BRIDGING THE GAP:
EASING THE TRANSITION FROM
PEDIATRIC TO ADULT HEALTH CARE

Michelle S. Clark, DO; BethEllen Davis, MD; Lorriane Carney, ARNP

Disclosure Information

- We have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider of commercial services discussed in this CME activity.

  We do not intend to discuss an unapproved/investigative use of a commercial product/device in this presentation.

Case 1

- Erica is a 12-year-old girl who was diagnosed at age 4 with diabetes after presenting to the emergency room in diabetic ketoacidosis. She is fairly good about checking her blood sugars and giving herself insulin daily but finds it hard to maintain an ADA diet, especially now that she’s in middle school.
Case 2

Joseph was born at 26 weeks gestational age and was diagnosed with spastic CP when he was a year old. Now almost 13 years old, he attends junior high. School testing done previously revealed that he has mild intellectual disability.

Case 3

Mark comes in for his 12-year-old well exam. It’s his first visit to the adolescent clinic. His past medical history is unremarkable except for seasonal allergies and eczema as a child. He gets mostly A’s and B’s in school and plans on joining a local soccer league.

What do all these patients have in common?

They’re growing up!!!

With reasonable biological certainty, most adolescents transition to adulthood. There is much less certainty about the manner in which health care professionals support this transition.
Need for Transition Training

- Only 38% of typical teens received anticipatory guidance for transition to adult health care.
  2005 Nat’l Survey of CSHCN

- <50% of families and individuals with special health care needs received guidance from their pediatricians on transitioning to an adult model of health care.
  2008 AAP Periodic Survey of Fellows

Transition

- In general, even typical teens become eligible to vote, attend college, and even go to war with little knowledge of health insurance, previous health care, immunizations, or personal health history.
- Transitions occur throughout the lifespan.
- Transition is a process, not an event.
- Transition to adulthood, including healthcare, should begin during childhood.

Transition

The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not.

Pediatrics 2011;128:182
The transfer of care to an adult medical home and to adult medical subspecialists involves more of a drift away from pediatric care rather than a clearly planned and executed handoff.

Transition to adult health care has been...

- Inexplicit
- Incomplete
- Late

Transition to adult health care should be...

- High quality
- Uninterrupted
- Developmentally appropriate

How do we bridge the gap?

Where are the pitfalls?

Gaps in Transition Support

- Limited staff training
- Lack of identified staff responsible for transition
- Financial barriers
- Anxiety (parent, patient, provider)
- Lack of appropriate transition readiness assessment tools
- Adult providers feel unprepared or no adult provider may be available
6 Core Elements of Health Care Transition

The Transition Timeline

<12 yrs | 12-13 years | 14-15 years | 16-17 years | 18+ years

6 Core Elements of Health Care Transition
Transition: Ages 12-13 Years

- The patient ages 12 to 13 years
  - What do you do now?
  - What works for your clinic?
  - How are your visits with a patient this age different?
- Meet privately with adolescent
- Anticipatory guidance
  - Nutrition and fitness
  - Sexuality and relationships
  - Substance abuse/ETOH

Transition: Ages 12-13 Years

- Provider Role
  - Present the transition policy
  - Identify patients “at risk” for a complicated transfer
- Parent/Family Role
  - Family discussion on child’s needs and goals of transition
- Patient Role
  - Portions of visit one-on-one with provider (if appropriate)

Provider Role: Present the Transition Policy

- Office Transition Policy:
  - Deliver → Discuss → Document
    - The expected age of patient transfer to an adult model of health care
    - Detail the responsibilities of
      - The patient
      - The family, parent, or caregiver
      - The medical provider
Provider Role: Transitioning Youth Registry

- Identify patients at risk for complicated transition
- 5 Questions
  - Does your child use medicine prescribed by a doctor?
  - Does your child need more medical care, mental health, or educational services than most children of the same age?
  - Is your child limited or prevented in any way in his or her ability to do things children the same age can do?
  - Does your child need or get any special therapy?
  - Does your child have an emotional, developmental, or behavioral problem for which he or she gets treatment or counseling?

