*A plain-language guide to benefits, accommodations, and family support for newly disabled young adults — and the families who support them.*

Written by Joanna

# Contents

*Read start to finish, or jump to what you need right now.*

# A Note Before You Start

I wrote this guide because I remember what it felt like to not know where to start.

In my early twenties, a traumatic event during college changed the course of my life. In its aftermath, I was blindsided by newly emerging psychosis — I didn't have language for what was happening to me, let alone a plan for what to do about it. That confusion eventually led to a diagnosis: PTSD and a mental illness. It was the start of a journey of living with mental illness that I'm still on today.

Suddenly I was supposed to understand a world of forms, acronyms, and systems that nobody had ever explained to me — SSDI, SSI, accommodations, appeals — while also just trying to process what was happening to my mind, my sense of who I was going to be.

Nobody handed me a map. I found things out the hard way, one confusing phone call and one denied application at a time. Years later, I became a social worker — partly because I wanted to make sure other people didn't have to figure this out entirely alone the way I did.

This guide is the resource I wish someone had given me back then. It won't have every answer for your specific situation — nobody's guide could — but it's meant to give you the foundation I didn't have: the vocabulary, the general shape of the process, and the honest, practical version of what to expect. Not the version written for caseworkers or policymakers. The version written for you, or for the family member sitting next to you trying to help.

A few things I want you to know going in:

**You're not behind.** However long it takes you to work through this — weeks, months, longer — that's the right pace for you. There's no clock you're failing to beat.

**Getting denied doesn't mean you don't belong here.** Most people don't get approved on the first try. That's not a reflection of you or how real your situation is — it's just how the system tends to work.

**You're allowed to ask for help, and you're allowed to need it more than once.** Whether that's a family member, a benefits counselor, an advocate, or just this guide — needing support isn't a failure of independence. It's how most people actually get through this.

If you're a family member reading this instead of (or alongside) the person who's newly disabled — thank you for being here. The sections written for you are meant to help you support without overwhelming, and to give you some of the same footing I wish my own family had going in.

Wherever you're starting from, I'm glad you found this. Let's get you oriented.

— *Joanna*

# 1 The First 30 Days

Getting a new diagnosis — physical, mental, or both — can feel like being handed a map written in a language you don't speak yet. You don't need to figure everything out right away. This section covers what actually matters in the first month: what to do, who to talk to, and what to gather, so you're not scrambling later.

## What This Month Is Really For

This isn't about applying for benefits yet or having a five-year plan. It's about building a foundation — paperwork, contacts, and basic understanding — so that when you're ready to take the next steps, you're not starting from zero.

## 1. Start a "Disability Binder" (Physical or Digital)

Before anything else, create one place to hold everything. This will save you hours later, especially when applying for benefits, which often ask for records going back months or years.

**What to put in it:**
- Diagnosis paperwork or letters from your doctor
- Contact info for every provider you see (name, clinic, phone, email)
- A running log of appointments, dates, and what was discussed
- Copies of any test results, evaluations, or assessments
- Insurance information (policy numbers, member ID)

*Tip: A simple folder in Google Drive or a physical accordion folder both work. The format matters less than starting now, while things are fresh.*

## 2. Talk to Your Doctor About Documentation

Ask your doctor directly: *"Can you document this in a way that would support a disability claim or accommodation request, if I need one later?"*

Doctors don't always know you'll need this unless you ask. Getting into this habit early — even if you're not sure you'll apply for anything yet — means you won't have to backtrack for records months down the line.

## 3. If You're in School: Contact Disability Services

Every college and many high schools have an office (often called Disability Services, Accessibility Services, or similar) that can set up accommodations — extended test time, note-takers, flexible deadlines, and more.

**What to do:**
- Look up "[your school name] disability services" or ask a school counselor
- You'll likely need documentation from a doctor (see step 2)
- Accommodations are usually not retroactive — the sooner you register, the sooner they apply

## 4. If You're Working: Understand Your Rights (Without Rushing)

You are not required to disclose a disability to your employer unless you're requesting an accommodation. If you do need one:

- The Americans with Disabilities Act (ADA) covers accommodation requests for employers with 15+ employees
- You can request accommodations through HR or a manager — a doctor's note is often required
- FMLA (Family and Medical Leave Act) may allow unpaid, job-protected leave if you need time off, if you qualify

*You don't have to decide this in week one. But knowing the option exists early can prevent panic later if things become urgent.*

## 5. Loop In Family — On Your Terms

If you want family involved, this is a good time to have an honest conversation about how much input feels helpful versus overwhelming. There's no one right answer — some people want a family member at every appointment; others want space to process first.

*A useful script: "I want your support, but I need to make some of these decisions myself. Can we agree on what that looks like?"*

(See the Family Section for guidance on how loved ones can help without taking over.)

