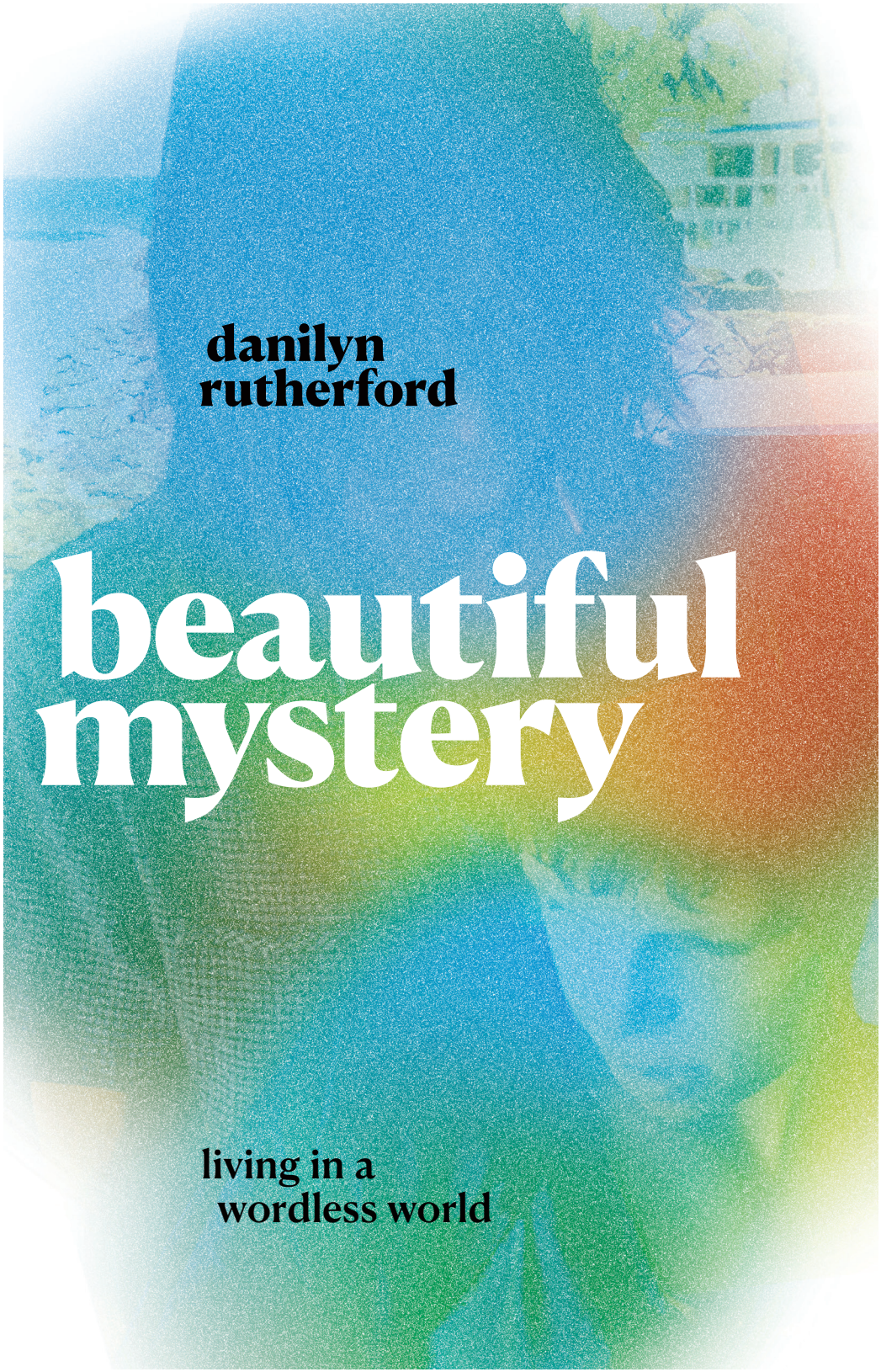
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LIVING IN A WORDLESS WORLD

