



Allison Christina Gainer

INVISIBLE LEASHES

Service Dogs, Institutional Barriers,
and the Fight for Authentic Access in
Higher Education

Disability Studies

Collection Editor

DAMIAN MELLIFONT

LIVED PLACES
PUBLISHING



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Abstract

Invisible leashes is the story of what it's really like to move through the halls of higher education as a disabled professional and doctoral student, never alone—always with Lily-Rue, a service dog who's as much companion as co-pilot. Part memoir, part policy critique, the book pulls back the curtain on the invisible barriers that linger even in schools and universities that swear they're inclusive.

Most people don't see the obstacles. They don't notice the way doors—literal and metaphorical—stay closed to anyone who doesn't fit the mold. For those of us with nonapparent or shifting disabilities, the hardest part is often having to prove, repeatedly, that we belong. Every meeting, every classroom, every “accommodation” request becomes a small battle: to be seen, to be understood, to be allowed to exist without apology or explanation.

Lily-Rue, my service dog, isn't just there to help with daily life. She's a walking reminder that some things need to be visible, even when society would rather, we keep them hidden. Together, we navigate not just the physical world but also the emotional and professional minefields that come with being “different” in spaces designed for sameness.

Through stories, snapshots, and sharp analysis, *Invisible leashes* calls out ableist systems and policies that still fall short—and argues that access shouldn't be a favor or an afterthought. It's

an invitation for anyone who's ever felt like a disruption just for being themselves. More than anything, it's a plea to universities and other institutions: stop pretending at inclusion. Build something real, rooted in equity and the full, unapologetic presence and inclusion of disabled people.

Key words

Disability advocacy, disability rights, disability identity, invisible disabilities, chronic illness, neurodivergence, academic ableism, institutional barriers, policy reform, accessibility

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Content warning

This book contains personal stories and reflections that may be difficult for some readers. Topics explored include ableism, disability discrimination, chronic illness, mental health challenges, medical gaslighting, institutional barriers, grief, anxiety, depression, and the emotional realities of living with a disability. There are also discussions of disability disclosure, service animal use, and navigating exclusion in educational and workplace settings.

Please know that these stories come from my own lived experiences as a disabled person and service dog handler. My perspective is uniquely my own and does not represent all disabled people. Disability experiences vary widely, and no two journeys are exactly the same. My hope in sharing these truths is not to speak for others, but to invite thoughtful reflection, encourage more compassionate practices, and push for meaningful change in systems that often overlook or exclude us.

Some sections may bring up strong emotions or uncomfortable memories, especially if you have faced similar challenges. I encourage you to care for yourself as you read. Take breaks if you need to, skip sections if necessary, and return only when you feel ready.

Your comfort and well-being matter. Please honor them throughout this reading experience.

Learning objectives

As you read this book, my hope is that you will:

1. Gain a clearer understanding of navigating higher education and professional spaces as informed by a disabled person.
2. Recognize how ableism and institutional barriers can quietly shape policies, relationships, and everyday experiences for disabled students and employees.
3. Explore the complicated, often personal journey of claiming disability identity, especially when living with dynamic or nonapparent disabilities.
4. Learn more about the unique role of service dogs in the lives of disabled people—including both the essential support they provide and the misconceptions that often surround them.
5. Reflect on the emotional weight that comes with disclosing a disability, asking for accommodations, or simply existing in spaces that weren't built with us in mind.
6. Understand why true accessibility means more than following policies—it means creating spaces where people are safe, included, and valued without having to fight for it.
7. Consider how you can show up as an ally, advocate, or supporter, whether in classrooms, workplaces, or your community.

8. Begin to see disability not just through the lens of compliance or accommodation, but as an important part of social justice and equity conversations.

Above all, this book invites you to listen, reflect, and imagine what could change if we all moved through the world with a little more care, curiosity, and commitment to inclusion.

Preface

But before we begin, there's something I need to get off my chest, something I wish I'd heard, really heard, from someone else when my own life started to unravel. Disability can be lonely.

Not the kind of loneliness you fix by texting a friend or filling the room with people. Not the kind a movie night or a crowded party can cure. This is a different breed entirely: the solitude that creeps in when your body rebels against you and the world pretends nothing's wrong. It's the silence between you and the rest of humanity, the ache that settles so deep you start to wonder if it's become part of your DNA.

