Same Course, *Different Shoes*

Understanding the Family Journey in Collaborative Care



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Financial disclosures

Presenters have no financial relationships to disclose.

A simple answer for this slide:

No.



LEARNING OBJECTIVES

By the end of this session, participants will be able to:

1. **Identify three checkpoints where family communication and support needs change.**
2. **Recognize three factors contributing to caregiver frustration, burnout, or loss of trust.**
3. **Apply three trust-building communication strategies that combine clinical and lived expertise.**
4. **Identify three areas requiring advance planning during the transition to adulthood.**

What do you see when you see a family?

A patient?

A caregiver?

A historian?

An advocate?

A partner?

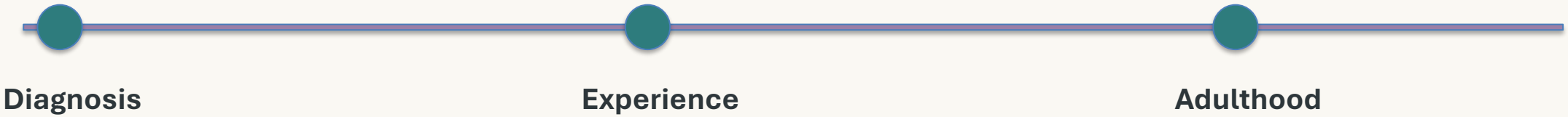
The answer may depend on where that family is in the journey.

CENTRAL IDEA

Same Course. Different Shoes. One Goal.

Providers may meet a family at a checkpoint.

Families live the whole course.



The family changes along the way. The system does not always change with us.

This isn't about bad providers.

"Most of us can name the provider who changed our child's life."

The person who listened. The person who figured something out. The person who treated us like partners.

Sometimes we are both trying to navigate a system that wasn't designed for either of us.

How do we become better partners?

THE COURSE

Three checkpoints

1

Diagnosis

From panic to a new normal

2

Experienced Parent

We’ve learned enough lingo to be dangerous

3

The Course Changes

The 18-year cliff: Now what?



CHECKPOINT 1

Diagnosis

A diagnosis can arrive with a stack of referrals.

OT • PT • SLP • Specialists • IEPs • Evaluations

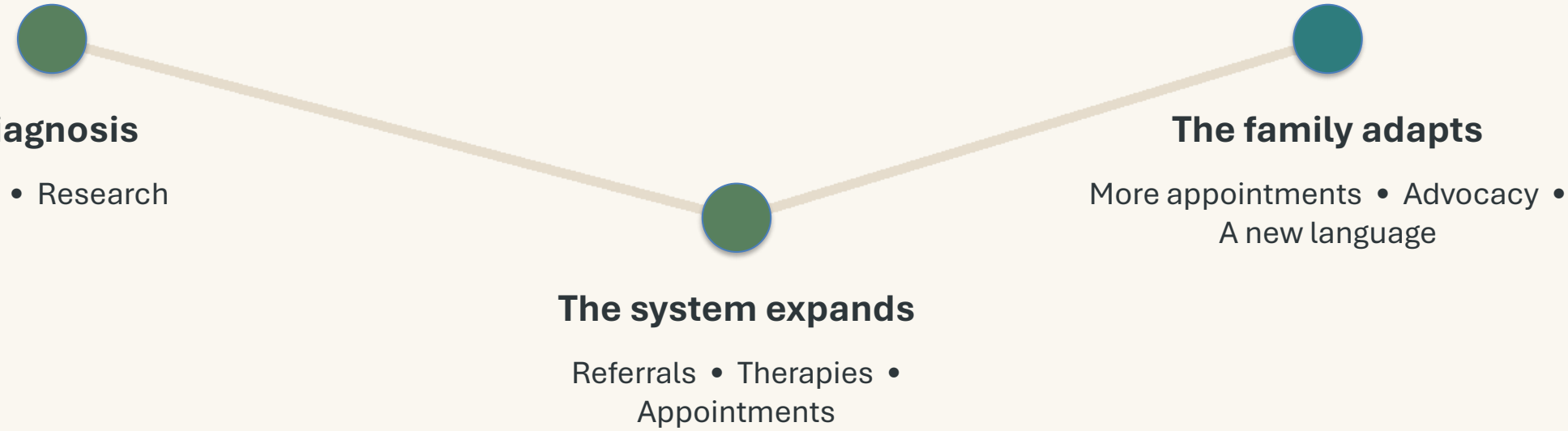
The parent is not only processing a diagnosis. They are learning an entirely new system.

Provider question: What does this family need from me right now?

CHECKPOINT 1

What it can feel like

The course fills quickly.