## 6. Don't Apply for Benefits Yet — But Start Learning the Names

You don't need to file anything in the first 30 days. But it helps to start recognizing the major programs you'll read about in Section 2:
- **SSDI** (Social Security Disability Insurance) — based on work history
- **SSI** (Supplemental Security Income) — based on financial need
- **Medicaid / Medicare** — health coverage programs
- **Vocational Rehabilitation** — state programs that help with job training/placement

You don't need to understand these fully yet — just enough to recognize them when they come up.

## A Note on Emotions

It's common to feel overwhelmed, angry, relieved, or numb — sometimes all in the same week. None of that means you're doing this "wrong." This guide focuses on practical steps, but the emotional adjustment is real too, and it's okay to move at the pace that feels sustainable for you.

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**By the end of this month, you should have:**
- ☐ A binder or folder with your key documents
- ☐ A conversation with your doctor about documentation
- ☐ Contacted disability services (if in school) or looked into ADA rights (if working)
- ☐ A rough sense of how family will be involved
- ☐ Basic familiarity with the terms SSDI, SSI, Medicaid, and vocational rehab

# 1 The First 30 Days

FAMILY EDITION

Watching someone you love adjust to a new diagnosis can leave you wanting to fix everything at once. This section is about how to help in a way that actually helps — supporting without taking over, and knowing what's actually useful to do right now versus what can wait.

## Your Role Right Now

The most useful thing you can offer in the first 30 days isn't a solution — it's steadiness. Your loved one is processing a lot: medically, emotionally, and practically. You don't need to have the answers. You need to help create structure while they find their footing.

## 1. Ask Before You Act

It can be tempting to start researching benefits, calling doctors, or making appointments on their behalf. Before doing that, ask directly:

*"Do you want me to help with paperwork and research, or would you rather I wait until you ask?"*

Some newly disabled people want a lot of hands-on help early on. Others need to process and make their own decisions first, even if it's slower. Both are valid — the key is asking rather than assuming.

## 2. Help Build the Documentation Habit (If Invited)

If your loved one wants help, one of the most useful things you can do is help start a "disability binder" — a single place (physical or digital) to keep:

- Diagnosis paperwork and doctor's letters
- Contact information for every provider
- A log of appointments and what was discussed
- Insurance information

This sounds small, but it saves enormous time and stress later, especially if benefits applications come up — many require records going back months or years.

## 3. Learn the Landscape, Quietly, in the Background

You don't need to become an expert overnight, but having a basic sense of a few terms means you can be a more useful sounding board when your loved one is ready to talk about it:

- **SSDI** (Social Security Disability Insurance) — based on work history
- **SSI** (Supplemental Security Income) — based on financial need
- **Medicaid / Medicare** — health coverage programs
- **Vocational Rehabilitation** — state programs that help with job training/placement
- **504 Plans / IEPs** — school accommodations, if your loved one is a student
- **ADA accommodations / FMLA** — workplace protections, if they're employed

You don't need to bring these up unprompted — just recognizing them when they come up in conversation can prevent a lot of confusion later.

## 4. Watch for Signs of Overwhelm — Not Just in Them, in Yourself Too

It's common for family members to feel their own grief, fear, or frustration during this time. That's normal. But it helps to keep those feelings separate from the support you're offering — for example, avoiding phrases that center your own distress in conversations meant to support them ("This is so hard for me too" can be true, but may land differently depending on the moment).

If you're struggling, consider finding your own outlet — a friend, a therapist, or a support group for family members of newly disabled people — rather than making your loved one manage your emotions on top of their own adjustment.

## 5. Avoid Taking Over Decisions

Even when it's faster or easier for you to just handle something — a phone call, a form, a decision — try to involve your loved one directly whenever

possible, even if it takes longer. Independence in decision-making, even in small things, matters a great deal during this period, both practically and for their sense of agency.

*A helpful reframe: your job is to remove obstacles, not to make decisions for them.*

## 6. Know What NOT to Rush

There's no need to apply for benefits or make big decisions in the first 30 days. If you find yourself wanting to push forward quickly out of your own anxiety, it can help to pause and check: is this urgent for them, or does it just feel urgent to me?

## A Note on Guardianship or Power of Attorney

For some situations — particularly certain cognitive or significant mental health disabilities — questions about guardianship or power of attorney may come up. These are significant legal decisions that deserve their own careful conversation, ideally with a lawyer, and are not something to rush into during the first month unless there's a specific urgent need.

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**By the end of this month, as a family member, you should have:**

- ☐ Had a direct conversation about how much help your loved one wants
- ☐ Offered (not imposed) help building a documentation system, if wanted
- ☐ A basic familiarity with key terms (SSDI, SSI, Medicaid, etc.)
- ☐ Identified your own support outlet, separate from your loved one
- ☐ Avoided rushing into big decisions (benefits applications, guardianship, etc.)

