

# From Strangers in a Foreign Land to Active, Engaged Citizens

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Despite many successes in patient- and family-centered care, including efforts to address cultural competency, much work remains to be done to fully understand and implement effective strategies for patient engagement. The Affordable Care Act and some state legislation have mandated programs and provided incentives that promote engagement and partnerships with patients and caregivers because patient activation and engagement have been shown to improve the quality of care and lower health care costs.<sup>1</sup> There are 3 key participants in the use, experience, and costs of health services: the provider, the payer, and the consumer. According to the tenets of health care reform, for quality to improve consumers must be empowered to make informed decisions.<sup>2</sup> Therefore, continuing progress and establishing a practice of engagement in patient care across the nation is critical to the survival of health care reform in the United States. One way to look at this engagement is to examine individual relationships between health care teams and patients and families. In pediatrics, an informative paradigm is in the care of children with special health care needs (CSHCN), with whom the highest degree of interaction occurs.

This article was jointly written by a parent of CSHCN and a primary care physician to offer a perspective on the evolution of family partnerships as parents and other caregivers gain experience working with the health care system. While pediatric health care systems transform to become more family centered, parents are often sought for feedback and, in

some cases, coleadership at the organizational level to help health care teams improve quality and delivery of services.

We describe the experience of our proactively engaged parent author (mother to 2 children born with permanent health needs) and discuss how engagement strategies might be applied to caregivers whose entry point begins at infancy. We realize that many family partnerships will be different (especially those involving children in foster care, adolescents transitioning to adult care, and families facing end-of-life decisions) and that the degree to which families choose to partner may vary. However, we hope that our discussion and parent stories might spark discourse about how to create optimal partnership models.

## JOINT INTRODUCTION

Most parents of children born with special health care needs walk through hospital doors for the first time as strangers in a foreign land, similar to Kingsley's<sup>3</sup> description in her short essay "Welcome to Holland." Kingsley, and most parents, love and see the beauty in their disabled children, although this beauty is different from what they expected when they decided to have kids; finding beauty in the health care system is not so natural. Parents face many variable barriers to engagement with health professionals: they may not speak the language of health care (and some may not speak English), they may not understand the culture, they may not understand the "currency" (insurance and payment structures), and many may not have

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Ms Scharpen and Dr Stille conceptualized and designed the article, drafted the initial manuscript jointly, and reviewed and revised the manuscript; all patient vignettes came directly from Ms Scharpen's experience as a parent of children with special health care needs; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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family supports or life experiences that help them navigate their way through the system. Like refugees seeking asylum, parents can start their journey as dependents of the host nation, trusting that they and their children will be cared for and kept out of harm's way. As they gradually grow accustomed to the health care culture, the desire for freedom and independence in decision-making can spawn an initial activation in parents to learn about and adapt to their new surroundings.

Each health care encounter offers opportunity for parents to gain confidence and skills that advance their efforts to blend their cultural beliefs and ideas with that of the health care team. When families are permanently placed in the health care system, they are not merely tourists, but they must establish residency in this new country; they become motivated to overcome the barriers that separate them, and some parents become proficient in health care processes such that they develop a calibrated "inner compass" to navigate their way and take up citizenship. However, physicians and other health care team members often are unaware of parents' health literacy or self-efficacy in the culture of health care. Although critical for health outcomes and measurable by existing tools,<sup>4-6</sup> these capabilities are seldom included routinely in the assessment process.

Parents of different ethnic, racial, and economic groups have the ability to engage at varying levels,<sup>7</sup> and they gain skills in stages of ability while receiving care for their children. Each parent will adapt to the system in their own way, but there are commonalities across the spectrum. First, each parent is equipped with a certain degree of self-efficacy (whether it is high or low) at the start of their engagement with the health care system.<sup>8</sup> Second, as their self-efficacy grows, parents become more capable to engage.<sup>7,8</sup> Third, over

time, motivated parents can become experts, with skills in knowledge, advocacy, and caregiving. Although parents will always be experts about their child, we discuss here how health care teams can facilitate parental progress through the stages of ability to enable actively engaged parents of CSHCN to be effective experts in negotiating a complex system.

### EARLY STAGES

My son was 5 days old, born with a skeletal dysplasia that was undetected during pregnancy, and we were at the hospital to undergo a battery of radiology tests and blood tests to confirm suspicion of dwarfism. We were there for 5 hours talking with hospital personnel. I cried the entire time. I was still recovering from the pain of childbirth and I was struggling to accept a diagnosis of permanent disability. The hospital staff and physicians continued to talk with me about the nature of his condition not seeming to recognize that I was grieving.

Parent

### Parent Input

The beginning of the journey for parents is probably the most difficult time, and their need for support is indispensable. Their self-efficacy is low unless they have previous knowledge and experience, such as being employed by the health care system or having the same medical condition. There is intense emotional pain in the early stage, and peer emotional support is important for comfort and hope so that parents can get back up on their feet after the heavy blow of a disease's diagnosis. Connectedness and confidence in their care team are not yet established and need to be nurtured. Most parents are learning by trial and error at this point and finding ways to adjust their interaction with the health system to gain the most benefit. Additionally, many parents may accept all treatment interventions without evaluating the recommendations on their

own. Health care team members should expect that when parents are not in contact with them, they are talking with friends and relatives, spending hours on the Internet reading, and struggling in the regular care duties of managing their child's condition.

