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# An Unmarked Path

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**When did you first know** there was something different going on with your child? If you're like most parents raising an atypically developing kid, there probably wasn't a pivotal aha moment neatly wrapped up with classic symptoms, an easy-to-peg label, and a clear course of action. More often than not, the realization that a child is different happens slowly and unevenly, like a head-to-toe Band-Aid being yanked off one hair at a time over a period of years. That's because when they're younger, kids with no obvious diagnosis or visible difference tend to fly under the radar. Sure, some might be colicky or more sensitive or less cuddly than other babies, but those traits and the way we experience them can all easily fit into the range of normal baby behavior. After all—aren't all babies difficult? All parents sleep deprived? All new families making it up as they go along?

That's what my husband, Derin, and I figured, anyway. Asher was colicky from day one. Nothing could settle him, his sleep patterns were hellish, and he seemed generally, for lack of a better description, *pissed off*. I viewed him as an old soul, annoyed for having been thrust back into such a tiny body and into a life where he'd have to wait a good, long time to get to the juicy stuff. So we read the baby books, tracked feedings and soiled diapers on a spreadsheet, and sought advice from seasoned parents about how to get our boy to sleep through the night. As first-time parents, we assumed our experience was no different from anyone else's. *Mostly*.

Shortly after Asher was born, we joined the Program for Early Parent Support (PEPS), a Seattle organization connecting new parents for community and support. New to the city and with no social circle to speak of, Derin and I were hungry for camaraderie and hoped to glean some wisdom about how this whole parenting thing was going to work. I remember getting together that first night, six couples sitting cross-legged on the floor cradling infants bundled up for the fall weather, nervously sharing our birth stories. Back then, we were all on equal footing—our babies blank slates, differentiated only by the number of hours our little ones slept or how severely they reacted to breast milk soured by the curry in the previous night's meal. As time went by, these families would become the first control group in our ongoing, high-stakes research project—figuring out how to parent a unique kid.

We survived year one, grateful to be on the other side of the colic and ready for things to get easier. But instead, things stayed hard, just in new and different ways. In our PEPS group, we witnessed our children evolving from helpless blobs into little people with distinct personalities, temperaments, and senses of humor. By the time he was two, we felt certain Marques was destined to be a pro athlete. Campbell was clearly the artist of the group, Ella a natural dancer. And Asher? Asher was the precocious one. The kid was intense. Stubborn. Sensitive to loud sounds. Fairly accident-prone. And also fascinating, delightful, and super-chatty.

By his second birthday, Asher was regularly turning heads with his rich vocabulary, along with his propensity for engaging in complex conversations with any willing adult. He could recite a book verbatim after hearing it read only once or twice. His focus for solving puzzles was remarkable. We knew enough toddlers to know his intellect wasn't typical, and Derin and I frequently found ourselves exchanging looks of both disbelief and pride at something Asher said or did.

Another thing Asher turned heads with? His apocalyptic connip-tions. The kid had lungs, not to mention an iron will. Whereas most

two-year-olds work from the same tantrum playbook—arched backs, flopping to the ground, red-faced screaming—Asher’s tantrums just seemed somehow . . . *bigger*. When other parents witnessed an Asher conniption, I noted the shock and awe in their eyes. Not wanting to make me feel worse than I already did, these parents would often confide in me about a recent meltdown they’d had to endure, the message being that this was a normal part of raising a kid.

But if the intensity of Asher’s tantrums was so normal, why were none of my friends regularly having to bail halfway through dinners out because their child was disrupting the whole restaurant? Why hadn’t they had an uncomfortable exchange with the woman in the moss-green house on the corner, the one who stepped outside one afternoon because Asher’s screaming apparently led her to believe he

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Holy crap. We were that family with the kid who drives the nanny to quit.

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was being abducted or abused, the one who eyed me suspiciously as she asked, “Is everything *okay* here?” And then there was the day our mother’s helper—warm, loving, experienced—carried a rigid, hysterical child upstairs, passed him back to me like a store clerk handing over a sack of heavy potatoes, and quit.