# 2 Understanding the Benefits Landscape (SSDI vs SSI)

This is often the most confusing part of the process — and one of the most important to get right early, because applying for the wrong program (or missing one you qualify for) can cost months of delay.

## The Short Version

Both SSDI and SSI are run by the Social Security Administration (SSA) and use the same medical definition of disability. The difference is about **how you qualify financially**, not how disabled you need to be.

| | SSDI | SSI |
|---|---|---|
| **Based on** | Your work history (or a parent's, in some cases) | Financial need |
| **Who qualifies** | People who've worked and paid Social Security taxes long enough | People with limited income and resources, regardless of work history |
| **Monthly amount** | Based on your earnings record — varies by person | $994/month for an individual, $1,491/month for a couple (2026 federal rate) |
| **Health coverage** | Medicare, after a 24-month waiting period | Medicaid, usually right away |
| **Asset limits** | None | $2,000 for an individual, $3,000 for a couple (unchanged since 1989) |

## SSDI: Social Security Disability Insurance

Think of SSDI as an insurance program you paid into through payroll taxes — either your own work history, or in some cases a parent's, if you became disabled before age 22.

**You may qualify for SSDI if:**
- You've worked and paid Social Security taxes for enough years (the exact amount depends on your age when you became disabled)
- Your condition meets SSA's definition of disability (expected to last at least a year, or be terminal)
- You became disabled before age 22 and a parent has a qualifying work record (this is sometimes called "Disabled Adult Child" benefits — important for many newly disabled young adults)

> GOOD TO KNOW
>
> There's a 5-month waiting period before payments start, and a 24-month wait before Medicare kicks in. To qualify medically, your earnings generally need to stay below the Substantial Gainful Activity (SGA) threshold — $1,690/month for non-blind applicants, $2,830/month if you're statutorily blind, in 2026. Once you're approved and want to test a return to work, a Trial Work Period lets you earn above SGA for up to 9 months (in a rolling 60-month window) without losing benefits — the 2026 threshold for a month to count toward this is $1,210 in earnings.

## SSI: Supplemental Security Income

SSI isn't based on work history at all — it's based on financial need. This makes it especially relevant for young adults who haven't built up a long work record yet.

**You may qualify for SSI if:**
- Your income and resources fall below SSA's limits — $2,000 in countable assets for an individual, $3,000 for a couple in 2026
- Your condition meets the same medical definition of disability used for SSDI
- You're a US citizen or meet certain non-citizen eligibility categories

> GOOD TO KNOW
>
> SSI usually comes with Medicaid eligibility right away, which can be a significant advantage if you need health coverage quickly. The maximum federal SSI payment in 2026 is $994/month for an individual — some states add a supplemental payment on top of that.

**A note for working young adults:** if you're a student under 22, SSA excludes up to $2,410/month (up to $9,730/year) of your earnings from counting against your SSI payment. This is called the Student Earned-Income Exclusion, and it's one of the most useful — and least known — provisions for

young people trying to work part-time or study while on SSI.

## Can You Get Both?

Yes — this is called "concurrent benefits." If your SSDI payment is low (because your work history is limited) and your income/assets are also low enough to qualify for SSI, you may receive both at once, with SSI essentially topping up the difference.

## Why This Matters Especially for Newly Disabled Young Adults

If you're in your early twenties, you may not have worked long enough to qualify for SSDI on your own record yet. Two things are worth knowing:

1. **The Disabled Adult Child (DAC) benefit** — if you became disabled before age 22, you may be able to draw SSDI based on a parent's work record, even if you've never worked yourself.
2. **SSI is often the more relevant starting point** for young adults without an extensive work history — and if you start working later, your situation may shift toward SSDI or concurrent benefits.

## Common Points of Confusion

- **"I don't have to be totally unable to work to qualify."** SSA's standard is about your ability to do "substantial gainful activity" (a specific income threshold), not a zero-work standard. Some limited work may be possible depending on program and amount.
- **Applying for the wrong one first can cost time.** If you're not sure which applies, it's worth applying for both simultaneously if you might qualify for either — SSA will sort out which applies.
- **State supplements vary.** Some states add money on top of the federal SSI amount; Connecticut and New York both have state supplement programs, though the amounts and rules differ. (Flagship state details go in Section 2A.)

## A Note on Change

The SSI asset limit ($2,000/$3,000) hasn't been updated since 1989, and there's active bipartisan legislation proposed in Congress that would raise it significantly — this hasn't passed as of this writing, but it's worth checking current status before relying on these exact figures, especially if you're reading this guide more than a year or two after it was written.

## What This Section Isn't

This section explains the difference between the programs — it isn't a walkthrough of the application itself. That's covered in Section 3 (the application process).

