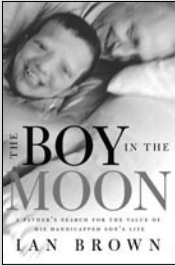


The Boy in the Moon:
A Father's Search for His Disabled Son, and
Writing What You See, Not What You Think You See



In late September, Random House Canada released *The Boy in the Moon: A Father's Search for His Disabled Son*.

From the dust jacket:

“Ian Brown’s son, Walker, was born with a genetic mutation so rare that doctors call it an orphan syndrome: perhaps a hundred people around the world live with it. At twelve, Walker is still in diapers: he is globally delayed, he can’t speak and he has to wear cuffs on both his arms so that he won’t constantly hit himself. Yet those details don’t capture him. Despite the turmoil and pain of his life, Walker still delivers to the world moments of joy so intense they seem supernatural.

“Brown first wrote about his son in a series for *The Globe and Mail*, which drew an unprecedented reader response. But the series only scratched the surface of what Brown needed to know and needed to say about his son.

“... Brown never shies away from the humour or the intense pathos of life with Walker. With the tender imagination and stark honesty Brown brings to the writing, the quality that infuses his book is love: for this amazing boy, for his family and for life. As much as this book is about one frail boy and the tiny constellation of people who surround him, it is also about all of us who try so hard to be parents worthy of our children.”

Literary Journalism Studies is pleased to publish three excerpts from Brown’s latest work. An essay, which been compiled from one of the author’s guest appearances at the School of Journalism, Ryerson University, Toronto, Canada, will follow the excerpts. In the essay, Brown discusses his views of personal journalism, the New Journalism, and literary journalism.



Ian Brown, one of Canada's most accomplished journalists, currently writes features for *The Globe and Mail* national newspaper. He is also the anchor of two documentary programs, *Human Edge* and *The View From Here*, on the province of Ontario's public broadcast station, TVO. For ten years he hosted CBC Radio's *Talking Books*. Brown's reporting and writing have won three National Newspaper Awards for the *Globe*, as well as seven golds, four silvers, and sixteen honorable mentions at the National Magazine Awards, for magazines such as *Saturday Night*, *exploire*, *Chatelaine*, *Canadian Business*, *Toronto*, and *Outdoor Canada*. He is the author of two previous books. The first, *Freewheeling: The Feuds, Broods, and Outrageous Fortunes of the Billes Family and Canada's Favorite Company* (Toronto: Harper Collins, 1989), is an entertaining history of the Canadian Tire Corporation. The second, *Man Overboard: True Adventures With American Men* (Toronto: Macfarlane Walter and Ross, 1993), is a mordant take on what it means to be a man in an age when a woman no longer requires him. He has also edited an anthology of twenty-five narrative essays, *What I Meant to Say: The Private Lives of Men* (Toronto: Thomas Allen Publishers, 2005). Brown lives in Toronto.

The Boy in the Moon

by Ian Brown, Toronto, Canada

(From Chapter One)

For the first eight years of Walker's life, every night is the same. The same routine of tiny details, connected in precise order, each mundane, each crucial.

The routine makes the eight years seem long, almost endless, until I try to think about them afterwards, and then eight years evaporate to nothing, because nothing has changed.

Tonight I wake up in the dark to a steady, motorized noise. Something wrong with the water heater. *Nnngah*. Pause. *Nnngah*. *Nnngah*.

But it's not the water heater. It's my boy, Walker, grunting as he punches himself in the head, again and again.

He has done this since before he was two. He was born with an impossibly rare genetic mutation, cardiofaciocutaneous syndrome, a technical name for a mash of symptoms. He is globally delayed and can't speak, so I never know what's wrong. No one does. There are just over a hundred people with CFC around the world. The disorder turns up randomly, a misfire that has no certain cause or roots; doctors call it an orphan syndrome because it seems to come from nowhere.

I count the grunts as I pad my way into his room: one a second. To get him to stop hitting himself, I have to lure him back to sleep, which means taking him downstairs and making him a bottle and bringing him back into bed with me.