“I can’t do this anymore.” She was crying, her arms raised in defeat. She mumbled apologies as she retreated down the stairs, grabbed her things, and bolted out the door. It was her fourth day on the job.

I stood there on the landing, a hapless mother in a Judd Apatow film, trying to process what had just happened. And all I could think was *Holy crap. We’re that family. The family with the kid who drives the nanny to quit.*

Suffice it to say that by the time Asher was two, Derin and I knew we were engaged in a more extreme form of parenting than most. We knew Asher was intense and challenging, or as one parenting book

labeled him, “spirited.” We were discovering he was freakishly smart. And we knew he didn’t respond to the parenting tools spelled out by the books our friends were relying on (*The Happiest Toddler on the Block*, *Positive Discipline*, *How to Talk So Kids Will Listen and Listen So Kids Will Talk*).

We didn’t have a clue as to what we were dealing with. We didn’t know how to differentiate between your standard “terrible twos” fare and what was happening inside our home. Our only frame of reference was what we saw in our community, in Asher’s drop-in preschool, and on TV. One day I’d see a child shut down the supermarket aisle with a tantrum while Asher quietly sat in our cart flipping through a book, and I’d think, *See? We’re all good here*. Then the next day Asher would stage an hour-long protest about getting into his car seat and I’d once again be bewildered. As the evidence mounted, the Band-Aid slowly peeled away, revealing small patches of red, irritated skin underneath. I began having dark moments of doubt, when I’d be convinced there was something seriously wrong, and then I’d read an article online that would convince me otherwise, or a pediatrician would chalk it up to normal three-and-a-half-year-old behavior and send us on our way with an “Everything looks fine to me.”

But things didn’t *feel* fine. Derin and I began distrusting ourselves and our experience. Was there something “going on” with Asher or not? Were we just overbearing parents with ridiculous behavioral expectations, or were we in denial of something everyone around us already knew? The fact that our friends frequently normalized Asher’s behavior added to our bewilderment. In retrospect, I’m sure they were trying to allay our fears, but back then, it just made us feel even worse.

By the time Asher turned four, Derin and I had accepted that our son was atypical. We just didn’t know how to figure out what that meant or what to do about it. Isolation set in. Other than my sister, my best friends, and our parents, no one knew how difficult things were at home. I longed for someone or something to help us fit Asher and

his behavior neatly into a box so I could get busy fixing whatever was wrong. I'm a resourceful person and a researcher by nature, but I was floundering. Where was the community of families like us? The concrete strategies? The path? And why did my husband and I constantly feel like we were the only parents struggling with these issues?

And then there was school. Notes home from preschool teachers about problems in class, on the playground, with other kids, and with authority became a regular experience. Tried-and-true strategies used by seasoned educators were proving futile when it came to my kid. I felt like I was raising a child method actor preparing for the roles of Jekyll and Hyde in an upcoming Broadway production. I mean, the kid was committed, especially to his anger, which seemed to be the prevailing emotion during that first year of school. After a string of bad weeks in which I received a phone call, note, or email from the school detailing yet another incident almost every day, I asked a friend, not for the last time, "Is it possible they would kick him out of preschool?"

We searched for clues about what was behind his anger, which was beginning to feel unpredictable and unsafe. More than once he'd whipped off his shoe and thrown it wildly in the car while I was driving, hitting the dashboard. I occasionally got calls from the preschool about dangerous things he'd done on the playground, wielding sticks or throwing small stones. The apology letters, dictated by Asher, written by me, and delivered to classmates before school, mounted up. Though the school worked tirelessly with us to help Asher, nothing improved things. I couldn't help but feel I was failing as a parent.

About midway through the year, a friend mentioned the words "sensory processing disorder," and something in me clicked. She jotted down the name of a must-read book, *The Out-of-Sync Child*, and I left her house feeling an instant sense of relief. *YES. Out of sync! Finally we have our answer!* Within a week I had tracked down the go-to occupational therapy clinic for kids with sensory processing challenges and added our name to the waiting list. A few months later,

Asher began seeing an incredible therapist named Kris, with whom he ended up working for the next four years.

