Excerpts from *Perfectibility: How A Small Boy Blew That Apart* by Carmen G. Farrell

My earliest memory of needing to be perfect is from Grade Two or Three, during Language Arts period. Mrs. Derrault called upon students to stand and read a passage aloud from a story. My turn came, and I rose confidently, knowing that Language Arts was an area where I shone, and that my teacher enjoyed my handwritten extracurricular stories about "Rinaldo the Mouse." The memory is old but still accessible — the hot, I-want-to-hide-feeling started in my knee-high socked legs, and rose through my belly like I'd swallowed a hot pepper, pausing at the base of my throat, then to burn on my cheeks. The word was "chaos" but did not come out of my mouth as "KAY-os." I heard the shuffling of bodies in desks and the quiet but unmistakable sounds of mockery from my classmates' lips at my expense. At how I'd said "CHAY-os." I'd done it wrong.

….. *the dots mean the next excerpt comes later in the book*

From my Grade Three paradigm of "perfect", I used to think my son was broken. Even more, before he was born and before I knew and loved him, I didn't want him. Today, this is what shames me. Not being wrong, or doing something badly, but being so disconnected that I thought people should be "perfect." Today, I'm suspicious of perfection. Sometimes I think of perfection as an iceberg floating in a frigid sea. A person sitting on the iceberg of perfection is isolated, offshore and away from others. I might be occasionally or temporarily in awe of it, but I don't connect with it.

Perfection is a conceit. It's a conceit because it's unattainable and subjective, ignoring how "perfect" varies over time, culture and perspective. It's more about a person's ego and their belief that they can bypass imperfection, or impose their ideal on a messed-up and flawed world. Perfection is an illusion, driven by ego, oblivious to human limitations. It colours how disability has been viewed.

Instead, what I admire, is the person who stands on the shore with the rest of us and says, "I'm going to swim out to that iceberg." "Wow," some of us might respond, eyes wide with wonder. I might be curious about how they're going to do that, I might ask questions, offer help, or stay behind to watch and cheer. It's the act of swimming out toward a goal, the act of perfecting that inspires me. I feel connected to their effort and their spirit to do what they want. I want to support them, be with them in some way as they pursue their goal. We are connected. We experience a sense of well-being and belonging.

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Play class was a rare glimpse of a group of children his exact age. Until today, I'd chalked up his passivity to being younger than his sister Jordan or brushed it off with the "Boys are different" reassurances from friends. My husband, Curtis, used to quip about baby Ges, "There are two kinds of people: those who do it for themselves, and those who let others do it for them. Ges is happy for others to do it." I'd bought into that for awhile, until today's tunnel unravelled something more profound and disturbing.

Pushing Ges on the swing, I barely register the forest greenery or the scatter of yellowed maple leaves. I'm not used to so much chatter in my brain. My brow furrows behind him as I stew. Why does this morning gnaw at me? Is it worry for Ges, or is it my bruised pride? Probably both.

Mothering Jordan was a different kind of vulnerability. First-time parenthood softened my guarded adult veneer, opening me to shared glances with strangers. Older moms who reminisced through my stroller-pushing days connected me to their memories and experiences of a different young child in an earlier time. I recall a bored Jordan I tried to amuse in the passport application line, and a silver-haired woman leaned in: “You'll never regret the time you spend playing with them. It goes by so fast.” With Jordan, I'd embraced that public vulnerability, the secret camaraderie of motherhood. It taught me people are mostly kind and inclusive.

But this with Ges? None of the mothers connect with what happened in the play class — or would admit to it. Not reading your child's cues is failed mothering. Other mothers want to be with good mothers. A good mother is one who knows her child and responds to them. A good mother creates conditions for their child to thrive. Clearly, Ges and I weren't thriving this morning. My reaction, my confusion, was on display for all to see. He and I were something to shy away from and exclude.

Ges's terror in the tunnel baffles me more than his lagging motor skills. His reluctance to try what he wants ignites a worry I'd been suppressing. Something's off. It thuds in my head, weighs my shoulders, squeezes my chest. I can't absorb Ges's enjoyment of the swing or the peace of having the park to ourselves. My worry for him and my shame from the morning drowns it all.

Is it real? Am I exaggerating? It doesn't feel like it. No soft nods or understanding smiles ease this isolation; there's only scorn and a toxic swirl of failure. The other mothers' silent, imagined gossip echoes into the forest, scolding me for not knowing my son's needs. I picture their at home conversations over dinner. “You should have seen this poor kid in the play class this morning. He was terrified and his mother was clueless. Clue. Less.” No support, no kindness. Just my ignorance on display.

Fifteen minutes of distracted swing-pushing later, I snap out of it. This spiral's going nowhere. It's time to pack up and get home to Jordan and the afternoon's to-do list. Ges chortles into my ear as I carry him to the car, the warmth of his little frame seeping through my jacket allows me to enjoy his weight perched on my hip.