You learn early: when your illness doesn't show on the surface, people don't see it, don't believe it, and if you're honest most of them just don't want to deal with it. They want the version of you that doesn't make things awkward, that doesn't need special treatment, who laughs off the hard parts and always "rallies" when plans are made. They want you to be easy. And so, you learn to be easy, or at least to fake it. You practice smiling through pain, nodding when people say, "But you look great!" as if that's a compliment and not a dismissal. You memorize all the ways to minimize your needs, to apologize for your existence, to shrink yourself to fit the space you're allowed.

The costs pile up, quietly at first. There are the obvious things: the appointments you must schedule and reschedule, the bills that show up in thick white envelopes, the medication bottles rattling

in your bag. But those are just the beginning. The bigger losses are the invisible ones, the ones you feel but can't name right away. Like the job you didn't even apply for because you knew you couldn't hack the hours. The friend who stopped inviting you because you canceled one too many times. The lover who grew tired of adjusting. The feeling of missing out on your own life, of becoming a bystander to your own story.

It's a special kind of grief, waking up in a body that won't do what you ask and then spending the rest of the day trying to convince everyone else that you're not making it up. You become an actor in your own life, rehearsing lines for every scenario. You learn to anticipate the questions: "Are you sure you can't just push through?" "Have you tried yoga?" "Maybe if you got more sleep?" You get good at editing your story, leaving out the worst moments, sanding down the sharp edges so people won't flinch. You learn to say "I'm fine" when you're anything but, because the alternative is too complicated, too heavy, too risky.

There's a cost to this constant performance—a cost that's hard to tally, because it's paid out in quiet, daily installments. Every time you swallow the truth because you know it'll make someone uncomfortable, you lose a little piece of yourself. Every time you force your body to keep up, knowing you'll pay for it later, you chip away at your reserves. Every time you ask for help and see the flicker of annoyance in someone's eyes, you shrink a bit more, until smallness feels like safety.

The world is designed for people who move through it without having to explain themselves. Doors open, stairs are climbed, plans are made without a second thought. For the rest of us, every

step is a negotiation. You scan every room for the nearest exit, you clock the distance to the bathroom, you weigh whether you have the energy to fake normalcy one more time. You become a master of logistics, a strategist, a reluctant expert in making it work. But sometimes you just want to let your guard down, to say, "This is really hard," without fearing you'll be accused of exaggerating or worse, seeking attention.

What no one tells you about having a dynamic, nonapparent disability is how much time you spend managing other people's discomfort. You become fluent in disclaimers, always ready to explain why you're limping today when you weren't yesterday, or why you need to rest when you looked fine an hour ago. You worry about being seen as unreliable, flaky, high maintenance. You worry about being pitied. You worry about being resented. You worry about being forgotten.

It's exhausting, living with this kind of vigilance. You start to second-guess your own reality. Was the pain really that bad, or did you just imagine it? Are you making too much of this? Should you just try harder? Self-doubt becomes a constant companion, whispering that maybe everyone else is right and you're the problem. The world gaslights you until you start to gaslight yourself.

Sometimes, the loneliness is so sharp it's physical. You sit in a room full of people, their laughter bouncing off the walls, and feel a thousand miles away. You watch your friends plan trips you can't join. You see your colleagues move up the ladder while you're stuck negotiating for basic accommodations. You scroll through social media and see lives unfolding

with a kind of casual freedom you barely remember. And you wonder if anyone notices how much it costs you, just to keep showing up.

There is a price to not being believed, to having your reality questioned, to being erased by well-meaning policies and ignored by systems that were never built for you. The price is paid in fragments: a little autonomy here, a sliver of confidence there, a handful of dreams you quietly let go. Some days, it's all too much. Some days, the weight of being unseen is heavier than the disability itself.

So yes, this book is about telling the truth. But it's also about survival. Mine, first. Maybe yours, too. I wrote it because I needed to say the things I was never allowed to say out loud the grief, the frustration, the small joys that still manage to break through. I wrote it because I needed to believe my own story, even if no one else did.

Because until we name the cost, we'll keep paying it in silence. Until we name the loneliness, we'll keep carrying it alone. Until we name the pain, we'll keep trying to convince ourselves it's not real. This is my attempt to break that silence to put words to the things we've been told to hide, and to say, plainly: I see you. I believe you. And you are not alone, even in the moments when it feels like you are.

If you're reading this and you recognize yourself here, know that this book is for you. For the days when courage feels impossible. For the nights when the distance between you and the world seems unbridgeable. For all the times you've wondered if you're the only one. You're not. I promise.

