

OWNING IT

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For this generation of disabled kids (and future ones, too!). Here are the words we wish we'd owned when we were your age. We hope you find comfort, laughter, joy and solidarity here.

OWNING IT

Edited by

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Dear reader,

This is the book we wish we'd had when we were young.

As disabled children, we didn't see many people like us in the books we read or the films we watched. And, when we did, we usually wished we hadn't! If they were the good guys, they were inspirational people whose disability was their 'superpower'. If they were the bad guys, their disability was part of their evilness – like Captain Hook – which was annoying. And boring.

Because, really, disability isn't like that, is it? Disability is a normal part of everyday life. Did you know that about a quarter of people are disabled?¹ That's a lot of people! And we think books and films should show that, too: how normal it is to be disabled.

Perhaps you are disabled yourself, or you know someone who is? You probably know someone who will be, one day. Some people are born disabled, and some become disabled later in life. Of the three of us editing this book, two of us – James and Jen – were born disabled, and one of us – Lucy – became disabled later.

¹ According to UK government disability statistics, published August 2023.

There are so many ways of being disabled, and so many ways of feeling about it, too. That's something we wanted to show and celebrate in this book. Each chapter is written by a different writer, and each writer was once a disabled child. This book is not a perfect cross section of the disabled community, though we did our best to find writers with as wide a range of disabilities and backgrounds as possible.²

We asked these writers to tell us about a memory from their childhood – something joyful or challenging or funny. In this book, you're going to read about Jan skating across the Norwegian ice in his wheelchair, Matilda stargazing with her mum in Nigeria, and James leaving his leg at home (yes, really!). However, while people have such different bodies and lead such different lives, the things they need and want and wish for are often similar, so this book celebrates that as well.

We can't change our disabilities. But we can own them. That's what the title of this book means. If you're disabled and you don't feel like you're owning it right now, that's OK. Hang in there. Growing up with a disability isn't easy, sometimes because of our own

2 We work as writers and publishing people in the UK, and we've reached out to writers, first and foremost. Our pool of contributors cannot help but reflect this.

bodies and sometimes because of the world around us. Many of us were made to feel ashamed of our disabilities when we were young. Many of us weren't given the words to talk about that part of ourselves, so we could be proud to be disabled and find strength in our togetherness.

Our hope is that you find the strength and the pride and the words you need. Some of them might even be in this book.

All our love,

Jen, James and Lucy



Teddy Bear Island

by Rebekah Taussig

United States

The evening of Family Fun Night at Carousel Park, I was nervous. An entire evening of unstructured play in a giant indoor amusement park with all the kids in our elementary school, plus their families, didn't really sound like a 'fun' night to me. I'd just started fifth grade, I was ten, and it wasn't going great. My class was crowded with twelve rowdy boys and five girls who held hands with those boys at recess and wore shirts with the words 'Gap' and 'Old Navy' and 'Limited' printed on the fronts.

My family couldn't afford to shop for clothes in stores like these. We went thrift shopping twice a year, when I would scour the aisles for shirts with the most expensive brands printed across the front. I thought maybe this would trick people into believing I was the same as them.

More than almost anything in the world, I wanted to fit in. It was more important than figuring out long division or being kind or drawing something that made me

proud. The only problem with this goal was that ‘fitting in’ wasn’t something I could really do. At least, not in the way I’d imagined it. I’d been using a hot pink wheelchair to get around since I was six. I wore leg braces that were strapped against my shins with brown Velcro. I used the bathroom in the nurse’s office, while everyone else used the stalls. Every single person in my fifth-grade class was different in some ways and the same in others, but everyone noticed my differences right away, and there wasn’t much I could do to hide them.

It’s not that the kids at my school were mean to me. People didn’t make fun of me or call me names. But I found myself alone a lot – sitting on the edge of the playground or relegated to the very end of the lunch table (the only spot my wheelchair could scoot under). Every once in a while, I was even a trend. For a week or so, the kids in my class would clamour to be my ‘helper’. It wasn’t an official title, but a self-appointed role. They’d get in line to push me to recess or carry my lunch tray. It wasn’t a literal line, but a list I stored in my desk to make sure I kept it fair – if someone wanted a turn, they had to wait until everyone else on the list got a chance. I thought it should feel good – isn’t it nice when people want to be around you? Instead, I felt a little

more like the class hamster than anyone's friend. An object of affection, but not an equal.