The Transition Timeline

<table>
<thead>
<tr>
<th>&lt;12 yrs</th>
<th>12-13 years</th>
<th>14-15 years</th>
<th>16-17 years</th>
<th>18+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Policy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assess for risk of having a complicated transition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anticipatory guidance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meet one-on-one</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Know cognitive and adaptive strengths</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apply for DYF/DOD services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6 Core Elements of Health Care Transition
Transition: Ages 14-15 Years

- The patient ages 14 to 15 years
  - What do you do now?
  - What works for your clinic?
  - How are your visits with a patient this age different?
- Greater autonomy in clinical encounter
- Anticipatory guidance
- Nutrition and fitness
- Sexuality and relationships
- Substance abuse/ETOH
- Future goals

Transition: Ages 14-15 Years

- Provider Role
  - Assess patient and family readiness for transition to adult health care model
  - Initiate transition plan with youth and parents
- Parent Role
  - Allow youth to assume greater role in self-management as appropriate
  - Apply for community and/or state resources as appropriate
- Patient Role
  - Ask questions

Provider Role: Readiness Assessment

- Transition Readiness
  - Assessment Tools
    - Expectations differ according to the individual
    - What are the patient's capabilities?
    - How should responsibilities between patient and family be delineated?
Provider Role: The Transition Plan

- Initiate a transition plan
  - Assess current readiness
  - What are the family’s needs?
  - What are potential gaps?
  - What are the youth’s strengths and weaknesses?
  - Detailed steps to achieve a successful transition

The Transition Timeline

<table>
<thead>
<tr>
<th>&lt;12 yr</th>
<th>12-13 years</th>
<th>14-15 years</th>
<th>16-17 years</th>
<th>18+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Transition Policy</td>
<td>Assess Transition Readiness</td>
<td>Individualized Transition Plan</td>
<td>Encourage autonomy during medical encounter</td>
</tr>
<tr>
<td></td>
<td>Assess for risk of having a complicated transition</td>
<td>Anticipatory guidance</td>
<td>Anticipatory guidance</td>
<td>Apply for DVR/DDC services</td>
</tr>
<tr>
<td></td>
<td>Meet one-on-one</td>
<td>Know cognitive and adaptive strengths</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6 Core Elements of Health Care Transition
Transition: Ages 16-17 Years

- The patient ages 16 to 17 years
  - What do you do now?
  - What works for your clinic?
  - How are your visits with a patient this age different?
- Anticipatory guidance continues
  - Nutrition and fitness
  - Sexuality and relationships
  - Substance abuse/ETOH
  - Educational/career plans

Transition: Ages 16-17 Years

Now is when things start moving...

- Provider
  - Review and update transition plan
  - Identify possible adult care providers
  - Portable Medical Summary
  - Emergency Care Plan
- Family and Patient
  - Meet and interview adult providers
  - Discuss educational/vocational/living arrangement goals

Transition Tools

- Health History Summary
- Transition Scales for Adolescents and Young Adults
- Emergency Care Plan
  - DNR
  - End of life issues
The Transition Timeline

- Transition Policy
- Assess for risk of
  having a
  complicated
  transition
- Anticipatory
  guidance

- Assess Transition
  Resilience
- Individualized
  Transition Plan
- Encourage
  autonomy during
  medical encounter
- Anticipatory
  guidance

- Identify adult
  provider
- Health History
  Summary
- Emergency Care
  Plan
- Increase
  autonomy in
  medical encounter
- Anticipatory
  guidance
- Educational
  goals graduate at
  18 vs 21

6 Core Elements of Health Care Transition

- Transfer of Care
- Transition Planning
- Transition Policy
- Transition Preparation
- Transitioning Youth Registry
- Transition Completion

Transition: Age 18 Years and Above

- The patient age 18+
  - What do you do now?
  - What works for your
    clinic?
  - How are your visits with
    a patient this age
different?

