Youth with Special Health Care Needs

Building towards Success in Adult Life

Mary Ciccarelli, M.D.
July 2012
Youth to Adult Transition

- Dynamic, lifelong process that seeks to meet an individual’s needs when moving from childhood to adulthood

- Maximize potential and lifelong functioning
  - Pediatric to Adult Health Care
  - School to Work
  - Family to Independent Living
  - Community Participation
Center for Youth and Adults with Conditions of Childhood

• **MISSION:**
  – “Steering YSHCN toward successful adult life”

• **VALUES:**
  – Youth as a whole person
  – Family-centered
  – Focused on self-advocacy, community inclusion
  – Interprofessional team – academic and community, promoting system change
CYACC

• Transition consults and care coordination for youth with special needs ages 11-22
  – Address health, education, employment, independent living, and recreation
  – Prepare in childhood, bridge during late teens/early adult years, transfer as activated educated program graduate
• **CYACC**
  - Opened 2007
  - YSHCN ages 11-22
  - Chronic illness, physical and intellectual disabilities
  - ~1,000 served

• **Team**
  - Social workers, Nurses, Physicians
  - Center for Independent Living - advocates
  - Parent to Parent - liaisons
  - Advisory board
  - Youth committee
• Of youth ages 12-17
  – 18.4% have SHCN
    • ~1/2 with intellectual disability/mental health illness
    • ~1/2 with chronic illness/physical disability
    • 22% always limited by disability
    • 37% sometimes limited by disability
  – 17.7% missed 11 or more school days
  – 7.8% SSI benefits
Factors influencing impact of chronic disease on youth

• Age of onset
• Nature and severity
  – Duration
  – Visibility
  – Mobility
  – Limit of activities
  – Cognition, sensory, emotional, social function
  – Expected course

Planning with YSHCN: Begin with the End in Mind

- Enjoy your childhood.

- Live one day at a time while also envisioning long-term goals.

- Don’t prejudge your abilities.
  - Keep daily normal routines as much as possible.
  - Balance integrated activities with peer support of others with special needs.
  - Parent as much as possible as you would a typically developing child.
Youth growing ready to become an Adult

Protected child >>>

>>> Self-reliant adult as manager

Parent as manager >>>

>>> Parent as consultant
Tasks of Adolescence

1. Independence from parents
2. Adapt to peer norms
3. Accept body
4. Establish identity – ego, moral, sexual, vocation

Tasks of Young Adults

1. Independent Living
2. Vocational stability
3. Permanence in Intimate Relationship
4. Financial stability
Emerging Adulthood 18-24 yo

- Self-focused exploration
- Feelings of ambivalence about adulthood
  - Arnett, JJ. J Youth Adolescence (2007)
- Increase in length of transition (and dependence)
  - up to late 20’s, early 30’s.
  - Racial and ethnic differences in transition
Whose job is it to prepare for and address transition?
Goals For Transition

- Manage own health
- Appropriately access services
  - Ex. adult primary care, specialists, therapies, supplies, with continuous health insurance
- Plan and implement education/vocational goals
- Develop independent living plan
- Participate as member of community

Questions for CSHCN 12–17 yo

- whether doctors discussed shift to adult providers
- whether doctors discussed child’s changing needs as he/she approached adulthood
- whether anyone discussed insurance coverage in adulthood
- whether child was usually or always encouraged to take responsibility for his/her health
How are we doing?

• Adolescent
  - with SHCN vs. w/o SHCN
  - Engaged in high risk behaviors (e.g., smoking, ETOH or drug use) within past month
    41% vs. 32%
  - Report symptoms of depression
    39% vs. 18%
  - Of youth 14-17 on SSI
    35-50% drop out of high school
    9-13% have Voc Rehab services
    32% in Justice System after 18

Transition Readiness Assets

Internal assets
• Take responsibility
• Belief in restraint from risks i.e. sex, drugs
• Know how to plan and make choices
• Resist peer pressure and danger
• Have personal control over happenings

External assets
• Positive family communication
• Caring, encouraging school
• Safe school and neighborhood
• Positive, responsible role models
• Loving, supportive family
Goals for Transition: Parents

- Protect child
- While also promoting autonomy and maximizing potential
  - Uneasiness with change in parental role
Create a Balance
Parenting teens: Responsibility and Privilege

What is responsibility?