That feeling of separation only grew when, a few weeks before fifth grade started, I was one of six nominated for our city's Outstanding Community Kid Award. I was ten years old. The local newspapers covered the story, recounting my life of 'painful treatments and surgeries', concluding, 'her courage inspires others to have faith and hope.' My mom snipped the articles out of the newspaper and sealed each behind the magnetic paper of my photo album, a black-and-white preservation of Rebekah Taussig, unconquerable fifth grader.

The gap between me and the kids around me felt wide. I lived on an island all of my own, and I didn't know how to build a bridge. So, I begged my mom to take me shopping in one of the expensive stores. My mom relented. I was allowed to pick out one top and one bottom for the new school year, despite the fact she really didn't have the money for either.

On Family Fun Night, I put on my brand-new khaki corduroy overalls and a long-sleeved striped top. It was a sweltering choice for that humid September, but wearing them made me feel a little bit like I belonged.

Carousel Park was supposed to be a hub for family entertainment, sprawled across the basement of a mostly abandoned mall. My parents dropped me off by the doors, and I pushed myself across the sidewalk in the bright heat of the late summer evening hours, sweat trickling down my neck. What games would I be able to play? Would anyone want to hang out with me? Or would they let me tag along out of pity? How would I know the difference?

Inside, my eyes adjusted to the dim party-scape. I pushed myself across the thick carpet covered in bright geometric shapes and tried to keep track of all the lights flashing across arcade games and small rides. Every minute I spent alone was a slow hour of torture. I felt people's eyes on me. Imagined? Real? Did it matter? I just needed to find a group of humans who wouldn't be annoyed by my presence. I tried to twist my mouth into a casual smile and kept rolling. Finally, I collided with a group of boys from my class playing an arcade game called Skee-Ball. The game was low to the ground, almost the perfect height for a girl in a wheelchair to throw a small ball and see what happens.

I didn't know these boys very well. There was the boy with a billion freckles who drew cartoons in his notebook

during recess; the boy who mumbled nervously when he did math problems on the board and always got them wrong; the boy who wore a Pokémon sweatshirt every other day – one that had started out white but turned pale pink because of what I could only assume was a laundry accident. I quietly approached, stopping a couple of feet from their circle, hoping I could seamlessly join their group without making waves. They smiled in my direction, but no one said anything to me.

Chad, the kid wearing the pale pink Pokémon shirt, threw the little skee ball towards the hoops and missed the bullseye by a mile. He threw up his hands dramatically, making a show of his misfortune: ‘I was so close!’ I thought about making a joke, like – ‘So close – to the gutter!’ – but suddenly my tongue felt very big, and my throat felt very tight. This was my moment to wave a friendly flag! I swallowed several times, but it didn’t help. I couldn’t will myself to speak. And suddenly, in the silence, a voice broke through – ‘Rebekah, you take a turn!’ Chad held out a small ball to me.

The invitation felt like sunshine cutting through a heavy cloud, a brief quieting of a violent windstorm, the rainbow after the flood. I didn’t know what I’d done to deserve this miraculous invitation, but I grabbed hold of

it with both hands. ‘Yeah, OK,’ I said, holding the ball and pushing myself into just the right position to throw.

That night, we were the awkward bunch – a group of outsiders clinging to each other in the blinking beeping jungle, travelling from Skee-Ball to air hockey to the mini basketball hoops as one bubble. Together in this chaotic, flashing wilderness we were foragers on an adventure, surviving only because we’d joined forces. We started collecting our tickets and wondered together if pooling our resources would mean we could get something extra cool. But first, we wanted to go on the biggest ride on the floor – the Flying Dragon.

As I sat in the plastic car – one part of this wild, mechanical beast whipping across the tracks – I felt like I was actually soaring through outer space, passing friendly alien spaceships, glittering stars and big bright moons, my pals beside and behind me. My cheeks ached from smiling. As I pulled myself out of the ride and back into my wheelchair waiting by the entrance, one of the managers approached me. Had I broken some kind of rule? Maybe they didn’t want kids who used wheelchairs on this ride?

The man pulled his trouser legs up a couple of inches and crouched low so his eyes were level with mine, his

forearms resting on his thighs. 'Hi, Rebekah!' he said, loud enough to be heard above the noise of games and noisy kids. 'We heard about your "inspirational kid award", and we just wanted to be able to do something special for you.' He had such a giant, expectant grin on his face.

