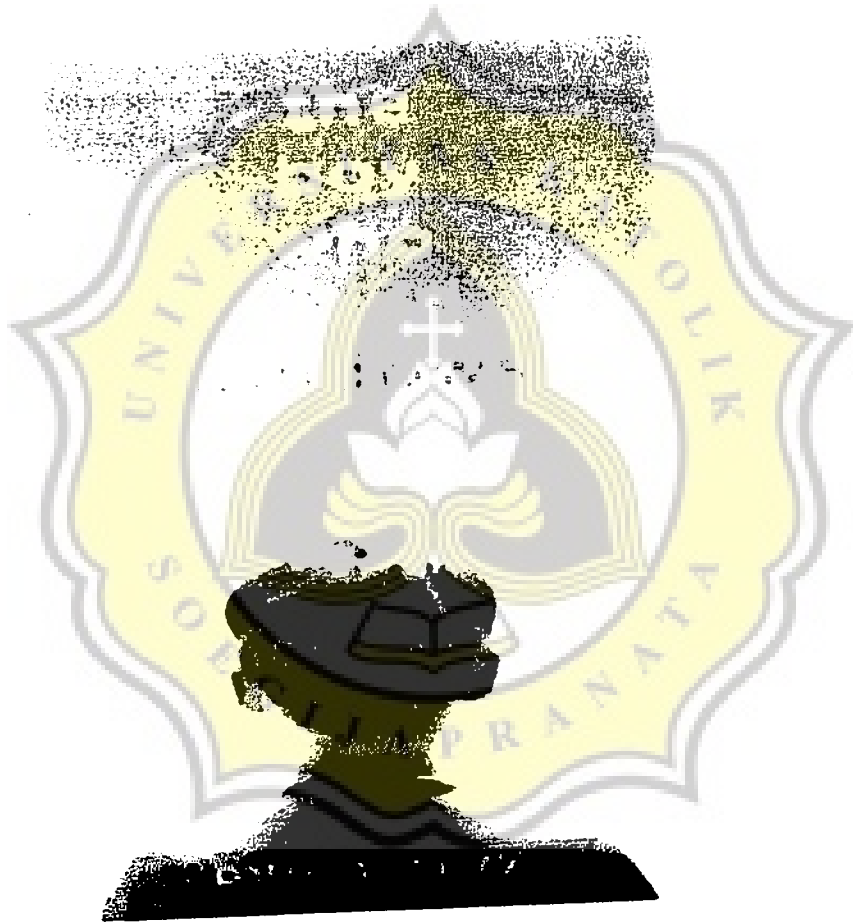


APPENDIX



1 / THE BOY WHO LOVED WINDOWS

would urgently grab me by the arm and insist, "Now listen. Don't move. I've got to do this again. We've only got ten minutes to get that baby out." She wouldn't know that a baby boy, wrapped backward against my spine, would be pulled out and handed to his father who would be standing next to me. How could she ever imagine that when I saw her brother for the first moment, I wouldn't feel what I knew I should?

When does one begin to know a child? It seemed to me we had known Elizabeth from the moment of her emergence. I had been stunned by her gaze the second she came into the world, all head, pupils, awareness—pure consciousness. "The eyes!" "The eyes!" the nurses, doctor, and even a technician had all called out at once. She grabbed my husband's finger and hasn't let go since.

Yet Walker's birth was different somehow. Nothing seemed right. He didn't cry when he was born. The nurses tried to make him but succeeded in producing only a whimper, and then, when they'd handed him to Cliff and he lay in his father's arms, he looked like a small, skinned ferret—bloody, arms awry.

Did other mothers of newborns feel the way I did?

I remembered that my former boss had once said of his daughter: "She looked like hamburger when she was born!" What struck me was the absolute affection, humor, joy with which he delivered the information, as if to say, "My wet little wad of gristle was really a swan."

to the Sirens first shalt thou come, who bewitch all men,
whosoever shall come to them.

