

TRANSITION-AGE YOUTH AND CONTINUITY OF CARE

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CONTINUITY OF CARE IN TRANSITION-AGE YOUTH

Challenges in Transition-Age Youth

Youth aged 16 to 26 face worsening outcomes due to gaps in transferring supports across care systems.

Differences in Care Models

Pediatric care provides structured support, while adult systems expect independent management and navigation.

Importance of Continuity

Continuity involves preserving functional supports and scaffolding decision-making as youth become adults.

Gradual Autonomy Development

Autonomy should be built gradually, not assumed abruptly at legal adulthood.



TRANSITION FAILURE MATTERS

Impact of Transition Failures

Failures in transition lead to relapse, academic failure, and increased hospitalization or legal risks after age 18.

System vs Individual Failures

Post-18 outcome deterioration reflects system failures, not patient noncompliance or illness severity.

Importance of Preventive Care

Reframing deterioration encourages clinicians to adopt preventive approaches in transition planning.

Transition Planning as Essential Care

Transition planning is crucial for high-quality care, not just an optional add-on for complex patients.

THE PEDIATRIC-TO-ADULT CARE GAP



Pediatric Care Model

Pediatric care is family-centered, structured, and proactive with shared responsibility among caregivers.

Adult Care Model

Adult care is patient-centered, reactive, and fragmented placing full responsibility on the individual.

Impact on Youth

Youth face a sharp transition and must manage complex tasks prematurely, leading to disengagement.

Clinical Implications

Recognizing the care gap helps clinicians anticipate failures and provide timely interventions.



DEVELOPMENTAL REALITY OF TAY

Ongoing Brain Development

The prefrontal cortex continues maturing into mid-20s, influencing impulse control and decision-making.

Legal vs Developmental Status

Legal adulthood begins at 18, but emotional and behavioral maturity develop gradually afterwards.

Clinical Considerations

Clinicians must balance autonomy and support for TAY to promote ethical decision-making and well-being.

THREE SIMULTANEOUS TRANSITIONS

Developmental Changes

Youth consolidate identity, increase independence, and form adult relationships during this critical period.

Situational Adjustments

Adjusting to new environments like college or work with less structure increases stress and responsibility.

Healthcare Transition

Shifting from child-centered to adult-oriented healthcare requires managing new responsibilities and providers.

Overlap and Stress Impact

Simultaneous transitions amplify stress and risk of decompensation, especially for youth with neurodevelopmental conditions.





EDUCATIONAL ACCOMMODATION SYSTEMS CHANGE

K-12 Entitlement-Based Supports

K-12 education provides entitlement-based accommodations under IDEA with schools identifying and implementing support plans.

Postsecondary Access-Based Supports

Postsecondary education requires students to self-disclose, provide documentation, and actively request accommodations under ADA and Section 504.

Transition Challenges

The shift from entitlement to access-based systems causes predictable transition breakdowns due to new skill requirements.

SKILLS PREDICT SUCCESS MORE THAN DIAGNOSIS



Focus on Functional Skills

Transition success depends more on skills like self-advocacy and health management than on diagnostic labels.

Developmental Skill Acquisition

Skill building is a continuous developmental process starting early and extending through adolescence.

Strengths-Based Approach

Clinicians should emphasize building capacities rather than only documenting impairments for sustainable adult outcomes.



HEALTHCARE TRANSITION = PROCESS

Transition as a Process

Healthcare transition is a longitudinal process, not a single event, involving multiple coordinated steps.

Core Elements of Transition

Key elements include policy establishment, readiness assessment, proactive planning, and care transfer.

