

Getting to “No, You”

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When people become parents, they encounter a slew of clichés meant as advice or wisdom on the journey of childrearing. While the quantity remains the same (it’s still a “slew,” whatever number that works out to), the clichés themselves change once that child is diagnosed as disabled. Such was our situation upon the birth of our son Gabriel. One statement that actually proved useful came from my sister, a neo-natal ICU nurse for over 20 years. Telling her of his situation after the delivery, she said, “Accomplishments will be few in number and long in coming, but I promise you that you’ll celebrate each and every one of them.”

That was well put and has held true over the years. However, I have also been told over and over, “It’s not going to be easy, but it will be worth it.”

Others elucidate how “everything happens for a reason” or that “the only disability in life is a bad attitude.” I also now know that my wife and I were “chosen” to be our son’s parents—I assume by the wisdom or grace of God, the universe, or some other supernatural entity. Then there is the more earthly advice.

Cite the following as also among the “greatest hits” of words of comfort:

“You are your child’s best therapist.”

“There are people you can turn to.”

“Be the voice of those who do not have one.”

“Believe in yourself.”

“You’re not alone.”

And the ever-popular, “You are your child’s best advocate.”

Don’t get me wrong. All these statements are generally if not entirely true, and they are dispensed with the best of intentions and in the spirit of comfort. Still, none of them counts as my “default” saying regarding my relationship with our son. With all the affirmations swirling around in my life since Gabriel’s birth, it seems ironically interesting that the most important word in making progress with or for him has become one of outright refusal: refusal to give up, refusal to go away, refusal to shrug our shoulders and say, “Oh, okay.”

Parents of the disabled navigate the usual maze of schools, paperwork, and officials of every level (be they federal, state, county, or municipal), but we also contend with added layers of bureaucracy depending on the complexity and extent of the condition involved. In our particular case, we deal with multiple disabilities that have the wrinkle of each itself being somewhat exotic: Gabriel suffered two strokes in utero, a metabolic disorder, orthopedic deformities, and is “developmentally disabled.” Taken in combination, it means that he is quite

unique. Because we deal with so many departments, bureaus, and committees, that legal labyrinth has forced us to find our mantra in that simplest and most basic term, and that one is “No.” In essence, every time we are told, “No, you cannot do this,” we respond in kind: “No, you.”

Some of the obstacles come in the form of companies, schools, departments, boards, or offices. Hearings and petitions—legal or otherwise—become a way of life, so preparation for these is almost (for lack of a better expression) a job description. In fact, that is exactly how I have come to look on my life to the extent that I know I will frequently be carving out time to gather information, contact medical professionals, and organize our thoughts in preparation for an anticipated or actual “contest.”

I am certain it is so for others who are trying to raise a child dealing with disabilities of whatever kind. Of course, it frustrates, but even these situations have their moments. I have two instances of satisfaction, when I can look at my wife and me and think, “Job well done.”

The first was an encounter with our insurance carrier. One of Gabriel’s medical conditions is a genetic metabolic disorder so rare that we have only been able to establish about 50 cases worldwide. While other parents claim their child is one in a million, I can realistically counter that mine is one in about 120 million. When he was about two, we learned of medical research in Dallas, Texas on a dietary additive that might help counter the deficiencies that Gabriel has in breaking food down, converting it into muscle, or storing it as energy. Figuring it was worth a try, we applied as a test case. Knowing he would have to spend some days in a hospital, we decided that—rather than using the emergency room—we would cover those visits beforehand. After explaining the situation, the company sent a letter denying our request.

We did, however, have the option to appeal the decision, so it was “off to the races” for us. We gathered more in-depth medical information, got letters from specialists, and after wrapping the whole thing up, sent the packet and waited. It didn’t take long for a reply—another “no.” Again, they wrote that we could take our case to mediation in front of a judge. We called the phone number, telling the person on the line to let us know when and where we should appear for any hearing.

About a week later, we received a letter noting that “upon review of new information,” the company had decided to cover his hospital stays while we were in Dallas.

