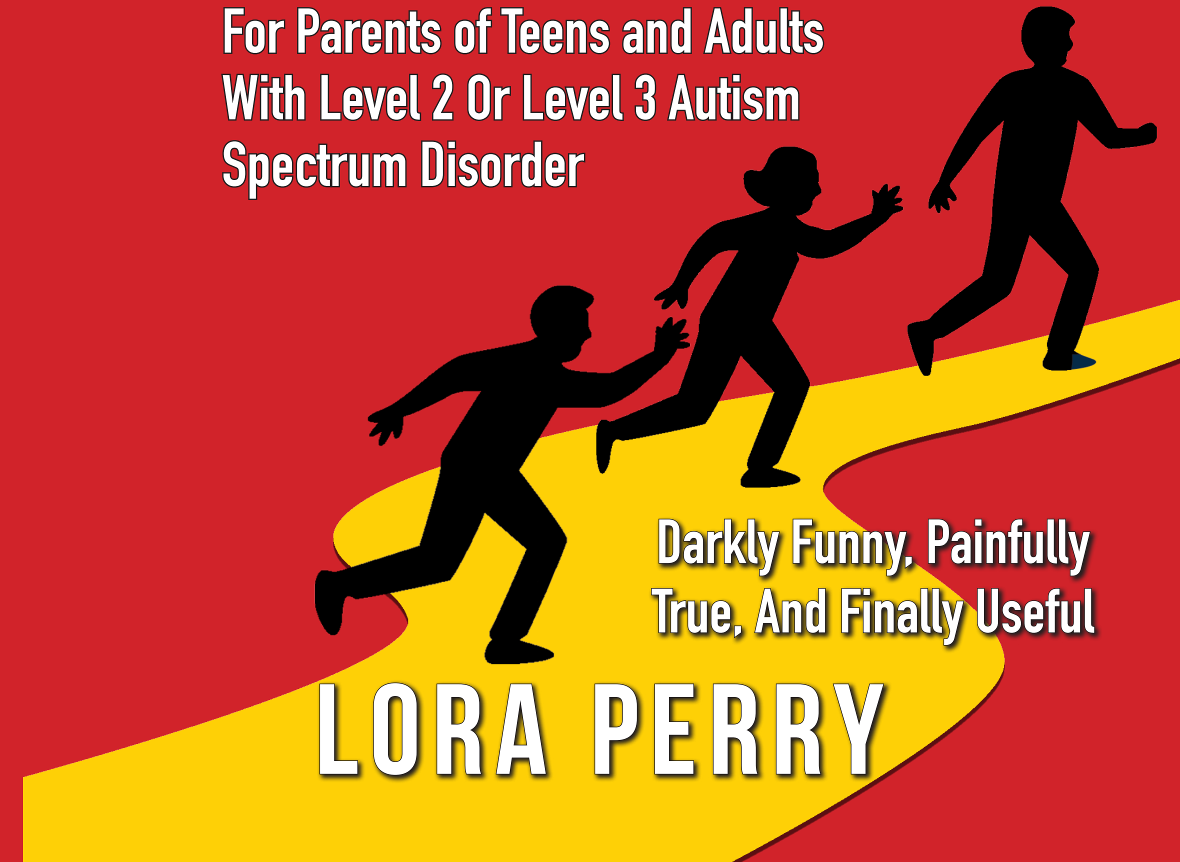
AUTISM ADULTING *SCARES ME* WITLESS

For Parents of Teens and Adults With Level 2 Or Level 3 Autism Spectrum Disorder



Darkly Funny, Painfully True, And Finally Useful

LORA PERRY

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My Quick Start Guide

If you're holding this book, you're probably caring for a young adult with autism—likely at Level 2 or 3—and you're starting to realize that adulthood doesn't come with a How To. No roadmap. No laminated checklist. Just a giant cliff where the school bus used to be.

