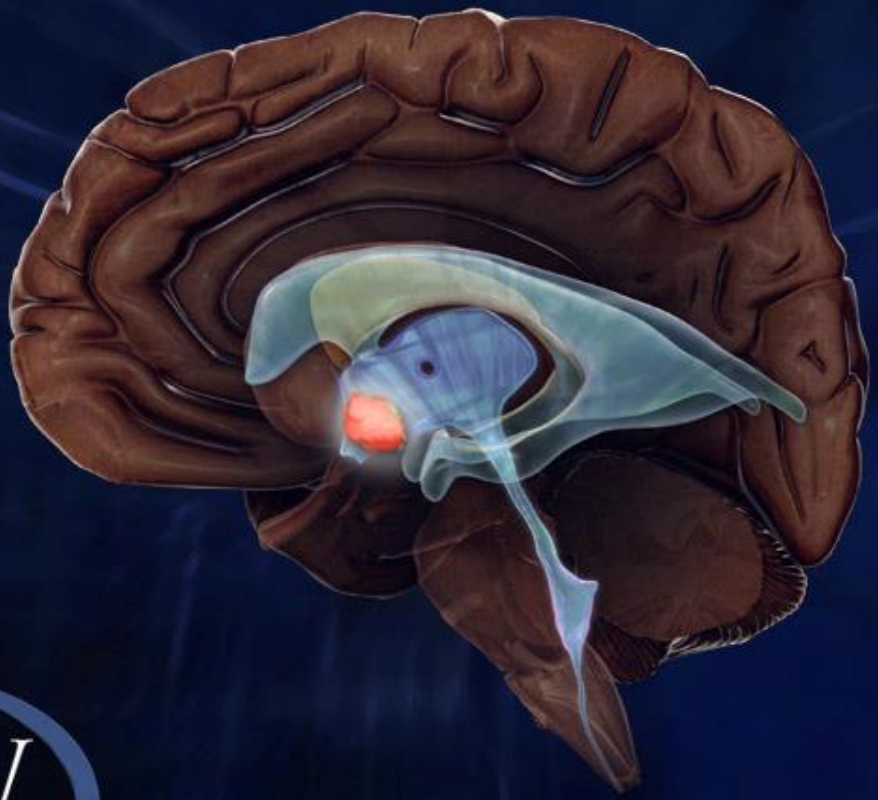
Independence and Empowerment
Transitioning and Managing Your Healthcare



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Today's Objectives

- Understand the necessity of transitioning to an adult care setting
- Demonstrate how adolescents can establish care with adult providers with minimal interruption of care
- Barriers to transition
- Understanding your role

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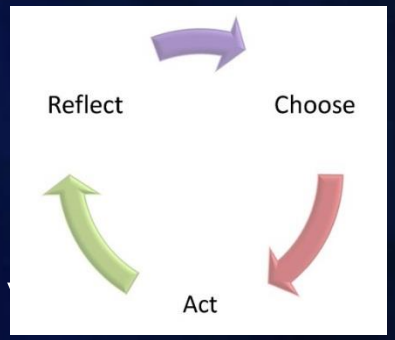
Transition vs Transfer

- Transfer
  - Responsibility of care changes from one provider to another (PCP and/or specialist)
  - Occurs for various reasons
  - No structure other than handing off records

- Transition
  - Process focused
  - Purposeful & deliberate action
  - Involves health care team, parent, and youth together
  - Preserves the *Medical Home* concept



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Goal of Transition

Maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services, that continue uninterrupted as the individual moves from adolescence to adulthood

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Why Transition at All??

Adult problems require adult doctors for surgical & medical management

- Heart, lungs, kidney conditions, hormonal dysfunction, etc.
- Mental illness
- Behavior challenges

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Adolescence
A Time of Change

- Physical growth and pubertal changes
- Development of personal identity
- Autonomy and independence
- Relationships and social activities
- Changes in school/employment
- Chronic illness/special needs superimposed on typical adolescence makes transition to adulthood even harder

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Why Transition over Transfer?

- Care delivery changes may cause anxiety and disrupt care
- Pediatric and Adult approaches to care differ
  - Pediatric
    - Family-centered
    - Developmentally appropriate
    - Warm & fuzzy feel
  - Adult
    - Individual/patient focused
    - Patient assumes responsibility
    - Patient privacy laws prevent engaging family w/o documentation
      - STM
      - Slow processing speed

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Barriers to Transition

- Adolescent
- Family/parents
- Pediatricians/specialists
- Adult PCP or specialists
- Hospitals
- Insurance industry/health care policies

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Barriers to Transition
Adolescent

- Adolescent doesn't want to take control
  - Not used to making decisions or taking initiative
  - Dealing with other challenges of puberty
- Cognitive delays prevent ability
- Fearful of leaving security of pediatric team

