



## **A Monograph – Reflections on Learning**

### **To – For – With: The Journey to Understanding Partnerships with Patients**

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In 2010, an awareness emerged for me that the single largest barrier healthcare team members face when developing person-and family-centered relationships is this: we believe we already have them. Just ask us! Otherwise, why would smart, caring, committed people act in ways that are counter to what patients and families tell us is important to them? Just offering more content or pointing out to these dedicated professionals that ‘you may think you are but you really aren’t’ was not a productive path to change behaviors!

From my readings in anthropology and sociology I expect that people act in ways that make sense to them in the context in which they function. Thus the challenge was to discover why, despite evidence that we are woefully lacking in effective partnerships with patients, families, and community members, we are slow to grasp the gaps in our behaviors and reluctant to change.

As I led the Institute for Healthcare Improvement team that developed the White Paper: *Achieving an Exceptional Patient and Family Experience*<sup>1</sup> in 2009-10 and conducted seminars to help people apply the clear lessons learned from exemplars, I re-learned that offering content is necessary but not sufficient. Compelling lessons from those who excelled in creating patient-centered organizations generated interest but little sustained behavior changes. At the same time, Jack Gilbert and I finished a study of transformational healthcare executives, published as [The Heart of Leadership](#)<sup>2</sup>. A striking theme in the leaders we interviewed was their ability to step away from the fray of daily pressures and reflect on both their own and organizational behavior. They sought others who could help them in this reflection, explored writings and different approaches to look at new paths to intractable problems, and were willing to try new behaviors to achieve their mission.

Building on these experiences and the lessons from impressive colleagues – Susan Edgman-Levitan, Jim Conway, Beverly Johnson, and others – I recognized that until we developed individual and collective insight into our cultural beliefs and behaviors we would remain stuck.

Recognizing that reflection on current practice and identifying the gaps to the desired outcomes we espouse is a key step in cultural development in organizations, I looked for tools that would assist this self-discovery. Finding none that were fast, simple, easy, and cheap I began reflecting on my own healthcare professional journey – what was it like caring for patients when I was a new nursing graduate, what changed along the way, how, and why? What were some of the ‘common wisdom’ behaviors that were held as the only way to do something that we later found laughable or embarrassing? I also asked colleagues in different professions about their experiences and a pattern of stories emerged. Many of the changes – and those that changed the fastest – turned out to be those prompted or demanded by patients and their loved ones.

My qualitative research interest was prompted and led to thinking about what language would group these behaviors. Others had talked about what we do ‘to’ patients. Nursing theory had the language of ‘doing *for* patients that which they would for themselves until they were able to do self-care’. Healthcare systems were built on ‘doing to’ – more similar to prisons than healing environments. Nurses and physicians often forgot to move to self-care once the patient was able and continued ‘doing for’, frequently with the assumption we knew best. I was confident there was a level of interaction that was more constructive and the language that seemed to illustrate that was ‘with’ or partnerships. The language of “Are we doing To – For – With Patients, Families, and Community Members?” resonated with those I worked with in early 2011 including the Change Foundation in Ontario, Canada and Institute for Healthcare Improvement patient experience seminar participants. The intervening four years has reinforced the utility of the language and exercise in reflecting on individual and collective behaviors.

The exercise involves five steps: 1) provide people with the concepts of “Where are you in the journey of doing To – For – With Patients, Families, Community Members?” including examples harvested from a variety of settings, professionals, and patient/family advisors; 2) ask them to think of their own examples in each category; 3) share their examples with others; 4) ask them to reflect on what gets in the way of moving to ‘doing with’ patients and families; 5) identify what they can test immediately in their setting to move to ‘with’. A variety of participants internationally have identified the exercise as both illuminating – ‘oh, we do that . . .!’ and as a highly useful way to identify ways to move forward. The framework provides a common language when healthcare professionals are working to change systems and behaviors. A colleague, Gail Nielsen, asked participants to draft their ‘with’ actions then asked them to critique one another about the proposed actions. The exercise provided a respectful means to point out when we were acting ‘to’ or ‘for’ but thought we were acting ‘with’. The most productive conversations are with patients, families, or community members as active participants. If they are not, the question ‘how can you verify your descriptions with patients, families, or community members?’ is the next step.

A complementary exercise is to ask healthcare professionals, especially leaders, to complete “Where are you in the journey of doing To – For – With *Staff and Providers?*”. The key point is that staff and providers cannot be ‘with’ patients/families/community members if they are being done ‘to’ in their work. The intent is the same – to reflect and act on embedded cultural aspects that limit our effectiveness, waste time, good will, and talent.

I believe there is a step beyond ‘with’ however the language for it and the examples are just emerging for me. When I mentioned this next evolution and that I was looking for examples, a Canadian colleague mentioned Dr. Lee Shoo, a Toronto neonatologist as one model. I contacted him and he generously shared his story of seeking better ways to break the logjam of plateaued outcomes for neonates. He explored the feasibility and safety of care by parents through a team co-led by healthcare professionals and parents. They then embarked on a study where parents were primary caregivers of their babies in the NICU. The results are impressive: parent involvement results in a measurable benefit to the babies’ health, allowing them to grow faster, suffer from fewer complications and go home faster.<sup>3</sup> I am confident that other examples will illuminate this next stage. The evolution will be accelerated as we have more conversations that explore what does To – For - With mean for different people and roles across time and a continuum of relationships. The journey is ongoing and necessary to transform healthcare.

1. Balik B, Conway J, Zipperer L, Watson J. *Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care*. IHI Innovation Series white paper. Cambridge, Massachusetts: Institute for Healthcare Improvement; 2011. (Available on [www.IHI.org](http://www.IHI.org))
2. Balik, B., Gilbert, J. (2010). The Heart of Leadership: Inspiration and Practical Guidance for Transforming Your Health Care Organization. Chicago: AHA Press.
3. Personal conversations 2013; <http://www.thestar.com/news/gta/2015/02/15/mount-sinai-reveals-state-of-the-art-neonatal-icu.html>