FOLLOWING THE CHILD FOR REAL

by Jennifer O'Toole

Jennifer O'Toole has an entertaining speaking and writing style and is a passionate advocate for children with Asperger's syndrome. She educates her audience with scientific descriptions of the phenomenon but also through metaphors that cause us to examine our own attitudes toward the way we treat people who are different. Most importantly, she has discovered that the Montessori environment is harmonious with the needs of Aspies, especially when the guide is compassionate and nonjudgmental.

As a writer, I am usually blessed that I find it supremely easy to express myself through my fingertips. In fact, as Flannery O'Conner wrote, I often "write to know what I think." But this particular article has been one of the hardest, and therefore most procrastinated, I've ever tried to assemble. Primarily because like all of us who love what we do and do what we love, it can be very difficult, sometimes, to separate emotion from the fidelity of our words.

So let's begin far and away with a hero of mine, Elizabeth Cady Stanton, an American social activist and the leading figure of the early women's rights movement. Her work targeted women's parental and custody rights, property rights, employment and income rights, divorce, and the economic health of the family. Beyond simply "looking out for her own," Mrs. Stanton was a true humanist,

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working for the abolition of slavery and the universal application of citizens' rights.

Yet almost no one knows anything about Elizabeth Cady Stanton. Instead, we know her protégé, Susan B. Anthony. Why? The Nineteenth Amendment to the United States Constitution, which granted women the right to vote, passed in 1920, *seventy-two years* after Mrs. Stanton's first keynote address on the topic and eighteen years after she died. In hindsight, we might see that as tragedy. "Look at the controversy she stirred," we might mourn. "See the resistance, the slander, the misunderstandings she endured just to secure treatment and understanding," we might say.

Maybe. But I see something more. My great-grandmother, Mary Pharao Johnston, was born in 1898, in New York. She came into adulthood unable to vote and lived long enough so that I can still clearly remember her as an old woman who loved the month of May and the color purple. Amazingly, my mother, her granddaughter, was an elected official for twelve years and was the only woman on our town council and was acting mayor as well. I even had the privilege of voting for her. Within the span of just a few generations, what great and real change.

> It takes greater vision and courage to stand and declare, over and over, that ***this*** is right and ***this*** is fair! Even if much of the "empowered" crowd cannot or will not understand.

Now here is my question: Was Mary Johnston any less of an American citizen than her daughter or granddaughter or great-granddaughter? Did her opinions matter less, simply because she was excluded where she ought to have been welcomed? Of course not. For the same reason, Elizabeth Cady Stanton is the pioneer I celebrate.

Dr. Martin Luther King, Jr. said that for his disenfranchised people, he had "seen the Promised Land." To me, the promised land is not a place but a mindset dedicated to infinite learning where men see with humility and know that typically the majority is not neutrality. Dr. King concluded much as I believe Mrs. Stanton might have, "I may not get there with you…but we, as a people, will get to the promised land."

I am no Elizabeth Cady Stanton. I am no Dr. Martin Luther King, Jr. But I am an educated, impassioned advocate who sees people–*my* people–being misunderstood, cast aside, hurt, and underserved by the "inheritance" which they have the right to share: the practice (not in the essential pedagogy) of Montessori. Like those champions, I have heartbreakingly come to see that the call to "follow the child"–that is, to follow the neurological legitimacy of every child–will not happen in time for my own children. But maybe if I keep respectfully educating the educators, and maybe if you'll listen with equal respect and kindness, maybe it will happen in times for their children.

As a teacher, social worker, author, speaker and, most importantly, individual with Asperger's syndrome and a parent of three children with Asperger's, I believe, as did Dr. Montessori, that everything that is right and natural about learning and wonder and curiosity and peace is already inside our children. *All* children. We all crave the joy of learning that we are capable, important, relevant human beings.

In many of my articles and books (see www.asperkids.com), I explain precisely why the Montessori match is so wonderful. But, you already know the "wonderful." What you need to know now is where the disconnects are happening. Because not infrequently, different vernaculars used by therapists and Montessori educators mean schools believe they cannot accommodate brilliant Asperkids, when in fact, with very few adaptations, Montessori is the ideal way for them to learn.

