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R&R

At Home with Down Syndrome

Caitrin Nicol

In storage at the Museum of Fine Arts in Boston is the secret to what one professor calls "the first Down Syndrome Association in the history of the world." In 1982, Dr. Brian Stratford, a specialist in developmental disabilities at the University of Nottingham, suggested in the journal *Maternal and Child Health* that the Italian Renaissance painter Andrea Mantegna used a little boy with Down syndrome as the model for his Christ child. Stratford made a "clear characteristic diagnosis" of the baby based on his distinctive facial features and the shape of his hands and toes. The curator at the MFA dismissed this theory, attributing the work to an unknown, less technically astute follower of Mantegna, and calling the resemblance to a child with Down syndrome accidental. In the meantime, however, Stratford heard from a history professor in Rome. The Gonzaga family of Mantua, Mantegna's sponsor, had a boy with an unidentified "sickness," she said, and one of the artist's own fourteen children shared this condition—a not insignificant factor in Ludovico Gonzaga's choice of Andrea Mantegna as his court painter. Gonzaga and Mantegna appreciated the humanity of these children whom some might have preferred to hide away or let die, and that shared sensitivity gave them a "sense of purpose" with respect to disability which Stratford regrets has been all but forgotten by our society: "Perhaps Mantegna saw in this child something beyond the deficiencies which now so occupy our attention and perhaps then, the qualities of love, forgiveness, gentleness, and innocence were more readily recognized. Maybe Mantegna saw these qualities as more representative of Christ than others we now regard so highly."

Down syndrome is a developmental disability resulting from an extra copy of the twenty-first chromosome. It is the most common single cause of human birth defects, occurring in about one in eight hundred births. Symptoms include mild to moderate mental retardation, lower muscle tone, an approximately forty percent chance of a congenital heart defect, and lesser but significant risks of gastrointestinal disorders and leukemia. Individuals with Down syndrome generally have outstanding social skills and in a supportive setting can be fairly high-functioning. Due to improving medical care, the life expectancy for someone born with Down syndrome has increased from twenty-five in the early 1980s to more than fifty today. In many other ways as well, a child born with Down syndrome today has brighter prospects than at any other point in history. Early intervention therapies, more inclusive educational support, legal protections in the workplace, and programs for assisted independent living offer a full, active future in the community. Adoption agencies report a high demand for children with Down syndrome.

However, the abortion rate for fetuses diagnosed with Down syndrome tops ninety percent. The alphafetoprotein maternal blood-serum test followed by amniocentesis are standard practice in prenatal care for women over thirty-five, who have an elevated risk of conceiving a baby with Down syndrome. Eighty percent of babies with Down syndrome are born to younger women, however,

Gifts: Mothers Reflect on How
Children with Down Syndrome Enrich Their Lives
(ed. Kathryn Lynard Soper)
Woodbine House ~ 2007 ~ 294 pp.
$18.95 (paper)

Count Us In:
Growing Up with Down Syndrome
by Jason Kingsley and Mitchell Levitz
Harvest ~ 2007 ~ 198 pp.
$14 (paper)

Chicken Soup for the
Soul: Children with Special Needs
(ed. Jack Canfield *et al.*)
HCI ~ 2007 ~ 334 pp.
$14 (paper)

Common Threads:
Celebrating Life with Down Syndrome
by Cynthia S. Kidder and Brian Skotko
Band of Angels ~ 2007 ~ 181 pp.
$22.95 (paper)

You Will Dream New Dreams:
Inspiring Personal Stories by
Parents of Children with Disabilities
(ed. Stanley D. Klein and Kim Schive)
Kensington ~ 2001 ~ 279 pp.
$14 (paper)

