, and for whom. Throughout my talk about family faculty as an important way to practice family-centered care, I will bring us back to Shane and his family. And perhaps when I do so, you will also think about families you know who touch, inspire, maybe even puzzle you. Above all, as I talk, please feel free to sink into yourselves, to reach back to inspirations in your work, to envision how you might expand and improve your professional work by partnering with families --- because that's what family faculty is all about. Partnerships and partnering.

Let me talk a little about family-centered care. I have been advised that you all know about family-centered care and that you practice it daily. And I am so glad. As the mother of one son who is medically fragile and has multiple disabilities and three others who were amazingly healthy children, as the grandmother of seven little ones, and as a family leader who has worked with hundreds of families and professionals for over two decades, I absolutely know that the true practice of family-centered care, with all its professional challenges and personal dynamics, leads to quality care and improved outcomes. Family-centered care does not take place without partnerships between families and professionals. And the best time for those partnerships to germinate is when health professionals are students --- and are taught by faculty that include families. You see the connection, I hope. So, let's begin with the definition of family-centered care from the Maternal Child Health Bureau:

The Definition: Family-centered care assures the health and well-being of children and their families though a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high quality services.

Note the word partnership in that definition. Remember, successful family faculty programs are about partnerships between families and professionals. Let's proceed now to MCHB's principles of family-centered care. As I talk about these principles, please think back to Shane's story and how partnerships and family-centered care were there for him and his family. I'll also quickly give some examples as they occur to me.

The Principles: The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- **Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.**
- **Everyone respects the skills and expertise brought to the relationship**.
- **Trust is acknowledged as fundamental.**
- **Communication and information sharing are open and objective.**
- **Participants make decisions together.**
- **There is a willingness to negotiate**.

That's partnership, the key, the foundation of family-centered care.

Based on this partnership, family-centered care:

1. **Acknowledges the family as the constant in a child's life.**

2. **Builds on family strengths.**
3. **Supports the child in learning about and participating in his/her care and decision-making.**
4. **Honors cultural diversity and family traditions.**
5. **Recognizes the importance of community-based services.**
6. **Promotes an individual and developmental approach.**
7. **Encourages family-to-family and peer support.**
8. **Supports youth as they transition to adulthood.**
9. **Develops policies, practices, and systems that are family-friendly and family-centered in all settings.**
10. **Celebrates successes.**

Why do I so emphasize the principles of family-centered care when this is a talk about family faculty? First, because the partnership between families and professionals is the basis of family-centered care and infuses its practice. And second, because family faculty cannot exist without the partnership. There is a distinct relationship here! When families and professionals model their partnership through their faculty roles, students observe and professional faculty experience a shift in the relationship between professionals and families. They discover that families and their children are not just done to, they are not just passive recipients of care, they are active partners in good health care. When students see families beyond a patient role, when they learn from and listen to families, when families and professional faculty are observed working together, the partnership is modeled and inspired in ways that no textbook or lecture can describe.

As you know, there are many models and programs where families are faculty. Today, I will mainly draw from three places: Vermont, where the Department of Pediatrics at the University of Vermont Medical School and Parent to Parent of Vermont launched their partnership in physician education in 1985, probably the first formal family faculty program in the country. New Mexico, where the Center for Development and Disability at the University of New Mexico and Parents Reaching Out expanded on the Vermont model in partnership with the School of Nursing, the Department of Pediatrics, the state Health Department, and many other state and community-based partners. And Indiana University, where the IU Medical Center has developed a family and community faculty model that uses the Medical Home concept to bring together partners from the Indiana Parent Information Network, Wishard Primary Care Center, and a variety of community-based programs and clinics.

Family faculty teach nursing students, medical students (particularly in their pediatric rotation), pediatric residents, and students in social work, education, and therapy schools in undergraduate and graduate programs. I'll give you a kind of broad survey, a synthesis, if you will, of family faculty programs. I will start with the simplest, most common form of families as faculty, and then end with family faculty programs that are more formal and are imbedded in the curriculum and teaching of health sciences centers and practiced in children's hospitals, community-based clinics, and private practices.