Asperger's syndrome is on the autism spectrum and includes symptoms such as anxiety, sensory issues, OCD, and ADHD/ADD. But these symptoms just show neurological *differences,* not disorders. I've been told by well-meaning schools that they choose to see children on the spectrum as "typically developing." That in doing anything else, we lessen them andreduce them to a one-dimensional diagnosis. Well, of course! If we understand any person to be defined by a single element of his or herself, yes, that would be tragic.

Let's take the terms *Aspie* and *diagnoses* out of the equation for a moment. I could be called female, adult, redhead, married, parent, any word is true and may help others to understand me depending upon the circumstances. Yet none is a complete descriptor. There's also history buff, dancer, writer, seafood lover. The descriptor most relevant to the situation is the one that is most helpful. Being a writer doesn't matter when I choose a restroom, but being female does. Logically, I ask for the ladies' room not the writers' room. A label is a communication tool. It helps us effectively ask for and get what we need.

At age seven I was told that I needed glasses. Apparently, I was pretty-darned nearsighted already. So, how was it that I had never noticed a problem? I'm sure I would have at some point, but I could easily see the paper in front of me, so I just presumed that the limits of my sight were the same as everyone else's. My body was my normal; it still is. Without comparison, I had no idea other kids could see farther and more clearly.

There was a time when moms said, "Boys don't make passes at girls who wear glasses!" So should I have been denied the tools (glasses and then contact lenses) that made the world more manageable? Would the label of *four-eyes* (which I was never actually called!) have been reason to let me try and muddle through, wondering why more and more of life's tasks seemed ill-fit for me? I'm going to guess that no one would say so. Give the kid glasses, tell others to close their mouths, and be sure to use whatever you need to be your best. Without those lenses, I would never be able to see the letters in front of me now, so thank goodness for diagnosis and resources. They have helped me maximize my abilities and never have I felt ashamed.

I will make a similar point using my husband as an example. My husband was diagnosed with juvenile diabetes at the age of fifteen. His pancreas doesn't work like mine does. It never will. So, he wears an insulin pump to give him the support he needs to live a happy, healthy, fulfilling life. Yes, he could toss the pump and cross his fingers, I suppose. But the fact is that his body doesn't work as typical bodies do. To not tell a diabetic about the way his body operates would clearly be irresponsible, and in his case, it would be deadly. Would anyone tell a diabetic fifteen-year-old that he was "weird" or defective for his biology? Never. The only issue of responsibility would be his parents' and doctors' for making sure he understood the way he worked and what supports he would need in the future.

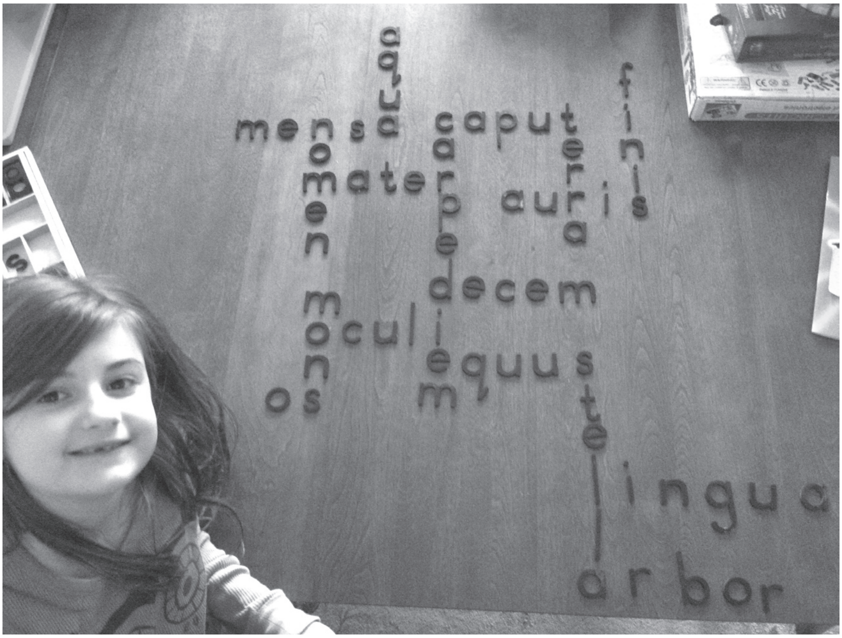
Understanding an Aspie is absolutely no different once adults forget about the stigmas they may be holding. A diagnosed Asperkid also has an organ that operates atypically, but it is not eyes or a pancreas. It is a brain with distinct neurological differences. Does that make the child any "weirder" or less worthy of self-care than if the organ in question were, in fact, the eyes or pancreas?

