

David's Journey

Our Happy Infant

David, my second child, was born happy.

He was a remarkably easygoing infant. When I fed or changed him, he never fussed. He was content to be in a jumper or a swing, or even just to lie on the floor so long as there were people around. His sister was two when he was born, and as an infant David was perfectly satisfied just to watch her run around and play, tracking her with his eyes.

Yet he was a little odd, or actually more than a little. For example, he didn't really like to eat. He never cried from hunger. So I did not get the normal signal from him that nearly all moms get from their babies when they need to be fed, though he did not resist when I gave him my breast.

David didn't like to sleep much either; he never slept more than 90 minutes at a time, and not more than twice in a 24-hour period. This was very hard on my husband and me, but lack of sleep did not make David himself irritable or edgy. He was so consistently cheerful that no one would ever guess, looking at him, that he was sleeping far less than normal babies do.

Also, David always wanted to be upside down. On my lap, he would wriggle and turn himself so that his head would be below his waist. If my husband or I had him on a shoulder, he would push himself to go down our backs, so that his feet would be above his head. Sometimes we'd have to catch his ankle before he slid down our backs to the floor, and then he'd giggle. Then we'd flip him back right side up, but he would continue to try and maneuver himself upside down.

He needed to be upside down in order to sleep at all. We learned to cradle him in a kind of "football hold" under an arm, such that his feet were elevated above his head. In bed, we'd position him on our legs so that his feet could be up and his head could be down. I was concerned that the blood rushing to his head might not be good for him. But whenever my husband or I would try to raise his head to be at least level with his feet, he would wake up immediately, startled.

In all of our family photos from David's first couple of years of life, even the formal ones, he is upside down, whether I'm holding him, his dad is holding him, or he's perched on some object.

You do what you have to do to calm a baby. We did not understand what was going on with him, but we tried to keep him happy and comfortable. And even though I had been a child psychologist for decades, I knew next to nothing about sensory processing disorders.

The Eight Senses

Most of us grew up learning that humans possess just five senses – sight, hearing, touch, smell, and taste – but this is incorrect. Actually, we have eight senses.

Please understand this is no esoteric or “new age” theory. This is now established cognitive science.

The three senses you may not have heard of are:

- **Vestibular processing sense.** Sometimes referred to as the body’s “internal GPS system,” vestibular processing is what orients us in space, so that we can maintain our balance. Among other things, it’s what allows us to accurately perceive the force and direction of gravity.

David’s vestibular processing disorder was the reason why he was most comfortable upside down.

- **Interoception.** It’s somewhat remarkable that this is only a “recently discovered” sense. It’s the most basic one of all, when we think about it.

Interoception is simply the ability to feel and respond to what is going on in one’s body, such as a stomach ache or a racing heart. Or, even more fundamentally – hunger, and the need to sleep.

David’s profound interoception deficit is why he was never hungry, and almost never sleepy.

- **Proprioception.** This is another sense that is so basic we generally take it for granted. Proprioception is the ability to know (without thinking) where our body parts are in relation to one another at any given moment, to know where our arms and feet are placed without looking at them, to sense immediately and automatically whether our hands are open or closed into fists. Proprioception is what enables our arms, hands, legs, and feet to work together seamlessly.

David often walked into walls as a toddler. He proprioception disorder was partly responsible for this.

All our senses work together, in concert. When one sense is askew, it affects the functioning of all the others.

My son came into our world with a “suite” of severe sensory processing disorders that made it impossible for him to perceive and respond normally to stimuli. David was a sweet-natured, intelligent, emotionally responsive child for whom the world of movement and sensation did not cohere the way it does for the vast majority of us.

Night Terrors and Faulty Diagnoses

Even though he was different from other babies, I didn’t start to seriously worry about David until he was about six months old, which is when his night terrors began.

He would wake up abruptly, screaming bloody murder. When I’d hold him and try to soothe him, he’d thrash and yell and kick at me ... until all of sudden he would “come to” and become himself again. Then he’d smile and hug me and, in an instant, he’d be happy and fine. My husband and I called this his “Dr. Jekyll and Mr. Hyde moment.”

David’s doctors didn’t believe us when we tried to describe this behavior, so we videotaped it. When they saw the videos, the doctors agreed something was abnormal. They assumed he must be in some kind of physical pain. Maybe he was having acid reflux, which is very common in babies. Maybe he had an ulcer that was hurting him, and causing him distress in his sleep.

Right about this time, we also noticed that he seemed to be having some trouble breathing. The doctors discovered that he had *tracheomalacia*; a condition in which the cartilage in the back of the throat is weak and partially closes over the breathing pipe. This sends the body into fight-or-flight mode, particularly in a baby. So we and the doctors figured that this must be the source of David’s sleep terrors as well as his inability to sleep for long stretches of time.

But within a couple of months, the breathing issue resolved on its own as he grew a little bigger and his trachea strengthened. Yet his night terrors and other unusual behaviors continued. Everyone was puzzled.

Then, when he was a year old, I stopped nursing him, and from that point forward he refused all milk. He would only drink juice or water. So we thought he might be allergic to milk, and perhaps that was at the root of all his problems. Or maybe something was wrong with his stomach or gastrointestinal tract.

