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## The Last Children of Down Syndrome

Prenatal testing is changing who gets born and who doesn't. This is just the beginning.



*Story by Sarah Zhang*

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*Photographs by Julia Sellmann*

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VERY FEW WEEKS or so, Grete Fält-Hansen gets a call from a stranger asking a

**E** question for the first time: What is it like to raise a child with Down syndrome?

Sometimes the caller is a pregnant woman, deciding whether to have an abortion. Sometimes a husband and wife are on the line, the two of them in agonizing disagreement. Once, Fält-Hansen remembers, it was a couple who had waited for their prenatal screening to come back normal before announcing the pregnancy to friends and family. “We wanted to wait,” they’d told their loved ones, “because if it had Down syndrome, we would have had an abortion.” They called Fält-Hansen after their daughter was born—with slanted eyes, a flattened nose, and, most unmistakable, the extra copy of chromosome 21 that defines Down syndrome. They were afraid their friends and family would now think they didn’t love their daughter—so heavy are the moral judgments that accompany wanting or not wanting to bring a child with a disability into the world.



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All of these people get in touch with Fält-Hansen, a 54-year-old schoolteacher, because she heads Landsforeningen Downs Syndrom, or the National Down Syndrome Association, in Denmark, and because she herself has an 18-year-old son, Karl Emil, with Down syndrome. Karl Emil was diagnosed after he was born. She remembers how fragile he felt in her arms and how she worried about his health, but mostly, she remembers, “I thought he was *so* cute.” Two years after he was born, in 2004, Denmark became one of the first countries in the world to offer prenatal Down syndrome screening to every pregnant woman, regardless of age or other risk factors. Nearly all expecting mothers choose to take the test; of those who get a Down syndrome diagnosis, more than 95 percent choose to abort.

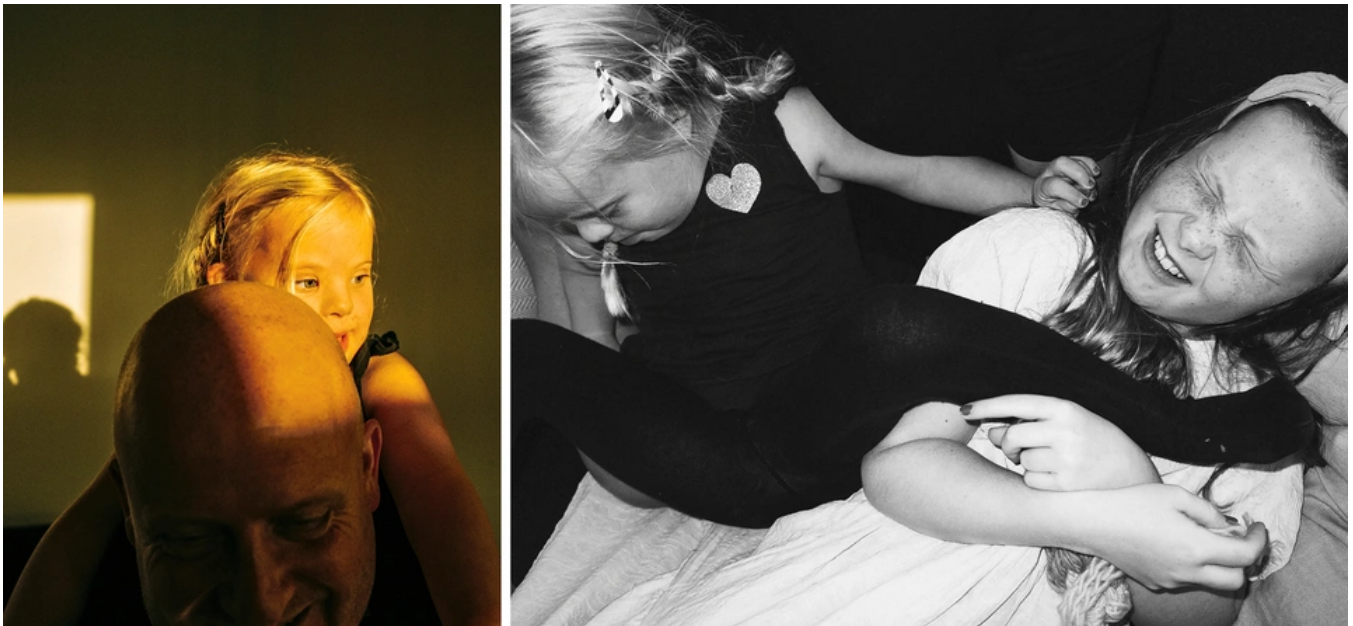
Denmark is not on its surface particularly hostile to disability. People with Down syndrome are entitled to health care, education, even money for the special shoes that fit their wider, more flexible feet. If you ask Danes about the syndrome,

they're likely to bring up Morten and Peter, two friends with Down syndrome who starred in popular TV programs where they cracked jokes and dissected soccer games. Yet a gulf seems to separate the publicly expressed attitudes and private decisions. Since universal screening was introduced, the number of children born with Down syndrome has fallen sharply. In 2019, only 18 were born in the entire country. (About 6,000 children with Down syndrome are born in the U.S. each year.)

