Transition of Youth with Disabilities to Adulthood

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Disclosures

- I have no financial or other conflicts to disclose.
- I will not be discussing the use of any medications or medical devices.

Transition
(what does it mean?)

- **Dictionary:** the passing from one place, period, state, subject, or the like to another
- A *transition* is a process, not an event. A transition occurs over time.
- *Transitions* occur throughout the lifespan.
- *Transition to Adulthood*, including health care transition, should begin at the time of diagnosis.
- *Transition* means different things **to** different people and **for** different people.

Adolescent Transition / Transition to Adulthood

Adolescents transition through multiple interrelated systems as they move from childhood to adulthood while being expected to take on increasing levels of independence.

- Family
- School / Vocation
- Social services
- Health care services
- Community / recreation

Transition from Childhood to Adulthood is like a Bridge

Transition?

Challenges faced by Youth with Disabilities

- Health – access to health care services
  - Health insurance
  - Appropriate adult-oriented providers
- Autonomy – decision-making
- Social Life
  - Lack of social & recreational opportunities
  - Social isolation
- Housing
- Employment

Key to Understanding
Unfunded Government Mandates

We live in the real world,

not the ideal world.

Reasons for Focus on Health Care Transition

- Increasing numbers of youth with significant disabilities and complex medical conditions living to adulthood
- Focus on quality of life and not just quantity of life
- Lack of adult providers appropriately trained or willing to take care of some childhood-onset conditions
- Youth not receiving all appropriate care including preventive services, reproductive health, etc.
- Adults who lack knowledge of their own condition and skills for self-care, self-determination, & self-advocacy
- Increased rates of ER utilization
- ? Poor health outcomes among young adults with SHCN

Maternal & Child Health Bureau Healthy People 2010 Goal #6 for CYSHCN

"All youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence."

Key to Understanding the System for Health Care Transition

There is no system.

Consensus Statement
AAP/AAFP/ACP 2002

Definition - ***transition*** is the purposeful, planned movement of adolescents and young adults with chronic illness/disability from child-centered to adult oriented systems (health, occupation, residence).

A consensus statement on health care transitions for young adults with special health care needs, Pediatrics, December 2002, 110(6 Pt 2):1304-6.

Goal of Transition in Health Care

"…to 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."

Consensus Statement
Critical First Steps

Ensure all youth with SHCN have:

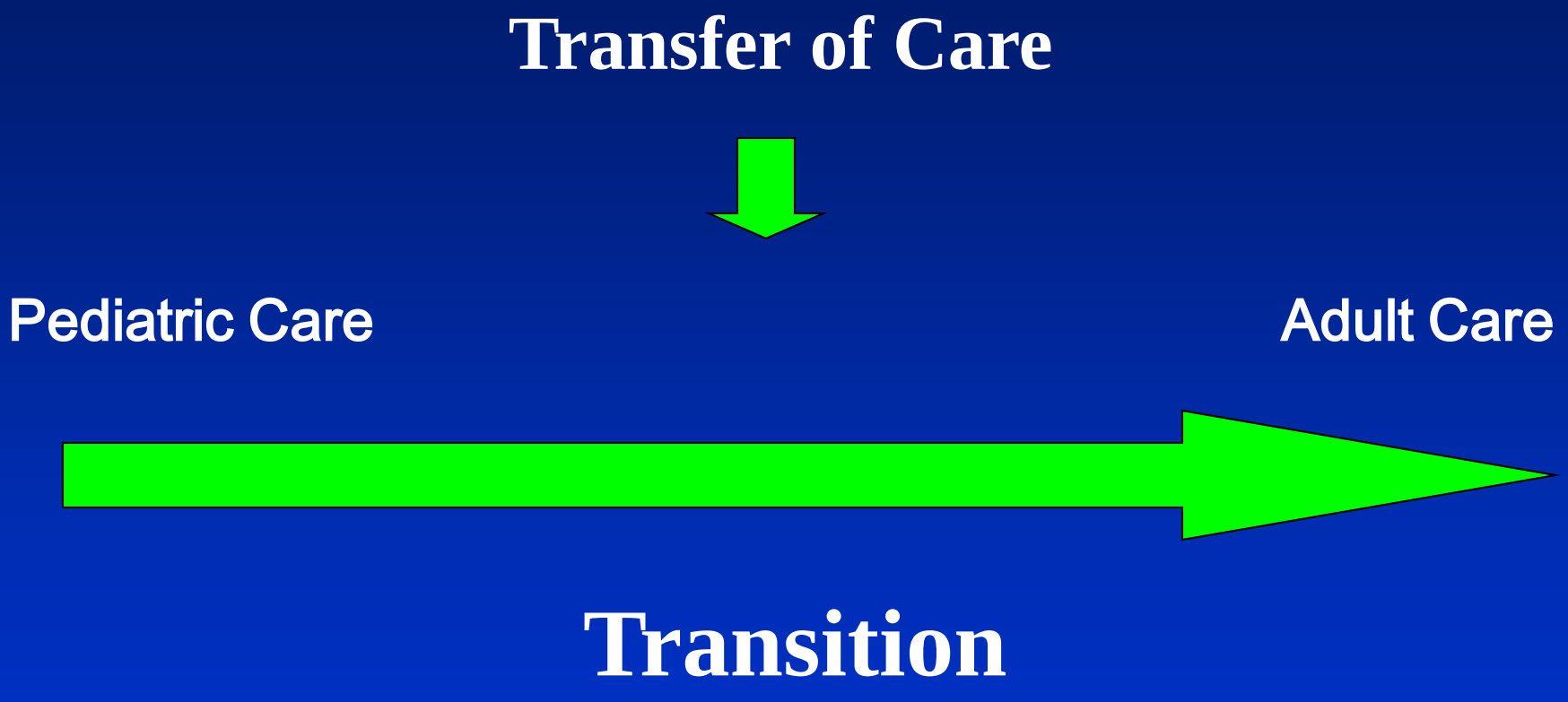
- Identified HCP who attends to unique needs in transition - Medical Home
- HCP with a core knowledge and skills. Make it a required part of training.
- A written health care transition plan by age 14
- A continuously current medical summary
- HCP who uses comprehensive guidelines for primary care
- Affordable, continuous health insurance