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Barriers to Transition
Family/Parents/Guardians

- Hesitant to leave established pediatric team

- Family concerns about the adult environment
  - More rigid approach
  - Will physicians work together for continuity of care?
  - Distance between offices
  - Worried about insurance network

- Loss of control

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Barriers to Transition
Physicians

- Pediatric clinicians
  - Hesitancy to let go
    - Relationship established early on
    - Time & effort understanding nuances & idiosyncrasies of patient
    - They are the experts in childhood condition
  - Change strategy in managing adolescent
    - Direct conversation away from parents
    - Include patient in treatment plan
    - Hold them accountable and participate in visit
    - Promotes independence of adolescent

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Barriers to Transition
Physicians

- Adult clinicians
  - Unfamiliar with childhood condition
  - Unfamiliar with intellectually or developmentally challenged patients
  - Will they receive support from pediatric specialist?
  - Not willing to take patient with chronic childhood disorder

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Barriers to Transition
Hospitals

- Concept of implementing hospital-wide policy is daunting
  - Must include clinical navigation, education, outreach, & research
  - Lack of resources
    - Coordinators to establish policy & guidelines, develop educational tools & outreach programs, & provide oversight & support to all departments
    - Will funding source "run out"
  - Transition managed the same among all specialists?
    - Age
    - Cognitive function
    - Other special needs

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Barriers to Transition
Insurance Industry

- Insurance networks may differ between adult physicians
- Hospital comprised of private practice & hospital employed physicians
- Networks can change annually
- Some physicians will not see OON patients

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Barriers to Transition

- Controllable
  - Adolescent's & parent's willingness & determination to transition
  - Taking necessary steps ***Early***

- Influential
  - State/National health care policies
  - Hospital transition policy
  - Physician's contribution/support

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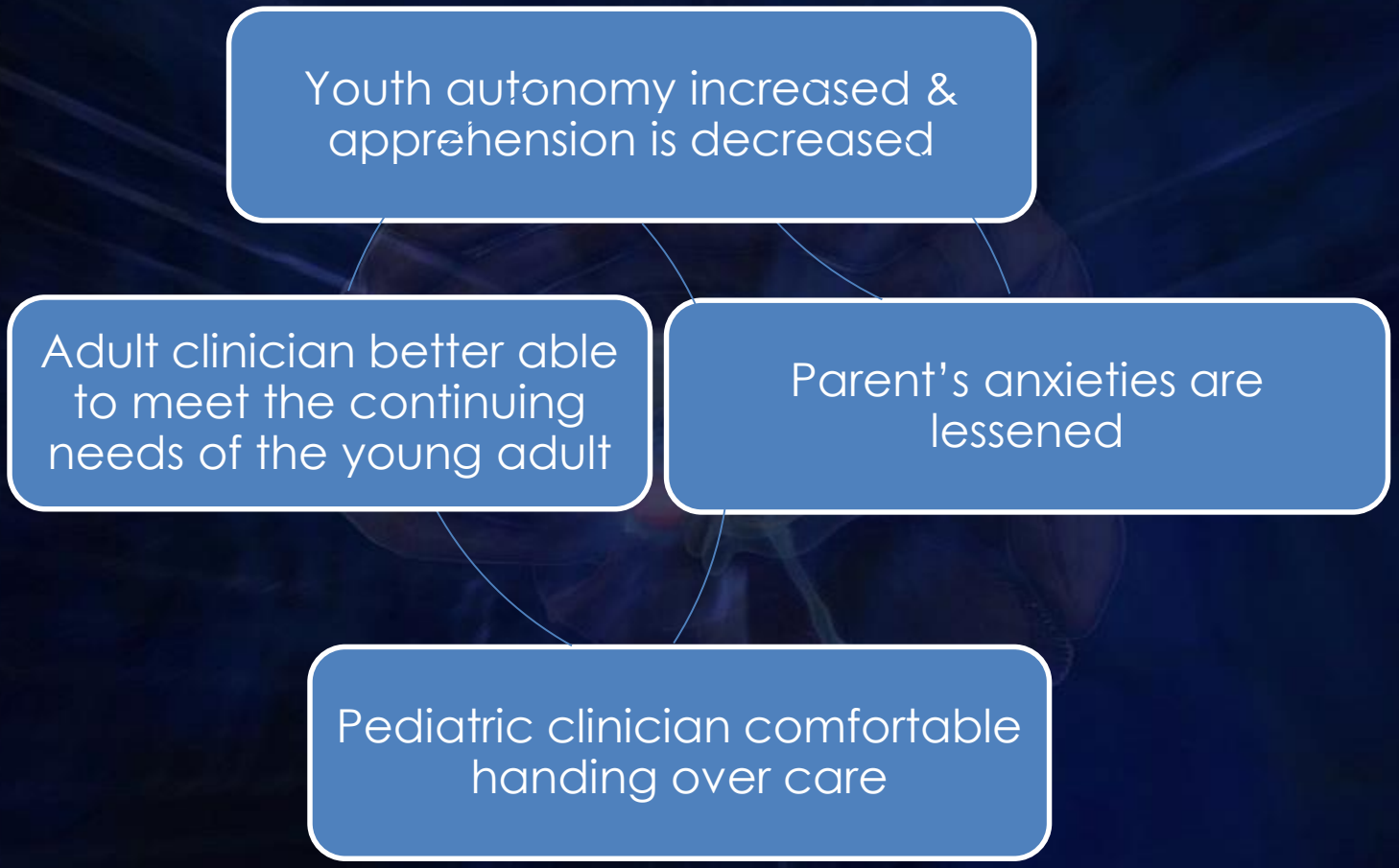
Benefits of a Smooth Transition