Danilyn Rutherford

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PROLOGUE

If you look at the right time, you can see them: improbable flashes of neon green flitting from tree to tree. Craig discovered them as soon as we moved in, less than a month after our daughter, Millie, was born. Feral parakeets. I was in Millie's room assembling the changing table when Craig called me up to our roof deck to look. "Right there!" I squinted at the patch of sky between two trees. The swarm of dots looked black until the flock wheeled and the green feathers caught the sun. "We have to show Ralph." Later that day, while Millie was napping, the three of us climbed up to look. Perched in his father's arms, Ralph stabbed his chubby finger at the horizon.

Some say they're descended from escaped pets that somehow found each other, these monk parakeets that live in the treetops. Others say a flock was released when a deal in the exotic animal trade went bad. Chicago isn't the most welcoming environment for these tropical exiles, but they've made it their home, breeding in the wild here for nearly forty years. That fall, the birds were bright against the sky; I watched for them with each changing season. In July, when the trees explode with new growth, you're less likely to see them than to hear them. A lone screech pierces the morning birdsong. Trills, cackles, and squawks mark sundown. In the winter, you'll see their dwellings, bundles of brown leaves suspended where the bare branches reach for the sky. Nestled beak to tail feathers—that's how I always pictured them. Warming each other and waiting for spring.

After Craig died, I was the one who took Ralph to the roof deck. Every April, we scanned the treetops and listened for their voices. In January and February, we surveyed the nests for signs of life. At the beginning of the summer, my mother drove down from Wisconsin with flats of marigolds and morning glories, and she squeezed in next to us and searched the sky. Did I ever take Millie to see the parakeets? Probably not. On that first day, she was a newborn, a soft

little ball curled up in her crib. By the end of our time in Chicago, she was almost too heavy to carry up the stairs. But even then, she still couldn't follow my gaze. She wouldn't have noticed what I was looking at.

I WAS A WIDOW by the time Millie got her first wheelchair. I was also a newly tenured professor. My daughter, who is now an adult, does not walk on her own, or speak, or communicate with signs or symbols. Millie was three and her brother was six when her father died suddenly of a heart attack. I was two weeks away from learning whether my promotion had gone through.

When the monk parakeets soared among the treetops, I longed for Millie to see them. I wanted her to experience this flash of wonder. Her disability felt tragic. I mourned all the things we might never share. Now I wonder whether I had it backward. Maybe Millie was the flash of wonder, and I was the one who couldn't see. Across the gulf between our species, I watched the monk parakeets and pondered the mystery of their existence. My own daughter has proven as fascinating to me, as much a stranger to the landscapes I used to take for granted. Millie has brought me into a world that stretches much further than the one that I once thought of as my own.

A MONTH AFTER CRAIG died, Ralph joined a support group at his elementary school for bereaved children. At the end of a session, the school psychologist pulled me aside. My son didn't seem to care about homework and grades. She was worried. "Ralph is floating above his life." Her words stung, and I thought of my own life, and Millie's. How far above the life of a typical mother—or professor—was I floating? How far was Millie floating above the lives of most toddlers her age? But was this really such a bad thing? This isn't a story about learning to fit in. It's a story about learning to fly. And, in the end, we had company up there in the air.

Worlds Without Words

In December 2020, National Public Radio ran the first report in a series on the fortunes of disabled people seeking health care during the pandemic.[1] One of these people, a middle-aged woman named Sarah McSweeney, lived in a group home in Oregon. Afraid that she had contracted COVID-19, the staff took her to the hospital. "That afternoon," the reporter said, "[the nurse at the group home] received a phone call from the doctor in the emergency room." The doctor was confused. Sarah McSweeney was multiply disabled. She couldn't speak for herself. And yet her care provider had brought with her a legal document stating that her client wanted all medical interventions. The nurse at the group home explained. "We had her at full code. So all treatment. Because she was young and vibrant and had a great life. And that was her wish, that's what we gathered from her. She wanted to be alive."