My family has been there—staring into that void, wondering if our kids will be safe, happy, functional, clothed, housed, medicated, fed, loved—and if we'll survive the process ourselves. Spoiler: It's a lot. That's why this book doesn't come at you like a textbook or a feel-good memoir. It's built like the world we're living in: full of fear, questions, and stubborn hope. It's also designed to circumvent the TL;DR (too long; didn't read) realities of our lives. Keep it short and to the point, please, it's not like I don't have other things to do.

I'm Not an Expert—Just Someone Who's Been Through It

I've really struggled with the fact that I'm not an expert in all this. I'm not an academic. I didn't get a PhD in autism or disability services. I'm just a parent who fumbled, Googled things, figured some stuff out, and kept going.

At best, I'm a "semi-expert" who's done the work, made the mistakes, and lived to tell about it. I don't have credentials in autism adulting. I have lived experience, messy family dynamics, and a boatload of fears.

So, apologies in advance for anything that's off or misses the mark. Take what works for you, use it as a jumping-off point, tweak it for where you're at, and ignore the rest.

I've split the book into two main parts:

Part 1 – What's the Worst That Can Happen?

This is where we start. These four narrative chapters—Who Am I, Risk, Vision, and What's the Worst That Can Happen?—aren't instructions. They're more like a warm hand on your back. They invite you into this messy, beautiful, high-stakes world of supporting a neurodiverse adult. You'll meet our family. You'll see where we started, what terrified us, and what helped us begin to move forward.

These pages are here to say: You're not alone. You're not crazy. And you're definitely not failing.

Part 2 – Domains of Fear and Planning

This is the what-do-we-do part: Each chapter addresses one of my many fears. If some of them sound like the things that keep you up at night, well then, we have something in common.

To keep it all from feeling like a firehose of dread, I've grouped the chapters into nine domains:

- Legal Status, Rights, and Safety Nets: Because turning 18 doesn't magically create judgment or wipe away support needs.
- Crisis, Death and Sudden Loss: A hard line to face—when we die first, when it happens suddenly, when it happens too soon for him, and what comes next when we can't step in.

- Safety, Risk, and Vulnerability: Including the gut-punch fears: jail, being lost, exploitation, digital danger.
- Health, Medical, and Hygiene: Where things get real about doctors, meds, meltdowns, and Snickers bars.
- Home, Housing, and Stability: From "Will he be homeless?" to "What if he lives in a pigsty?"
- Employment, Finances, and Independence: Money, work, poverty, and the fine line between them.
- Socialization, Identity, and Meaning: The ache of friendship, loneliness, sex, and drive-thru coffee.
- Aging, Decline and Death: Because one day we'll be 80, and so will he.
- Family Impact and Collapse: Painful stuff. Burnout, grief, lost marriages, lost selves.

Each chapter stands on its own. You don't need to read them in order. Start wherever your fear is loudest. No judgement.

The tone is deliberately direct—no sugarcoating, but no doom spirals either. These aren't academic essays or inspirational puff pieces. They're field reports from parents who have fought for services, wrestled with guilt, handed over the meds, cried at meetings, laughed at the absurdity, yelled at the absurdity, and kept going.

I wrote this book not to give you answers (though there are a few), but to help you gain clarity. You don't need to master all of it. You just need a head start on knowing what's possible, what to ask for, and who to ask.

And maybe, just maybe, to know that you're doing better than you think.

A Quick Word About Pronouns

I use "he" throughout this book because my kids are boys, and that's the lived experience I'm drawing from. But everything here applies just as much to girls and young women on the spectrum. I'm not trying to make anyone invisible—I'm just trying to avoid the linguistic gymnastics of "he/she/they" in every sentence. Please read every "he" as shorthand for "your kid, whoever they are." A few chapters focus on topics specific to females—like managing menstruation or accessing gynecological care (thank you Miss Easter and Miss Leslie for your experiences with your daughters)—but unless otherwise noted, the guidance applies to sons and daughters alike.