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> **KEY TAKEAWAY**
>
> SSDI = based on work history. SSI = based on financial need. Many young adults qualify for SSI first, may qualify for SSDI through a parent's record if disabled before 22, and some people qualify for both at once.

# 2A State Supplements — Connecticut and New York Examples

Some states add money on top of the federal SSI payment. Connecticut and New York both do — but they run very different programs, which makes them useful side-by-side examples of how much "it depends on your state" really matters.

## New York

New York automatically adds a State Supplement Program (SSP) payment on top of federal SSI — you don't need a separate application if you already qualify for SSI.

**2026 amounts:**
- Living alone: federal $994 + state $87 = **$1,081/month total**
- Living with others: federal $994 + state $23 = **$1,017/month total**
- Higher amounts apply for congregate care and residential settings, which vary further by region (NYC and surrounding counties have different rates than the rest of the state)

> GOOD TO KNOW
> New York is what's called a "1634 state," meaning SSI approval automatically triggers Medicaid enrollment — no separate Medicaid application needed.

## Connecticut

Connecticut works differently. Rather than a flat add-on to SSI, it runs a separate program called **State Supplement to the Aged, Blind, or Disabled**, administered by the Department of Social Services (DSS) — not the SSA.

**Key details:**
- You need another source of income to "supplement" — SSI, SSDI, or VA benefits all qualify
- Asset limit: **$1,600 for a single person, $2,400 for a married couple** — note this is *different* from (and stricter than) the federal SSI asset limit of $2,000/$3,000
- Income limit: generally up to three times the current maximum SSI amount, though your specific benefit depends on your living situation and other income
- DSS calculates your benefit by comparing your "needs" (rent, up to certain caps, plus a personal needs allowance) against your income — the supplement fills the gap
- People eligible for this program are also categorically eligible for Medicaid

> GOOD TO KNOW
> Because Connecticut's supplement uses its own separate asset and income tests, it's possible to qualify for federal SSI but not fully qualify for the state supplement, or vice versa in some edge cases — this is genuinely one of the more confusing parts of the CT system, and worth double-checking directly with DSS (1-855-CONNECT) rather than assuming.

## Why This Comparison Matters

If you're newly disabled and deciding where to live, or trying to understand why a friend in a different state gets a different monthly amount than you, this is why: **SSI's federal base is the same everywhere, but the "extra" on top of it depends entirely on which state you're in** — and some states (like Connecticut) run a genuinely separate program with its own rules, rather than a simple add-on (like New York's).

## A Caution on These Numbers

State supplement amounts, asset limits, and income thresholds change based on state budgets and legislative action — more often than the federal SSI amount, which is tied to an annual cost-of-living formula. **Always confirm current figures directly:**
- New York: NY Office of Temporary and Disability Assistance (OTDA)
- Connecticut: CT Department of Social Services (DSS), 1-855-CONNECT

**KEY TAKEAWAY**

Both states supplement federal SSI, but New York adds a fixed amount automatically ($87 or $23/month depending on living arrangement), while Connecticut runs a separate needs-based program with its own asset and income rules. Don't assume your state works like either of these — check your own state's specific program.

# 3 The Application Process, Demystified

The application process is where a lot of people get discouraged — not because it's impossible, but because it's slow, repetitive, and often ends in a denial the first time around. Knowing what to expect ahead of time makes it much less disorienting.

## Before You Apply: Gather Your Documents

Having everything ready before you start saves you from delays later. You'll generally need:

- Social Security number and birth certificate (or other proof of birth)
- Proof of citizenship or lawful residency, if applicable
- Medical records, or at minimum contact information for every doctor, clinic, and hospital that's treated you
- A summary of your work history for the last several years (job titles, dates, duties)
- W-2 forms or self-employment tax records from the prior year
- If applying for SSDI based on a parent's record (Disabled Adult Child benefits), that parent's Social Security number

*This connects back to the "disability binder" from Section 1 — if you built one, you're already most of the way there.*

## How to Apply

- **Online:** ssa.gov lets you complete what's called the "Adult Disability Report," which covers both SSDI and SSI in one application. Most people finish in 1–2 hours, and you can save progress and return later.
- **By phone:** Call 1-800-772-1213 (8:00 a.m.–7:00 p.m.) to apply by phone or schedule an appointment.
- **In person:** You can also apply at a local Social Security office, though appointments are recommended.

## The Five-Step Disability Determination Process

Once your application is submitted, it goes to your state's Disability Determination Services (DDS) office, which evaluates your medical eligibility using a standard five-step process:

1. **Are you currently working above the SGA threshold?** ($1,690/month non-blind, $2,830/month blind, in 2026) If yes, you generally won't qualify, regardless of your condition's severity.
2. **Is your condition "severe"?** It must significantly limit basic work-related activities.
3. **Does your condition meet or equal a "listed" impairment?** SSA maintains a list (sometimes called the "Blue Book") of conditions with specific criteria — if you meet one, you're typically approved at this step.
4. **Can you do the work you did before?** If your condition prevents you from doing your past work, the process continues.
5. **Can you do any other kind of work?** SSA considers your age, education, work experience, and remaining abilities.