THESE

THE DAY BEFORE my son was born, my four-year-old daughter, Elizabeth, and I were sitting in her room looking out at the treetops. That afternoon, mid-October in New England, the leaves seemed almost burning with color—yellow, orange, and purple—and I was trying to explain to her how something, before death, could be so glorious. At that moment I wanted to tell her everything, about the science of trees, about the odd and mysterious cycles that make up this life, the paradoxes. I had the perverse idea that she might want to know that the trees themselves were choking their own leaves of chlorophyll, but Elizabeth exclaimed, "Oh, I just have to be *there*—out there!" She ran down the stairs. I followed slowly, hefting my stomach, breathing like a geriatric. (By then I couldn't even see my feet.) Outside, the wind was up, a hundred leaves seemed to be raining toward us, and she held her hands in the air, the way kids do on rainy days, as if she wanted to catch every living and dying thing in the sky. Afterward, I pushed her on the tree-swing and she jumped high into a pile of leaves, laughing and falling so deeply she almost disappeared.

What she didn't know those moments of that day in 1996, what I couldn't have known either, was that our lives were about to change forever. She didn't know that by six the next morning someone would put a needle into my spine, that I would flinch, that a doctor

sister had any connection at all. Their laughter harmonized, filled those great bathroom acoustics with high-pitched mirth. Elizabeth squeezed and squeezed as Walker laughed and laughed. This was the moment I had been waiting for. We were a family, finally.

One more squeeze. *Squeeeeeek*. And nothing.

Squeek again. But no reaction. The veil had fallen.

For days, perhaps even weeks after that, Walker seemed profoundly sad, disinterested. No matter how we positioned his body, he always, much like a needle on a compass, found his way to the light, staring out the windows, obsessively, incessantly.

Light was his true north. And the rest of us remained somewhere just to the east or west or south of his gaze, never in view.

Yet by the time Walker was five months old, it was clear something was wrong. We knew we were losing him; he was slipping away into the shadows. "Perhaps he's just uncomfortable because of his perpetual cold," suggested our family practitioner casually. Yet by now Walker still couldn't look at me at close range. Worse, he gazed away more often than he looked at us. He seemed more interested in the light that flooded into the house through the slatted blinds than in our daughter or us. He searched the windows, obsessively, compulsively. *What was it about those windows?* They seemed somehow significant to him. When he looked out, which he did now almost constantly, it seemed he wasn't just staring blankly but that he was reading something into the light, or the frame, or the blinds, as if there were an entire scene being played out for him there between the dust motes and the windowpanes.

One night when he was four and a half months old, Walker was in the bathroom with Elizabeth and me. He was lying in his baby basket; she was in the tub.

Elizabeth plunged her hands into bubbles and produced a plastic frog. It squeaked. Walker began laughing—uproariously, hysterically: the first time we had ever heard our baby laugh.

Elizabeth jumped out of the tub and squeezed the frog in his face: *Squeeeeeekkkkk!* We saw a baby we had never seen before—a child of boundless joy and energy, laughing, responding, asking for more with quivering, excited hands. It was one of the first times brother and

You'll Have to Wait

BY THE TIME WALKER was six months old, we had little doubt that he was seriously ill. He was riddled with eczema and continued to struggle to breathe at night. He moved jerkily and could barely grab a toy. More difficult to describe, but just as compelling, was the deepening sense he was suffering some disturbance of the soul—he flailed in space, could still not look at us at close range, and there was the maddening, inexplicable affinity for windows.

Finally Cliff and I managed to talk our way into the office of a senior pediatrician at our HMO in the nearby town of Amherst, Massachusetts.

The doctor came in quickly, with an oversized duffel bag. He wrapped a tape measure around Walker's head and measured him in all the ways it's possible for a doctor to measure a baby: checking his length, his reflexes, his muscle tone. Then he tried to talk to Walker. "Walker," he said firmly.

Walker didn't respond.

The doctor dug into his duffel and pulled out a red, fuzzy ball and began waving it in Walker's face. "*Walker! WALKER!* . . ." he said first firmly, then animatedly, and finally yelling.

Walker lay staring out the window, impassive, ineluctably drawn to the light.

