

## IV

A SENTENCE FROM A 1715 ISSUE OF *TOWN TALK*, A London periodical, summed up our sentiment: "It is a wise dictate of Nature that we love those children dearest whom she presents to our care with the most infirmities." At the beginning of each day I would pass through the laundry room and open the white door to August's sleeping quarters, a small room at the back of the Capote house. August's little elfin grot was a space about the size of a one-car garage. The door, baseboards, and two window frames were painted white, and the four walls were a baby blue shade that Benjamin Moore called Windmill Wings.

Every morning during the late summer, at a few minutes past seven o'clock, a horizontal ray would shoot through an east-facing window and flare diagonally through the chamber. For the time it takes a matchstick to burn, it would illuminate the room's west wall. The signature of this beam would be no larger than a quarter, and it would land just above and to the right of the headboard of August's electric hospital bed. Sherwin-Williams would label this hue Laughing Orange. This spot on the wall was the sunrise and the cue for my aubade to August. "Wakee! Wakee!" I would call out as I came through his white door. I would touch his shoulder and pull down his covers and then raise the blinds.

Light of the new day—the good-morrow—would stream in. August would open his eyes, stretch, coo, grin, and kick at the bed covers with glee.

From outside would come the resolute tapping of woodpeckers and the morning calls of gray catbirds, brown thrashers, and mockingbirds, all singing their hearts out. This was our parliament of fowls. For the most part I didn't know which birdsong was which; I just knew that these were common birds in our area. I would join in with my own morning call, the "Good Morning Song." As I began to sing sweetly, August would brighten further and wait for what he knew was coming. When I came to the penultimate line, I would screech it out in an exaggerated, creaky voice like that of Margaret Hamilton's Wicked Witch of the West from *The Wizard of Oz*: "Good morning to the bunny rabbit named August!" Hearing this, August would kick and squeal.

I then would get him ready for the day by changing his diaper, bathing him, brushing his teeth, and dressing him. I loved his warmth, his body heat, as I tended to him. Every day, I would silently note that he had a belly button like a jellyroll.

August had an exquisiteness about him. At birth his eyes had been green, but over time they softened to hazel. He had a winsome, well-shaped face with high cheekbones. His hair when he was born had been red, but over time it settled into light brown and became soft, thick, and fluffy.

In the mornings August's vision was at its best because he was rested. His eyes would roam about, scanning and visually taking in the room and me as I went about assembling everything to prepare him for the day—washcloths, toothbrush, fresh diaper, and clothes. August could see very little, and the condition of his sight was officially labeled

*cortical visual impairment*, or CVI. With CVI, his optic nerves worked perfectly well, but because he had suffered brain damage, the cortex had great difficulty making sense of the data it was receiving from these nerves. Therapists told us that sight for August was like looking through many sheets of cellophane. If he had experienced a good night's sleep, he might be able to pick out colors and shapes, but little more. Whether he could make sense of them was another matter. The only major sign from August's appearance that he had suffered a significant brain injury was the way his eyes moved. His eyeballs shifted in slow motion. His saccades—or fast movements of the eye (something we all have but don't notice in one another because the movements are so rapid)—were poor, owing to the damage to his cortex. And so, with slowed saccades, August swept his visual field.

His best vision was peripheral: he could take things in with brief sideward glances. Consequently, when he appeared to be looking directly at me, I knew that he actually wasn't seeing me at all. But if his body was turned ninety degrees away from me, as when he sat sideways on my lap, and he shifted his head slightly toward my face and gave me a quick glance out of the corner of his eye, I knew that he was briefly taking me into his field of vision. On these occasions he'd shoot me an infatuating little smile.

Sometimes he would stick his finger into his eye socket, and a vision specialist we consulted speculated that he was doing this to stimulate light sensation. I wouldn't let him do this though—not because he was going to gouge an eye out, but because I didn't want him to damage the cornea. "Don't do that," I'd say each time as I removed his finger from his eye. "You're not Oedipus."

