

Katie Reginato Cascamo is a champion. A classic overachiever that holds herself to the highest standards. Good and noble. Right up until it's not. Katie shares her story about not being heard professionally, the frustrations that go along with that, and what ultimately led to stress and trauma during her pregnancy. Thanks to compassionate NIDCAP trained nurses in the NICU following the arrival of her son, Katie's voice was heard and respected. Katie learned how to read the voice of her newborn son and how to support him. In her story, Katie shares with us how her NICU journey had a transformative impact on her career path and contributed to her taking on a role as a parent leader in the NICU. Katie is a shining example of the positive influence of NIDCAP.

From Corporate Climber to NICU Advocate: How NIDCAP Transformed My Life as a Parent in the NICU

Katie Reginato Cascamo

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Defining moments can alter our life course in unimaginable ways. That moment came into my life on December 12, 2009, when my son Giovanni was born prematurely at 30 weeks and three days gestation, weighing two pounds and eight ounces (1270 grams). Little did I know that this experience would lead to a profound transformation, both personally and professionally, and that NIDCAP trained nurses would become my greatest teachers.

Before Giovanni's birth, my life was consumed by a relentless pursuit of corporate success. I was entangled in the world of corporate insurance, where external values for performance awards overshadowed my well-being. The pressures of meeting unrealistic performance standards set by management eroded my self-esteem, pushing me to internalize the stress. My physical health began to deteriorate, and I became a hollow representation of myself.

The word *burnout* was a word that had yet to exist in my vocabulary in 2009. The World Health Organization defines burnout as a syndrome arising from chronic workplace stress that remains unmanaged. Burnout manifests through three dimensions: 1) feelings of energy depletion or exhaustion, 2) increased mental distance from one's job, encompassing negativism or cynicism towards the job, and 3) reduced professional efficacy.¹ Burnout transcends a mere reluctance to go to work; it is a persistent state leading to fatigue, disengagement, self-doubt, and a sense of being trapped and defeated. As a small business owner, my financial investment and liabilities, left me feeling trapped without exit. Threats by my District Manager to "ruin" me led to *toxic burnout*, an idea that the environment or circumstances contributing to burnout are physically and psychologically harmful or detrimental to one's human nature. Toxic burnout may occur because of a toxic work culture, unrealistic expectations, poor leadership, lack of work-life balance, or other factors that negatively impact a person's well-being.

Toxic burnout while pregnant substantially impacted the growth and health of my unborn son. My obstetrician neglect-



Giovanni and Katie in the NICU

ed to consider my concerns and downplayed the significance of my personal experiences, particularly regarding the potential adverse outcomes of toxic stress and burnout.² Throughout my seven-month pregnancy, numerous crises hindered any opportunity for excitement or joy associated with the experience. These crises ranged from a flood in our home and a fractured



Giovanni in the NICU

hand to workplace bullying, resulting in a 55% reduction in income and the abrupt end of my career. I faced challenges such as jury duty, H1N1 Swine Flu, hand reconstructive surgery, and a clinical failure to address early signs of pre-eclampsia.

On December 8, 2009, a blizzard blocked the emergency airlift helicopter's attempt to transport my unborn son and me to a regional hospital with a Neonatal Intensive Care Unit (NICU). The fear of being stranded triggered a freeze response, causing me to dissociate and complicating my ability to advocate for my health. My proactive decision to purchase airlift insurance months earlier proved lifesaving. I was transferred by ambulance to a fixed-wing plane, over a 5500-foot mountain, and then by ambulance to a regional health system known for its excellent neonatal healthcare. Upon arrival, a team of nurses and physicians seamlessly coordinated my care, demonstrating a level of collaboration and skilled expertise that starkly contrasted with my own professional experiences. This pivotal moment not only instilled feelings of trust, but also planted the seed that would go on to shape my future role as a NICU Parent Leader.

I underwent four days of bed rest, hopeful that reducing stress would support the extension of my pregnancy. During this time, we consulted with a neonatologist who detailed the various stages of the neonatal journey at 30 weeks, 32 weeks, and 34 weeks. This meeting proved instrumental in helping me visualize the possibility of an extended stay in the NICU, enhancing my reserves of courage and strength as I prepared for my son's premature birth.

The experience of trauma during pregnancy revolved around the absence of listening. Distinguishing between hearing and listening is important. Hearing involves the physiological processes of receiving auditory sensations through the ears and transmitting them to the brain. Listening is a more

psychologically complex activity that involves interpreting and understanding the significance of the auditory information.³ Our clinical records document healthcare providers acknowledging the information transmitted in writing. The lack of action following this acknowledgment indicates a failure to truly listen and respond appropriately.

My husband John, and my parents, Jim and Caroline Carter supported me as primary caregiver for our 56 days in the NICU. Our two months in the NICU led me to appreciate *active listening* that equipped me with wholehearted healing. Our NICU nurses did not just care for Giovanni; they became our mentors, guiding us step by step in caring for our fragile infant. Our NICU nurses understood the voice of fear that came with this responsibility and provided individualized care that empowered me to overcome my uncertainty and gain the skills needed to care for Giovanni independently.