- Complete autonomy in
  clinical encounter (if
  appropriate)
- Anticipatory guidance
- Nutrition and fitness
- Sexuality and
  relationships
- Substance abuse/ETOH
- Education/career goals
- Living arrangements
**Transition: Ages 18+ Years**

- **Provider Role**
  - Transfer medical records
  - Discuss care with adult provider
  - Follow-up with family and new provider
- **Parent/Family Role**
  - Allow young adult as much autonomy as possible
  - Choose/meet new physician
- **Patient Role**
  - Take responsibility for own health care
  - Choose/meet new physician

**Unique Transition Roadblocks for Individuals with Disabilities**

- **Guardianship** – age 18 (it is not all or nothing)
- **SSI** – age 18 (it is about FUNCTION, parent income not considered at this age)
- **Incapacitated ID Card** – age 21 (military AD/RET)
  - Get packet at ID Facility
  - Remind families that if their child were living in a facility they would be paying about $3,000/mo for what they provide, so they need to figure out their “in kind” services.
- **IEP stops at age 21. 504 can continue**

**The “real world” paperwork**

- **Guardianship** – age 18 (it is not all or nothing)
- **SSI** – age 18 (it is about FUNCTION, parent income not considered at this age)
- **Incapacitated ID Card** – age 21 (military AD/RET)
  - Get packet at ID Facility
  - Remind families that if their child were living in a facility they would be paying about $3,000/mo for what they provide, so they need to figure out their “in kind” services.
- **IEP stops at age 21. 504 can continue**
Guardianship

<table>
<thead>
<tr>
<th>Rights of 18</th>
<th>Responsibilities of 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Vote</td>
<td>- Tried in adult court</td>
</tr>
<tr>
<td>- Get married</td>
<td>- Self support</td>
</tr>
<tr>
<td>- Make a will</td>
<td>- Jury duty</td>
</tr>
<tr>
<td>- Sign a contract</td>
<td>- Register for draft</td>
</tr>
<tr>
<td>- Apply for credit</td>
<td></td>
</tr>
<tr>
<td>- Consent or refuse medical treatment</td>
<td></td>
</tr>
<tr>
<td>- Enlist in military</td>
<td></td>
</tr>
</tbody>
</table>

Types of Guardianship

- Full or limited
- Permanent or temporary.
- Parent or friend
- Financial successor without guardianship

Many Parts to SSI

- Non medical parts
  - Requires (re)determination of need
  - Parent’s income irrelevant
- Medical parts
  - “Must have a physical or mental impairment that is expected to keep him/her from doing substantial work”
  - Meets a “listing” dx ?
  - Functional impairments must be noted.
The Transition Timeline

<table>
<thead>
<tr>
<th>&lt;12 yrs</th>
<th>12-13 yrs</th>
<th>14-15 years</th>
<th>16-17 years</th>
<th>18+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assess Transition Readiness</td>
<td>• Assess Transition Readiness</td>
<td>• Identify adult provider</td>
<td>• Complete autonomy in medical encounter</td>
<td>• Complete autonomy in medical encounter</td>
</tr>
<tr>
<td>• Anticipatory guidance</td>
<td>• Anticipatory guidance</td>
<td>• Health History Summary</td>
<td>• Transfer medical records</td>
<td>• Transfer medical records</td>
</tr>
<tr>
<td>• Assess for risk of having a complicated transition</td>
<td>• Assess for risk of having a complicated transition</td>
<td>• Emergency Care Plan</td>
<td>• Discuss care with adult provider</td>
<td>• Discuss care with adult provider</td>
</tr>
<tr>
<td>• Anticipatory guidance</td>
<td>• Anticipatory guidance</td>
<td>• Increase autonomy in medical encounter</td>
<td>• Follow-up with family and new provider</td>
<td>• Follow-up with family and new provider</td>
</tr>
<tr>
<td>• Meet one-on-one</td>
<td>• Meet one-on-one</td>
<td>• Anticipatory guidance</td>
<td>• Guardianship</td>
<td>• Guardianship</td>
</tr>
<tr>
<td>• Know cognitive and adaptive strengths</td>
<td>• Know cognitive and adaptive strengths</td>
<td>• Educational goals; graduate at 16 or 21</td>
<td>• SSID</td>
<td>• SSID</td>
</tr>
<tr>
<td>• Apply for DVI/DDO services</td>
<td>• Apply for DVI/DDO services</td>
<td></td>
<td>• Indefinite military ID</td>
<td></td>
</tr>
</tbody>
</table>
References

- www.gottransition.org
- http://depts.washington.edu/healthtr/
- Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home; Pediatrics 2011; 128:1 182-200
- www.help4adhd.org