Fält-Hansen is in the strange position of leading an organization likely to have fewer and fewer new members. The goal of her conversations with expecting parents, she says, is not to sway them against abortion; she fully supports a woman's right to choose. These conversations are meant to fill in the texture of daily life missing both from the well-meaning cliché that "people with Down syndrome are always happy" and from the litany of possible symptoms provided by doctors upon diagnosis: intellectual disability, low muscle tone, heart defects, gastrointestinal defects, immune disorders, arthritis, obesity, leukemia, dementia. She might explain that, yes, Karl Emil can read. His notebooks are full of poetry written in his careful, sturdy handwriting. He needed physical and speech therapy when he was young. He loves music—his gold-rimmed glasses are modeled after his favorite Danish pop star's. He gets cranky sometimes, like all teens do.

One phone call might stretch into several; some people even come to meet her son. In the end, some join the association with their child. Others, she never hears from again.

These parents come to Fält-Hansen because they are faced with a choice—one made possible by technology that peers at the DNA of unborn children. Down syndrome is frequently called the "canary in the coal mine" for selective reproduction. It was one of the first genetic conditions to be routinely screened for in utero, and it remains the most morally troubling because it is among the least severe. It is very much compatible with life—even a long, happy life.



Elea Aarsø, 6, shown with her father and her sister (and in the opening image), is the youngest of five children. Her parents opted out of the prenatal screening for Down syndrome because, though they support the right to abortion, they knew they would have the baby either way. (Julia Sellmann)

The forces of scientific progress are now marching toward ever more testing to detect ever more genetic conditions. Recent advances in genetics provoke anxieties about a future where parents choose what kind of child to have, or not have. But that hypothetical future is already here. It's been here for an entire generation.

*[ Read: 'I am a man with Down syndrome and my life is worth living.' ]*

Fält-Hansen says the calls she receives are about information, helping parents make a truly informed decision. But they are also moments of seeking, of asking fundamental questions about parenthood. Do you ever wonder, I asked her, about the families who end up choosing an abortion? Do you feel like you failed to prove that your life—and your child's life—is worth choosing? She told me she doesn't think about it this way anymore. But in the beginning, she said, she did worry: "What if they don't like my son?"

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**I**N JANUARY, I took a train from Copenhagen south to the small town of Vordingborg, where Grete, Karl Emil, and his 30-year-old sister, Ann Katrine Kristensen, met me at the station. The three of them formed a phalanx of dark coats waving hello. The weather was typical of January—cold,

gray, blustery—but Karl Emil pulled me over to the ice-cream shop, where he wanted to tell me he knew the employees. His favorite ice-cream flavor, he said, was licorice. “That’s very Danish!” I said. Grete and Ann Katrine translated. Then he zagged over to a men’s clothing store and struck up a conversation with the clerk, who had just seen Karl Emil interviewed on a Danish children’s program with his girlfriend, Chloe. “You didn’t tell me you had a girlfriend,” the clerk teased. Karl Emil laughed, mischievous and proud.

We sat down at a café, and Grete gave her phone to Karl Emil to busy himself with while we spoke in English. He took selfies; his mother, sister, and I began to talk about Down syndrome and the country’s prenatal-screening program. At one point, Grete was reminded of a documentary that had sparked an outcry in Denmark. She reclaimed her phone to look up the title: *Død Over Downs* (“Death to Down Syndrome”). When Karl Emil read over her shoulder, his face crumpled. He curled into the corner and refused to look at us. He had understood, obviously, and the distress was plain on his face.

Grete looked up at me: “He reacts because he can read.”

“He must be aware of the debate?” I asked, which felt perverse to even say. *So he’s aware there are people who don’t want people like him to be born?* Yes, she said; her family has always been open with him. As a kid, he was proud of having Down syndrome. It was one of the things that made him uniquely Karl Emil. But as a teenager, he became annoyed and embarrassed. He could tell he was different. “He actually asked me, at some point, if it was because of Down syndrome that he sometimes didn’t understand things,” Grete said. “I just told him honestly: Yes.” As he’s gotten older, she said, he’s made his peace with it. This arc felt familiar. It’s the arc of growing up, in which our self-assuredness as young children gets upended in the storms of adolescence, but eventually, hopefully, we come to accept who we are.

*Suddenly, a new power was thrust into the hands of ordinary people—the power to decide what kind of life is worth bringing into the world.*

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The decisions parents make after prenatal testing are private and individual ones. But when the decisions so overwhelmingly swing one way—to abort—it does seem to reflect something more: an entire society’s judgment about the lives of people with Down syndrome. That’s what I saw reflected in Karl Emil’s face.

Denmark is unusual for the universality of its screening program and the comprehensiveness of its data, but the pattern of high abortion rates after a Down syndrome diagnosis holds true across Western Europe and, to a somewhat lesser extent, in the United States. In wealthy countries, it seems to be at once the best and the worst time for Down syndrome. Better health care has more than doubled life expectancy. Better access to education means most children with Down syndrome will learn to read and write. Few people speak publicly about wanting to “eliminate” Down syndrome. Yet individual choices are adding up to something very close to that.





Karl Emil Fält-Hansen, who is 18, lives with his family in the small town of Vordingborg, Denmark. (Julia Sellmann)

In the 1980s, as prenatal screening for Down syndrome became common, the anthropologist Rayna Rapp described the parents on the frontier of reproductive technology as “moral pioneers.” Suddenly, a new power was thrust into the hands of ordinary people—the power to decide what kind of life is worth bringing into the world.