That sounds simple enough, doesn't it? But with Walker, everything is complicated. Because of his syndrome, he can't eat solid food by mouth, or swallow easily. Because he can't eat, he takes in formula through the night via a feeding system. The formula runs along a line from a feedbag and a pump on a metal IV stand, through a hole in Walker's sleeper and into a clever-looking permanent valve in his belly, sometimes known as a G-tube, or mickey. To take him out of bed and down to the kitchen to prepare the bottle that will ease him back to sleep, I have to disconnect the line from the mickey. To do this, I first have to turn off the pump (in the dark, so he doesn't wake up completely) and close the feed line. If I don't clamp the line, the sticky formula pours out onto the bed or the floor (the carpet in Walker's room is pale blue: there are patches that feel like the Gobi Desert under my feet, from all the times I have forgotten). To crimp the tube, I thumb a tiny red plastic roller down a slide. (It's my favorite part of the routine—one thing, at least, is easy, under my control.) I unzip his one-piece sleeper (Walker's small, and grows so slowly he wears the same sleepers for a year and a half at a time), reach inside to unlock the line from the mickey, pull the line out through the hole in his sleeper and hang it on the IV rack that holds the pump and feedbag. Close the mickey, rezip the sleeper. Then I reach in and lift all forty-five pounds of Walker from the depths of the crib. He still sleeps in a crib. It's the only way we can keep him in bed at night. He can do a lot of damage on his own.

This isn't a list of complaints. There's no point to complaining. As the mother of another CFC child once told me, "You do what you have to do." If anything, that's the easy part. The hard part is trying to answer the questions Walker raises in my mind every time I pick him up. What is the value of a life like his—a life lived in the twilight, and often in pain? What is the cost of

his life to those around him? “We spend a million dollars to save them,” a doctor said to me not long ago. “But then when they’re discharged, we ignore them.” We were sitting in her office, and she was crying. When I asked her why, she said, “Because I see it all the time.”

Sometimes watching Walker is like looking at the moon: You see the face of the man in the moon, yet you know there’s actually no man there. But if Walker is so insubstantial, why does he feel so important? What is he trying to show me? All I really want to know is what goes on inside his off-shaped head, in his jumped-up heart. But every time I ask, he somehow persuades me to look into my own.

(From Chapter Eleven)

Six weeks later, in Cuise-la-Motte, a village ninety kilometres northeast of Paris, I saw an even more precise version of a possible future for Walker.

Cuise-la-Motte is one of four villages with L’Arche communities that form a tight knot in Picardie—Pierrefonds, Trosly-Breuil, and Compiègne, which is large enough to have a university, being the other three. A 36,000-acre forest—one of France’s famous hunting preserves, a former forest of the king—sits in their midst. Joan of Arc hid in these woods before her capture in Compiègne in 1430. The same forest was where Marshal Ferdinand Foch signed an armistice with the Germans on behalf of the Allies on November 11, 1918, and where, twenty-two years later, Adolf Hitler forced France formally to surrender to the Nazis. There are two grand châteaux in the region, one of which is said to be the inspiration for the castle in Walt Disney’s *Sleeping Beauty*. But no tourist plaques mention the L’Arche communities, though the people who live in them walk the streets like ordinary citizens.

The most critically disabled residents, both intellectually and physically, lived in a maison d’accueil spécialisé called La Forestière, in Trosly-Breuil. La Semence—the seed, in French—where I was planted, was home to people mostly incapable of speech, but mobile, after a fashion; conscious, and capable of registering their consciousness, but incapable of doing so alone. Walker would have fit in here, at the bottom end of the range. I was staying in the guest room, the sole person in a room that accommodated four. Outside my window a magnolia tree was flowering. Rosemary and lavender bushes were in bloom. It was April.

My flight had arrived that morning in Paris, and I’d arrived in Cuise-la-Motte just before lunch. My plan was to stay a few days, see how L’Arche worked, talk to Jean Vanier. He was one of the world’s foremost thinkers on the subject of disability, and I wanted to know what he thought would comprise a satisfying, decent, just life for Walker. I had read some of Vanier’s books, and found them radical. Vanier believed the disabled deserved a place of their own, that they often wanted to live apart from their families and parents if they could find a sufficiently supportive environment. That was an idea I thought I could get behind. He also insisted that the disabled were capable of teaching the able-bodied more than the able-bodied could ever teach them. If Vanier was right, I didn’t have to feel so bad about letting Walker live his life at least to some degree on his own. In some way I was there to find out if I was letting my son down. I unpacked my bags and sat down at the table in my room’s small kitchenette to look over the questions I planned to ask Vanier that afternoon. I had a page or two of notes prepared when there was a knock on the door. I opened it to a tall man wearing a beard and a red sweater. He immediately offered me some water. I said yes, invited him in, and offered him a seat at the kitchenette table.