As my confidence grew, so did my ability to listen and empathize with others. Our nurses listened to my story of professional burnout and toxic culture and helped me navigate my identity crisis that was rooted in my professional endeavors.

The practice of listening, modeled after my NIDCAP trained nurses, became one of my pillars of leadership. Our nurses not only taught me how to care for Giovanni, but also how to recognize signs of stress in both him and me. I began to understand the value of wholehearted connection and used these skills to calm my son and myself.

According to Otto Scharmer, Ph.D., there are four types, or levels, of listening:

1. Downloading: Listening is limited to reaffirming what we already know, and new information struggles to break through our established understanding.
2. Factual listening: We let the data speak to us and pay attention to information that contradicts our existing views. This requires opening our minds and setting aside habitual judgments.
3. Empathic listening: We try to understand the situation from another person's perspective. This involves opening our hearts and using our feelings to tune into and appreciate someone else's point of view.
4. Generative listening: We actively listen for the emergence of the best possible future outcome, creating a space for new and innovative ideas to take shape.⁴ (Scharmer, 2018, p. 48)

As I recovered from my traumatic birth experience, my nurse's unwavering commitment to listening played a crucial role in my ability to practice the skills I acquired to care for my son. Our NICU journey gained attention in local media, prompting me to volunteer for our NICU and actively fundraise for its expansion (Aho, 2010).⁵ The NICU transformed my heart into a space of healing and renewal, prompting a shift in my values. I no longer prioritized corporate success at any cost.



Giovanni (aged 13 years) and Katie in January 2023

After completing our NICU journey, my focus shifted toward understanding the impact of leadership on shaping organizational culture. My personal experience as both a patient and a parent of a premature baby deepened my connection with NICU practitioners and heightened my interest in the dynamics of these relationships. Long before the crisis of burnout in healthcare providers was as prevalent as it is today, my redefined purpose in life was to deeply care for NICU practitioners. The idea that a NICU parent could provide credible, professional leadership as an equal to physicians, nurses, occupational therapists, and technicians had yet to exist.

Intuition became my second pillar of leadership. In 2012, I began graduate school with the vision of a NICU Parent Leader reshaping health systems. Though an unsubstantiated notion, my commitment to NICU practitioners, coupled with intuition learned from my NICU nurses, evolved over two years during my career transition. Early exploration of the NICU Parent Leader role led to identifying crucial workforce skills, reinforcing the idea that NICU parents could apply pre-NICU experiences to serve maternal-infant health. I had

a notion to empower NICU parents with transferable skills, fostering economic self-sufficiency beyond the NICU.

At 14 years old, Giovanni is 5'6" and 125 lbs (170 cm and 56.7 kg). He loves caring for others, a reflection of his own evolving recognition of his lived experience. Giovanni has an extraordinary sense of humor and aspires to become a YouTube star and professional video gamer. He attends an arts academy charter school that cultivates creative thinkers in visual and performing arts with a focus on career and technical education.

As a Ph.D. Candidate in Leadership Studies at Gonzaga University my dissertation explores the credibility of the NICU Parent Leader. As the Founder and Principal Consultant of Courageous Steps, I aspire to exemplify profound listening skills cultivated during my NICU journey, offering valuable insights into this shared pain.

At the heart of our collective journey through the NICU is the commitment of our NICU provider's practice of listening. NIDCAP trained staff impact babies and families. It was our NICU nurses' training in NIDCAP that led to my healing and courageous journey. The NIDCAP approach to observing and listening to babies and the parent's skills and developmental training extends beyond the NICU. For those of us who accept the invitation to serve as a Patient Leader and improve the way neonatal care is delivered, we have an incredible opportunity to pay NIDCAP forward for generations.

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(Behind the Scenes, continued from p. 22)

It's easier and faster to reach a greater audience now, and that's a good thing, but sometimes I miss the tactile experience of seeing and hearing the printing presses running, and holding the finished product.

KS. What have you learned about NIDCAP during your years with the DO?

RC. Everyone I have worked with at NIDCAP over the years has been wonderful, and they are a very caring group.

As we rely more and more on technology, we lose some personal connectiveness and touch. What I have learned about NIDCAP is the practice of medicine, though rooted in science and technology (i.e. all the technology in a neonatal intensive

care unit), can be practiced un-scientifically. After laying out many newsletters filled with many abstracts and research articles, I have no doubt the NIDCAP teachings are heavily rooted in science, but what I enjoy seeing is the touching/caring/bonding, the un-scientific things that unite these parents and their children. And they all seem very grateful to have had the experience.

KS. Thank you, Rob, for sharing these insights. I have learned a lot about you and look forward to working with you as the *Developmental Observer* continues to grow and to hear more about your creative ideas.