The doctor took a seat, removed his glasses, and began. He explained that we needed to prepare ourselves for the limitations of our son's abilities. He was delayed in all areas of development. He might never walk or talk—and cognitively? The doctor hinted broadly that our son might be mentally retarded, perhaps even

We wanted to know if there was a name for his problem. Wasn't there an X-ray or test to find out what was going on?

"No," he said. "There's not a pediatrician in the country who's going to give you a diagnosis at six months old. You'll have to wait."

I queried him about cerebral palsy.

"Cerebral palsy affects the muscles, but not the intelligence," he said, shaking his head. I knew what he was implying. He was saying we couldn't count ourselves among those lucky to have a child with healthy intelligence.

Walker at that time had a small bump on his forehead. I often wondered if his behavior hadn't in some way been linked to it. Now, sitting in the doctor's office, I found myself hoping, in a rather desperate way, that the protrusion was malignant. (Cancer, the old scourge seemed a welcome comrade, operable, removable, compared to what the doctor was intimating.)

"When was the last time you met a baby with cancer?" the doctor asked dryly.

"But he could imitate our speech when he was three months old," I insisted.

The pediatrician assumed a sympathetic expression and looked at the floor.

This not looking was becoming familiar—our son couldn't do it, and now, neither could his doctors. We left our HMO and spent hours the following weeks in pursuit of a specialist with an explanation, but the doctors could offer none. Instead, they could only recommend

"But a cure?"

"Cure . . . ?" she said, and her voice trailed off. "I don't know. But it may be possible to desensitize someone. We'll talk about that more when I see you."

I couldn't let her hang up. "Please," I said, stalling. "Give me something I can do."

"You can help by not smiling too broadly when you're close, and by playing with him."

"But he doesn't like to play."

"Find the brightest, flashiest toy you can find. Take him by the elbow and bring his hand toward it. If he's not going to come to the world, the world will have to come to him."

The director of REACH, Darleen Corbett, suspected that she knew what was wrong with Walker, before she met him. Yet she was reluctant to tell me over the phone.

"It could be a lot of things. He's only six and a half months old," she said.

I insisted. Finally she was bold enough to reveal her suspicions.

"Your son may have sensory integration disorder," she said. "I can't be sure until I see him, but this certainly sounds like S.I. to me."

"S.I.?"

"An extreme form of sensitivity." She explained that it tended to pervade a variety of systems simultaneously. "A child with S.I. dysfunction is likely to have allergies as well as being sensitive to a variety of stimuli."

"Stimuli?"

"Well, touching. These babies often don't like to be touched. Or to be exposed to light. He may be very sensitive to light."

"I doubt it," I said. "He loves to stare out of windows."

There was a pause.

"Is that what someone does with sensory integration problems?"

"Yes," she said. "Often."

The mystery that was Walker was falling into place—the allergies, the aversion to touching, Windows.

"We'll see you in two weeks, then," she said, bringing the conversation to a close. Still, I couldn't hang up. For the first time in months, someone had answers.

"Please," I insisted. "How serious is this problem? Can you tell me if it's possible to cure it?"

"I'm not saying I know for sure what your son has."

YOU'LL HAVE TO WAIT / 17

One day I went by myself to our Unitarian Society for a Sunday service while Cliff stayed at home with Walker and Elizabeth. I sat in the balcony alone, not listening to the sermon. Instead, I focused obsessively on a baby, about six months old, sitting in her mother's lap in the pews below. The baby was drinking up the world with her eyes, with her fingers, with her tongue. I could see that. She was filling her senses, loading the huge cup of her wanting. She was pushing up from her feet, moving her hands out toward the world, flirting with the woman in the box next to her, grabbing everything around her, as if she hadn't eaten for days and she were all mouth and stomach. She fingered the pews, pulled her mother's hair, played with her collar, grabbed at the hymnal, wantonly touched a stranger's face. The mother looked frustrated; she probably wished she could relax, listen to the sermon like everyone else. *She doesn't realize she has a healthy daughter. A brilliant daughter, I said to myself.*

Nights under the single gray kitchen light Walker, six and a half months old, strapped into his car seat, nowhere near able to sit up. Always looking aside toward the white blinds, even at midnight. The light was brightest off their white surface, or his head was cranked upward facing the bulb on the ceiling.

