

# **LESSONS FROM NIKKI**

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“Are you acquainted with the term cerebral palsy?,” the developmental specialist asked my wife, Anita, and me as we sat anxiously in his office. We had been aware that our 10-month-old daughter, Nikki, was not developing like other children her age. We had never been given such a specific diagnosis, however, and it hit us like a tidal wave. As Anita fled the room in tears, I frantically began asking questions which I knew probably had no answer. “Will she ever talk?” “Will she ever be able to live independently?”

Nikki’s diagnosis shattered our expectations for our first child’s life. We felt anxious and overwhelmed as we grappled with our fear that Nikki would never be able to live independently or communicate with us. We craved meaningful contact with our beautiful little girl with wildly curly black hair. Nikki was very much wrapped up in her own world, however, and took little or no interest in anything around her, including us.

At age one, Nikki could barely extend her arms from the front of her chest and made only fleeting eye contact. She tensed her limbs when we held her as if she had to defend herself from an outside intrusion. Music, though, seemed to draw her out. When I played Beethoven’s 7th Symphony for her, she’d smile and sometimes even laugh as I danced with her in my arms. As I swirled around the living room, caught up in the music and dazzled by Nikki’s momentarily expressive face, I fantasized that one day she would respond to me with a hint of recognition.

Anita and I were thrilled by Nikki’s relentless efforts to move her arms and legs

effectively. She appeared to be driven by some internal force which thrived on challenges and we rejoiced in her look of satisfaction whenever she accomplished something new. I vividly remember Nikki spending an entire afternoon trying to roll over before she finally succeeded. I was awed by Nikki's determination, but frustrated that I couldn't make life easier for her.

Nikki's small victories were not enough to fend off the helplessness we felt when she did not respond to our efforts to engage with her. In order to save what little energy we had for Nikki and ourselves, we shut out the outside world except for our families who were eager to help care for Nikki. They were also always available to provide much needed support and share in our hopes and fears for the future.

One of the most difficult challenges Anita and I faced was responding to the many people who implied to us that it was a terrible fate to have a child such as Nikki. For instance, Nikki's first pediatrician repeatedly told us how "tragic" it was that Nikki didn't have the "unlimited potential" of most children until we replaced him with someone who could view us and Nikki without pity. Other people would simply shake their heads sadly and say things such as "The poor dear, God bless her soul" or "At least she is pretty."

We were also told by numerous friends that they could never cope with having a child like Nikki. This comment baffled us because we wondered what they would do instead of coping if they were in our shoes. We have come to realize that people say this sort of thing in an attempt to protect themselves from something they fear. They seem to reason: "If I am a member of the group that can't cope, perhaps I will be spared."

Although Anita and I shared a deep commitment to do everything we could do to help Nikki, our different reactions to our situation sometimes drove a wedge between us. When Anita expressed the doubts we both felt about our ability to make a difference in Nikki's life, I tried to persuade her that Nikki was progressing along well and that we had to focus on the positive. When our endless discussions left neither one of us feeling understood, we retreated into our own worlds to cope as best we could.

We eventually agreed that we had to pull together for Nikki's sake. We also recognized that our fears and anxieties about Nikki drained our energies and didn't help her or us in any way. We longed for a perspective on Nikki which allowed us to celebrate rather than worry about her life.

We were stuck, however. Stuck in the despair we felt when Nikki seemed beyond our reach. Stuck in our fear that we would need to spend the rest of our life taking care of her. Most importantly, stuck in an unknown territory where our attitudes and beliefs hadn't adapted to the landscape.

We reached a point where the pain we were experiencing became unbearable. We had no choice but to look within ourselves and change the beliefs and expectations which trapped us in fear and anxiety. With the help of the Option Institute in Sheffield, Massachusetts, we began to ask ourselves questions such as why we couldn't be happy even if Nikki didn't progress in her development or if we needed to spend the rest of our lives taking care of her. We finally realized that we found great meaning in the care we provided for Nikki and that we had the capacity to make each day a happy one regardless of her level of independence.

It also dawned on us that we could probably be more connected to and effective with Nikki if we tried to let go of any expectations we had for her and replace our fear and anxiety with happiness and peace of mind. We were relieved to discover that, as we worked towards this goal, it was much easier for us to simply enjoy her as she was and to encourage any efforts she made to do something new without worrying about whether or not she would succeed.