Transition to Adulthood: the Role of Health Care Providers

TWO BROAD GOALS

1. Transition to adult-oriented health care (health care transition)
   - Education about medical condition, teaching self-care
   - Ensuring access to appropriate health care during the transition years
   - Hand-off to appropriate adult-oriented providers
2. Facilitate transition to adulthood (preparation for all aspects of adult life)
   - Information and linkage to appropriate community resources
   - Assessment and referral for development of skills
   - Promoting independence as much as possible

Health Care Transition Process



Rosen DS. Grand Rounds: all grown up and nowhere to go: transition from pediatric to adult health care for adolescents with chronic conditions. Presented at: Children's Hospital of Philadelphia; 2003; Philadelphia, PA

Important Considerations during the transition process

- SSI (both for income and for access to Medicaid)
- Health care decision-making (Guardianship, Surrogate Decision-Maker, Durable Power of Attorney, Health Care Agent)
- Education:
  - diploma track or certificate track (in school until 18 or 21 years of age)
  - Opportunities for post-secondary education (Think College!)
- Transportation / mobility
- Recreation
- Sexuality
- Mental health
- Independent living

Health Care Transition Efforts

- Dissemination of information
  - AAP Medical Home teaching module
  - MCHB-sponsored website and content
    was “Healthy & Ready To Work” www.hrtw.org
    now “Got Transition” www.gottransition.org
  - Organizations e.g. Spina Bifida Association
- Skill-Building and/or Employment-focused
  - Adolescent Employment Readiness Center (P. White)
- Health Care Provider driven
  - Primary care
  - Condition-specific
  - Specialty-specific

What are some health care providers doing?

- Bringing up the importance of transition as early as possible
- Discussing the importance of youth developing skills as health care consumer
- Using checklists to be proactive in preparing for adulthood
- Assessing youth knowledge and skills, i.e. Transition Readiness Assessment (TRA)
- Educating youth about his/her condition
- Teaching self-care skills
- Skill-building in other areas
- Referring to community resources
- Providing a medical summary
- Coordinating hand-off / transfer of care

Got Transition

www.GotTransition.org

- Website & Clearinghouse of information on health care transition
- Process for how to implement health care transition in a practice
  - From standpoint of pediatric specialist
  - Provider who sees children and adults
  - Adult specialist
- Quality improvement
- Tools

Got Transition Core Elements

- Transition Policy
  - Policy & **approach** to transition / accepting and integrating patients into practice
  - Education of staff and patients
- Transition tracking and monitoring
- Transition readiness assessment / orientation to practice
- Transition planning / Integration into adult practice
- Transfer of care / Initial visit
- Transfer completion / Ongoing care

Key to Understanding Services for Individuals with Disabilities

If you know one state,

you know one state.