He was sixty-four years old, but he looked fifty. His name was Garry Webb and while he wasn’t

disabled, he too lived at Semance. Webb was L'Arche's director of special projects: he'd just returned from taking fifteen L'Arche residents on a trip to Portugal. He'd grown up in Vancouver, but left home at eighteen. "It wasn't my culture," he said matter-of-factly. I asked him how he came to work at L'Arche, but that didn't work, because he refused to classify what he did as work. "It's living. Being. Working is only part of it. Everyone who comes here is transformed by it. Relationship is our priority. And then we tell people about it just by being who we are." All of which was interesting, free, spirited, and made me extremely nervous. But that was often the way conversations with people at L'Arche began. They didn't seem to suffer from the self-consciousness the rest of us do: disabled or not, they launched forthwith into the act of "relationship" with whomever they met, whenever they met them. I found their enthusiasm alarming. Were they high? Had they been smoking kindness? What the hell were they up to, anyway! I admired their openness, but being a city boy, had no desire to emulate it; I appreciated their generosity, but as a product of twentieth-century capitalism, doubted its sincerity. If Walker ever lived in such a place, would he be surrounded by people who cared for him for his own sake or by people who cared for him because they were in a cult? I didn't want Walker in a cult.

Webb had trained as a Jesuit and spent seven years in a Trappist monastery when he took a leave of absence to reassess his life. He had a lot of options. He'd studied philosophy and theology and psychology at university; his parents had been artists, and Webb was himself a part-time sculptor and sometime actor. He had strict requirements for his new path. It had to unfold in a new community; it had to be responsible work, with the poor or their equivalent; it had to be non-exclusive, nothing that shut out the rest of life (he didn't want to be locked away in a monastery again); it had to be a long-term commitment; it had to be holistic; and, most importantly, had to occur in a community that respected "the spirituality of each person." The first time he visited L'Arche, "I asked to stay for three days. But then I asked to stay for three weeks, then three months, then for a year."

I was about to ask if living at L'Arche ever got boring, but at that moment Webb explained he was only popping in to say hello on his way to the nearby village of Trosly-Breuil, to visit Jean Vanier at his home. They met every other week.

"What do you talk about?"

"Us," Webb said.

"Not the business of L'Arche?"

"Oh God, no. Us. My stuff. Why I'm still shitting my pants, figuratively speaking, in my dealings with the world. Why he's still running around like a rooster with his head cut off."

As he got up to leave, I confessed I was a little nervous at the prospect of talking to people who couldn't talk. Webb scoffed and waved his hand. "I think the core members of L'Arche are our teachers," he said. "And if you communicate with them, you'll be okay. Lunch is at twelve-thirty." Then he left.

An hour later, in the dining room, I met the people I was to live with for the next three days. Gérard was in his fifties. He could speak, after a fashion, but made whinnying noises as he did. He liked to tell stories, and was known to go into town for a beer. Laurent (also known as Lorenzo, because he was born in Italy) was trim and well dressed; he made a soft moaning noise as he ate, and liked to walk into a room and then stand stock-still for long stretches. Lydie, a young woman from the south of France who was Laurent's assistant, said, "Laurent

loves trains. He has all sorts of books about trains.”

“*Train!*” Laurent said, in French. It was the only word I ever heard him speak.

“*C’est ça,*” Lydie replied.

Several of the residents wore large neckerchiefs, bib fashion, in preparation for lunch. Francine was in a wheel chair; thanks to cerebral palsy she never spoke, though she could make noises, and was keenly interested in those around her. Another resident, Jean-Claude, could power himself in a wheelchair, liked cognac, could hear what people said, could not respond, and carried his favorite object, a stuffed raccoon, wherever he went. He was my age. Sabina appeared to have a severe form of Down syndrome, and spent all her time silently in her wheelchair.