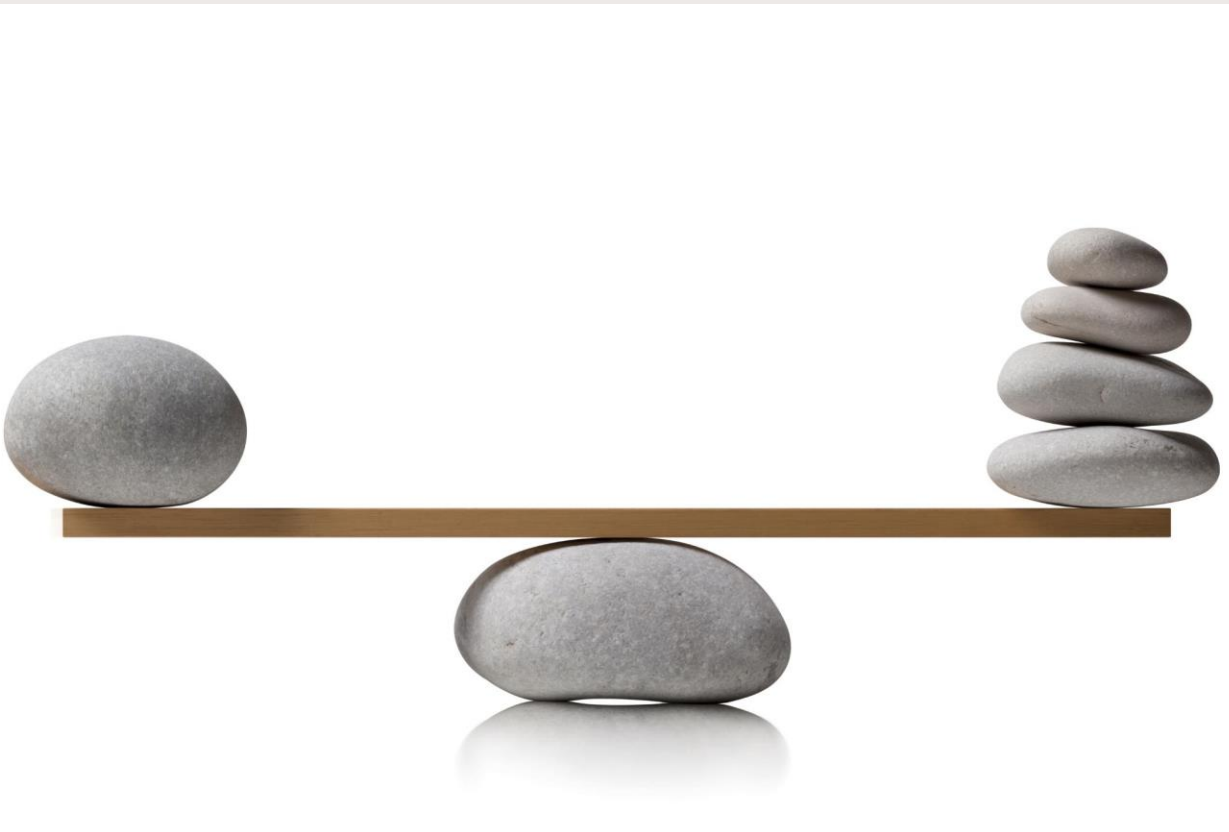
Importance of Readiness and Planning

Failures often result from insufficient readiness and planning prior to transfer of care.

Integration into Routine Care

Clinicians should integrate transition conversations and skill-building into regular care before adulthood.

ETHICAL TENSIONS IN TAY CARE



Conflicting Ethical Principles

Autonomy, beneficence, nonmaleficence, and justice often conflict in transition-age youth care decisions.

Youth Autonomy Challenges

Youth may refuse treatment or parental involvement asserting their autonomy during this period.

Clinician Safety Concerns

Clinicians focus on safety and long-term outcomes, sometimes conflicting with youth autonomy.

Ethical Discomfort Signals

Ethical discomfort indicates need for careful reasoning, documentation, and consultation in care.

A glowing blue crystal ball with a cracked, mosaic-like surface sits atop an ornate, dark metal stand with intricate scrollwork. The background is a deep blue gradient.

PREDICTABLE RISK POINTS

Loss of Educational Accommodations

Transition often causes loss of educational supports, increasing risk of academic and functional decline.

Healthcare Disengagement

Patients frequently disengage from healthcare during transition, risking unmanaged conditions.

Medication Nonadherence

Nonadherence to medication increases during transition, threatening health stability.

Environmental Stress Increase

Abrupt changes in environment and expectations escalate stress, undermining transition success.

THE CLINICIAN'S ROLE



Early Skill Building

Clinicians should start early to build skills deliberately, helping youth gain gradual autonomy over time.

Ethical Communication

Anticipate ethical challenges by clearly communicating about confidentiality, decision-making, and capacity.

Sustainable Well-being

Focus on sustainable functioning and well-being into adulthood, rather than independence solely at age 18.

Developmental Systems Approach

Adopt a developmental, systems-aware approach to extend the benefits of early intervention across lifespan.

LONGITUDINAL CASE TRAJECTORY



Early Childhood Challenges

Early emotional dysregulation and social difficulties trigger intervention and family supports to address needs.

School Age Stability

School accommodations and adult advocacy provide stability and promote skill development during school years.

Adolescent Skill Gaps

Emerging independence in adolescence reveals previously masked skill gaps requiring targeted support.

Young Adult Self-Management

Sudden self-management expectations in young adulthood expose gaps, increasing risk for functional decline.

DISCUSSION PANEL

