


DONNA THOMSON

FOREWORD BY JOHN RALSTON SAUL

THE
FOUR
WALLS
OF MY
FREEDOM



"A clear-eyed look at
the value of a life."

Globe and Mail

LESSONS I'VE LEARNED

from a LIFE *of* CAREGIVING

The
Four Walls
of My Freedom

Donna Thomson



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To my family

FOREWORD

This is a book that had to be written. It had to be written for two reasons. The first is to explain the world of people with disabilities. They have rights and needs that must be looked at by all of us from a philosophical view and a policy point of view. Secondly, this book had to be written because it tells the story of Nicholas and his family, Donna, Jim, and Natalie. This story needed to be told for Nicholas' sake. He has something to say to us, as does his family.

It is essential to put these two things together — the ideas surrounding the world of disabilities and the reality lived by those with disabilities and their families. It all makes sense if these two elements are put together. It makes sense because it forces us to realize that Nicholas is a citizen with citizen's rights, and none of the services he receives are the result of the kindness of the rest of us. The services he should and must receive have nothing to do with charity. They should come to him as any service comes to a citizen. And that is as it should be in a fully functioning civilization where we make the effort to imagine the Other. Donna Thomson has done a wonderful job at blending these two themes together. And so *The Four Walls of My Freedom* is an eloquent expression of both personal lives and public philosophy.

I first met Donna at Government House in Ottawa a decade ago. We talked about her involvement with PLAN, a wonderful organization that has developed whole new approaches towards the linking of citizenship and people with disabilities. She asked me if I would become the Patron of PLAN and I immediately agreed. The simplest explanation for my enthusiasm is that my brother Anthony had disabilities. And he had them at a time when Canada had virtually no decent public services for him. Canada treated the whole question of disabilities as one of charity. He was a wonderful brother. And my mother, like mothers almost everywhere, had to fight the system to ensure that he was treated properly — as a citizen. We have come a long way in Canada and in other democracies when it comes to disabilities. Our civilization has evolved in the right direction. But Donna's story is a reminder that we have not gone far enough and we certainly haven't gone fast enough.

I think what she brings to the table is a very clear evocation of the contributions that people with disabilities make to our society. They want to make every contribution they can. And they have to make a greater effort than most people in order to carry out those contributions. That energy and courage and consciousness of people with disabilities carries a strong lesson for their fellow citizens who, quite frankly, have an easy time of it in comparison.

One of the themes that keeps coming through in Donna's writing is that every time a circle is created to ensure that there are contacts and friendship around a person with disabilities, the people who join the circle quickly realize that they are the primary beneficiaries.

This is a moving book, in part because it is about Nicholas, but also because it is about all of us and our capacity to live together. If we can embrace the citizenship of people with disabilities, then we will all learn how to live together.

John Ralston Saul

The Beginning

The baby book said to rock a crying infant at the same rate as a mother's heart rate. Anywhere between 60 and 100 beats per minute it said. I split the difference and tried 80 beats per minute which is VERY fast, if you have never tried it. Not rocking really, just an oscillating pressure on the ball of one foot if one's legs are crossed.

But my baby son kept crying and crying, once for thirty-seven hours in a row. His back arched, his high-pitched catlike screams would pierce the night. I rocked and sang Christmas carols to the time of 80 beats per minute. Keeping my arms relaxed was tricky. I thought if I could just relax the arms that held him, my baby would sink limply and quietly into sleep.

"Who knows what makes the little turkeys cry?" mused the doctor a little too quickly when I reported that perhaps my baby was crying much more than he should. "Change the formula." At a new mother's group, I noticed that other babies weren't screaming. There was coffee on offer and I took a muffin as well. Nick screeched, arched his back and the coffee spilt, the muffin broke on the floor. The group leader stared in horror and all the mothers and babies blinked in alarm. "We don't belong here," I thought, and ran out, leaving the mess on the floor. After that, I kept indoors. The blinds were closed because light seemed to infuriate Nicholas. We kept our voices to whispers because an exclamation or laugh caused his arms and legs to flail outwards suddenly, setting off some horror on which he knew. I kept him swaddled so he wouldn't feel like his legs and arms would fly off his body in these moments of panic.

I couldn't persuade Nicholas' mouth into an effective suck. Why couldn't he swallow without choking? His nappy remained dry for a day and the baby book said "take him to the hospital." The check-in clerk in Emergency at the Ottawa Children's Hospital asked Nick's age. "One month," I replied. My turn to choke.

The white-haired doctor stooped to look closely at Nicholas and asked, "Has anyone spoken to you about your son's development?"

"No," I answered, "he is small because he was a bit premature at thirty-three weeks. Someone crashed into the back of my car at twenty-six weeks and they think that's why he was born early." Only later I learned that "development" meant cerebral palsy or mental retardation.

Three months later, Nicholas was admitted to hospital so that tests could be performed. The doctor asked me if I would like to hear the results. I nodded. She closed the ward playroom door for privacy. We were alone. She, in her lab coat, was sitting in a sturdy mother's wooden rocker. I was squeezed

into a plastic child's chair. Around us lay discarded toys and empty chunky bright tables and chairs, all toddler-sized. Tears glistened on the doctor's cheeks as she told me my baby was severely disabled. "Never be normal" are the words I remember. I also remember "generalized cerebral atrophy." Pea brain, I wondered?

"Esophageal reflux," she said. "Nothing to keep food down where it belongs. Common in cerebral palsy. Pain similar to heart attack." There were blue stripes on her blouse. I looked down and something red caught my eye. Blood was oozing from the edge of my thumbnail where I had bitten it. "Well, I'm in the right place," I thought.

I stood up and felt a lightness, a sense of relief and purpose. "Now I will be able to feed my child," I thought. "I will become an expert. I will apply myself to becoming a great mother, and my baby will grow into someone perfectly perfect." Passing the desk, I noticed the nurses half turned, whispering, their pitying eyes fixed on us. I scooped up Nicholas, deposited him into a pram and paraded up and down the hospital halls, back straight, eyes fixed directly ahead. But I was not all right. I wrote in our baby book: "February 22–25, 1989: Nick admitted to hospital. Cat scan, PH probe and digestive barium x-rays all abnormal — we trying [sic] to absorb this terrible news."

