— A FREE GUIDE FOR CAREGIVERS

What's Coming, and What To Do Before December

A plain language guide for parents and caregivers of people with disabilities, on what has already changed, what's still ahead, and what to do about it right now.

WRITTEN BY KEITH — XZANDER'S DAD

BEFORE WE START

It has been a while since you heard from me, and I owe you an explanation.

My own health took a hit. My parents needed more care than any of us expected. And I still have my own child with a disability to care for, which never pauses for anything. All of it landed at once, and for a stretch there was nothing left over for anybody else.

If you are reading this, I suspect you already know that feeling. You do not get to put your kid's needs on hold while you handle the rest of your life. You carry all of it at the same time, and some seasons you just carry it badly.

I am telling you this because it is the whole reason for what follows. While I was heads down, a great deal changed for families like ours. Most of it has not hit yet. The biggest pieces land right after this November's election.

So I went and did the work. I read the law, the agency rules, the court filings, and the reporting. What I found is in this guide. It is free, it is yours, and there is nothing in it I have not checked.

I am not a lawyer or a financial advisor. I am a parent. Take this as a map, not as advice for your specific situation.

PART ONE

Why this feels different

Every few years something threatens our kids' services and we all brace for it. This is not that.

What makes this moment different is not the size of any one change. It is that several separate things are moving at the same time, aimed at different parts of the same family's life.

Here is what has happened, all within about a year.

- **A federal law rewrote the money.** The reconciliation law signed July 4, 2025, changed how Medicaid and SNAP are funded and who qualifies. Most of it has not taken effect yet.
- **A new rule already cut some SSI checks.** As of June 4, 2026, an adult with a disability living at home with family can lose up to a third of their monthly SSI payment. This one is not coming. It is here.
- **The Justice Department stepped back from the rule that keeps our kids out of institutions.** In June 2026, the DOJ issued a legal opinion saying federal law does not actually require states to serve people with disabilities in the community rather than in institutions. In July they withdrew their own enforcement guidance on it.
- **The office that investigates schools lost about half its staff.** The Department of Education's Office for Civil Rights, the place you file a complaint when a school refuses to follow your child's IEP or 504 plan, has been cut hard and its enforcement work has been handed to a different agency.
- **And a new federal voucher program sends public money to private schools that do not have to take our kids.** In a sample of more than 1,600 private schools, nearly half said outright they will not provide the services and protections students are entitled to in public school.

Any one of these would be a bad year. Together, in the same year, they mean something different. The money is tightening, the rules are tightening, and at the same time the places you would normally turn for help are being emptied out.

That is why I no longer think it is dramatic to plan for the worst case. It is just paying attention.

PART TWO

What has already happened

Let me walk through this in order, because the order matters.

NOV 2025

SNAP work rules widen

The law raised the age for food assistance work requirements. People up to their 65th birthday now have to document 80 hours a month of work or qualifying activity, where the cutoff used to be 55.

It also narrowed who counts as an exempt caregiver. It used to be a parent caring for a child under 18. Now it is a child under 14. If you have a disabled 15 year old at home who cannot be left alone, you are no longer automatically exempt. You have to prove your case separately.

Automatic exemptions for veterans, people experiencing homelessness, and young people aging out of foster care were repealed.

SPRING 2026

Arizona shows everyone what this looks like

Arizona moved faster than any other state, and roughly 450,000 people lost food assistance. That is about half the people in the program there. More than 100,000 of them were children.

Here is the part that matters for us. Most of those people were still eligible. They did not stop qualifying. They got tangled in paperwork and could not get untangled.

The New York Times reporter Jason DeParle went to Phoenix and documented it. Two things from his reporting have stayed with me.

The first is a 28 year old working mother named Alejandra Casillas. She had been trying since December to complete a required phone interview. She got a notice in the mail telling her to complete it by a date that had already passed a month earlier. She went to the office in person on her day off and was told she could not do it there, she had to call. The reporters stood next to her while she called. The recording told her the call volume was too high and hung up on her. She said it does that every single time.

The second is what Arizona started demanding as proof. If you had income from panhandling, you used to give the office your best estimate. Under the new approach, applicants were told to go get written documentation from the people who had dropped money in the jar. State workers admitted to the reporter that this was impossible, and that they knew it, and that they were required to ask anyway.

And here is the piece that explains all of it. Under the new funding rules, if a state pays a benefit and gets something wrong, that counts as an error, and errors can cost the state a fortune. If a state denies someone who actually qualified, that does not count as an error at all.

So the safest thing a state can do, financially, is say no. That is not a conspiracy theory. That is how the incentive is built.

Arizona also cut about a third of its caseworkers at the same time it started demanding more paperwork. More forms, fewer people to read them.