State Resources Useful for Transitioning Youth with Disabilities

- ID/DD Agency (formerly MR/DD agency)
- Vocational Rehabilitation Agency
- Developmental Disabilities Council
- Protection & Advocacy Agency
- Centers for Independent Living (CILs)
- Family to Family Health Information Centers
- State Title V Program for CSHCN
- Got Transition has links to state agencies by state

Centers for Independent Living (CILS)

- Information and Referral
- Individual & Systems Advocacy
- Independent Living Skills Training
- Peer Counseling
- Other services: housing resources, assistive technology resources, ADA consulting, benefits planning, travel training, etc.

Social Security Administration

SSA administers two programs for people with disabilities

- Supplemental Security Income (SSI)
- Social Security Disability Insurance (SSDI)

Social Security Benefits
SSDI

Who is eligible?

- Retirees (≥65 yrs) receive Social Security retirement benefits
- Adults (<65 yrs) who have paid into system and become disabled receive **SSDI**
- Any dependent child of an adult on SSDI or SS retirement benefits can receive SS benefits
- Persons >18yrs, disabled before age 22yrs, if they have parent receiving SS retirement or disability benefits, or is deceased and was eligible for social security benefits
- Social Security Disability Benefits
  - Income based on amount paid in
  - Eligibility for Medicare after 2 years

Supplemental Security Income (SSI)

- Administered by Social Security Administration
- **For children <18years**
  - Family needs to meet financial eligibility
    - Low income and limited resources (assets)
    - Determined by local Social Security Office
  - Needs to meet disability criteria for children
    - Physical or mental impairment expected to last > 1 yr and resulting in marked and severe functional limitations
    - Review done by Disability Determination Services
  - Monthly income assigned to representative payee
- **For adults ≥ 18 years**
  - Individual needs to meet financial eligibility
  - Needs to meet disability criteria for adults
    - Inability to work expected to last > 1 year

SSI Cont.

- Benefits of SSI
  - Monthly Income (varies by state)
    - Federal Benefit Rate 2005 $579/month
  - Medicaid - in most states individuals receiving SSI automatically eligible for Medicaid
  - Work Incentives - adults are eligible for work incentives through Social Security
- Redetermination at 18 years
  - ~30% will lose benefits
- Recipients virtually prevented from accumulating assets
  - Limit $2000 individual, $3000 couple

National Resources on Health Care Transition

- **Got Transition** is the National Center for Health Care Transition

  http://www.gottransition.org/
- Interdisciplinary Collaborative on Healthcare and Education Transition (ICHET)

  http://education.ufl.edu/education-healthcare-transition/
- **Adolescent Health Transition Project** – University of Washington

  http://depts.washington.edu/healthtr/index.html

Summary of **everything** that I have learned about Successful Transition

- Start early (at time of diagnosis) - preparing and planning
- Focus on abilities, not disabilities
- Find opportunities for success and build on successes
- Develop sense of responsibility (e.g. chores)
- Envision a future / set goals
- Have realistic expectations
- Identify needed supports & locate resources
- Find opportunities for skill-building (health care, life and vocational skills)
- Promote self-determination & self-advocacy
- Re-assess knowledge, skills, and goals frequently during the transition process

Concrete Recommendations for Health Care Providers

- At Diagnosis:
  - Discuss the future/adulthood
  - Start early promoting household chores, responsibilities, developing life skills
- At age 14 years
  - Discuss transition as part of IEP at 14
  - Determine if youth is diploma track or certificate track
  - Consider extending high school for those who are diploma track
  - Consider highest level of independence that may be achievable
  - Get the families thinking about resources they will need
- At age 17 years
  - Discuss decision-making including health care
  - Discuss health insurance. Will they be eligible for SSI.
  - Discuss eventual transfer of care to adult-oriented providers
  - If diploma track, is Vocational Rehab (VR) involved
- At age 20 years
  - If certificate track, explore different DD service providers
  - Transfer to adult-oriented health care services as appropriate

Thank You!

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