"That emergency doctor would be the first at the hospital to raise a question that would shadow decisions about McSweeney's care," the reporter went on. "Why does a woman with significant and complex disabilities have a legal order that requires the hospital to take all measures to save her life?"

One by one, McSweeney's service providers offered an answer to this question by describing the woman they knew. A woman who loved manicures and pedicures. Who loved having her makeup done. Who enjoyed the mall so much that she was learning to use a voice output device so she could get a job greeting customers at the door. McSweeney had her dark hair dyed red so it clashed with her wheelchair. She loved country music. She loved watching people swing dance at country bars. The manager of the group home chimed in: "Her smile would bring a smile to everyone in the room."

But the doctors who cared for McSweeney pictured her differently: as a quadriplegic patient who "couldn't even use her hands." Over the course of the next three weeks, they made decisions on the basis of what they saw as her poor quality of life. During her stay in the hospital, she contracted aspiration pneumonia and grew seriously ill. At a critical moment, the hospital ethicist advised against intubating her. When her care providers protested to the doctor, he scoffed. "Oh, can she walk? And talk?" He used his middle and index finger to mimic two moving legs.

A week later, McSweeney's lungs failed, and she died.

When I heard this story, I was making dinner in my kitchen in Santa Cruz. I wasn't really listening to the radio when it came on. I used to love *All Things Considered*, but the coverage during the pandemic had soured me on the program. If I heard one more show about the suffering of middle-class schoolchildren, I was going to scream. But these words froze me in place. Jeanette, one of Millie's care workers, who stuck with us throughout those difficult months, stepped into the kitchen to prepare Millie's meds. "Hi!" she called out, her dark brown eyes smiling above her mask. The daughter of a farm foreman, with a three-year-old son at home, Jeanette confronted COVID with the unflagging good humor of a Mouseketeer. I shook my head and pointed at the radio. "They're talking about someone like Millie."

The story I was hearing was about more than whether Sarah McSweeney had a life worth living. The report captured our dominant American views of what makes a person a "whole person." Forced to justify their client's existence, McSweeney's care providers spoke of her career goals and consumer preferences; it makes sense that they had so much to say about her trips to the mall. But her care providers also spoke of something more profound. What struck me so hard was not McSweeney's capabilities but her relationships. To focus on the first is to beg the question: Would it have been okay to deny her a ventilator if she had been less vivid, ambitious, and fun? To focus on the second is to give thought to the impression McSweeney made on the people interviewed for the

story. Those who worked with her learned how to ask her direct questions and recognize when she answered "yes" or "no." But they had to experiment with a variety of activities and pay close attention to her responses. How many games of twenty questions did it take for her to name her favorite country star—Kenny Chesney—and pick the perfect pink for her nails? Her care providers went to all this trouble because it is their job to help their clients gain access to mainstream society. But they also acted for other, more intimate reasons. Without saying a word, McSweeney pulled others into her orbit. With them, she created a new way of being together. She created a world.

I've lived through a similar process of creation. This book relates the lessons I have learned from my daughter, Melitta Alta Rutherford Best, who is in her early twenties as I write this. Millie, as we call her, doesn't walk or talk, and she communicates exclusively through sounds and gestures. But she's taught me how to fashion what Michele Friedner and Emily Cohen call an "inhabitable world"—a shared space of dwelling, both real and forever in the making, that evades the limits that mainstream society places on what it means to be a person, to relate to others, and to live a meaningful life.[2]

Language isn't an essential ingredient when it comes to making worlds—or at least not in the form people often take for granted. People talk to each other, they reach agreements, and they speak from the heart. But there's more to communicating than what they can express in words. Among the many things language does, utterances describe thoughts and perceptions. But they only do this when a speaker belongs to a community where there's a link between their voice or signing hands saying "this tree" and the bark they're slapping in the forest. The same is true of all the other ways of communicating that scholars describe as sign use.[3] Weathervanes point in the direction they do because they are pushed by the wind. But someone raised in their absence might not know what that little metal rooster is doing on your roof. This book explores my journey with Millie to a different side of our lives together—a side where co-presence matters more than convention, where we struggle to make ourselves felt, instead of insisting on making ourselves understood.

