Health Care Transition from Adolescence To Emerging Adulthood among Youth with Special Health Care Needs

Yolanda Evans MD, MPH
Adolescent Medicine
University of Washington
Special Health Care Needs: A Definition

• Having an increased risk for chronic physical, developmental, behavioral, or emotional condition and a requirement for health and related services as a type or amount beyond that required by children generally (McPherson and Arango, 1998)

• ~22% of 14-17 year olds

• Youth with chronic conditions are living longer
Health Care Transition

Transition is a process that is deliberate, and leads to the coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.
What does transition mean?

• To the health care system:
  – Changing providers and settings
  – Changing who is in charge of care
  – Becoming an adult
  – Becoming independent

• To the youth and family
  – All of the above but from the whole-life perspective
  not just in the context of the healthcare setting
What are the goals for transition?

• To provide high quality, coordinated, uninterrupted healthcare which is patient-centered, age and developmentally appropriate

• To promote skills in youth in communication, decision-making, assertiveness, self care, self determination and self advocacy

• To enhance sense of control and interdependence in healthcare

• To maximize life long functioning and potential

• To support the parent(s)/guardian of the young person during transition and in particular to enhance their advocacy skills

McDonagh (2005, p. 365)
In the ideal world transition is:

• A rite of passage
• A natural part of growing up and becoming a responsible adult, as developmentally able
• A step toward becoming independent from one’s family
• A step toward finding a place in the adult community
But what can happen...

• Anxiety producing for youth and parents
  – Young people may be uncomfortable in an adult health care consumer role
  – Parents may feel uncomfortable with their youth in that role

• Barrier to getting good care
  – It can be hard to find an adult health care provider trained in pediatric conditions
  – Youth need to start all over with a new provider
Resulting in:

- Family and patient may have trouble letting go of the system they know
- Worsening of disease control resulting in the potential for significant setbacks
A Graduation That May Carry Unnecessary Risk

By PERRI KLASSE, M.D.
Published: June 13, 2011

Right before I moved from Boston to New York City, I went to see one of my patients graduate from high school. I was in an elegiac mood — leaving the city, saying goodbye to friends — and I teared up as I watched her from the balcony. It felt right that her time as my pediatric patient was ending not with my moving away, but with her marching proudly into the future.

In adult medicine, patients don’t graduate. You don’t provide adult primary care with an eye toward the day that your patients outgrow you and pass triumphantly on to the next doctor. Pediatrics, on the other hand, is about growth and change. The goal is to help a healthy child grow into a healthy adolescent — and then the pediatrician says goodbye, and the patient moves on.

But we have a lot to learn about helping families make that transition. Studies show that the zone at the end of the pediatric period is fraught with uncertainties and risks, especially for children with chronic illnesses and disabilities.
Tasks of Adolescence

- Autonomy
- Healthy self-esteem, image, and identity
- Set & achieve educational/vocational goals
- Achieve independence in living and finances
- Marriage/partnership
- Define role in community/society
Health Care Transition

• Part of all the transitions that youth have to make toward adulthood

• Health is everything
  – Poor health → all other transitions can be derailed
  – Poor health → developmental task of adolescence/young adulthood are more difficult
What does it take to transition successfully in health care?

– Health consumer skills:
  • Knowing how to make an appointment, fill a prescription, talk with a doctor about a concern
  • Knowing how to find an appropriate provider
  • Understanding insurance coverage

- Disease self management skills
  - Understanding medications and how they work, recognizing symptoms and how to manage them

- Life skills
  - Understanding how their disease affects their life choices (school, relationships, drugs, alcohol, work, etc)
How are we doing with Transition Currently
MCH Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adult health care, work and independence

http://cshcndata.org
Factors Associated with Meeting Core Transition outcome (2003 data)

- Female gender
- non Hispanic white race ethnicity
- English spoken at home
- Income \( \geq 400\% \) FPL

Lowenstein et al, 2009

- Having special health care need that never impacts activities
- Having a medical home
- Insurance coverage
Transition Part A: CSHCN ages 12-17 yrs receiving anticipatory guidance for transition to adult health care
Nationwide vs. Washington
Youth's doctors have discussed transition to providers who treat adults -- CSHCN ages 12-17 only
Nationwide vs. Washington
Youth's doctors have discussed his or her health care needs as he/she becomes an adult -- CSHCN ages 12-17 only
Nationwide vs. Washington
A Concern

• 90% of YSHCN reach their 21st birthday.
• 45% of YSHCN lack access to a physician who is familiar with their health condition.
• 30% of 18 to 24-year-olds lack a payment source for needed health care.
• Many youth lack access to primary and specialty providers.

CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 2002
A Life Span Process

• Increase use of emergency system of care: 40% versus 25% of typical youth annually.

• There are fewer work opportunities, and many are fearful of losing Medicaid eligibility.