Parents Tell Stories. Parents who have children with special health care needs are frequently invited to talk about our experiences with health care systems. We tell our stories to students,

faculty, hospital and clinic staffs and administrators, boards of directors. I might tell a particular story to a particular class once a semester. Or to an all-staff meeting. Or perhaps to administrators or a board of directors after a problem has arisen. These family stories are valuable and can be a great beginning in considering family as faculty. But family stories are only that: They are one family's experience with a particular diagnosis, or hospital stay, or procedure, told from one family's perspective. Family stories tend to be told and heard in isolation, leaving little opportunity for an ongoing partnership that might improve systems. Certainly, one story told in a compelling way could overturn a lousy policy or even a law, but that is the exception. I consider story-telling a start. A start for families, who learn how to tell their stories and feel at ease in a new role. A start for faculty and staff who might begin to see families in a different light and will, we hope, take home a lesson or two from that particular family's experience. When a family is invited to tell its story, it's important that they are given some guidance about the setting, context, audience and expectations. A family whose story will be about a negative experience should be prepared for the inevitable reaction. And audiences should be prepared to accept and acknowledge the story for what it is and what it means for that specific family and institution.

Families as Advisors. Hospitals, health profession training programs, community programs and clinics often find that having a patient or family advisory board can provide them with new insights and ideas for systems improvement --- a kind of sounding board. In fact, across the country, family advisory committees are responsible for a series of changes that have led to family-centered care: rooming-in, family support programs in the NICU, home visits from students, and ultimately to family as participating faculty. In New Mexico, I can trace our excellent family faculty program back to a group of families and a pediatric chair who sat down together to talk about ways to improve the pediatric program. As a result of a series of informal conversations, they started a family advisory board to the university hospital. Family advisory boards are usually appointed by a department chair or hospital or program administrator. Advisory committees meet regularly, often tackling operational problems that families experience or that staff or faculty alert them to. These committees bring their advice or recommendations to administrators or policymakers. But remember, it is only advice and need not be heeded. Unlike boards of directors, advisory committees do not make policy; they give advice. On the other hand, advisory boards are ongoing and can be effective change agents. Such committees are a great training ground for family leaders. Advisory boards also provide an opportunity for staff and faculty to get to know families as advisors or experts. Some advisory board members move on to family faculty positions or to membership on boards of directors. It goes without saying that education and peer support for advisory board members is critical, as are other kinds of support to the families who are advisors: child care, stipends, travel money, meals!

Grand Rounds. For many family leaders, this is our initial formal experience as a peer, a partner in teaching as part of a professional team in a health sciences setting. When I was first invited to do grand rounds, I pictured myself walking around the hospital, lecturing students in a rather grand and medical way. I was wrong, of course. Because I just stood in front of a large gathering of staff, students, and faculty at the university hospital and shared my knowledge about state and federal child health legislation, and answered questions, along with a faculty member who was a friend. This was a step beyond just telling my story, because I was doing this as part of a

professional team --- for the moment. It was one time, as grand rounds usually are. Doing grand rounds as a parent can be intimidating and requires preparation and support from the professional leading grand rounds. It really is an effective way to begin to be considered an expert, perhaps worthy of faculty status.

Teaching Classes. Beyond telling stories, beyond doing grand rounds, teaching a class for a semester, or teaching several times to one class, or co-teaching with a professional not only provides a forum for imparting family expertise, it models partnership with families. It is living proof that families are more than just patients or just parents to a child who is a patient. As we all know, teaching requires credentials, it requires preparation, it implies a place in the broader curriculum of the institution. The department that brings on family as faculty, adjunct or otherwise, has definitely made a statement about the unique expertise that families bring to a discipline. And for families, it can be exciting: "This is the most fun I have ever had, " says Donna Olsen, who is adjunct faculty at Indiana. "I love it that my family expertise is my degree in this job." Speaking of degrees, institutions that hire families to teach classes, whether alone or with a professional partner, must go through a process to credential their family faculty in some way. Vermont, New Mexico, and Indiana prove it can be done.

