Lost in Transition
from Pediatric to Adult Health Care

Janet Hess MPH, CHES
John McCormick MD
Diane Straub MD, MPH

September 27, 2012
Definition of Health Care Transition (HCT)

- Health care transition is the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to an adult-oriented care system.”

Source: Blum et al., 1993
Definition of Health Care Transition (HCT)

- **Transfer:** event, physical transfer from pediatric to adult care
- **Transition:** process, transition from childhood to adulthood

Source: Blum et al., 1993
Changing Epidemiology of Childhood or Congenital Conditions

- **Congenital Heart Disease**
  - ~800,000 adults in the U.S. have CHD
    - 419,000 with moderate to severe complexity
    - At risk for re-operation, premature mortality
  - More adults than children

- **Cerebral Palsy**
  - In US ~800,000 people have CP
  - ~Half or 400,000 are adults

United Cerebral Palsy website, www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447
Sickle Cell Disease

Cystic Fibrosis

Adults with cystic fibrosis now account for 40% of the CF population.

REF: CF Foundation Website (accessed 5/15/06)
Prevalence

- 17% of youth have SHCN
- 7-10% have “significant” physical or mental (or both) health conditions that could benefit from support during transition
- 4-5% youth have disabling SHCN
  - Complex physical health conditions
  - Developmental disabilities
- 4-5% have serious mental illness
- ~1-2% on SSI

Source: USDHHS, 2001
Why is HCT Important?

“A poor transition in health care can threaten health and undermine other transitions, for example in education, work, social relationships, and independent living.”

Source: Institute of Medicine, 2007
How Are We Doing?

- National Survey of Children with Special Health Care Needs (every 4 years)
  - State and National Level Reporting