The medical field has also been grappling with its ability to offer this power. “If no one with Down syndrome had ever existed or ever would exist—is that a terrible thing? I don’t know,” says Laura Hercher, a genetic counselor and the director of student research at Sarah Lawrence College. If you take the health complications linked to Down syndrome, such as increased likelihood of early-onset Alzheimer’s, leukemia, and heart defects, she told me, “I don’t think anyone would argue that those are good things.”

But she went on. “If our world didn’t have people with special needs and these vulnerabilities,” she asked, “would we be missing a part of our humanity?”

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**S**IXTY-ONE YEARS AGO, the first known prenatal test for a genetic disorder in the world took place in Copenhagen. The patient was a 27-year-old woman who was a carrier for hemophilia, a rare and severe bleeding disorder that is passed from mothers to sons. She had already given birth to one infant boy, who lived for just five hours. The obstetrician who delivered the baby, Fritz Fuchs, told her to come back if she ever became pregnant again. And in 1959, according to the published case study, she did come back, saying she couldn’t go through with her pregnancy if she was carrying another son.

Fuchs had been thinking about what to do. Along with a cytologist named Povl Riis, he’d been experimenting with using fetal cells floating in the yellow amniotic fluid that fills the womb to determine a baby’s sex. A boy would have a 50 percent risk of inheriting hemophilia; a girl would have almost no risk. But first they needed some amniotic fluid. Fuchs eased a long needle into the woman’s abdomen; Riis studied the cells under a microscope. It was a girl.

The woman gave birth to a daughter a few months later. If the baby had been a boy, though, she was prepared to have an abortion—which was legal under



Danish law at the time on “eugenic grounds” for fetuses at risk for severe mental or physical illness, according to Riis and Fuchs’s paper describing the case. They acknowledged the possible danger of sticking a needle in the abdomen of a pregnant woman, but wrote that it was justified “because the method seems to be useful in preventive eugenics.”

That word, *eugenics*, today evokes images that are specific and heinous: forced sterilization of the “feebleminded” in early-20th-century America, which in turn inspired the racial hygiene of the Nazis, who gassed or otherwise killed tens of thousands of people with disabilities, many of them children. But eugenics was once a mainstream scientific pursuit, and eugenicists believed that they were bettering humanity. Denmark, too, drew inspiration from the U.S., and it passed a sterilization law in 1929. Over the next 21 years, 5,940 people were sterilized in Denmark, the majority because they were “mentally retarded.” Those who resisted sterilization were threatened with institutionalization.

Eugenics in Denmark never became as systematic and violent as it did in Germany, but the policies came out of similar underlying goals: improving the health of a nation by preventing the birth of those deemed to be burdens on society. The term *eugenics* eventually fell out of favor, but in the 1970s, when Denmark began offering prenatal testing for Down syndrome to mothers over the age of 35, it was discussed in the context of saving money—as in, the testing cost was less than that of institutionalizing a child with a disability for life. The stated purpose was “to prevent birth of children with severe, lifelong disability.”

That language too has long since changed; in 1994, the stated purpose of the testing became “to offer women a choice.” Activists like Fält-Hansen have also pushed back against the subtle and not-so-subtle ways that the medical system encourages women to choose abortion. Some Danish parents told me that doctors automatically assumed they would want to schedule an abortion, as if there was really no other option. This is no longer the case, says Puk Sandager, a fetal-medicine specialist at Aarhus University Hospital. Ten years ago, doctors—especially older doctors—were more likely to expect parents to terminate, she told me. “And now we do not expect anything.” The National Down Syndrome Association has also worked with doctors to alter the language they use with patients—“probability” instead of “risk,” “chromosome aberration” instead of

“chromosome error.” And, of course, hospitals now connect expecting parents with people like Fält-Hansen to have those conversations about what it’s like to raise a child with Down syndrome.

*[ Pepper Stetler: The gap between my daughter and her peers is growing ]*

Perhaps all of this has had some effect, though it’s hard to say. The number of babies born to parents who chose to continue a pregnancy after a prenatal diagnosis of Down syndrome in Denmark has ranged from zero to 13 a year since universal screening was introduced. In 2019, there were seven. (Eleven other babies were born to parents who either declined the test or got a false negative, making the total number of babies born with Down syndrome last year 18.)

Why so few? “Looking at it from the outside, a country like Denmark, if you want to raise a child with Down syndrome, this is a good environment,” says Stina Lou, an anthropologist who has studied how parents make decisions after a prenatal diagnosis of a fetal anomaly. Since 2011, she has embedded in the fetal-medicine unit at Aarhus University Hospital, one of the largest hospitals in Denmark, where she has shadowed Sandager and other doctors.

Under the 2004 guidelines, all pregnant women in Denmark are offered a combined screening in the first trimester, which includes blood tests and an ultrasound. These data points, along with maternal age, are used to calculate the odds of Down syndrome. The high-probability patients are offered a more invasive diagnostic test using DNA either from the fetal cells floating in the amniotic fluid (amniocentesis) or from placental tissue (chorionic villus sampling). Both require sticking a needle or catheter into the womb and come with a small risk of miscarriage. More recently, hospitals have started offering noninvasive prenatal testing, which uses fragments of fetal DNA floating in the mother’s blood. That option has not become popular in Denmark, though, probably because the invasive tests can pick up a suite of genetic disorders in addition to Down syndrome. More diseases ruled out, more peace of mind.