We were now able to more effectively pace ourselves according to Nikki's speed and to pick up on her subtle, but highly significant, communication signals. When we were able to respond to these signals and move in tune with her, we entered what we labeled the "Nikki zone". Our ability to enter and remain in this unique place was dependent on our capacity to be completely present in the moment and to join with Nikki in her world.

Nikki responded to our new attitude and approach to her with enthusiasm and became more animated and responsive in our presence. She clearly enjoyed the freedom she now had to explore the world on her own terms. Paradoxically, our ability to celebrate Nikki as she was appeared to motivate her to achieve new accomplishments. All of us yearn for unconditional acceptance and Nikki was no exception!

Encouraged by Nikki's growing connection to us and more confident that we could finally make a difference in her life, Anita and I made a commitment to provide Nikki with focused one-on-one attention twelve hours each day. We made this possible by rearranging our work schedules and my switching to part time work. We massaged her arms and legs to coax them into relaxation, made funny faces and sounds to try to get her attention and placed favorite toys where she could reach for them. While toys were

motivating, food was compelling for Nikki. We often couldn't resist holding cheese twists in front of her, which she grabbed and jammed into her mouth with gusto.

Since Nikki took great delight in standing whenever we held her on her feet, we decided to help her stand on her own. We began by helping Nikki lean against the wall with her hands. Although she had great difficulty keeping her balance at first, she was tenacious in her efforts and quickly learned to lean against the wall without any assistance. After standing for a couple of hours each day for four months, Nikki learned to balance herself for a few seconds without holding on to the wall. The first time she stood for five seconds we responded as though it was a miracle.

By the time Nikki was 2 1/2, she could stand for more than a minute on her own. She beamed pure joy as we excitedly counted off the seconds. As she stood proudly working on her balance and frequently swaying back and forth, we sat in front of her and called her name, placed yogurt on a spoon in front of her which we hoped she would try to get, and danced around her, singing walking songs we made up. I even blew up twenty-five balloons and piled them in front of her in one rush of creativity.

Nikki stood for at least a couple of hours a day for a year, creating the best lesson in patience Anita and I had ever experienced. Every fiber in her body appeared to want to move forward, but she just couldn't figure out how. My frequent dreams about walking became more vivid as her desire to do so became more urgent.

When Nikki was 3 1/2, we visited relatives in Florida. I was sitting on the floor of a porch with Nikki standing a few feet in front of me. Suddenly, she took a few halting,

but definite, steps towards me. Just before she reached my waiting arms, Nikki paused and then continued her odyssey in another direction. I shouted for Anita and we stood with tears in our eyes and watched our little trooper make her way across the floor as our relatives cheered her on.

The intense look of determination and satisfaction on Nikki's face as she struggled fiercely to maintain her balance will be forever etched in my mind. On our way to Key West the following day, we stopped every half hour to make sure she hadn't forgotten her new accomplishment. Each time we put her on her feet, Nikki launched herself forward as if walking was the sole purpose of life.

Another focus of our efforts with Nikki was language development. We mimicked all the sounds she made and tried to stretch them into words, repeated words to her, and created situations where she needed to use some form of communication to get something she wanted, such as food.

Since Nikki loved to eat, we spent a good deal of time helping her learn to feed herself. After many months of effort, she learned to pick up a spoon with food on it and bring it to her mouth. Baked beans worked best since they usually stuck to the spoon as Nikki labored to get them to her eagerly waiting mouth. It often took an hour for her to finish off a bowl but she never lost enthusiasm for the task at hand.

We constantly came up with different ways to encourage Nikki's development or simply bring her pleasure. The only criterion we used to evaluate the effectiveness of our activities was whether they were fun for all involved. Whenever anything became a

chore for us or Nikki, it was immediately discontinued. Nikki especially enjoyed it when we joined her in what she was doing such as banging on a tambourine or clapping her hands. She also loved any activity involving movement through the air such as swinging. Because she appeared to be very much in tune with us when she laughed, we did everything we could to make her laugh and laughed with her when something struck her as funny.

In addition to our home-based treatment program, Anita and I created our own team of professionals to help Nikki through speech therapy, sensory integration, music therapy, and therapeutic horseback riding. We viewed ourselves and Nikki as the experts, however, regarding what was best for her and followed our own instincts when in doubt.