To not tell a child why he thinks, feels, and acts as he does is, frankly, not fair. It's like slipping the diabetic some sugar and hoping he makes it through alright. He won't! Or like telling me to read the computer screen without help. I can't! But give an Asperkid information, and you give him self-acceptance. Give him resources and you give him a future.

How very sad and misinformed to say, as many do, "You don't want a kid to have to walk around with *that* label." When it fits, the diagnosis, or label, *Aspie* is a gift, not a curse. I know, I have three Asperkids and was diagnosed, myself, as an adult. More than my Ivy League diplomas, or any professional accolade I've won, *Aspie* is my label of authentic self-awareness, acceptance, and true empowerment. I understand now that I may be different, but I am not deficient. Labels tell us how to react to a particular situation.

A bad cold and the flu can look very much alike. So can a neurotypical child who is misbehaving and an Asperkid who is misunderstanding or frightened. That is why we have to match our responses to the circumstances, not the standards.

Don't floor it when you see a stop sign and don't tell an Asperkid to "just go make friends." Neither one will have very good consequences. If the child says "push," don't pull. And when a teacher or parent has the courage to worry less about impressions and more about the child involved, great things can happen for everyone involved. Why pigeonhole a kid with one more (big) descriptor.



Spectrum kids are normally developing but according to their own DNA, their own hard-wiring. But by definition, one who is on "the spectrum" is not typically developing. This label doesn't disempower a person any more than would *gay* or *black*. No, by sheer numbers, we are not typical. But we are not *abnormal*. Could you imagine saying that to someone who is homosexual or is a person of color? Our normal is as legitimate as any other. The confusion between "normal" and "typical" is, I believe, the root of the problem in Montessori schools and everywhere else.

Asperkids Are
Better with facts than folks
Professorial on particular subjects
Better with adults and younger children than peers
Painfully compassionate
Playground/moral police
Imaginative
Fantastic mimics
Socially naive
Intense: poetic, musical, theatrical
Loyal
Harder on themselves than anyone else will ever be
Beautifully brave

Seeing-Eye Minds

Dr. Montessori's conclusions about human tendencies come from her observations of "neurotypical" (non-spectrum) children. Observations of part of a whole cannot be called universal. As such, her doctrinal descriptions of "normal human tendencies" are incomplete. They presume a typical *theory of mind*: naturally-occurring, ever-fine-tuning, organic awareness, and interpretations of others' thoughts, feelings, and intentions. By virtue of our very identification, we, on the spectrum, have deficient or impaired *theory of mind*. These tendencies are not naturally occurring to us nor will they develop with maturity. That would be like expecting a physically blind person to develop sight. just at an older age.

Instead, we look to compassionate people and insightful adaptations to provide "seeing-eye minds" that are nonjudgmental supports within the developmental planes that will enable spectrum learners to also "become a part of the group....and develop as [an authentic and celebrated] part of the culture."

> We on the spectrum live in a world that can feel terrifying in its random cruelty, uncertainty, and inconsistency. That's why we are, so often, aggravated by changes in structure, routine and rules. It's why we cling to favorite topics....Aspies love collecting facts – names, dates, tidbits, models, titles – because facts are like little pearls of reliability and constancy in a world that feels confusing and unpredictable.
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> We are not being obstinate for the sake of being obstinate. We are scared. And that is why, it seems to me, that the most difficult but the most important thing for our loving families, friends, therapists and teachers to convince us of is that there is "more than one way to get to ok"—whether that's folding towels, solving a math equation or packing a school bag. (O'Toole *Nouns & Street Signs)*

Aspies will *not* intuit social skills that you think are given. It's not a matter of time. It's not a matter of bad manners or egocentrism. It's neurology. So, we *need* you to act as frequent translators of everything and everyone, and this clarification can only benefit other children's emotional intelligence, as well. When we don't understand something, we think that something may go wrong. We think there will be a hurt or failure or disappointment or danger of some kind. We then feel confused and afraid. We can't trust that everything will just "work out" and so we do whatever we can to eliminate the confusion and fear by trying to gather facts (concrete, reliable, safe) and struggling to create a (false) sense of control out of the chaos. Unzip the process. Unravel it. Understand the thoughts and you'll understand the feelings, then you'll help alleviate the disruptive (to ourselves and to you) behaviors and thoughts.