Finally—we had our answer. We were taking the right action, and I expected the intense and disruptive behavior to fizzle out pretty soon. It would totally work. Any... day... now...

But as Asher entered his second year of preschool, things continued to grow more difficult. Emotionally, I was a wreck, experiencing some form of embarrassment, shame, anger, or confusion on an almost daily basis, mostly stemming from pressure I placed on myself to handle everything in the “right way.”

At the urging of a friend, we did a more thorough assessment with Asher that spring. The results: provisional diagnoses of pervasive developmental disorder not otherwise specified (PDD-NOS),

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That’s when it hit me. This wasn’t a meeting to brainstorm how to meet Asher’s needs at all. It was an ambush.

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which we were told is akin to “mild autism,” and ADHD. The diagnoses were provisional because he was only five and over time might outgrow certain behaviors. But I was skeptical about *all of it*. In my mind, the testing procedures were too subjective, and all of Asher’s diagnoses—giftedness, the sensory

issues, the ADHD, the PDD-NOS—shared nearly identical “symptoms.” So what exactly was what? And what, if anything, would actually “work”?

It was also time to figure out the plan for kindergarten. Derin and I had assumed Asher would go to the neighborhood public school, yet the general consensus among people who knew him was that smaller classrooms and a more individualized curriculum were his best bet. So we reluctantly turned our attention to private schools.

The following fall, we sent him off to a private school for highly gifted kids. We crossed our fingers and, miraculously, Asher made it through that first year—thanks to a seasoned teacher who shared his



love of engineering and cats. I did have weeks at a time in that first year when I allowed myself to stop worrying and warily consider that maybe Asher had found his place. But two months into first grade, things fell apart. I began having concerns about the way some of his classmates, as well as his teacher, were “shaming” Asher for things he was doing his own way (read: wrong) or that were tied to his challenges. His self-esteem was taking a serious hit.

Then, in an after-school meeting with Asher’s entire teaching team, the head of the lower school announced that she’d never encountered a child as intense as Asher in all her thirty-plus years working in education. I nervously laughed and called her bluff.

“I find it hard to believe that Asher is the *most* intense child. I mean, *seriously*.”

Without missing a beat, she curtly replied, “It’s true.”

But they were just getting warmed up. For the next half hour, I sat there and listened to a chorus of teachers relay tales of daily outbursts. Here I’d shown up to the meeting with a journal and pen in hand, ready to capture notes about our new plan, but those props were completely unnecessary. When the art teacher, who I knew was one of Asher’s favorites, began listing off his offenses in the studio, it hit me. This wasn’t a meeting to brainstorm how to meet Asher’s needs at all. It was an ambush.

I sat in that dimly lighted classroom, my body uncomfortably wedged into a chair meant for a six-year-old, and listened to the guidance counselor tell me other kids were beginning to fear Asher, that they didn’t want to partner with him because of his unpredictable outbursts. My face grew hot and tingly. I was embarrassed. I said all the things someone in denial says about support mechanisms and getting ahead of the problem. But as I walked back to my car, their parting words kept running through my mind: *Maybe this school isn’t the right fit for Asher. We need to see a significant change if he is to continue here next year.*

Over the next two weeks, I organized meetings, brought in

experts, and created colorful “zone charts” and scripts to help the teachers support Asher’s dysregulation. But the thought of Asher normalizing the way he was being treated made me dizzy. I felt like I was feeding him to the sharks when I dropped him off each morning, gritting my teeth, hoping I wouldn’t run into anyone as I walked back to the parking lot. As soon as I was safely inside my car, I’d sink back into the seat and cry tears of frustration, trying to reach Derin, my sister, or my mom on the cell phone for moral support. I was slowly falling apart, heartbroken over the possibility that my son’s beautiful spirit was being permanently damaged, and outraged at the way things were playing out. The day before winter break, we walked out of those double doors for the last time and never looked back.

Operation Elementary School, take two.

