Transition To Adult Care

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Acknowledgement

• Slides courtesy of David Wood, MD, MPH
  April 2, 2015

• http://hscj.ufl.edu/jaxhats
Objectives

• Define Health Care Transition
• Understand factors impacting health care transition for youth with epilepsy
• Discuss Barriers to Transition to Adult Care
  • Patient and Family Related Barriers
  • Provide Barriers
• How to improve health care transition
  • At the patient and family level
  • At the provider level
90% of seriously ill children become adults
The bad news:
They have to go through this to get there!
Health Care Transition

• 18 million U.S. adolescents (ages 18-21) are moving into adulthood.

• Adolescents will need to transition from pediatric to adult-centered health care

• Transition planning between youth, family, and provider is important

• Demonstrates improvements in satisfaction, continuity of care, and greater adherence to care.

Source:
• U.S. Census Bureau, Current Population Survey, 2013
• McDanagh et al, 2007; Wojciechoski et al, 2002
What is Health Care Transition?

Health Care Transition (HCT)

The purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems.

Transition Preparation
Increased responsibility for health care self-management; understanding and planning for changes in health needs, insurance, and providers in adulthood; should occur across ages 12-21+

Transfer of Care
Discrete event, physical transfer from a pediatric to an adult provider; should occur between ages 18-21+

Successful Transition
Patients are engaged in and receive on-going patient-centered adult care.

AAP Consensus Statement, 2011

Slide courtesy Dr. Wood, 2015
### Six Core Elements of Health Care Transition

**Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)**

1. **Transition Policy**
   - Develop a transition policy/statement with input from youth and families that describes the practice’s approach to transition, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. **Transition Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning youth and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth's transition progress with the Six Core Elements.
   - Incorporate the Six Core Elements into clinical care process, using EHR if possible.

3. **Transition Readiness**
   - Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.

**Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)**

1. **Transition Policy**
   - Develop a transition policy/statement with input from youth/young adults and families that describes the practice’s approach to transitioning to an adult approach to care at 18, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. **Transition Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth/young adults’ transition progress with the Six Core Elements.
   - Incorporate the Six Core Elements into clinical care process, using EHR if possible.

3. **Transition Readiness**
   - Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.

**Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)**

1. **Young Adult Transition and Care Policy**
   - Develop a transition policy/statement with input from young adults that describes the practice’s approach to accepting and partnering with new young adults, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.

2. **Young Adult Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry.
   - Utilize individual flow sheet or registry to track young adults’ completion of the Six Core Elements.
   - Incorporate the Six Core Elements into clinical care process, using EHR if possible.

3. **Transition Readiness/Orientation to Adult Practice**
   - Identify and list adult providers within your practice interested in caring for young adults.
   - Establish a process to welcome and orient new young adults into practice, including a description of available services.
   - Provide youth-friendly online or written information about the practice and offer a “get-acquainted” appointment, if feasible.

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Source:
## Six Core Elements of Health Care Transition

### Transitioning Youth to Adult Health Care Providers
(Pediatric, Family Medicine, and Med-Peds Providers)

4. **Transition Planning**
   - Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.
   - Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
   - Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
   - Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.
   - Obtain consent from youth/parent for release of medical information.
   - Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.
   - Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

5. **Transfer of Care**
   - Confirm date of first adult provider appointment.
   - Transfer young adult when his/her condition is stable.
   - Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.
   - Prepare letter with transfer package, send to adult practice, and confirm adult practice’s receipt of transfer package.
   - Confirm with adult provider the pediatric provider’s responsibility for care until young adult is seen in adult setting.

6. **Transfer Completion**
   - Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibility to adult practice and elicit feedback on experience with transition process.
   - Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.
   - Build ongoing and collaborative partnerships with adult primary and specialty care providers.

### Transitioning to an Adult Approach to Health Care Without Changing Providers
(Family Medicine and Med-Peds Providers)

4. **Transition Planning/Integration into Adult Approach to Care**
   - Develop and regularly update a plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents.
   - Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
   - Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
   - Plan with youth/parent/caregiver for optimal timing of transfer from pediatric to adult specialty care.
   - Obtain consent from youth/parent for release of medical information.
   - Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

5. **Transfer to Adult Approach to Care**
   - Address any concerns that young adult has about transferring to adult approach to care. Clearly explain adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.
   - Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss needed self-care skills.
   - Review young adult’s health priorities as part of ongoing plan of care.
   - Continue to update and share portable medical summary and emergency care plan.

6. **Transfer Completion/Ongoing Care**
   - Assist young adult to connect with adult specialists and other support services, as needed.
   - Review ongoing care management tailored to each young adult.
   - Elicit feedback from young adult to assess experience with adult health care.
   - Build ongoing and collaborative partnerships with specialty care providers.

### Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)

4. **Transition Planning/Integration into Adult Practice**
   - Communicate with young adult’s pediatric provider(s) and arrange for consultation assistance, if needed.
   - Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.)
   - Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences.
   - Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

5. **Transfer of Care/Initial Visit**
   - Prepare for initial visit by reviewing transfer package with appropriate team members.
   - Address any concerns that young adult has about transferring to adult approach to care. Clearly explain adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.
   - Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult’s needs and goals in self-care.
   - Review young adult’s health priorities as part of their plan of care.
   - Update and share portable medical summary and emergency care plan.