While sensory input is a big part of all young children's lives, it's nothing compared to Asperkids. Our whole central nervous system is different. The little tweaks we need to calm kids and help them to focus for longer time periods are, once again, beneficial for *all*! Misbehavior is usually missed behavior, so know what to look for. See the chart on the following page.

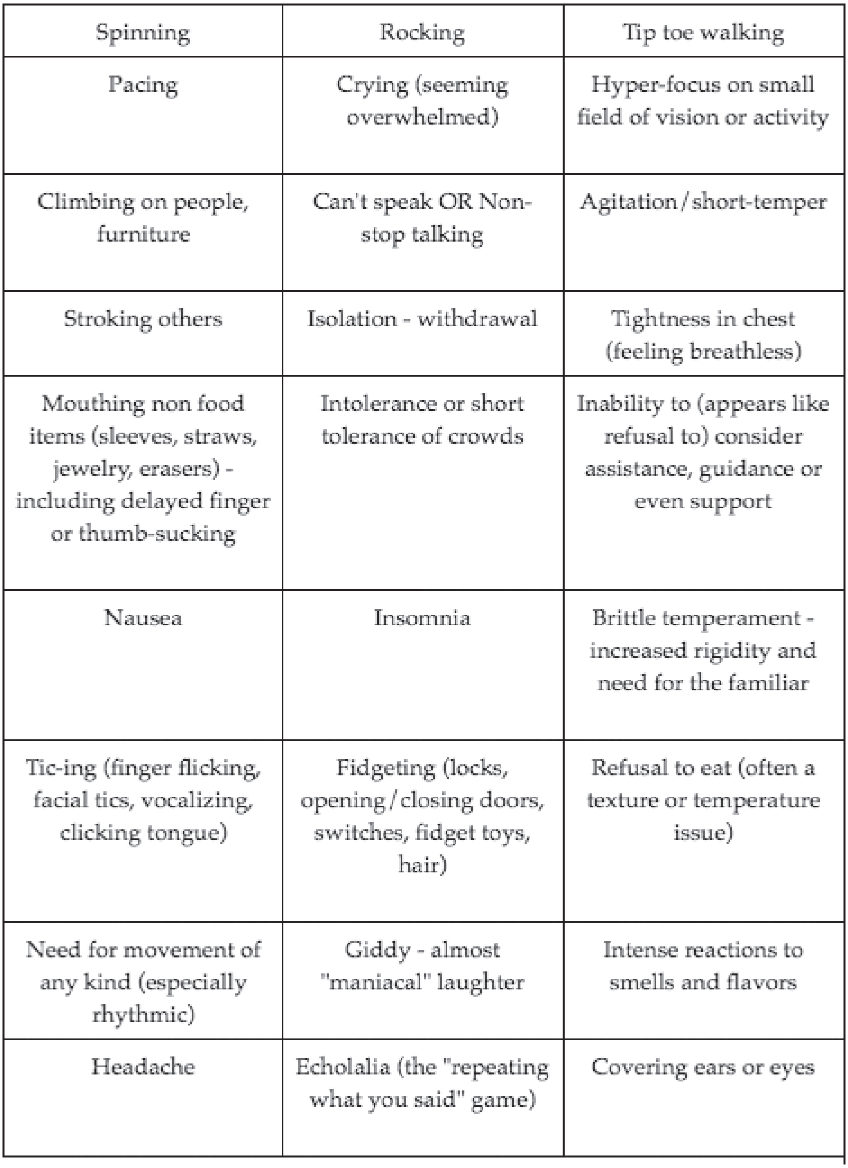
Step in faster. In small ways, you can make a huge change in a child's ability to relate and learn.