IT'S NOVEMBER 2023, and I catch sight of Millie when I reach the foot of the stairs. She's sitting in a high-backed chair, and she's rocking back and forth, head down, intent on her work. Her work is a salmon-colored, crocheted octopus, a gift from her care provider Julie, who has a sharp sense of Millie's obsessions. The octopus has tentacles—obviously!—and Millie is holding them in her field

of vision, moving her head back and forth to shift her angle on these alluring shapes. Every so often, she brings a tentacle to her mouth and brushes it gently across her lips.

Millie is wearing a cotton hoodie and leggings under her orthotics, plastic sheaths that run from her knees to her feet, where they are squeezed into shoes designed to be worn with them. Millie is long-limbed and built like an athlete—a five-foot-tall version of me. I clomp around the house and knock things off counters. When she's gliding in her wheelchair, Millie is ethereal—not an ogre, but a sprite. Her hair, which is a color midway between auburn and dirty blonde, is cut in a pixie. She looks like Julia Roberts playing Tinker Bell when she smiles. Right now, Millie is not smiling. She hasn't registered my arrival. I take a seat close to her and say her name. A beat goes by, and then another, and her face lights up. She lifts the octopus off her lap and gives it a playful shake. I study her profile. Did she recognize my voice? Is that the meaning of this pleasure? Or did a tentacle catch the sun?

Six years ago, I left the local university and started working for a New York–based foundation. I haven't been back to Santa Cruz in over a month. I want to believe Millie is happy I'm home. But I never see more than part of the picture, foothills of a mountain range barely visible above the clouds.

I don't understand my daughter. What she likes to eat, what she likes to touch, what noises she prefers: I think I have a grip on this. But much of what Millie does still seems inexplicable to me even after more than twenty years of living together. Millie hums, and I assume she's happy; she cracks up, and I tell myself she thinks I'm hilarious. But then her humming turns sour, and her laughter spins out of control, and I'm faced with the possibility that she's actually in distress. And, yet, the mystery Millie is to me has pulled me close to her. It has also made me wonder whether I have ever truly understood any of the other people I have loved.

Other parents—and other academics—have had similar experiences. In *A World Without Words*, the sociologist David Goode reported on research he'd done in the 1970s on children exposed to German measles in utero. Here's a description of Bianca, a nine-year-old with cognitive disabilities, cerebral palsy, and sight and hearing impairments, as the staff at her school experienced her: "While in class, she appeared to be generally unaware of her surroundings or the actions of teachers and therapists. She was not 'with it,' as [her teacher] would say. She was considered to be one of the most 'low functioning' children in the school."[4]

But at home Bianca was a different person than "Bianca-as-she-existed-in-the-organization-of-a-special-education-school." To put it more precisely,

she was a person: someone with aims and a personality, someone you might even call imperious. When Goode fed her, she let him know when he wasn't doing it correctly. She wanted her milk cold, and if he poured it too long before serving it, she ordered him to get her a fresh glass. She did this through facial expressions, vocalizations, and gestures. Instead of using a formal language, Bianca and her family communicated via "guessing games," which yielded what Goode calls "routine signs" made of conventions that lived and grew. "If, when Bianca stamped her feet at the dinner table, she quieted down after her parents gave her a piece of fruit, then the pounding was interpreted to have meant 'I want fruit.' If she refused fruit but did not mind being picked up and taken to the couch, then the pounding was taken to have meant 'Take me to the couch.'" "As some of my notes indicate," Goode writes, "when one watched Bianca and [her mother] Barbara communicating, it was artful, balletlike in precision, and uncannily accurate."[5] This "lived order of communication" was also highly idiosyncratic and tightly tethered to Bianca's life with her family.