### Physician Response

Given parents' limited experience at this initial stage, it is relatively easy for health care team members to know where parents stand once health literacy can be assessed. The care team should assess parent preferences, provide information appropriate to their level of understanding while being careful not to overwhelm them, and support their growth and engagement, making use of team members most trusted by parents. Parent questions should be encouraged, but being new to the system, they may not have many at the start.

### INTERMEDIATE STAGES

Our son was vomiting every day and suffering severe headaches that woke him in the middle of the night. We sought care from our local hospital. After examination of the MRI, they did not see anything. They told us not to bother coming in for follow-up. Knowing that something was wrong, and having knowledge of what could happen with his condition from our support group, we continued to pursue medical care and eventually had to fly across the country for surgery.

Parent

### Parent Input

Parents gain skills as they are immersed in the responsibility of caring for their child, gaining community support, and engaging the system. They are learning to ask questions and be more discerning of accurate direction versus inaccurate recommendations. They will notice inconsistencies in the system, and many parents of children with more complex needs experience wasted time and

money on fruitless interactions. By the intermediate stage, parents are gaining a higher degree of knowledge about their child's condition. They have been explaining their child's condition to friends, relatives, schools, and sometimes complete strangers, so they are becoming community educators. Their demand for more information will increase because they want to be informed decision-makers and caregivers.

Some parents may start to express concerns about care management protocols and will want to get involved in initiatives to improve them. Asking them to consider serving on hospital, private clinic, or community health committees will help them feel connected to their health care team as partners in care delivery. By their advanced engagement, they will continue to learn how the processes of care work, and they can sometimes even educate health care professionals on practices.

### Physician Response

In the intermediate stage of parent engagement, parents may have an explosion of questions and ideas. They often have read extensively on their child's condition and may have questions that seem unusual to the care team. It is important to remember at this stage that parents are still "learning the language" as well as the culture of health care, and there should be no such thing as a "dumb" or "crazy" question. At this stage, care team members should guide parents toward more evidence-based and at times advanced sources while continuing to ask how they are coping with their child's condition and treatment and its effect on their family. For parents interested in engaging in more advanced ways, offering programs such as the Family Leadership Training Institute<sup>9</sup> and giving them tasks appropriate to their level of interest and ability

in parent advisory groups can be helpful.

### EXPERT STAGES

I've been serving on committees at the hospital and I've seen that providers do care about patients. They are battling a rigid system that is the same one that I battle.

Parent

### Parent Input

Parents at this stage typically have had hundreds of encounters with the hospital over many years. They have seen errors, they have gone to unnecessary visits, they have watched their child suffer, and they have felt the pain of thousands of dollars in cost to their family budget. They are understandably hesitant to seek care and they have learned how to weigh all of the observable evidence to make decisions on when to seek medical care. Their decision capacity is high because the barriers to communicating with health professionals no longer exist. Parents can become frustrated during this stage because they require an advanced level of engagement to feel satisfied with care. The needs that they had in the early and intermediate stages may still be present, and some may oscillate across stages as new health problems arise. Regardless, the primary concern for parents in the expert stage is full inclusion on the team.

### Physician Response

Health care teams' sharing information and having mutual respect in partnership with the parents becomes paramount because parents see themselves as medical directors for their children. Valerie Billingham's phrase, "nothing about me without me,"<sup>10</sup> should always be the mantra of the health care team during each phase, but it is imperative in the expert stage because the

parents are now equipped with equally valuable assets to the investigation, detection, and treatment of disease. Providing evidence-based conversations that are inclusive of the parents' views and knowledge will promote strong partnerships in care. Parents should be encouraged to take a leadership role within the health care team<sup>11</sup> because as expert parents they are experienced care managers with strong skills in knowledge, advocacy, and caregiving. Consequently, tension that may present in the doctor-parent partnership can be relieved by including parents' advanced abilities and preferences for care more fully.

### JOINT CONCLUSIONS

A culturally adaptive health system that engages parents and patients according to their stages of ability will make for more efficient, effective, and compassionate health care. In pediatrics, the burden of decision-making is particularly heavy; decisions are being made for vulnerable people that are not yet able to make decisions for themselves, and supportive engagement that reflects the needs and abilities of parents is vital to their well-being. Taking this into consideration, a health care team that can assess an appropriate level of engagement according to the attributes of the early, intermediate, and expert stages will improve overall parent satisfaction with care. Furthermore, facilitated engagement that is stratified according to parents' experience can help parents make more informed decisions, direct teams toward improved treatment outcomes, and optimize the collaborative use of health services. Every parent has the capacity to advance by increasing their self-efficacy and promoting their growth during each stage of development. Therefore, supporting parents as they take up "health

care citizenship” by meeting their varying needs as they adapt over time will make for engagement that has great potential to sustain families

during times of hardship as well as promote improved patient and family experiences and more effective health care.

#### ABBREVIATION

CSHCN: children with special health care needs

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