Back in 1999, when we were still in San Francisco, one of August's therapists—a friend—had written in a report that on account of August's brain injury he had increased tone in all of his limbs, but decreased tone in his neck and trunk muscles. This combination brought about "severely limited active volitional movement." Seven years later, her assessment remained accurate. He couldn't move his limbs, except for his legs, which he was able to kick, and his left arm, which he could flail. Moreover, August never improved intellectually. His developmental gap continued to widen. He was only going to make it to about a one-year-old level by the time he was an adult, if that. He was like a baby who kept growing bigger and bigger without any increase in skills and abilities.

The therapist producing this report was describing him from the vantage point of science, and what she wrote was accurate, as far as it went. "Profoundly retarded" was the label that another professional used regarding him. "Retarded" is the condition that society, in the words of English professor Janet Lyon of Penn State (and mother of Jamie Bérubé), assumes to be "the lowest rung" of humanity.

When we brought August home from Loma Prieta years earlier, we had entertained high hopes regarding recovery from the brain injury. Dr. Anderson at the family consult seven days after the birth had been so encouraging, saying that August would probably meet his milestones. But Ilene and I had never encountered a child who was in this state. I myself was unaware that such children even existed. Had we parented August with only the doctors' and therapists' descriptions to go by, we might have thrown up our hands in despair. But we knew that August was more than a smoking heap of terrible conditions. Because we saw that he was a

happy and lively being, we didn't let the medical terminology or bioethical stereotypes govern our thinking about him.

We turned instead to the imagination, because that is what makes us human. Life without it would be life in a dungeon. If knowledge is power, imagination is destiny. A scientific, empirical description turned August into human rubble, a car wreck that had happened in the delivery suite, but imagination allowed us to move the medical diagnoses to the curb so we could reach our boy. In our minds' eye he wasn't all that different. He was August, just one member of a quirky family.

August had become a devotee of the senses. Cultivating whatever gave pleasure became the chief business of his life. He did not know of any occupation that was more important, and he was extravagantly fond of good food. August would bite his left hand when he was hungry, and that's when I knew it was time for him to eat. Fearing reflux, San Francisco therapists had directed us to only give him Pedia-Sure. The therapists at the DLC Nurse & Learn helped him transition to eating bananas, sweet potatoes, and other soft dishes. He could consume food with textures, food finely chopped but not pureed.

Each portion of food and sip of liquid had to be hand-delivered to his mouth, like feeding a baby bird. Because he could not see, we cued each bite or sip with the clearly articulated words "food!" "milk!" or "water!" whereupon his little pink mouth would pop open. We would bring the spoon or cup to his mouth, he would take in the food or drink, and then we would linger, sometimes for up to thirty seconds, allowing him to swallow before offering him more. We could not hurry; if we did, he might aspirate what was in his mouth.

August was not a fussy eater. Banana mashed with a crushed graham cracker became one of his preferred mid-afternoon snacks. For dinners, sweet potatoes with a pat of butter and a dab of maple syrup proved a preferred dish. To vary his diet, we produced thick, semi-pureed concoctions of enchiladas, lasagna, or chicken mixed with carrots, broccoli, and broth. Tasty food made him utter a soft, murmuring coo. Eventually, for dessert, we were able to feed him a cookie.

His sense of smell was sharp too. He loved the aroma of coffee, and whenever I placed a steaming cup beneath his nostrils, his smile broadened.

He loved ice cream the most. Whenever he took in the first bite, his face would scrunch up into a deep pucker, seemingly an agonized response to the coldness. Next, he would work it around his mouth with his tongue, and finally he would swallow it. We could practically see his brain freeze. You might conclude from his initial pained expression that he wouldn't want more, that eating ice cream was too excruciating. A couple of seconds would elapse, though, and then—without anyone having to say the cue word "food!"—his mouth would open for more. So entertaining a spectacle was this that it became performance art.

He delighted in parties. During Clio's annual birthday celebrations, with her young friends shouting, laughing, and playing games, he remained silent in his wheelchair, perplexed by the sounds. But then, after the party had wound down and the children had gone home, he would begin to bellow loudly, as though he had finally figured out the meaning of the voices. Now, belatedly, he had something to contribute. Or perhaps he wanted her friends to come back.