To "get" Bianca, as Goode argues, "you had to be there and for a long time."[6]

I love Goode's book. I also love the wealth of more recent writings by other scholars, like Joshua Reno, whose book *Home Signs* covers similar ground.[7] But I'm fascinated by what comes before the conventions, before the second, third, or umpteenth iteration that tells Bianca's parents that their daughter's stamping foot is demanding fruit. It turns out to be something less explicable than routine or habit—not the solution, but the problem, not the prize, but the desire. At a conference on assistive and augmentative communication, I happened upon a session that I found surprisingly moving. Some Japanese engineers had come all the way from Tokyo to explain a scanning device they'd designed to capture otherwise imperceptible movements in people considered to be in a permanent vegetative state. They looked for patterns in how these individuals reacted to different kinds of music. They wanted to hold open the possibility that they were alive to their surroundings and that they cared about the sounds their world contained.

The engineers' research was built on the same foundation as Goode's research, a foundation consisting not of surety but of faith, that the being before them was a someone. Someone with a take on the world and a stake in how others treated them. Someone whose pleasures they could imagine making their own. Signs, routine and otherwise, rest on this tacit belief: that we are confronted with a person, and there's more to them than is immediately evident. Medical professionals and school systems describe Millie as severely to profoundly cognitively disabled. But the force that has shaped my life with her is not disability, or even difference: It's cognitive mystery, to give a name to the puzzle of a mind and heart that seem impossible to plumb.

In the United States, where Millie was born and raised, one response to cognitive mystery is to impute intentionality: to act as if someone is trying to communicate in situations when it's not clear that they are.[8] You squeeze into a crowded subway car. Someone elbows you in the ribs, and you turn to glare at them. They look away. It rankles. Did someone shove them, or do they not like your looks? Hope, fear, and doubt are common companions when the intentions of others seem opaque. In response, people try to make their behavior make sense.

People do the same thing with their pets, gods, and ancestors.[9] I'm on the wharf with my partner watching the sea lions that congregate on the struts below the walkway. Our poodle cocks her head, and we can tell what she's thinking: "They have fish that bark?" Animals supposedly don't have language. But who doesn't talk to their cat? Evangelical Christians talk to God and are sure He talks back by shaping the course of daily events. Ethnographers working in other parts of the world have described conversations in which the spirits speak in the sound of the wind, the shape of a chicken's entrails, or a rip in a piece of cloth. A French expert on religion, Pascal Boyer, went so far as to suggest that the very idea of spirits reflects the evolutionary value of imputing intentionality in the face of cognitive mystery.[10] That shadow stirring in the bushes might not be a leopard. But it's better to be safe than sorry when your life is at risk.

People apply the same kind of logic with newborn infants, who, when you think about it, are a little like gods. A baby's lips curl into an expression somewhere between a smile and a grimace. "You're happy!" we exclaim. Then comes the burp. We talk to babies and we act like they understand us: This is how children learn to speak. Honed over the course of our species' history, this strategy works by virtue of what developmental psychologists have described as a deeply felt impulse: Communication begins with "basic affiliative need."[11] Babies want to connect with the adults around them—that's why they copy them, look where they're pointing, and gaze into their eyes. For their part, adults want to connect with their babies. That's why adults work so hard to get their attention and make them smile.