But Lou was interested in the times when the tests did not provide peace of mind, when they in fact provided the opposite. In a study of 21 women who chose abortion after a prenatal diagnosis of Down syndrome, she found that they

had tended to base their decisions on worst-case scenarios. An extra copy of chromosome 21 can cause a variety of symptoms, the severity of which is not known until birth or even later. Most people with Down syndrome learn to read and write. Others are nonverbal. Some do not have heart defects. Others spend months or even years in and out of the hospital to fix a heart valve. Most have healthy digestive systems. Others lack the nerve endings needed to anticipate bowel movements, necessitating more surgeries, possibly even a stoma bag or diapers. The women who chose abortion feared the worst possible outcomes. Some even grieved the possibility of aborting a child who might have had a mild form of Down syndrome. But in the end, Lou told me, “the uncertainty just becomes too much.”



Stina Lou, an anthropologist, studies the decisions prospective parents make after a prenatal diagnosis of an anomaly. (Julia Sellmann)

This emphasis on uncertainty came up when I spoke with David Wasserman, a bioethicist at the U.S. National Institutes of Health who, along with his



collaborator Adrienne Asch, has written some of the most pointed critiques of selective abortion. (Asch died in 2013.) They argued that prenatal testing has the effect of reducing an unborn child to a single aspect—Down syndrome, for example—and making parents judge the child’s life on that alone. Wasserman told me he didn’t think that most parents who make these decisions are seeking perfection. Rather, he said, “there’s profound risk aversion.”

It’s hard to know for sure whether the people in Lou’s study decided to abort for the reasons they gave or if these were retrospective justifications. But when Lou subsequently interviewed parents who had made the unusual choice to continue a pregnancy after a Down syndrome diagnosis, she found them more willing to embrace uncertainty.

Parents of children with Down syndrome have described to me the initial process of mourning the child they thought they would have: the child whom they were going to walk down the aisle, who was going to graduate from college, who was going to become president. None of this is guaranteed with any kid, of course, but while most parents go through a slow realignment of expectations over the years, prenatal testing was a rapid plummet into disappointment—all those dreams, however unrealistic, evaporating at once. And then the doctors present you with a long list of medical conditions associated with Down syndrome. Think about it this way, Karl Emil’s sister, Ann Katrine, said: “If you handed any expecting parent a whole list of everything their child could possibly encounter during their entire life span—illnesses and stuff like that—then anyone would be scared.”

“Nobody would have a baby,” Grete said.

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**A** PECULIAR EFFECT of Denmark’s universal-screening program and high abortion rate for Down syndrome is that a fair number of babies born with Down syndrome are born to parents who essentially got a false negative. Their first-trimester screening results said their odds were very low—so low that they needed no invasive follow-up testing. They simply went on with what they thought was an ordinary pregnancy. In other words, like the couple

Grete once counseled, these are parents who might have chosen to abort, had they known.

The day after I met Grete, I attended a meeting of the local Copenhagen Down syndrome group. The woman who invited me, Louise Aarsø, had a then-5-year-old daughter with Down syndrome, Elea. Aarsø and her husband had made the unusual choice to opt out of screening. Though they support the right to abortion, they knew they would want to have the baby either way. At the meeting, two of the seven other families told me their prenatal screening had suggested extremely low odds. At birth, they were surprised. A few others said they had chosen to continue the pregnancy despite a high probability for Down syndrome. Ulla Hartmann, whose son Ditlev was 18, noted that he was born before the national screening program began. “We’re very thankful we didn’t know, because we had two twin boys when I got pregnant with Ditlev and I really don’t think we would have been, ‘Okay, let’s take this challenge when we have these monkeys up in the curtains,’” she told me. “But you grow with the challenge.”

Daniel Christensen was one of the parents who had been told the odds of Down syndrome were very low, something like 1 in 1,500. He and his wife didn’t have to make a choice, and when he thinks back on it, he said, “what scares me the most is actually how little we knew about Down syndrome.” What would the basis of their choice have been? Their son August is 4 now, with a twin sister, who Christensen half-jokingly said was “almost normal.” The other parents laughed. “Nobody’s normal,” he said.

Then the woman to my right spoke; she asked me not to use her name. She wore a green blouse, and her blond hair was pulled into a ponytail. When we all turned to her, I noticed that she had begun to tear up. “Now I’m moved from all the stories; I’m a little ...” She paused to catch her breath. “My answer is not that beautiful.” The Down syndrome odds for her son, she said, were 1 in 969.

“You remember the exact number?” I asked.

“Yeah, I do. I went back to the papers.” The probability was low enough that she didn’t think about it after he was born. “On the one hand I saw the problems. And on the other hand he was perfect.” It took four months for him to get

diagnosed with Down syndrome. He is 6 now, and he cannot speak. It frustrates him, she said. He fights with his brother and sister. He bites because he cannot express himself. “This has just been *so many times*, and you never feel safe.” Her experience is not representative of all children with Down syndrome; lack of impulse control is common, but violence is not. Her point, though, was that the image of a happy-go-lucky child so often featured in the media is not always representative either. She wouldn’t have chosen this life: “We would have asked for an abortion if we knew.”