If you're approved at any step, the process stops and you receive an award letter. You can check your application status roughly 30 days after filing to confirm it was received, and periodically after that to track progress through these steps.

## How Long It Takes

Be prepared for this to take a while:

- **Initial decision:** Typically **6–8 months**
- **SSI payments** begin the first full month after your filing date, if approved
- **SSDI payments** have a built-in 5-month waiting period from the onset of disability (see Section 2)

## If You're Denied: You're Not Alone, and It's Not Necessarily Over

This is genuinely important to know going in: **fewer than 1 in 4 applicants are approved on their first try.** A denial is common, not a sign that your case is weak or that you did something wrong.

**The appeals process has several stages:**
1. **Reconsideration** — a new reviewer looks at your case with any additional evidence

2. **Hearing before an Administrative Law Judge (ALJ)** — you can present your case in person or by video, often with a representative
3. **Appeals Council review** — if the hearing decision is unfavorable
4. **Federal court** — the final option, rarely needed

*Many successful claims are approved at the reconsideration or hearing stage, not the initial application — so a denial letter is a normal part of the process for a lot of people, not a dead end.*

## A Note on Getting Help

You are allowed to have a representative (attorney or non-attorney advocate) help with your application or appeal, and many disability attorneys work on contingency — meaning they only get paid if you win, out of your back pay, at a rate set by law. This can be worth exploring, especially at the appeals stage, though it's a personal decision and not required.

## What This Section Isn't

This covers the mechanics of applying and appealing — it doesn't replace legal advice for your specific situation. If your case is complicated (multiple conditions, past denials, work history gaps), talking to a disability attorney or advocate before you apply can help avoid common pitfalls.

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> **KEY TAKEAWAY**
>
> Gather documents first, apply online or by phone, expect 6–8 months for an initial decision, and don't be discouraged by a denial — most approvals happen after reconsideration or a hearing, not on the first try.

# 4 School and Work Accommodations

This section matters most if you're newly disabled while still in school, entering the workforce, or already working. The accommodation systems for school and work are genuinely different from each other — and if you're transitioning from one to the other, that difference can catch people off guard.

## In K-12 School: IEPs and 504 Plans

If you're under 22 and in a K-12 public school, you may qualify for one of two types of support:

**IEP (Individualized Education Program)** — under the Individuals with Disabilities Education Act (IDEA). This is the more involved option: it includes specialized instruction, not just accommodations. If you need direct teaching support (e.g., speech therapy, a modified curriculum), this is the path.

**504 Plan** — under Section 504 of the Rehabilitation Act. This is about equal *access*, not specialized instruction. A 504 plan changes *how* you access material (extra time on tests, a note-taker, preferential seating) without changing *what* you're taught. If you don't need specialized instruction but do need accommodations, this is usually the right fit.

**How to start either one:** Contact your school's special education coordinator or 504 coordinator (sometimes the same person) and request an evaluation in writing. Schools are required to respond to these requests.

## The Big Transition: College Is Different

This is one of the most important — and most surprising — things for newly disabled young adults to know: **your IEP or 504 plan does not automatically transfer to college.**

In K-12, schools are required to *identify* students who need support. In college, **you have to self-identify and request accommodations yourself** — nobody will do it for you, and your old IEP/504 paperwork often isn't sufficient documentation on its own.

**What to do:**
- Contact your college's Disability Services (or Accessibility Services) office — ideally before the semester starts
- Bring current documentation from a doctor or evaluator (your old school paperwork can help, but many colleges want a more recent assessment)
- Accommodations are typically not retroactive, so the earlier you register, the sooner they apply

## In the Workplace: The ADA

Once you're employed, the relevant law shifts again — to the Americans with Disabilities Act (ADA), which covers employers with 15 or more employees.

**How it works:**
- You are not required to disclose a disability unless you're requesting an accommodation
- To request one, you typically go through HR or a manager, and a doctor's note may be required
- The employer must provide a "reasonable accommodation" unless it would cause "undue hardship" — this is a real legal standard, not just a suggestion
- Examples of accommodations: modified schedules, remote work, assistive equipment, extra breaks, adjusted job duties

> GOOD TO KNOW
>
> You can request accommodations at any point — not just when you're hired. If your condition changes or worsens, you can request new or additional accommodations later.

## FMLA: A Different Kind of Protection

The Family and Medical Leave Act (FMLA) is separate from the ADA — it's about *job-protected time off*, not accommodations while working.