I looked back at my new-found group of friends. They stood in a cluster, watching me and the man from a few feet back, unsure what to do. I wasn't terribly interested in the special thing this man had in store for me. At the same time, I didn't want to take away the good feeling he had about giving it to me, and I didn't want my friends to have to wait for me either.

'You guys go ahead,' I said. 'I'll catch up with you.'

I followed the man towards the middle of the arcade where the bright booth full of prizes radiated rewards: snap bracelets, whoopee cushions, neon plastic yo-yos, inflatable penguins, miniature basketballs, all kinds of candy.

'Do you see those bears on the very top shelf?' he asked, leaning down to talk directly in my ear. I pulled back and smiled, looking up at a row of giant bears I hadn't noticed. Each bear was dressed in a different outfit

and sat about three feet tall. They were enormous and childish. I nodded to the man.

‘Those are our very biggest prizes, and we would like to give one to you,’ he said, beaming.

I didn’t have to ask the man why. Despite the fact that I hadn’t earned more than thirteen tickets the whole night, I already knew. It was the same reason I’d been given the Outstanding Community Kid Award. For inspiring everyone with my ‘painful treatments and surgeries’ – my courage to show up in my wheelchair.

I was also almost eleven. If I was going to be given something for nothing, I’d much rather a box of Skittles or one of the cheap beaded bracelets. Still, the man in front of me looked excruciatingly proud of himself. So, I turned to him.

‘Wow! That’s so nice of you! Thank you, **thank you!**’ I gushed. I picked the one with the wire spectacles and blue overalls. Even then, I knew the intent behind this exercise was to make me feel special. I also knew it left me feeling lonely and uncomfortable, but I couldn’t have told you why. It took me much longer to realise that I didn’t actually want to feel special. Or, at least, not special for my wheelchair and leg braces. I wanted to

feel something else – seen, known, accepted, connected
– something.

I didn't find my way back to my group of misfit pals that night. I don't remember why. Maybe because I could barely see over the giant stuffed animal in my lap? Maybe I just found my parents and told them I was ready to go home? Either way, the spell was broken.

The morning after Carousel Park, there was a picture of me in the local newspaper, beaming like a star, holding a teddy bear almost as big as me in my lap. The caption described the large turnout to Family Fun Night, listing all the fun activities of the night, including the presentation of a giant teddy bear to the girl who won a 'most inspirational kid' award. The article concludes, 'Many kids thought the highlight of the night was singing to the karaoke machine and dancing to the Macarena!' I must have missed that part of the festivities.

When I saw the group of boys again at school, it was like our night together had never happened. We looked at the floor and returned to our little islands. My mom helped me put the teddy bear up on the highest shelf of my closet. I didn't know what else to do with it.

For seven years, that teddy bear sat in my closet. It sat there while I struggled through and finally finished fifth grade. It sat there as I started middle-school with the worst haircut in human history. It sat there as I slowly started to realise that maybe other people are also looking for a way to belong – and maybe being the same as everyone else isn't the same as belonging. It sat there as I slowly started to take pride in quirky thrift store finds, filling up my closet with one-of-a-kind retro graphic tees and brightly coloured sneakers. And it was still sitting there when I became friends with Bertie and Marie.

Bertie was quiet with a big wide smile and pink cheeks that flushed even pinker when she was flustered. We both played flute in the seventh-grade band, when we were twelve, and whenever I found myself sitting quietly to the side as people filed loudly and clumsily into or out of the band room, Bertie was always there too. We'd roll our eyes together at the chaos and wait for the dust to settle before making any moves. We also went to the same church, which is where we met Marie, a girl with long dark hair and bangs cut just above her glasses. Marie was never the loudest kid in the room, but the first time I invited her over to my house we watched *The*

Princess Bride on a tiny TV in my brother's bedroom and laughed so hard we collapsed on the floor in tears. And when the three of us were together, we were as busy and silly as three baby squirrels jumping from branch to telephone wire to rooftop.

For most of my childhood, my wheelchair felt like a sort of wall between me and my peers. Sometimes it led to a literal barrier of separation – a flight of stairs, an inaccessible playground or a lunch table that didn't work well with my wheelchair. Other times it was harder to pin down. People treated me differently, like they were afraid – if they got too close, played freely or said the wrong thing, I might break. Or maybe I expected them to treat me differently and put the wall up myself before they had the chance. Maybe it was a little bit of both. Either way, I didn't want to be anyone's class pet – cute and novel until I became a chore – and I didn't need anyone trying to make me feel special. I just wanted real friends. I couldn't even imagine what that would look like until I found it.