Playing in the Concrete

Neurotypical children progress from concrete to abstraction, and thus teachers may expect (or require) an essentially predictable schedule of concept work. Because of working memory issues and anxiety, spectrum kids may require concrete materials for much longer, or even indefinitely. This does *not,* however, indicate that they are not ready for (or already having) extremely advanced thought, analysis, and application. Albert Einstein, very clearly an Aspie, conceived of his Theory of Relativity (which I'd sure call "abstract") while analyzing his real commute on a real bus traveling away from a real clock tower. I've seen the same type of thinking at work in my own children.

> As I began to write this book, my daughter asked about the red-hair analogy she had spied on the first page. I explained that I had been getting at the idea of how being different can feel. Grown-ups had a word, *marginalized,* and….oh gee, how to explain this to an eight-year old. "OK, so think of the word 'margin'," I said, expecting to have to talk about blank parts of a paper and then maybe go from there. But from the back seat of the car we rode in, a little voice interrupted me casually, as she looked

ALERT: ASPERKID SENSORY NEEDS ARE INTENSIFYING
PAY ATTENTION NOW! (Missed Behaviors = "Mis"behavior)



Spinning	Rocking	Tip toe walking
Pacing	Crying (seeming overwhelmed)	Hyper-focus on small field of vision or activity
Climbing on people, furniture	Can't speak OR Non-stop talking	Agitation/short-temper
Stroking others	Isolation - withdrawal	Tightness in chest (feeling breathless)
Mouthing non food items (sleeves, straws, jewelry, erasers) - including delayed finger or thumb-sucking	Intolerance or short tolerance of crowds	Inability to (appears like refusal to) consider assistance, guidance or even support
Nausea	Insomnia	Brittle temperament - increased rigidity and need for the familiar
Tic-ing (finger flicking, facial tics, vocalizing, clicking tongue)	Fidgeting (locks, opening/closing doors, switches, fidget toys, hair)	Refusal to eat (often a texture or temperature issue)
Need for movement of any kind (especially rhythmic)	Giddy - almost "maniacal" laughter	Intense reactions to smells and flavors
Headache	Echolalia (the "repeating what you said" game)	Covering ears or eyes

out the car window. “Like a leaf.” Huh? “Margin,” she replied, “like of a leaf.”

Ohmigoodness, yes! The month before, I had begun teaching my children about botany, using mainly Montessori materials because of their sensorial basis for learning. For clear understanding, all children need the concrete before the abstract, and this is especially true, and often extended for Asperkids. Eventually, our lessons had evolved into advanced naming and classification; but we started with hands-on activities such as going outside and collecting examples from nature, planting our own vegetable garden, and then moving to scientifically accurate, wooden puzzles of the parts of animals, insects, and plants. One of the botanical words the kids learned was *margin*, the exterior edge of any leaf. And though it was far from my mind, when I said “margin” she recalled touching the smooth wooden leaf puzzles, tracing the veins and limits of real, discovered leaves with her fingers, feeling how the crayon dipped when she did paper rubbings of differently sized and shaped leaves. Yes, instantly, she understood that *margin* meant “an outer boundary” from tangible experiences, not from regurgitating a vocabulary word.

Smiling secretly, I pushed her. “Right, like of a leaf. So, if that’s what *margin* means, how do you think someone who is *marginalized* feels?” Split second pause. “At the edge. Not included. On the outside.” From a concrete botany lesson, this little child had just applied her understanding to a totally different genre (psychology), been able to accurately hypothesize the meaning of a word *and* intellectualize as to what the feelings of another person might be. I practically danced in my chair. “You are such a good thinker, Sweetheart,” I sang out. “Great job making those connections. You rock.” And to tell you the truth, I’m not sure which of us was more proud.