- Ability to act with internal motivation and without superior authority.
- Develop a sense of right and wrong
- Make decisions using problem-solving, critical thinking and coping skills
Responsibilities

- Looking out for other family members
- Taking care of young, old, sick family members
- Doing chores
  - cooking, cleaning
- Protecting family belongings
- Sharing
- Contributing to family resources
Privileges

• Rights granted as a particular advantage or favor
  • With development of skills in problem solving and decision-making
  • Earn privileges by demonstrating responsible behavior
    • Can be at home alone, having demonstrated ability to follow safety rules.
    • Can drive the car, having demonstrated ability to follow the rules of the house and the road.
Decision Making Skills

- not a yes or no judgment
<table>
<thead>
<tr>
<th>Steps in Self Determination</th>
</tr>
</thead>
</table>
| **Thinking**                | Each of these components has two steps, as shown below.  
|                             | Identify and express own needs, interests, and abilities.  
|                             | Set expectations and goals to meet these needs and interests.  
| **Doing**                   | Make choices and plans to meet goals and expectations.  
|                             | Take actions to complete plans.  
| **Adjusting**               | Evaluate the results of actions.  
|                             | Alter plans and actions, if necessary, to meet goals more effectively.  |
School Transition Planning

- Help students develop and practice self-determination skills
- Be aware of the wide variety of alternatives to and options within the guardianship process

Opportunities for Supported Decision Making

- Advocate
- Representative payee
- Health Care Representative
- Power of Attorney
- Limited vs. Full Guardianship
Options in Limited Guardianship

• Handle money up to a specified amount
• Maintain certain personal property
• Determine degree of participation in interpersonal relationships and community activities
• Make decision vs. consult guardian re:
  – Living arrangement
  – Employment
  – Health care decisions
• Vote
• Drive
Education

- Education transition plan
  - Beginning at age 14 (or younger)
  - Focus on anticipated needs as an adult
  - Option to remain in school through 22\textsuperscript{nd} yr
  - Inclusive activities
    - Cafeteria, music, art, PE
  - Vocational activities
    - At school and in community
Post Secondary Education

- Office of Disability Services
- Self-advocate for accommodations
- Special programs
  - Supported academic
  - Life skills
Work

- Income
- Sense of value
- Keep busy and productive

- Maintaining eligibility for benefits
  - Health insurance - MED works
  - SSI status
  - Value of resources – special needs trusts
Living

- Independent
- With family
- Supported living
- Personal Care Attendants
- Group home
- Institutional living
- Nursing home
- Independent Living Centers
  - [www.in.gov/fssa/servicedisabl/vr/ilcenters](http://www.in.gov/fssa/servicedisabl/vr/ilcenters)
Community participation

- Volunteer
- Advocate
- Voting

- Sports
- Clubs
- Peer support
- Transportation
Health Care Transitions

- Healthy habits
- Self-care
- Adult health needs
- Health insurance
- Transfer to new physicians
### Strategies for Maintaining Insurance

<table>
<thead>
<tr>
<th>Public</th>
<th>Private</th>
</tr>
</thead>
<tbody>
<tr>
<td>State Title V</td>
<td>Family plan until 26</td>
</tr>
<tr>
<td>Medicaid</td>
<td>Youth’s own plan</td>
</tr>
<tr>
<td>– eligibility change</td>
<td>- college student plan</td>
</tr>
<tr>
<td>– Buy-in</td>
<td>- employer plan</td>
</tr>
<tr>
<td>– Waivers</td>
<td>i.e. part time work</td>
</tr>
<tr>
<td>Medicare</td>
<td>- individual plan</td>
</tr>
<tr>
<td>SSI criteria change</td>
<td>- COBRA</td>
</tr>
<tr>
<td>– Ticket to Work</td>
<td></td>
</tr>
</tbody>
</table>

- Medicare
- SSI criteria change

- Family plan until 26
- Youth’s own plan
  - college student plan
  - employer plan
    - i.e. part time work
  - individual plan
  - COBRA
Developmental Stages of Health Transition Preparation

• 3-5 year old
  – (or as developmentally appropriate)
  – Teach about health condition
  – Begin to foster decision making

• 6-11 year old
  – Begin to interact directly with physician
  – Begin to learn about consequences to decisions
  – Begin to take on responsibilities

• 12-17 year old
  – Begin to meet with physician alone
If you answer yes to:

11-15 Statements
Super! You are already taking on adult responsibilities. You are ready to transition your health care and should speak with your health care providers about a transition plan.

6-10 Statements
You are on your way. You are actively taking on many responsibilities in your health care. Pick a few more responsibilities from the checklist to do for your next appointment. Also, start talking about transitions with your health care providers.