I remember hearing a radio news report a long time ago about a terrible road accident in rural England. A young family — parents and three children — had all perished. The grandfather's public response was, "I don't understand — we brought them up so carefully so nothing like this would ever happen." I felt like this grandfather — the experience of falling victim to random tragedy and a serious derailment of one's life plans caused such profound shock and questioning of all I believed was solid and true.

At that time, my husband, Jim, was on loan from Foreign Affairs to the Prime Minister's Office and would come home near bedtime, still suited, to feed Nicholas while watching the news. Word spread in our family about the "condition." A cousin came over with a friend to give advice. The friend's business card read "Volunteer Consultant to Families with a Child with a Disability." Her name was Kathleen Jordan and she had a son of sixteen with incomprehensible difficulties. He was blind, had cerebral palsy, Tourette syndrome and epilepsy. I started to examine this blonde woman in my living room. Her nails were beautiful, glossy red and perfectly rounded. I asked, "How is it you have time to do your nails?" I really wanted to know.

Kathleen had a huge pile of papers with her. She patted me and said, "I have some information here but I completely understand if you want to look at it some other time." "No!" I cried, "Give them to me now! All of it." Years later, I heard the expression "cognitive lifeboat." In that moment, I found mine, and, gasping, climbed aboard.

Sometimes, words on a page leap out and punch you in the face. Wake up! This is what you need to know! In that pile of paper was a story about something called "Conductive Education." First of all, I like the word education. It suggests a capacity for learning. It suggests power and control through knowledge.

Andras Peto was a Hungarian and a practical innovator. He looked at the state education system of his country, saw that walking was a prerequisite of accessing the national curriculum, looked at the thousands of bright children who did not walk because of disability and decided to think of a way around the problem. Peto devised a system of teaching children with cerebral palsy and adults who

had had a stroke how to control their own bodies. He believed that each functional, bodily movement could be broken down into smaller movements that could be taught and practised, using rhythm as the primary teaching tool. People with no functional movement could be taught to brush their own teeth, sit independently, and even walk through the school doors. This was an approach that required hope and determination. “Right,” I thought, “this is for us.”

A speech therapist advised that Nicholas could suck and swallow if he was fed sitting upright. I had discovered Conductive Education. Nicholas smiled. The screaming continued, but in between, oh the power of those smiles! I nicknamed him “Bunnybear” as a nod to his Jekyll and Hyde personality. For his first birthday, I made two cakes: one a bunny, the other a bear. Jim and I drank champagne and congratulated ourselves on surviving.

The local treatment centre for children with disabilities made us sign a paper promising not to pursue alternative therapies. I signed. Then I hired a private Conductive Education specialist, Rosalind, who had trained in England, and came for our first home appointment. “Look at the window look at the door. Look at the ceiling, look at the floor,” she sang as she held Nicholas on her knee. My mother was visiting. As Rosalind sang, Nicholas looked around, up and down. My mother clapped her hands. Nicholas startled, screamed, and I hugged Rosalind.

Another woman called Barbara came to our house once a week to help me teach Nicholas something called infant stimulation. She suggested that I use a photo album with large magazine pictures or photographs of things he knew something about — things like “Mum,” “dog,” “flower.” Barbara walked with me to the park down the street on a sunny, warm day. She instructed me to let Nicholas lie in the grass on his back and then gently turn him on his side. His mouth opened and he began to chew on several blades of grass. “Terrific!” Barbara proclaimed. “Now let’s do some tree bark.” She reassured me that none of these natural items could kill Nick and encouraged me to make the most of our dog Amanda in the stimulation regime. Amanda was a golden retriever with a strong mothering instinct — sometimes, I thought, stronger than mine. Nicholas would lie on a blanket on the floor with Amanda lying alongside, her head resting on his belly. Nicholas would open and close his tiny fists in her fur and suddenly, fist clenched, he would pull hard, unable to let go. Amanda would simply turn to look at this spot on her back where a clump of fur was being yanked with appalling strength. Then her mouth would reach his fist. She licked his fist until it relaxed and opened. She would jump up and run to me, tail wagging, eyes watery. She would bury her head between my legs and I’d say, “I’m sorry, darling. But you are such a good mum to Nick, so gentle. Good girl.”

“You should write a book,” people said. No, I thought, why should anyone care about a family such as ours? We are so different, such an aberration. Like anyone who has tried to protect the integrity of a loved one with a nasty chronic condition, my life with Nicholas has been infused with a desperate love. There have been days with lots of laughter, but there have also been days when Nick was in terrible pain or was unable to eat or drink, his stomach angrily rejecting its role as a digestive organ.

What happened to him? Why is he like that? Did you smoke? Did you drink? How about the hair dye you used? Maybe you were too old to have babies. It must have been something you did. He’s underweight. What are you feeding him? Can’t you feed him more? Can’t you stop him arching backwards like that? Don’t let him roll over in that position. I know that mothers with their first babies can feel incompetent and sometimes depressed. I felt assaulted by fear. I knew for a fact that

every professional was judging me, every relative, every neighbour. Maybe even God was judging me.

When Nicholas was about one year old, I decided to have him baptized. Brought up as a Catholic, had not been to church in years. Jim is an Anglican who spent his Sunday mornings immersed in newspapers, coffee in hand. I have often thought of my Catholic roots as like those of my grey hair. No matter how much dye you apply, those roots keep growing back. I worried about Nicholas dying before being baptized. I had read that the Church had officially discarded Limbo as a concept, but what if they were wrong? I found a nearby Catholic church in the Yellow Pages and made an appointment for a home visit with the priest. I nervously set out the tea with favourite cups belonging to my grandmother. A distinguished, outdoorsy-looking gentleman with a thick shock of steely grey hair and wearing all-weather gear arrived at my door. I ushered Father Laurie in and explained the lapse in my lapsed Catholic status. Feeling childish, guilty and frightened, I asked him if he would baptize Nicholas. He took the porcelain blue and white cup in his large, sunburnt hand and lifted it to take a sip of tea. The saucer, stuck with sugary tea to the cup, suddenly clattered on to the glass tabletop and shattered. Father Laurie swept up the broken pieces with his hands as he promised to christen Nick. I might be condemned, but Nicholas would be redeemed.

On June 11, 1989, Nicholas was baptized. The mass that day had a children's choir marching down the centre aisle singing and waving a banner that read "We all belong."