Another parent chimed in, and the conversation hopscotched to a related topic and then another until it had moved on entirely. At the end of the meeting, as others stood and gathered their coats, I turned to the woman again because I was still shocked that she was willing to say what she’d said. Her admission seemed to violate an unspoken code of motherhood.

Of course, she said, “it’s shameful if I say these things.” She loves her child, because how can a mother not? “But you love a person that hits you, bites you? If you have a husband that bites you, you can say goodbye ... but if you have a child that hits you, you can’t do anything. You can’t just say, ‘I don’t want to be in a relationship.’ Because it’s your child.” To have a child is to begin a relationship that you cannot sever. It is supposed to be unconditional, which is perhaps what most troubles us about selective abortion—it’s an admission that the relationship can in fact be conditional.

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**P**ARENTING IS A PLUNGE into the unknown and the uncontrollable. It is beautiful in this way, but also daunting.

In the cold, scientific realm of biology, reproduction begins with a random genetic shuffling—an act of fate, if you were to be less cold, more poetic. The 23 pairs of chromosomes in our cells line up so that the DNA we inherited from our mother and father can be remixed and divided into sets of 23 single chromosomes. Each egg or sperm gets one such set. In women, this chromosomal division begins, remarkably, when they themselves are fetuses in *their* mother’s womb. The chromosomes freeze in place for 20, 30, even 40-plus years as the fetus becomes a baby, a girl, a woman. The cycle finishes only when

the egg is fertilized. During the intervening years, the proteins holding chromosomes together can degrade, resulting in eggs with too many or too few chromosomes. This is the biological mechanism behind most cases of Down syndrome—95 percent of people born with an extra copy of chromosome 21 inherited it from their mother. And this is why the syndrome is often, though not always, linked to the age of the mother.





A Danish woman who chose abortion after a prenatal diagnosis of Down syndrome said she was disappointed to find so little in the media about women who had made the same decision. (Julia Sellmann)

In the interviews I've conducted, and in interviews Lou and researchers across the U.S. have conducted, the choice of what to do after a prenatal test fell

disproportionately on mothers. There were fathers who agonized over the choice too, but mothers usually bore most of the burden. There is a feminist explanation (my body, my choice) and a less feminist one (family is still primarily the domain of women), but it's true either way. And in making these decisions, many of the women seemed to anticipate the judgment they would face.

Lou told me she had wanted to interview women who chose abortion after a Down syndrome diagnosis because they're a silent majority. They are rarely interviewed in the media, and rarely willing to be interviewed. Danes are quite open about abortion—astonishingly so to my American ears—but abortions for a fetal anomaly, and especially Down syndrome, are different. They still carry a stigma. “I think it's because we as a society like to think of ourselves as inclusive,” Lou said. “We are a rich society, and we think it's important that different types of people should be here.” And for some of the women who end up choosing abortion, “their own self-understanding is a little shaken, because they have to accept they aren't the kind of person like they thought,” she said. They were not the type of person who would choose to have a child with a disability.

For the women in Lou's study, ending a pregnancy after a prenatal diagnosis was very different from ending an unwanted pregnancy. These were almost all wanted pregnancies, in some cases very much wanted pregnancies following long struggles with infertility. The decision to abort was not taken lightly. One Danish woman I'll call “L” told me how terrible it was to feel her baby inside her once she'd made the decision to terminate. In the hospital bed, she began sobbing so hard, the staff had difficulty sedating her. The depth of her emotions surprised her, because she was so sure of her decision. The abortion was two years ago, and she doesn't think about it much anymore. But recounting it on the phone, she began crying again.

She was disappointed to find so little in the media about the experiences of women like her. “It felt right for me, and I have no regrets at all,” she told me, but it also feels like “you're doing something wrong.” L is a filmmaker, and she wanted to make a documentary about choosing abortion after a Down syndrome diagnosis. She even thought she would share her own story. But she hadn't been

able to find a couple willing to be in this documentary, and she wasn't ready to put herself out there alone.

When Rayna Rapp, the anthropologist who coined the term *moral pioneers*, interviewed parents undergoing prenatal testing in New York in the 1980s and '90s, she noticed a certain preoccupation among certain women. Her subjects represented a reasonably diverse slice of the city, but middle-class white women especially seemed fixated on the idea of “selfishness.” The women she interviewed were among the first in their families to forgo homemaking for paid work; they had not just jobs but *careers* that were central to their identity. With birth control, they were having fewer children and having them later. They had more reproductive autonomy than women had ever had in human history. (Rapp herself came to this research after having an abortion because of Down syndrome when she became pregnant as a 36-year-old professor.) “Medical technology transforms their ‘choices’ on an individual level, allowing them, like their male partners, to imagine voluntary limits to their commitments to their children,” Rapp wrote in her book *Testing Women, Testing the Fetus*.

*“I have guilt for not being the kind of person who could parent this particular type of special need,” one woman said. “Guilt, guilt, guilt.”*

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But exercising those “voluntary limits” on motherhood—choosing not to have a child with a disability out of fear for how it might affect one's career, for example—becomes judged as “selfishness.” Medical technology can offer women a choice, but it does not instantly transform the society around them. It does not dismantle the expectation that women are the primary caregivers or erase the ideal of a good mother as one who places no limits on her devotion to her children.