6. **Transfer Completion/Ongoing Care**
   - Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.
   - Assist young adult to connect with adult specialists and other support services, as needed.
   - Continue with ongoing care management tailored to each young adult.
   - Elicit feedback from young adult to assess experience with adult health care.
   - Build ongoing and collaborative partnerships with specialty care providers.

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Source:
Changing Epidemiology of Diseases Arising in Childhood

• Cerebral Palsy
  • In US ~800,000 people have CP; >400,000 are adults
  • 85% of young adults with CP will reach age 50, 70% will reach age 60;
• Spina Bifida
  • 80% probability of survival until age 30

Sources:

Slide courtesy Dr. Wood, 2015
Increasing Life Expectancy in Persons with Spina Bifida

Cambridge Cohort born in late 1960s

New York Cohort born in late 1980-2000s

Figure 2. Survival probability for spina bifida and congenital hypertrophic pyloric stenosis, New York, birth years 1983 to 2006.

Kaplan-Meier data censored if participant was not yet 40. One death in a very severely disabled case was not included in the survival curve as it occurred after the age of 40. No loss to follow-up. Log rank test for comparison of survival p=0.001.

*All seven with minimal disability could walk and had normal IQ and all but one was continent. The 34 with moderate disability could walk, usually with callipers, one third had low IQ but none were severely mentally retarded. The 24 with severe disability could walk less than 20 yards, many had severe kyphosis and/or scoliosis, and only one was continent. The 12 with very severe disability were incontinent and unable to walk, and all but one was severely mentally retarded.

Slide courtesy Dr. Wood, 2015

Sources:
Why is HCT Important?

• Without support during transition youth may:
  • Lose of insurance
  • Decreased access
  • Decreased medication adherence
  • Increased ER visits, hospitalizations
  • Deterioration in health; poor out comes
    • HIV-decreased CD4 counts; Diabetes-worsening control; Transplant-rejection; Congenital Heart Disease—premature death

Slide courtesy Dr. Wood, 2015

Sources:
Institute of Medicine, 2007; Boyle et al. 2001; Callahan et al. 2001; Betz 2003; Freyer et al. 2008; Tuchman et al. 2008); Watson 2000; Annunziato et al. 2007; Gurvitz et al. 2007; Dugueperoux et al. 2008; White 2002; Williams 2009. AHRQ Technical Brief #15; 2014
<table>
<thead>
<tr>
<th>AGE</th>
<th>12</th>
<th>14</th>
<th>16</th>
<th>18</th>
<th>18-22</th>
<th>23-26</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Make youth and family aware of transition policy</td>
<td>Initiate health care transition planning</td>
<td>Prepare youth and parents for adult model of care and discuss transfer</td>
<td>Transition to adult model of care</td>
<td>Transfer care to adult medical home and/or specialists with transfer package</td>
<td>Integrate young adults into adult care</td>
</tr>
</tbody>
</table>

Source:
Childhood Epilepsy

• 1% of children
• Association with other conditions (prematurity, ICH), syndromes, genetic conditions (NF, TS, Fragile X, etc.)
• ~30% with associated intellectual disability
• ~30% with learning disorders
• ~30% behavioral/mental health
Figure 2. Reported impairments of young people with PIMD (%).

Source:
Trajectory of Care for Epilepsy Patients

- well-controlled epilepsy in cognitively normal patients
- difficult to treat epilepsy in cognitively normal patients, most commonly focal onset;
- intractable epilepsy associated with cognitive delay

Slide courtesy Dr. Wood, 2015
Lifespan health trajectory is shaped by risk and protective factors

Source:
- Halfon, Inkelas and Hochstein, 2000
Factors Impacting HCT

- Social Trends
- Youth development
- Health insurance
- Availability of adult providers
- Preparation by pediatricians and pediatric specialists

"First they make you button your own shirt, then they make you tie your own shoes...you gotta ask yourself — where’s this all heading?"
Secular Changes: Emerging Adulthood 18-29

• More youth pursuing higher education
  ▪ 1940’s—14% post HS ed.  1990’s—60%
  ▪ Mixed paths of education & vocation
  ▪ Including youth with serious health conditions

• Age of marriage is increasing
  ▪ 1940-1950’s it was 20 years of age;
  ▪ 1990’s it rose to 25-29 years of age

• Increase in length of transition
  • —up to late 20’s, early 30’s.

Source: U.S. Census Bureau, 1997

Slide courtesy Dr. Wood, 2015
Cognitive Development: Piaget’s Formal Operational Thought

<table>
<thead>
<tr>
<th></th>
<th>EARLY (11-13)</th>
<th>MIDDLE (14-16)</th>
<th>LATE (17-21)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Concrete thought</td>
<td>Abstraction</td>
<td>Established abstract thought</td>
</tr>
<tr>
<td></td>
<td>No future perspective</td>
<td>Has future perspective; not always used</td>
<td>Future oriented</td>
</tr>
</tbody>
</table>

Slide courtesy Dr. Wood, 2015
Adolescent Brain Development

Slide courtesy Dr. Wood, 2015

Source:
Somerville, Jones, & Casey (2010)
Family and Youth Factors Complicating Epilepsy Care for YYA