We started fresh that January at a lovely, private school whose focus was emotional development, critical thinking, and social justice. While I adjusted to the new drop-off and pickup drill, Asher did what he always does—be himself no matter what. As was his style, in class he blurted out his opinion freely, let his frustration flag fly when anything happened he perceived to be unfair, and found creative loopholes that enabled him to turn any school project into something squarely centered on his area of interest, which, at the time, happened to be origami. Within six weeks, Asher had spearheaded the Origami Frog Olympics, an idea that had classmates obsessively folding paper frogs and apparatuses. (Asher’s inspirations are nothing if not infectious.)

After a brief honeymoon period, things started to deteriorate. By May, Derin and I were sitting in the school director’s office listening to their concerns about meeting Asher’s intellectual needs as well as how much teacher time his disruptions were costing the rest of the class. The bottom line: If we chose to return the following year, we would need to bring in a part-time paraprofessional, at our expense, to support Asher. It was another situation of “it’s not us, it’s you.” Another goodbye. Another loss. For us, and for Asher.

Operation Elementary School, take three.

This time we opted for a full-time gifted program in public school with classroom accommodations outlined in an individualized education plan (IEP). I joked to friends who were empathizing with our plight, “At least they can’t kick him out!”

As Asher adjusted to life in his third school in as many years, I adjusted to what was beginning to feel like my new full-time job—educating Asher’s teachers about how to manage his behavior in the classroom and advocating for him when things went south. It was clear to me he was bored, disengaged, and unmotivated—from what I could tell, the only thing Asher was learning in school was how to sneak-read his Kindle and build a successful side business selling origami Pikachus (at ten cents apiece, they were a steal). And although it was nice that Asher was bonding with the kind principal because of the sheer amount of time he spent in her office, I came to realize that his IEP wasn’t enough, concluding that most mainstream schools just aren’t designed to meet the needs of kids who think differently.

It had been three years since Asher’s first assessment, so that year Derin and I added our name to a five-month-long waiting list, eventually getting him evaluated at the University of Washington’s Autism Center, a two-week process that involved controlled observations, teacher evaluations, written tests, and parenting interviews. The process was both eye-opening and painful, because although I craved concrete answers, I didn’t necessarily want the ones we got—autism spectrum disorder, ADHD, and disruptive behavioral disorder not otherwise specified. Derin and I digested the final report, feeling overwhelmed and uncertain about what it all meant in the long run. Eventually, we concluded Asher’s diagnoses were just another piece of the puzzle, insight to be folded into our growing picture of Asher’s unique way of being.

By the end of second grade, it was clear Asher was striking out on the school front. On top of that, I was exhausted—from our crazy therapy schedule (four sessions at four different places per week), from

the social pressures . . . from all of it. Asher was perpetually anxious—his poor little fingernails and the skin around them were gnawed into oblivion. At home, his intensity meant living in what sometimes felt like a war zone—explosions were big, frequent, and unpredictable. We knew Asher deserved more than being shoved into a system that wasn't designed for him, and that by continuing on this path, our actions (or perhaps inaction?) would likely lead to even more dysregulation, anxiety, insecurity, bullying, and challenges for our family. Something had to give.

Desperate for a solution, Derin and I put it out to the universe that we wanted a big change. And in a case of karmic conspiracy, the universe answered with a resounding *yes* when Derin's company asked us to move to Amsterdam. Leaving everything behind and starting from scratch in the lowlands of the Netherlands, a place I'd never even visited, was more than a little terrifying, but by that point, we figured we didn't have much to lose. (Our other thought: *If it's going to be hard, it might as well be hard in Europe!*)

So shortly after the school year wrapped up, we painfully extricated ourselves from our life in Seattle—sold our house, lost our dog to cancer, made the choice to homeschool, and did our best to support a certain eight-year-old boy who was furious we'd made the choice to move without consulting him.

The next year was one of intense adjustment. Finding our footing took a while and was easily one of the hardest transitions I've ever gone through. But slowly, over time, things got better. Although I felt (a lot of) resistance about the idea of homeschooling Asher, over that first year I gradually found my groove, eventually realizing I was better equipped for the role than I had previously believed. Together, Asher and I fostered a new relationship while I grappled with my own insecurities about what it meant for him to follow an unorthodox educational path.