If light were air, I'd say he was trying to inhale it

But there was a new problem. Shortly before the appointment with the pediatrician who had waved the ball in Walker's face, our family practitioner had called to say Walker had fallen off the charts for weight gain. He had descended below the lowest chartable weight for his age—below the fifth percentile. *So his body was slipping away too now.* The pediatrician gave me a quota of several ounces a day of rice cereal I needed to somehow force into him. He ate, but awkwardly. I often spent forty-five minutes trying to feed him the cereal, but food fell off his lips in clumps like snow slipping off a roof in spring. He seemed uninterested in eating. I sometimes found myself shaking with the effort.

For two weeks, before the director arrived from REACH, I worked with Walker every chance I had. I laid him on the bed or the floor, but usually in a baby seat, so he could face me, though he didn't seem to want to look. Over and over I held his elbow, bringing it forward, wrapping his tiny, desireless fingers around various objects.

knew then that he had been shocked by the abrupt assault of the bag, yet I couldn't help somehow taking his retreat personally. *It is as though he can't get far enough away from me*, I thought.

I tried to move into his line of vision, smiled and cooed. Darleen had told me not to smile too broadly around Walker. He needed a calm, even face. Now, I barely lifted the corners of my lips, trying to win his gaze. He turned harder to the left.

Perhaps I could interest him in something else. I nudged the toy against the back of his limp hand. Nothing. I placed the solar system into his palm.

He didn't respond.

I took his arm by the elbow and moved it forward, the way Darleen had described. Over and over I held his elbow, bringing it forward, wrapping his lifeless fingers around the thin plastic tubes.

"Look!" I said, waving the bright object in his face. I put it in Walker's lap. His fingers twitched a little, though the movement might not have meant anything.

His fingers moved again.

I brought the toy closer, wrapped his fingers myself around one of its blue tubes. He clung to it for a moment. *Has he trying to hold on?*

I pulled the toy into the air. His hand stayed grasping for a moment, as if it had been glued to the blue tube, stuck there. Still he wouldn't look my way or at the toy.

My head fell into his lap. I was exhausted—and fought my emotion. And then we went to bed.

That night, after Walker had eaten what he could, I put him up on the table in his car seat as usual. Cliff was upstairs, already asleep. So was Elizabeth.

"I have a present for you," I said softly. "I bought it today when I was out. Back in a second."

I returned to the kitchen and stood in front of Walker with a bag from the toy store. I began to tell him I bought just what Darleen Corbett at REACH told me to buy and was in the midst of pulling at the bag when, in the moment, Walker's hands flew up, shook wildly, and fell. The bag had made a loud popping noise as I'd opened it.

"Did I scare you?" I whispered. "I didn't mean to."

Ugh! I thought to myself. *Is this what Darleen Corbett meant by sensitivity? The mere sound of a bag opening tears through my sons' nerves?*

I took the bag into the bathroom, opened it slowly so Walker would not hear the crackling, which suddenly struck me as very loud, and brought out my secret weapon. I produced a brightly colored object that looked like a little solar system, slightly larger than two hands clasped. The toy was a sphere, composed of heavy wires covered in bright, soft plastic—yellow, blue, red—perfect for grabbing and chewing and sucking, all those activities that other six-month-olds delight in.

When I came close, Walker's face was turned hard to the left, his head seemed to meld with the car seat, his back arched forward. I

name. We had a goal. We had a problem that might even be less threatening than cancer.

I was feeling extremely positive about the progress we had made, was nearly buoyant the afternoon after I thought I saw some improvement. Soon after, Cliff and Elizabeth and Walker and I visited Cliff's parents. I sat happily in the family room explaining that Walker was just extremely sensitive. I tried to explain the progress we had made—that we had moved his elbow, winning in the effort his interest in toys. They frowned, looked away, said "Humm," skeptically. Cliff wouldn't come to my defense.

