
PART ONE

Receiving the News

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Could It Be Autism?

Your toddler or young child isn't developing as you think he should. You're comparing him against your other children, to other kids his own age, what you've read or seen on TV, or what other well-meaning parents (including your own perhaps) are telling you.

Your child is not talking, walking as he should, playing with other children, or playing properly, period. Instead he sometimes seems deaf to your calls, behaves overwhelmed in the middle of Wal-Mart, and lines up Legos by size and color instead of *building* something with them. You've been hearing so much about autism these days—could it be that? The question gnaws at the pit of your parent's gut, the seat of your intuition, and the conflict sets in motion an internal ricochet. Maybe wait a few more months and see; after all, you were a late bloomer. But no, he *should* be toilet trained, enjoying neighborhood birthday parties, and watching *anything* other than the same three Barney videos, over and over, by now.

At the urging of your conscience, you ask your pediatrician: "Could it be autism?" In response you may be coddled condescendingly and made to feel as neurotic as Rosemary

in *Rosemary's Baby* for even suggesting anything could be wrong. You may be told that your new-parent anxieties have simply and unnecessarily exaggerated trivial concerns that your child will grow out of in time. In comparison, this scenario may seem like the lesser of two evils—a placating patronization in lieu of the ton of bricks about to drop when you discover the truth: “Yes, your child has *autism*.”

How you react to that word, *autism*, depends on your point of reference and the context in which that word has been communicated to you. Does it conjure despair and desperation? Flashbacks of odd or difficult kids from special ed? Projections of burdensome, perpetual caregiving? In some instances, parents are patted on the head, told to take their child home, and “do the best they can.” In worst-case situations, parents are told to institutionalize their son or daughter for life. Now the ton of bricks may feel not unlike a death in the family.

But where is hope? What about love?

Finding Hope

Within the past few years, I’ve noticed a disturbing trend: parents are telling me their child’s autism diagnosis is like “a death sentence” (their phrase). In fact, I’ve known incidents of parents equating their child’s level of functioning with that of a dog! Others have defined their children as “mutants.” *Where is this coming from?* In my opinion, it originates from one, or a combination, of two sources.

As an autism consultant, I have had the pleasure of collaborating closely with some terrific, well-informed clinicians who

“get” autism as closely as anyone “normal,” or *neurotypical*, can; but I have also had the misfortune of interacting with those old-school doctors who cling to their antiquated beliefs about autism (can you imagine that there are *still* mothers being told their inability to bond with their children caused the autism?) and refuse at all costs to confess there may be something new to learn from a different perspective. These are the doctors who are not gentle, sensitive, and compassionate when breaking the diagnosis to parents already overcome with worry.

Instead, autism’s supposed pathology—its social and developmental limitations—has been bluntly conveyed, fostering a hopeless prognosis for the future of one’s child. Clearly this is not helpful; but given the status to which we elevate our MDs and PhDs, many parents accept this heartbreaking outlook without question, devastated by the loss of the child they envisioned parenting.

Defending this dire prognosis as necessary in order to prepare parents for the worst is without merit, in my opinion. Clinicians are not infallible and none of them can forecast long-term outcomes and capabilities accurately for *any* child with autism. My friend, fellow author, and self-advocate, Stephen Shore, had been recommended as a candidate for institutionalization as a youngster—he now has his doctorate and travels the world advising on autism issues. As I once told a couple lamenting their child’s diagnosis upon returning home from the doctor’s office, the child in the backseat of their car is still the *same* child he was on the trip to the doctor; the only thing that’s changed is their perception of him based solely on a label, a single word: autism.

Additionally, the mass media are responsible for dividing our humanity into two camps: us and them. Personally, I am wearied and angered by news reports I hear or read that define those on the autism spectrum as “afflicted sufferers stricken by a devastating disorder that robs them of their ability to function normally.” If you are the parent of a child newly diagnosed by one of the aforementioned clinicians (of the not-helpful variety), having that doctor’s bleak and hurtful prognosis reinforced by the media’s tragic spin on autism can be devastating! There have been several recent incidents of parents actually murdering their child with autism. I can’t help but wonder if consuming guilt and unrealistic pressure hasn’t driven these parents to believe that a world without their child in it is the better alternative.

