

1 Becoming

Margaret Mead must have taken the call with excitement, expecting to offer congratulations. I imagine her delight quickly dissolved into dismay.

On the phone was Erik Erikson, at the time a little known forty-two-year-old child psychologist practicing in Berkeley. Born in Vienna, he had been trained in psychoanalysis by Anna Freud and came to the United States as Adolf Hitler began his brutal ascent to power. Erikson's work with children at the Pine Ridge Reservation in South Dakota, and his later collaboration with anthropologist Alfred Kroeber among the Yurok Tribe in Northern California influenced his theory of personality formation, which emphasized an individual's journey through developmental stages over the course of a lifetime. Each stage involves resolution of an existential crisis, as individuals reconcile their psychological needs with social expectations. His book *Childhood and Society*, published in 1950, would rocket him to international renown as an author and academic. At the time of the phone call, Mead and Erikson had known each other for years, connecting over their shared interest in the role of culture in shaping childhood and the socialization of children into adults. Erikson's wife, Joan, a Canadian dancer and artist he had met in Vienna and his lifelong collaborator, was expecting the couple's fourth child.

Hearing Erikson's somber tone, Mead would have pressed the phone against her ear, listening intently.

Joan had just given birth to a son they had named Neil. It was 1944. Franklin D. Roosevelt would soon be elected to a fourth term as president of the United States as World War II entered its final year. Like other social scientists of the time, both Mead and Erikson participated in research and writing for the war effort, with Mead contributing to national character studies and Erikson analyzing Hitler's rise to totalitarianism, a psychology of Nazism.¹ Joan's labor had been difficult, Erikson told Mead, and surgery followed. She was still heavily sedated. The doctors, he said, had just given him unexpected news.

Your son, they told Erikson, suffers from "Mongolian idiocy," a reference to what is now called Down syndrome. The baby should be put away.

In that era, it was routine for doctors to recommend that "mongoloids" be sent to special institutions. They told parents like the Eriksons that their babies would likely die before reaching two years old. That they would never learn to read.² Raising a mongoloid would sap the mother's emotional energy, her constant fatigue and detachment becoming a psychological burden for the other children, the normal ones.

Unsure of what to do, Erikson phoned his friend Margaret Mead.

After they encountered each other in 1934 at a month-long conference in Hanover, New Hampshire, just a year after he came to the United States, Erikson became close with Mead as well as with other anthropologists such as Ruth Benedict, both of whom influenced his thinking on identity and personality.³ Mead was known for questioning norms and challenging authority. As a young woman in the late 1920s, she left her first husband and travelled to Samoa for research as she completed her PhD at Columbia University's Barnard College. A young American woman traveling by herself across the Pacific Ocean to study an exotic culture was a newsworthy endeavor, comparable with those of other trailblazing women who charmed the public imagination, such as Amelia Earhart. Her field research became the basis of her 1928 book *Coming of Age in Samoa*, a cultural analysis of adolescence that explored the sexual lives of teenage girls. Based on the relatively carefree experiences of Samoan teenagers, she argued that the sexual angst experienced by Americans was hardly universal or determined by human biology, but rather a product of

cultural learning. The provocative book quickly became a bestseller, launching Mead's career as a famous intellectual. An adventurous image of Mead took shape in the public imagination: bushy hair cropped just below her ears, parted down the middle with bangs curving like crescent moons around prominent cheek bones, slack cotton dress with short sleeves and large pockets near the hip for her notebooks, its open collar revealing pale skin drenched with tropical sun. The image is one of a gentle, contemplative White woman sitting among dark-skinned native children.

By the time Neil was born, Mead was a giant in the blossoming field of anthropology who had cultivated an uncommon celebrity. *Coming of Age in Samoa* was followed just two years later with *Growing Up in New Guinea*, establishing her as a pioneering anthropologist and expert on the role of culture in the psychological development of children. It is through childrearing that something anthropologists had only recently started calling "culture"—the learned behaviors, norms, and beliefs that make a people unique—is transmitted from one generation to another. But childrearing practices also form a window into how shared cultural values and beliefs become imprinted into the personality of individuals. In 1942, she published *And Keep Your Powder Dry: An Anthropologist Looks at America*, solidifying her status as an anthropologist who studied unfamiliar peoples to reflect on and challenge her own culture's way of doing things.