None of these steps is unusual by itself. Together, they can become the family's new normal.



CHECKPOINT 1

Same course. Different shoes.

A diagnosis.

A treatment plan.

A set of recommendations.

The entire world around the family may also have changed.

The chart captures the visit. The family lives everything between visits.

DON'T MISTAKE AN OVERWHELMED PARENT

FOR AN UNINVOLVED PARENT.

37 questions

may mean terrified

a notebook

may mean making sense of chaos

what matters now?

can be the most valuable guidance

Partnership here: Help us find our footing.

CHECKPOINT 2

The Experienced Parent



We have read enough to be dangerous.

We have tried therapies, equipment, medications, diets and schedules.

Eventually the question changes from “What should we do?” to “What actually works for my child?”

Experience is not a challenge to clinical expertise. It is information.

AUDIENCE REFLECTION

You've met this parent.

The binder.

The 37 questions.

"We already tried that."

What do you assume?

Difficult? Demanding? Noncompliant?

What if they're not difficult? What if they're experienced?



CHECKPOINT 2

Please don’t put us through the regular cycle

Another intake.

Another history.

Another round of proving what has already been tried.

Sometimes the family is not resistant. They are exhausted by starting over.

Start with: “Tell me what you have already tried.”

Sometimes we don't need another

"regular cycle."

We need the

PERMANENT PRESS / WRINKLE CONTROL

A child may not be "failing therapy."

The child may have reached a functional plateau.

The goal may shift from "How do we change this?" to "How do we make life work?"

CHECKPOINT 2

What experienced parents need

LESS	Have you tried…?	MORE	**What have you already tried?**
LESS	Here’s what the textbook says.	MORE	**Tell me what this looks like at home.**
LESS	Let’s start over.	MORE	**Let’s build on what you already know.**
LESS	Here’s another referral.	MORE	**What’s the actual problem we’re solving?**



CHECKPOINT 2

You have clinical expertise. We have lived expertise.

The best care needs both.

Listen to what we already know.

Build from the family's existing map instead of automatically starting at mile one.

Partnership is not agreement on everything. It is respect for both kinds of expertise.



CHECKPOINT 3

The Course Changes

The 18-year cliff does not mean the person's needs suddenly changed.

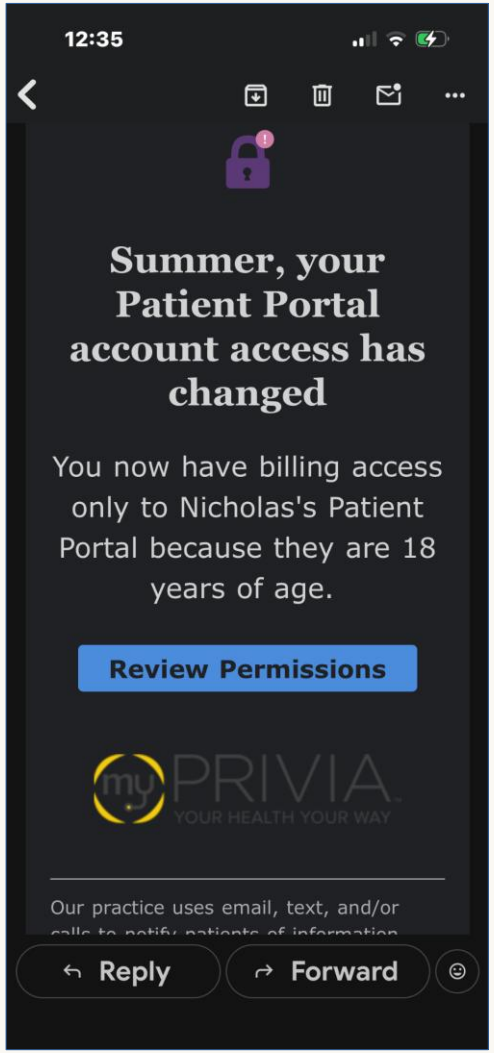
Medical care may continue with the same providers, even as access, rights, services, and expectations change.

Families can be experienced advocates and still feel like beginners again.

Yesterday I was the person everyone called. At 18, the rules changed.

A REAL TRANSITION MOMENT

The rules changed overnight.