Introduction

I've never been any good at looking away when something's wrong. Maybe it's stubbornness, maybe it's survival, or maybe it's what happens when social justice is stitched into your bones before you even know the words for it. For me, it wasn't just an idea in a textbook or a slogan on a T-shirt. It was the rhythm of my childhood—present in the background of family dinners, in the way my parents noticed and named unfairness, and in the moments that planted those seeds in me, early and deep.

I remember sitting cross-legged in Girl Scouts, a mess of construction paper and markers around me, writing letters to city officials about sidewalks that crumbled under our feet. We were supposed to be earning a civics badge, but to me it felt like a dare—a chance to say out loud that things could be better, that we didn't have to just accept what was broken. I still remember the grown-ups acting surprised that we cared so much that we really believed someone might listen to us. But I did believe it. I believed small voices could make change, even if the change started slow. That badge might be long gone, but the feeling stuck with me: if something's wrong, you say so. And if you can't fix it, you keep trying, or you find someone who will try with you.

That's how social justice took hold in me, not as a theory, but as a habit. It was watching my mom write letters to the school board

about classroom resources, her pen moving with a mix of hope and frustration. It was the way my dad shrugged off tiredness to help neighbors fill out forms they couldn't read. In our house, fairness wasn't optional; it was the point. "You don't get to complain if you're not willing to do something about it," my mom said more than once, her voice sharp and loving all at once. It was a lesson I didn't realize I was learning until years later, when I found myself unable to keep quiet in rooms where silence was the norm.

So maybe it's no wonder that by the time I made it to college, the first in my family to do it, I had this radar for injustice that never shut off. I noticed who was left out, who was questioned, who got to belong without having to explain themselves. I tried to blend in, to say thank you, to keep my head down and not rock the boat. But that itch, that Girl Scout still living in my chest, never let me forget that just because something's "normal" doesn't mean it's right.

I never really pictured myself in higher education, not as a student and definitely not as a professional. Most of my early years, I spent trying to pass, hiding what made me different, pushing through pain, apologizing for needing time or help. I thought if I just worked harder, needed less, tried not to make trouble, I'd finally fit. But that's the thing about spaces that weren't built for you, they're never safe, even when you follow all the rules. Fitting in, I figured out, is about erasing your edges. Belonging is about refusing to disappear. And social justice, for me, is about refusing to stop naming what's broken, even when it would be so much easier to stay quiet.

My journey through higher education and through disability has been shaped by this constant tension: the push to hide, the pull to be seen, the bone-deep need to do what's right even when it costs me. Sometimes that looks like speaking up in meetings, sometimes it looks like writing yet another email about why access isn't optional, sometimes it's just showing up, again, when I'd rather disappear. The Girl Scout in me is still here, still writing letters—sometimes with words, sometimes just by refusing to shrink.

So, welcome. Welcome to a space where we stop pretending everything's fine. Where accommodations aren't a prize or a privilege, but a baseline. Where "need" isn't a dirty word, and where the work of justice is never done alone.

This isn't a book of easy answers or perfect stories. It's a collection of truths—mine, and maybe yours too. It's for the student who's afraid to ask for help, for the adjunct who hides his chronic pain, for the staff member who memorizes every ramp and bench but never says why. It's for anyone who's ever been praised for being "resilient" while breaking under the weight of relentless adaptation.

If you're looking for a manifesto, you won't find it here. What you will find are stories of discomfort, of heartbreak, of connection, of hope. Stories that remind us that social justice isn't something you arrive at—it's something you do, repeatedly, in big ways and small.

So come in, with your questions, your doubts, your hope, your exhaustion. Set down your mask for a minute. Imagine what could happen if we all stopped pretending, all stopped apologizing for needing a seat at the table.

Let's start, right here. Let's start, together.

1

Invisible leashes

There's a moment I return to often, though not always by choice. It's stitched into the fabric of my memory, quiet but unshakable. I'm standing just outside a classroom, one hand gripping the leash of my service dog, Lily-Rue, and the other hovering near the door handle, unsure whether to go in or turn back. From the outside, I might have looked calm, collected, maybe even confident. But inside, I was shattering, caught in a place that was both familiar and foreign.

I was physically present, yes, but emotionally, I was floating somewhere between belonging and being completely out of place. Was I there as a student eager to learn? As a university staff member quietly scanning the environment? As a disabled woman trying not to take up too much space? Or all three, collapsing into one anxious heartbeat?

At that moment, I didn't feel like I had permission to show up as all of me.

I wasn't just a student. I wasn't just a professional. I was both. And I was also someone navigating the realities of a dynamic, nonapparent disability, one that doesn't come with predictable flare-ups or refined timing. My body doesn't RSVP in advance. One minute, I can be participating in a meeting, answering emails, moving through my day like anyone else. The next, my joints

dislocate. My heart races when it shouldn't. Fatigue crushes me mid-sentence.