• Youth
  • Learning Disorders
  • Behavioral and Mental health
  • Intellectual Disability
  • Co-Morbid Medical Problems
  • Social Stigma

• Family Challenges
  • Coping, isolation
  • Social challenges such as poverty, housing and relationship instability

Source:
• R.P.J. Geerlings, A.P. Aldenkamp, et. al. Transition to Adult Medical Care for Adolescents with Epilepsy. Epilepsy & Behavior 44 (2015) 127–135
Medical Decision-Making and Disease Self Management

• Immediate benefits outweigh long term risks
  • Inconvenience of Bowel program vs. complications from constipation
  • Taking daily medications requires commitment to routine
  • Pain of Depo shot vs. risk of pregnancy
  • Staying out with friends vs. self-catheterization

• Future orientation & abstract through needed for competent self management
Medication Adherence in Epilepsy During Transition

- Associated with side effects, behavioral, mental health issues, ID/cooperation,
- 35% missed >1 dose in the past month
- 55% reported stopping AED w/i 1-3 months.
  - Among those 2/5 reported they had a seizure as a consequence.
  - 70%, forgetfulness or not having the pills with them was the reason for not taking the prescription.
- Caregiver commonly responsible

Sources:
- Asato MR, J Child Neurol 2009;24:562–71;
Impact of Epilepsy on Adolescent Development

Figure 1. Seizure history.

Figure 3. Negative outcomes experienced due to seizures.

Source:
Family Barriers

• Readiness to let go
  • Attachment to pediatric providers

• Recognition of child’s ability to care for self and self-advocate

• Family cohesion and communication
  • Stressed from many angles

• Poverty and disadvantaged environment
  • Less services and supports
  • Perhaps more natural supports
Inadequate Health Insurance

- Aging out of health care plans/services
  - Medicaid—18
  - SCHIP/KidCare—19
  - Title V Safety Net funds--21
- Benefits in temporary jobs often limited
- Change in eligibility rules for SSI
  - Loose Medicaid in non-expansion states
- Cost barriers for families to keep youth on parental work-related insurance
### TABLE 2
Insurance Characteristics for Young Adults With and Without Disability During the 36-Month Survey Period

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Reported Disability, % (SE)</th>
<th>No Disability, % (SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health insurance coverage at start of study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>56.0 (2.6)</td>
<td>70.6 (0.9)</td>
</tr>
<tr>
<td>Public</td>
<td>22.1 (2.2)</td>
<td>7.0 (0.5)</td>
</tr>
<tr>
<td>Uninsured</td>
<td>21.9 (2.2)</td>
<td>22.4 (0.8)</td>
</tr>
<tr>
<td>Months of uninsurance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>44.1 (2.6)</td>
<td>46.4 (0.8)</td>
</tr>
<tr>
<td>1–12</td>
<td>27.7 (2.4)</td>
<td>26.1 (0.8)</td>
</tr>
<tr>
<td>13–36</td>
<td>28.2 (2.4)</td>
<td>27.5 (0.8)</td>
</tr>
<tr>
<td>Months uninsured (mean)</td>
<td>15.2 (0.8)</td>
<td>16.5 (0.3)</td>
</tr>
</tbody>
</table>

Data source was our analysis of the 2001 SIPP.*

* Data are the difference between groups significant at $P < .01$.  

Source:  
Callahan and Cooper. Pediatrics. 2007:119;1175
Percentage of Uninsured Young Adults Declined from 2011 to 2013; Gains Were Largest Among Low-Income Young Adults

Percent of young adults ages 19–29

<table>
<thead>
<tr>
<th>Year</th>
<th>&lt;133% FPL</th>
<th>133%–249% FPL</th>
<th>250%–399% FPL</th>
<th>400% FPL or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>22</td>
<td>48</td>
<td>13</td>
<td>22</td>
</tr>
<tr>
<td>2013</td>
<td>21</td>
<td>41</td>
<td>11</td>
<td>9</td>
</tr>
</tbody>
</table>

Note: Totals may not equal sum of bars because of rounding. FPL refers to federal poverty level.

Slide courtesy Dr. Wood, 2015
Pediatric versus Adult Care

- Pediatric Care
  - Relational
  - Developmental
  - Family Centered—1 to many
  - Social support/nurturing
  - Specialty focused or Interdisciplinary (care coordination)

- Adult Care
  - Cognitive
  - Static/declining function
  - Patient Centered--1:1 communication
  - Knowledge = Empowerment
  - Primary Care focused or Multidisciplinary

Slide courtesy Dr. Wood, 2015

Source: Rosen D. J Adolesc Health 1995;17:10
Comfort of Adult Providers by Condition 2008 New Hampshire

Treatment Comfort Level By Condition

- Healthy Young Adults
- Asthma
- Hypertension
- Intellectual Disabilities
- Mental/Behavioral Health Conditions
- Diabetes / Type 1
- Seizure Disorders
- Cardiac Conditions
- Cerebral Palsy/Spina Bifida
- Autism
- Cystic Fibrosis
- Chromosomal / Metabolic Disorders
- Technology Dependent

Slide courtesy Dr. Wood, 2015
Confidence of Adult Neurologists
Childhood Epilepsies

• Survey of Canadian Neurologists at the Canadian Neurological Sciences Federation Congress in 2013

Table 3. Survey responders and their level of confidence managing epilepsies (n = 115)