Service providers who work with people like my daughter try to provide the same kind of "social scaffolding" that researchers have shown is so important for typically developing babies.[12] School districts hire aides, teachers, and therapists to help Millie and others like her function as normally as possible. Their goal is to prepare them to become productive workers and citizens by teaching them to communicate in ways that the average American can understand. Their efforts can lead in unexpected directions. Sometimes the sheer pleasure of establishing a connection takes precedence over any other purposes an interaction might fulfill. Autistic authors and bloggers have acted as emissaries from worlds without words, using letterboards and laptops to describe

the breadth of their experience. "My language," Mel Baggs explains in a video on the topic, "is about being in constant conversation with every aspect of my environment."[13] When Baggs flaps, hums, and stims, they are communing with the things around them, from the branches outside their window to the chain dangling from the shade. Cognitive mystery—that puzzle presented by an inaccessible mind—can spark efforts to normalize those who seem different, to make disabled people fit a typical mold, under pressure from the unequal social orders in which so many of us live. But it also directs us toward ways of living more creatively and humanely with beings very different from ourselves.

At the heart of this book, thus, are questions of ethics. Philosophers have long relegated people like Millie to what Eva Feder Kittay has called the "margins of moral personhood."[14] They supposedly don't deserve equal treatment because they lack the traits that make the rest of us fully human: rationality, autonomy, foresight, and the ability to use language to demonstrate that these exist. Yet moral personhood doesn't exist in isolation. We offer it to one another, and we claim it for ourselves, as we go about our daily routines. Life with Millie has forced me to confront cognitive mystery and, for better or worse, find a way to relate to it. To live with Millie is to find personhood in a space in between what we can know of one another and what we cannot.

"YOU HAD TO BE there, and for a long time."

I'm a rower, a runner, a meditator, and a pretty good cook. I'm descended from four generations of college graduates; my grandmother majored in math at Barnard in the 1910s, and two of my three siblings have PhDs. My great-great-grandfather was a German American minister; my Scottish American father was a deacon in the local Presbyterian church. I have ancestors who were killed in the French and Indian War. I'm pretty sure they deserved it. With America's roots in slavery and the theft of Native land, I'm one of the people my country loves.[15]

Most importantly for my purposes here, I'm an anthropologist. This book belongs to an unusual genre—more personal than an academic study, more analytic than a memoir. I've done my best to write in a way that draws near—near to my daughter, and near to the forces involved in shaping our lives. I have not written a medical mystery novel or a bildungsroman. Millie still doesn't have a diagnosis, even though I have a chapter on the topic. Doctors have misunderstood Millie and failed to define her in biomedical terms. This is significant for a variety of reasons, but it's not why I wrote this book. You'll see me change, but my character development is also not the point.

What follows starts as a travelogue, then opens up like an accordion. I begin on the South Side of Chicago, where Millie was born, and end on the Central Coast of California, where she lives now. Midway through, I stop at some way stations, where I pause to expand on some lessons I've learned. Part I explains how I arrived in Millie's world; part II describes what I found there; part III pays homage to our fellow inhabitants, our local experts and companions, and the stuff from which Millie's world is made. I write from two standpoints: that of a mother, and that of a scholar. As I hope my readers will come to realize, these two viewpoints are intimately connected. Thanks to Millie, the mother and the anthropologist are one and the same.

In *The Body Silent*, his remarkable memoir documenting his gradual loss of feeling from the neck down, the anthropologist Robert F. Murphy portrays the shrinking of a social world. He could still write—he published important work until the end of his life—and he could teach, thanks to some jerry-rigging that made his building accessible. But the threads that once attached him to friends and colleagues slowly dropped away. Other professors stopped asking for his opinion. Waiters talked to his wife instead of him. Murphy's memoir offers a searing critique of the boxes into which our society places disabled people. In what follows, I bear witness to the damage wrought by this violence. But my trajectory has been different. Millie's disability has welcomed me into a world that grows with each passing year.

Most academic books begin with a detailed road map. This one does not. My goal in this chapter is not to tell you where we're going. It's to offer you reasons for coming along.