"Hmmm," I realized, "I love this! They CAN'T kick us out!" I circulated a celebratory photograph to the family showing Nicholas munching on the baptismal order of service. I called it "Nicholas trying to digest organized religion."

By that time, Nick and I were already regulars at the local rehabilitation centre where we attended physio, occupational and speech therapies every week. The speech therapist was a kind, enthusiastic woman from New Jersey. I joked with her that when Nicholas learned to talk, he'd be taken for a Yank. In her small white room, she placed a doll on Nick's wheelchair tray and asked him to choose a piece of clothing for her to wear. Nick stared at the ceiling. She asked me if I was using bubbles with him at home. "Bubbles?" I asked. "Um, no. Sorry."

"Well, you should definitely be using bubbles. Children like Nicholas need practice visually tracking a moving object. And when he reaches to pop bubbles that are in front of his face, he will be reaching toward the midline of his body — something that is naturally very difficult for him to do. You must have noticed that his arms are usually bent by his head and arching backwards." I lowered my eyes and nodded silently.

I drove home, stopping to buy a plastic jar of bubbles with its potent life-changing possibilities. I blew the whole jar at Nick when we got home and we giggled as they popped.

In the mail, I received a letter inviting me and Jim to a meeting of Nick's team at the rehab centre. They would discuss his progress in therapy and announce to us their results of his cognition testing. They would recommend a preschool placement. Nicholas was just over a year old at the time.

I had begun to understand that meetings about Nicholas took place amongst professionals without me or Jim there. Jim and I arrived an hour early for our "team" meeting. I managed to locate our social worker and in urgent whispers pleaded with her to allow us into ALL discussions about Nicholas. I was afraid of them talking and deciding my son's fate without us. I had reason to be afraid.

There was a fish tank in the waiting room and other families waited quietly with us. Some children

were much older and sat in elaborate wheelchairs, heads turned, teeth crooked. I still wasn't quite used to such differences, but I wasn't staring. I felt anxious and breathless in this atmosphere of inertia. I scanned the hallway behind me for activity of familiar faces; I tried to peer into the boardroom window to see if our "team" was meeting without me. Lynn, our social worker, finally swept around the corner and apologized for the delay in proceedings. She ushered Jim and me into the boardroom to greet seven frozen half-smiles. Something felt terribly wrong. Each therapist was asked to review Nick's progress or lack of it and I noticed that Lynn was concentrating on her notes. Everything they said seemed to be truthful enough until: "We find that Nicholas is profoundly delayed. We recommend that he goes to a preschool operated by the Ottawa District Association for the Mentally Retarded."

I looked around the room. There were two doors, one leading back into the waiting room and another leading to a hallway on the opposite side. So they had already conducted Nicholas' case conference without me and Jim. At the end of their private meeting, Lynn had walked out the back door of the boardroom, around the corner to the waiting room and now she wasn't looking me. I felt my face hot, it was hard to swallow. "I am one of you!" I shouted silently. "I am on this team!" I shook some nonexistent stray lock of hair off my forehead, breathed deeply into my nostrils and began. "Nicholas is a very bright boy, exceptionally bright, in fact." The occupational therapist, head tilted and looking miserable and desperately sad, whispered, "Is there an example of that you can tell us about?" I was beaten, cheated and I knew it.

We went to have a look at the brand-new Cumberland Hub Preschool about half an hour outside Ottawa. Moira was the petite, gentle, redheaded director who greeted us. Nick's classmates would be other children with severe physical and mental disabilities. There was a boisterous gang of children with Down syndrome, but they were kept separate from our little group. Nick's classroom was sunny warm and quiet, except for some soft classical music playing in the background. Moira exuded reassurance, competence and kindness. I knew that destiny had nudged me through these doors and I knew it was the best place for my baby son who still couldn't manage any kind of sudden noise. Still, I knew he wasn't mentally challenged and I resolved to defend his intellect at all costs.

In times of trouble, my principal survival tool is my telephone. Around the time of Nicholas' diagnosis, I rifled through the Yellow Pages searching for information and assistance for our family. I had telephoned every listing under Associations, Societies, Institutes and Foundations. I even rang up the Opimian Society and made a note of their number when I was told it was a club for wine lovers. I might need it some day! Who knew what the future held? But when I discovered the Easter Seals Society, I realized that I had struck gold.

They sponsored a Parent Participation group that held regional as well as provincial conferences for families to exchange experiences and information about their children who had physical disabilities. Here, one could advocate for political change. In those days, Easter Seals had money to fly us out of town for the province-wide conferences. I was severely sleep-deprived and emotionally exhausted, but as I chatted with other parents, my hunger for sharing and listening overcame all bodily concerns. I explained to another Ottawa mum how Nicholas screamed during the night.

"My daughter Carey did that until she had a surgery to correct reflux," she said. I was riveted. I knew that Nicholas had this self-same diagnosis of esophageal reflux and that he spat up many times

every day. It never occurred to me, though, that all the sour milk on my shoulders could be the cause of his nighttime distress.

“There’s a young doctor at the hospital who did a study on this new surgery and how it can help our kids. Yes, and when they opened my Carey up, they told me she was full of it, just full of it!” Years later, I wondered what exactly the surgeons had found in Carey’s chest. In that tidal wave of hopefulness, I had forgotten to ask.

The young, bespectacled doctor greeted us earnestly. As he began to explain his understanding of digestive difficulties, he crackled with the enthusiasm of a science fair prizewinner. I told the doctor Nicholas’ story and he inquired about Nick’s spit-up habits. On cue, I felt a familiar warm ooze on my shoulder. “Oh, I think we have a perfect candidate for this procedure right here!” he declared. I remember feeling so optimistic. I remember thinking that modern medicine and the power of love could “beat” the effects of cerebral palsy. How wrong I was.

While Nicholas was in surgery, Jim and I passed the hours in the surgical waiting room. Time dragged on and, finally, we decided to wait near Nick’s bed on the ward. Another hour passed and I asked the nurse in charge if she could find out when Nicholas would be back with us. It was dusk now and she said that Nicholas was in recovery, but was “breath holding” so they were keeping him a little longer to monitor the situation. Twenty minutes later, a nurse and an orderly appeared down the hall wheeling a cot towards us. Inside was Nick, his mouth open and rigid, eyes wide with panic. He gasped, writhing, and exhaled a hoarse cry. He was in the room now, and we hovered like birds, flapping uselessly.

