Contents

Proem

I've spent most of my career in institutions, hospitals, managed care companies, and disability services agencies. These are large, slow-moving systems with their own inertia, logic, and knack for designing processes that work best for billing, and not so well for those receiving or providing services. I should know. I've been inside these systems as a clinician, boss, consultant, caregiver, and patient.

The boldest changes I was part of didn't come from a consultant's report. They didn't come from a board retreat or a leaders' strategic planning day off-site — though, Lord knows, I've sat through plenty of those. They came from the moment when someone, usually someone with very little institutional power, said: *This doesn't work. It's hurting us.*

The hardest part wasn't hearing that. The hardest part was finding the gumption to act. Institutions are good at explaining why things are the way they are. They have binders of policies for that.

My secret as a consultant was embarrassingly simple: the people who hired me already had the answers they needed. The nurse who'd been there fifteen years knew. The member who couldn't get her calls returned knew. I sought them out, listened, and translated their words into a PowerPoint that the boardroom could hear.

I want to tell you about three times I got it right. Three moments when the change that mattered was a no. No to visiting hours that kept families from the people they loved. No to a prior authorization process that treated patients and clinicians like suspects and required an army to administer that suspicion. No to a system that let care aides disappear from people's lives without warning or goodbye, as if the people whose lives they were in didn't deserve a heads-up.

None of these nos were mine originally. I heard them from a family pacing a waiting room, from a member who couldn't get the help she needed, and from a man with a disability who sat on our

board and told us, plainly, what it felt like to wake up one day to find that someone essential to his life was simply gone.

Participatory governance sounds like it belongs in a policy manual, right between *stakeholder alignment* and *learning organization*. When participatory governance works, it's permission. Permission for the people living and working within a system to tell the truth about it. And the willingness, on the part of whoever's in charge, to let that truth land. Even when it's inconvenient. Especially then.

Part 1: ICU Doors Open

My first experience as a boss was as an ICU nurse manager, a job I got, I should mention, without ever having worked in an ICU or having been a boss. A story for another day. The honeymoon was short. Strictly prescribed visiting hours, ninety minutes in the morning, ninety in the evening, were leaving families miserable. I could see it. They could feel it.

In collaboration with my bosses, the ICU medical director, and the chief nurse, I eliminated visiting-hour limits entirely. My staff, who had recruited me for the role, now deeply regretted it. I hadn't consulted them or thought through the workflow implications. They were furious, and they weren't wrong to be.

But we kept the visiting hours open. Over time, something shifted. I learned how to be a boss. Nurses learned to include families in care and treatment. Patients and families arrived home better prepared. Physicians, for their part, didn't much care either way.

The lesson I learned: this was a story about control. Mine, the nurses', and ultimately the families'. We eventually set up an informal patient and family advisory group, not because I had planned to, but because we needed them in the room.

Part 2: Seven Visits, No Questions Asked

My job title was Director of Quality at a behavioral health managed care company. If you've spent any time in managed care, you know what that means: Director of Trying to Get an A+ in Every Measure, Whether It Has Meaning or Not.

Prior authorization was the centerpiece. A member needs therapy. Their provider submits a request. Someone on our end reviews it, approves or denies it, requests more information, waits, and follows up. The member waits. The provider waits. And somewhere in all that waiting, the person who needed help either got it, gave up, or got worse.

I inherited this process. I did not invent it.

My boss and I set up an advisory group with members on one side and providers on the other. We asked about their experiences with our company. They were not subtle. Members said the pre-auth process made them feel they had to prove they deserved care. Providers said the company's default assumption was that they were lying. Neither response was a ringing endorsement.

So, we experimented: seven visits, upon request. No authorization required. If a member or their provider asks, they get them. No forms, no review, no waiting.

The result: outcomes held. Members received care faster. Providers stopped spending half their administrative time on the phone with us. And our call center, the engine room of the prior authorization machine, grew quieter. Then quieter still. A substantial portion of our staff spent all day managing a process that, in large part, was designed to manage itself. Strip it out, and you didn't need nearly as many people to run it.

The bureaucracy wasn't protecting anyone. It was the cost.

We had real data. Member satisfaction trended up. Providers, for the first time in recent memory, said something positive about the company. The advisory group had surfaced a truth that no quality metric had found, because no quality metric had asked the right people the right question.

Then the company was acquired. New owners, new priorities, no appetite for any of this. The program was terminated, and the advisory group disbanded. I can only assume the prior authorization process resumed its proud tradition of making everyone miserable in the name of oversight.

I learned that participatory governance surfaces the truth faster than most quality improvement methodologies I've encountered. But institutions don't always want the truth. Sometimes they want the process. The process is familiar. It distributes responsibility. It means nobody has to decide. The advisory group uncovered a truth. It turned out that the people who bought the company got a veto.

Part 3: The Right to Say Goodbye

There's a particular kind of organizational meeting where everyone knows something is wrong, the data is right there on the slides, and somehow the conversation goes nowhere. Lots of nodding. Lots of concern. Lots of commitment to further analysis.