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When Ges was little, spending so much time in hospitals, clinics, and waiting rooms of experts whose rules I was socialized to respect, I bought into the idea that Ges's disabilities were a “thing” ...something to be diagnosed, analyzed. Ges's health conditions could be “fixed” in ways similar to how I could alter myself in order to “fix” Trent [Carmen's childhood bully]. The world didn't change for either of us — I was expected to stay perfect and smart...and make him stop. In that way, I was like medical and therapy systems that react to Ges, seeking to change him to fit into the world better. In reacting to Trent, I was expected to fix his behaviour.

In the medical paradigm, Ges's limitations imply brokenness. His not meeting standardized childhood development markers meant pathology and flaws in his health. That view of disability — as a tragedy housed in his body — screamed, “If we can diagnose this, we can fix it.” In a sense, the medical experts implied their work could make Ges's disability disappear. My dad thought I could make Trent's behaviour disappear.

Then I moved into therapizing Ges and his disabilities, telling myself, “Okay, a reality exists, so let's maximize it. Let's work around his impairments and make him the best version of himself through therapy and capacity-building.” These paradigms, known as the medical and therapeutic models of disability felt right when we were immersed in them, but as we moved through them, I saw their limitations. The therapeutic mindset accepted Ges's impairments but focused on how he had to be different to fit into the world around him. How to maximize his skills to be more “normal.” How to change him to fit with the majority.

Gradually, I began realizing the dangers of majority thinking. Beyond the us-them polarity, it sets up false narratives that tie expectations to numbers: because one group outnumbers another, its beliefs and values seem more valid, important, or “normal.” Sometimes, the majority thinks it’s doing the minority a favour by insisting on compliance with their norms and expectations, as if conformity equals improvement. That someone with different cultural beliefs and systems would be better if they changed and did things like the majority. That people with health conditions and impairments would be improved if therapies and systems made them as close to “normal” as possible.

Neither approach of medicine nor therapy was taking me and my mothering where Ges needed: a place where I could embrace the paradox of his impairments and not think about him, me, or anyone else as defined by ability or disability. For a long time, I used to say, “Humans exist on a continuum. We’re not all one thing or another: fully capable or fully incapable. All of us have abilities and disabilities.” As Ges moved toward the intermediate grades of elementary school, I thought more and more about how I wanted to be in the world. My evolving awareness of the limitations of my old stories about how “fixing” and “curing” kids like Ges become reality, my fears of difference, and my growing realization of how I’d reacted to this in the past set the stage for developing a new way of being. Less focused on being perfect. More focused on seeing the world gently. Using kind eyes to see my son and his community. I was incredibly imperfect in my pursuit of these goals.

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I thought Teresa and I were discussing the astounding successes of “Club G,” the ones that have sparked numerous newspaper articles, national and provincial awards, and how adults marvel at the quality of inclusion the children generate, even if the kids shrug it off. It’s no big deal. Still, the child leaders of “Club G” create a playground world where kindness reigns, and everything is geared so everyone can play.

The adults, like me, remember how unforgiving childhood elementary school playgrounds could be. Cruel, even. These same adults are tempted to embrace this Disney-esque outcome, to feel inspired by the kids’ inclusiveness. The term hadn’t been understood yet, but today we know it as “inspiration porn”, coined by activist Stella Young; when non-disabled people objectify people with impairments by holding them up as models of inspiration only because they are disabled. Club G doesn’t, and didn’t, inspire because of Ges’s disabilities. That may have been the kernel of creativity, but it blossomed because the kids showed the adults new ways of thinking about play. Many kids benefited...some who were naturally sensitive, less athletic, or less expressive who enjoyed a place where the gateway to inclusiveness was kindness. Expansive acceptance was the inspiration. Ges just happened to have impairments.

“They’re such compassionate kids,” I tell Teresa.

“Yes, they are...but it’s him who makes them great,” she responds. I take a moment to let that sink in. She’s right. My son is truly a beautiful child...and not just on the outside. I’m starting to realize Ges's positive impacts on his peers and how he’s helping them become wiser, more compassionate risk-takers through their generosity and inclusion.

But then she says, “You should be proud of him.”

As she says this, the background elementary school noises disappear. Only she and I sit across the table in the learning centre with her words between us. Guilt takes root in me like an invasive garden weed. My love for Ges is the mother-killing kind, always putting him first, an unforgiving devotion that could bury me early. I know this, but it's the only state of being with him. I can't let go and imagine another way of mothering. Gentler parenting that spares me.

Despite this, I've rarely felt proud of my ten-year- old. I am ashamed to admit this.