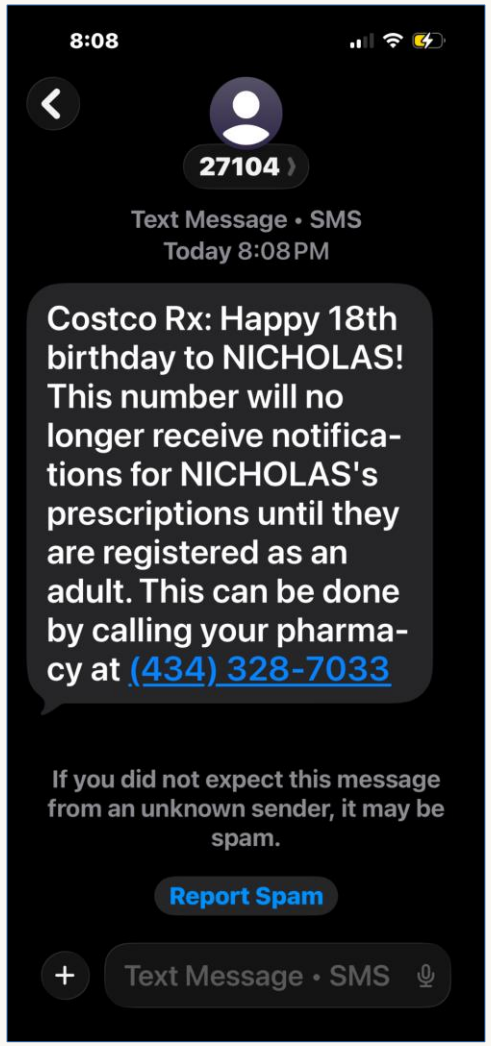


The access changed.

The relationships changed.

The person didn’t.

And it wasn't just one system.



Medical portals.

Prescriptions.
Medical records.
Therapy.
School.
SSI. Medicaid.
Employment. Volunteering.

Multiple systems can change at once.

THE 18-YEAR CLIFF

A whole new vocabulary

POA	SSI	Medicaid	DARS
Guardianship	Supported decision-making	HIPAA	Adult services

Families spend 18 years learning one system — then are expected to understand another.

SSI STORY

The systems know this. The family still has to figure it out.

6 months

waiting for a disability review

18th birthday

rules, rights, and paperwork change

Back pay

can collide with benefit eligibility

Reschedule?

after waiting six months

The complexity isn’t one rule. It’s the collision of rules.

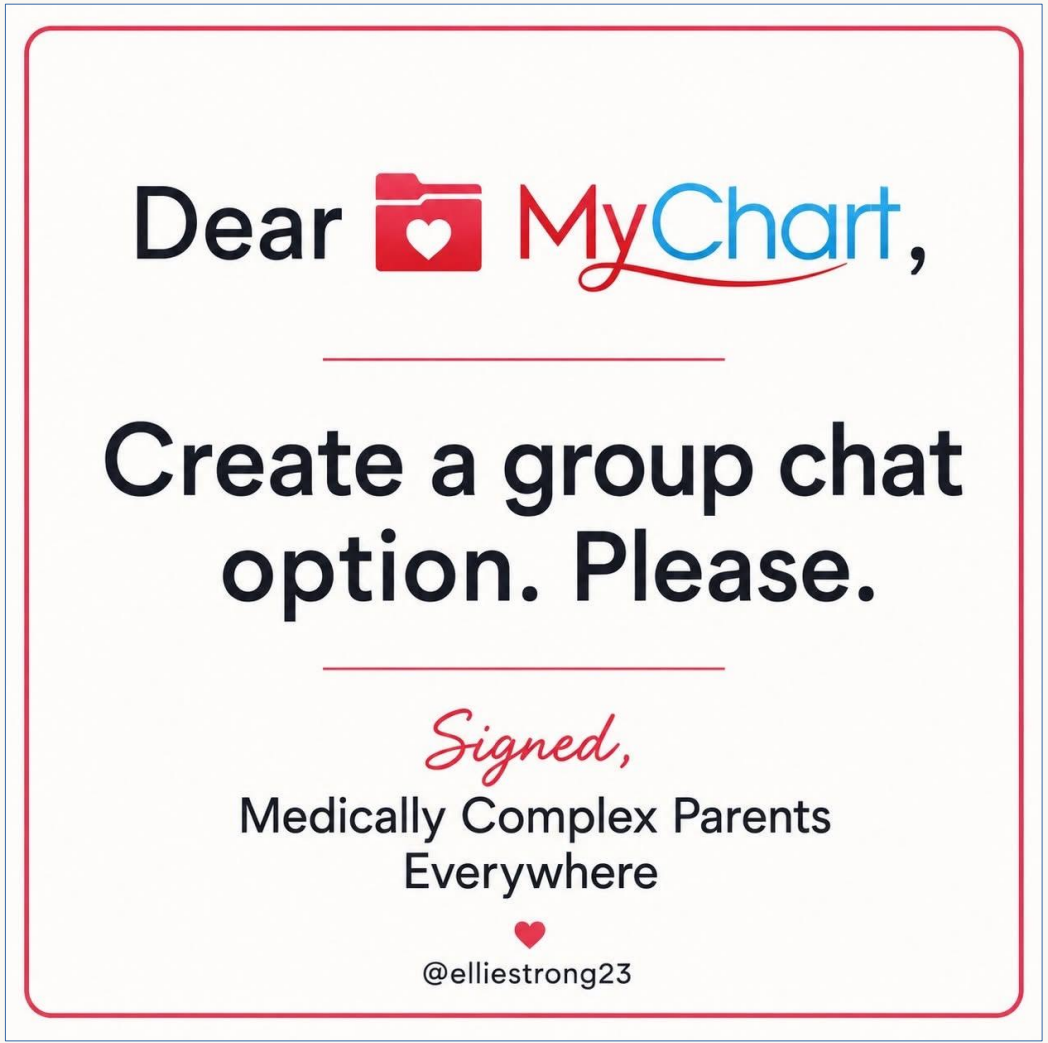
WHERE IS THE BRIDGE?