A Word About "Child"

I use the word "child" throughout this book, even though most of the people we're talking about are adults. That's not a mistake, it's just how I talk about my own sons, even now that they're grown. It's also a lot less clunky than saying "your adult son or daughter with autism" in every sentence. Most of the time, "child" refers to an adult navigating life on the spectrum. Occasionally I mention something that could be started earlier, though I know most readers come to this book long after the early years. When I say "child," read it as shorthand for "your son or daughter—at whatever age they are now."

A Note About "Explaining"

Throughout this book, I use the word "explain:" explain safety, explain sexuality, explain what's happening and why. For some families, that's a meaningful exchange. For others, especially those caring for someone with profound cognitive disability, it may not be realistic.

If your child can't process verbal reasoning or cause-and-effect logic, you can still approach those moments with clarity and respect. Sometimes we explain for ourselves, to substantiate that there is some logic to all this. Sometimes we use pictures, gestures, or simple phrases. And sometimes, we explain even when it seems no one is listening—because we never know what's being absorbed.

That said, explanation isn't the only tool. If words don't help, focus on action, repetition, environment, and predictability. Every person, no matter how complex their needs, can be supported in understanding the world in their own way.

Let's Be Honest—I Haven't Done All This Either

I haven't done everything in this book. I don't know anyone who has. Some chapters are about things I've actually done. Some are things I mean to do. And a few are just me thinking out loud with a keyboard.

If you're flipping a page and thinking, "Holy cow, what's up with this woman?"—remember, I'm just like you. Overwhelmed. Scared. In the middle of a job I never signed up for.

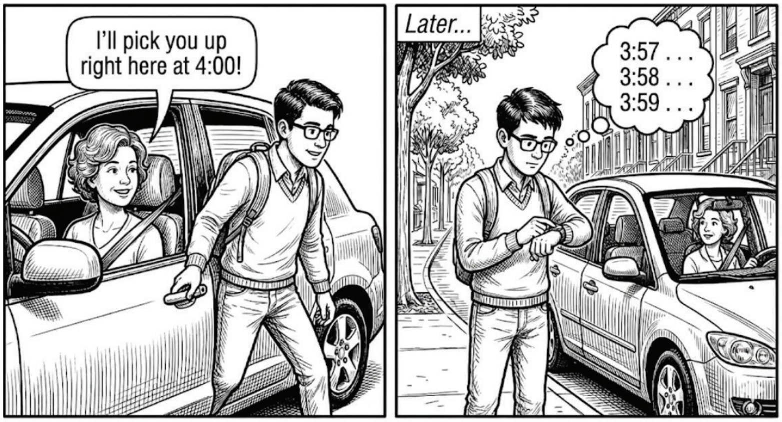
Not everything in here applies to every person, and remember: it explores across the whole lifespan—his and ours. Don't add this book to the pile of "should-dos" or "should-have-dones" that make us feel inadequate.

This is an idea factory. If even one idea here helps you breathe easier, that's good enough for both of us.

Deep breath. Let's go sort this out.

PART 2

Legal Status, Rights, Safety Nets


I'll pick you up right here at 4:00!
Later...
3:57 . . .
3:58 . . .
3:59 . . .

He'll Have Adult Rights But Not Adult Judgment

"Adulthood is like looking both ways before you cross the street and then getting hit by an airplane."
— Anonymous

Dante hit his head skateboarding.

He didn't fall hard, but he clipped the curb and flipped sideways, helmet off. Landed headfirst. Got up slow, holding his temple like it was buzzing.

He walked himself to urgent care, quiet but steady. The nurse asked questions. He answered them all, just a beat too late.

The doctor suggested a CT scan—just to be safe.

Dante shook his head. "I don't want the radiation."

They handed him a clipboard. "It's routine. Just sign here." He frowned at the paperwork, skimmed the words. "Nope. Too many risks. I looked it up."

His voice was flat. His pupils didn't match. But he stood and handed the forms back, so they let him go.

No scan. No call home. No follow-up.

He walked back to his apartment. Turned off all the lights. Didn't eat. Slept for ten hours with one shoe still on.