5 or Lower Statements
Now is a good time to start taking on more responsibility in your health care. Pick one new responsibility from the checklist and practice it at your next appointment. If you need help, ask a friend, parent, nurse, social worker, or doctor.
How to create healthy habits in youth with special needs

- Dietary
- Physical activity
- Toileting
- Sleep
- Stress management
- Hygiene & self-care
- Relationship safety
- Environmental safety

- Special attention to youth who:
  - Have altered sensation
    - i.e. spina bifida
  - Have altered cognition
    - i.e. autism
Important information in transfer

- Patient's health history
- Baseline cognitive, functional and neurologic status
- Condition-specific emergency treatment plans
- Information about advance directives
  - Decision-maker proxy or support system
  - Advance-care planning
- Communication preferences and anticipated needs for clinical accommodations
  - Use of sign language interpreter, augmentative communication, special exam table, etc.
Finding a new physician

• Seek potential providers
  – Board certification
  – Experience in serving people with chronic illness/disability
  – Experience with community organizations
  – Experience with family members
  – Personality
• Ask other families/support group members
• Check with insurance company
## Portable Medical Summary

<table>
<thead>
<tr>
<th>Legal Name</th>
<th>Address, City, State, Zip</th>
<th>Phone, cell, email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance</td>
<td>Certificate # / BC Plan 1</td>
<td>/ 800-XXX-XXXXXX</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Legal/Health POA</th>
<th>Name</th>
<th>Relationship</th>
<th>Cell</th>
<th>Work</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>DOB</th>
<th>xx-xx-xxxx</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>ADVANCE DIRECTIVES</th>
<th>YES NO</th>
<th>DNR</th>
<th>YES NO</th>
<th>ORGAN DONOR</th>
<th>YES NO</th>
</tr>
</thead>
</table>

### Allergy

**Health Issues**

<table>
<thead>
<tr>
<th>Body System</th>
<th>Name of Health Issue</th>
<th>Age on Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medications</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Rx</th>
<th>What for?</th>
<th>Name of Drug, Dosage, x ? how many times a day, ADD RX #</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>OTC</th>
<th>List any over the counter Drug - indicate daily or PRN</th>
</tr>
</thead>
</table>

### Medical History

**Body System**

<table>
<thead>
<tr>
<th>Diagnosis?</th>
<th>Age on Onset</th>
<th>Age Next Episode</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Surgeries</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>What treatment?</th>
<th>Age on Onset</th>
<th>Age Next Episode</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Medical Tests

<table>
<thead>
<tr>
<th>Test Type</th>
<th>Month/Year</th>
<th>Pos./Neg.</th>
<th>Summary Results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Immunizations

<table>
<thead>
<tr>
<th>Jaundice</th>
<th>TB</th>
<th>Pneumococcal vaccine</th>
</tr>
</thead>
<tbody>
<tr>
<td>YR</td>
<td>YR</td>
<td>YR</td>
</tr>
</tbody>
</table>

### Family History

<table>
<thead>
<tr>
<th>Father</th>
<th>Alive/Deceased</th>
<th>Age?</th>
<th>Health Issues, Cause of Death</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Mother</th>
<th>Alive/Deceased</th>
<th>Age?</th>
<th>Health Issues, Cause of Death</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Other</th>
<th>Alive/Deceased</th>
<th>Age?</th>
<th>Health Issues, Cause of Death</th>
</tr>
</thead>
</table>

### Physicians

<table>
<thead>
<tr>
<th>Primary Care</th>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dental</th>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Rx-Pharmacy</th>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
</tr>
</thead>
</table>
Emergency plan

**PRIMARY DIAGNOSIS:**

**BASELINE DATA:**

- vital signs: BP __ HR __ RR __ Wt. __ Ht. __ O2 sat. __
- Physical findings: Neuro exam:
- Devices: Lab/diagnostic test findings:

**MANAGEMENT SUGGESTIONS:**

- Allergies/medications & foods to avoid/rationale
- Procedures to avoid/rationale
- Common presenting issues/findings & specific diagnostic/management considerations:
- Management-related specialty physician info:
SAMPLE – CYACC Health Transition Plan

1. Primary Care:
2. Subspecialty Care:
3. Health care financing:
4. Health care decision making:
5. Health knowledge/self-care:
6. Advance planning:
7. Teen health/preventive care:
8. Health habits/physical activity/nutrition:
9. Mental health/stress management:
10. Clinic accommodations/accessibility:
11. Condition specific:
12.
13.
Sources of Info re: Chronic Conditions

- Diagnosis specific organizations
  - i.e. Spina Bifida Association www.sbaa.org
- National Institute of Neurological Disorders and Stroke www.ninds.nih.gov/disorders
- National Dissemination Center for Children with Disabilities http://nichcy.org/disability/specific
- Family Village www.familyvillage.wisc.edu
Community Resources

- Centers for Independent Living
- Vocational Rehabilitation
- Area Agencies on Aging
- Diagnosis organizations
- Self-Advocates
  - www.selfadvocacyonline.org
  - www.fvkasa.org
  - www.sabeusa.org
- Fraternal organizations