Road Map to Holland:
How I Found My Way Through My Son's
First Two Years with Down Syndrome
by Jennifer Graf Groneberg
New American Library ~ 2008 ~ 304 pp.
$14 (paper)

due to their higher overall fertility rate, and the American College of Obstetricians and Gynecologists (ACOG) recommended in 2007 that *all* pregnant women be offered screening for Down syndrome. While ACOG insists on its neutrality with regard to abortion, it is not difficult to interpret this move as an effort to reduce the number of individuals with Down syndrome who are carried to term. Obstetricians are not well trained in explaining the diagnosis and have little if any clinical experience with individuals with a developmental disability, and medical school deans indicate that such training is not a priority. A 2004 survey of mothers of children with Down syndrome, published by then-medical student Brian Skotko in the *American Journal of Obstetrics and Gynecology*, reported that the prenatal diagnostic process sorely lacked information on the nature of the syndrome. While the physicians did a satisfactory job of explaining the actual test procedures, the women felt that a discussion of the symptoms and the potential of individuals with Down syndrome was either cursory or delivered with highly negative overtones. One was shown "a really pitiful video first of people with DS who were very low tone and lethargic looking" and then told that "our child would never be able to read, write, or count change." Others regretted that they had not been offered contact information for other parents who have children with Down syndrome—connections that, where made, proved to be one of the most important and supportive factors in the mothers' decisions to continue their pregnancies.

Such inadequate diagnoses fail to serve the needs of pregnant women feeling anxious, pressured, and frightened for their babies' welfare, and they fail to do justice to the dignity and potential of persons living with a disability. Several recent books, however, offer a more human view of the experience of Down syndrome—five by parents and friends of an affected child, one by two individuals with Down syndrome themselves.

Gifts is a collection of short essays and stories by mothers of children with Down syndrome, women from all walks of life who want the world to know that their children are not a tragedy. Published by Woodbine House, a company specializing in books about children with special needs, *Gifts* is explicitly geared toward offering hope and support to parents who have just learned of their child's Down syndrome. Proceeds are invested in providing free copies to families dealing with the diagnosis.

A similarly-intended book is *Common Threads*, a lovely oversize volume of photographs and stories celebrating the lives of young artists, athletes, students, friends, and dreamers with Down syndrome. *Common Threads* is published by Band of Angels, a Down syndrome outreach and advocacy group; its authors are Dr. Skotko, whose sister Kristin has Down syndrome, and Band of Angels president Cynthia S. Kidder. For parents wondering what their child's future looks like, the luminescent photos are a better bard than any of the anecdotes. One features a bespectacled young sailor solemnly performing a trumpet solo for a row of teddy bears. Another sneaks a peek of two budding fashionistas at a glitzy nail salon smack dab in the middle of a sunlit field. Another shows a pint-size cowboy reading a story to a puppy. *Common Threads* also includes a survey of the current research on the syndrome in layman's terms, geared to positive steps parents and educators can take to encourage development.

Not wanting to miss out on the party, the *Chicken Soup for the Soul* series (the behemoth of inspirational publishing, with over a hundred titles from *Chicken Soup for the Ocean Lover's Soul* to *Chicken Soup for the American Idol's Soul*) last fall came out with a volume on children with special needs, including but not limited to Down syndrome, with essays by parents, grandparents, therapists, and others connected to a child with a disability. A less cutesy, more grounded version of the same idea, *You Will Dream New Dreams*, is named for a conversation one new mom had with her own mother the day that she received her daughter Jesse's diagnosis, grappling with all the milestones she might not ever reach: "I know that thinking about all of those things is very painful right now," the grandmother says, "but you have to remember that those are your dreams, sweetheart, not hers. Jesse will have dreams of her own. They may not be like those of other children, but they will be her dreams, just the same."

Adding breadth to the pith in these anthologies' vignettes is Jennifer Graf Groneberg's *Road Map to Holland*, a tender memoir of the first two years of her son Avery's life. Groneberg writes with the grace of a natural mother and the wisdom of someone who has been through the wringer. Her happy little family was sent reeling when she gave birth to twins several weeks prematurely, one facing major surgery and the other diagnosed with Down syndrome. Before they were born, she, her husband, and their four-year-old son Carter had redecorated the nursery, writing secret wishes on the walls before painting over them, such as "happiness," "laughter," "music," and (Carter's contribution) "chocolate milk."

> I can barely stand to think about that time now. We chose all the wrong things. We should have written "good health" or "normal chromosomes" or "please, let everything be okay." I want to peel up the paint to get to the words hidden underneath, turn it all back, do it over. How foolish

> I was. I can't stand the thought of that happy afternoon, and all those silly hopes surrounding me on all four sides.

