How I got into this…

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Overview

- What is Transition and is there a problem?
- What are barriers to successful transition?
- Making your practice friendly to YSHCN
- Tricky issues in YSHCN
- Using Local Resources

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Transition is a process.

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

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Which is most consistent with the AAP/AAFP/ACP clinical recommendations on health care transition?

A: The movement patients make between health care practitioners and settings during the course of their chronic condition.

B: The transfer of an adolescent from his/her pediatric provider to an adult provider by the young adult's parent of guardian.

C: An event that occurs on the young adult's 18th birthday and requires all youth be seen alone after the 18th birthday.

D: The deliberate process of moving seamlessly from child-oriented health care to adult-oriented health care that involves self-determination, person-centered planning, independence, and community life.

Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home , Transitions Clinical Report Authoring Group *Pediatrics* 2011;128;182

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Which of the following is NOT true regarding the AAP/ACP/AAFP clinical report on transition?

A: It contains guidance on how to plan and implement better health care transitions for all patients.

B: It includes a step-by-step algorithm.

C: It only applies to youth with special health care needs

D: It extends through the transfer of care to adult health care professionals.

Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home , Transitions Clinical Report Authoring Group *Pediatrics* 2011;128;182

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Who are we talking about?

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Who are we talking about?

- Intellectual disabilities
- Physical disabilities
- Sensory disabilities
- Cerebral palsy/spina bifida
- Autism

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Who are we talking about?

- The usual chronic conditions

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Who are we talking about?

- The usual chronic conditions ***BUT WITH A TWIST!***
  - Hypertension
  - Diabetes 1&2
  - Asthma, CF
  - Congenital heart disease

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Problems in Transition

- YSHCN **increasing**(1988-2006 2x) 85%
- **Only 1/3 YSHCN** successfully transition
- Services **less integrated**
- **Losing health care coverage!**
- It's a time of **great change** for patient
- **High costs**—ED/hospital utilization (3x)

Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, Pediatrics 2011
Health services use and health care expenditures for children with disabilities.Pediatrics. 2004 Jul; 114(1):79-

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Challenges: disabilities in general

- 11.8% of population with a limitation in activities due to a chronic condition (CDC)
- Less access to health care
  - Pap smears
- More health care dollars spent
- More likely to be underinsured

Drew, J Sexual/Reproductive Health, 2010
Newachek, Pediatrics July 2004

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Challenges: adolescents as a group are vulnerable

- Emerging young adults 18-25 are less healthy than adolescents 12-17 or young adults 26-35
- As a group have the highest use of ER among those younger than age 75
- More likely to report no health care visits in the last 12 months

Decline in health/healthcare during transition to adulthood is common

- Specific examples (tx, sickle cell, obesity)
- Worsened adherence
- Decreased follow-up
- Lapses in insurance
- Unmet needs predict adverse adult health outcomes (13-52% more likely)

Hargreaves, PEDIATRICS September 2015
White, Pediatrics Dec 2002

Cascade of Disparities

Krahn, Gloria. *A cascade of disparities: Health and health care access for people with intellectual disabilities.* Mental Retardation and Developmental Disability Research Review January 24, 2006

- Higher prevalence of adverse conditions
- Inadequate attention to care needs
- Inadequate focus on health promotion
- Inadequate access to quality health care services

BARRIERS to successful transition

- Pediatric side
- Adult side
- Differences between pediatric and adult models of care

Clinical Report **Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, Pediatrics 2011**

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Barriers for the adult provider

- Discomfort with medical issues
- Time limitations
- Psychosocial needs take time
- Lack of information from peds
- Paperwork
- End of life issues

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home, Pediatrics 2011

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Same planet, different worlds

Pediatric Care	Adult Care
Nurturing	Informing
Parent Centered	Patient Centered
Universal funding	Underfunded
Family insurance provided	Employment based insurance
Paternalistic	Total Autonomy
Centralized	Fragmented
Usually informed providers	Potentially less informed providers

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American Academy of Pediatrics

Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

abstract

www.gottransition.org

6 ELEMENTS OF SUCCESSFUL TRANSITION

got transition?

OPENING DOORS TO A HEALTHY FUTURE

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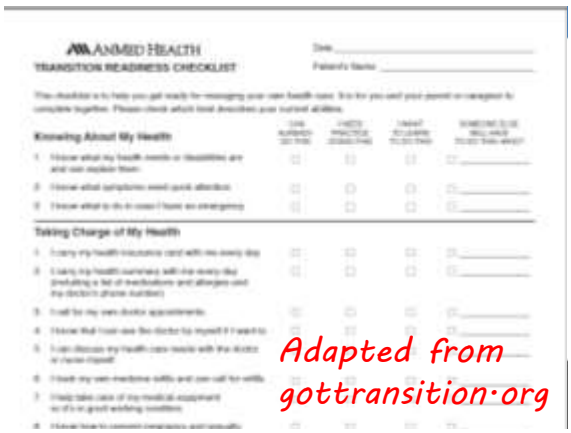