That night was the first, but not the last, time that I saw in my son’s eyes a terrible pleading. I turned away and put my hand down on the corner chair to support myself from falling. Jim warned, “Donna, you can’t do this. Come here!” I came back to Nicholas, murmuring apologies through tears. A nurse showed us how to hold the oxygen mask over Nick’s face and at first he did calm down a little. The surgical resident stopped outside the door to glance at the chart and strode in. He was short with thick, black curly hair and a great deal of self-confidence. He made some inquiries about Nick’s breath holding and left the room. Moments later, an awful spasm gripped Nick and we again struggled to help him breathe and relax his tiny body. His chest was bandaged where they had cut from sternum to navel and then opened his rib cage. They had inserted a feeding tube to the left of the scar that protruded like a rubber asp. It’s a Foley catheter, they explained, the same as ones used for urinary purposes. It seemed huge and was sticky to the touch, an awful pseudoflesh colour. Nicholas was desperate by now, in a cycle of pain and spasm. I shouted for the nurse to help and she confided quietly that in her ten years of nursing, she had never seen a child in so much pain. As she whispered to me, the young doctor who had recommended the surgery walked in, registered the fear in our room and turned on the lights. He examined Nicholas, asked some questions about Nick’s breath holding and told us that he was transferring our boy to intensive care immediately.

As we hurriedly packed up Nick’s things, his babysitter came through the door, smiling and holding the string of a huge happy-faced balloon that trailed behind her. The balloon had accordion legs and paper feet that made it “walk.” With its cartoon grin, it seemed mocking and ridiculous. Lise tried to smile and chat cheerfully. It was as if she had rehearsed this scenario and had no idea how to veer away from her carefully prepared script. Later, I found out that she had been quite traumatized, never

having witnessed such horror before in her young life.

In intensive care, Nicholas continued to suffer spasm and difficulty breathing, but it was not quite so bad with the stronger drugs on offer there. A little parent room down the hall was meant for use by neonatal intensive care mums and dads. But luckily, the room was empty and someone had abandoned a crumpled sheet on the sofa. I curled up inside the sheet and dozed off for a couple of hours. I staggered back into the blinding light of the treatment bays and to my baby boy, all wires and quiet beeping. He began to stir and I held his head, trying not to touch his swaddling bandages, by now with patches of brownish blood showing through. I sang “You are my sunshine, my only sunshine; you make me happy when skies are grey...” Suddenly a loud voice interrupted my intimate reverie with Nicholas. It was the curly-haired surgical resident. He moved towards us and barked, “What are you doing here!”

“I beg your pardon?” I asked dumbly.

“Who told you to leave the ward and come to ICU?”

I stared, fascinated, at a vein in his neck that was throbbing.

“The recommending consultant told us to come here. He arranged it.”

“That doctor is NOT your doctor, I am! Your son is on the surgical team and I AM the surgeon in charge!” I might have laughed at this young underling’s puffed-up ego, but instead I turned back to Nick and ignored him. The doctor swept out of the room in a swirl of indignation. I felt oddly disembodied and slightly amazed at this man’s poor manners. I resumed my song, “You’ll never know dear how much I love you, please don’t take my sunshine away.”

Official reports reflect so little of human drama. Here is what was written on Nicholas’ discharge summary: “The patient was admitted to the hospital and the next day was taken for operation Nissen fundoplication and Stamm gastrostomy. He tolerated the procedure without complication. He was admitted to Pediatrics again and patient was having spasmodic attacks. The parents were very worried so he was brought down to ICU for further management for his pain. A consultation with the gastroenterology physician regarding the problem was done and he suggested to continue the patient on Lorazepam and Demerol.”

Days later, a specialist feeding nurse took me aside to show me how to use the feeding tube. There was a plastic bag with a length of tubing protruding from one end, plastic syringes and a radio-sized electric feeding pump. The nurse explained that I must wash my hands with Zest soap before beginning the preparation. She showed me how to prime the length of tubing without flooding the drip chamber. Next came the demonstration of how to fit the chamber into a slot in the pump, lock it in place, and then program the pump with the desired drip speed, total dose and total volume. Finally she showed me what to do if Nicholas felt sick. “He will retch, but won’t be able to vomit except out of his tube. You can just let his stomach contents drain into a kitchen cup if he feels unwell,” she said breezily. I was still wondering about the Zest soap, but I must have nodded my head to register an acceptable level of comprehension because after teaching me how to clean the tubing with dish soap, clear water and finally white vinegar, she exited the room, leaving me to pack up all the mysterious equipment. Just before leaving for home, a patient copy of the discharge note was thrust into my hand. The contact details for the nutrition specialist were pointed out to me in case of emergency. It was a number that I would come to know better than any other.

None of us knew then that when reflux is caused by intestinal incoordination below the stomach, preventing reflux by capping off the esophagus is like capping an active volcano. Nicholas began to retch as we turned into our driveway. Nick's feeding tube was inserted into his abdomen through a piercing in his tummy. A small, water-filled balloon that lodged against the lining of his stomach prevented the tube from popping out, much like the back of an earring stud. I would mix powdered formula with water, then decant it into a plastic bag attached to a long tube. I primed the tubing as I was instructed. The pump was similar to an IV pump and could be programmed to dispense the correct amount of feed over a period of hours by dripping slowly through a chamber in the mechanism. Nicholas continued to scream often throughout the night and one night, about eleven o'clock, I heard quiet but unnatural coughing and choking sound from his room. I ran into Nicholas' bedroom and turned on the light. Nick was retching violently and struggling to breathe. Instinctively, I went to turn off the pump, but the feed bag was empty. Almost a litre of formula had disappeared. I struggled to comprehend how a feed meant to drip slowly over eight hours could be gone in under half an hour — had only started the pump minutes before. As my eyes scanned the length of tubing, a terrible realization dawned on me. I had connected the feed, but forgotten to wind the tubing around the pump mechanism, so all the formula had raced through the tubing, unimpeded, by gravity. I pulled apart the coupling and the pressure in Nicholas' stomach caused his Foley catheter to snake wildly, spraying the ceiling with formula. "I'm sorry, Nicholas, I'm so sorry," I sobbed. I held him, rocking, as we both wept.

