

Nina.

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The word that evokes the greatest emotion in me is a name. Nina. Nina is my sister, my love, my strength, my Achilles heel, my purpose. My identity is so intertwined with Nina that it's impossible to imagine who I might be without her. Nina's story is also my story.

I was four years old when Nina was born. My parents brought a third beautiful baby girl home from the hospital to join my sister, Laura, and me. Nina's first six months likely resembled the first half year of any typical newborn's life, although I will confess I do not remember much from that time. My first memories of Nina aren't actually memories of her. Rather, they are memories of a time in my head resembling a Monet painting - fuzzy watercolors tinged with swirls of confusion running into one another. "Nina is sick."..."surgery"..."Mommy and Daddy are at the hospital with her"..."seizures."

Of course I know the story now, but didn't then. Nina suffered status epilepticus - a period of time where she would have one seizure, after another, after another, for hours on end, leaving her with severe brain damage. Nina has an intellectual disability and is nonverbal. She uses a wheelchair and needs a great deal of assistance with her daily living. But this is the Nina who YOU see...not the Nina who I see.

When I look at Nina today, I see a thirty-two year old woman of determination and strength who proved everyone wrong. She wasn't expected to live much past being a toddler, let alone well into adulthood. I see a soulful individual who has withstood more adversity and prejudice than anyone I know could handle. Growing up with Nina, I witnessed a doctor who refused to x-ray her broken leg because "kids like her don't move around much anyway." I recall the time she became dehydrated because her teacher believed the spouted cup she drank from was not age-appropriate. More common though, were the stares I'd notice both from other children and adults when we were out shopping, at the playground, or really anywhere. The younger version of me would stare back at those people until they'd catch my eye and look away, embarrassed.

If Nina were in school today, we would say she needs "multiple disabilities support." Back when Nina

was in school, this type of "support" looked like a secluded room in the basement of a West Philadelphia school. 1989 multiple disabilities support in Philly looked like a semi-dilapidated building with



bars on the windows adjacent to a topless club and drug dealer neighbors. My parents refused to send Nina to this program. However, lacking the knowledge and resources to dispute such a placement, they privately paid for her to attend a parochial special education school. The most generous adjective with which I can characterize Nina's education is "mediocre." While she was taught by some very lovely and caring individuals, I don't know that we will ever truly realize her full potential due to years of missed opportunities.

Not long ago, I visited the preschool of an incoming student who was recommended to attend a private school for students with cognitive and physical impairments. As I watched the child participate in circle time, smile at his teacher, recite his alphabet, and engage with peers, the appropriate recommendation became infinitely clear to me. This child would not be relegated to a setting where telling time and counting change was the most ever expected of him. He would attend Kindergarten in his public school. As I drove home from my observation, I began to cry in the car. *What if someone had taken the time to see the potential in Nina? How might her life have been different?* That day I realized what an awesome and humbling responsibility we have as educators. What might seem like a simple decision can radically alter the entire course of someone's life.

While I don't hide the fact that I grew up with a sibling with a disability, it's not something I've generally advertised either. This is partly due to my fear that people would think I have an "agenda" or that I'm in this field for some type of vindication for Nina. However, I realized recently that people who think this are right. I do have an agenda. I want better for our students than what Nina received. Because while Monet's waterlilies are at first swirling confusion and illogical progression, when you look closely, the masterpiece reveals itself.

I don't know where Nina's story ends and mine begins. I can't separate the two. Nina. My love. My strength. My Achilles heel. My purpose.