Don't get me wrong. Even as things were improving, I still struggled—a lot—mostly with things like jealousy of my friends

raising “normal kids” or panic over what the future would look like. I also struggled with truly accepting that we weren’t screwing Asher up if his childhood looked different from that of his peers. Still, there was no denying that this forging of our own path, this questioning-everything approach, was working. Because Asher? He was *thriving*. The kid was happy. Joyful. Light. He loved school. And his anxiety was gone. I’m talking, *I had to cut his fingernails*.

The most important thing I learned that year was that my biggest source of conflict in parenting Asher was my relationship with myself—more specifically, my thinking about what my life as a mom “should” look like. That realization was a biggie. Because once I figured that out, I could surrender to what my momhood actually *did* look like. And how our child was. And what *his* life could look like. It was only after I started the hard work of surrendering that my energy began to shift. More remarkably, and I’m sure as a direct result, Asher’s did too.

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My biggest source of conflict was my own thinking about what my life as a mom “should” look like.

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In many ways, making the choice to adapt our life to support who Asher is sparked a renaissance for our family. And today, five years later, we are continuing to create our new, perfect “normal.” Instead of being at odds with one another, together we’re mostly in flow. Today, Asher is anxiety-free, and his tantrums are rarer-than-rare occurrences. Over time, he’s become more and more present. With presence has come connection. And because he’s no longer in chronic fight-or-flight mode—because he is able to just be the awesome person he is without being told he’s bad or screwing up or doing it wrong—his beautiful qualities such as empathy and compassion and a dogged desire to stand up against inequality are flourishing. He’s secure and confident. And it’s been the most incredible thing to witness.

When people ask me how we've gotten to a place where our family is thriving, I tell them this: We embraced and accepted who Asher is while exploring alternative ways of being as a family. More than anything, we let go. Of control. Of what other people thought of our child or our parenting techniques. Of what the future "should" look like. We started truly living in the now, noticing the gifts that are here every day.

. . . . .

I've talked with enough parents to know that my family's story isn't even close to unique. I know parents like me are literally everywhere, all moving through the unmarked journey in their own way, grappling with the unexpected detours and the roadblocks that emerged on the path they assumed they'd be on when they first brought their children into the world.

Parents like Amy, who presumed her son would start kindergarten at the neighborhood charter school in Atlanta where she herself was a teacher until she finally admitted to herself it wouldn't meet his sensory needs. "There was a little bit of mourning as I saw people he played with go off to the school I helped build, but I also knew it wasn't the right thing for him." A move across the country, a few more diagnoses, and a handful of schools later, Amy once again finds herself at a crossroads, as their most recent school in Portland, Oregon, has closed its doors and she's left trying to figure out what's next. But Amy is relentless in her quest to understand her boy's unique needs and find the right environment where he'll be seen for who he is. As she said to me during a recent conversation about raising atypical kids, "It's just what you do."

Jill, a speech pathologist by training who works with high school students with disabilities, didn't recognize what was going on with her son until she went to a professional development class on sensory processing disorder. As the instructor rattled off the characteristics of

children with sensory issues, she realized the instructor was describing her four-year-old son to a tee. “For some reason, I hadn’t put two and two together. But in that moment, it was like a wave washed over me. I had chills over my entire body, and I just started weeping.”

Bari, a psychologist by training, found herself in uncharted territory when she learned about the challenges stemming from asynchronous development in her two gifted children, both of whom have received a diagnosis of ADHD, auditory processing disorder, and executive function issues. But she leaned in to who they are and tapped into her gifts to become their most powerful advocate. A few years ago, Bari and her husband made the decision to pull their kids out of private school and (reluctantly) moved to the suburbs so their kids could attend a public school. Bari says things there are working out “okay,” though she never stops questioning their choices, looking for the opportunities that will help her kids thrive, and educating the school about the needs of different types of learners. As she explains, “I’m full of ideas, but my advocacy has come more in the form of trying to change our immediate family and educational milieu and raising awareness and understanding. Because I think that that kind of shift and awareness can benefit all children, not just ours.”