The person who captured my interest most was a small, stooped, watchful man named Gégé. He was forty-six years old and he reminded me of Walker. The similarity smacked me like a blow: I could see Gégé’s ceaseless curiosity, and his permanent loneliness. He never spoke, but observed the action around him intently and slyly, with his head tilted. Singing made him smile. He made popping noises with his mouth, and walked in a crabbed forward crouch, half bent over. He had a habit of staring at his hands as if they belonged to someone else, the way Walker did.

No one at L’Arche talked about integration, the way staff sometimes do at conventional homes for the disabled: this community existed for the disabled and made no pretense that residents eventually would be part of the “normal” community. People like me were the outsiders here. There was a routine, a structure, a community of individuals, and their lives counted for what they were, no added value required. The table was set, grace was sung. Red leather pill-wallets were set out carefully at the head of each resident’s place setting, alongside any required digestive powders—a small neat pharmacy of remedies next to each water glass. Some of the residents could eat on their own, but just as many needed their food spooned into their mouths. As we ate, the assistants talked to their wards, and the wards grunted or laughed or moaned or peeped in reply. Gerard was the only resident at the table who could initiate what someone on the outside would recognize as conversation, but that didn’t stop everyone from interacting. It was a form of speaking, but you had to let it lead you.

After lunch, the residents who worked in L’Arche’s workshops making trinkets and jewellery returned to their labours; the others went for a walk. It was a community for the disabled, there was no question of that, but because the disabled were considered, and considered themselves, equals, none of it felt like a “special” arrangement. This was their world, not ours; these were their standards, not ours. The pace of life was slower, life itself was simpler; there were delays and problems, but no one took them seriously. It was a pleasant place to be, and conveyed no sense that life ought to be otherwise.

A couple of months after I visited L’Arche, at a party in Toronto, a friend scoffed at Jean Vanier’s saintliness. “It’s just so hard to accept that a guy with his intelligence and his opportunities would want to live with those people,” my friend said. “But maybe he just always wanted to make sure he was the smartest guy in the room.” Which he conceded was a terrible joke almost as quickly as Vanier would have laughed at it.

But there was something to the joke. Vanier had an imposing reputation, the result of a life dedicated to accomplishment. He had founded L’Arche. He was a perennial candidate for the Nobel Peace Prize, and had written dozens of pamphlets and books, including the

international bestseller *Becoming Human*.

But in person, Vanier was anything but intimidating. His house—the house he lives in when he isn't travelling the world for L'Arche—was a tiny stone cottage that backed onto the main street of Trosly-Breuil. Inside, in a cramped study off a modest kitchen, I found a tall, shy, unassuming white-haired man in a pale blue sweater.

Jean Vanier was born in Geneva, Switzerland, on September 10, 1929, while his father, Georges Philius Vanier, a retired general in the Canadian army, was stationed there on a diplomatic mission. Vanier attended school in England, but at the outset of the Second World War went to live, for reasons of safety like many other English children, with his brothers in Canada.

Late in 1941, he approached his father for a meeting. As his father was by then the nineteenth governor general of Canada, this required making an appointment. Jean wanted to join the British Navy, by way of the Royal Naval College in England. He had to cross the dangerous waters of the Atlantic, an idea his mother strongly opposed. But his father held a different view. "If that is what you really want to do," Georges Vanier said to his son, "then go. I trust you." Vanier later remembered the conversation as a formative moment of his life.

He was too young to see active service, but did witness the liberation of Paris, and in the years that followed helped process the return of survivors from the concentration camps at Dachau and elsewhere. By 1950 he was assigned to Canada's largest aircraft carrier.

At sea, Vanier began to wonder if he really wanted to be in the navy. He had begun to pray, for starters. He later wrote in *Toute personne est une histoire sacrée*, his account of his spiritual call to arms, that he had begun to feel "called to work in a different way for peace and freedom." He was more attentive to reciting the Divine Office than he was to night watch. He felt he was being called to God, and within a few years had resigned his naval commission and enrolled as a student of philosophy and divinity at Paris's L'Institut Catholique. He also joined L'Eau Vive, a small community of students devoted to prayer and metaphysics under the direction of a French Dominican priest, Père Thomas Philippe. Shortly after Vanier's arrival, Père Thomas fell ill. Vanier was asked to run the community, which he did for six years.