The centrality of choice to feminism also brings it into uncomfortable conflict with the disability-rights movement. Anti-abortion-rights activists in the U.S. have seized on this to introduce bills banning selective abortion for Down syndrome in several states. Feminist disability scholars have attempted to resolve the conflict by arguing that the choice is not a real choice at all. “The decision to

abort a fetus with a disability even because it ‘just seems too difficult’ must be respected,” Marsha Saxton, the director of research at the World Institute on Disability, wrote in 1998. But Saxton calls it a choice made “under duress,” arguing that a woman faced with this decision is still constrained today—by popular misconceptions that make life with a disability out to be worse than it actually is and by a society that is hostile to people with disabilities.

*[ Pasquale Toscano and Alexis Doyle: Selective-abortion bans treat disability as a tragedy.]*

And when fewer people with disabilities are born, it becomes harder for the ones who *are* born to live a good life, argues Rosemarie Garland-Thomson, a bioethicist and professor emerita at Emory University. Fewer people with disabilities means fewer services, fewer therapies, fewer resources. But she also recognizes how this logic pins the entire weight of an inclusive society on individual women.





Sally Dybkjær Andersson, age 6, is one of very few children in Denmark with Down syndrome. Since universal prenatal screening was introduced in 2004, the number of children in the country born with the syndrome has fallen sharply. In 2019, it was just 18. (Julia Sellmann)

No wonder, then, that “choice” can feel like a burden. In one small study of women in the U.S. who chose abortion after a diagnosis of a fetal anomaly, two-thirds said they’d hoped—or even prayed—for a miscarriage instead. It’s not that they wanted their husbands, their doctors, or their lawmakers to tell them what to do, but they recognized that choice comes with responsibility and invites judgment. “I have guilt for not being the kind of person who could parent this particular type of special need,” said one woman in the study. “Guilt, guilt, guilt.”

The introduction of a choice reshapes the terrain on which we all stand. To opt out of testing is to become someone who *chose* to opt out. To test and end a pregnancy because of Down syndrome is to become someone who *chose* not to have a child with a disability. To test and continue the pregnancy after a Down syndrome diagnosis is to become someone who *chose* to have a child with a disability. Each choice puts you behind one demarcating line or another. There is no neutral ground, except perhaps in hoping that the test comes back negative and you never have to choose what’s next.

What kind of choice is this, if what you hope is to not have to choose at all?

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**D**OWN SYNDROME IS unlikely to ever disappear from the world completely. As women wait longer to have children, the incidence of pregnancies with an extra copy of chromosome 21 is going up. Prenatal testing can also in rare cases be wrong, and some parents will choose not to abort or not to test at all. Others will not have access to abortion.

In the United States—which has no national health-care system, no government mandate to offer prenatal screening—the best estimate for the termination rate after a diagnosis of Down syndrome is 67 percent. But that number conceals stark differences within the country. One study found higher rates of termination in the West and Northeast and among mothers who are highly educated. “On the Upper East Side of Manhattan, it’s going to be completely different than in Alabama,” said Laura Hercher, the genetic counselor.

*How do you choose between one embryo with a slightly elevated risk of schizophrenia and another with a moderate risk of breast cancer?*

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These differences worry Hercher. If only the wealthy can afford to routinely screen out certain genetic conditions, then those conditions can become proxies of class. They can become, in other words, *other people's problems*. Hercher worries about an empathy gap in a world where the well-off feel insulated from sickness and disability.

For those with the money, the possibilities of genetic selection are expanding. The leading edge is preimplantation genetic testing (PGT) of embryos created through in vitro fertilization, which altogether can cost tens of thousands of dollars. Labs now offer testing for a menu of genetic conditions—most of them rare and severe conditions such as Tay-Sachs disease, cystic fibrosis, and phenylketonuria—allowing parents to select healthy embryos for implantation in the womb. Scientists have also started trying to understand more common conditions that are influenced by hundreds or even thousands of genes: diabetes, heart disease, high cholesterol, cancer, and—much more controversially—mental illness and autism. In late 2018, Genomic Prediction, a company in New Jersey, began offering to screen embryos for risk of hundreds of conditions, including schizophrenia and intellectual disability, though it has since quietly backtracked on the latter. The one test customers keep asking for, the company's chief scientific officer told me, is for autism. The science isn't there yet, but the demand is.

The politics of prenatal testing for Down syndrome and abortion are currently yoked together by necessity: The only intervention offered for a prenatal test that finds Down syndrome is an abortion. But modern reproduction is opening up more ways for parents to choose what kind of child to have. PGT is one example. Sperm banks, too, now offer detailed donor profiles delineating eye color, hair color, education; they also screen donors for genetic disorders. Several parents have sued sperm banks after discovering that their donor may have undesirable genes, in cases where their children developed conditions such as autism or a degenerative nerve disease. In September, the Georgia Supreme

Court ruled that one such case, in which a sperm donor had hidden his history of mental illness, could move forward. The “deceptive trade practices” of a sperm bank that misrepresented its donor-screening process, the court ruled, could “essentially amount to ordinary consumer fraud.”



August Bryde Christensen, who is 4, was born after his parents were told that the odds of Down syndrome were extremely low. His father says he's relieved they didn't know. (Julia Sellmann)

Garland-Thomson calls this commercialization of reproduction “velvet eugenics”—*velvet* for the soft, subtle way it encourages the eradication of disability. Like the Velvet Revolution from which she takes the term, it's accomplished without overt violence. But it also takes on another connotation as human reproduction becomes more and more subject to consumer choice: *velvet*, as in quality, high-caliber, premium-tier. Wouldn't you want only the best for your baby—one you're already spending tens of thousands of dollars on IVF to conceive? “It turns people into products,” Garland-Thomson says.