THE WRITTEN VERSION OF the report on Sarah McSweeney on the NPR website features images. There's a picture of her, followed by portraits of the individuals the reporter interviewed for the story—long-haired, middle-aged women who pose gravely for the camera. Several of these women stand against the gray clapboards of a wooden building, perhaps the one where McSweeney lived, near windows reflecting trees and sky. The piece ends with a photograph of a collection of painted rocks that residents and staff had placed in memoriam outside the group home. There are flowers, rainbows, cartoon faces, and the silhouette of a woman reclining next to a tree. One of the rocks reads, "The world just lost some sparkle." This world is the world that Sarah McSweeney made.

I thought of McSweeney a few years ago when I turned sixty. Among other things, I celebrated by baking myself a cake made with lemons from my garden. My partner carried it into the dining room, and I perched on a chair

next to Millie and started singing "Happy Birthday." Startled by the commotion, Millie rocked uncomfortably on her stool. At the climax of the song, she tucked her face into her shoulder and grimaced, clearly frustrated by the noise. We've been through this ritual many times, and it always feels forced. But I can't stand the thought of skipping these little ceremonies. On birthdays and holidays, it feels crucial to affirm to myself and others that we are a family and that Millie belongs. When the cake arrived on the table, Millie lunged for it hungrily. I quickly cut her a slice. She leaned forward eagerly as I guided forkfuls into her mouth. Our dog stood by to catch the crumbs.

Later, when it was time to tuck Millie in, I sat on her bed and spoke softly into her ear. "Thank you for helping me blow out the candles." I often hear Millie at night during the hour or so it takes her to fall asleep. I sometimes mistake her for the owls that nest in the trees around our house. She coos, and I can imagine her fingering the coverlet, swaying softly, entertained by things the rest of us can't see. But now Millie was still. She was leaning slightly forward, her head lifted off the pillow. Her eyes were steady, and her lips were curved into a slight smile. "We *Rutherfords* like cake, but you *Bests* are supposed to like pie," I whispered. She chuckled—right when I pronounced her last name. A jolt went through me. Did Millie know she was a Best? Or was it the warmth of my voice and the closeness of my breath that had stirred her? I searched Millie's face. Her expression had gone blank. I still don't understand Millie. But, for a moment, I could have sworn she understood me.

Millie survived the pandemic—Zoom school, disinfected vegetables, itchy masks, and all. But I lived in fear she would end up in a hospital alone. COVID or not, that day may be coming. When Millie is Sarah McSweeney's age—forty-five—I'll be eighty-four. Neither of my parents lived much longer than that, and my mother's dementia separated her from her children. What happened to McSweeney could happen to my daughter when I'm no longer around. Perhaps writing this book has been a wishful project. I'm trying to reassure myself that Millie will always have a social world, one that can defend her from this fate or, if not, commemorate her once she's gone. You might think someone has to meet certain criteria to participate in social life, or even to deserve to live. It's not just disabled people; our enemies are also beyond the pale. But I can't get away from the fact that on this warming, warlike planet, we are in it together whether we understand each other or not. It's not the job of people like Millie to be the teachers of people like me. Still, there are things we can learn from them. Grappling with cognitive mystery may be key to the survival of all our worlds.

NOTES

WORLDS WITHOUT WORDS

1 Joseph Shapiro, "As Hospitals Fear Being Overwhelmed by Covid-19, Do the Disabled Get the Same Access?," *All Things Considered*, December 14, 2020, https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc.

2 Michele Friedner and Emily Cohen, "Inhabitable Worlds: Troubling Disability, Debility, and Ability Narratives," *Somatosphere*, April 20, 2015, *Inhabitable Worlds* series, http://somatosphere.net/2015/inhabitable-worlds-troubling-disability-debility-and-ability-narratives.html/, p. 1. Friedner and Cohen draw from the philosopher Martin Heidegger's notion of "worlding," which anthropologist Mei Zhan takes up in her description of worlds as "emergent socialities entangled in dynamic imaginaries of pasts, futures, and presents." See Zhan, *Other-Worldly*, loc. 251. Like Zhan, I am interested in exploring (and, to be honest, defending) the "plural ways of being human that are contained in the very different orientations of the world." See Zhan, *Other-Worldly*, loc. 561. I am also inspired by Ginsburg and Rapp, "Disability/Anthropology"; and Ginsburg and Rapp, *Disability Worlds*.