"I suppose I had been hopping around," Vanier told me that afternoon over a cup of tea. "I'd been a naval officer, I'd left the navy, I'd come to a community near Paris. I was searching. I didn't know quite what to do. Later I got a letter from St. Michael's College in Toronto: Will you come and teach? And it was interesting." By 1963, at the age of thirty-four, Vanier had defended his doctoral dissertation at the University of Toronto (*Happiness: Principles and Goals of Aristotelian Morality*) and was a popular lecturer with a scholarly interest in the ethics of friendship. "But I knew that teaching wasn't my thing. There was something in me that wanted a commitment to people, and not ideas." He spent a lot of time visiting the edges of society—notably prisons near Ottawa, where he took to praying with the inmates, guards, wardens, and in-house psychologists alike. "After a while, no one knew [during the prayer sessions] who was a prisoner or who was a guardian," he later wrote. It was his first experience of non-hierarchical life—an early model for what L'Arche would later become, with its residents and assistants living side by side, as equals. Raised as he had been in the protocol-encrusted diplomatic community and in military college, casteless society was a revelation to him.

During the summer of 1963, after the school year finished in Toronto, Vanier visited his old spiritual mentor, Père Thomas. Thomas had retired from teaching following a disagreement with the Vatican, and was by then serving as chaplain at Le Val Fleuri, a small institution for men with

developmental disabilities in the tiny village of Trosly-Breuil. “I was a bit scared,” Vanier said of his first visit, “because—well, how do you share with people who don’t speak, or speak badly?”

But his encounters with the intellectually frail men of Trosly were the opposite of frightening. “What touched me was that everyone, in one way or another, said, ‘Do you love me? And, will you be my friend?’ I found them so different from my students at the university. My students wanted my head, and then to leave, to get a position, get money, found a family. But here was something else. I think their cry—‘Will you be my friend?’—triggered off things within me. I think I was searching for a place of commitment.

“These were the years of Martin Luther King,” Vanier explained. “He wanted to liberate those who were oppressed. I think my impression of people with disabilities was that they were among the most oppressed people of this world. I suppose that somewhere at the heart of the beginning of L’Arche was a desire for liberation, to liberate them.

“It seemed obvious. That was the period in Canada where there were twenty institutions for the handicapped just in Ontario; here in France it was the same type of thing. And I had visited institutions where there were a thousand people with disabilities all cluttered together. And I thought: What is the meaning of this? And so my sense was just, why not get a house? And why not welcome two people? And see what happens? In a way, I’m quite naive. I think I like risk. And if you put naïveté and risk together, then you start L’Arche.”*

A small house was available in the centre of Trosly-Breuil. Vanier bought it. The house was so primitive it had no indoor toilet. On August 6, 1964, he moved in with three intellectually disabled men (one of whom quickly proved beyond his capabilities and moved out again). Neither of the remaining men, Raphael and Phillippe, could speak. Vanier’s only other asset was an unreliable Renault, in which he and his companions roamed the countryside.

“I can say that as soon as I began, I think I became a child. I could laugh, we could have fun. We’d sit around the table and fool around. I had been quite serious up to that time. As a naval officer you’re quite serious. You know how to command people. Then when I started teaching, I was quite serious: you have to give the impression that you know something when you teach.

“But here it was something else. We could fool around. Because the language of people with disabilities is the language of fun. But you know that with Walker. Don’t be too serious. Celebrate life, have fun.” A profound three-way ritual of acceptance developed: Vanier’s acceptance of his two new disabled companions, their acceptance of him, and perhaps most significant of all, Vanier’s acceptance of himself in his new, less ambitious, counter-cultural role.

*I’m always surprised by the range of people I meet who have experienced the energy of the handicapped, however difficult and even embarrassing that energy can be. Not long ago, for instance, at a Christmas solstice party, I found myself at the cheese tray, standing next to John Ralston Saul, the writer and public intellectual, and his wife, Adrienne Clarkson, the former governor general of Canada. I had only just learned that Saul had written about disability. I asked him what had drawn him to the subject. Saul—a fairly intimidating figure at the best of times—revealed that he had an intellectually disabled brother. “He was certainly the most influential person in my life,” Saul told me, reaching for the Havarti. “Why?” I asked. But he only looked at me, thinking, until Clarkson answered for him. “Because John and his brothers were always trying to communicate with him. All the brothers, they wanted to include him. And they couldn’t. And so that left them always wanting to get through to him. Everything else in John’s life has flowed from that.” The process can work the other way, as well. The playwright Arthur Miller renounced his own Down syndrome son, and even denied he existed; a number of critics maintain this is when Miller’s decline as a writer began.