Aside from the effects of my exhaustion, Nicholas was suffering from a strange set of recurring symptoms, known to me, but inexplicable by all the science at our disposal. After a change of his Foley catheter, he would be all right for a couple of weeks. One day, he would retch maybe a couple of times and this behaviour signalled the start of a total intolerance of anything in his stomach, including water. I began to predict how many days it would be till even a teaspoon of water would cause bilious vomiting. In hospital, Nicholas would remain on IV fluids for three or four days, followed by the slow introduction of clear fluids and half-strength formula. Even though there was never anything functionally wrong with the catheter, often a change to a new one would cure his misery. All of these symptoms were a great mystery to me and to Nick's physicians.

Despite numerous hospital stays and a myriad of tests, Nicholas continued to be very ill and unable to digest his formula. In July 1992, his nutritionist wrote: "Nicholas has significant problems with gastrointestinal symptomatology including episodic retching, vomiting, pain and ongoing severe constipation. We have tried various motility medications and antacid medication with only limited success. His gastrostomy [feeding tube] appears to be utilized to provide between 30–50% of calories when he is relatively well and will provide more calories and fluid when he is having difficulty." Most of the time, Nicholas was having "difficulty."

Nicholas turned two years old on August 30, 1990. Four days later, early on September 3, rain pelted down as a yellow schoolbus pulled up in front of our house. I remember one thing: standing in my doorway, waving, looking at his little face through the foggy bus window. His head was tossed back, his mouth open in a scream I couldn't hear. I waved and blew kisses, thinking, "My God, what am I doing letting him go off like this?" And then, "How wonderful to have quiet, coffee, a newspaper!"

At 10 a.m. that same morning, the telephone rang. It was Moira, the school director at Cumberland Hub. “Now I don’t want you to worry, but Nicholas is in an ambulance on his way to Children’s Hospital. We think he has had a seizure. He fell asleep in his wheelchair and we couldn’t wake him up. We called the fire department, you remember it’s just across the street...they couldn’t wake him up either. I told the ambulance driver that you would meet them at Emergency.”

Driving while sobbing isn’t easy, especially on a rainy day. But I managed to arrive at Emergency before Nicholas. I waited, imagining him on a stretcher, eyes rolled back with horribly jerking limbs.

I heard him before I saw him. The ambulance attendant held him out to me, explaining over his wails that he had woken up halfway to the hospital and screamed like a banshee ever since. Oh, here was my boy, he was all right. He was himself. I hadn’t realized how frightened I had been that a seizure, something I knew nothing about, would somehow lobotomize him and render him unrecognizable. I thought that seizures inevitably caused more brain damage. I held him tightly, breathing deeply with relief at his wholeness.

Although the EEG test looked normal, the neurologist said, yes, it was probably a seizure. It might happen again today, in a month or never again. If you insist on medication, she said, it is Phenobarbital, but it slows learning development. I thanked her very much for the information and went home without a prescription. Years went by before I could hear a telephone ring without my heart pounding.

The next day, I brought Nicholas to school myself and stayed with him. My jaw was still set against this school and the diagnosis for Nick’s learning that it represented. But I sat in this sunny, quiet room listening to Beethoven. Only two other children were in class: one in a hammock swinging gently and the other stacking blocks on his wheelchair tray, his teacher whispering encouragement. I had to admit that this was the perfect place for Nicholas to gently begin his schooling. I was determined that a mainstream classroom was his future, but for now, the Cumberland Hub would keep him safe and soothed.

After a year of quiet caring in that sunny, warm room with its woven hammock for gentle “sing and swing” therapy, I began to explore preschool options in my neighbourhood. After the seizure, I had decided the bus was unsafe for Nick, and the Cumberland Hub was more than half an hour from home which meant I was spending two hours a day driving. I was thrilled when Nicholas was accepted as an exceptional student at a local church preschool. But I hadn’t realized that in transferring Nick to his new preschool, he would lose all his therapies. If physio, speech or occupational therapies were going to be part of his weekly routine, I would have to book these appointments at the hospital treatment centre. Mainstream school and therapies didn’t mix, I was told. The trade-off to have Nick in the mainstream translated into a terribly punishing schedule for us both.

Fighting to streamline services at one location was my first political battle and my first victory. Eventually, Nicholas would stay at school after hours two days a week for occupational and physiotherapies. Therapists would train the school staff how to engage Nicholas with his classroom and its contents. They came with ideas and equipment that made it possible for Nick to paint, play with blocks and use the outdoor playground. Nicholas was happiest watching the boisterous activity of his classmates. His report identified a principal strength as “smiles a lot.” I was annoyed at how patronizing this sounded with its inference that passivity and simple-mindedness constituted academic

achievement.

But fatigue and a nagging sensation of mild nausea distracted me from my usual ire. I was pregnant. Jim and I had been trying for another child, and the previous year I had experienced the sadness of a “missed abortion” — our embryo had died in utero. But this baby was meant to be and nine months later, our Natalie was born, a sister for Nicholas. A few moments after her appearance in the operating room, the doctors placed Natalie on the steel table to wash her. Lying on her stomach, she pushed up with her arms, lifting her upper body off the table. Natalie was only a few minutes old and already she could perform a move that Nicholas could only imagine! Mothering a healthy baby was a revelation to me. With each of Natalie’s milestones, the extent of Nicholas’ differences was revealed in harsh light. With her first steps, I cheered and cried tears of amazement and pride mingled with sadness for Nick’s loss.

But babies have a way of seducing those who care for them and Natalie firmly established her personhood almost immediately. I was more nervous than a first-time mother, thinking I was incapable of sensing what a “normal” baby might need or want. Soon I knew her hungry cry from her painful ones. I knew her frustration with confinement — suddenly the world had shifted to make room for another kind of future for our family.

Amartya Sen and the Capability Approach

In many ways, the peripatetic lifestyle of diplomacy has been good for our family. As a young couple, our first posting was to Moscow in 1978. Living with limited freedoms there taught us the value of resilience and creativity when faced with oppression. Later, a second posting in Washington, DC, was memorable for career-building and weekends at the East Coast seaside with friends. But when Nicholas and Natalie arrived in our family, the idea of packing up seemed daunting, yet I was determined to try. London beckoned and four years in England proved to us that not only could we travel, but we could also thrive in a foreign land. We returned to Ottawa and lived quietly for ten years. Then in 2006, Jim told me that the prime minister had asked him to be high commissioner in London, and I was thrilled. I play-acted thinking about the offer, and then shouted “Yes!” as we laughed and hugged each other and the children. On August 27, 2006, we arrived in London and moved in to No. 3 Grosvenor Square, the official residence of the Canadian high commissioner.