But in the course of two years, she finds those hidden wishes were the right ones after all. The cover photo is the cherry on the cake—a candid shot snapped the moment (after months of having no idea when he would ever walk) that Avery took his first steps, carrying his mom a batch of pretty leaves he picked up off the ground.

Groneberg takes her book's title from Emily Perl Kingsley's classic 1987 essay "Welcome to Holland," which compares the experience of raising a child with a disability to getting on a plane to Italy and inexplicably ending up in Holland—a *different* place, not as glitzy, not as fast-paced, but with windmills and tulips and Rembrandts and lovely people of its own. Spending your life regretting that fabulous Italian vacation, she warns, may blind you to the wonderful charm of Holland. Kingsley, a writer for *Sesame Street*, was instrumental in getting kids with disabilities included on the show. In 1994, her son Jason, then nineteen, and his friend Mitchell Levitz co-authored the lively autobiography *Count Us In* on growing up with Down syndrome. Jason takes a saucy satisfaction in blazing past the expectations of his mother's obstetrician, who informed her way back when that he would not amount to anything and belonged in an institution. "He never imagined how I could write a book!" he laughs. "I will send him a copy…so he'll know." Written on the cusp of adulthood and assisted independence, Kingsley and Levitz's reflections are an invaluable complement to the anthologies and *Road Map to Holland*, which mostly deal with infants and young children. A new edition, with an afterword by the authors to bring us up to date on their adventures and aspirations, was released in 2007.

Together, these books offer an account of growing up with forty-seven chromosomes that is not terribly different from growing up with forty-six. These kids read, write, play sports, make friends, throw parties, enjoy stories, start food fights, sing show tunes, and parade around the house in "full pirate regalia" instead of getting ready for school. Sometimes it takes them a little extra spunk to learn to do things that come more easily to others, but they do learn them, in their own time. Their parents emphasize that they are more alike than different from children without Down syndrome—they have their ups and downs and dreams and disappointments, and fundamentally they want what anybody wants—to be valued and respected, to be part of a community. One mother's proudest moment came when she received what she thought was a mistaken announcement about the eighth-grade class luau for her son Alex, who was only in seventh grade. When she called the office to report the error, she learned that he had been invited as the guest of honor by the entire eighth-grade student body. On the day of the event, she drove a delighted Alex to the school, thinking they would stick together, do the rounds, grab a couple hot dogs, and head out; but before she knew it, he was spirited away by a party-happy group of girls and ended up dancing out the night. "It was all I could do not to cry, I was so proud. This is what I have always wanted for him: Acceptance."

Some parents explicitly object to the "idealization" of their children (one astonished woman was informed by her mother-in-law that her daughter is the Bodhisattva), feeling that setting them apart in this way just makes fitting in more difficult. Putting people on a pedestal, however well intended, makes them seem not quite human. But, as Avery's grandmother notes, the special talents of people with Down syndrome may lie in what is *most* human—"they seem to bring out the good in people," she says. They also see the good in people when it is not obvious to others: One morning out grocery shopping with her five-year-old daughter Julie, one woman recounts, she spotted a bedraggled homeless man and thought to herself indignantly that the least he could do was get cleaned up, as there was an excellent shelter nearby. Julie, however, took off across the store and flew into his arms. "She snuggled into his disgustingly dirty neck" as her horrified mother looked on. "My heart panicked as I ran over to him."

"Excuse me, this is my child," she announced. The man turned to look at her, his eyes full of tears: "Lady, I can't remember the last time anyone wanted to hold me."

"Julie saw hurt and hugged it," her chastened mom explains. Nineteen years later, mother and daughter are frequent volunteers at the shelter. They never saw the man again, but have been praying for him ever since.

A substantial—almost surprising, given the festive billing—number of the essays in the anthologies, as well as a large part of Groneberg's story, focus not on some cute kid's shenanigans but on the scare of diagnosis. Many of those who learned of their child's disability prenatally faced pressure to abort. One older mother who declined an amnio because she didn't want to risk a miscarriage insisted to her incredulous doctor that she meant to keep the baby anyway, "so what difference does it make?" "Well, that's what everyone says," the doctor shrugged. "But they change their minds when they get the test results."