He called the house L'Arche, after the French word for ark, as in Noah's ark. To his surprise, the venture attracted attention over the ensuing years, and eventually donations and public funding that allowed it to expand.

"In the beginning Jean was still in the very traditional thing of doing good for the poor," Jean-Louis Munn had told me when we met. "But then it switched: he realized he was benefiting. After that Jean wanted to be a voice for people who had no voice. He quickly discovered that the simple life, living with Raphael and Phillippe, was satisfying." Gradually, lured by Vanier and word of mouth, young people from around the world began to show up at L'Arche to do a year or two or more of service. (Jean-Louis Munn and Garry Webb were two of them, as were many of the people who still work for the organization thirty years later.) By 1971, as L'Arche expanded internationally, demand for places was overwhelming, especially from parents who could no longer look after their adult children. L'Arche couldn't build homes and communities to serve them all, but that year, with the help of a colleague, Marie-Hélène Mathieu, Vanier created Faith and Light, a net of extended support groups for people who have no recourse to a full-service L'Arche residence. Today there are nearly fifteen hundred Faith and Light networks in seventy-eight countries that cater as much to the parents of the disabled as to the disabled themselves—an evolution with which Vanier did not feel comfortable at first. "At the beginning my concern was not with them: It took me a long time to really listen to parents," he said, leaning back in his seat in his study. "Because most of the people we brought in to begin with, their parents were either dead or had abandoned their children young. And so there was inside of me to begin with a little bit of upsetness with parents." I understood that feeling: I had a little bit of upsetness with myself for letting Walker live somewhere else, however necessary it was. But as Vanier met more parents who had not abandoned their children but who nevertheless couldn't care for them, his strict views began to moderate. He was struck more and more by the immense lake of pain and guilt in which many parents of disabled children tried to stay afloat.

"The guilt. The guilt. The parents of the disabled were as a group the most pained people, because many of them feel guilty. They ask that terrible question, why has it happened to me? You find in the Knights chapter of St. John, when Jesus and his disciples meet a man born blind. And their immediate question is: Why? Whose fault is it? Did he commit a sin, or did the parents commit a sin? Why do you have a son like that and why does someone else not have a son like that? Wracking your brains about that sort of stuff—we can spend a lot of time asking the wrong questions. The right question is: How can I help my son, to be happier? The wrong question is, is it my fault?"

"But the social disapproval is still intense," I said. "People don't like to be reminded of the disabled. Why is that?"

"I think people are frightened at seeing people with disability," Vanier replied. "It might say to them, one day, you might have an accident and you will be disabled. You know, we are frightened of death. And the disabled are a sign of death." He then embarked upon a story about the first person who ever died in a L'Arche home in Trosly, an assistant named François. As the word got around among the residents, two of them decided they wanted to see François. Another assistant led them into the visitation room where François's body was lying in an open coffin. One of the men, Jean-Louis, asked the assistant if he might kiss François goodbye. The assistant said sure. And so Jean-Louis kissed dead François. "Oh shit!" he

exclaimed. "He's cold!" Then he left. On his way out the assistant heard Jean-Louis say, "Everyone's going to be so surprised I kissed a dead person!"

Vanier stopped speaking, looked at me and shrugged his shoulders. "What is happening?" he said then. To my relief I wasn't supposed to have an answer: Vanier was going to tell me. "My belief," he said, "is that he's kissing his own handicap. And so accepting people with disabilities is some way of accepting one's own death."

I suddenly found myself telling Vanier the story of Walker's bath—how when I felt out of sorts, when nothing helped, I could feel better if I gave Walker a bath, because it made him feel better too.

"You see?" Vanier said. "You are bathing your own handicap."

It was a point of view I'd never encountered before, I can say that for it.