Because August was not able to walk, he had little of what is called vestibular stimulation. This is the process

of sending specific electric messages to a nerve in the ear. When he was much younger and smaller, I had been able to lay him over my shoulder and hop up and down, either on pavement or in the swimming pool at the Jewish Community Association. When he became bigger and heavier, therapy balls substituted. After laying him face down on a very large one, I would roll him rapidly back and forth or bounce him up and down in place, and these motions would make him shriek with pleasure. As he grew, Ilene and I had to keep moving up to larger and larger therapy balls. When he had grown so much that no ball was large enough, we had to go big or go home by ordering the most massive such thing in the catalog, the blue peanut. The blue peanut was a two-and-a-half-foot-high oblong “ball” indented in the middle, and it was huge—it took up a lot of the playroom. We were able to plant August face-down in the peanut’s middle, and he would become ecstatic whenever we gave him a workout. When I would make him go really, really fast, backward and forward, he’d screech.

When I went running, August would join me—by sitting in a blue, supersized “special needs” Baby Jogger, the largest the company made. I remember one mid-afternoon, when he was nine years old, in 2008. The humidity being relatively mild and the temperature not overly hot, I judged it would be a good time to put him in the Jogger. It was overcast when we set off, but not, I thought, so dark that a storm threatened. Very often, summer afternoons all over Florida are positively gothic, with lightning, thunder, and dense tropical rain. The state also is the lightning-strike capital of the world.

Running, I pushed August north on San Jose Boulevard, past the wide expanse of the Duck Pond, the one-story red-

brick schoolhouse (and the lush green meadow surrounding it), and the eastern tip of primordial Craig Creek. We crossed Hendricks Avenue at the traffic light and headed toward the eastern edge of the San Marco neighborhood, where a rail line intersects St. Augustine Road. There, on the south side of the tracks, and three quarters of a mile east of Craig Creek, is a three-acre tree-shaded graveyard, a secluded spot where the rude forefathers of our hamlet sleep. Dating back to the 1840s, the Philips-Craig Swamp Cemetery was, by 2008, forgotten and overgrown. It was tidied up in 2017, but when August and I went there, it was wild. Inside the gates, he and I made our way.

This was my favorite place in Jacksonville. Ironically, it was this graveyard where the city first came alive for me. Ragged, fully grown trident maples and moss-draped live oaks populated the grounds. A tall scruffy cypress stood by the tracks, and a low ancient palm tree squatted in the center. Toward the back, a large tree had fallen in a long ago hurricane, and now its rotting trunk lay lengthwise along the ground like a low, cylindrical wall. No lawn surrounded the mossy tombstones, just weeds, and I maneuvered as well as I could over the uneven surface, an infielder's nightmare. The turf heaved throughout these burial grounds with tree roots and branches and moldering graves. Both Union and Confederate dead had been interred there. The Jogger careened around them as we dodged frail memorials and toppled monuments. Pushing August over the soil's jagged plane jostled and jarred him, and the rough motion made him squeal. The more rugged the terrain, the bumpier the ride, and the more it jolted him, the more he shouted for joy.

I'd been so caught up in his excitement that I hadn't noticed the storm clouds moving in. Leaving the cemetery, we



smelled the rain before we felt it. August delighted in the droplets that began landing on his bare arms and legs, and he made appreciative sounds. The Jogger's awning protected his head. As we reached Hendricks Avenue and headed south, I was grateful that it was only sprinkling. We crossed Hendricks at the light and skirted the eastern tip of Craig Creek, but then, heading south on our home street, the storm exploded. Instantly I was soaked. Powerful winds began to blow, and I wondered if a tornado was forming. Lightning and thunder commenced, with forked incandescent streaks rippling the sky. The interval between the flashes of light and the thunderclaps became about a second. We still had half a mile to go. August sat silently, stunned by the sublimity. The torrent slapped my face, and the world withdrew into gray: the red schoolhouse and green meadow vanished. The broad surface of the Duck Pond, pelted with rain, shimmered. I dashed August up our long driveway to the protection of a carport. After whisking him out of the Jogger, I carried him into the house, laid him on his big changing table, removed his drenched clothes, towed him off, and dressed him in dry clothes. All the while he beamed and cooed, invigorated by our big adventure in the wild.