<table>
<thead>
<tr>
<th></th>
<th>AN</th>
<th>ANE</th>
<th>PN</th>
<th>PNE</th>
<th>p-Value\textsuperscript{a}</th>
<th>p-Value\textsuperscript{b}</th>
<th>p-Value\textsuperscript{c}</th>
<th>p-Value\textsuperscript{d}</th>
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</thead>
<tbody>
<tr>
<td>Responders (%)</td>
<td>61.73</td>
<td>13.04</td>
<td>14.78</td>
<td>10.43</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Professionals working in academic centre (%)</td>
<td>80</td>
<td>93.3</td>
<td>76.4</td>
<td>83.3</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Professionals working predominantly in clinical activities (%)</td>
<td>97.2</td>
<td>93.3</td>
<td>100</td>
<td>100</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Confidence dealing with temporal lobe epilepsy (%)</td>
<td>93</td>
<td>100</td>
<td>94.1</td>
<td>100</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Confidence dealing with idiopathic generalized epilepsies (%)</td>
<td>93</td>
<td>100</td>
<td>94.1</td>
<td>100</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Confidence dealing with poststroke epilepsy (%)</td>
<td>98.5</td>
<td>100</td>
<td>94.1</td>
<td>75</td>
<td>0.03</td>
<td>NS</td>
<td>NS</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Confidence dealing with focal cortical dysplasia (%)</td>
<td>50.7</td>
<td>86.6</td>
<td>88.2</td>
<td>100</td>
<td>&lt;0.001</td>
<td>0.028</td>
<td>0.006</td>
<td>0.002</td>
</tr>
<tr>
<td>Confidence dealing with other MCDs (%)</td>
<td>33.8</td>
<td>73.3</td>
<td>94.1</td>
<td>100</td>
<td>&lt;0.001</td>
<td>0.016</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Confidence dealing with epileptic encephalopathy (%)</td>
<td>11.2</td>
<td>53.3</td>
<td>82.3</td>
<td>91.7</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Confidence dealing with epilepsy in association with GS (%)</td>
<td>9.8</td>
<td>53.3</td>
<td>94.1</td>
<td>83.3</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Confidence dealing with moderate to severe ID (%)</td>
<td>15.4</td>
<td>53.3</td>
<td>NA\textsuperscript{e}</td>
<td>NA\textsuperscript{e}</td>
<td>0.02</td>
<td>NA\textsuperscript{e}</td>
<td>NA\textsuperscript{e}</td>
<td>NA\textsuperscript{e}</td>
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<tr>
<td>Confidence dealing with autistic features (%)</td>
<td>15.4</td>
<td>40</td>
<td>NA\textsuperscript{e}</td>
<td>NA\textsuperscript{e}</td>
<td>NS</td>
<td>NA\textsuperscript{e}</td>
<td>NA\textsuperscript{e}</td>
<td>NA\textsuperscript{e}</td>
</tr>
</tbody>
</table>

Source:

Slide courtesy Dr. Wood, 2015
# Confidence of Adult Neurologists

**Childhood Epilepsies -- II**

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**Table 2: Reported comfort level in treating patients with selected neurological disorders: Adult neurologists**

<table>
<thead>
<tr>
<th>Neurological disorder</th>
<th>n</th>
<th>Completely comfortable n (%)</th>
<th>Somewhat comfortable n (%)</th>
<th>Not comfortable n (%)</th>
<th>Impossible n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>98</td>
<td>1 (1%)</td>
<td>10 (10%)</td>
<td>57 (58%)</td>
<td>30 (31%)</td>
</tr>
<tr>
<td>Chromosomal or metabolic disorders</td>
<td>98</td>
<td>1 (1%)</td>
<td>25 (26%)</td>
<td>61 (62%)</td>
<td>11 (11%)</td>
</tr>
<tr>
<td>Cognitive or Behavioral disorders</td>
<td>98</td>
<td>16 (16%)</td>
<td>33 (34%)</td>
<td>46 (47%)</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>Neuromuscular disorders</td>
<td>98</td>
<td>14 (14%)</td>
<td>43 (44%)</td>
<td>39 (40%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Tourette Syndrome</td>
<td>98</td>
<td>21 (21%)</td>
<td>39 (40%)</td>
<td>34 (35%)</td>
<td>4 (4%)</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>99</td>
<td>19 (19%)</td>
<td>53 (54%)</td>
<td>23 (23%)</td>
<td>4 (4%)</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>94</td>
<td>56 (60%)</td>
<td>19 (20%)</td>
<td>18 (19%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>98</td>
<td>54 (55%)</td>
<td>37 (38%)</td>
<td>7 (7%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Headaches</td>
<td>97</td>
<td>67 (69%)</td>
<td>26 (27%)</td>
<td>4 (4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>97</td>
<td>68 (70%)</td>
<td>25 (26%)</td>
<td>3 (3%)</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>


Slide courtesy Dr. Wood, 2015
Why Internists Won’t Take YSHCN

- Lack of training in conditions arising in childhood
- Lack of Time/reimbursement
- Lack of support for care coordination
- Lack of Access to super-specialists
  - adolescent medicine;
  - adult congenital heart;
  - adult spasticity management, etc.
- Lack of medical summary /communication