"What is it that makes you open your heart to someone else?" Vanier asked.

I stared at him. I had no answer.

"A weak person," Vanier said. "Someone who is saying, 'I need you.'" If the need of the person is too great to be satisfied, as is often the case with parents looking after a severely disabled child on their own, the result is guilt and disaster. "But parents in a village where there are young people who are going to come and sit by Walker and take him for a walk, and all that sort of thing, then life changes. But alone, it's death.

"I mean, it's crazy. We all know we're going to die. Some of us will die at the age of ten. Some of us will die at eighty-five. We begin in fragility, we grow up, we are fragile and strong at the same time, and then we go into the process of weakening. So the whole question of the human process is how to integrate strength and weakness. You talk about your vulnerability with Walker. Something happened to you, which people who haven't lived what you've lived will never be able fully to understand—you have been able to become human by accepting your own vulnerability. Because you were able to say, I didn't know what to do.

"We're in a society where we have to know what to do all the time. But if we move instead from the place of our weakness, what happens? We say to people, I need your help. And then you create community. And that's what happened here."

We talked on for an hour and a half. By mid-afternoon the light outside was a burnished yellow. "Unless we move from a society based on competition to a society based on welcoming people back to the village," Vanier said, "we will never get away from our obsession with strength. In a way, that's all that L'Arche is: It's a village where we meet each other. We celebrate life. And that's what these people do. They celebrate around the weak. When you're strong, the way you celebrate is with whisky."

Vanier paused, and laced his hands behind his head. "In 1960, the big question in France was, what sort of a society do we want? Was it the society of Mao Zedong? Was it the society of Russia? Was it a slightly different form of communism? Nowadays, nobody's asking what sort of society we want. They're just asking the question: How can I be a success in this society? Everyone, they're on their own. Do the best you can, make the most money you can. So what sort of vision have we? Somewhere in L'Arche, there is a desire to be a symbol—a symbol that another vision is possible. We're not the only ones who are doing this sort of thing, of course. There are lots of little communities."

A community of the disabled as a model of how the world might co-exist more effectively: I have to say, that struck me as a radical idea, even a gorgeous one. It also struck me as hopelessly unrealistic—the sort of idea that is beautiful in repose, that an idealist would love, Vanier included.

So I said, “I think that’s a beautiful idea, but the world doesn’t work that way. People don’t work that way. It takes a massacre of eight hundred thousand people in Rwanda before we try to stop it. We can’t seem to act to prevent the most obvious tragedies—never mind the small, individual ones. So how can I hope to convince the world that Walker ought to be seen as a human being—not just as a disabled human being, because he is that, but also as a human being, who may have talents—just not the talents we expect to find?” What I meant was that I wished the world might see Walker not just as a boy without many common qualities, but as a boy with uncommon qualities as well. But it was too much to think that might be possible. “The truth is,” I said, “the world isn’t that kind of place.”

“There’s a beautiful text of Martin Luther King’s,” Vanier said, without hesitation. “Someone said to him, will it always be like this—that someone will always despise people and want to get rid of others? And he said yes, until we have all learned to recognize, accept, and love what is despicable in all of us. And what is that despicability? That we are born to die. That we have not full control of our lives. And that’s part of our makeup. But we need to discover that we are built for something else, too, which is togetherness, and that we have to try and stop this need to be the best. Only then can we build something where there are fewer of these things that are going on in Rwanda and elsewhere.”

I left Vanier soon after that. We were done for the day, and he was preparing to depart for Kenya soon. I ducked out of the cramped stone house in Trosly, walked down the street and up a lane and across a field. I couldn’t decide if I was defeated or enthralled. Vanier’s ideas appealed to people: Two of his books had been best-sellers, and several had been translated into nearly thirty languages. He had been awarded the Légion d’Honneur in France and had been made a Companion of the Order of Canada. He had radical ideas: frailty was strength, peace no longer lay in the tolerance of difference, but in the bridging of it through a mutual concession of weakness. I wondered how that would go over in the Middle East—if Israel, say, confessed its fears and weaknesses to Hezbollah, and asked for the Palestinians’ help, instead of vowing to annihilate the source of any threat to Israel’s security. In Vanier’s world, Walker was not a weak link, but an extra-strong one.