So the gastroenterologist began doing tests on him. One test required injecting him with a radioactive dye and strapping him down to a board, while the dye worked through his system to illuminate how well he was digesting his food. For another test, he had to have a feeding tube down his nose for 48 hours, during which time he also had to wear a plastic device called “penguin wings.” The penguin wings kept his elbows from bending, thereby preventing him from ripping the tube out.

As a one-year-old, David was really being put through the medical wringer, though he did not fuss terribly. He cried a bit from the discomfort, but never in an angry or hysterical way. It was more of a whining, “this isn’t fair!” type of crying. He was frustrated, trying to move around in those penguin wings, but he didn’t shriek about it.

But the gastrointestinal doctors ultimately concluded that he was A-OK! There was nothing wrong at all with his gastrointestinal tract. So he preferred not to drink milk – fine! That was just a preference. My husband and I simply had to find another way to get calcium in him (which we did; it turned out that he loved Greek yogurt).

It was his pulmonologist – the lung specialist – who first pronounced that David was autistic. “You should know that this child has autism,” he said, as if that explained everything once and for all.

I replied that there was no way David was autistic. Yes, he had sleep problems, and some strange behaviors. But he was looking us in the eye, he was babbling, he was engaging with people and trying to play with his sister. He displayed none of the criteria for autism other than sleep issues. The idea that he was autistic made no sense to me. I knew my son was not autistic.

Bruises, Bumps, and Scary Playground Behavior

Unfortunately, simply being certain that David did not have autism was not enough to know how to help him. His sleep terrors grew worse. The bigger he got, the harder he became to calm down, and the longer it took him to “come back to himself.” Once he was able to walk, he would run into walls upon waking from his terrors. His eyes were fully open but he was not really seeing. He’d climb to the top of bookshelves, and he even “escaped” outside the house on more than one occasion, which was absolutely terrifying. My husband and I eventually had to remove all furniture from his room and dead bolt his door at night.

Also, by the time he was 18 months old, his playground behavior was frightening to other parents. He liked to go down the slide head first, on his back. He learned to slow himself down by spreading his legs and letting his shoes scrape against the borders of the slide, so he was (usually) able to stop himself before banging his head badly at the end. But other kids would mimic the things he did, and that was dangerous.

He also seemed to be able to climb anything, anywhere, anytime. Other adults would gasp. Once in a while, someone would say, “Hey, your child’s climbing on that pole over there. You should probably get him down!” But we couldn’t get him down because we couldn’t even reach him; we’d just have to wait for him. To David, that was a joke; it made him giggle. It was charming in a way. His charm was something of a saving grace.

Climbing ability notwithstanding, David continually bumped and bruised himself, though he didn't seem to mind. Even when he wasn't having night terrors, he often ran into walls full force, and then he'd bounce away and giggle and keep running. He didn't care because he didn't feel it; that was his interoception disorder. In one photo of him as a toddler, he has seven or eight visible contusions on his head and face.

My husband and I called him our "little bruiser." We would often look at him and say, "He's not okay ... but he's okay." Meaning, yes he has a goose egg on his forehead because he just bumped his head very intensely, but he doesn't seem to mind. He's just being his "normal" self.

This is not to say we were complacent about how David repeatedly injured himself, but we simply could not control him every second of the day. We wound up bringing him to the emergency room many times, even if he seemed perfectly at ease with his latest welt or lump. In retrospect, the way that the ER staff treated us – as if we must be bad, neglectful parents -- reflected their utter lack of knowledge about sensory issues. (Then again, we were still in the dark ourselves at that point.) Because we showed up there so often, regulations eventually required them to notify Child Protective Services. I understood why they had to do this, and I readily cooperated with all CPS's evaluative protocols. I wasn't afraid; I was familiar with how CPS operated. In my profession, I had called them to investigate people fairly frequently. But CPS's involvement was far more distressing to my husband, who feared at the time that we might lose our children.

Definitely Not Autistic

On the playground, David also loved to spin and swing for hours and hours, far beyond the point where other kids would be tired and ready to go home. This is actually a type of behavior that autistic kids do. It's called *stimming behavior*; they do it to calm themselves. David would get very angry and distressed – absolutely inconsolable – when we would make him stop these activities.

Yet I knew that David was not autistic. He was far too connective and communicative for me to believe he had autism, even for a second.

At one and a half, he did not have much language, but he had plenty of grunts and squeals and clicks. I could articulate what I thought he was trying to communicate, and if I got it wrong he'd tell me, "Uh uh." He fully understood my speech. I might ask, "Are you wanting a juice right now?" and he'd nod his head yes or shake it no.

He loved to climb over the back of the lazy boy chair, head first, and fall to the floor on his head, which was frightening, but he found soft things to land on. He'd pull the rug from the

kitchen and place it on the floor behind the lazy boy, or he would pull all the cushions from the couch and free fall backwards onto those. This was an impressive amount of forethought for a toddler!

Also, we had a little coffee maker machine in our kitchen, and he figured out how to make coffee for me before he was even two years old. I'd put him on the counter and he would go through all the steps to prepare my morning coffee. That became his little ritual.

Not that his cleverness made everything okay – far from it. But I was in such a sleep-deprived state that it seemed all I could do just to keep him alive.

It was during this time period – shortly before his second birthday -- that I went to David's pediatrician and adamantly demanded two things: a sleep study, and an occupational therapy evaluation.