"What's wrong?" I asked in the car on the way home. "Why didn't you help me explain to them Walker's difficulties are not necessarily that bad?"

"I'm not sure I believe it," he said.

"What do you mean? The director of REACH did say it was possible to desensitize someone."

"I don't think we're out of the woods yet, Pat."

"What do you mean?"

"I looked up sensory integration on the Internet. Thousands of cross-references. Most of them to autism."

The light changed and the car made a hard left, a ninety-degree turn.

One day I took Walker in his stroller and walked into town with my friend Julie, she with her child and I with mine, strollers moving in tandem down the street. On the way home, Julie's baby, Kezia, played with a small pig on wheels and looked up at Julie from time to time. Walker kept his face at an angle, forced away from me. The motion seemed to deepen his concentration, his obsession with the peripheral. He was cranking his back around, uncomfortable. It had been wrong of me to take the walk. I felt sure that as we did Walker was evaporating, casting off more ounces. Julie began talking about a problem, the kind of conflicts that women often share; she had a friend whom she didn't feel close to any more. What should she do?

Friends? Closeness? Didn't Julie know that I was wading through chest-high water? I'm not even sure I was able to answer her. But what I knew was that everything was changing, the sky was chang-

Grasping

IT WAS HIGH NOON; the sun was forcing through the window. Walker still obsessed with the light. What was this tendency to move toward the sun—was it like a plant's tropism, or was he attracted to something else, patterns? The blinds with their horizontal slats, dark, light, dark, light. Whatever it was, it was hypnotizing, charming his nascent mind. I tried to attract his attention, but my smile, as muted as I could make it, was no match for the sun.

My next opportunity was at lunch. This time, some improvement. I noticed that his grasp on the wires was firmer.

Yet was he holding harder on purpose?

I pulled his fingers away and put the toy just beyond his reach. He twitched, his hands flailed around, his knuckles knocked against the toy. My hand was shaking now too—that had to have been desire. I felt sure of it—at least I thought I felt sure. I held the toy up higher. The hand flew to it and grasped. *Damn*, I thought, it *was* desire.

Within two weeks Walker was grabbing the toy every chance he had, lifting it to his mouth, sucking it. Doing what babies do.

Nuances are difficult to record. Some of our happiest times can contain dissatisfactions, moments of worry, distress, boredom. Some of the most dismal and distressing moments can contain some element of whimsy, lightness, salvation. Philosophers from several traditions know about this. They refer to the double-edged sword of experience—that we are always carrying heaven and hell with us in each moment. And then there's the way that moments have of coloring and informing each other, as we compare one to the next, we adjust our expectations

Later, during our interview, Darleen said evidence was growing that Walker indeed was suffering from S.I. disorder. "How can you tell?" I said. "He's been sleeping the whole time you've been here."

She held up the apple. "Who else but a hypersensitive baby would sleep the minute you showed him this? Babies sleep to protect themselves. This toy is remarkably stimulating—the color, the bright face, the chime."

"You mean even that child's toy was too much for him?"

She nodded yes.

Walker slept for nearly an hour as we discussed his and my medical history and alternative therapies. When he finally stirred, Darleen brought Walker to a blanket and produced another toy, red with concentric circles. She held it in front of him, as if she were doing a snake charmer's dance. A stunning woman with blond hair and full lips, she seemed to be luring Walker into her field of attention. He followed the toy with his eyes—something I had never seen him do before. It was as if you could change a person just by acting a certain way. How could this woman who had never met our son lure him, entice him, draw him into her spell? And why was this toy attracting Walker when the apple made him fall asleep? What was she doing differently? It seemed that I had spent hours playing gently with Walker and had rarely if ever seen such high levels of attention.

For a week I was happy, explaining to my friends that Walker was capable of more than we realized.

Yet within days, the wheel was turning again.

Within a week, Darleen brought Arlene onto Walker's case. Arlene was a physical therapist with training in motor (movement) problems and sensory integration, and she came to give Walker a full evaluation.