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**N**ONE OF THIS suggests that testing should be entirely abandoned. Most parents choosing genetic testing are seeking to spare their children real physical suffering. Tay-Sachs disease, for example, is caused by mutations in the *HEXA* gene, which causes the destruction of neurons in the brain and spinal cord. At about three to six months old, babies begin losing motor skills, then their vision and hearing. They develop seizures and paralysis. Most do not live past childhood. There is no cure.



In the world of genetic testing, Tay-Sachs is a success story. It has been nearly eliminated through a combination of prenatal testing of fetuses; preimplantation testing of embryos; and, in the Ashkenazi Jewish population, where the mutation is especially prevalent, carrier screening to discourage marriages between people who might together pass on the mutation. The flip side of this success is that having a baby with the disease is no longer simple misfortune because nothing could have been done. It can be seen instead as a failure of personal responsibility.

Fertility doctors have spoken to me passionately about expanding access to IVF for parents who are fertile but who might use embryo screening to prevent passing on serious diseases. In a world where IVF becomes less expensive and less hard on a woman's body, this might very well become the responsible thing to do. And if you're already going through all this to screen for one disease, why not avail yourself of the whole menu of tests? The hypothetical that Karl Emil's sister imagined, in which a child's every risk is laid out, feels closer than ever. How do you choose between one embryo with a slightly elevated risk of schizophrenia and another with a moderate risk of breast cancer?

Not surprisingly, those advocating for preimplantation genetic testing prefer to keep the conversation focused on monogenic diseases, where single gene mutations have severe health effects. Talk of minimizing the risk of conditions like diabetes and mental illness—which are also heavily influenced by environment—quickly turns to designer babies. “Why do we want to go there?” says David Sable, a former IVF doctor who is now a venture capitalist specializing in life sciences. “Start with the most scientifically straightforward, the monogenic diseases—cystic fibrosis, sickle cell anemia, hemophilia—where you could define very specifically what the benefit is.”

What about Down syndrome, then, I asked, which can be much less severe than those diseases but is routinely screened for anyway? His answer surprised me, considering that he has spent much of his career working with labs that count chromosomes: “The concept of counting chromosomes as a definitive indicator of the truth—I think we're going to look back on that and say, ‘Oh my God, we were so misguided.’” Consider the sex chromosomes, he said. “We've locked ourselves into this male-female binary that we enforced with XX and XY.” But

it's not nearly so neat. Babies born XX can have male reproductive organs; those born XY can have female reproductive organs. And others can be born with an unusual number of sex chromosomes like X, XXY, XYY, XXYY, XXXX, the effects of which range widely in severity. Some might never know there's anything unusual in their chromosomes at all.

When Rayna Rapp was researching prenatal testing back in the '80s and '90s, she came across multiple sets of parents who chose to abort a fetus with a sex-chromosome anomaly out of fear that it could lead to homosexuality—never mind that there is no known link. They also worried that a boy who didn't conform to XY wouldn't be masculine enough. Reading about their anxieties 30 years later, I could sense how much the ground had moved under our feet. Of course, some parents might still have the same fears, but today the boundaries of “normal” for gender and sexuality encompass much more than the narrow band of three decades ago. A child who is neither XX nor XY can fit into today's world much more easily than in a rigidly gender-binary one.

Both sex-chromosome anomalies and Down syndrome were early targets of prenatal testing—not because they are the most dangerous conditions but because they were the easiest to test for. It's just counting chromosomes. As science moves past this relatively rudimentary technique, Sable mused, “the term *Down syndrome* is probably going to go away at some point, because we may find that having that third 21 chromosome maybe does not carry a predictable level of suffering or altered function.” Indeed, most pregnancies with a third copy of chromosome 21 end as miscarriages. Only about 20 percent survive to birth, and the people who are born have a wide range of intellectual disabilities and physical ailments. How can an extra chromosome 21 be incompatible with life in some cases and in other cases result in a boy, like one I met, who can read and write and perform wicked juggling tricks with his diabolo? Clearly, something more than just an extra chromosome is going on.

As genetic testing has become more widespread, it has revealed just how many other genetic anomalies many of us live with—not only extra or missing chromosomes, but whole chunks of chromosome getting deleted, chunks duplicated, chunks stuck onto a different chromosome altogether, mutations that should be deadly but that show up in the healthy adult in front of you. Every



person carries a set of mutations unique to them. This is why new and rare genetic diseases are so hard to diagnose—if you compare a person’s DNA with a reference genome, you come up with hundreds of thousands of differences, most of them utterly irrelevant to the disease. What, then, is normal? Genetic testing, as a medical service, is used to enforce the boundaries of “normal” by screening out the anomalous, but seeing all the anomalies that are compatible with life might actually expand our understanding of normal. “It’s expanded mine,” Sable told me.