Look: I wanted to believe it. Every ounce of me knows my odd little boy can teach everyone something about themselves. Whether that will ever happen is another story.

(From Chapter Fourteen)

Every time we meet someone who is severely handicapped, Jean Vanier believes, they ask two questions: Do you consider me human? Do you love me? The more we meet the handicapped on their own ground, Vanier believes, the more our answers evolve. We begin in fear of their appearance and behaviour; move on through pity; pass through the stage where we help them and respect them, but still see them as lesser beings; until finally we experience “wonderment and thanksgiving,” and “discover that, by becoming close to disabled people and entering an authentic relationship with them, they transform us.”

In Vanier’s last and highest stage of consciousness, “we see the face of God within the disabled. Their presence is a sign of God, who has chosen ‘the foolish in order to confound the strong, the proud and the so-called wise of our world.’ And so those we see as weak or marginalized are, in fact, the most worthy and powerful among us: they bring us closer to God.”

I wish I could believe in Vanier’s God. But the truth is, I do not see the face of the Almighty in Walker. Instead, I see the face of my boy; I see what is human, and lovely and flawed at once.

Walker is no saint and neither am I. I can't bear to watch him bash himself every day, but I can try to understand why he does it. The more I struggle to face my limitations as a father, the less I want to trade him. Not just because we have a physical bond, a big simple thing; not just because he's taught me the difference between a real problem and a mere complaint; not just because he makes me more serious, makes me appreciate time and my daughter and my wife and friends, and all the sweetness that one day ebbs away. I have begun simply to love him as he is, because I've discovered I can; because we can be who we are, weary dad and broken boy, without alteration or apology, in the here and now. The relief that comes with such a relationship still surprises me. There is no planning with this boy. I go where he goes. He may be a deleterious effect of evolution as far as a geneticist is concerned, but he has few peers as a route to developing what Darwin himself in *The Descent of Man* called the evolutionary advantages of "the social instincts . . . love, and the distinct emotion of sympathy." Darwin's opponents pointed out that man was weaker than the apes, and so there was no logical way he, man, could be the result of the survival of the fittest. But evolution is smarter than that, Darwin replied. "We should . . . bear in mind that an animal possessing great size, strength, and ferocity, and which, like the gorilla, could defend itself from all enemies, would not perhaps have become social: and this would most effectually have checked the acquirement of the higher mental facilities, such as sympathy and the love of his fellows. Hence it might have been an immense advantage to man to have sprung from some comparatively weak creature."

My own goals are modest: to step from time to time into Walker's world; to come to know a few intellectually disabled people (rather than simply permitting them to live in my milieu); to face my fear of the broken people who are The Other—not to fix them or even save them, but merely to be with them until I stop wanting to run away. At my most optimistic and confident I hope those might qualify as a few steps toward what the evolutionary biologist Julian Huxley imagined when he wrote his famous essay "Evolutionary Ethics" in 1943. A clearer ethical vision as human beings, Huxley writes, will never "prevent us from suffering what we feel as injustice at the hands of the cosmos—congenital deformity, unmerited suffering, physical disaster, the early death of loved ones. Such cosmic injustice represents the persistence of chance and its amorality in human life: we may gradually reduce its amount but we assuredly shall never abolish it. Man is the heir of evolution: but he is also its martyr.

"But man is not only the heir of the past and the victim of the present: he is also the agent through whom evolution may unfold its further possibilities. . . . He can inject his ethics into the heart of evolution."

The face of God? Sorry, no. Walker is more like a mirror, reflecting much back, my choices included. For me—and this is the grandest and yet most consistent way I can think of him, amid all the others, head bonker and beagle and hyperkinetic maniac and gurgling drooler and intermittently curious boy and sad sweet son—Walker is like the vessel Wallace Stevens wrote about:

*I placed a jar in Tennessee,
And round it was, upon a hill.
It made the slovenly wilderness
Surround that hill.
The wilderness rose up to it,
And sprawled around, no longer wild.
The jar was round upon the ground
And tall and of a port in air.*

*It took dominion every where.
The jar was gray and bare.
It did not give of bird or bush,
Like nothing else in Tennessee.*

I realize it's not much to go on, not much of a light to see by. It easily wavers. But it's the best I can do.

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