Every night after I had dressed him in his pajamas, brushed his teeth, and placed him on the sheets, it was time for a lullaby, "Returning," by Ajamu Mutima. Mutima is a master of the kora, the twenty-one-string West African harp-lute. I would turn on the CD player, turn off the overhead light, snap on his little night lamp, and make certain the sound monitor was on.

Some people may suppose that, because my son's character was as airy as a dandelion gone to seed, I never got a chance to know my boy. In the darkness, as Mutima softly

played the kora, I would lean over the bed railing so that my face would be very close to his head. As the moon waxed and waned, rose and fell, pulling the tides in ebbs and flows all around the planet, I would think of two lines from a John Donne poem: "For love, all love of other sights controls, / And makes one little room an everywhere."

Our communication was closest at bedtime, when we entered our separate reality most profoundly, and I would speak nonsense sounds into his ear, telling him wordlessly that I loved him, and he in his own singular way would tell me the same thing. His response would be to incline his face toward mine and grin, and sometimes he would cackle with glee, the laugh of Medusa. I would whisper, "My darling boy, my moon and stars," and he—a little chucklehead—would giggle. Into the night August and I had many a deep conversation, ones as sweet as being put under with Propofol.

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After August's birth, I didn't find many role models of fathers taking care of disabled children. I read quite a bit of helpful material by women on mothering such children, with Eva Feder Kittay's 1999 book *Love's Labor* being particularly helpful. Traditionally the caregiver role has almost always fallen on women; it is only recently that men have begun assuming it. When men become active caregivers, their work is regarded as unusual and therefore heroic. By contrast, women become remarkable only when they refuse, whereupon they become the butt of criticism. This difference reminds us of our society's profound and persistent patriarchal bias.

What sources of inspiration would I need to help me learn how to play this new role? I was looking for examples

of men who had taken up this challenge. I came across Dick Hoyt, the father of Rick, who lives with cerebral palsy. Years later I would read Dick's 2010 memoir, *Devoted: The Story of a Father's Love for His Son*. Together they had taken part in more than thirty Boston Marathons, with Dick pushing Rick in a modified wheelchair.

Reading opened me to other models. In the decade or more following August's birth, I found other notable books by men caring for children with impairments, including Michael Bérubé's *Life as We Know It* and his follow-up, *Life as Jamie Knows It*, Ralph Savarese's *Reasonable People*, Gary Dietz's *Dads of Disability*, George Estreich's *The Shape of an Eye*, Kirby Wilkins's *Life with Jake*, Diogo Mainardi's *The Fall*, and Ian Brown's *The Boy in the Moon*.

This isn't to say that there aren't good caregiver accounts by women. Many exist, too many to name. A list would have to include Vicki Forman's *This Lovely Life*, Glenda Prins's *Lessons from Katherine*, Emily Rapp's *The Still Point of the Turning World*, and Rachel Adams's *Raising Henry*. I was learning a lot about disability, and, in turn, I was discovering my own disablism—prejudice against disabled people.

People first hearing about our boy immediately assume heartbreak. They do so because they have in their minds a single story about disabled children and the families that raise them—the tragic story. “Society sees disability as the worst thing that can happen,” says scholar and disability rights activist Tom Shakespeare. “It's one thing that can happen, but not the worst.”

As August grew older, we grew too. We were learning the difference between disability and impairment. As disability studies scholar Lennard Davis puts it in *Bending Over Backwards*, impairment “is the physical fact of lacking

an arm or a leg. Disability is the social process that turns an impairment into a negative by creating barriers to access." A building without a ramp or an elevator turns mobility impairment into a disability. The overarching idea behind this insight is one that Davis expresses in another context: "The 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person." Davis's distinction—known as the *social model* of disability—made sense to me because it usefully differentiated impairment from disability. It was also tactically effective when disability rights activists campaigned for greater access and accommodation. We didn't know it at the time, but back in early 2000, when we sued the Child Care Center at Presidio Heights to get August re-instated, it was this very distinction between disability and impairment that was at stake.