I worked as VP of Quality at an organization supporting forty thousand people with disabilities, many of them living in group homes, relying on personal care aides for the most intimate parts of daily life. Getting dressed. Eating. Toileting. Moving through the world.

At my first Board meeting, we reviewed satisfaction survey results, which were poor. They were not nuanced, requiring careful interpretation. They told us something was bad. And we were doing what organizations do: analyzing, discussing, and scheduling follow-up meetings to review the analysis.

We were not asking the people who lived there.

The agency was committed to resident/patient participation in governance committees, including the Board; in this case, a resident of one of our group homes served on the Board. Not as a symbol. As a Board member. At one of these meetings, in the middle of what was shaping up to be another productive session of collective concern, he said something that stopped the room.

He said: People leave without warning. A personal care aide, someone who helps you start each day, who knows how you take your coffee, which jokes make you laugh, and how you like your blanket folded, is just gone one morning. No notice. No goodbye. Someone new shows up, and you're expected to adjust.

He said it plainly, not as an accusation but as a fact. He apparently assumed, incorrectly, that we already knew.

We didn't. Or rather, someone knew. The people living in the homes knew. The aides probably knew. It just hadn't made it into the meeting room until he put it there.

The fix was insultingly simple. When an aide left, for any reason, residents would be told in advance. A chance to say goodbye. A proper introduction to whoever came next, rather than a key, an address, and good luck.

That was the intervention. Advance notice, a goodbye, a hello — the basic courtesies we'd extend to anyone, anywhere, in any other context.

Survey results improved dramatically in the next cycle. Not in one or two categories. Across the board. Because what was wrong wasn't a program or a resource allocation. It was that the people living inside the system had been treated as though their experience of it didn't count as information.

The lesson I carry from that room is the simplest I know: the person living inside the system always knows. They know what's breaking, what would fix it, and they've usually been waiting, sometimes for years, for someone to ask.

You just have to put them in the room and believe them when they speak. The keyword is *just*. Just assumes a lot.

Synthesis: What's Common Across All Three

Three organizations. Three populations. Three problems, unresolved within systems staffed by smart, well-meaning people. In every case, the answer was already there. It lived in the wrong room.

I want to be honest about something. Looking back, only one of these three was truly participatory governance: the man in the group home who served on our board. The ICU families and advisory group members had real influence but no structural authority. They could inform decisions, but they couldn't stop them. That distinction matters, and I don't want to paper over it.

What they all shared was something simpler yet harder than governance design: someone with institutional power chose to ask, then chose to act on what they heard.

The families pacing the ICU waiting room knew visiting hours weren't protecting patients; they were protecting the unit's sense of order. The members and providers in that behavioral health advisory group knew prior authorization wasn't ensuring quality; it was ensuring paperwork. The man on our board knew what was breaking down wasn't resources or staffing ratios. It was the simple human expectation of a goodbye.

None of them needed a consultant. They needed someone with enough authority to ask the question and enough humility to sit with the answer.

Here's what I've come to believe: participatory governance, done seriously, is the fastest and cheapest diagnostic tool any leader has. Faster than a consultant. Cheaper than a task force. More accurate than a satisfaction survey that asks the wrong questions of the right people and calls it listening.

The nos in these stories weren't radical. They were obvious, embarrassingly obvious, once you asked the people who already knew. What made them feel radical was the gap between where the knowledge lived and where decisions were made.

That gap has a name. Several, actually. We call it hierarchy, liability, chain of command, and expertise — the comfortable assumption that the people at the top understand a system better than those inside it every day. Sometimes that's true. Often it isn't. And the cost of acting as though it's always true is borne by those with the least power to push back. The anxious family in the hallway. The member who couldn't get through. The man in the group home who, generously, assumed we already knew what he was about to tell us. They were the experts. We had the org chart.

Reflection

Honestly, I'm proud of these three stories, but I'm not sure I deserve much credit.

In each case, the hard work, the observing, the enduring, the knowing, was done by someone else. A family pacing a hallway. A patient who kept calling back. A man who showed up for board meetings and told the truth to a room that had been avoiding it. I contributed a willingness to ask and enough positional authority to act on what I heard.

I'm struck by how long those answers had been waiting. The ICU families weren't new. Frustration with prior auth wasn't a surprise to anyone who'd navigated it. How long had group home residents been losing people without warning? Nobody seemed to know exactly, long enough that it had stopped registering as a problem and had started registering as just the way things were.

That's the part I can't shake: the way systems normalize their own failures. The way *this is how we do it* becomes indistinguishable from *this is the only way it can be done*. And the people most hurt by that confusion are usually the least positioned to correct it.

I got lucky. Three times, I was in the right seat, and the right person was willing to tell me what I needed to hear. Not every leader gets that, and not every leader goes looking for it.

The question I'd leave you with — the one I still ask whenever I walk into a new system, a new organization, or any room where decisions are being made about people who aren't present:

Who already knows the answer? And what would it take to let them say it out loud?

If you've been in that room — where someone finally said the quiet part and the right no was finally spoken — I want to hear about it. Find me at dannyhealthhats@gmail.com. Tell me your version. I promise you: it's better than you think. And someone out there needs to hear it.