Over the years, Mead had become a "strong, guiding female presence" in Erikson's life.⁴ When Erikson called her, she was not only a friend, but also an expert who could offer a unique perspective on the crisis he was facing. As perhaps the best-known student of Franz Boas, the German-born scholar who had reshaped American anthropology in the early twentieth century, Mead embraced a broad understanding of what it means to be human and was intimately familiar with the varied ways in which families are formed across cultures. She and others in the Boasian circle, such as Ruth Benedict and Edward Sapir, also challenged the racial and biological explanations of human difference that dominated in the United States and inspired the atrocities of the Nazi regime in Europe. Mead is still remembered today for championing alternative ways of being human, for a fervent tolerance of diversity and respect for humanity in all its forms.⁵

She also tested the limits of Western cultural norms in her personal life. In an era when women were expected to fill conventional roles as wives, mothers, and homemakers, Mead was an independent professional who married and divorced three times and cultivated close, intimate relationships with other women, including Benedict. When Erikson called, she was the mother of a four-year-old daughter, a child with her third husband, Gregory Bateson. She famously drew on her cross-cultural experiences to challenge American childrearing norms, which in the 1940s emphasized rigid schedules and discouraged breastfeeding, and Benjamin Spock was her daughter's pediatrician.⁶ *If anyone could advise Erikson, it would be Margaret Mead.*

Send it away. At once. Institutionalize the child, Mead told Erikson.

Don't let Joan get attached. If Joan were to hold her newborn, even one time, or even see it, the ordeal would be more difficult for her. Caring for a mongoloid would be damaging to the other children and the family's stability, Mead reasoned.⁷

Neil was gone when Joan regained consciousness. Erik informed her of what happened. Then he went home to his three other children. He wanted to protect his family, but instead he had planted the seed of a shared psychological trauma that would haunt them for decades. Neil's sister, Sue, was five years old at the time. "I anticipated the arrival of Neil with a special excitement," she recalls in her memoir. "Mom and I were to share something very special. I imagined that I would be needed and would earn Mom's love and approval by helping her with the baby's care. I would learn from her how to be a mother, and we would be close."

"Dad arrived to give me the news," she continues. "His face was anguished. The baby, he said, had died at birth."⁸

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I am both an anthropologist and the father of a daughter with Down syndrome, so this story hits me close to home. I have wrestled with that same impulse to reject my own child, to deny her basic humanity. And I have turned to my training in anthropology, with mixed feelings about what I found, to help resolve the emotional turmoil.

For me, it began in February 2015. Barack Obama was still president and the world felt like a predictable place. The previous fall, a wave of unrest had swept through Ferguson, Missouri after the death of Michael Brown at the hands of the police, propelling the Black Lives Matter movement to national consciousness, but the upheaval remained localized, a story in the news. Donald Trump had yet to announce his candidacy for the following year's presidential election and was best known for his reality TV shows. I had been teaching full time at the University of Wisconsin-Stout for five years and owned my first home, an early twentieth-century Craftsman with a covered front porch extending the width of the house, where I lived with my partner, Tiffani, and our two-year-old son, Aidric. Having been at Aidric's birth, I was calm the second time around. I knew what to expect. Perhaps Erikson had felt the same naive confidence.

I accompanied Tiffani to the birthing center in the evening, returning home briefly to put Aidric to bed when a friend arrived to look after him. Tiffani labored most of the night. We walked the empty, dim halls of the small rural hospital, chatting about the past, about the future, pausing now and then when the pain gripped her. Early in the morning the labor progressed sufficiently and the doctor, a local family practitioner, was beckoned from his home. He rushed into the room, hair disheveled from sleep, to guide Michaela into the world. The nurse lifted her onto Tiffani's bare chest, and I saw a newborn embraced by her mother for the first time. Tiffani lightly stroked Michaela's forehead, her index finger tracing the creases on her brow, gazing at her with a mixture of adoration and exhaustion. I marveled at the raw beauty of it all.

Later, the nurse invited me to assist with measuring Michaela, a hospital ritual for new fathers that helps solidify their role. I picked up Michaela and nestled her close to my body, thinking she felt a bit limp or floppy. I even remarked that she seemed "light," but the nurse simply ignored my comment. This nurse had been cheerful and welcoming the day before, but now barely made eye contact as she briskly went about her work. I placed Michaela on a scale and straightened her legs while the nurse measured her length. I then pressed an ink pad against the bottoms of her feet. Her footprint was undeniably adorable, with a cute little gap between her first and second toes. The nurse stared at the print. After that I spent hours holding my daughter, peering into her scrunched face, stroking her

tiny fingers and hands as she slept, gently rubbing my thumb into her palm. She had puffy cheeks and small ears, almond-shaped eyes, and her round head seemed to disappear into her shoulders. I was falling in love.

I had a faint suspicion in those early hours, nothing more than a muddled feeling, an inkling that something was not right. Michaela seemed different than Aidric had been as an infant, and the nurse's cold demeanor nagged at me. But the signs were subtle, and if others noticed, nobody said anything—not the delivering physician, none of the nurses, not even the pediatrician, who examined Michaela and told us she was perfectly healthy. My parents had driven six hours from Chicago and were the first extended family to meet Michaela. My dad commented on her "Asian eyes," picking up on the epicanthal fold that made her eyelids appear slightly slanted. I scoffed at him for being racially insensitive and explained that her features would smooth out after a few days. Infants are all scrunched up at first, I said. A friend who is a doctor and works at the hospital visited and held Michaela. A couple days later, we brought her home.

