Meaningful Engagement or Tokenism?

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I want to tell you a story.

The consultant with the expensive shoes

Six years ago, my son attended a speech program at a local hospital (Hospital A), and I was asked to attend a strategy session for the hospital as a family rep. As a Mom, I was excited about being invited and I had lots of input to share about our experience at the facility. I understood strategy development from my professional life at the department of health and as a board member on our local Down syndrome society.

I arranged child care for my youngest, and for my other two kids to be picked up from school so I could attend the two-hour session. There was no written material sent in advance and I just had a meeting room number and time emailed to me.

I came to the hospital, paid for parking, and spent some time finding the meeting room – which was tucked away in the basement of the hospital. When I arrived, the room was filled with families of paediatric patients and some former patients from the adult side. Some of the adults had caregivers with them, and obviously had put a great amount of effort to attend.

There was nobody from the hospital there – just a very well-dressed woman at the front of the room, who introduced herself as a consultant. I knew she was well-paid by looking at her expensive shoes.

The next two hours were spent answering general questions about where we, as families and patients at the hospital, thought the hospital's direction should be. I was watching the consultant and noticed she took no notes at all over the two hours, which was awfully strange to me.

Afterwards, I asked her if I could receive a copy of the draft strategy for review, or at least a final copy for my files. I wanted to see how our comments would be incorporated in the document.

"Oh, yes, I'll email you a copy" said the woman with the expensive shoes. I didn't see her write down that request either.

You probably can guess what happened next. We were thanked for our time, ushered out, and I never saw a copy of the strategy – draft or otherwise.

Now, this was only two hours in my life, but it was an indicator for future involvement at that facility. I persevered in participation – presented to a senior management group about family-centred care, talked to clinic staff about family experience, and I also sat on their parent council as a volunteer for four years.

But that hospital never really 'got' what meaningful participation meant, and how to engage families. Meeting times were often set arbitrarily and with short notice, without consultation of family schedules, presentation times changed last minute, and nobody ever met me beforehand to prepare. I was just told to show up. When I got there, I often was not introduced to those around the table, and that felt very intimidating to me, as a Mom.

I finally ended up giving up and fading away because I felt my voice was not heard.

The happy ending to this story is that I started to volunteer for another hospital (Hospital B) where my son went to clinic. This hospital recognized the value and worth of their family volunteers, and soon offered me a contract as a paid Family Advisor for their facility. My main purpose was to engage other family members in the facility at the operational level, in ways that were meaningful and 'non-tokenistic'. And that's what I have been doing for the past two years.

The check mark phenomenon

Over these two years, I've learnt lessons about what meaningful engagement is, and what is tokenism. Some of these lessons have been hard-fought, and garnered through making mistakes, reflecting on the crucial work of family engagement and endeavouring to make things better.

There are two aspects to family engagement in the paediatric health system. One is engagement directly in care, directly at the bedside or in the clinic office. This occurs when families are full participants in decision-making for and care of their child.

The other, operational engagement of family representatives can happen at senior levels of the hospital system. Families can participate on councils, committees and interview panels; review policies, procedures, survey questions and educational materials; and present their family perspectives to educate staff, physicians and students. This type of family participation 'around the boardroom table' requires careful planning and support so the engagement is meaningful and doesn't veer into the territory of tokenism.

Hospital A's story is a clear illustration of tokenism at work. The consultant had a list of stakeholders she needed to confer with – including families and patients.

But inviting the stakeholders to the strategy session was only the first step; she also needed to document the session and meaningfully listen to the participants. Patients and families also needed to know that their feedback has been incorporated in some way, and if their feedback wasn't used, the reasons why needed to be communicated too. To close the feedback loop, the draft strategy should have been circulated to the stakeholders for review, or at least the final product should have been shared with the families and patients. The consultant did none of the required actions to make the experience meaningful for the stakeholders. This resulted in a 'Check Mark Phenomenon', where the consultant only ticked a box off her list after meeting with patients and families and had no intention of incorporating any of their feedback into the hospital strategy.

Taking a few steps back, tokenism can also occur even before a strategy session occurs. If families and patients are brought into the information collection process too late, and the content of the strategy has been decided by other stakeholders, then their feedback is rendered meaningless.

The myth of the ducks in a row

The secret to meaningful engagement is two-fold: first, build meaningful relationships with those you wish to engage, and then strive to flatten the hierarchies that are inherent in the health system.

Building relationships can start immediately; hospitals don't have to wait for them to have their 'ducks in a row' to begin. In a system as complex as health, all the 'ducks' are never going to be in a row, and facilities will always be striving to improve quality and patient experience. Ironically, unless families are actually engaged in the health system, both at the bedside and operationally, the hospital will never get their ducks in a row without patient and family involvement.

Patients and families are already well-aware that the health system is not perfect. Families spend a great amount of time sitting in waiting rooms, or parked beside their children's inpatient beds, with not much else to do except observe what's going on around them.