JUN 4
2026

The SSI rule that is already costing families money

This is the one I most want you to know about, because it is already in effect and there is something you can do.

Some background. SSI has a rule about what it calls in kind support and maintenance. If someone gives you free housing or food, SSA can reduce your check by up to a third on the theory that you needed less cash. For years there was an exception: if you lived in a household that received public assistance, including SNAP, that reduction did not apply. The logic was obvious. A household poor enough to need food stamps is not secretly subsidizing anybody.

On June 4, 2026, that exception went away.

> ALREADY IN EFFECT
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> If your adult child receives SSI and lives in your home, and your household gets SNAP, the value of the bedroom they sleep in can now be counted against them. Their check can drop by up to a third, roughly **$330 a month.**
>
> The Center on Budget and Policy Priorities estimates about 400,000 low income disabled and older people are affected. SSA's own internal analysis, obtained by ProPublica, projected more than 275,000 people seeing a reduced check and more than 100,000 losing SSI entirely.

This hits exactly the family I am writing to. The adult son or daughter with Down syndrome or autism or an intellectual disability, living at home, where home is not a wealthy place.

What to do about it is in Part Four. Please do not skip that part.

JUN–JUL 2026

The legal floor gets weaker

On June 18, 2026, the Justice Department's Office of Legal Counsel issued an opinion stating that federal disability law does not contain an integration mandate. That is the principle from the Supreme Court's *Olmstead* decision, the one that says people with disabilities have the right to receive services in the community instead of being warehoused in institutions.

On July 20, 2026, DOJ formally withdrew its own guidance on enforcing *Olmstead*.

Disability rights organizations are right that a legal memo cannot overturn a Supreme Court decision. *Olmstead* is still the law. But the memo sets what the federal government will actually do about it, and the answer appears to be less than before.

There is a lawsuit in Texas, now called *Texas v. Kennedy*, where three states are asking a court to strike down the integration rule. It started with 17 states and most have dropped out under pressure from disability advocates, which is a real victory worth naming. Texas, Alaska, and Florida are still going. And the federal government, which is supposed to be defending the rule, has now taken a legal position that lines up with the states suing it.

Why this matters to you practically: the integration mandate is the backstop. It is the thing that says a state cannot just cut home based services until your child's only option is a facility. If that backstop weakens at the same moment states are under financial pressure to cut, the risk is not theoretical.

THROUGH 2025–26

The help desk empties out

Social Security was already at a 50 year staffing low. Since then it has lost roughly 7,500 to 8,000 more employees, its largest one year staffing drop on record. By January 2026 the agency had fewer workers than at any point since 1967, back before it even ran the SSI program. Forty two states and DC lost more than ten percent of their SSA staff.

The agency's internal plan calls for cutting field office visits in half. SSA says no offices have permanently closed. The union representing SSA workers says more than a dozen are sitting closed right now because there is nobody to staff them, some for over a year.

The Department of Education's Office for Civil Rights was cut from around 550 staff, with at least 243 people terminated or placed on leave, and seven regional offices closed. In June 2026 the department announced it is handing civil rights investigation and enforcement to the Justice Department, and moving special education grant administration to Health and Human Services. The proposed budget for next year would cut the civil rights office another 35 percent and reduce it to about 271 positions.

Funding for the Protection and Advocacy agencies, the free legal help in every state for people with disabilities, was proposed to drop from $148 million to $69 million. Congressional appropriations committees have recommended keeping it level, so that one is a live fight, not a done deal.

I include all of this for one reason. The advice everybody gives is "appeal it, call your P and A, contact the agency." That advice is still correct. It is just going to take longer than it used to, and you should start earlier than feels necessary.

YOU ARE HERE — AUGUST 2026

Less than a sixth of this law's total effect has landed. The rest is below.

PART THREE

What has not happened yet

This is the part almost nobody is talking about, and it is the reason I wrote this now instead of next year.

Most of this law has not taken effect. Here is what is still ahead.

NOV 2026

SNAP administrative funding cut in half

The federal government cuts in half the money it gives states to administer SNAP. States go from splitting administrative costs evenly with the federal government to covering 75 percent themselves. If you want to know what happens next, look at Arizona, which cut a third of its caseworkers and watched half its caseload disappear.

DEC 31 2026 – JAN 1 2027

The Medicaid work requirement, nationwide

Adults 19 to 64 in the Medicaid expansion group have to document 80 hours a month of work or qualifying activity, or qualify for an exemption. States also begin checking eligibility every six months instead of once a year, which doubles the paperwork.