After our first night home, I found myself Googling "Down syndrome." I was sitting on the toilet with my iPad. I don't know exactly what prompted me to type the words, but I recall with striking clarity the moment I hit the search button. The internet expelled its findings, including many callous medical definitions that describe Down syndrome as an "abnormality" or "birth defect." I read about the "atypical" characteristics, the underlying chromosomal "disorder," and the inevitable developmental "delays." My breathing slowed even as my heartbeat quickened. I clicked on images and studied seemingly unusual traits—low muscle tone, upward-slanting eyes, small ears, flattened facial profile, a single deep crease across the center of the palm—many portrayed through the crude, somewhat inhuman sketches used to illustrate diseased conditions on medical websites. I read that the wide space between Michaela's first and second toes is considered a "sandal gap deformity," visible by ultrasound on "abnormal fetuses." But our ultrasound had shown nothing awry—or at least the technician had not noted anything.

I walked slowly upstairs, iPad in hand, contemplating with trepidation how to address this with Tiffani. The wooden stairs groaned with every reluctant step. I stopped midway on a landing to gaze out a window. Now and then I fall prey to preposterous doubts about my own health. In my

mid-thirties, I experienced chest cramps when running, and quickly went to see my doctor, who ordered a battery of tests. He did so out of precaution. I have a thin, athletic build, exercise regularly, and had never had a serious health issue. He knew I was fine and confirmed that it was all in my head. In the two years since our son was born, I had redirected my irrational health worries toward his wellbeing, experiencing periodic episodes of halting anxiety that clouded my judgement. But I had to share this with Tiffani, I thought. I inched into the bedroom where she was nursing Michaela and noticed her computer open in her lap. She had tears in her eyes. I looked at her screen. She was already reading about Down syndrome.

That day we were scheduled to bring Michaela back to the birthing clinic for jaundice treatment, a common condition among newborns in my family. When we arrived, Tiffani immediately shared our suspicions with a nurse, who only then revealed that the possibility of Down syndrome had been discussed with the doctors after Michaela's birth. She told us they couldn't agree at the time whether lab testing, much less a diagnosis, was warranted. Since the physical signs weren't blatantly obvious, they had decided they would wait until the one-week check up to say anything, just to be sure. But now that we were asking about it, the nurse called the pediatrician, who immediately ordered a blood draw.

They would need to count her chromosomes.

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Tiffani and I sat shoulder to shoulder in a consultation room, Michaela in my lap. The examination table was directly across from us, a wide strip of clean, white paper pulled down over the light blue cushions, a metal cabinet beneath. We undressed Michaela until only her diaper remained. I stood up and placed her on the table, resting my hand on her chest as the paper crinkled beneath her. Technicians tried to find a vein in which to insert a tiny needle, first in her arm, then her ankle and feet. It's tricky, with infants. Bright light illuminated the cold room from the ceiling.

Down syndrome results from a chromosomal condition that occurs during fertilization, when reproductive cells come together into a new cell to set the stage for human life. As the new cell divides, subsequent cells

package pairs of chromosomes, one copy from each parent. Chromosomes are in the nucleus of cells, and each carries a single molecule of DNA, the instructions for how a living creature will develop. Most people have twenty-three pairs of chromosomes, for a total of forty-six. The diagnosis “Down syndrome” describes an extra copy of the twenty-first chromosome—three chromosomes rather than a pair—an arrangement known as trisomy 21. The trisomy occurs at the moment of fertilization. Scientists first discovered it only in 1959 and they now understand how it transpires (a process called nondisjunction), but not precisely why. Trisomy 21 accounts for 95 percent of all Down syndrome occurrences, and less common chromosomal arrangements such as translocation and mosaicism account for the rest. Roughly six thousand children are born each year in the United States with Down syndrome, about one out of every seven hundred babies.⁹ While incidences tend to increase with maternal age, heredity is not a factor in trisomy 21, nor are environmental conditions. Its appearance is random, occurring around the world and throughout human history. Like many things in nature, there is no *why*, no specific reason the trisomy happens. It just does—a variation of chromosomes in the entanglement of biological reproduction and cellular formation. It is a natural part of the human condition, part of the diversity of humankind.

To make a diagnosis, they first needed Michaela’s blood, dark liquid pulsating into small glass vials, which would be taken to a lab for analysis. The lab would produce an image of her chromosomes, called a karyotype, allowing them to be lined up and counted. Before the ability to visualize human chromosomes, for example when Neil Erikson was born, all sorts of wild theories were offered up about the cause of Down syndrome. Some nineteenth-century observers speculated the condition represented a reversion to a previous stage in human evolution, brought on by disease or even personal failing. By the early twentieth century, hereditary explanations were common, even as some scientists began to speculate that chromosomes had something to do with it.

As the vials were collected, the pediatrician talked about physical features, comparing Michaela to me and Tiffani. That extra twenty-first chromosome, repeated in trillions of cells throughout the body, shapes the array of characteristics commonly associated with Down syndrome. Older