The tests for Down syndrome are administered around twenty weeks gestation, when the fetus has already begun to move around and kick. Peltered with bleak statistics—the learning impairments and health problems, the strong possibility of heart surgery in the first few months of life, the reputedly high divorce rate of parents of a child with special needs—the majority of expectant parents fall into a vortex in which abortion is offered as the sensible way out. (They are also told that they have just a couple weeks to do it, as most state laws limit selective abortion to the first and second trimesters, although under *Roe v. Wade*, these state laws are unenforceable.) Some who had always considered themselves pro-choice suddenly, as one of the contributors to *Gifts* puts it, found they "wanted no share of this choice." For others, it was a more difficult decision. They agonized over the surgeries and pain their children might have to face and the obstacles to their acceptance in society, as well as their own emotional and financial capability to care for a child with special needs and the toll that it might take on their marriages. They worried and they wept, and had very little time to process the news and decide what to do. One story in particular, an impossibly close call, perhaps expresses some part of what went on for the many women we don't hear from in these books, the ones who made a different choice.

Andi Matthews, pregnant for the first time, received the diagnosis near the end of her second trimester and was given an abortion appointment by default for the following week while she went home to think it through. "My husband and I talked for hours on end and cried together and separately," she writes. "We raged at the injustice of our situation. We mourned the loss of our healthy baby boy who we had never even met. We mourned the loss of our happiness, of our innocence. We struggled to justify this decision to terminate our much-wanted pregnancy." Wanting to spare her son what she believed would be a life of suffering, she wrote him a letter "explaining why his dad and I had made the choice to send him to heaven" and planned to plant a tree in his memory and have a little service. She asked the doctor whether she could have a chance to hold the baby after the abortion was over. The doctor told her there would be no remains intact.

After a harrowing weekend of heartbreak by day and nightmares by night, she and her husband landed in the office of a less-than-helpful family therapist, whose mucilaginous advice was to internalize the mantra "I do my best for who I am today." Gamely trying to repeat this mantra at home, she suddenly flew into a psychotic rage and kicked a hole in the bedroom wall. "I can't kill my baby," she wept over and over. Her family and health care providers rallied around her, and, apprehensive but finally at peace, she went forward with her pregnancy. "Live long. Laugh often. Love much," she concludes (the title of her essay, and surely a far better mantra than the New Age family therapist's). In a postscript written one year after her baby's birth, she adds, "We were so scared of what life with Riley would be like, and now the scariest thing I can imagine is what my life would be like without him."

While prenatal diagnosis forces parents to grapple with the possibility of abortion, it also allows for adjustment and preparation before birth, so that the child's entrance to the world might be as normal and as happy as any baby's. But for those who learned of their child's diagnosis in his first few days of life, it was surreal. Some recall processing the news in an extreme daze—"Oh, a chromosomal problem," one new mother filed away abstractedly. "I'm sure they can fix it." A father's first thought was, "'Oh! An extra chromosome. Smart kid. Chip off the old block.' An extra *anything* seemed like an advantage." But then the reality began to sink in—scads of tests were ordered—long parades of doctors came and went at strange hours—the uncomplicated joy of other new parents on the wing seemed almost personally insulting—friends and family members didn't quite know what to say. Descending into a deep, heartbreaking tangle of emotions, the parents grieved for the "loss" of a child who had paradoxically just been born, who might at the same time be fighting for his life, who suddenly seemed like a stranger. Some, including Groneberg, entertained wild plans of running off and starting over—"I'd get on the highway and drive east, toward the night, toward the city, a woman with a secret past, abandoned children, an ex-life"—plans as desperate as they were insincere.

It is not long after this that all these mothers and fathers fall madly in love with their babies, and go to the mat to "advocate" for them in the ensuing maze of tests, treatments, therapies, and some unfortunate social encounters. No one could ask for more loving and enthusiastic parents. But many carry with them a dark cloud of regret for their initial confusion and dismay, regret that they ever could have questioned how they were going to love their children.

One hopes that staving off the avalanche of unknowns from the start might diminish this ordeal for similar new parents, and books like these will surely help, if only to assure them that they are not crazy and not alone. But it would be a mistake to downplay the challenges of raising children with special health and educational needs, especially in a society not inclined to see beyond the symptoms. One physician had the gall to lecture a shaken father, his baby in his arms, for not getting an amnio and "terminating." Alex, the seventh-grader luau king, had trouble gaining entrance to his local middle school (a fight the school administration is now very glad it lost). Groneberg had a longtime friend who dropped her cold. One woman, whose daughter, Cariana, "sparkled with joy and sprinkled it like glitter onto everyone around her," lost her to leukemia after only a few years of life. Others came very close.