Source:
Okumura et al, JGIM 2008; AAP Periodic Survey 2008;
Thompson et al, Pediatrics, 2009; Peter N. Pediatrics. 2009; 123:417

Slide courtesy Dr. Wood, 2015
National Survey of Parents of Children with Special Health Care Needs

• 17,114 parents of YSHCN aged 12-17

• Only 40% of parents got transition communication
  1. Shifting care to an adult provider
  2. Future adult health care needs
  3. Upcoming eligibility changes in health insurance
  4. Encouraging youth to take responsibility for their care

• Less likely to receive HCT counseling if male, non-white, public/no insurance

• More likely if have a medical home (55% vs. 29%)

Source:
• McManus et al, Pediatrics, 2013
• Lotstein et al, Pediatrics 2009

Slide courtesy Dr. Wood, 2015
Transition Preparation

• Parents of youth with Cerebral Palsy report low rates of transition counseling
  • 46% were counseled on self-management; 29% discussed transfer to adult providers
• Parents of youth with Profound ID report not feeling prepared to move to adult care.
  • Limited preparation; Fragmented care in adult system; Their suggestions to improve transition: early start, information provision, coordination between pediatric and adult care.

Slide courtesy Dr. Wood, 2015

Sources:
Transition Framework

Preparation Process

- Changing Medical Care
- Changing Insurance
- Developing Self-Care Abilities
- Education/Job Planning

Outcome

- Access to Continuous, High Quality Medical Care
- Maximized Quality of Life And Role Attainment

Slide courtesy Dr. Wood, 2015
Source: Lotstein et al, Pediatrics 2011
Integrated Model of HCT

Figure 3: The professional transition model. In this model, the focus is on the health care professional rather than on the patient. It aims to ensure that the expertise that the child has benefited from while under the care of paediatric services continues to be present once he or she comes under the umbrella of the adult service.

Slide courtesy Dr. Wood, 2015
Improving Transition for YYA with Profound ID

• 131 Parents of YYA (16-26 in Holland)
  • Inquired about HCT experience

• Recommendations
  • Early start
  • Information provision
  • A joint consultation between pediatric and adult care
  • Just the start!

How To Improve Health Care Transition: Patient and Family Strategies
# Autism Speaks Transition Tool Kit

## Table of Contents

**Introduction**

**Self-Advocacy**
- Where Do I Start?
- What is Self-Advocacy?
- When Do I Begin to Teach Self-Advocacy Skills?
- How Do I Teach Self-Advocacy Skills?
- Self-Advocacy and the Transition Process

**Why do we need a Transition Plan?**
- Transition Planning and the Individual Education Program
- What are My Child’s Rights and How Do They Change When He/She Leaves the School System?
- Getting Started
- How Do We Create and Implement A Transition Plan?

**Community Living**
- Picking the Right Activities
- Social Skills in the Community and the Workplace
- Travel Training
- Safety

**Employment and Other Options**
- Preparation
- Career Exploration
- What Types of Employment are there?
- Job Matching and Searching
- Options other than Employment

**Post-Secondary Educational Opportunities**
- Types of Post Secondary Education
- 504 Plans
- Differences between High School and College
- Preparing for College While still in High School
- Choosing the Right School
- Key Skills, Common Issues and Concerns

**Housing**
- What Are the Options for Housing and How Do I Find Them?
- Types of Housing
- Funding Options
- Some Questions to Ask

**Legal Matters to Consider**
- What is Long-Term Planning?
- Health Insurance
- Guardianship
- Special Needs Trusts
- Support Programs
- Letter of Intent

**Health**
- Physical Health
- Female Health
- Mental Health
- Sexuality
- Advice for Parents

**Internet and Technology**
- Internet Safety
- Social Networking
- Technology

**Getting Organized**
- Getting Started
- Forms

**Conclusion**

**Resources**
### 10 Steps to Successful Health Care Transition

**Success in the classroom, within the community and on the job requires that young people stay healthy. The best ways to stay healthy are to understand your health, participate in health care decision making, and receive age-appropriate care. Here are 10 ways to ensure a smooth transition from pediatric to adult health care for teens and young adults with disabilities or chronic health conditions.**

1. **Start early!** Begin preparing for transition even when very young, like starting a health summary and talking about health needs.
2. **Focus on responsibility for health care.** Taking responsibility for health care should be based on age and abilities. Become more independent by learning the skills for managing health care, like scheduling appointments, arranging transportation, taking medication, filling prescriptions, and talking to doctors.
3. **Create a health summary.** Put important information about personal health in one place, including medications and plans for an emergency.
4. **Create a health care transition plan.** Work with your primary care provider to develop a written health care transition plan that includes future goals, services that will be needed, who will provide them, and how they will be paid for.
5. **Maintain wellness.** Support good habits that will continue into adulthood! Talk about risky behaviors such as alcohol use and smoking as well as sexuality and relationships.
6. **Know options for health insurance and public assistance programs in adulthood.** If you’re unsure about eligibility, it’s always best to go ahead and apply.
7. **Find adult providers.** If still in the care of pediatric providers, identify a primary care physician and specialists (including mental health professionals) who work with adults.
8. **Include health in other areas of transition.** Ask your primary care physician to provide documentation of medical conditions and special health care needs for other programs or agencies, as needed.
9. **Integrate health care transition activities in the school setting.** An Individualized Education Plan (IEP) or 504 Plan. Consider self-determination and self-advocacy skills, understanding personal health conditions and needs, and health care self-management skills.
10. **Learn about other community services and supports for adults.** Be knowledgeable about rights and responsibilities at age 18!