Living with conditions like Ehlers-Danlos Syndrome and Postural Orthostatic Tachycardia Syndrome means learning to function in a state of constant unpredictability, and doing so in a world that demands consistency, proof, and poise. But there's no neat way to package or perform that kind of experience. So, I stood there, holding Lily-Rue's leash, trying to remind myself that showing up in that space wasn't a disruption. It was a declaration. I deserve to be here, even when the room wasn't built with someone like me in mind.

And yet, I still questioned it.

Should I step back and let someone else go first? Should I apologize for the space we take up, for the dog by my side, for the accommodations I need, for the way my disability refuses to stay invisible? Should I prepare a script for the questions I knew were coming?

"Is she in training?"

"Is she here for someone else?"

"Oh, what a cute therapy dog!"

Every part of me wanted to walk into that classroom as my full self. But every part of me also knew what it meant to do that: vulnerability, assumptions, correction, exhaustion. All before the lecture even began. That's the weight of being both seen and misunderstood. That's the weight of standing on the threshold, not just of a classroom, but of visibility itself. In that moment, I wasn't sure which part of me had the right to enter. Was I taking up too much space? Was I going to be seen as capable or

coddled? Would they assume Lily-Rue was just for comfort or attention, a kind of accessory? And the question that haunted me most: Was I even *disabled enough* to justify her presence?

It's hard to explain the mental gymnastics of constantly having to calculate your own worthiness, of wondering if your pain is visible enough, if your diagnosis is legitimate enough, if your presence is palatable enough. I didn't always call myself disabled. In fact, for a long time, I avoided the word altogether. It felt heavy, like something I hadn't earned the right to claim.

I had been raised to be independent. Capable. Helpful. My value came from doing, achieving, and performing well, on the field, on the stage, in the classroom. I was the one who got things done, the one who showed up early and stayed late, the one who didn't complain. Being an athlete and dancer reinforced that narrative. There was always applause for pushing through the pain, always praise for "toughing it out." So, I learned to smile through discomfort. To tell my body *not now* when it asked for rest. To carry my exhaustion like a badge of honor.

But the whispers from my body didn't stop. They got louder. And eventually, they turned into screams.

By the time I was diagnosed with Ehlers-Danlos Syndrome (EDS) and Postural Orthostatic Tachycardia Syndrome (POTS), I had already internalized years of doubt, my own and others. I wasn't surprised by the diagnosis. I had known something wasn't right for a long time. But knowing and accepting are two very different things. I thought I would feel relief. I thought finally having a name for my symptoms would bring clarity. Instead, I felt grief. Grief for the life I thought I could still push my way back into.

Grief for the version of me who had always relied on effort alone to compensate for pain.

Chronic illness didn't just disrupt my routine, it redefined it. Some days, I could run errands, attend meetings, and carry conversations with ease. Other days, I couldn't get out of bed without bracing myself for dizzy spells, joint dislocations, or overwhelming fatigue that made brushing my teeth feel like a marathon. I needed help. And asking for help felt like failure. Like letting go of the narrative I'd clung to my entire life: that strength meant doing it all on your own.

That's when Lily-Rue came into my life.

I didn't know how much I needed her until she was there, grounding me. Her presence was more than physical assistance. It was assurance. It was the soft, steady reminder that I wasn't broken. I just navigated the world differently. Training with her gave me things that I hadn't felt in a long time: safety, confidence, and agency. She helped me walk into places that I had started to avoid. She interrupted symptoms before they became emergencies. She gave me back parts of my life that illness had quietly stolen.

But Lily-Rue did something else too, something I wasn't fully prepared for.

She made my invisible disability... visible.

And with visibility came the questions

"Is she in training?"

"Is she for someone else?"

"You don't look disabled." "You're not blind though, does she really need to go everywhere with you?"

I expected these comments from strangers at grocery stores or the occasional nosy passerby. I didn't expect them from the people I worked alongside. From colleagues in staff meetings. From supervisors. From academics who regularly touted diversity and inclusion in PowerPoint slides but flinched at the presence of my dog. That was the betrayal that I wasn't prepared for.

And what made it even more complicated was knowing that Lily-Rue is privately trained by me. In New Jersey, that's a legal right, and an essential one for people like me who don't have the \$30,000 or the multi-year waitlist required for an organization-trained dog. But having a privately trained service dog adds an extra layer of pressure that people don't always see. She's incredible, but she's also an animal. A living being. Not a robot. She learns. She makes mistakes. She might sniff someone's bag, or bark once if startled. She might lick a friendly hand before I can cue her otherwise. And every time that happens, I feel the shame creep in. The sense that I must prove, again, that we belong. That she is trained. That we're "legit."