Our concrete-seeking minds crave clarity and predictability. When most of our day is spent negotiating a world that doesn’t match our neurological hardwiring, it is no wonder that we find calm in objects and activities that simplify things as much as possible. Look in a thesaurus for a synonym for “predictable” and you will see “humdrum, boring.” That’s a neurotypical understanding for sure. It’s not wrong, but it’s not ours. A more Aspie-aligned version of “predictable” would mean “knowable, understood, not surprising.” That means we are a whole lot likely not to

> mess it up. If we don't "do it wrong," but instead find success in our play, we feel good about ourselves, and are able to develop our learning to higher levels of complexity. The issue is merely that we start our engagement of the world (through play) differently than other children; it's not defective, it's not bad, it's just different. (*Asperkids: An Insider's Guide to Loving, Understanding and Teaching Children with Asperger Syndrome)*

Show Me, Again

Another difference in the way we operate is that Asperkids need a clear "roadmap" (i.e., when you've finished this lesson and can do this, then you get to do that) and to see an example (or ten) before generating their own original ideas. As Walt Whitman said, "I will take things from all sides and filter them through myself." Unless you explicitly *show* a spectrum child that, for example, the brown stairs and pink tower can be used together, he will most likely never conceive of the combination or think it is permitted. However, show one extension, maybe two, and then watch the creativity explode.

> Obsessive behaviors and thoughts are coping mechanisms. They are the way we, Aspies, most naturally try to relieve perceived threats.

> Until I told her recently, my mother never knew that I'd always found my friends' building blocks to be really fascinating. I clearly remember feeling their wooden planes and wishing I could imagine up some fantastic building to design. But I never could. So, I'd just put them down and move on. I learned later (while struggling to perfect the art of high-school English essay-writing from too-vague instructions) that Aspies first need a tangible, observable model to study and copy. We are excellent at detecting patterns. Give us some models first–not to copy, but to examine. Once we've mastered the patterns within the original examples, we can own the method and be as creative (if not more so) than anyone else.
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> A building plan would've changed everything for me with those blocks. I needed a guide to follow. But I never learned that neatly interlocking construction pieces, complete with step-by-step guides, were readily available at

> any Toys 'R' Us in the Lego aisle. I didn't know that kind of toy existed. So, I never asked.
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> An Aspie's imagination will show itself in grand leaps of logic, intertopical connections, and creative problem-solving…We are ever-so-creative in our own time, on our own trajectory. The beginnings may simply look a little bit different…. (*Asperkids: An Insider's Guide to Loving, Understanding and Teaching Children with Asperger Syndrome)*

Constant anxiety from misreading social cues, voice modulation, and past emotional scars require explicit positive feedback from adults. Eventually, of course, the goal is self-motivation and self-satisfaction. But you're not dealing with "typical." You're dealing with wounded people who, even by age three, often say, "The world is stinky just because I was born." And that's a child in a family who loves and supports him. But being misunderstood by peers and well-meaning educators leaves scars that are deeply internalized and deeply personalized. Even as they begin primary level, these are kids who are managing PTSD. And that, esteemed colleagues, is not typical.

There is so much more I could tell you and so much more I could share about the beautiful children who simply need instructors who are willing to add their kind of *normal* to the body upon which Montessorian doctrine was built and will evolve. They, too, deserve to be "followed." I ask you to consider if you've learned anything new in reading this article, wondered anything new, challenged your own ideas in any way. Then, let me ask one final question: I have Asperger's, would I have been welcome in your classroom? Because you, friends, are very welcome in mine.

And before you leave, I'd like to tell you a little story, one I wrote just for you:

THE ELEVATOR BANK

> It's Tuesday. Noon. The morning wasn't too exciting, but now things are on the upswing. You're waiting in the lobby of a fabulous Art Deco skyscraper where you'll meet an old friend for lunch. Unfortunately, she doesn't seem to be anywhere around yet, so while you pass the time, you grab a coffee and stroll over to admire the ornate elevator

bank. A dozen sets of shiny doors, each with lights blinking above and showing the individual cars' movement up the high-rise.

From your casual observation, each of the elevators appears the same. They look identical. They are all, at least according to the lights, moving upwards through the floors, just as expected. Oh, sure, you guess that maybe one moves a bit more swiftly. Maybe another's pulleys are stronger. Maybe another is brighter inside. But all-in-all, they move predictably and as designed, from the first floor, through the second, then the third, and so on.