**Key facts:**
- Provides up to 12 weeks of unpaid, job-protected leave per year for a serious health condition
- You generally need to have worked for your employer for at least 12 months and 1,250 hours, and your employer needs 50+ employees within 75 miles
- Leave can be taken all at once or intermittently (e.g., recurring medical appointments)
- Your employer must continue your health insurance during FMLA leave, as long as you keep paying your share of the premium

*If your disability requires more leave than the ADA accommodation process and FMLA combined can offer, that's a genuinely difficult situation — this is a good point to talk to a disability rights organization or employment attorney rather than navigate alone.*

## A Note for Parents/Family Supporting a Student or Employee

FMLA can also apply to *you* as a parent — for example, taking intermittent leave to attend your child's IEP or 504 meetings, which the Department of Labor has confirmed qualifies as caregiving under FMLA. If you're a family member supporting someone with a disability, you may also have some protection from discrimination based on that relationship (sometimes called the ADA's "association provision"), though it doesn't guarantee accommodations for you.

## What This Section Isn't

Every school, employer, and situation is different, and disability rights law has real nuance in how "reasonable" and "undue hardship" get interpreted. This section gives you the map — for a specific dispute or denial, contacting your school's disability services office, your HR department, or a disability rights organization for guidance is the right next step.

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**KEY TAKEAWAY**

K-12 uses IEPs/504 plans, and schools must identify you. College and work require *you* to self-identify and request accommodations — nothing carries over automatically. ADA covers workplace accommodations; FMLA covers job-protected leave; they're related but separate protections.

# 5 For Families — Supporting Without Taking Over

If you're a parent or family member, this section goes deeper into one of the hardest parts of supporting a newly disabled young adult: figuring out how much decision-making support they actually need, and choosing the right legal tools for that — without defaulting to the most restrictive option out of fear.

## Start With the Principle: Least Restrictive Option First

Guardianship is the most well-known legal tool, but it's also the most restrictive — and by law in most states, it's meant to be a **last resort**, not a default. Courts are generally required to consider less restrictive alternatives before granting guardianship. This matters because guardianship can remove someone's legal right to make decisions about where they live, their medical care, their finances, and in some cases even the right to vote or marry.

The question worth asking isn't "should we protect them?" — it's "what's the *least* restrictive way to protect them while preserving as much of their own decision-making as possible?"

## The Options, From Least to Most Restrictive

**1. Release/consent forms** — Simple documents (like a HIPAA release) that let a doctor, bank, or school share information with you. This doesn't transfer any decision-making — it just allows communication. Often the first and easiest step.

**2. Supported Decision-Making (SDM) Agreement** — The person with a disability chooses trusted "supporters" who help them understand information, weigh options, and communicate their choices — but *they* make the final decision. SDM is now legally recognized in over 20 states, and even where it isn't formally legislated, courts increasingly treat it as evidence that guardianship isn't necessary. It costs little to nothing to set up (often free using a state template).

**3. Power of Attorney (POA)** — The person authorizes an "agent" to make specified decisions on their behalf — either immediately or only if they become unable to. Unlike guardianship, a POA *shares* authority rather than removing it, and the person can revoke it at any time (as long as they still have capacity). There are two common types:
- **Healthcare POA** — medical decisions
- **Financial/Durable POA** — financial and legal decisions

**4. Representative Payee** — Specifically for Social Security benefits (SSDI/SSI). The SSA appoints someone to manage benefit payments — this covers money only, not medical or housing decisions, and doesn't require court involvement.

**5. Limited Guardianship** — A court grants authority only over specific areas where the person genuinely cannot make decisions, leaving everything else under their own control.

**6. Full (Plenary) Guardianship** — The most restrictive option: a guardian is granted authority over nearly all decisions. Courts increasingly reserve this for situations where someone truly cannot participate in decision-making, even with support.

## Why This Sequence Matters

Many families reach for guardianship first because it feels like the most protective option — but it's often more restrictive than the situation actually requires, and it's also the most expensive and time-consuming (guardianship typically costs $3,000–$10,000+ in legal and court fees, versus $0–$2,000 for an SDM agreement or POA). A combination of tools — say, a healthcare POA plus an SDM agreement for everyday decisions — often fits real situations better than an all-or-nothing choice.

## A Common Mistake Worth Avoiding

Families sometimes set up a financial POA to handle banking and benefits, then discover at a medical appointment that they have no legal ability to access records, speak with a doctor, or help with treatment decisions — because financial and healthcare authority are separate documents. If you're setting up a POA, consider both types, not just the one that seems most urgent right now.

## These Decisions Aren't Permanent

Whatever you choose doesn't have to be forever. Guardianship orders can be modified or terminated as someone's abilities change — through therapy, education, or simply growing older and more independent. It's worth revisiting the arrangement every couple of years with an attorney, rather than only when a crisis forces the conversation.