At the beginning I had just assumed that the experience of raising a disabled child was supposed to be anything but beautiful. But my mind was changed by the late Harriet McBryde Johnson, whose article "Unspeakable Conversations" came out in a February 2003 Sunday edition of the *New York Times*. A disability-rights campaigner and a woman living with a muscle-wasting disease, Johnson had visited Peter Singer in his Princeton University classroom, doing so on behalf of Not Dead Yet, a group opposing child euthanasia and physician-assisted suicide. She was gutsy, diplomatically confrontational, and smart in her exchange with the man the *Encyclopædia Britannica* calls "one of the world's most widely recognized public intellectuals."

Because she was born with a congenital impairment, Johnson could have been one of the infants whose life was terminated shortly after birth. Consequently, she was an

ideal person to debate Singer. She was also an atheist, so he couldn't accuse her of arguing against his position on religious grounds, which he dismissed outright. People of faith who opposed his beliefs were a dime a dozen. It was precisely because she was both an atheist and someone living with a significant congenital defect that Singer was somewhat thrown back on his heels.

Singer advocates in favor of decriminalizing child euthanasia, and he lays out this view in various writings, including his 1988 book *Should the Baby Live? The Problem of Handicapped Infants* (coauthored with Helga Kuhse). He believes that new parents ought to be given the option of deciding whether or not to keep their impaired (or even their unimpaired) newborns alive. These parents should have an assessment period of up to twenty-one days after the birth to choose whether or not they want to take the baby home or to allow doctors to terminate his or her life. Singer does not address the issue of what to do in the case of a myriad of serious medical conditions that do not present in the first twenty-one days of life. With regard to an infant born with an apparent problem, parents would be able to reject that infant so that they could try again, to see if they could conceive a "better" baby. The core of his proposal—putting an end to suffering and eliminating waste—aligned with the Enlightenment goal of improving quality of life by judiciously organizing human affairs.

Singer is a *preference utilitarian*, meaning his stance is rooted in a strain of utilitarianism that stems from Jeremy Bentham and Bentham's student John Stuart Mill, both of whom contend that what should be considered "the good" is whatever benefits the greatest number of people. Along utilitarian lines Singer maintains that society has an interest

in conserving its limited resources, and so cost of treatment and care should be a major consideration in public policy decisions. Society, he argues, should allocate its assets for the maximum benefit of its members who are physically and mentally able and not expend them on those born with serious defects.

Singer believes that legalizing child euthanasia would promote "the good" of couples by expanding the range of choices available to them when it comes to forming the kinds of families they want to have. When explaining the reasons why new parents would want to terminate their infants' lives, Singer often brings up the example of infants born with Down syndrome. Down syndrome is the test case he frequently returns to, and here he seems to be working from an old paradigm. But conditions have changed, as M. Lynn Rose makes clear in *The Routledge History of Disability*:

Only a generation or two ago, babies born with Down Syndrome were not expected to live very long, and so they were routinely placed in institutions, where, denied the basic comforts of childhood, they didn't live very long. Since the early 1980s, the life expectancy of people with Down Syndrome has doubled, not because of some breakthrough medical advance, but because of higher expectations coupled with appropriate resources.

Our understanding of Down syndrome and what is possible for those born with it has changed dramatically just in the course of a few decades. Yet Singer continues to espouse his ideas in his lectures and more recent writings.

While Singer most frequently invokes babies born with Down syndrome to make his case, the lives of those born

with other impairments such as fragile X syndrome, spina bifida, cystic fibrosis, cerebral palsy, profound cognitive impairment, and so forth also would be subject to the parents' preference if he had his way. In fact, depending on the decision of the parents, *any* baby—regardless of health status or impairment—could then be subject to having his or her life ended. It would be as though legal abortion would extend into the fourth trimester. Still, babies with birth defects are his main focus because infants with impairments, he believes, will be inherently worse off than those unimpaired. Their lives will be permeated with suffering and therefore will not be worth living. He is one of the many philosophers who are openly skeptical of the idea that disability is not intrinsically suboptimal.