It's a strange thing, advocating for accessibility while simultaneously trying to be as invisible and unobtrusive as possible. I tried to be kind. Patient. Informative. I tried not to make people feel bad for asking, even when I was asked the same thing for the fifth time that week. I didn't want to seem "difficult" or "defensive." I wanted to be the easy employee, the flexible one, the one who wasn't a burden. But at the same time, I knew I had to hold the line, not just for myself, but for others who might not have the privilege, the language, or the job security to push back.

So, I corrected people. Kindly. But firmly.

No, she's not in training.

Yes, she's working.

Yes, she needs to be here.

No, I'm not blind, and you don't have to be to have a service dog.

It was, and still is, a balancing act. One foot in advocacy. One foot in self-preservation. I found myself navigating this tight-rope between education and exhaustion. Between grace and grit. Between wanting to belong and needing to be seen accurately. Because the truth is, I do take up space. And I am disabled enough. And Lily-Rue's presence isn't up for debate.

The hardest part? Knowing that the students, often first year, barely out of high school, were the ones asking thoughtful questions, respecting boundaries, and adapting with kindness. It was the professional staff and faculty, those tasked with setting the tone of inclusivity, who seemed the most resistant, the most uncomfortable, the most uninformed.

And yet, those same students gave me hope. They were willing to learn. Willing to listen. Willing to advocate for others even before fully understanding what advocacy meant. They treated me, and Lily-Rue, with a kind of openness that reminded me why I still believe in higher education, even if I don't always feel believed by some of the people in it.

There's this unspoken expectation in higher education that everyone's smart enough to "get it." We're surrounded by people with advanced degrees, published articles, and framed credentials on their office walls, people who pride themselves on being

progressive, informed, and inclusive. But when it comes to disability and service dog etiquette, I've seen some of the most educated professionals behave with breathtaking ignorance.

The very people who speak at diversity panels, who lead strategic planning meetings about equity and access, who proudly share DEI hashtags on social media, these are often the same individuals who flinch when Lily-Rue walks into a room. Who whisper, "Should she really be here?" as if I can't hear them. Or who corner me with comments that are equal parts passive-aggressive and performatively polite: "Well, you should've told us ahead of time," as though my presence with a clearly working service dog is a disruption to be managed rather than a right to be honored.

It's not always overt. It's the silence when I enter a meeting room, the subtle glances exchanged between colleagues. The way people step around me and Lily-Rue like we're in the way. It's the change in tone during a conversation when I mention that I'll need to bring her along to a professional development event. Or worse, the time someone casually joked, "We'll make sure there's a corner for the dog," like we were an inconvenience instead of attendees.

And yet, paradoxically, it's our students who continue to model what real inclusion looks like.

They ask questions with curiosity, not condescension. They don't pretend to have all the answers, but they show up, open, respectful, and willing to learn. I've had students approach me after class just to ask if Lily-Rue has a preferred side to walk on, or how they can advocate for other students with service animals. I've watched them gently redirect peers who tried to pet her,

“Hey, don’t do that, she’s working”, with a casual confidence that even seasoned professionals sometimes lack.

It gives me hope. Not just for higher education, but for the future of leadership, of allyship, of human connection. Maybe change won’t come from top-down policies, but from the grassroots empathy that students bring into these spaces.

Still, hope is complicated when you’re living in two roles. When you’re trying to stay afloat while carrying the emotional weight of systems that weren’t built with you in mind.

As a student, I had a supportive experience with Accessibility Services. They knew what to ask. They didn’t require me to prove myself at every turn. They helped me craft a plan that allowed me to learn, rest, and advocate without having to explain the same things repeatedly. It was one of the few spaces on campus where I felt like my disability didn’t need to be justified.

But when I transitioned into my staff role at the very same university, everything shifted.

HR wanted more forms. More documentation. More justification. Policies that once protected me now felt like obstacles, used not to facilitate support, but to delay, dilute, or deny it. I was the same person, with the same diagnosis, the same dog, and the same medical documentation. But suddenly, I was seen differently. Not as a student to be supported, but as an employee to be scrutinized.

I’ll never forget the meeting where I brought up the idea of updating our internal policies around service animals. I came prepared, articles, ADA guidance, case law examples. I didn’t expect immediate change, but I expected conversation.