3 For students of semiotics, a sign is an object that stands for another object to a mind. My understanding of what language does, and what signs more generally do, is drawn from the American philosopher Charles Sanders Peirce. See Parmentier, *Signs in Society*.

4 Goode, *World Without Words*, loc. 710.

5 Goode, *World Without Words*, loc. 752.

6 Zola, foreword to *World Without Words*, loc. 44.

7 In addition to Reno's remarkable study, Friedner and Wolf-Meyer, "Becoming Malleable," provides a bibliography of recent work. Green, *Making Sense*, shares my interest in the emergence of conventions and how we need to understand this as a matter of ethics. See also Edwards, *Going Protactile*.

8 Keane, *Ethical Life*, 16, makes this point adroitly; so does Keane, *Animals, Robots, Gods.*

9 Haraway, *Companion Species Manifesto*; Harding, "Convicted by the Spirit"; Luhrmann, *When God Talks Back*; Keane, *Signs of Recognition*; and Bubandt, *Empty Seashell*, provide good examples of this.

10 Boyer, *Religion Explained*.

11 Rogoff et al., "Firsthand Learning"; Rochat and Callaghan, "What Drives Symbolic Development?," 27.

12 See Rogoff, "Cognition as a Collaborative Process"; Rogoff et al., "Interaction with Babies"; Bates and Elman, "Learning Rediscovered"; and Namy and Waxman, "Symbols Redefined," 274. Vygotsky, *Mind in Society*, inspired much of this work. Grove et al., "See What I Mean," extends the insight to interactions with disabled people. "It is extremely common to encounter claims that a person with a disability can communicate complex information in ways that are hard for outside observers to verify. Such beliefs result not only from an understandable commitment to realizing the potential of individuals, but from the nature of interactions with people who function at an early level of communicative development, and the developmental path of intentional states" (197). Jorgensen, "Least Dangerous Assumption," pioneered this approach.

13 Mel Baggs, "In My Language," *YouTube*, January 14, 2007, video, 8:37, https://www.youtube.com/watch?v=JnylM1hI2jc. See also Mukhopadhyay, "Five Poems"; Ochs and Solomon, "Autistic Sociality"; Autistic Self-Advocacy Network and Bascom, *Loud Hands*; Wolf-Meyer, *Unraveling*; and Botha, "Academic, Activist, or Advocate?"

14 Carlson, "Philosophers of Intellectual Disability"; Carlson, *Faces of Intellectual Disability*; S. Taylor, *Beasts of Burden*; and Kittay, *Learning from My Daughter*, also cover this fraught ground.

15 Hannah-Jones et al., *1619 Project*, 376. See also Coates, *Between the World and Me*.

WHAT TO EXPECT

1 Bérubé, "Life as We Know It"; see also Bérubé, *Life as We Know It*.

2 What to Expect First Year Month-by-Month, "6-Month-Old Baby," accessed January 15, 2015, http://www.whattoexpect.com/first-year/month-by-month/month-6.aspx.

3 Eisenberg et al., *What to Expect*, 245.

DIAGNOSIS

1 Davis, *Enforcing Normalcy*, 3–12; Davis, *Bending Over Backwards*, 92. See also Shakespeare, "Disability Studies"; and Shakespeare and Watson, "Defending the Social Model."

2 Davis, *Enforcing Normalcy*, 10.

3 See McKearney and Zoanni, "Introduction"; see also Friedner and Wolf-Meyer, "Becoming Malleable."