Family as Staff. To ensure a family presence and to infuse family-centered care in all aspects of training and clinical programs that affect children and adults with disabilities, the University of New Mexico's Center for Development and Disability has hired several parents for their family expertise. Led by Tanya Baker-McCue, parents are program managers, teach graduate and undergraduate classes, connect pediatric residents with families and family organizations, provide peer support, design curriculum, infuse family-centered care into the LEND program, provide expertise to the department of pediatrics, help staff a continuum of care program for people with disabilities, and expand the Medical Home concept and its practice.

Students in Homes and Community Programs. One of the most effective ways to introduce the idea of families as partners is to take students to families and to community programs. The students can come from undergraduate and graduate nursing programs, medical school rotations, pediatric residency programs, any professional school whose graduates will take care of children and families. In home visits, which can happen once or over a period of time, students are assigned to trained families who teach them about their child's diagnosis, show them feeding or bathing routines, let them see the complexities of family life when there is a child with special needs, introduce them to community resources.
The effect is profound and, in most cases, life altering. "This visit reminded me how much a child's health is dependent on their emotional support at home. And how much a parent's emotional stability is dependent on a trusting relationship with their physician," said a student after a visit. In most places where home visits are imbedded in the curriculum, the department or professional school has an ongoing relationship with a parent organization that finds and trains the families to be teachers and guides. Family and professional faculty together guide the students during the visit period and, critical to the learning process, encourage them to reflect on the visits through writing exercises and classroom discussions.

Designing Curriculum. Here's where Vermont definitely leads the way. Nancy DiVenere and others from Parent to Parent of Vermont began to assist the Vermont School of Medicine design

its medical school curriculum several years ago. It seemed a natural evolution. But it did not happen over night. Over more than a decade, the Vermont partnership had developed, implemented, and improved on all of the models of family faculty --- family stories, grand rounds, families as advisors, as classroom teachers, family as staff. All of this was built upon a firm belief by everyone, medical faculty and family leaders alike, in the importance of the family home visit program. It seemed inevitable that families would now help design a medical school curriculum to reflect the successful partnership between professional and family faculty.

How do you begin?

In each of the sites I queried, and based on my own experience with family faculty around the country, every successful family faculty endeavor begins with a vision and a leader. Or two or three. Vermont might argue that their family faculty experience began by accident --- when a group of disabled people came to their hospital for services and were not served well. In this instance, someone actually noticed the problem and chose to dig deeper into the why of it. Was it that hospital staff was ill-prepared for people who could not communicate well? Who behaved differently? Who had multiple needs? In Vermont, a problem became a solution became a vision became a model national program.

You certainly can have a vision! Perhaps you start with a couple of parents whom you invite to talk to your classes. That might evolve into a comfortable relationship with them that moves into conversations about the school of nursing curriculum, and then to the suggestion of home visits --- and off you go! There is no recipe. There is no formula. Every place will do this differently. You can find ideas by scrolling through web pages, Googling family faculty leaders, asking your friends in other states and schools.

What Makes it Work?

When there is a leader who believes in family-centered care and family professional partnerships, it's a logical next step to some version of family faculty. It's best if that leader, of course, is in a decision- and policy-making position. But just having the vision of a department chair, for example, is not enough. Because family faculty is a partnership, there has to be a family partner who shares that vision. Any institution --- public or private, department or academic medical center, hospital or clinic --- that is open to change and improvement, is fertile ground for family faculty. In the absence of an inviting institutional environment, pioneers --- visionary family and professional leaders --- can take the first steps, prove it works, and grow from there.

Once a family faculty program of some sort is in place, leaders in this movement suggest several things:

- Family faculty should come from and be attached to family networks, so that family faculty don't work in isolation from other families. And so that you have access to a wealth of family experiences and perspectives.
- Family faculty must be trained, know expectations, and be supported by the professional team they work with. They also need support from their family peers back at their organization, which is probably their comfort zone.
- There must be time set aside, weekly is best, for team meetings, discussions, planning, tweaking, reflection.