Some states did not wait. Nebraska went live May 1, 2026. Montana went live July 1. Arkansas started running checks July 1 without cutting anyone off yet. Iowa starts December 1, 2026. If you live in one of those states, your clock is already running.

OCT 1 2027

The squeeze on home and community based services begins

The limit on provider taxes starts ratcheting down, from 6 percent toward 3.5 percent. That sounds like accounting trivia. It is not. Provider taxes are one of the main ways states raise their share of Medicaid money, and that money is what pays for home and community based services.

> THE FACT UNDERNEATH EVERYTHING
>
> **Home and community based services are optional.** Nursing homes are not. Under federal Medicaid rules, institutional care is mandatory and states must cover it. The waiver services your child depends on — the attendant, the day program, the respite, the in home support — are optional benefits that states choose to offer. When a state's budget gets squeezed, the optional things are what get cut first. Not because anyone is cruel, but because the mandatory things legally cannot be.
>
> This is the single most important structural fact in this entire guide.

FY 2028

SNAP error rate penalties begin

States start paying penalties of 5 to 15 percent of their SNAP benefit costs if their error rates are too high. Those penalties are calculated using error data collected in 2025 and 2026, right now.

OCT 1 2028

Mandatory copays begin

Copayments of up to $35 per service become mandatory for expansion enrollees between 100 and 138 percent of the poverty line. Primary care and mental health visits are exempt. Specialty care, therapy, imaging, and durable medical equipment are not.

Look at those dates again. The big Medicaid changes land about eight weeks after the November 2026 election. The SNAP administrative money gets cut the same month as the election.

I am not going to tell you what to conclude from that. The reporter who covered Arizona for the New York Times noted the same thing plainly: the law deferred most of the SNAP changes until after the midterms. You can decide for yourself what that means.

What I will tell you is what it means practically. **Most of this is still in front of us.** If you have been thinking the worst has passed because your family has not been hit yet, that is not what the calendar says.

PART FOUR

What to do now

This is the part that matters. Everything above is context. This is the work.

1 Find out which Medicaid pathway covers your family member

This is the single most important thing on this list, and most families do not know the answer.

If your child qualifies through SSI, a disability determination, a waiver, Katie Beckett or TEFRA, or a Medicaid buy in program for workers with disabilities, they are generally **not** subject to the new work requirement. If they are covered as a Medicaid expansion adult, which many disabled adults are because they never went through a formal disability determination, they **are** subject to it unless they get an exemption.

Same person, same disability, completely different exposure depending on a category most people have never looked at. Look at your most recent eligibility letter, log into your state's Medicaid portal, or call and ask your caseworker for your eligibility category in writing. Do this now, not in December.

2 If you are in the expansion group, get exemption documentation early

The exemption is usually called medically frail. Under the federal rule issued June 1, 2026, states have to verify it, and in most places that means a form signed by a licensed medical provider, renewed annually.

Call your doctor's office now and ask what they need to complete a state medical frailty or work exemption form. Get the appointment on the calendar. Every family in your state is going to need this same signature in the same few months. The people who get through are going to be the ones who started early.

3

If someone is waiting on an SSI or SSDI decision, do not assume they are covered

A pending disability application or appeal does not automatically exempt someone from the work requirement. They need the separate medical frailty documentation, on top of whatever is pending with Social Security. Given how backed up SSA is right now, this gap could last a long time. Handle it separately.

4

Protect the SSI check if your child lives with you

If your adult child gets SSI, lives in your home, and your household receives SNAP, the June 2026 rule change puts up to a third of their check at risk. SSA's own rules provide a way out: the reduction does not apply if the person pays their fair share of household costs.

- **Pro rata share.** Total shelter costs divided by household size. Three people, $1,800 in shelter costs, means $600 each.
- **A rental agreement** paying at least the presumed maximum value, $351.33 a month in 2026.

Put it in writing. Pay by check or bank transfer, not cash. Keep every record. Set this up before your next redetermination, not after you get a letter. If a special needs trust is involved, this is worth a professional conversation, but do not let that stop you from starting.

5

If you have a disabled teenager and you receive SNAP, check your exemption

The caregiver exemption now stops at age 14. If your child is 14 to 17 and needs constant supervision, your automatic exemption is gone. Ask your SNAP office what documentation establishes an individual exemption, and get your child's doctor to complete it before benefits stop, not after.

6

Get on every waiting list, today

If your family member is not on your state's HCBS waiver waiting list, get on it, even if the wait is years, even if you do not need services yet. Ask for written confirmation of your application date, since in some states your position depends on it. Rules vary by state, so ask specifically how yours prioritizes.