Oddly, when Arlene met Walker, he wasn't at all the baby he had been in the specialist's office, or for her director. In fact, he seemed to have swung dramatically in the opposite direction. No longer dumb struck, he seemed electric, a caricature of excitement. Walker's head swung from side to side, he was laughing, almost maniacally, and his

ached.

I hadn't seen Julie for three weeks when I was able to get away to see her at a local restaurant called Paul and Elizabeth's for dinner. We ordered our usual vegetable fried rice with tofu and a large roll to share. Julie was grappling with the question of having another baby. An acupuncturist had advised against it, since Julie's immune system had been compromised since her pregnancy. Still, she was wondering what to do with her life. She wanted to have a child, but she also wanted to study something called the Alexander technique (a method for improving coordination).

"I'd like to study the Alexander method in the fall, but if I do, I won't be able to have a baby until the summer," she began, pondering. "If I have the baby right away, I won't be able to begin studying until two years from now. I guess I could try to get pregnant in the winter. . . ." Her thinking went on like this. Julie was doing what we all do, trying to plan a life inevitably complicated, hoping to rein in what is wild and unmanageable about life with a child when you're a woman who hopes for more than just children. Yet all the while, as she was talking, my back was getting hot. I felt myself leaving my body, somehow floating over the tinkling glasses and the sparkling tables, the ferns. "Damn, Julie," I suddenly blurted out. "Don't you get it? Nature resists planning. Nature *resents* planning. You may never have a child! Your child may have Down syndrome and you won't work for years."

Julie looked down at her lap. Her hands began shaking, her chin.

Tears fell.

I tried to explain myself, tried to back out.

Friendship was changing.

The director of REACH, Darleen Corbett, came for her assessment. Walker lay across one of Cliff's arms. She opened a large canvas bag and pulled out a red plastic apple with a bright painted-on face. Walker looked at it. He seemed interested. She tipped it to the side.

They're giving you something to do at last I wrapped my fingers around the arms and pushed.

On her first official therapeutic visit a few days later Arlene and I talked, and we watched Walker. I noticed that he changed dramatically the minute she entered the room. His body began moving more and more, his hands swinging. Now he was making that odd sprinting motion through the air, something he had rarely done when he was alone with the family. Yet he wasn't oriented to Arlene or relating to her. It was almost as if he was too excited to even look at her.

I asked her about autism, but on this first visit she could only repeat: "You have a very sensitive son."
"I do you think he has autism?" I repeated.
She shook her head. No one could know.

repetitively—as if he were sprinting through the air again.

Folding her long athletic legs under her, Arlene positioned herself gingerly in front of Walker and studied him in obvious alarm. We pressed her for an explanation but she chose her words carefully. While she spoke her gentle words, I translated them into my own. She didn't want to damn Walker before she gave him a chance.

She said that he had severe low upper-body tone. She stressed the word "severe" as she watched him lying on the floor. His thin arms seemed sunken toward the ground as if he were supporting something heavy.

"Is that something we can change?" Cliff asked. "Can't he exercise, build up some muscle?"

"This kind of weakness comes from the brain," she explained.
"You mean muscles have something to do with the brain?" I said, perplexed.

"Yes," she said.
"But what could be wrong with it?"

Both Arlene and her supervisor shrugged.
I wanted to know if we could give him some tests, but to my astonishment, Darleen Corbett said, "You can give him an MRI, but I don't recommend it."

"But why?"
"I think it will just confuse you—give you an idea about your son before you know who he is."

"An MRI?"
"I've seen kids with brains that looked shot full of holes like the surface of the moon who were fine—other kids with perfect MRIs who were very ill. You don't want to be thinking of your son that way, as damaged or full of holes while you're playing with him."
"So what can we do to help him?" Cliff asked.

She put her hands around Walker's thin arms, one around the upper, one around the lower, and pushed his forearm toward his elbow as if she were trying to snap it in place. "You can do this."

Great, I thought. They're telling me my son might not walk or talk, is weak in the upper body, and we will start by pushing on his arms. How can any of what you're doing amount to anything? Yet another voice said,