## Starting the Conversation

This is a hard conversation to start, and there's no single right way to open it. Some families find it easier to frame it around shared planning rather than around loss of ability — something like: *"I want to make sure we have a plan for the situations where you might want backup — not to take anything away from you, but so we're not scrambling if something comes up."*

Whenever possible, include your loved one directly in this conversation and decision, not just about them. Even when a limited or full guardianship does turn out to be necessary, involving them in the process — explaining what's happening and why — matters for their sense of dignity and trust in the process.

## What This Section Isn't

This is general information, not legal advice specific to your state or situation — guardianship and SDM laws vary significantly by state, and a special needs attorney can help you evaluate what actually fits your family. Organizations like The Arc (national and state chapters) and your state's disability rights organization are also strong starting points for local guidance, often at low or no cost.

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**KEY TAKEAWAY**

Guardianship is a last resort, not a default — start with the least restrictive option (release forms, SDM agreements, POA, representative payee) and only move toward limited or full guardianship if the situation genuinely requires it. These arrangements can be revisited and adjusted over time.

# 6 Common Pitfalls

These are the things people often don't find out about until they've already run into them — small rules with outsized consequences. Knowing them ahead of time can save real money and real stress.

## 1. The SSI Marriage Penalty

This is one of the most consequential — and least talked about — rules in the entire system, and it's worth understanding well before a wedding, not after.

**If you're on SSI and marry someone who also isn't on SSI and has income:** a portion of your spouse's income can be "deemed" (counted) as if it were yours, which can reduce or even eliminate your SSI payment. In 2026, deeming typically doesn't start affecting your benefit until your spouse earns roughly **$1,080/month or more in gross income** — but past that point, the reduction can be significant.

**If you're on SSI and marry someone who is also on SSI:** you both lose the individual rate ($994/month each = $1,988 combined) and drop to the couple rate ($1,491/month combined) — a loss of nearly $500/month, or almost $6,000/year, simply from getting married.

This is genuinely why some couples on SSI choose not to legally marry, even when they'd otherwise want to — it's a real and difficult tradeoff, not a hypothetical one. There is bipartisan legislation proposed (the SSI Marriage Penalty Elimination Act) to change this, but as of this writing it hasn't passed.

> GOOD TO KNOW
> This deeming rule applies to SSI specifically — **SSDI is not affected by marital status or a spouse's income at all**, since it's based on your own work record, not financial need.

*If marriage is part of your plans, running the numbers ahead of time — with a benefits counselor if possible — can help you go in with clear eyes rather than surprises.*

## 2. The Frozen Asset Limit — and What Doesn't Count Toward It

SSI's asset limit ($2,000 individual / $3,000 couple) hasn't changed since 1989, and it's easy to accidentally go over it — a modest emergency fund, an inheritance, or even a gift from a well-meaning family member can push someone over the line and suspend their benefits.

**What's excluded and doesn't count:**
- Your home (primary residence)
- One vehicle, regardless of value
- Household goods and personal belongings
- Burial funds up to $1,500
- **ABLE account funds, up to $100,000** — a tax-advantaged savings account specifically for disability-related expenses, without affecting SSI eligibility

> GOOD TO KNOW
> ABLE accounts are one of the most underused tools available. If you weren't eligible before because your disability began after age 26, note that the eligibility age was raised to age 46 as of January 2026 under the ABLE Age Adjustment Act — meaning significantly more people can now use one.

## 3. Not Reporting Changes Promptly

Overpayments — being paid more than you were owed — are one of the most stressful and common problems people run into, and they usually happen because a change wasn't reported quickly: a new job, a raise, a move, a marriage, or receiving a gift or inheritance.

**If you're overpaid, you have options** — you're not simply stuck repaying it in full:
- You can request a **reconsideration** if you believe the overpayment is wrong (60 days to file)
- You can request a **waiver** if it wasn't your fault and you can't afford to repay it — there's no deadline to request this
- If SSA proceeds with recovery, they generally withhold about 10% of your monthly SSI payment by default, though this rate can sometimes be negotiated lower

**The best defense is prevention:** report income changes, living arrangement changes, and marital status changes as soon as they happen, not at your next scheduled review.

## 4. Missing the 60-Day Appeal Window

Every decision SSA makes — approval, denial, payment amount, overpayment — comes with a written notice, and you generally have **60 days from receiving that notice** to appeal. Miss the window, and you may need to start over rather than simply appeal the original decision.

> GOOD TO KNOW
>
> If you appeal a non-medical decision (like a payment change) within that 60-day window, your benefits often continue unchanged while the appeal is processed — so appealing promptly can also protect your current payments.

## 5. Working Without Understanding the Trial Work Period

People sometimes avoid working at all out of fear of instantly losing SSDI — but the Trial Work Period (see Section 2) allows you to test working for up to 9 months while still receiving full benefits. The mistake goes the other direction too: not tracking earnings carefully during this period and accidentally working past the trial months without realizing the SGA threshold now applies.