Bertie and Marie learned how to load my wheelchair on and off the yellow school bus and weren't afraid to scuff it up. When we arrived somewhere my wheelchair couldn't easily glide, one of them would stoop beside

me and I would climb on her back. Natural. Easy. It felt more like playing around than being helped. Which is probably what it looked like, too. One morning, soon after Bertie turned seventeen and got her driver's licence, we made a quick trip to the gas station for Slurpees. We left my chair in her driveway, and when we arrived at the shop I hopped on Marie's back. As soon as we walked through the front doors, the shop clerk shouted at us, 'None of that roughhousing in here!' We all feigned innocence. Bertie said, 'She's **paralysed**,' her eyes accusatory and dramatic. He looked sceptical. Also embarrassed. 'Well, be careful,' he mumbled, eyeing us as we pranced down the aisles, giggling.

Everything we did, we did big. Make some treats for the church bake sale? Let's spend the entire weekend making fifteen pies, six gallons of puppy chow and five trays of Rice Krispie treats! Celebrate one of our birthdays? Let's plan an elaborate murder-mystery party, complete with clue books and a whole cast of characters performing all the parts! Go thrift shopping? Let's fill a van with our friends and take a mini road trip to another town where we'll spend the entire day trying on outfits for each other! Play a midnight practical joke? None of this default toilet-papering someone's yard – let's buy rolls of

plastic wrap and cocoon an entire car! Which is exactly how we found ourselves in a back-and-forth war of pranks with the boys from our church.

One weekend, the three of us sat in my bedroom coming up with ideas. We needed the perfect prank – the kind the average prankster hadn't dreamed of, but when they saw it, they'd know: genius. Should we sprinkle birdseed all over their yards so they'd wake up to a million crows feasting? Something with instant potatoes, that would lie in wait until it rained, when the yard would explode into a gooey mess? Everything felt too elaborate or mean. We looked around my room for ideas – a closet full of pictures, my old flute, and there at the top, tucked away for safe-keeping, a row of old stuffed animals from years past – a raggedy lamb named 'Lucy' I used to take with me to chemotherapy treatments, the pink bunny with the stuffing falling out of one foot, and, of course, the giant teddy bear with the wire spectacles. It was probably the first time a human hand had touched him in years. His fur was dusty.

We grabbed as many as we could and loaded them into Bertie's car, laughing maniacally into the night. We turned down our music when we arrived at the house where all the boys were staying that night, their cars

parked in the driveway. I climbed onto Bertie's back, holding stuffed animals in each hand. Marie was close behind, her arms full. We stifled our giggles as we quietly opened one of the car doors and stuffed as many animals as we could under the strap of each seat belt.

Finally, we turned to our crown jewel – the giant teddy bear with the wire spectacles. He'd arrived on my lap seven years before, an unwanted, awkward gift. For years, the sight of him brought a tiny weight to my gut – a mixture of embarrassment from being made into a spectacle and rage from feeling so powerless to opt out or say no. But that night, as we tucked him in the driver's seat, paws reaching for the steering wheel, seat belt pulled across his blue overalls, the story of me and this bear shifted. Suddenly, it felt ridiculous. Hilarious. Feather light. I couldn't stop laughing at this giant bear with a belly full of fluff driving a teenage boy's car. I pictured the guys coming out of their house the next morning, so cool and above it all, only to be met with a child's oversized bear in overalls. I could hardly breathe with the giddy power of being the authors of such a nonsensical scene. I didn't know it right then, but that night, I took a story I'd been given against my will, and, with the help of my friends, I wrote a new one.

We bolted back to Bertie's car and drove into the night with the windows down, blasting our mix CD of Chicago's greatest hits. Free and silly and together.

I learned at a young age that my wheelchair and leg braces prompted a lot of reactions in people – pity, fear, a desire to help. I think that's where the special awards and lunchroom helpers and giant teddy bear came from. But being with Bertie and Marie felt different. While there would always be parts of my life they couldn't understand first-hand, they saw me – my dramatic lip-synching, my monochromatic, mixed-print, thrifted outfits, my disability, my obsessive baking ambitions – and wanted to be my friend. My body wove seamlessly, lightly, playfully into our rhythms, just like anything else. I didn't need a giant teddy bear on my island. I wanted an island with a bridge. And the three of us laid down so many bridges between our cluster of islands we built our own kingdom where we could prance back and forth, under and over – a universe all our own.