The curious thing is we *all* have autism to one degree or another! We’ve all experienced neurological crossed wires that result in motor-control blips, misfires, and disconnects.

Know Your Own Autisms

Ever awoken in the middle of the night and realize your arm is “asleep” from the elbow down? It is a common situation experienced by nearly everyone at one time or another. As much as your brain is willing that arm to budge, it’s deadened to the signals or impulses your brain is sending it—a neurological impotence, if you will. How many of you have actually had to physically move the asleep arm with your other hand in order to free up circulation and regain its use?

If that same paralysis harbored in more than one limb, or your voice box, you might experience autistic-like symp-

toms, or something akin to autism's possible "cousins," such as Asperger's Syndrome, dyslexia, Tourette's, Parkinson's, Alzheimer's, cerebral palsy, ALS or Lou Gehrig's disease, ADD, ADHD, OCD, sensory integration disorder, and a realm of other human experiences on the neurological continuum.

You have experienced additional autisms if you've

- Driven from Point A to Point B, but upon arriving at Point B you have no recollection of the drive.
- Begun driving from Point A with Point B as your final destination but intending to make a special stop to pick up something or someone—and you end up driving your regular route, having forgotten to make the detour.
- Been driving along, hear a song you like, and you intend to listen all the way through, but soon realize your mind has wandered and you haven't heard a word of it.
- Been driving along and you hear a song you haven't heard since high school—and what happens?
Experiencing the song immediately conjures memories of that era in your life. We create strong associative connections in the same way with scents and smells (of food, cologne or perfume, or tobacco) that we link in memory to certain people and places, as well as to life-defining events such as an accident, a birth or death, or a disaster of some sort (you could probably relate details about where you were and what you were doing on September 11, 2001).
- Happened upon someone familiar while out shopping, but seeing her out of the context in which you know her

somehow prevents you from recollecting her name on the spot (although it may come to you after you've had sufficient process time).

- Had to retrace your steps physically in order to remember something, or thought you'd misplaced something (a pair of scissors or your eyeglasses, perhaps) and then suddenly realized you'd been holding it the whole time you were searching for it.
- Lost track of time or self-awareness (no need to eat or use the bathroom) while immersed in an activity for which you hold great passion (painting, dancing, gardening, watching a film, or the like).
- Had a case of the giggles so severe that you could not regain your composure until the experience ran its course.
- Been so angry, or afraid, that words escaped you in the moment.
- Absolutely *had* to scratch an itch, and could not focus on anything else until you were so relieved.
- Been so overcome with worry and anxiety that you couldn't sleep, or were restless, tossing and turning all night.
- Calmed your anxiety by biting your nails, tapping a pen, shaking your leg, rocking yourself, twirling strands of your hair or toying with a piece of jewelry, or talking or humming to yourself.
- Created a new pain, by biting your lip or chewing the inside of your cheek, for instance, in order to take your attention away from a stronger, involuntary pain.

- Experienced uncontrollable shivers so intensely that your teeth chattered involuntarily.
- Struggled to decipher the meaning of certain words in the appropriate context, such as in the sentence, “she shed a tear over the tear in her new dress.”
- Had to ask someone to slow down or repeat the name or phone number you’re trying to transcribe.
- Been unable to hear the TV reporter because you were focusing on reading the news ticker at the bottom of the screen.
- Organized your items in your kitchen cupboards, bathroom, work space, or clothes closet in alphabetical order (canned goods with labels facing out), by color coordination, or at right angles.
- Come in from frigid weather and found your hands so numb with cold you could not use them to hold an eating utensil, write longhand, or unbutton your coat.
- Had a song in your head that absolutely would not go *away!* It may have been *The Star-Spangled Banner*, a commercial jingle, or a Barry Manilow tune. You may even have awakened in the middle of the night hearing the song you cannot seem to banish. Imagine how it would feel if that experience of being stuck with the song in your head (which precludes your thought processes) transferred throughout your body, or lodged in your throat and hindered your vocalizations?