Until recently, I had not considered writing a book about our family life with Nicholas. I always believed that Nick’s disability was an accident of nature and had no bearing on society in general. I knew from experience that when I began to talk to most people about my daily life, their eyes would glaze over and they would turn away, muttering excuses. Anyway, the disability community did not need another piece of misery porn or worse still, inspirational lit. But all that changed in 2008 during casual conversation with Dr. Susan Hodgett of Ulster University in Belfast. Susan had nominated my husband, Jim, to receive an honorary doctorate from her university on account of his own and Canada’s role in forging an enduring peace in Northern Ireland (Jim had worked on the peace process during our previous posting to the UK in the 1990s).

As Susan and I stood waiting for Jim to be capped and gowned, we chatted about my interest in learning lessons for disability and nonprofit work from those working in the area of development and extreme poverty. Susan breathed in and said quietly, “You should know about Amartya Sen.” As she began to describe Sen’s ideas, I almost felt the earth shift underfoot. I realized that using Sen’s ideas of human freedom and potential gave Nicholas’ life and my own experience an important ethical connection to the rest of society. If his ideas could be harnessed as a language to speak about having the freedom to live a life of value even for us, then this had to be important to anyone who cared about fairness and justice in society generally. Suddenly, I saw that we were not just the victims of bad luck — rather we had something fundamental in common with the oppressed groups in Sen’s research.

Surely this was something worth exploring and writing about.

Amartya Sen won the Nobel Prize in 1998 for his work in combining the disciplines of economics and philosophy. He advocated dispensing with the usual measures of assessing poverty, such as household income and GDP, believing they offered insufficient insight into the real causes of human misery and injustice. He began to explore poverty through the lens of the choices or freedoms that individuals have within circumstances of deprivation. The key idea of the Capability Approach is that social arrangements should expand people's capabilities, or their freedom to promote whatever activities and lifestyle they value. Sen argues that the central concern of having a decent and valued life worth living is that of freedom. It is not money and it is not "accomplishments." The approach examines the range of possibilities for human flourishing within a given set of circumstances, especially circumstances involving adversity.

An example that Sen often uses to illustrate his Capability Approach is that of two starving people. One is in the last stages of a hunger strike, the other a victim of a prolonged drought. Measured without benefit of Sen's approach, these two individuals appear identical. It is Sen's approach that offers us insight into their very different options or possible choices for action to alleviate their suffering. Sen calls this their "capability space." In his Nobel Prize-winning autobiography, Sen wrote: "The approach explored sees individual advantage not merely as opulence or utility, but primarily in terms of the lives people manage to live and the freedom they have to choose the kind of life they have reason to value. The basic idea here is to pay attention to the actual 'capabilities' that people end up having. These capabilities depend both on our physical and mental characteristics as well as on social opportunities and influences (and can thus serve as the basis not only of assessment of personal advantage, but also of efficiency and equity of social policies)."¹

Significantly, Sen uses the word equity rather than equality — an important distinction for those concerned with disability. The word equality applied to people with handicapping conditions has often led to abandonment, such as the child in a mainstream school with no support services because extra help would be unequal treatment. It seems to me that equity is a much more helpful aspiration — one that encompasses the recognition of capacity and resilience on the part of vulnerable individuals, as well as those who love and support them. This approach shifts attention away from the medical model of disability to a view of personal freedom and the choices that one has, given the effects of impairment on those available choices. Effectively, the disability experience is positioned alongside gender and age as just one aspect of human diversity.

For me, Sen's Capability Approach represents a lens through which I can assess the value of my life, and understand my choices in relation to programs, services and policies that have affected us throughout my son's life. Sen speaks of the "freedom to live the life you value and have reason to value." I had a life mapped out for myself before Nicholas was born, a life that I imagined I valued. The circumstances of our family life with Nicholas forced me to reconsider my values and my reasons for holding those values. In his body of work, Sen is responding to the horror of extreme poverty and famine. I have never been hungry. I live in a beautiful home and in many regards have led a highly privileged adult life. Yet the questions that Sen's Capability Approach poses about human potential and the barriers to achieving it are the cornerstone of understanding the experience of our family. If

Sen's idea of the capability to live a life worth living is dependent on one's physical and mental characteristics as well as one's social opportunities and influences, how could a family like ours possibly survive, much less thrive? My son's physical characteristics cause him to be completely dependent on others.

Although Amartya Sen has focused on issues relating to poverty and justice, he has also spoken about disability. At a World Bank Conference on Disability in 2004, he lamented the failure of theories of justice to address the issue of disability adequately. In his keynote speech at that conference, Sen explored the relationship of wealth, disability, freedom and justice:

Wealth or income is not something we value for its own sake. A person with severe disability need not really be judged to be more advantaged than an able-bodied person, even if he or she has a higher level of income or wealth than the thoroughly fit person. We have to examine the overall capability that any person has to lead the kind of life she has reason to want to lead, and this requires that attention be paid to her personal characteristics (and this includes her disabilities, if any) as well as to her income and other resources, since both can influence her actual capabilities. To ground a theory of justice on the information foundation of opulence and income distribution would be a confusion of ends and means: income and opulence are things that we seek "for the sake of something else," as Aristotle put it.²

Here, Sen is distinguishing between "earning handicaps" and "conversion handicaps," or how one is able to convert money into good living. Giving someone with disabilities a million dollars doesn't give them a good life if the money stays in the bank and the individual sits at home unable to convert his riches into enjoyable living. It is easy to see why, for people with disabilities, this line of thinking is extremely helpful in understanding the injustices that plague them. But Sen does not limit his definition of a conversion handicap to finances. He also points out that social facilities are a "common good," which are often not accessible to people with disabling conditions. Community centres, schools and churches may exist, but if someone like Nicholas cannot get into these buildings, they will hardly contribute to his wellbeing. For people who require care, it is their loved ones who naturally take it upon themselves to mediate a deal for turning community resources into good living.