Of course, the only “new” information was that we weren’t going away. They had told us “no,” but we replied with our own “not good enough,” apparently with greater resolution than they were willing to push against. In other words, an office told us to give up; we, instead, told them, “No, you give up.” Thus, we began our quest in getting to “no, you.”

The second incident involved a period when, for reasons unknown, Gabriel’s body temperature would drop to dangerous levels after he fell asleep at night.

And when I say unknown, I mean literally “unknown.” The only thing anyone knew was that it was happening; “why” was the one answer no one could get to. He was run through all sorts of medical wringers, including the pain of spinal taps. Neurology administered brain wave tests; getting him to allow those electrodes to be placed on his head was its own challenge there. Other tests by all sorts of medical specialists at UCLA were tried. They even called in experts from the department of endocrinology, so yet another specialist was added to the list of doctors we visit. However, in the end, the only action to counter his circumstances was round-the-clock monitoring and care. Since he couldn’t stay hospitalized indefinitely, we requested additional care from the state in the form of an aide to monitor him at night. The outfit we approached on this said, “No.”

Of course, we said the same. He needed the extra attention, and we planned in getting that care. In this case, we did end up going before a judge in arbitration, and that was when the real fun began—at least for me.

I think one problem many of these regulators have is their assumption that outright refusal is enough to drive people away. After all, they have the weight of a state government and several departments looming before a pair of worried and frazzled parents. So when we were told, “No. You will not get this assistance,” we repeated our mantra: “No. You will provide it.” In short, “No, you.”

Actually, this “battle” became one of the easiest, and my theory is that those confronting us come in with a confidence born out of too many easy victories wherein people immediately cower and retreat from the thought of locking horns with a large and seemingly powerful entity. We, however, had one edge: we were battling for our son’s health, not resting on any laurels, real or imagined. Perhaps this tale is best begun at the end. As we were leaving the hearing room and taking the elevator down, my wife said, “I didn’t like their lawyer.”

“Why?” I asked.

“She kept squirming in her seat, playing with hair, and tapping her fingers.”

“You’ve never played much poker, have you?” I smiled. “That was exactly what I loved. She was getting beat like a rug, and she knew it.”

I didn’t enter all that confidently, mostly because I had talked on the phone with the woman beforehand and feared I might’ve dropped my guard, giving her some information to use against us. Apparently not. In fact, I had the feeling she came in with a stock, rehearsed argument that might as well have come from a file cabinet. The routine might have worked in the past but didn’t help much that day. Right from the start, I felt optimistic, especially after her opening statement was predicated on the claim that our “civil rights have not been violated in this case.” We had, of course, written our own opening statements and arguments, which we thought were pretty strong. But with the opening she presented, I pounced.

“Before I read my prepared statement, your honor,” I said, only fearful of looking like the Cheshire cat, “I have to say I have no idea where this ‘civil rights’ argument came from. We have never said this care was owed us; we simply maintain that it is the most logical solution to a medical situation that borders on emergency.”

From there, it was easy to tear not only her basic approach to shreds but many of her “witnesses,” most of whom didn’t even have cursory knowledge about Gabriel or his condition. In full disclosure, like my father before me, I love knocking overconfident people down a few pegs, and that was a good day.

And of course, we achieved our goal: getting to “No, you.”

It is worth noting that many of the people in offices of “public assistance” are humane, decent, and most helpful. The problem is that there are also many who have business cards proclaiming them as “service providers” who behave in a way that brings both parts of that title into question. Unfortunately, no matter how many positive experiences one has when dealing with such agencies, the negative experiences that one endures tend to dominate memory. We have confronted these situations in the past, and we will most certainly confront them in the future, and all of this ties back in nicely with my own slogan, which came into being whenever we meet other parents or attend seminars, encounter groups, or social events. Recall the previously-mentioned oft-repeated aphorism that “you have to be an advocate for your child.” Eventually, I instituted my own aphorism.

It goes like this. As soon as I hear that well-worn statement or some variation of it, I reply, “I am not an advocate for my child.”

Once that announcement sinks in with those hearing it—usually a bit shockingly, I then follow up, giving the qualifier: “I am a pit bull for my child”