These common experiences—*brain fades* or instances in which the *body vetoes brain signals*—affect us all, making

us kindred in our humanity. But if you did them with any degree of regularity, *you'd be eligible for an autism diagnosis!* The next time someone suggests your child's hand flapping or finger flicking is maladaptive, gently remind them that they do it too; it looks just like the times they sit and shake a leg or tap a pen!

Seeing Beyond the Backroom Kids

From the outset, as you've read, many parents are given a grim projection for their child's future. They are led to believe their child with autism is incapable, unaware, and of substandard intellect, a lost cause that will always function at the level of a four-year-old, even as an adult. This often results in parenting approaches of two extremes: either tireless endeavors to eradicate autism through high-cost, intensive, one-on-one (adult to child) behavioral therapy for countless hours on end (which in some cases may also involve a regimen of physical restraints and antipsychotic medications), or an abdication of effort that results in *backroom kids*, children with autism who are left to their own devices with little supervision or interaction.

The proper response to autism is to reenvision this diagnosis as a neurological disconnect that can be related to the disconnects of cerebral palsy, Tourette's, Hodgkin's, Parkinson's, recovering from a stroke, or any other such experience that compromises brain-body connections and impairs movement or articulation of speech. Even though many aspects of the physical body are unreliable or not of good service, the *cerebral* aspect is intact, thought processes

operate at capacity, and mental capability is completely competent (it just doesn't measure that way through IQ scores). It's important for parents to know that there is emerging scientific research to support the reevaluation of people with autism, using nonverbal intelligence testing to reveal their true intellect commensurate with, or beyond, their chronological age.

Some parents who don't foresee true intellect as a possibility for their children, have bought into the myth of autism—that autism equals intellectual inferiority or mental retardation. In addition to shame and guilt, despair, denial, and hopelessness may prevail. These parents begin thinking only of day-to-day maintenance and minimal standards of caregiving. Hence they tend to create their own backroom kids.

I see these children, watching me from their baby-gated existence within the screened-in porch or the distant bedroom at the rear of the house. Many of them don't have much meaningful connection with their families. They have free rein to do as they please because their parents are afraid to apply fair discipline or have been told not to bother because their child won't understand.

Some backroom kids are overweight, have poor diets, and are provided age-inappropriate books, toys, and videos. Some are still on bottles and in Pampers at age five . . . six . . . *nine*. This is unacceptable.

When I meet them, I think: "I see you there, little one. You with your grubby bag of orange cheese curls and the *Veggie Tales* video looping repetitively. You with your bright, glistening, welcoming eyes. You with your hunger

for knowledge and information beyond the backroom, or even your backyard. I see how very smart you are inside. I see *you*.”

Deconstructing the Myth of Autism

Refusing the myth of autism, building relationships founded upon a belief in competence, and challenging autistic intellect is what will create a cultural shift for the growing numbers of very young children diagnosed with autism each day. It will also yield hope for the adults with autism who have endured in silence, offered only Little Golden Books, Strawberry Shortcake puzzles, and *Lady and the Tramp* videos.

The regrettable irony is that we have a long and unfortunate history of backroom kids—*retarded defectives* as they were once known—only in earlier eras the backroom was often confinement to the basement or an attic with a door locked from the outside. Shame and guilt were very much a motivation for those parents then, as much as they are for some parents now.

Isn't it curious that what's called for is simply adjusting *our* behavior to our own true interests, and compelling ourselves to be more sensitive—to listen more carefully with our eyes and hearts as well as with our ears? We're not only talking about presuming intellect, we're talking about demonstrating a renewed respect. As much as we all (including some “experts” in the medical community) are on a learning curve about autism, we are also all on a curve of similarities and differences in our collective human experience. This begs the question, Is there really any such thing as *normal*?

Maybe autism isn't really as *autistic* as it seems. Let's consider that your child with autism presents an opportunity to the world, to command and compel acceptance and compassion for diversity in the same ways that the rights of others—African Americans, Latinos, Asians, Native Americans, and members of the gay community—have been championed.

Rest assured, given the proper respect, appreciation, and opportunity your child with autism *will* change the world in ways that are right and true and good and kind.