My own experience tells me that converting money into fulfillment requires imagination and self-discipline. Money squandered, like any gift, can lead to misery (as in the case of gambling addicts). But the same could be said of disability. That particular fact of life can be converted into a positive force that reveals the best in human qualities, such as determination, resilience, creativity and compassion. It is a serious misconception to believe that money automatically translates to good living, or that disability converts to misery. Mark Oakley, our priest and old friend, put it best: "It is not circumstances that make or destroy a life. Anyone who has survived the death of a lover, the loss of a position, the end of a dream, the enmity of a friend knows that. ...It is the way we live each of the circumstances of life, the humdrum as well as the extraordinary, the daily as well as the defining moments, that defines the quality of our lives. Each of us has the latitude to live life either well or poorly. Ironically enough, it is a matter of decision. And that decision is ours."

The American philosopher Eva Feder Kittay has spent most of her professional life writing about what it means to mother her daughter, Sessa. Sessa is now a grown woman and because of a severe developmental disability and cerebral palsy is completely reliant on others. Kittay weighs in on Sen's ideas and how they might affect families such as mine. In thinking about equality, she identifies the fact that all people are not alike with the same abilities as a starting point. In her discussion of Sen's

ideas, she explains: “What we want to insure, claims Sen, is not merely that everyone has access to the same goods with fair equality of opportunity, but that we equalize each person’s capability to function freely.”³ This is true equity wherein individuals are free to convert all the aspects of their lives into good (or bad) living. If Sen’s ideas of freedom, capability and justice had been taken as both a means and an end to disability policy, programs and services, how would Nicholas’ early years have been different?

More than two years after my first conversation with Susan Hodgett at the University of Ulster, I managed to make contact with Amartya Sen of Trinity College, Cambridge. With the assistance of generous, well-placed friends and a fair amount of tenacity on my part, I had managed to organize the hottest date of my life. I needed to ask Professor Sen if my application of his Capability Approach to disability in a developed world setting was valid. I wondered whether proposing the idea of a maximum capability set (especially in the area of education) was appropriate. After all, this approach was originally conceived in order to understand minimum levels of capability in the case of people living in circumstances of extreme poverty.

On January 21, 2010, I found myself boarding the train from London to Cambridge. The train was nearly empty, so I spread my papers out on the table opposite my seat. I looked at them and wondered if my meeting with this Nobel Prizewinner would result in my manuscript being left in a Trinity College wastebasket. I arrived early and found what I thought was the correct waiting room. I attempted to compose myself by pretending to read my notes. I moved to the bottom of the stairway that seemed to lead into an upstairs dining room. Suddenly from a lower hall, Professor Sen appeared. We climbed the stairs as he explained the dining arrangements and the menu. Being unfamiliar with academia, let alone casual conversations with Nobel Prizewinners, I wondered if we would have a chance to discuss my book at all. Other academics sat at the long tables and we took our places amongst them. As Professor Sen chatted amicably to others at the table, I smiled nervously and listened. Finally, we finished our dessert and Sen suggested that we retire to the reading room to discuss my project. We found two armchairs by the fire and breathlessly, I asked my questions — was the Capability Approach a valid lens for my family experience? Yes. “It would be a shame if the approach had nothing to offer anyone living above a subsistence level,” he said. Could I apply the approach in an effort to include maximum levels of opportunity and choice? Yes, definitely. I asked his advice on how to present complex ideas in a coherent way for general audiences without losing authenticity. “Ah,” he replied. “Generally I find that readers are generous. If you express a fact or opinion, they will assume you’ve done the work. Don’t worry so much.” I left Trinity that day feeling relieved and resolved. After my conversation with Professor Sen, I was sure that the capability framework would present disability as just one aspect of human complexity in a world where we all interact differently with our physical, economic, social and cultural environments. This was a belief that I considered to be true and a value that I will always hold precious.

Beginning to Think Differently

I remember being a parent representative on a committee to restructure local services for families like mine. Nicholas was in nursery school at the time. All the heads of social and health-care facilities were at the table and I suggested that we offer direct payments to parents so that they could choose which services they wanted. The director of the children's rehabilitation centre looked at me, alarmed and asked, "But what if they buy leather pants with the money?" I wondered aloud whether employers would voice the same worry about their workers' paycheques.

John Maynard Keynes once remarked, "Practical men, who believe themselves to be quite exempt from any intellectual influences, are usually the slaves of some defunct economist."⁴ I would suggest that those who believe social change can be debated without consideration for its most vulnerable members are slaves to defunct philosophers.

Traditionally, economists have measured standard of living by the ability to buy a basket of commodities or by utility, understood as happiness. The Capability Approach focuses on the kind of life that people manage to lead and whether that life has value to the individual, from their perspective, not ours. This way of looking at the rich and poor of the world takes into account how some poor people can be happy and how those with monetary wealth may be miserable.

Sen's approach is particularly helpful in assessing the wellbeing of people with disabilities and their families, because their values, aspirations and circumstances are so different from the status quo. They may not be able to convert wealth into good living if there is no access to the outside world and its riches.

On the other hand, they may have very little of what is considered important by others, yet they are happy and healthy. Furthermore, people with disabilities are little known to the general public and as such, are likely to be misunderstood. When the Ontario government gave us a little money for respite care, often I didn't hire helpers, I hired a cleaning lady — especially when Nicholas was ill or in pain. I wanted to be with him and he wanted his mum. Sen is concerned more with a person's interests than his or her actions or behaviours.

Now that Nicholas is an adult, the extent to which he pursues interests and enjoys a life that he values is wholly dependent on the assistance of caregivers, together with technological support. Nicholas is

reliant on technology to eat, breathe, speak and remain pain free. He is tube-fed by an electric pump and uses an oxygen-saturation monitor at night to alert the carer if he stops breathing. Nicholas has used a switch-operated speaking computer and has used adapted software to learn at school. Recently by directing his helper on the computer, Nicholas completed an online IT course and he used that knowledge to become a seller on eBay. Nick's exploration of the Internet, with the help of his carers, has even allowed him to discover the experience of being able-bodied in virtual worlds.