- In fact, reflection by all parties --- students and faculty alike --- is critical to family faculty success. Written reflections by students are helpful not only for students, but also for faculty who can use student thoughts and ideas to improve the program.
- It's obvious that any kind of family faculty initiative be evaluated ---by students and faculty, as well as anyone touched by the family faculty program. Indiana does an annual evaluation, for example.
- Resources of time and money can make or break a program. Family faculty must be paid, of course. Meetings to plan, reflect and evaluate must be inserted into everyone's schedule.

Where do you find family faculty?

The easiest answer is within your own networks and practices and relationships. That's where you find families who can tell stories or help with grand rounds or perhaps staff a program. But better than one parent are many parents, from diverse cultural, economic, education and ethnic backgrounds; who speak many languages; whose kids have different special health care needs; who each come with a unique experience. And that's where parent organizations and family networks are a rich resource. Rather than depend on one articulate parent who can make a particular point, look for many. When you form a partnership with your local parent organization, you have access to diversity, to training, to peer support. Should you hire someone who's connected to a parent network, it's much more likely that she or he will be able to go beyond one personal experience and will be able to call up many different stories and perspectives. I recommend that you visit the websites of Family Voices or Parent to Parent USA, both of which have parent leaders in almost every state. You can also contact the various national diagnostic organizations for representatives in your area.

Ah, the barriers.

There will always be barriers and reasons not to use family faculty as a way to practice family-centered care. Such as money. Indiana supports some of its family and community faculty programs through Medical Home and Dyson grants, but also through some of its community program partners: who would have thought an academic medical center like Indiana would find funding for community and family faculty through US Department of Justice grants?

In New Mexico, the Center for Development and Disability saved the skin of the university hospital CEO when the center happened to go before the Board of Regents with an idea for family-centered care at a time when the hospital was in trouble --- and was rewarded by the hospital with ongoing funds.

MCHB and other grants also support UNM's family faculty. The University of Vermont family faculty program received grants from the Children's Miracle Network and Robert Wood Johnson; RWJ then required that family faculty become a line item in the medical school's annual budget. On the other hand, an exemplary family faculty program recently closed because of funding problems at the University of Wisconsin.

However, I always say, if New Mexico, poor New Mexico, can figure it out, anyone can. Other barriers can and often do include deans and others in leadership positions. I believe you can work around those who are not the initial visionaries, especially if you can prove, as Vermont does, that many students choose that school because of its preceptor family faculty program.

Evaluation. Here's where we tend to fall flat. Most of the evaluations used by family faculty programs are narratives and reflective pieces, which are fine for internal training and program purposes. But I suggest that if we really want to prove that family faculty leads to family-centered care and that it ultimately improves quality care and health outcomes, we need evidenced-based evaluation tools. Perhaps those used by the Medical Home projects. Vermont believes that testing students competencies through the LCGMEs also works as a measure. Going out into the field where graduates of family faculty programs are practicing is an obvious step. Evaluation is important. It is not my area of expertise at all, so I leave that up to the researchers to do, with persuasion and guidance from the rest of us.

As we learned a few minutes ago, almost every minute of every day for Shane's family can be a teachable moment. Imagine what it would be like for a nursing student to spend a couple of days at home with Shane, feeding him thru his G-tube, staying in his room at night, suctioning him, doing the circuits on the vent, hoping he's getting enough sleep for school tomorrow --- and then accompanying Shane and his nurse to school, shadowing Shane and his parents to medical and therapy appointments, observing his family as they work out schedules or look for recreation opportunities in the community. David and Celina Murchio have now become advocates for children and families, both working at the state parent organization, PRO, until Celina recently pulled back to replenish her energies. David and Celina are experts. They could be and sometimes are family faculty. Just like the families you know and work with every day.

Thank you.