Visit [www.FloridaHATS.org](http://www.FloridaHATS.org) to find resources and services.

Become a fan on Facebook and share your health care transition experiences!

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**Suggested Citation:** Long, L. (2011). Supplemental Security Income: What Happened to My SSI When I Turn 18? Tip Sheet 3. Worcester, MA-UMMS, Dept. of Psychiatry, CMHSR, Transitions RTC. For help, contact the Work Incentives Planning and Assistance (WIPA) Program in your state. The contact information can be found on the Social Security website by clicking on the Service Provider Directory link at [https://secure.ssa.gov/apps10/oesp/providers/nys/bystate](https://secure.ssa.gov/apps10/oesp/providers/nys/bystate). Please visit us online at [http://labs.umassmed.edu/transitionsRTC](http://labs.umassmed.edu/transitionsRTC)
LEGAL WAYS OF PROTECTING RIGHTS

PLENARY GUARDIANSHIP (SECTION 741.1070, FLSA)
Appointments are made when there is a clear and present danger to the person, with the purpose of avoiding further neglect or abuse. A guardian is appointed if a person is appointed and a guardian is appointed to make all decisions for the individual.

LIMITED GUARDIANSHIP (SECTION 741.110, FLSA)
An appointment of a guardian is made when there is a clear and present danger to the person, with the purpose of avoiding further neglect or abuse. A guardian is appointed if a person is appointed and a guardian is appointed to make all decisions for the individual.

GUARDIAN ADVOCATE (SECTION 394.12, FLSA)
An appointment of a guardian advocate is made when there is a clear and present danger to the person, with the purpose of avoiding further neglect or abuse. A guardian advocate is appointed if a person is appointed and a guardian advocate is appointed to make all decisions for the individual.

FOREIGN GUARDIAN (SECTION 741.1080, FLSA)
An appointment of a guardian is made when there is a clear and present danger to the person, with the purpose of avoiding further neglect or abuse. A guardian is appointed if a person is appointed and a guardian is appointed to make all decisions for the individual.

Trust
A legal arrangement where a trustee holds property and/or assets for the benefit of the beneficiary of the trust. Trusts can only be used for the person granting the trust to be divided.

Representative Payee
An individual may be given the payee of Social Security Administration to receive and manage federal benefits for another person. A representative payee can manage trust funds on behalf of another person to whom it is appointed.

Durable Power of Attorney
Persons may be given the power of attorney to make decisions on behalf of another person. The durable power of attorney may be appointed to make decisions on behalf of another person to whom it is appointed.

MARRIAGE SERVICES
A marriage is a legal contract between two persons by which one of them is a legal contract between two persons. The power of attorney may be given to another person to make decisions on behalf of another person to whom it is appointed.

ACCOUNTS
A legal contract between two persons by which one of them is a legal contract between two persons. The power of attorney may be given to another person to make decisions on behalf of another person to whom it is appointed.

ACCOUNTS
A legal contract between two persons by which one of them is a legal contract between two persons. The power of attorney may be given to another person to make decisions on behalf of another person to whom it is appointed.

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A legal contract between two persons by which one of them is a legal contract between two persons. The power of attorney may be given to another person to make decisions on behalf of another person to whom it is appointed.
Encourage Patient Self Management and Adherence

- Make patients — including those who have cognitive disabilities — central members of their health-care team
  - Have them participate in care decisions
- Help them build self-advocacy skills,
  - Speak directly to them about their care
- Caregivers to step into a supportive, rather than directive, role
- Arrange for formal neurocognitive and functional testing of patients who have cognitive impairment
- Refer to disability-related advocacy and support groups for youth and young adults
What YOU can do:
Take Charge Of Your Health Care!

• Use the GLADD approach when talking to doctors or nurses and in managing health care:
  • Give information
  • Listen and learn
  • Ask questions
  • Decide on a plan
  • Do your part
• Teach your child how to use GLADD!

Source:
• www.floridahats.org
Practice Good Listening Skills

- Listening includes UNDERSTANDING
- Pay attention to body language

**SLANT**

- Sit up
- Lean in
- Ask questions
- Nod
- Track the speaker

Slide courtesy Dr. Wood, 2015
Take Charge Now!

Give – Listen – Ask – Decide – Do

1. Communicate how you are feeling  (Handy High 5)
2. Practice good listening skills  (SLANT)
3. Remember what your doctors/nurses say (use a voice recorder!)
4. Learn more about your condition (books, web site)
5. Prepare questions ahead of time (Ask Me 3)
6. Participate in developing a plan of care  (FloridaHATS resources)
7. Practice negotiating skills (self-advocacy guides)
8. Carry a health summary with you (My Health Passport)
9. Learn how to schedule and navigate doctor’s visits (watch videos and practice!)
10. Manage your medications (MyMedSchedule.com)
HillsboroughHATS Post Card

ASK THEM 3!
All teens and their families should ask their pediatric doctors these 3 questions:

1. When should I/my child transfer to adult primary and specialty care physicians?
2. Who should I/my child go to for adult primary and specialty care?
3. Will you help with the transfer of care by communicating my/my child’s needs and providing a transfer summary?

