Parents as Practitioners in Pediatrics

It is uncommon, in health care settings, for parenting to be acknowledged as a practice in the same respect that nursing and doctoring are accepted as practices. It is unusual for the knowledge and expertise of parents to be granted the same moral weight as the expertise of others who are considered practitioners of a skill.

Yet, parenting is indeed a practice, drawing from a rich storehouse of learning that includes observation, experiential learning and the generational transfer of knowledge. Parents invest in their practices by adopting a range of learning strategies—seeking out mentors, learning collaboratively with peers and reflecting upon their accumulated knowledge. This investment is heightened in families of children with chronic illnesses and disabilities, given the higher stakes involved. These parents routinely become skillful at advocating for their child, navigating complex medical systems and making complex and ethically challenging health care decisions.

The strength and depth of this kind of parental practice is captured in the following account by a parent of a child with special health care needs, whose daughter recently graduated from high school.

When my daughter was one year old, I was told she would never have children of her own, go to college or live independently. All my dreams were destroyed in a 20-minute office visit. That conversation was also the beginning of my becoming an expert, both in terms of understanding my daughter’s physical and developmental disabilities and in terms of knowing her as a unique human being—a funny and courageous kid, talented artist, lover of animals and the foundation of our family. Our clinicians understand some pieces of the puzzle; I understand many others. More and more, our relationships with the medical team are fueled by mutual respect. When that happens, I can relax a bit, knowing that my daughter will get what she needs from all of us.

When we think about how best to engage with parents and families, we should consider the nature, extent and depth of parenting practices. When we extend ourselves to acknowledge parents’ skills, knowledge and values, we put ourselves in the position to learn more deeply from each other and to partner more effectively and robustly on behalf of children with complex health care needs.

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