The sound of an incoming text alerts you that your friend is running late. You've got more time on your hands than expected, so you sit down in a deeply cushioned chair, and absent-mindedly watch the elevator banks. After a little while, something different catches your notice. One of the elevators seems to be stuck. But, just before you can notify anyone, it jumps forward, going straight from Level 3 immediately to Level 6.

A glance at another set of doors reveals another pause-and-then-bolt sort of movement. Confused, you watch the other banks more closely. Yes, there's a steady even progress on some as you had presumed was the case for all. The truth, however, is that several of the elevators seem entirely nonfunctional. Broken. The one at Level 3, which had seemed fine for a while, was still at Level 3. Another zoomed to Level 5 then stayed there.

This is, you decide, more like watching bumper cars in fits and spurts than watching elevators. Befuddled, you walk over to the bellman and ask, "Sir, what's wrong with these elevators?" The man looks back at you, silently perplexed, so you press on, "I mean, they look like normal elevators. But obviously they're acting strangely. It is really quite uncomfortable to watch!" The bellman cocks his head to one side. "Ma'am? I'm sorry, I don't understand. The elevators are working perfectly."

Now you're feeling disrespected, not to mention a bit challenged. "Look," you say, trying to sound congenial, "I happen to be an engineer. I have taken elevators apart. I have watched them be assembled – layers of intricate, beautiful mechanisms that begin as simple machines and become increasingly complex, sophisticated, functional creations!" "Yes, ma'am," the bellman nods. "I'd say these elevators meet the standards you describe."

"But they aren't working properly! There's something unbalanced. Or out-of-sync. Or, well, generally unpleasant about them! Acceleration should be, within a certain amount of deviation, reliable. Not precise, but typical advancement, typical movement through the planes–the floors, I mean." You struggle to think of how to simplify the point. "An elevator bank should be smooth, steady, its parts generally in harmony." The man listens, smiles, waits.

"Well, this elevator system is – splintered! There's nothing even-keeled about it," you scold. "Some of these elevators are stuck near the bottom. Others raced so fast to higher floors, they can't possibly have picked anything up along the way." In a lowered voice, you go on. "I mean no disrespect, but I happen to know what I'm talking about. I know how elevators work. And these elevators are either not being cared for properly or not working as they should."

The bellman shakes his head. "No. I can assure you that they are being cared for beautifully. In fact, they probably are more-closely observed and tended to than most – we have lots of experts in. Sometimes weekly – though it can get very expensive. And I can most certainly tell you that all of those folks – plus myself, seeing as how I'm with them every day – will agree that the elevators are working as best they can."

"Then," you conclude, sure of your knowledge, "they must've been designed wrong. You'd need a special facility to work with these. They're not normal." The bellman stands up a bit straighter then. "They are fine right here. And they are exactly as they were designed. Beautifully."

"I realize that you know much about most elevators, ma'am," the bellman says. "And I admire it – your interest, the time and care you put into your craft. I'd bet that loads of your ideas would work for these elevators, too."

He pauses, thinking, then lifts his eyes to the shiny doors and smiles. "Did you know that Einstein imagined the Theory of Relativity while watching a real clock tower? Sometimes, even for us adults, the most complicated ideas happen while you watch real things. That's why I was thinking….well, it's just…." His voice trails off. "Yes?" you urge him on. "It's just what?"

"Well. These elevators *are* wired differently. So, I was thinking….*maybe all you know is true. But maybe you don't know all that is true.* And not everything you know applies to *every* elevator," he says, his gaze past you.

He follows the elevators. You follow a doctrine. "Perhaps," he begins slowly, "what you perceive as malfunction is, in fact, the most logical operation based on their hardwiring. Not understanding a difference doesn't make it a malfunction." He laughed then. "It'd be like me calling you a malfunctioning man!"

"I'm a perfectly functional woman, sir," you retort. "Exactly! You see? You're not broken! You're just designed differently. The same is true for our elevators. That's why all this fuss! Your whole, underlying assumption is wrong."

Come again? Philosophy? From a bellman? But no, you have the self-confidence to know you may not yet know all there is to know – not even about elevators. So you bite. "My underlying assumption? What do you mean?" "Just that you've got one thing wrong, ma'am." He looks right into your eyes, a sincere smile spreading across his face. "Normal and typical. They're not synonyms."

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