Health Services Directory for Young Adults
Search for services and programs by community, county, key word or type of service.

For additional information and assistance with resources in Hillsborough County that support transition from pediatric to adult health care, please contact:

Joane White, Family Support Worker
Children’s Medical Services
(813) 396-9772
Joane_White@doh.state.fl.us

Slide courtesy Dr. Wood, 2015
School Resources

What’s HEALTH Got To Do with TRANSITION?

Moving from Pediatric to Adult Health Care

HILLSBOROUGH COUNTY PUBLIC SCHOOLS

Florida Developmental Disabilities Council

Classroom Curriculum
Links to Lesson Plans
Parent/Student Handouts

Slide courtesy Dr. Wood, 2015
My Health Care

• A health literacy and communications training program sponsored by FDDC

• 22-hour curriculum
  • Designed for classroom of learners
  • PPT presentations with imbedded videos
  • Interactive role play, modeling, games
  • Implement in 2-3 hour blocks over 9 weeks
  • Step-by-step Instructor’s Guide and accompanying video

• [http://www.fddc.org/about/task-force-projects/health-care-prevention](http://www.fddc.org/about/task-force-projects/health-care-prevention)

• Available online in 2015

Slide courtesy Dr. Wood, 2015
Educational Materials

10 Steps to Successful Health Care Transition

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5. Maintain wellness. Support good habits that will continue into adulthood! Talk about risky behaviors such as alcohol use and smoking as well as sexuality and relationships. You can ask to speak to your physician alone!
6. Know options for health insurance and public assistance programs in adulthood. If you’re unsure about eligibility, it’s always best to go ahead and apply.
7. Find adult providers. If still in the care of pediatric providers, identify a primary care physician and specialists (including mental health professionals) who work with adults.
8. Include health in other areas of transition. Ask your primary care physician to provide documentation of medical conditions and special health care needs for other programs or agencies, as needed.
9. Integrate health care transition activities in the student’s Individualized Education Plan (IEP) or 504 Plan. Consider self-determination and self-advocacy skills, understanding personal health conditions and needs, and health care self-management skills.
10. Learn about other community services and supports for adults. Be knowledgeable about rights and responsibilities at age 18!

Visit www.FloridaHATS.org to view in large print.
Para español, visite nuestro sitio web.
Pour l’espagnol, consultez notre site web.

Health Care Transition Guide for Teens in Middle School
Health Care Transition Guide for Teens in High School

When You’re 18
You are in Charge of Your Health

Now that you’re in High School...
It’s time to be more in charge of your health.

Slide courtesy Dr. Wood, 2015
Archive the Transition Information Form on a secure MY PLACE site at HealthyTransitionsNY.org
Key Elements of a Patient-Oriented HCT Care Plan

• Information to make the patient an informed consumer
  • Know their medication, devices, equipment, supplies...
• Basic history, physicians, providers, insurance
• Know how to take care of themselves on a day-to-day basis
  • Know what to be concerned about
• Know what to do in an emergency
Tools to Assist

My Health Passport

If you are a health care professional that will be helping me, PLEASE READ THIS before you try help me with my care or treatment.

My full name is: ____________________________
I like to be called: ____________________________
Date of birth: ______/____/____
My primary care physician: ____________________________
Physician’s phone number: ____________________________

Attach your picture here!

This passport has important information so you can better support me when I visit/your in hospital or clinic. Please keep this with my other notes, and where it may be easily referenced.

My signature: ____________________________ Date completed: ______/____/____
You can talk to this person about my health: ____________________________ Relationship: ____________________________

I communicate using: (eg. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

Slide courtesy Dr. Wood, 2015
Source:
• My Health Passport
Slide courtesy Dr. Wood, 2015
Empowering Providers

• Systems approach
  • Within large University/HC System settings
    • Pediatrics and Adult Specialty Care
    • Children’s Hospital embedded in adult health care system

• Transition Clinics: General/Specialty
  • Toronto Epilepsy Transition Clinic

• Handoff or overlap: General/Specialty
  • Got Transition: 6 Core Elements
  • FloridaHATS/JaxHATS Provider Transition Toolkit
Evidence for Transition Support Effectiveness

- No evidence of HCT interventions in Epilepsy
- Most research from outside the US
- Studies done in CF, Type 1 Diabetes
  - Contact with adult providers before transfer
  - Involvement of care coordinators in transition preparation and system navigation
  - Emerging interactive, web-based tools,
New Models of Health Care Transition Clinics

- **Sub-specialty based:**
  - Intellectual Disabilities (Down Syndrome), Nephrology (STARx Program at UNC), Peds Cancer Survivor/Late Effects Clinics
  - Toronto Epilepsy Transition Clinic (Sick Kids)

- **Primary care based:**
  - JaxHATS Program at University of Florida
  - UCLA Med-Peds Transition Care Program
  - Texas Children's/Baylor Transition Program