Groneberg's eldest son, four-year-old Carter, perhaps spoke silently for all of them with his response to the family's ordeal—when the twins were in the neonatal intensive-care unit, he began to wear his bike helmet all the time, everywhere he went. "Neither Tom nor I have asked Carter about the helmet, and I don't think we will. I understand it intuitively, and I think it's the most honest reaction to the last few weeks that anyone has had. I wish I could wear a helmet around, too, and maybe some big hockey pads."

A few months later, feeling that she ought to offer him some sort of explanation while trying not to scare him with the medical risks or damage his relationship with Avery, she sat him down to have "the talk" about Down syndrome. Everybody's different, she said; everybody has a different height, a different eye-color, and everybody has a different speed. Avery's speed will probably be slow. "It may take him longer to grow big, and it may take him longer to learn new things. But if we let him take his time, and if we love him, he will be fine."

"I get it," Carter said.

"You do?" she asked, a little skeptical.

"It's like Clifford," he explained (of the picture book series *Clifford the Big Red Dog*). "Little things grow big with love."

Any society struggling with how to deal with Down syndrome would do well to take its cues from Carter, as well as all the other siblings, parents, and friends of Kristin, Jason, Mitchell, Alex, Julie, Riley, Cariana, Avery, and company. People with Down syndrome, like all of us, come into the world by way of their families, not as isolated individuals who may or may not be capable of certain functions. Groneberg gets at the significance of this elliptically with a story in which she rues the way she had viewed people with mental disabilities until one came into her life. The locus of her shame becomes a man who works at a thrift store that she frequents and announces every day that it's his birthday—can he have a hug? One morning soon after Avery's diagnosis, she suddenly is struck with guilt that she never wondered about this man's mother:

> It never occurred to me that somewhere there is a woman who held him as a little baby, who changed his diapers, who rocked him and sang to him and cradled him through the night. I never considered the baby, the child, the family. In my mind, it was as if the man had always been grown, had always lived in the thrift store, waiting to tell me each month that it's his birthday. By denying him a childhood, I'd made him

> less than a full person. And now I wished I knew about it. How did he get there? Where is his family? Where is his mother?

Most of us don't go around imagining the childhood of every person we pass on the street, but the point is taken all the same. The man seemed different, and Groneberg, meaning no ill will, didn't know what to make of that and so set him aside. When Avery's brothers grow up, however, they will not have occasion for a crisis of conscience with respect to the man of a million birthdays; they'll know him as a "full person" innately, just as they know Avery—not as a point of principle, but as a marvelously unremarkable matter of fact. "Wouldn't it be wonderful," another proud big brother asks in *Gifts*, "if every family had a kid with Down syndrome?"

That question, of course, does not express the wish that more children would struggle with disabilities, but rather that more families might find within themselves the means to understand, and to transmit to future generations, the profound truth that every life is filled with meaning, and every child is a source of joy. The deepest consequences of that discovery, it seems, have to do not with the recognition or acceptance we might offer to those who are disabled, but with the strength, compassion, happiness, and wisdom we might gain by the discovery itself, and by our acting on it. The ruling emotion that unites all the various stories told in these books is gratitude, and the reader cannot help but be left grateful as well, for the strengths on display in these stories of children with Down syndrome and of their families are the strengths we today can least do without.

One has only to look at Emily Perl Kingsley, who never gave up on Jason even when established medicine told her to put him away, to see that this is true; at Dr. Skotko, who is devoting his career to fighting for the welfare of people like his sister; at Andi Matthews, who had the guts to give Riley a chance, despite her serious misgivings; at Andrea Mantegna, who looked at his disabled child and saw the image of God. These are people from whom to take our moral bearings—people from whom to learn of hope and courage, of community and human worth, of the meaning of our limitations and of what it means to rise above them; and most of all, these are people who remind us that life is a gift, in all shapes and sizes.

Caitrin Nicol *is assistant editor of* The New Atlantis.