Bridging the Gaps:

*Transitioning from Pediatric to Adult Care*

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Presentation Objectives

• Definition and Goals of Transition
• Obstacles
• Recommendations
• Stages of Adolescence
• Specific conditions
• Advances in transitioning
What is Transition?

“Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system”

*American Society for Adolescent Medicine*
Goal of Transition

To maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the young adult moves from adolescence to adulthood.
Transition is a Process

Child

Adolescent

Adult
Transition is a Journey

• Childhood to adulthood characterized by:
  – Anger, confusion, hope and despair, mastery of essential life skills for independence.
  For youth with chronic illnesses this process can be delayed.
  – Exploring limits
  – Reality testing
  – Self-image development
Obstacles to Transition

- Prognosis of patient’s diagnosis
- Understanding need for transition by patient and family
- Environmental or familial stressors
- Need to control by either parents or health care team
- Distorted perception of patient outcome
Negative Messages

• Patient/Child is incapable of independent care

• Patient/Child is not expected to assume self-responsibility and will be taken care of

• Patient/Child is very different from his or her peers

• The medical prognosis is too poor to warrant planning for the future
Importance of Transition - Consensus

• Identified health care provider (HCP) to partner with youth/families during transition

• HCP with core knowledge and skills

• Maintain current medical record

• Create written plan by age 14

• Apply preventive and primary care to youth with/without special health care needs

• Ensure affordable and continuous health insurance coverage

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Transition Framework

Healthy People 2010 - Department of Health & Human Services

**Goal** - All young people with special health care needs will receive the services necessary to make the necessary transition to all aspects of adult life

- Health care
- Work
- Independent living

**Steps to achieve goal**

- Knowledge
- Medical summary
- Written plan for family
Where to Begin?

• Need to understand the stages of adolescence
• Health care transition process
• Responsibilities of the patient, family, and health care team
• Tools for gaining knowledge of ‘what and when’ the patient needs to know in order to complete the transition successfully
“Ingredients” of Transition

- Getting consent and cooperation of the patient
- Enlisting active support of the family
- Getting the support of all the medical professionals
- Instituting a policy on timing of transfers
- Establishing a preparation and education program prior to transition
- Define expectations
- Gather information about available adult services
- Consider having pediatrician and adult M.D. as co-managers for a period of time.
What You (Patient/Family) Expect

- Medical regimen and clinic visits that promote adherence, education
- Educational tools
- Monitoring for side effects/complications
- Support and promote healthy lifestyle
- Identification as an unique individual
- Guidance for long term care
- Identification of long term care providers
- Support for insurance issues
- Support for career planning
Know your health care team members!

- Take full advantage of the various health care team members
  - MDs, RNs, TX RNs, CCLS, LMSWs, RDs

Wealth of information and tools at your reach!

Ask questions? You are the best advocate!
Stages of Adolescence & Medical Tasks

**Management of Care**

- **Late**
  - 17-20+ years
  - Basic understanding of diagnosis and treatment
  - Taking medications independently, ask and answer questions, makes appointments

- **Mid**
  - 14-16 years
  - Early
  - 10-13 Years
Early Adolescence (10-13 years) & The Medical Team

- Learn about normal body function
- Describe the diagnosis in age appropriate terms
- Name medications taken
- Manage tasks at school
Mid Adolescence (14-16 years) & The Medical Team

• Recognize symptoms that indicate a need for immediate treatment
• Seek help when problems arise
• Keep a medical journal or personal health notebook
• Call for prescription refills
• Take charge for scheduling appointments
• Acknowledge understanding of changes in medications and treatment
• Know the difference between primary and specialist care
• Assents to medical care (age 15)
• Understand they will be transferring to adult care
For children age 13-14 years with a chronic illness, which statement is a good indicator that they will have a successful transition?

A) “I have told my best friend about my diagnosis”

B) “I have a supportive family”

C) “I do chores around the house”
Late Adolescence (17+ years) & The Medical Team

• See medical team members independently
• Know common complications of diagnosis
• Call for lab results
• Discussions regarding plan of transfer should become more frequent
• Manage all regular medical tasks—self advocate!
• Aware of medical insurance coverage
• Identifies rights and responsibilities of being a patient
• Signs consents (18 years of age)
• Learn about the systems that will apply to them as adults (i.e. insurance, social security, guardianship, advanced directives)
Insurance Issues

• Types of coverage varies state by state (Medicaid, MediCal, CSHCN, etc.)

• Some commercial insurances will cover until 25 years of age if a full time student

• Limitations or restrictions

• “Preexisting” clause 😞

• Supplemental Security Income (SSI)
  – Means tested along with diagnosis
  Check eligibility for SSI month she/he turns 18

Their financial resources are evaluated; not parents/guardians

Read the fine print!
Questions to Ask

• How often should I see the physician/medical team?

• Will my appointments have a major impact on my education and or employment?

• How will I find out test results?

• How will I obtain prescriptions?

• Who do I call if I become ill between visits?

• What do I do if I have trouble with insurance?

• If I need surgery, who will be consulted?

• What will the effects of aging have on my condition?