## 6. Overlooking the Disabled Adult Child (DAC) Benefit

Covered in Section 2, but worth repeating here because it's so often missed: if you became disabled before age 22, you may be able to draw SSDI on a parent's work record — even if you've never worked yourself. This is frequently missed simply because people don't know to ask about it.

## What This Section Isn't

These pitfalls are common, but not universal — your specific situation may involve other rules entirely. A benefits counselor (often available for free through Centers for Independent Living or state vocational rehabilitation programs) can review your specific situation before a major life change like marriage, a new job, or receiving an inheritance.

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> KEY TAKEAWAY
>
> The costliest mistakes in this system are usually about *timing and reporting*, not effort or eligibility — knowing about the marriage penalty, asset limits, appeal deadlines, and reporting requirements ahead of time can prevent real financial harm.

# Resource Appendix

Contact information changes over time, so treat this as a starting point — if a number or link doesn't work, search the organization's name directly to find their current contact info.

## Crisis and Immediate Support

- **988 Suicide & Crisis Lifeline** — call or text **988** (24/7, national)
- **Crisis Text Line** — text HOME to **741741** (24/7, national)

## National Disability Rights & Legal Help

- **National Disability Rights Network (NDRN)** — umbrella organization connecting you to your state's federally mandated Protection & Advocacy (P&A) agency, which provides free legal advocacy for people with disabilities. Every state has one. (ndrn.org)
- **The Arc** — national organization advocating for people with intellectual and developmental disabilities, with local chapters in most states. (thearc.org)
- **National Organization of Social Security Claimants' Representatives (NOSSCR)** — directory of attorneys and advocates who specifically represent SSDI/SSI claimants. (nosscr.org)
- **Job Accommodation Network (JAN)** — free, confidential guidance on workplace accommodations, for both employees and employers. (askjan.org)
- **Disability Rights Education and Defense Fund (DREDF)** — national civil rights law and policy center focused on disability rights. (dredf.org)

## Benefits & Financial Navigation

- **Social Security Administration (SSA)** — 1-800-772-1213 (8:00 a.m.–7:00 p.m.), or ssa.gov to apply online or check application status
- **Your state's Vocational Rehabilitation agency** — free services to help with job training, placement, and workplace accommodations; search "[your state] vocational rehabilitation" to find yours
- **ABLE National Resource Center** — information on opening an ABLE account for tax-advantaged disability savings (ablenrc.org)
- **Centers for Independent Living (CILs)** — community-based organizations offering free benefits counseling, peer support, and independent living skills; search "Centers for Independent Living [your state]" to find your local center

## Connecticut-Specific Resources

- **Disability Rights Connecticut (DRCT)** — Connecticut's Protection & Advocacy system; free legal advocacy for discrimination, abuse, education rights, and more. Toll-free: **1-800-842-7303**. (disrightsct.org — verify current local number on their site, as it has changed in recent years)
- **CT Department of Social Services (DSS)** — for SSI State Supplement and other state benefits. 1-855-CONNECT (1-855-626-6632)
- **Connecticut 211 (Infoline)** — call **211** or 1-800-203-1234 for local health, housing, and social service referrals, 24/7
- **CT Bureau of Rehabilitation Services** — vocational rehabilitation services for Connecticut residents

## New York-Specific Resources

- **Disability Rights New York (DRNY)** — New York's Protection & Advocacy system; free legal and advocacy services. (drny.org)
- **NY Office of Temporary and Disability Assistance (OTDA)** — administers the State Supplement Program (SSP) on top of federal SSI
- **NY Office of Mental Health / Office for People With Developmental Disabilities (OPWDD)** — state agencies offering additional services depending on disability type
- **New York 211** — call **211** for local health, housing, and social service referrals, 24/7
- **ACCES-VR (Adult Career and Continuing Education Services–Vocational Rehabilitation)** — New York's vocational rehabilitation agency

## For Families

- **The Arc's Center for Future Planning** — guidance specifically on guardianship alternatives, supported decision-making, and long-term planning (thearc.org/center-for-future-planning)

- **National Resource Center for Supported Decision-Making** — state-by-state guide to SDM laws and sample agreements (supporteddecisionmaking.org)
- **Parent Training and Information Centers (PTIs)** — federally funded centers in every state that help families navigate special education and IEP/504 processes; search "[your state] Parent Training and Information Center"

## A Note on Using This List

Not every resource here will apply to your specific situation, and some organizations serve particular disability types or age ranges more than others. If you're not sure where to start, both **211** (in almost every state) and your state's Protection & Advocacy agency are strong first calls — they're designed to help you find the right next resource, not just answer one narrow question.