Pediatric services  **Adult services**

The question isn't only "Why did you discharge him?"

It's "Who helps a family cross the gap?"

This is bigger than one family.



Parents of medically complex young people are asking for systems that recognize the transition — not just the birthday.

The need is not unlimited access.

The need is a thoughtful handoff.



THE 18-YEAR CLIFF

Simultaneous loss and gain

Pediatric care may continue → Access and support may still change

Parental access → Adult privacy, consent and authorized access

School supports → Adult services, employment and benefits

Provider transition, when needed → Referrals and coordinated handoffs

Different systems. Different rules. Different timelines. One family.

CHECKPOINT 3

Whose shoes are we wearing?

THE YOUNG PERSON

“This is my life.”

THE FAMILY

“This is what we know about this person.”

THE PROVIDER

“This is what I know about health, treatment, and care.”

None is complete by itself. Collaborative care makes room for all three.

PARTNERSHIP

Five things parents want providers to know

1. **Ask where we are in the course.**
2. **Value what we know about our child.**
3. **Don’t confuse advocacy with hostility.**
4. **Tell us what happens next.**
5. **Don’t make us start over every time.**

We have spent years building a map to this course.

What worked. **What didn't.** **What we learned.**

Please don't throw away the map because we crossed into a new care system.

THE COURSE

Three checkpoints. Three ways to build trust.

CHECKPOINT	FAMILY EXPERIENCE	WHAT WE NEED
Diagnosis	“I’m overwhelmed.”	**GUIDE ME**
Experienced Parent	“We’ve done this before.”	**LISTEN TO ME**
Transition to Adulthood	“I don’t know what’s next.”	**HELP ME NAVIGATE**

Underneath all three: Don’t assume. Ask.

FIVE MOVES

How do we become better partners?

ASK	**Which checkpoint are we at?**
LISTEN	**What do you already know?**
BUILD	**What have you already tried?**
ALIGN	**What matters now?**
CONNECT	**What is the next checkpoint?**

THE HANDOFF

Don’t wait until 18 to talk about 18.

What changes?

What doesn’t change?

Who becomes responsible for what?

Who is the next provider?

Who is the next system?

Where is the bridge?

Even if you don’t know the answer, help the family find the person who does.

Start transition planning years before a change, not after access is lost.

NOW, LET'S TURN THE

MICROPHONE AROUND.

Collaborative care can't only mean providers understanding families.

What do you want families to know?

If you could tell a parent one thing before they leave your office, what would it be?

THE FINISH LINE

ISN’T THE GOAL.

There are checkpoints.

Diagnosis • School • Therapy • Adolescence • Adulthood

Employment • Independence • New challenges • New seasons

The course changes. The shoes change. The systems change.

But the goal doesn’t.



A good life.

A meaningful life.

A life where the young person is known, supported, valued,
and able to participate as fully as possible.

The goal isn't to get families to the finish line.

It's to make sure no one has to run the course alone.

SAME COURSE. DIFFERENT SHOES. ONE GOAL.

Let's navigate it together.



REFERENCES & PRACTICE RESOURCES

Evidence anchors for the broader clinical guidance

American Academy of Pediatrics. Patient- and Family-Centered Care and the Pediatrician's Role. Pediatrics. 2012;129(2):394–404. Reaffirmed 2025.

White PH, Cooley WC; AAP/AAFP/ACP Transitions Clinical Report Authoring Group. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics. 2018.

Got Transition®. Six Core Elements of Health Care Transition™ 3.0.

Lived-experience stories in this presentation are illustrative and are not presented as clinical evidence.