He's incapable of most of what his Grade Four peers demonstrate. He doesn't understand much nuance or non-literal language and cannot do physical tasks his peers take for granted. He relies on technology to speak for him and types simple sentences into voice output software to make himself understood. There are no typical achievements.

I know I'm supposed to feel proud of him.

Ges's learning support teacher believes in Ges in a way I haven't. She judges him worthy of pride? She — this woman I've judged — has something to teach me? Most of our thrust-and-evade fencing matches over what's best for Ges send me home wounded and depleted. "I can't keep doing it!" I cry into my husband's shoulder. "She sucks all the energy out of me!" When this happens, Curtis holds me and listens, saying, "Carmen, try to see her the way you want her to be." I couldn't imagine it. "Try to approach her as if she's already doing and saying what you hope," he counsels. Okay, I told myself, Try to see her good intentions first. She's not trying to hurt Ges or me. She's doing what she thinks is best.

I had put her in the same box as Ges's neurologist...clinical to the extreme and focused on all his can'ts — he can't understand time, has no sense of future and past, and has a vocabulary of only three hundred words. Her list went on and on.

"He's the one teaching them. They think they're helping him, but he's helping them," she continues. Yes, I know he's sweet and kind and enjoys a good corny joke and the company of his peers. He's generous, laughs easily, and often gives splendid hugs. His blond curls, blue eyes and cherubic complexion impact strangers who notice his beauty. To me, he's wonderful. But Ges teaches them? It never struck me that he shapes those around him.

I had felt fortunate. Holding him back a year from entering kindergarten equated to the best parenting decision of my life. Because of this, his cohort of elementary school kids felt like a lottery we'd won. They're extraordinary, kind kids. Maybe. Or maybe it's not about them at all, nor my choices.

It's about who they're becoming because of him! I imagine how this might translate into their adult lives, how their character might shift because, from a fledgling age, they learn to feel compassion without pity. They learn to demonstrate generosity without wondering what's in it for them. Seeing underneath a person's difficulties and figuring out how to be a friend becomes part of their humanity. Part of who they are. And so much more than I ever was at their age — or was when I became Ges's mom.

I have to agree with her when I imagine a world of my son's friends. "Yes." I swallow hard. "You're right." And I mean it. All my frustrations with this teacher diminish with what she's just shown me. I resolve to park my unkind judgements and learn from her. Allowing her to influence me unfurls the possibility of grace inside me. For giving — forgiving — her imperfections and mine a place to be seen.

Something shifts in my brain.

Pride for Ges. Grace for myself.

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The biggest obstacle to creating a culture of inclusion and kindness, Ges's experience showed from kindergarten onwards, was never Ges himself. His disabilities were never "a problem." The most significant limitation was a complacent world around him that remained content to let him sit at the periphery, not learning how to draw him out — that judged and criticized him for trying to hug others inappropriately, seeking a connection he couldn't verbalize — and, that put his behaviour in a "different" box, judging it with a degree of complacency that they're better because they're in the majority. All ability's different — it's not an on-and-off switch. Normal humans exist on a continuum of disability and its absence.

I don't pretend to be a disability scholar. However, Ges's elementary school experience shows our lived experience of this social model of disability. This model doesn't talk about a disability existing because of medical and physical reasons but because of social ones. Disability is created in the social interactions between neurotypical people and people with health conditions and impairments. Environments filled with systemic barriers — whether physical, attitudinal, social or communication are responsible for disability. Look at how almost an entire school community shifted to enable Ges to participate equally. Different, yes, but equal. In Ges's preschool years, I had been struggling with the medical model of disability — that his differences were an abnormality to cure and fix.

Ges's peers became more accomplished in their friendship skills by learning to relate to difference. Someone's different ability isn't a fixable, labelled abnormality. It's a materiality to understand. The adaptations the children learned served as handling instructions for Ges and others like him. Ges's autism label became a portal for inclusion that secured the care and attention he needed, taught his classmates about compassion, and created caring relationships between them that lasted throughout their schooling.

Humans aren't designed to be the same, yet in our standard lexicon, we've incubated notions that idealize normal. We layer onto this ableist language a plethora of cultural, socioeconomic, and political expectations and systems that reward our interpretations of normal and marginalize the uncommon. Previous generations sequestered difference through institutionalization. It still happens. As a child, I never saw a student like my son. Anyone who behaved unexpectedly, beyond the norm, was jeered. "Ree-tard!" was a common put-down. People with 'less than normal' intelligence were classed as idiots, morons ...and retards.

Social, intellectual, and physical impairment aren't the problem; they only become a disability when others judge them as less than normal. Different is normal, likeable, and capable. We all deserve to live to our fullest capacity. Some of us require adaptations and modifications to do that. That's not a cure. It's not a fix. It's different.

[These excerpts end around page 50. Three quarters of the book still to go...]