- Councils on Developmental Disabilities
  - www.acf.hhs.gov/programs/add/states/ddcs.html
- State Protection and Advocacy Agencies
  - www.acf.hhs.gov/programs/add/states/pas.html
- University Centers in Developmental Disabilities (UCEDD)
  - www.acf.hhs.gov/programs/add/states/ucedds.html
<table>
<thead>
<tr>
<th>Service</th>
<th>Website</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Security Administration</td>
<td><a href="http://www.ssa.gov">www.ssa.gov</a></td>
<td>800-772-1213</td>
</tr>
<tr>
<td>Medicaid/Hoosier Healthwise</td>
<td><a href="http://www.healthcareforhoosiers.com">www.healthcareforhoosiers.com</a></td>
<td>800-889-9949</td>
</tr>
<tr>
<td>Family Helpline</td>
<td><a href="http://www.in.gov/isdh/programs/mch/ifh.htm">www.in.gov/isdh/programs/mch/ifh.htm</a></td>
<td>800-433-0746</td>
</tr>
<tr>
<td>Mental Health America of IN</td>
<td><a href="http://www.mentalhealthassociation.com">www.mentalhealthassociation.com</a></td>
<td>800-555-6424</td>
</tr>
<tr>
<td>Indiana Institute on Disability &amp; Community</td>
<td><a href="http://www.iidc.indiana.edu">www.iidc.indiana.edu</a></td>
<td>800-433-0746</td>
</tr>
<tr>
<td>Division of Disabilities, Aging and Rehabilitative Services</td>
<td><a href="http://www.in.gov/fssa/servicedisabl/ddars">www.in.gov/fssa/servicedisabl/ddars</a></td>
<td>800-545-7763</td>
</tr>
<tr>
<td>Indiana Council on Independent Living (ICOIL)</td>
<td><a href="http://www.in.gov/fssa/ddrs/4960.htm">www.in.gov/fssa/ddrs/4960.htm</a></td>
<td>800-545-7763</td>
</tr>
<tr>
<td>Governor's Planning Council for Persons with Disabilities</td>
<td><a href="http://www.in.gov/gpcpd">www.in.gov/gpcpd</a></td>
<td>800-772-1213</td>
</tr>
<tr>
<td>ARC of Indiana</td>
<td><a href="http://www.arcind.org">www.arcind.org</a></td>
<td>800-382-9100</td>
</tr>
<tr>
<td>Department of Education - Special Ed</td>
<td><a href="http://www.doe.state.in.us">www.doe.state.in.us</a></td>
<td>877-851-4106</td>
</tr>
<tr>
<td>Indiana Protection and Advocacy Services</td>
<td><a href="http://www.in.gov/ipas/">www.in.gov/ipas/</a></td>
<td>800-622-4845</td>
</tr>
<tr>
<td>Indiana Justice Center</td>
<td><a href="http://www.indianajustice.org/Home/PublicWeb">www.indianajustice.org/Home/PublicWeb</a></td>
<td>800-869-0212</td>
</tr>
<tr>
<td>INdata</td>
<td><a href="http://www.eastersealstech.com">www.eastersealstech.com</a></td>
<td>888-466-1314</td>
</tr>
<tr>
<td>About Special Kids (ASK)</td>
<td><a href="http://www.aboutspecialkids.org">www.aboutspecialkids.org</a></td>
<td>800-964-4746</td>
</tr>
<tr>
<td>IN*SOURCE</td>
<td><a href="http://www.insource.org">www.insource.org</a></td>
<td>800-332-4433</td>
</tr>
<tr>
<td>Family Voices of Indiana</td>
<td><a href="http://fvindiana.blogspot.com">http://fvindiana.blogspot.com</a></td>
<td></td>
</tr>
<tr>
<td>Center for Youth and Adults with Conditions of Childhood</td>
<td><a href="mailto:cyacc@iupui.edu">cyacc@iupui.edu</a>, 317-948-0061, fax 317-948-7577</td>
<td>866-551-0093</td>
</tr>
</tbody>
</table>
Summary

• Adults with or without disabilities have the right to be treated as adults

• Success in transition relies
  – Awareness and preparation
  – Communication and collaboration
    • youth and their families
    • pediatric and adult primary care and subspecialty providers
    • other service providers, community
Websites

- National Health Care Transition Center
  www.gottransition.org
- Adolescent health transition project, U Wash
  http://depts.washington.edu/healthtr
- National Council for Disability
  www.ncd.gov
- Institute for Child Health Policy, U Florida
  http://hctransitions.ichp.edu/
- PACER Center in Minnesota
  www.pacer.org
- CHOICES
  www.shrinershq.org/choices
- www.montanayouthtransitions.org
- www.healthytransitionsny.org
- www.mdtransition.org