• YSHCN are 3 times more likely to live on income under $15,000.
Barriers to the Provision of Transition Services

• Low Incentive to Assure Transition
  – Poor reimbursement for providers to focus on transition
  – Insurance changes
  – Care divided between institutions results in low institutional support

• Challenge of Multiple Systems
  – Poor communication and coordination between pediatric and adult providers. (Reiss et al., 2005)

• Other System-level Barriers
  – Poor anticipation of need/competing demands
  – Few adult providers with comfort/requisite expertise
What is an ideal progression towards transition to adult care?
## Shared Management Model

*Kieckhefer and Trahms, (2000)*

<table>
<thead>
<tr>
<th>Age/Time</th>
<th>Parent/Family</th>
<th>Young Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>Provides care</td>
<td>Receives care</td>
</tr>
<tr>
<td>Increasing Age</td>
<td>Manages</td>
<td>Participates</td>
</tr>
<tr>
<td>Increasing Age</td>
<td>Supervisor</td>
<td>Manager</td>
</tr>
<tr>
<td>Adult</td>
<td>Consultant</td>
<td>Supervisor/CEO</td>
</tr>
</tbody>
</table>
# Age at Which Pediatricians Think Transitions Planning Should Begin

**AAP, 2008 Survey**

MacManus et al, 2008

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Adolescents with SHCN</th>
<th>Adolescents without SHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;12</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>12-14</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>15-17</td>
<td>25%</td>
<td>26%</td>
</tr>
<tr>
<td>18-20</td>
<td>62%</td>
<td>65%</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>4%</td>
<td>2%</td>
</tr>
</tbody>
</table>
AAP recommendations

• Create a written transition plan by age 14 with young person and family. Update it annually.

• Guidelines for primary and preventive care should be applied to all adolescents and young adults. Attention is given so YSHCN have access to more resources and services than their peers.

• Ensure affordable, continuous health insurance throughout adolescence and adulthood, including
  – Health care transition planning

• Care coordination
Transition Support Services in Pediatric Practices

• Support for nearly all or most adolescent patients with special needs
  – 47% assist with referral to specific family or internal medicine physicians
  – 27% assist with creating portable medical summary
  – 12% assist with creating an individualized health care transition plan
Discussion – How Can We Improve Transition?
Adolescent Transition Components in Pediatric Ambulatory Health Care

**Pediatric Health Care**
- Key worker identified to assist patient
- Documented individualized transition plan
- Education about transition issues, self-care and preparation time given to youth and parents
- Education of professional staff about transition care
- Provision of primary and preventive care

**HEALTH CARE PROVIDER**
- Consider provider co-management
- Liaison person in pediatric and adult setting
- Portable medical summary

**PREPARED YOUTH**
- Meet adult doctor prior to transfer
- Portable medical summary
- Youth active in decision-making and process of care

**SYSTEM SUPPORT**
- Maintain affordable continuous health insurance
- Network of relevant supportive local agencies and target adult services
- Written transition policy agree by multidisciplinary team members
- Administrative Support

**Adult Health Care**
What Types of Interventions Might Improve Transition

- Patient Level
- Provider Level
- System Level
- Community Level
Patient Level

– Encourage an early start – forward thinking

– Foster personal and medical independence and creative problem solving throughout adolescence

– Teach youth about adult health care culture

– Skills training for youth in communication, decision making, assertiveness, self care and self management

– Create a written care transition plan

– Engage youth and family active member in decision making and health care process
Provider Level

- Education of professional staff pediatric and adult about transition
- Develop a database with patients approaching transition and transfer of care
Health Care System

- Build in flexibility of age or timing of transfer
- Written transition policy agreed by all team members
- Develop a network of relevant supportive local agencies and target adult services
- Consider short term co-management between pediatric and adult provided
- Liaison person (care coordinator, case manager) in pediatric and adult setting
- Assure affordable continuous health insurance coverage throughout adolescence and young adulthood
Community Level

• Identify and make accessible appropriate resources

• Link vocational and educational services to medical system more closely
Discussion Questions

• Can all youth successfully transition?
  – Who might have the greatest challenge?
  – How do we know if youth can transition or not?

• What factors other than health status affect the ability to transition?

• How do culture and cultural expectations affect transition?
Health Care Transition

• A natural part of growing up!

• Questions????
What is the National Survey of Children with Special Health Care Needs (NS-CSHCN)?

National Survey of Children with Special Health Care Needs (NS-CSHCN) is a national survey that was conducted by telephone in English and Spanish for the first time in 2001. The survey was conducted a second time in 2005-2006 and for a third time in 2009-2010. The survey provides a broad range of information about the health and functional status of children with special health care needs collected in a manner that allows for comparisons between states and at the national level. Telephone numbers are called at random to identify households with one or more children under 18 years old. Each child in the household is screened for special health care needs using the CSHCN Screener. In each household, one child was randomly selected to be the subject of the interview. The survey results are weighted to represent the population of non-institutionalized children with special health care needs 0-17 nationally and in each of the 50 states plus the District of Columbia.