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How Do We Begin?

- Identify the goal of transition for your family
  - Degree of potential long-term independence
    - Cognition, intellect, behavioral, physical limitations
    - POA, guardianship documentation
- Recognize the barriers to navigate through
  - Controllable, influential, out of your hands
- Start the conversation early
  - Decreases anxiety
  - Time allows for more choices
  - Choices gives you power
- Understand the steps of transition

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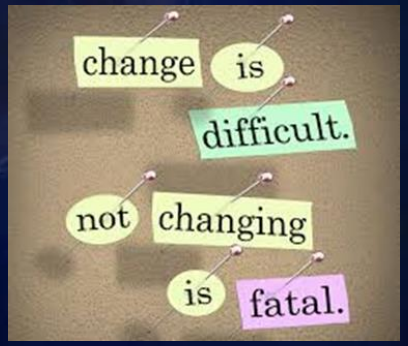
Core Elements of Health Care Transition (AAP & AAFP 2011)

- Preparation
  - Is the adolescent ready to move on?
  - Are you ready?
    - Assess your own perception of transitioning
    - Recognize this change is emotional for everyone
    - Adolescent will inherently pick up on your reluctance

- Planning stage
  - Where & when do you start?
  - Who can help you?



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Transition Preparation

- Observe & track readiness (adolescent and parent)
  - Knowledge related to medical condition and treatment plan
  - Ability to provide self care
  - Emotional readiness to change doctors
  - Can the parent relinquish control?
  - Use spreadsheet, bulleting board, etc. to track readiness

- Obtain necessary education
  - Health condition
  - Treatment
  - Life changes
  - Management of risks

Transition Preparation

- Involve adolescent in decision making and taking responsibility
  - Prescriptions
  - Missed medications
  - Appointments
  - Maintaining medical records/health summary

- Ask pediatric doctors to direct conversations to adolescent

- Empower adolescent to take charge at every opportunity

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Transition Planning

- Start process at 12 years of age
- Take baby steps
- Address health care needs/gaps

- Research potential adult provider and pending transfer date
- Seek out "get acquainted' materials
- Arrange pre-transfer visit = reduces anxiety

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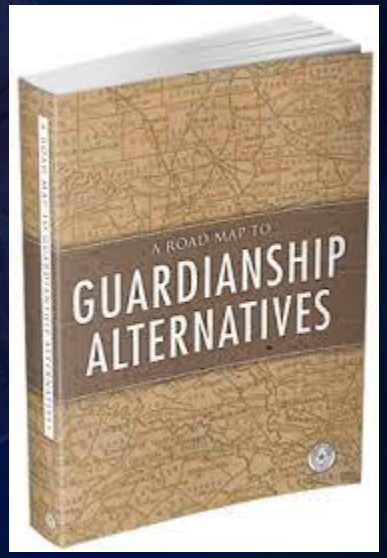
Addressing Intellectually Challenged Adolescents

- Address feelings of grief
- Recognize that parental/guardian involvement will continue
- Educate yourself
  - Legal/guardianship issues
  - Long-term care planning
  - Community resources
    - State appointed agencies
    - Churches
    - Schools
    - Hospital programs
    - Non-profit organizations



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Transition Planning

Create & Maintain a Health History

Medical Summary
Emergency Care Plan

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Phone Apps or Documents

- Problem list
- Medications
- Specialists
- Allergies
- Surgeries/procedures
- Diagnostics (labs/MRI)
- Family health history
- Emergency contact
- Emergency treatment plan
- Insurance

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Transition Planning

- Use pediatric team as a resource
  - Referrals to adult doctors
  - Introductory letter
  - Ask the pediatric doctors to serve as resource for adult doctors for the 1st year after transition
  - Ask local hospitals or doctor's office for transition policy

