Bridging the Gap: Transition from Pediatric to Adult Care

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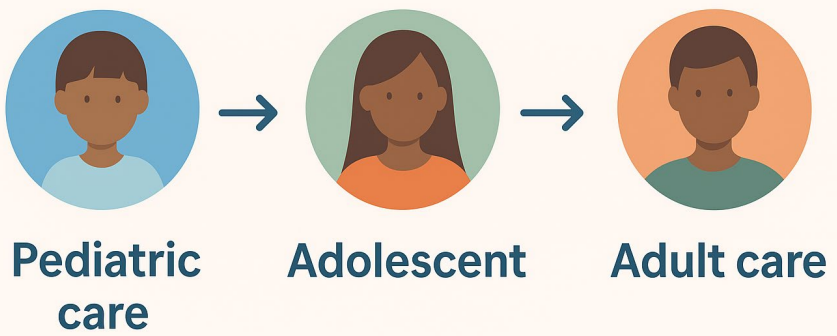
What comes to mind?

Growing Pains



- Advances in medical care mean kids with chronic or complex needs are living longer.
- However, less than 20% of youth with special health care needs receive transition preparation
- Gaps in care can put patients are risk for health complications and may lead to first adult visits occurring in ER or hospital

What is transition of care?

The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.

- a multi-step process, not a single event
- a positive step and hope for the future
- starts EARLY!

Why Transition Matters

- Goal is to not just survive, but to thrive
- Dedicated adult care maintains long-term follow-up for vulnerable adolescents
- Responsibility can shift: parent-managed → shared → self-management

Legal & Decision-Making Changes

- Consent, privacy, and decision-making shift at 18
- Support needs vary; foster independence where possible
- Guardianship is complex, though sometimes necessary.
- Goal is to preserve rights and autonomy whenever appropriate.
- Alternatives such as Power of Attorney, supported decision-making agreements, or consent forms can allow families to stay involved.
- Access to records/communication changes abruptly
- Start early, revisit often; involve CMH Social Work as needed

Finding an Adult Health Care Provider

- Finding the right adult provider can be challenging
- Insurance often drives options
- Consider asking about extended appointments during scheduling for complex needs
- Advance communication helps set everyone up for success

Questions to Ask a New Adult Health Care Provider

Access & Communication

How do I contact you or your office after hours?

Is there an on-call team available 24/7?

What is the typical turnaround time for messages or refill requests?

Care Team & Support

What does nursing support look like in your clinic?

Is there a nurse navigator or care coordinator available?

Is there access to social work, mental health, or counseling support?

Does your clinic work with DME (durable medical equipment) providers?

Services & Logistics

Where are labs and imaging done?

Are urgent care or same-day appointments available for acute issues?

What hospital(s) are you affiliated with?

Questions to Ask a New Adult Health Care Provider

Specialty Care

Do you coordinate care with subspecialists?

Which subspecialists are part of your system?

How do referrals work and who helps manage them?

Transition & Planning

How do you support young adults moving from pediatric care?

Can you communicate directly with my pediatric/subspecialty provider during transition?

Insurance & Paperwork

Do you accept my insurance?

Who can help with prior authorizations, specialty pharmacy issues, or insurance questions?

Making the First Adult Appointment Successful

Prepare a **medical summary** to always carry, including:

- Med list, medical history summary, updated equipment/medications.
- Names of current specialists and the diagnoses they manage
- Current medical therapies and allergies
- Critical details (e.g., trach size, feeding plan, favorite show/music)
- Health insurance information
- Emergency contacts
- Legal paperwork (medication decision-making, POA)
- Specialty pharmacy information
- Personality/behavioral details of the child
- Optional: condition fact sheets for complex/rare conditions

Making the First Adult Appointment Successful

- Families can **request pediatric/subspecialist join by phone** for discussion

Encourage Youth to Speak at Visits

- Start early in pediatrics. Have them answer a few questions directly at each visit.
- Before visits, help them practice sharing their history or concerns in their own words.
- Normalize stepping back as a parent. Let them answer first, then fill in gaps.
- At the first adult visit, providers can direct questions to the young adult, or ask parents to briefly step out for part of the visit if appropriate

Specialty Care in Adult System

- You may now see separate adult specialists instead of co-located teams
- PCP (primary care provider) is still central provider and can often manage stable chronic conditions/ issues previously managed by specialist
- Coordination may require more patient/family involvement (e.g., self-scheduling, tracking referrals)
- Families may need to track appointments

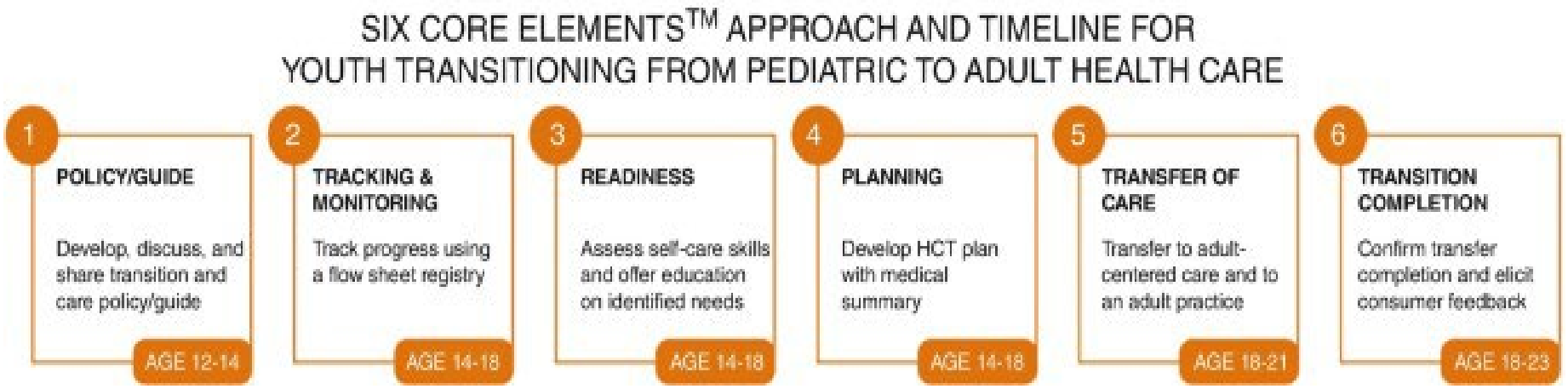
Care Coordination / Social Work Support

- Adult clinics often have social workers, care coordinators, or nurse navigators, but their roles can be less centralized than in pediatrics.
- “Is there a social worker or care coordinator I can connect with?”
- “Is there a nurse navigator support?”
- Support may include insurance navigation, DME ordering, transportation help, mental health resources, and connection to community supports.
- Access may require a referral from the PCP or subspecialist.

Changing Roles for Parents

- Parents shift from “managers” → “coaches/supporters”
- Encourage youth to take over some tasks
- Parents remain as strong advocates

Evidence-Based Transition Interventions



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Key Takeaway Points

- **Transition is a process, not a single event.** Starting early and planning sets the stage for success.
- **Preparation matters.** Youth who receive structured transition support have **smoother transfers, fewer care gaps, and better health outcomes.**
- **Partnership is key.** Youth, families, pediatric teams, and adult providers all play a role in building a coordinated bridge.
- **Empowerment builds confidence.** Gradually shifting responsibilities helps youth develop skills to manage their own health.
- **Success is possible.** With thoughtful planning, families can move from pediatric to adult care with **continuity, confidence, and support.**

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