• Will my condition affect my ability to have children?
Considerations

- Process should be gradual and individualized
- Discussions should be held at regular intervals (i.e. Care Plan Meetings) starting early in adolescence
- Progress and limitations noted
- Transfer should occur by the age of 18-21 years
  - AAP have “floating recommendations”
  - “Special circumstances” such as chronic illness may make pediatric care optimal for some beyond age 21
Transitioning for the Renal Patient

- CKD
- Dialysis
- Transplanted
- Transplant list
Expectations of Adult Practice

- Patient has the knowledge of condition, treatment and plan of care
- Knows medications
- Written summary
  - Can be done with dictation of last visit
  - Last set of labs, x-rays, ultrasounds, etc.
Attachment

Transition Timeline for Children and Adolescents with Special Health Care Needs:
Chronic Illnesses/Physical Disabilities

Parent and Child Interactions that Encourage Independence

Birth to 3-5, or according to your child’s developmental ability
- Assess your infant the world is a good place in which to live.
- Development of a sense of trust is vital to the development of a healthy personality.
- Allow your child to develop at his/her own individual rate.
- As a parent it is important to take short breaks with your child to renew energy with which to enjoy him/her.
- Keep a record of your child’s educational and medical history, including immunizations.

By ages 3-5, or according to your child’s developmental ability
- Assign your child chores appropriate for his/her ability level.
- Assign chores in accordance with your child’s ability level.
- Teach consequences of your child’s behaviors and choices.
- Continues involvement in community and recreational activities that includes children with and without special needs.
- Begin asking, “What do you want to do when you grow up?”
- Begin teaching your child about his/her special health care needs.
- Begin teaching your child self-care skills: normal skills and those related to his/her special health care needs.

By ages 6-11, or according to your child’s developmental ability
- Begin helping your child interact directly with doctors, nurses, therapists, and teachers.
- Assess your child’s perception based upon knowledge of his/her special health care needs. Build on their understanding.
- Continues teaching your child normal self-care skills as well as skills related to his/her special health care needs.
- Determine whether reasonable accommodations are needed to ensure equal access to school programs; if so, ask if your child qualifies for a 504 plan.
- Encourage hobbies and leisure activities: includes exploring community and recreational activities, clubs, 4-H, Scouts, Campfire, YMCA, sports, etc.
- Continues to encourage decision-making skills by offering choices.
- Continues assigning your child chores appropriate for his/her ability level.
- Takes your child shopping accessible places so he/she can help in choices.
- Let your child choose how to spend some or all of allowance.
- Teach your child the consequences of his/her behaviors and choices.
- Allow your child to experience the consequences of a poor choice as well as a good choice.
- Begin teaching your child self-advocacy skills.
- Begin asking your child “What will you do when you grow up?”

By ages 12-18, or according to your child’s developmental ability
- Assess your teen’s perception and basic knowledge of his/her special health care needs. Fill in gaps in understanding.
- Continues teaching your teen normal self-help skills as well as skills related to special health care needs.
- Begins helping your teen keep a record of his/her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and 504 plan if he/she has one.
- If he/she has a 504 plan, encourage teen to participate in any 504 meetings.
- Begins helping your teen take responsibility for making and keeping his/her own medical appointments, ordering their own supplies, etc.
- Begins exploring health care financing for young adults at age 17.
- Discuss sexuality with your teen.
- Help your teen identify and build on his/her strengths.
- Explore support groups, if teen is interested.
- Begin to explore and talk about possible career interests with your teen.
- Help your teen find work and volunteer activities.
- Continues to allow your teen to help with family chores.
- Continues to encourage hobbies and leisure activities.
- Help your teen identify and be involved with adult or older teen role models.
- Begins, with your teen, looking for an adult health care provider.
- Encourages teen to contact campus disabled student services to request accommodations if he/she will be attending college.
- With teen, check eligibility for SSI the month he/she turns 18. At age 18, the teen’s financial resources are evaluated, not the parents’ guardians.

By ages 18-21, or according to your child’s developmental ability
- Act as a resource and support to your young adult.
- Encourage your young adult to participate in support groups and/or organizations relevant to his/her special health care needs.
- Finalize health care financing with your young adult.
- With your young adult, finalize transfer of medical care to adult providers.
- For young adult attending college, encourage continued contact with disabled student services as needed for accommodations.
- Encourage young adult to investigate services provided by Division of Rehabilitation Services (DRS) if he/she has not already done so.

Advances in Transition Programs

• More and more pediatric centers developing their own programs for transitioning
• Creating “toolkits” and “passports”
• Connecticut Children’s Medical Center’s Kit:
  – File Folder, ongoing use and update at every visit
  – Check list according to 3 stages of adolescence
• Knowledge of condition
• Healthcare
• Bone Health
• Lifestyle Issues
• Psychosocial
• Sexual Health
• Education/Vocation
• Implementation of transition
Resources

Build your own care notebook
www.medicalhomeinfo.org/tools/care_notebook.html

CMS Health Care Transition Workbooks
hctransitions.ichp.ufl.edu/resources.html

National Dissemination Center for Children with Disabilities
www.nichcy.com

National Center in Secondary Education and Transition
www.ncset.org

Youthhood. Transition planning for youth with & without disabilities.
www.youthhood.org
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• Secal P. Transition for Youth With Chronic Conditions: Primary Care Physicians’ Approaches. Pediatrics 2002;110:1315-1321


• Transition Toolkit, Connecticut Children’s Medical Center. Supported by Genentech Inc.
Start small. Start slow. Start now!