In conversations with parent after parent about raising differently wired children, I’ve heard about the same challenges: uncertainty about a child’s neurodiversity; lack of school fit; tough behavior; families, friends, and educators who don’t get it; and difficulty getting the information, resources, and tools we need. The details about who our kids are differ, but the common experiential thread is the same—frustration, confusion, sadness, and a pervasive sense of being overwhelmed.

Because differently wired kids can often “pass” as “typical kids,” it’s not always easy for teachers, other parents, and sometimes even our own families to recognize or respect the challenges we’re going through. Our kids can be super-intense. Strong-willed. *Tricky*. The usual parenting approaches simply don’t work for us. Every decision

about our child involves just a little more consideration, stress, and anxiety than what other parents might experience. It's no cakewalk. Yet we continue to show up every day with no map and a dull blade to

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The stigmas of raising different kids drive us underground, to suffer in secrecy.

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hack at the brush in search of a viable path. It's difficult, lonely work, our only markers occasionally helpful therapists and self-help books offering disorder-specific tools that serve as a constant reminder: There is "something wrong" with our child.

The stigmas associated with most neurological differences are enough to drive us underground to suffer in secrecy, lest anyone know what's really going on. Raising different kids in a parenting culture that thrives on sameness and conformity doesn't leave room for us to openly share the reality of our experience. So instead, we soldier on, fielding frequent emails from frustrated teachers, ignoring the glares of other parents when our kids do something "off" in public, and pretending we're not hurt when playdates aren't reciprocated. We want to figure out where and how to fit our kids in so everything doesn't have to feel so hard. We want them to have access to the same kind of life success as everyone else.

To be clear, I'm not talking about a handful of kids here. According to the latest estimates, approximately one in five school-aged children is in some way neurologically diverse, meaning that how their brains function is "atypical" from what's considered "normal." In reference to this statistic, author John Elder Robison wrote on his blog *My Life with Asperger's*, "That makes neurodiversity (in total) more common than being six feet tall, or having red hair."

It's obvious to me that being differently wired is no more an aberration than being left-handed, yet here we are at a crisis point, where 20 percent of today's kids are struggling to fit in at school and in society because the way they think, learn, and show up is inconvenient



or presents challenges to the status quo. Their neurological differences are treated like deficits instead of part of the essential fabric that makes up these creative, complicated, awesome beings.

I don't believe there is any one way to be okay or typical or "normal" in today's world. (And who came up with the definition of "normal" anyway? Since when is normal what we're striving for?) How many people have to receive diagnoses of "disorders" before we start realizing that maybe there's something else going on here... an influx of children with creative gifts who have the capacity to positively change the world? If anything, our uniquely wired children, with their sensitivities and gifts, *are* the new normal.

It's time society stopped looking at our kids' neurodifferences as things in need of "fixing" and instead considered the possibility that today's increasingly large population of atypical children may actually be a modern-day evolution. It's time for our children to be seen and celebrated for who they truly are. It's time for our families to thrive.

But to change everything for our kids, and for us, we're going to have to throw out the current parenting paradigm. It just isn't practical anymore, and it's doing more harm than good. We need to lead in the creation of a new one, one that embraces difference and uniqueness in children, rejects fear- and guilt-based messaging, supports those of us raising atypical kids, authentically reflects our families' realities, and provides options for us to access or design the ideal education for our child's unique needs.

Listen, I know this isn't easy stuff. I know that sometimes you might wish you could wave a magic wand and become a member of the other club, the one full of neurotypical families, the one whose manual is so much more straightforward. I know that many people, from educators to parents of neurotypical kids, might be afraid to consider a new definition of normal because it would require them to question their own status quo. I know that staring convention and fear in the face and forging ahead in your own way can be harrowing.

But I also know we can do it. I believe that we—you and I and every other parent raising an atypical kid—have the capability to truly change this paradigm from the inside out. Even more than that, we're the only ones who *can* do it. When we voice our reality, educate others, and stand up for what we and our family need from a place of compassion, strength, confidence, and peace, the whole outdated, ineffective, intolerant parenting paradigm that we've lived with for decades is going to come tumbling down.

Are you with me?