Singer's philosophy fits in well with a culture that equates *personhood* with autonomy, self-reliance, and individuality. A *person*, according to Singer, is an entity that has consciousness of itself in relation to time and space and is aware that it is going to die. As for the supposed right of infants to life, he maintains that they are not legally persons (fully human) with rights. A baby lacks this awareness and so is not yet a person with a right to life. Regarding infants with impairments, because they are not yet persons, and because they supposedly will be miserable when they grow older, it would not be wrong—but in fact would be humane—to end their lives at the beginning. He writes in his 1979 book *Practical Ethics*:

That a being is a human being . . . is not relevant to the wrongness of killing it; it is, rather, characteristics like rationality, autonomy and self-consciousness that make a difference. Defective infants lack these characteristics.

Killing them, therefore, cannot be equated with killing normal human beings, or any other self-conscious beings. This conclusion is not limited to infants who, because of irreversible mental retardation will never be rational, self-conscious beings. . . . Some doctors closely connected with children suffering from severe spina bifida believe that the lives of some of these children are so miserable that it is wrong to resort to surgery to keep them alive. . . . If this is correct, utilitarian principles suggest that it is right to kill such children.

Singer is hardly alone in advocating child euthanasia. Throughout his life Joseph Fletcher, a pioneer in the field of bioethics, was a leading proponent of it. And other bioethicists, such as Jeff McMahan and Jacob Appel, have presented similar ideas. Many bioethicists, in fact, see the reasonableness of child euthanasia.

Child euthanasia is not a new concept. It became popular during the eugenics era—the first four decades of the twentieth century in Britain and the United States. (Eugenics was the belief that various peoples and nations and even the whole human race could be improved through better breeding, somewhat like creating thoroughbred lines of dogs and horses.) In 1915 the chief surgeon of a major Chicago hospital, Harry Haiselden, on becoming involved in the Baby Bollinger case, campaigned vigorously for child euthanasia. He convinced the parents of the infant John Bollinger that the best option for society and for John, their child born with physical anomalies, was to let him die, claiming that the child would live a miserable life and drain public resources. In the face of public protest, Haiselden argued at a press conference that “mercy killing” for such a



child was more humane than letting him live. Many prominent figures defended him, among them Helen Keller and Clarence Darrow.

In 1917 Haiselden wrote and starred in the movie *The Black Stork*, a polemical film supporting “lethal eugenics”—the third stage in eugenic thought—the active taking of life, euthanasia. The first two stages did not involve deliberate killing. The first entailed encouraging only the “fittest” individuals to form into couples and procreate. The second involved the forced sterilization of mental or physical “defectives,” and a number of states executed this practice; the US Supreme Court ruled the procedure constitutional in its 1927 decision *Buck v. Bell* on the grounds that eugenic sterilization served the good of the state. (California, by the way, outpaced all other states in the number of people its officials ordered sterilized.) Haiselden was an early supporter of a third stage, the taking of life, the kind of thing Singer now advocates. By the time of *Buck v. Bell*, the public was becoming more and more accepting of all three stages, including Haiselden’s lethal eugenics. While support was widespread, it also was quiet. It wasn’t until the liberation of the Nazi death camps in 1945 that support evaporated. Interest in “neo-eugenics” is now rising under the auspices of the Human Genome Project, and genetic engineering is gaining traction with the public.

When Harriet Johnson debated Singer in his Princeton classroom before his philosophy students, in effect she had to argue in favor of her own existence. With regard to this encounter, she later wrote, “I am reminded of a young woman I knew as a child, lying on a couch, brain-damaged, apparently unresponsive, and deeply beloved—freakishly perhaps but genuinely so—living proof of one family’s no-

matter-what commitment." During the interchange, she had brought this young woman up, and Singer had responded by asking, "Don't you think continuing to take care of that individual would be a bit—weird?"

"Done right," Johnson replied, "it could be profoundly beautiful."

When I read this in her *New York Times* account, I was stunned. It had never crossed my mind in quite that way. It could be beautiful? The rational thing to do would have been to smother the person with a pillow. Johnson had given me a vision. The question then became how, as a dad, I was to do this. I now desired not only to be August's champion and friend but also to perform the whole affair with a sense of aesthetics, as the masterwork of my life. If I couldn't be a great scholar, at least I could be a great father to August. I would make caring for him as profoundly beautiful as I could.