Grete Fält-Hansen and her son, Karl Emil, have met many expecting parents who are deciding what to do after a prenatal diagnosis of Down syndrome. (Julia Sellmann)

Sable offered this up as a general observation. He didn’t think he was qualified to speculate on what this meant for the future of Down syndrome screening, but I found this conversation about genetics unexpectedly resonant with something parents had told me. David Perry, a writer in Minnesota whose 13-year-old son has Down syndrome, said he disliked how people with Down syndrome are portrayed as angelic and cute; he found it flattening and dehumanizing. He pointed instead to the way the neurodiversity movement has worked to bring autism and ADHD into the realm of normal neurological variation. “We need more kinds of normal,” another father, Johannes Dybkjær Andersson, a musician and creative director in Copenhagen, said. “That’s a good thing, when people show up in our lives”—as his daughter, Sally, did six years ago—“and they are just normal in a totally different way.” Her brain processes the world differently than his does. She is unfiltered and open. Many parents have told me how this

quality can be awkward or disruptive at times, but it can also break the stifling bounds of social propriety.

Stephanie Meredith, the director of the National Center for Prenatal and Postnatal Resources at the University of Kentucky, told me of the time her 20-year-old son saw his sister collide with another player on the basketball court. She hit the ground so hard that an audible crack went through the gym. Before Meredith could react, her son had already leapt from the bleachers and picked his sister up. “He wasn’t worried about the rules; he wasn’t worried about decorum. It was just responding and taking care of her,” Meredith told me. She had recently been asked a simple but probing question: What was she most proud of about her son that was not an achievement or a milestone? The incident on the basketball court was one that came to mind. “It doesn’t have to do with accomplishment,” she said. “It has to do with caring about another human being.”

That question had stayed with Meredith—and it stayed with me—because of how subtly yet powerfully it reframes what parents should value in their children: not grades or basketball trophies or college-acceptance letters or any of the things parents usually brag about. By doing so, it opens the door to a world less obsessed with achievement. Meredith pointed out that Down syndrome is defined and diagnosed by a medical system made up of people who have to be highly successful to get there, who likely base part of their identity on their intelligence. This is the system giving parents the tools to decide what kind of children to have. Might it be biased on the question of whose lives have value?

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**W**HEN MARY WASSERMAN gave birth to her son, Michael, in 1961, kids with Down syndrome in America were still routinely sent to state institutions. She remembers the doctor announcing, “It’s a mongoloid idiot”—the term used before chromosome counting became common—and telling her “it” should go to the state institution right away. Wasserman had volunteered for a week at such an institution in high school, and she would never forget the sights, the sounds, the *smells*. The children were soiled, uncared for, unnurtured. In defiance of her doctor, she took Michael home.

The early years were not easy for Wasserman, who was a divorced mother for much of Michael's childhood. She worked to support them both. There weren't really any formal day cares then, and the women who ran informal ones out of their homes didn't want Michael. "The other mothers were not comfortable," one of them told her after his first week. Others rejected him outright. She hired private babysitters, but Michael didn't have playmates. It wasn't until he was 8, when a school for kids with disabilities opened nearby, that Michael went to school for the first time.

Michael is 59 now. The life of a child born with Down syndrome today is very different. State institutions closed down after exposés of the unsanitary and cruel conditions that Wasserman had glimpsed as a high-school student. After children with disabilities go home from the hospital today, they have access to a bevy of speech, physical, and occupational therapies from the government—usually at no cost to families. Public schools are required to provide equal access to education for kids with disabilities. In 1990, the Americans With Disabilities Act prohibited discrimination in employment, public transportation, day cares, and other businesses. Inclusion has made people with disabilities a visible and normal part of society; instead of being hidden away in institutions, they live among everyone else. Thanks to the activism of parents like Wasserman, all of these changes have taken place in her son's lifetime.

Does she wish Michael had had the opportunities that kids have now? "Well," she says, "I think maybe in some ways it was easier for us." Of course the therapies would have helped Michael. But there's more pressure on kids and parents today. She wasn't shuttling Michael to appointments or fighting with the school to get him included in general classes or helping him apply to the college programs that have now proliferated for students with intellectual disabilities. "It was less stressful for us than it is today," she says. Raising a child with a disability has become a lot more intensive—not unlike raising any child.

I can't count how many times, in the course of reporting this story, people remarked to me, "You know, people with Down syndrome work and go to college now!" This is an important corrective to the low expectations that persist and a poignant reminder of how a transforming society has transformed the lives of people with Down syndrome. But it also does not capture the full range of

experiences, especially for people whose disabilities are more serious and those whose families do not have money and connections. Jobs and college are achievements worth celebrating—like any kid’s milestones—but I’ve wondered why we so often need to point to achievements for evidence that the lives of people with Down syndrome are meaningful.

When I had asked Grete Fält-Hansen what it was like to open up her life to parents trying to decide what to do after a prenatal diagnosis of Down syndrome, I suppose I was asking her what it was like to open up her life to the judgment of those parents—and also of me, a journalist, who was here asking the same questions. As she told me, she had worried at first that people might not like her son. But she understands now how different each family’s circumstances can be and how difficult the choice can be. “I feel sad about thinking about pregnant women and the fathers, that they are met with this choice. It’s almost impossible,” she said. “Therefore, I don’t judge them.”

Karl Emil had grown bored while we talked in English. He tugged on Grete’s hair and smiled sheepishly to remind us that he was still there, that the stakes of our conversation were very real and very human.

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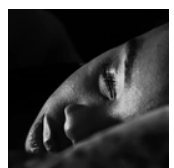
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