The next morning, he couldn't remember what day it was. Burned his toast. Forgot his PIN at the grocery store. When his support worker knocked, he didn't answer—he was inside, curled up on the floor, whispering about someone watching through the ceiling.

Why This Keeps Me Up at Night

In my bad dream he turns eighteen and the world decides he's ready. Wahoo. Not kind of ready—fully, legally, unconditionally ready, with level 2 or 3 autism.

He can make every medical decision, sign every contract, walk away from every service. Overnight, the system pivots: instead of asking me, providers ask him—even when he doesn't grasp the risks, the words, or the consequences. It's like handing someone a marathon bib and saying, "Good luck," when they've never laced up their Nikes.

In my nightmare, a man in a shiny shirt waves paperwork in a strip mall office that smells like printer toner and burnt coffee. "Just first month and deposit," he says. My son signs. He swipes the debit card ($2,000 limit) and $1,500 is gone. The fine print—utilities, pest fees, lockouts—doesn't compute. Three weeks later, the toilet floods, the door sticks, and there's no smoke detector. He calls me. I call the landlord. The landlord says, "He signed the lease. We don't talk to you."

I print the lease, highlight the confusing parts, bring a letter from the case manager and a note from the psychologist. "He thought repairs were included," I say. The landlord shrugs. "He's an adult."

While I'm pleading, my son sits in that tiny room with the flickering light, setting up a camping chair beside a dead outlet, wondering why the fridge won't turn on.

Oh—and he can marry.

At a Glance

People with ASD gain full legal rights when they turn 18 (except to drink alcohol or use recreational cannabis, which are legal in Maine at 21, thank goodness for small blessings, I suppose). This is regardless of the degree to which the person's judgment about adult matters has been honed, or to which they have documented support needs.

- At 18 full legal rights transfer to the individual, even if their judgment isn't fully developed.
- At 18, most providers automatically make the switch of responsible party from you to the child (self) without a lot of fanfare, which makes the process invisible, and can lead to some unpleasant surprises.
- Providers follow the letter of the law, even if it means ignoring obvious signs of confusion or vulnerability, because it's the law.
- Families become unable to communicate with doctors, records, and services without legal permission.
- Families become unable to exert rights in the IEP processes, if the child is still in school.
- Releases signed by him that permit practitioners to share protected information can help a lot.
- Guardianship is an option, but is a last resort from the courts' perspectives.

- Less-restrictive alternatives like power of attorney or supported decision-making agreements may be a better fit.

"Everyone Has the Right to Fail" Sounds Noble—Until Your Kid's Flat on the Pavement

This is controversial, and my opinion. You can have another opinion and we can still be friends.

Respecting self-determination is one thing. Watching someone you love get crushed by consequences they have limited ability to fully grasp is another. When professionals talk about the right to fail, they mean well, but they don't stick around to clean up the mess. When your adult child has cognitive limitations, that mess comes faster, hits harder, and can take years to undo. Sometimes it can't be undone at all.

Our level 2 and 3 ASD kids may or may not learn life lessons from poor decisions, which can lead to accidents, illness, injury, eviction, loss of benefits, legal complications or deep emotional trauma.

- "Let them fail" often means letting them burn bridges they don't even know they're standing on.
- Many systems don't accommodate regret or confusion after the fact. He's not a kid anymore.
- Emotional resilience takes longer to build when someone doesn't fully understand what went wrong or why.
- Autonomy without scaffolding isn't freedom, it's abandonment.

I salute the sentiment of "everyone has a right to fail," but am extremely wary of the wreckage that follows when no one can legally step in soon enough. As the ones who navigate the fallout, we are stakeholders in the process.

The Part Where We Figure Stuff Out

Start Planning by Age 16

The shift happens at 18, but start the work earlier. Research which of your rights will be retained (like joint checking accounts), and which will (most often invisibly) disappear without action.

- Ask your school team when they will begin conversations with your child about transfer-of-rights, and how you'll be included in these conversations prior to when your child turns 18.
- Reach out to case managers, health care and service providers for advance insight into what each entity requires for you to remain informed and involved. Leave time in the timeline to make it happen in a timely manner, so you're not caught out on something important.
- Involve your child in learning about this early, so he understands the choices coming his way.