Since there will never be a perfect time to engage consumers, that time is now.

It is only with the heart that one can see rightly; what is essential is invisible to the eye – Antoine de Saint-Exupery

Building relationships with families involves both tangible elements (like paying for volunteer parking) and intangible elements that are invisible to the eye (like listening). The way work environments function in this new millennium is that a manager will email her staff with a meeting invite and tell them to show up to a meeting. However, this is not the way to engage families in the operations of a hospital.

First, families have to have a true relationship with a person from the hospital in order to want to volunteer their time and give back to a facility. Ideally, there should be a staff assigned to do this important community outreach work as part of their job description.

To build a relationship, we all need to start listening to each other. Families often need to tell their experiences in the health system in order to be engaged in the system. Staff need to be open to listening to the stories without judgement. Sometimes the stories involve bad experiences, or adverse events. Or stories are about babies who are born too early, children who are gravely sick, or children who have died. Even despite difficult experiences, families still want to give back to the system to create change. Staff need to honour the vulnerability of the families, and listen to the family experience with great reverence.

M.O.M. or D.A.D. = M.D. or Ph.D?

To build a relationship, we first have to commit to listening. In order to listen effectively, families and health clinicians need to be equals. The health system is filled with well-educated professionals who value academics and intelligence. Family representatives often do not come to the table with these credentials. It is therefore important for staff to examine their own personal value systems about how they view others who may not be as well-educated or articulate as they are. Compounding that may be differences in language or culture, and in order to engage families effectively, staff have to believe that every family voice is as valuable as theirs.

Creative Outreach

After embedding a philosophy of respectful listening, outreach to families requires creative thinking and tactics. These seemingly small things can be big deals to families. Tangible strategies include: adding the family schedule considerations when meetings are being set up; giving a lot of notice for meetings so families can take time off work and/or arrange childcare; and striving to never change a meeting on short notice. Being innovative with the time of the meeting helps too, including considering evening and weekend work to make the times more family friendly. The premise behind these tactics is that staff should never arbitrarily schedule a meeting and just expect families to show up.

Location for family engagement is important too. Meeting on neutral ground, like a coffee shop or restaurant, extends out to families in their own communities, and helps staff get out of the hospital environment and to help them think more creatively too. Treating family representatives to a meal is a good way to provide recognition for volunteer work, and meeting over 'breaking bread' helps build relationships. Staff who are especially portable can consider meeting in family homes to make it easier for child care and transportation for the families. The key is not expecting families to always come to the hospital, and at least considering meeting them half way.

Family representatives who are volunteers should never be out of pocket for the work they are doing for the hospital. Paying for

parking, or providing lunch for a mid-day meeting is significant to families, as it sends a message to them as to their value and worth.

Understandably, many meetings are held in the hospital, but creative outreach can happen here too. Always providing confirmation, directions and a map to the meeting room is helpful, as is meeting the family representatives in the lobby to welcome them and walk them up to the meeting room. If it is a standing meeting, informing and preparing the members that a family member is attending helps with the welcome and expectations. First impressions can set the tone for the rest of the engagement.

At the beginning of the engagement, it is crucial to set the expectation of the engagement. Are you merely sharing information with the family, or are they empowered to make decisions (or something in between?). Communicating the expectation helps avoid misassumptions. After the engagement is over, the value of a sincere 'thank you' cannot be understated. Handwritten thank you cards are appreciated, and recognizing the families' contribution to a committee or project is important. Finally, designing a feedback loop that lets the families know how their input has been used (or not) helps ground meaningful engagement.

Flattening the hierarchy

The health system is rampant with internal hierarchies that can be daunting to families approaching from outside the system. The nature of health care is a great power imbalance – think of how most patients are asked to remove their clothes and wear a flimsy gown when they first arrive at a hospital. This very act renders patients powerless and illustrates the imbalance of power between patients and clinical staff. For families who have children in the health system, there is added chronic stress of having a child who is sick. Add to that stress are the acronyms used in hospitals that can make families trying to learn an entirely different language, and families in the hospital can feel like they are visiting an alien world.

This imbalance needs conquering to meaningfully engage families in the system. If it isn't addressed openly, then engagement can tip into tokenism territory.

Seemingly simple things like welcoming family representatives to meetings; assigning a staff member to sit beside a family representative; facilitating round table introductions; and using ice breakers to set a friendly tone can help flatten that hierarchy. Scheduling a debrief afterwards with the families helps too – staff can meet families afterwards for coffee to answer questions and translate proceedings.

Doing the right thing and doing things right

We know we are doing the right thing by engaging patients and families in the health system. But are we doing it the right way? Adopting strategies for the engagement of families and patients based on philosophies of building relationships and flattening hierarchies can steer engagement from tokenism to being mutually meaningful for all those involved.

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