Slowly, but surely, Nikki's perseverance enabled her to develop her coordination and mobility in ways we once could not have imagined. This process had many starts and stops, however. Nikki went through periods where she eagerly tackled new challenges such as drinking out of a cup or walking up an incline behind our house. At other times, she retreated into her own and rebuffed our attempts to interact with her. When this occurred, we backed off and gave her the space she needed. When she was ready, she would nonchalantly do something new as if it had always been part of her own secret plan.

Nikki has also gradually left her protective shell and become highly attached to us as well as the other people in her life who adore her as much as we do, such as her grandparents for whom she reserves a special smile. The first time she saw her sister,

Chelsea, in the hospital, she walked over to her, put her head down on the bed in front of her and smiled radiantly. During Chelsea's early months, Nikki always searched her out and stared at her with fascination and amusement. As Chelsea has gotten older, they have begun to enjoy playing together and clearly communicate in ways only they understand.

A few summers ago, Nikki and I were walking along a sandy road in the Pine Barrens of New Jersey when I knelt down in front of her and encouraged her to walk to me. She took a few steps towards me, then veered around me. As I turned my head to see where she was going, she laughed, walked up behind me and put her little arms around my neck. There are no words to describe how privileged I felt to be the recipient of the first joke she ever played.

Nikki is now an energetic and cheerful fourteen year old who loves to roam around the house looking for something fun or noisy to play with, such as my guitar which she plucks with great intensity. She has an incredible appetite and often makes a beeline for the kitchen, where she runs her hands over all the counter tops looking for the fruit we leave just within her reach. When she gets tired or bored, she plops herself down in one of our laps, looking to snuggle.

Nikki is currently in an excellent, private school for "special needs" children. She gains from her interaction with her peers and the attention she receives from a variety of adults who enjoy her as much as we do. Each day when I pick her up, Nikki lights up when she sees me and gives me a big hug which washes away any stress I might be feeling. Since Nikki is in school and often enjoys playing by herself when she is

at home, we now work intensively with her only a few hours each day. Much of our focus is on her language development. Nikki periodically says “more” (usually when she is impatient for more food), and “good” (when she is pleased with something). She also said “dog” once, emphatically, when she spotted one in the woods behind our house. We believe that Nikki will learn more words as she realizes that they will help her better communicate her wants and needs.

Although Anita and I have been thrilled by Nikki’s relentless drive towards greater independence, the primary impact she has had on our life has been in the lessons we have learned from her. In fact, we believe Nikki understands that she is as much our teacher as we are hers, and that this mutuality has helped cement the deep bond we have with her.

The most profound lesson Nikki has taught us is that a powerfully motivating and healing energy is created when we are able to appreciate her and each other with unconditional acceptance. This energy brings our spirits alive and compels us to seize the moment and tackle new challenges.

With Nikki as our teacher and guide, we have become happier, more peaceful and better able to live fully in the present. When we stray off course and allow expectations or judgments to contaminate our relationships, our cure is to tune into Nikki and allow her relentless spirit and goodwill to wash away whatever is preventing us from being at our best.

Nikki has also given us a greater sense of mission in life and prevented us from

becoming overly self-absorbed. We experience a sense of purpose when we envision the possibility of spending the rest of our lives responding to Nikki's needs since we know we will always be involved in a passage into unknown territory. We are also freed of the emptiness we used to feel when we spent most of our lives trying to get our own needs met.

Finally, our relationship with Nikki has reinforced our belief that all human beings are inherently worthy and capable, regardless of their level of achievement or ability. Unfortunately Nikki lives in a society where people like her are frequently evaluated according to their "intelligence" and given labels such as "retarded" or "handicapped" when they are judged to be deficient. These words have no meaning for us since we will always view Nikki as perfect just as she is.

Anita and I know we will face other challenges such as how we can insure that Nikki's needs will always be met. However, the hurdles we have overcome over the past ten years have brought us closer together and increased our trust in ourselves. As a result, we face the future with a sense of confidence we would never have had without Nikki in our lives.

We have no idea how far Nikki's adventure will take her. We now know, however, that the quality of life's journey is much more important than the realization of specific achievements and that we can always count on the sparkle of Nikki's being to show us the way.