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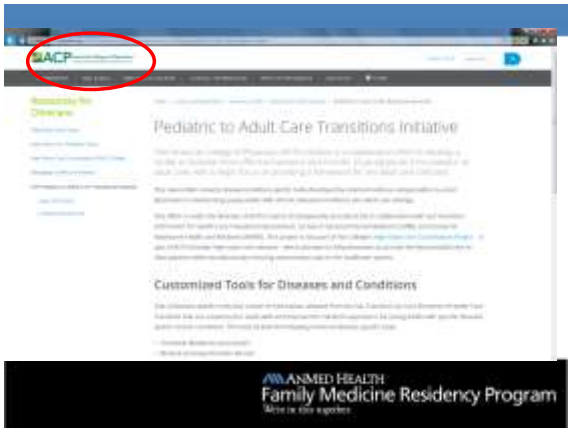
TRANSITION READINESS CHECKLIST

Knowing About My Health

Taking Charge of My Health

Adapted from gottransition.org



What your patients with disabilities wish you learned in your professional training

- Negative attitudes and assumptions are often taught (and learned) in health care education
- Physician, patient, and family attitudes vary widely
- Knowledge about disability may be more helpful than **specific** knowledge on prevention or treatment of **specific** disabilities

Dr. Bethany Ziss

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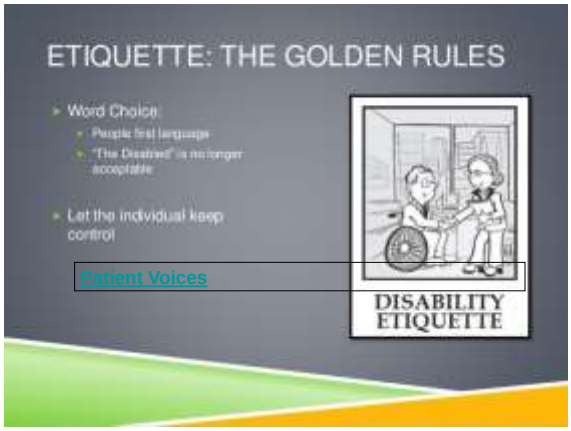

The ideal first visit

- Office policy for transition
- Educate your staff
- Info from pediatric provider
- Transition tools
  - Will show from ACP website
- Meet and greet

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The Wrong Way

- https://www.youtube.com/watch?v=W1CVs7j5x3U

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The Right Way

- https://www.youtube.com/watch?v=6EJkOYmkxmE

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Tricky Issues

- Sex and Contraception
- Psychological and behavioral issues
- Funding

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Sexual activity

- Assume rates comparable to young people without disabilities
- Possibly *increased* sexual activity with nonvisible physical disability
- At risk for sexual abuse
- If appropriate, interview patient alone

Greydanus, Sexuality Issues and Gynecologic Care of Adolescents with Developmental Disabilities, Pediatric Clinics of NA, 2008.

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Estrogen-containing methods

- Estrogen may thromboembolism
  - Complicated migraine
  - Complicated congenital heart disease,HTN
  - Non-ambulatory
- Continuous combined OCP's
- Beware enzyme inducers (AED's)

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Progestin-only methods

- Depot medroxyprogesterone
  - Weight gain, decreased bone density
- Progestin implant
- Progestin-only pill (minipill)
- IUD—levonorgestrel
- Beware enzyme inducers

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Contraception and disabilities

- Periods often appear too heavy
- Assess for something besides anovulation
- Consent/assent
- Make sure there is no abuse
- Menstrual regulation/suppression

Menstrual Concerns in an Adolescent with Disabilities, American Family Physician, Nov 2015

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YSHCN are prone to

psych/behavioral issues

19 yo liked his neighbor to warm blankets in a dryer and wrap him

Day/night q 6 hr schedule

24 yo stealing diapers from CVS and caressing them

Constant masturbation

Throat clearing constantly when taken out

Banging head

Depressed after "graduating" from school

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Psych/behavioral issues

- Behavior is communication
- Triggers and responses to the behavior
- Workup is kind of like that for delirium
- Not much evidence for antipsychotics
- Need a psychologist or psychiatrist who is interested

Medicaid/TEFRA

Tax Equity and Fiscal Responsibility Act, 1982

- Medicaid for children with disabilities
- Based on disability, not parents' income
- Runs out age 19
- Apply for SSI before 18th birthday—the medicaid gets changed to SSI category

Supplemental **S**ecurity **I**ncome

- Physical/mental impairment
- Prevents employment >12 months
- Takes into account family income/expenses
- Automatically eligible for Medicaid
- $733/month but can still earn $
- **Section 1619b—lose SSI keep Medicaid**

Community Resources

- Family Connection SC
- Able-SC
- DDSN
- Local school
- Vocational Rehabilitation

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PHYSICAL OR MENTAL DISABILITIES (DSM-4,ADDICTIONS)
DISABILITY JEOPARDIZING JOB
HIGH SCHOOL—LEARNING DISABILITY

VOCATIONAL EVALUATION
COUNSELOR
TRAINING CENTER
FURTHER EDUCATION
CAN TAKE SSI, DDSN

In summary, we discussed

- **Transition**
- **Barriers**
- **Disabilities Etiquette**
- **Tricky issues**
- **Local Resources**

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THANK-YOU!

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