Slide courtesy Dr. Wood, 2015
## 6 Core Elements of HCT

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Providers (Pediatric, Family Medicine, and Med-Peds Providers)</th>
<th>Transitioning to an Adult Approach Without Changing Providers (Family Medicine and Med-Peds Providers)</th>
<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Transition Policy</td>
<td>1. Transition Policy</td>
<td>1. Young Adult Transition and Care Policy</td>
</tr>
<tr>
<td>2. Transition Tracking and Monitoring</td>
<td>2. Transition Tracking and Monitoring</td>
<td>2. Young Adult Tracking and Monitoring</td>
</tr>
<tr>
<td>3. Transition Readiness</td>
<td>3. Transition Readiness</td>
<td>3. Transition Readiness/Orientation to Adult Practice</td>
</tr>
<tr>
<td>5. Transfer of Care</td>
<td>5. Transfer to Adult Approach to Care</td>
<td>5. Transfer of Care/Initial Visit</td>
</tr>
<tr>
<td>6. Transfer Completion</td>
<td>6. Transfer Completion/Ongoing Care</td>
<td>6. Transfer Completion/Ongoing Care</td>
</tr>
</tbody>
</table>
Transition Readiness (TR) Assessment and Training

• Assess readiness to transition
  • Self management skills
  • Making appointments and talking with providers
  • Understanding of insurance
  • Other life goals

• Specific Transition Readiness Visits
  • Assess transition readiness
  • Education, negotiate transition goals
  • Homework assignments
    • make medication list/calendar;
    • bring list of questions for the doctor or nurse
    • next visit be in room alone with doctor

Slide courtesy Dr. Wood, 2015
# Transition Readiness Assessment Questionnaire (TRAQ)

**Directions to Youth and Young Adults:** Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

**Directions to Caregivers/Parents:** If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. Check here if you are a parent/caregiver completing this form.

<table>
<thead>
<tr>
<th>Managing Medications</th>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>No, but I am learning to do this</th>
<th>Yes, I have started doing this</th>
<th>Yes, I always do this when I need to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you fill a prescription if you need to?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
<td></td>
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<tr>
<td>3. Do you take medications correctly and on your own?</td>
<td></td>
<td></td>
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<tr>
<td>4. Do you reorder medications before they run out?</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Appointment Keeping</th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>5. Do you call the doctor’s office to make an appointment?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6. Do you follow-up on any referral for tests, check-ups or lab?</td>
<td></td>
<td></td>
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<tr>
<td>7. Do you arrange for your rides to medical appointments?</td>
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<td>8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?</td>
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<td>9. Do you apply for health insurance if you lose your current coverage?</td>
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<tr>
<td>10. Do you know what your health insurance covers?</td>
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<tr>
<td>11. Do you manage your money &amp; budget household expenses (For example: use checking/debit card)?</td>
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<thead>
<tr>
<th>Tracking Health Issues</th>
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</thead>
<tbody>
<tr>
<td>12. Do you fill out the medical history form, including a list of your allergies?</td>
<td></td>
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<tr>
<td>13. Do you keep a calendar or list of medical and other appointments?</td>
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<tr>
<td>14. Do you make a list of questions before the doctor’s visit?</td>
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<td>15. Do you get financial help with school or work?</td>
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<thead>
<tr>
<th>Talking with Providers</th>
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<tbody>
<tr>
<td>16. Do you tell the doctor or nurse what you are feeling?</td>
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<tr>
<td>17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?</td>
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<table>
<thead>
<tr>
<th>Managing Daily Activities</th>
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</thead>
<tbody>
<tr>
<td>18. Do you help plan or prepare meals/food?</td>
<td></td>
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<tr>
<td>19. Do you keep home/room clean or clean-up after meals?</td>
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<tr>
<td>20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?</td>
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</tbody>
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© Wood, Sawicki, Reiss, Livingood & Knaemer, 2014

*Source: TRAQ: Transition Readiness Assessment Questionnaire*
Key Elements of a Provider-Oriented Transition Care Plan

• Provides good hand-off to adult providers—primary care and specialists
  • Key history summarized
  • Multi-disciplinary input
  • Recommends future supports and treatment
    • Anticipates future complications
    • Recommends monitoring approach and frequency
Medical Transfer Summary for YYA with Epilepsy

- **Etiology/Epilepsy syndrome** Age of onset (first seizure)
  - Age of onset (first seizure)
- **Neurological examination and intellectual assessment**
- **Laboratory/CT results and dates/MRI results and dates; EEG summary of findings and date of most recent EEG**
- **Clinical Course**
  - Seizure types over the course of the illness
  - Present seizure control with seizure description(s) and frequency (date of most recent by type); precipitating or provoking factors
  - Longest seizure-free interval
  - Episodes status epilepticus or non-convulsive status
- **Medications**
  - Medications used previously, top dosage and reason for discontinuation
  - Present AEDs and length of time on this regime at the time of transfer
  - Rescue medications presently used
- **Additional treatments** (ketogenic diet, VNS; Epilepsy surgery (what, when and hospital name along with pathology reports))
- **Other significant medical conditions and treatments**
- **Social History, Driving, Education, Work, Sexuality, Living Situation, Life Goals**

**Source:**
Camfield and Camfield, Epilepsy Currents; 2012
Florida's clearinghouse for health care transition information
www.FloridaHATS.org

National Center for Health Care Transition Improvement Collaborative
www.gottransition.org

Slide courtesy Dr. Wood, 2015
References *(From Dr. Wood’s Powerpoint Slides)*

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