Building understanding early helps everyone prepare for a transition to more diverse distribution of authority, curated for the realities of your child's capabilities.

Decide What Level of Support Is Actually Needed

People with level 2 and 3 ASD all need different and personalized levels of oversight, and those can change over the lifespan. Some adults can manage with occasional guidance. Others rely on others fully.

- Identify where he functions independently, and where he needs help.
- Ask professionals involved in his life what support they've seen him rely on.

- Specifically secure assessments by qualified psychologists and physicians rendering an objective, outside view of what your child is prepared and not prepared to undertake safely.
- Use everyday tasks as your guide: medication, healthcare, banking, contracts, emergencies.
- Revisit the list episodically, because some skills are learned, some are strengthened, and some fade over time

Evaluate the decisions he's making today, and how well he makes them. Teach to overcome deficits where you can, and then make an oversight plan for the rest.

Explore Less-Restrictive Legal Tools

Having been our kids' guardians with full authority since the day they were born, we often mentally default to the concept of guardianship as the only option for when they turn 18 and have not yet honed adult judgement. However, the courts have a say in this (we are, after all, talking about diminishing someone's rights), and require us to explore and exhaust less restrictive options that preserve more of the person's autonomy and responsibility for self. (See chapter on Guardianship and Other Legal Oversight).

- Learn the difference between guardianship, conservatorship, and supported decision-making.
- Understand how power of attorney and supported decision-making options work.
- Talk to a disability rights attorney about your child's specific needs and risks.
- Settle upon the options that respect his capacity while still offering protection.

These alternatives keep your child engaged in decision-making while still providing support.

Use Supported Decision-Making If He Can Participate

Supported decision-making means your child stays in charge, but with help. He can name people he trusts to guide him through major decisions, while keeping his full legal rights.

- Talk with him about how he makes decisions, and who he turns to for help.
- Use your state's supported decision-making forms if available.
- Involve his service team so everyone knows their role in the process.

When done right, this model builds confidence and interdependence.

Prepare for Resistance

Even if you know legal protection is needed, others might not agree. Some providers hesitate to discuss guardianship, and your child may resist losing any independence.

- Expect some pushback—from educators, providers, or your child.
- Frame conversations around safety and support, not control.
- If needed, get a neutral third party to help facilitate the discussion.

It's all about finding the path that keeps him safest.

Put Backup Plans in Place

Even with a plan in place, life happens. What if you're unreachable in an emergency? What if he refuses help? Having fallback options gives everyone a better sense of security.

- List who can step in temporarily if you're unavailable.
- Create a one-page summary of his needs and supports to keep in his wallet or phone.

- Discuss emergency options with your child and team, including when to override consent.

Contingency planning gives your child and team a road map when things go sideways.

Final Thoughts

It's really scary to contemplate that one birthday will rock our entire world. There's no avoiding that pinch point at age 18 in raising our kids with ASD. It requires both logistical and emotional adjustment from us, as our role shifts from protector to partner, from doing for him to doing with him. That shift that can be gradual, with proper planning, or abrupt, if we just let nature take its course.

This honest, practical and sometimes darkly funny book tackles the real fears we face as our children with autism become adults. From guardianship and housing, to mental health, money, driving, sex, medical care, caregiver death and more, each chapter names a nightmare—and the logistics to navigate it.

Written by a mom of twins with autism who's been through it, this book will make you feel seen, supported, and less alone.

Equal parts tantrum and logistics.

— About the Author —

Lora Perry is a behavioral consultant working with schools, human services, and performance-driven organizations. She's been known to say, "If that was going to work it would have worked by now," "Your system is perfectly designed for the results you're getting," "If it's predictable it's preventable," and "Act, don't yak." Before they raised a family, Lora and her husband sailed widely aboard their Downeaster 38 ketch, *Arabella*. Lora, Steve, and their adult sons on the spectrum live in Midcoast Maine.