7 Update your contact information everywhere

Medicaid, SNAP, Social Security, the waiver agency, all of it. I know how small this sounds. It is not small. A very large share of people who lose benefits lose them because a notice went to an old address, or went out so late the deadline had already passed. Alejandra Casillas got a letter telling her to do something a month after the deadline. If your state offers electronic notices, sign up.

8 Learn the two different appeal clocks before you need them

This trips people up constantly. There are two deadlines and they are not the same.

- To keep benefits flowing while you appeal, you generally have about **10 days** from the notice date. Often called aid paid pending.
- To file the appeal at all, you generally have up to **90 days**.

So if you open a termination letter on day 20, you have likely lost automatic continuation of benefits, but you have not lost your right to fight it. When you request a hearing, say explicitly you are requesting continued benefits pending the hearing, in writing.

9 Know who to call, before it is an emergency

Your state Protection and Advocacy agency. Every state has one, federally funded, free. Find yours at ndrn.org.

Centers for Independent Living. Directory at ncil.org.

Your Area Agency on Aging, for older adults or dual eligible situations. Directory at usaging.org.

Legal aid in your county, for benefits appeals. All of these are stretched thin right now. Reach out before you are in crisis, not during.

PART FIVE

Why you have not seen this in the news

I want to name something, because I think a lot of us have been quietly wondering if we are imagining things.

You have probably seen headlines about millions losing coverage. What you have almost certainly not seen is a single number telling you how many of them were disabled.

That is not an oversight in the reporting. It is that the number does not exist.

The federal Medicaid data system tracks people by eligibility category. A disabled adult covered through the expansion group is filed as an expansion adult, full stop. There is no flag that says this person has a disability. So when a state reports how many people were terminated for paperwork reasons, nobody can say how many were disabled. Not because they are hiding it. Because it was never collected.

The Agriculture Department does not publicly report how many people asked for a disability exemption from SNAP work rules, or how many were denied.

And there is no federal standard for how states count HCBS waiting lists. Some count only people already screened as eligible. Others count everyone who applied. So the national waiting list number, usually around 700,000, is really a pile of numbers that do not mean the same thing.

The people making these decisions do not know what they are doing to us, and they have not built any way to find out.

So if you have felt like the news is describing a different world than the one you are living in, you are not imagining it. You are just living in the part nobody is counting.

WHERE THIS LEAVES US

I want to be careful here, because there is a version of this document that just frightens people, and frightened people freeze.

So let me be precise about what I actually think.

I do not know that the safety net is going to collapse. Nobody does. Some of these changes may get delayed, softened, enjoined, or reversed. Six states already dropped out of that Texas lawsuit because families like ours made noise. That happened. It counts.

But I no longer think it is unreasonable to ask the question our parents never had to ask. What is our plan if the supports we built our children's lives around are smaller in five years than they are today?

For most of my life as a parent, the honest answer to that question was that the system would probably hold, more or less, and the work was learning to navigate it. I do not think that is the honest answer anymore. Not because of one law. Because of the money, the rules, and the enforcement all moving the same direction at the same time.

The families who come through this best are not going to be the ones who saw it coming first. They are going to be the ones who did the boring work early. Found out their eligibility category. Got the form signed in September instead of December. Got on the list. Put the rent agreement in writing. Built a circle of people who know their kid.

None of that is dramatic. All of it is doable this month.

Start with one. The eligibility category is the one I would pick, because everything else depends on knowing the answer.

ABOUT THE TWO BOOKS

I want to mention these once and then get out of your way.

Everything above is about the next eighteen months. But the bigger question, the one that keeps most of us up at night, is not about December. It is about what happens to our children when we are not here, in a world where the supports may be thinner than the ones we planned around.

When the Safety Net Breaks

Written for that bigger question. It goes domain by domain through your child's actual life — healthcare, housing, food, transportation, work, friendship — and asks the same question about each one. What if this goes away, and what do we build instead. The financial and legal architecture, plus the workarounds families are inventing when the system does not deliver.

It's You Now

A companion, written for the person who takes over when you cannot anymore. The sibling, the adult child, the friend who said yes. The book you hand to them, so that what they inherit is a plan instead of a mystery.

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If you never buy either one, the guide you just read is still yours, and I hope it is useful. That is not a sales technique. I mean it.

Take care of yourself. You are no good to your kid running on empty, and I learned that the hard way this past year.

Keith

XZANDER'S DAD

Everything in this guide reflects the best information I could verify as of August 2026, drawn from the statute, federal agency rules, court filings, and reporting from outlets including the New York Times, KFF, ProPublica, and the Center on Budget and Policy Priorities. Rules change, and states differ enormously. Always confirm the current rules in your own state before you act.

I am a parent, not a lawyer or a financial advisor. Nothing here is legal or financial advice for your specific situation.