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Pilot Study
Adolescent/Family Feedback

- Early dialog between adolescent/parents/pediatric providers
  - Guided parents in starting the conversation with adolescent
  - Helped them take small steps & avoid feeling of being overwhelmed
  - Conversation directed at patient early
    - Promoted independence of adolescent
    - Held them accountable and participate in visit

- Transition Tools
  - Readiness questionnaires helped them navigate process with adolescent
  - Medical Summary
    - Care binders offered a simple organizational tool
    - Phone app

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Transition Overview

- Assessed readiness
- Addressed deficiencies in knowledge
- Start the conversation early
- Start planning move to adult team early
- Complete health history & ER treatment plan

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Transition Complete

- Can you help the adult provider/staff to accommodate other special needs patients in the future?

- Give your pediatrician feed back!!!!

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Take-a-Ways

- Begin with communication early
- Transform these conversations into action
- Until a systematic plan is in place we must each assume responsibility for creating a smooth transition process for our families

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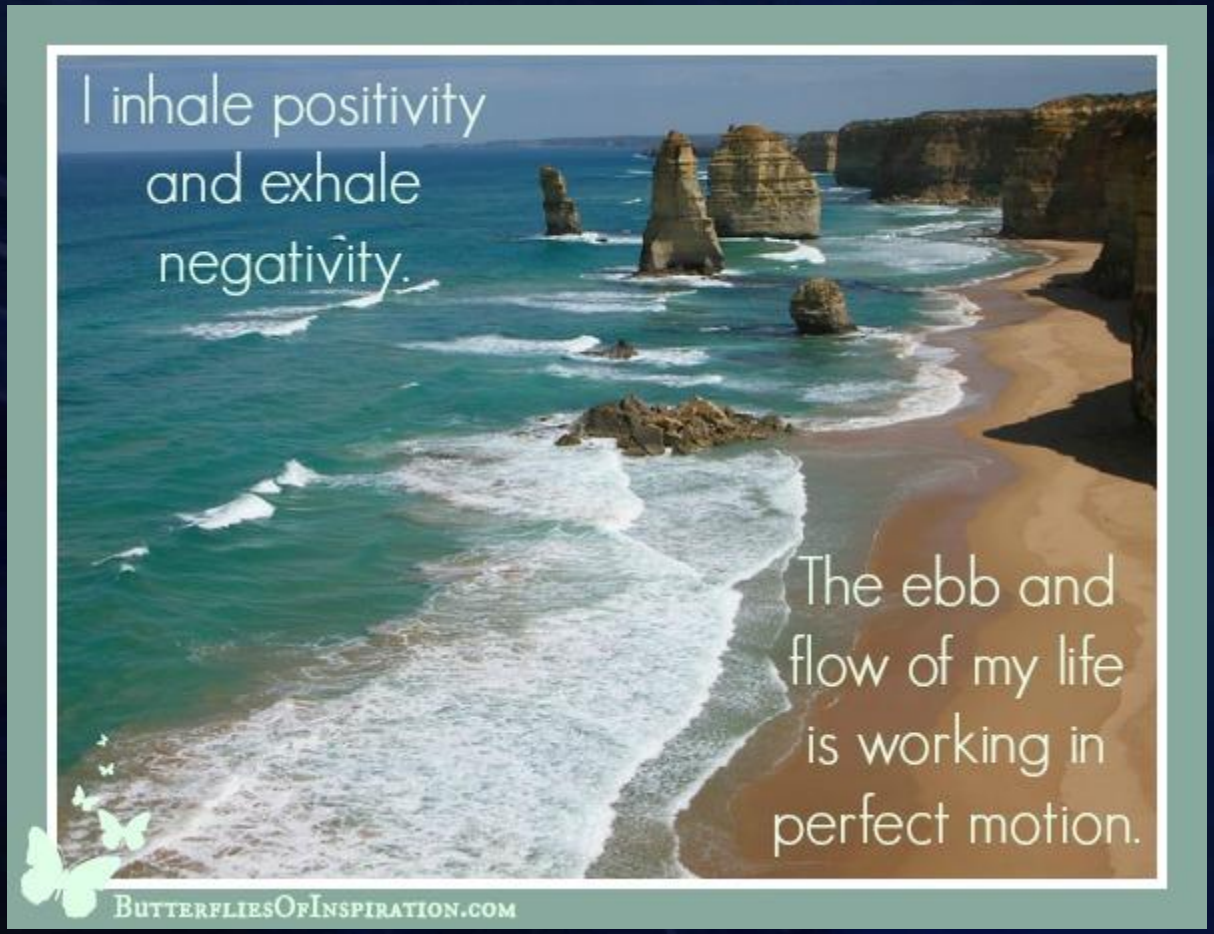

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