Trying to imagine Nicholas' life without technology is difficult, but not impossible. Back in 1998 when Nicholas was ten, much of eastern Canada was declared to be in a state of emergency. Over the course of eleven days, almost 40 millimetres of freezing rain fell, crushing power lines and toppling the entire power grid serving Ottawa and Montreal. While the temperature dropped and we huddled beside our fireplace, the realization dawned on me that without electricity, I could not feed Nicholas. Nick is tube-fed and his pump is electric. His principal mode of communication at that time was a speaking computer, operated via head switches. Without power, Nicholas could not speak. Without heat in the house, he began to shiver. A natural disaster suddenly caused Nick to become much, much more disabled than I had ever known him to be. Luckily, a hotel unaffected by the power outage made room for Jim, me and both children as well as Goldie, our dog. We were all delighted to have an all-inclusive "adventure holiday." Nicholas has a life that he values, and that value is almost wholly derived from assistive devices, including computer technology. Without electrical power, Nicholas cannot eat or speak. Even worse for him, he is completely cut off from the rest of the world. The ice storm was a lesson in dependency for everyone, especially the frail. Thank goodness for us, it lasted less than a week.

Left to his own devices, Nicholas would die of thirst and starvation. Left to the government, he would exist, but not flourish. With government support and the care of family and friends, Nick has a future as an active citizen whose contributions are valued by all those around him. The Capability Approach in the context of extreme poverty is very much about minimum levels of freedom or operating space within which a person can function and aspire to achieve goals. But Sen has deliberately been vague about how his approach might be implemented and assessed in the real world. I've decided to apply the principles in their broadest sense and in the comparative context of my own culture and neighbourhood. Sen advocates using his approach to expand capabilities by removing injustices. But his theories do not directly address the case of disability where physical and mental capacities vary so widely. So, in the context of my own family experience, I have decided to use the Capability Approach to expand the capability space of my family to its maximum, rather than to a minimum. I do so because that is the level I have come to expect as rightfully mine in Canada and the UK as an educated, middle-class person. So, for my family, "What is a good life?" followed by "How can we get one?" are good places to start.

A Plan for the Future

For me, the dawn of the millennium held more fears than just that of a possible Y2K disaster. Nicholas was almost twelve years old and had survived multiple near-death experiences. Clearly, my son was a survivor. So, the mantra of my worry, “What if he dies?” was slowly becoming “What if he lives?”

In 1999, I began to help my old friend Kathleen Jordan in her efforts to plan a safe and happy future for her son, Christopher. Chris Jordan is Nicholas’ senior by almost fifteen years, and through him I had a glimpse of our family’s future. I didn’t like what I saw. Kathleen and her husband, Bill, still looked after Chris at home. They managed to cope with almost daily emergencies, even as they endured failing health themselves. By that time Kathleen had begun to organize parents in Ottawa, telling us about a revolutionary idea from Vancouver called PLAN. Together, we became convinced that this organization could save our lives and teach society how to be more caring in the bargain.

PLAN: AN IDEA IS BORN

In the late 1980s, a small group of people began meeting together in Vancouver, British Columbia, to think about futures that were not their own. Each of them had a son or daughter with a developmental disability, and together, they considered these sons and daughters. They considered their joys and their fears. They considered their dreams and their safety. They considered their places in the world. All of the parents bore well-earned scars from the political battles and guerilla actions they had fought to enable their children to receive the support they needed: schooling; housing, medical and psychological care; money. They knew the system well, could negotiate its highways and its alleys and its cul-de-sacs. But they were tired. And they were afraid, because they realized that advances in health care meant they would have to face a problem few people in history had ever faced. Their disabled children were likely to outlive them. Despite their hard-won expertise, their intricate knowledge of the agencies and organizations meant to serve the disabled community, they knew that, sooner or later, their children would be without their advocacy, cast adrift in an institutional world that could not protect them from the devastating personal and systemic loneliness that the parents feared the most.

In many ways the small group of parents had itself been born of loneliness. The group was the work of a peculiar synchronicity. Each member had suffered recent and profound loss: death, illness, divorce — disorienting chords that had left them bruised and battered individually, but also open to

thinking about the world and working with each other in a new way.

And a new way of thinking and working was exactly what they sought. They sensed that the current model of providing for the disabled, the familiar twentieth-century concoction of institutional services and legal contest, provided few answers to their sons' and daughters' most meaningful questions and yearnings. And they knew that the nonprofits that worked within the disabled community were deeply embedded in this model, both mentally ("How else could we do this work?") and financially, since they received most of their money from government agencies. In fact, group members had been intimately involved in many of these nonprofits, founding them, working for them, sitting on their boards. They knew a lot about governance and policy and legal and financial issues. They had a particular expertise in estate planning; several people in the group were involved in workshops that helped parents develop wills and trusts appropriate for supporting disabled offspring. But they all felt that the structures they had participated in and helped create were missing something vital.

Jack Collins was there. He says, "We all spent years building these nonprofit organizations that were supposed to be providing services to our children, but they did not really look at the needs of the person . . . [Our local association] didn't offer anything but programs which suited the needs of the association." He talks about his daughter Pam: "Whenever we asked for something, they put her in a training program." He pauses and stares at his hands. "They trained her to bake muffins once."

Jack says that what the members of this small group shared, in addition to a particular family experience with disability, was "complete dissatisfaction with this system." They wanted to create something entirely different, an organization, a movement, a way of understanding the world that would secure the futures of their children and others like them by acknowledging and responding to their deepest human needs, not simply their superficial predicaments.

The group, however, had little notion of what that something might be. So they talked with each other and they visited different programs. They opened, without mercy, their own assumptions and wounds. Funded by research and planning grants, they spent three years in deep inquiry, immersed in profoundly honest, occasionally contentious, dialogue with each other and with the world around them. Slowly, a fresh way of understanding the disabled community and the organizations meant to serve that community began to emerge. A fledgling model of a different kind of organization with a different way of seeing the world took shape. Like all fledglings, the model was damp and awkward and fuzzy in places. But in 1989, with a tiny office, and still only the vaguest idea of what it would all mean eventually, the Planned Lifetime Advocacy Network, PLAN, was born.⁵

Like all innovative, simple and brilliant ideas, this model of support began with an unexpected question. Rather than asking who would look after their sons and daughters, or who would pay for their care, these parents asked, "What IS a good life?" Their consensus was that a good life for people with disabilities is not very different from a good life for anyone else: friends and family, a place of one's own, financial security, choice and the ability to make a contribution to society are the key ingredients.

First and foremost in realizing these values or freedoms in the lives of people with disabilities is a understanding that caring relationships are the key to a good life. Furthermore, these wise parents recognized that people with disabilities often find it difficult to forge and sustain friendships. But caring relationships alone are not enough to sustain a good life — individual contributions must be

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