Ask an Expert FAQ

FUTURE PLANNING

HOW TO AVOID “FALLING OFF THE CLIFF” WHEN YOUR DISABLED CHILD TURNS 18

www.experiential-life.com

ABOUT THE FAQ

If you registered for this conversation, you already know something most parents figure out too late...

You can't navigate the systems that support your neurodivergent/disabled child alone.

And you know how crucial it is to get the right information at the right time.

If we haven't met yet, I'm Christy.

I'm a parent of an autistic teen, a former nonprofit founder, and a 15-year healthcare and disability advocate.

I built Experiential Life Community because I kept watching families get lost in systems that weren't designed with us in mind.

Every month inside ELC, we sit down with the experts who actually work inside the systems your family is navigating.

This FAQ captures the questions families asked during our conversation with ***Eric Jorgensen*** **about planning for our kids' future.**

You registered because this mattered to you. That matters to me.

Christy xoxo

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They say that when your child turns 18, it’s like falling off a cliff.

Our kids go from having services and supports guaranteed in school to a maze of disability services, government programs – and waitlists – waiting to see if they’ll get the support they need to live in the community and not an institution.

That is what made this conversation so important - and so necessary.

The questions below came directly from parents who showed up to our Ask An Expert conversation with Eric Jorgensen about future planning.

Some were submitted in advance. Some typed them in the chat. Some jumped on camera after the recording stopped to ask their question live.

The full replay lives inside of Experiential Life.

THE BASICS

“When should we even start planning for the future?”

As soon as you get a diagnosis - or as soon as you suspect your child will receive a formal diagnosis (yep - even before you have one).

Waiting lists for evaluations can run two to three years depending on where you live, and the earlier you start, the more options you have.

“What’s the most important first step?”

Find out what services and programs your state has available for disabled people, and apply for them.

Every single state in the country has at least one Developmental Disability (DD) waiver. If you have a child with a developmental disability, they are likely eligible for some kind of waiver - even if services don't begin until after age 21.

If you don't apply, they can never get the help. And waiting lists in some states can be decades long.

Apply early, even if you don't know yet what your child will need.

MISTAKES MOST FAMILIES MAKE

"Help me not screw this up!"

The biggest mistake is waiting too long to apply for a Home and Community Based Services (HCBS) waiver or Supplemental Security Income (SSI).

For waivers: As soon as your child receives a diagnosis, apply for services through your state agency that administers HCBS waivers. This is usually your state Developmental Disabilities Administration or Agency.

For SSI: apply on the first day of the month your child turns 18. Before 18, your income and assets are counted against them. On that first day at 18, Social Security stops looking at yours entirely.

Expect to be denied. Roughly 70-80% of initial SSI applications are denied. File the appeal within the window they give you and list every diagnosis - not just the primary one. Autism alone may not prevent someone from working in SSI's view, but autism combined with co-occurring diagnoses builds a much stronger case.

WHAT IS GUARDIANSHIP

"Is guardianship the only option when my child turns 18?"

No - and it's worth understanding what guardianship means before assuming it's the only option.

There are two types of guardianship.

Guardian of the Person: the individual cannot make decisions about themselves, including signing contracts.

Guardian of the Property: the individual cannot manage their finances.

Both *require going before a judge* and making the legal case that the individual is incompetent to manage their own affairs.

Guardianship is hard to get out of once it's in place. If you move, you may need court permission. You file an annual report to the state. And when you die, the state takes over as guardian.

Alternatives to guardianship include:

- **Healthcare Proxy**: They speak for your child if they're unconscious or unable to decide in that moment - but cannot override them if they're capable of deciding.
- **Financial Power of Attorney**: You act on their behalf without removing their rights entirely.

At 18 (in most states), your child reaches the **age of majority** - meaning they can legally sign contracts.

Before your child’s 18 birthday, you need to consider what legal structures make sense for your family.

PLANNING FOR WHEN YOU’RE GONE

“How do I even start to plan for when I am no longer here to care for my child? It’s my worst nightmare.”

Start with one question: is there someone willing and able to care for your child after you're gone?

Don't assume. Have the conversation explicitly - with siblings, with friends, with whoever you're counting on. Plans made without that conversation have a way of falling apart at the worst possible moment.

From there, think about what a meaningful life looks like for your child specifically - not the life you want for them, but the life that is safe and purposeful for them. Then work backward to figure out what financial and legal structures need to be in place to support that life.

WHAT YOU JUST READ IS THE FOUNDATION.

The questions in this FAQ came directly from parents who showed up - some to just listen, some totally overwhelmed, some just relieved to finally be in a room where someone knew the answer.

What this FAQ couldn't capture is what happened in the live conversation.

The follow-up questions. The moment Eric left us with his parting advice:

"***It's not going to get any easier if you put it off.***

Write down three things you need to do. Close your eyes, pick one, and just do that one thing. Not a hundred options - three. Pick one. That's enough for today."

The full conversation lives inside Experiential Life.

And it's one of many you get access to the moment you join.

THIS IS WHAT EXPERIENTIAL LIFE WAS BUILT FOR

The systems your family is navigating were not designed with us in mind.

They're complex and overwhelming. They seem to be connected and simultaneously siloed.

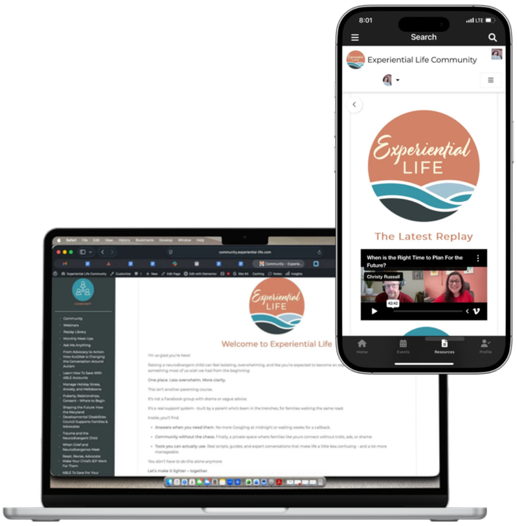
And most families are left to figure it out by crowdsourcing answers from people who are just as lost as they are - or worse, from falling down the research rabbit hole for hours.

That's what Experiential Life Community exists to fix.

It's not just the resources, replays, and scripts I curated for families like ours...

It's my 15 years of healthcare and disability advocacy - my connections and knowledge that I spent years refining.

That's why we get the experts in the room with you - to answer your questions directly.



And - you get a community of parents like you - only it's protected from internet searches, ads, and that pesky algorithm.

You stop wondering if you're missing something important.

You stop carrying the mental load of figuring this out alone.

You start making decisions with clarity - because you finally have the information and the people to back you up.

$29.99/month. Less than one therapy co-pay.
Or $299.90 for the year - two months free.
30 days free to start.

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