Bridging the Gap
From Peds to Adult Care
For Youth with Special Health Care Needs

How I got into this…

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
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)

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.

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.
Who are we talking about?

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

Who are we talking about?

- The usual chronic conditions
Who are we talking about?

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

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)

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
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)

Cascade of Disparities


- 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

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

Same planet, different worlds

<table>
<thead>
<tr>
<th>Pediatric Care</th>
<th>Adult Care</th>
</tr>
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<tbody>
<tr>
<td>Nurturing</td>
<td>Informing</td>
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<tr>
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<td>Patient Centered</td>
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<td>Employment based insurance</td>
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<tr>
<td>Paternalistic</td>
<td>Total Autonomy</td>
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<td>Centralized</td>
<td>Fragmented</td>
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<tr>
<td>Usually informed providers</td>
<td>Potentially less informed providers</td>
</tr>
</tbody>
</table>
6 ELEMENTS OF SUCCESSFUL TRANSITION

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
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

The Wrong Way

• https://www.youtube.com/watch?v=W1CVs7l5x3U

The Right Way

• https://www.youtube.com/watch?v=6EJkOYmkxmE
Tricky Issues

• Sex and Contraception
• Psychological and behavioral issues
• Funding

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

Estrogen-containing methods

• Estrogen may thromboembolism
  – Complicated migraine
  – Complicated congenital heart disease, HTN
  – Non-ambulatory
• Continuous combined OCP’s
• Beware enzyme inducers (AED’s)
Progestin-only methods

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

Contraception and disabilities

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

YSHCN are prone to psych/behavioral issues

19 yo liked his neighbor to warm blankets in a dryer and wrap him
Throat clearing constantly
Banging head

24 yo stealing diapers from CVS and caressing them
Constant masturbation

Day/night q 6 hr schedule
Depressed after “graduating” from school
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 Security Income

- Physical/mental impairment
- Prevents employment >12 months
- Takes into account family income/expenses
- Automatically eligible for Medicaid
- $733/month but can still earn $2000
- Section 1619b—lose SSI keep Medicaid
Community Resources

• Family Connection SC
• Able-SC
• DDSN
• Local school
• Vocational Rehabilitation
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
THANK-YOU!