- 4 questions—anticipatory guidance on:
  - Changing health needs in adulthood
  - Transition to adult health provider
  - Insurance needs into adulthood
  - Youth encouraged to take increased responsibility for care
<table>
<thead>
<tr>
<th>STATES</th>
<th>National Transition Outcomes</th>
<th>Presidential Transition to Adult MCO by any Care Provider</th>
<th>Discussion about Transition to Adult MCO by any Care Provider, Not Happened</th>
<th>Discussion about Changing Health Needs, Not Happened</th>
<th>McKee “sometimes” or “never” encourage YSHR to take increased responsibility for care</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>43%</td>
<td>61%</td>
<td>27%</td>
<td>38%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Missouri</td>
<td>54</td>
<td>59</td>
<td>21</td>
<td>29</td>
<td>24</td>
</tr>
<tr>
<td>Nebraska</td>
<td>54</td>
<td>44</td>
<td>30</td>
<td>30</td>
<td>5</td>
</tr>
<tr>
<td>Minnesota</td>
<td>53</td>
<td>52</td>
<td>21</td>
<td>23</td>
<td>16</td>
</tr>
<tr>
<td>Vermont</td>
<td>52</td>
<td>62</td>
<td>17</td>
<td>25</td>
<td>7</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>52</td>
<td>60</td>
<td>20</td>
<td>27</td>
<td>19</td>
</tr>
<tr>
<td>North Dakota</td>
<td>51</td>
<td>41</td>
<td>24</td>
<td>29</td>
<td>21</td>
</tr>
<tr>
<td>South Dakota</td>
<td>51</td>
<td>32</td>
<td>18</td>
<td>22</td>
<td>5</td>
</tr>
<tr>
<td>Kansas</td>
<td>50</td>
<td>40</td>
<td>23</td>
<td>30</td>
<td>16</td>
</tr>
<tr>
<td>Maine</td>
<td>49</td>
<td>51</td>
<td>12</td>
<td>25</td>
<td>9</td>
</tr>
<tr>
<td>Ohio</td>
<td>49</td>
<td>61</td>
<td>30</td>
<td>33</td>
<td>18</td>
</tr>
<tr>
<td>Iowa</td>
<td>47</td>
<td>38</td>
<td>26</td>
<td>35</td>
<td>18</td>
</tr>
<tr>
<td>Washington</td>
<td>47</td>
<td>56</td>
<td>24</td>
<td>31</td>
<td>16</td>
</tr>
<tr>
<td>Colorado</td>
<td>47</td>
<td>57</td>
<td>17</td>
<td>40</td>
<td>9</td>
</tr>
<tr>
<td>Wyoming</td>
<td>47</td>
<td>59</td>
<td>24</td>
<td>33</td>
<td>7</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>47</td>
<td>60</td>
<td>20</td>
<td>30</td>
<td>20</td>
</tr>
<tr>
<td>Montana</td>
<td>46</td>
<td>44</td>
<td>26</td>
<td>37</td>
<td>17</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>45</td>
<td>61</td>
<td>20</td>
<td>34</td>
<td>24</td>
</tr>
<tr>
<td>Idaho</td>
<td>45</td>
<td>37</td>
<td>21</td>
<td>34</td>
<td>22</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>45</td>
<td>55</td>
<td>24</td>
<td>35</td>
<td>18</td>
</tr>
<tr>
<td>Illinois</td>
<td>44</td>
<td>58</td>
<td>32</td>
<td>37</td>
<td>21</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>44</td>
<td>48</td>
<td>24</td>
<td>41</td>
<td>21</td>
</tr>
<tr>
<td>Oregon</td>
<td>44</td>
<td>56</td>
<td>21</td>
<td>22</td>
<td>20</td>
</tr>
<tr>
<td>Connecticut</td>
<td>43</td>
<td>77</td>
<td>21</td>
<td>41</td>
<td>20</td>
</tr>
<tr>
<td>Kentucky</td>
<td>43</td>
<td>53</td>
<td>30</td>
<td>35</td>
<td>24</td>
</tr>
<tr>
<td>Utah</td>
<td>43</td>
<td>57</td>
<td>22</td>
<td>33</td>
<td>23</td>
</tr>
<tr>
<td>Delaware</td>
<td>42</td>
<td>63</td>
<td>23</td>
<td>42</td>
<td>20</td>
</tr>
<tr>
<td>Alaska</td>
<td>42</td>
<td>48</td>
<td>23</td>
<td>33</td>
<td>25</td>
</tr>
<tr>
<td>Nevada</td>
<td>42</td>
<td>54</td>
<td>20</td>
<td>34</td>
<td>24</td>
</tr>
<tr>
<td>West Virginia</td>
<td>41</td>
<td>46</td>
<td>31</td>
<td>33</td>
<td>10</td>
</tr>
<tr>
<td>Indiana</td>
<td>41</td>
<td>44</td>
<td>27</td>
<td>38</td>
<td>21</td>
</tr>
<tr>
<td>Louisiana</td>
<td>41</td>
<td>50</td>
<td>27</td>
<td>39</td>
<td>22</td>
</tr>
<tr>
<td>Michigan</td>
<td>41</td>
<td>58</td>
<td>26</td>
<td>41</td>
<td>19</td>
</tr>
<tr>
<td>North Carolina</td>
<td>40</td>
<td>61</td>
<td>34</td>
<td>62</td>
<td>21</td>
</tr>
<tr>
<td>Tennessee</td>
<td>40</td>
<td>66</td>
<td>26</td>
<td>41</td>
<td>10</td>
</tr>
<tr>
<td>Arizona</td>
<td>39</td>
<td>56</td>
<td>29</td>
<td>40</td>
<td>21</td>
</tr>
<tr>
<td>Hawaii</td>
<td>39</td>
<td>67</td>
<td>32</td>
<td>38</td>
<td>20</td>
</tr>
<tr>
<td>New York</td>
<td>38</td>
<td>75</td>
<td>36</td>
<td>34</td>
<td>20</td>
</tr>
<tr>
<td>Alabama</td>
<td>38</td>
<td>69</td>
<td>24</td>
<td>27</td>
<td>21</td>
</tr>
<tr>
<td>New Jersey</td>
<td>38</td>
<td>79</td>
<td>24</td>
<td>42</td>
<td>26</td>
</tr>
<tr>
<td>Virginia</td>
<td>39</td>
<td>64</td>
<td>25</td>
<td>48</td>
<td>21</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>39</td>
<td>71</td>
<td>25</td>
<td>36</td>
<td>20</td>
</tr>
<tr>
<td>Maryland</td>
<td>39</td>
<td>70</td>
<td>31</td>
<td>39</td>
<td>25</td>
</tr>
<tr>
<td>South Carolina</td>
<td>37</td>
<td>54</td>
<td>29</td>
<td>39</td>
<td>21</td>
</tr>
<tr>
<td>California</td>
<td>37</td>
<td>67</td>
<td>28</td>
<td>40</td>
<td>28</td>
</tr>
<tr>
<td>Texas</td>
<td>37</td>
<td>54</td>
<td>25</td>
<td>38</td>
<td>24</td>
</tr>
<tr>
<td>Georgia</td>
<td>37</td>
<td>64</td>
<td>29</td>
<td>42</td>
<td>22</td>
</tr>
<tr>
<td>Florida</td>
<td>34</td>
<td>73</td>
<td>32</td>
<td>41</td>
<td>30</td>
</tr>
<tr>
<td>New Mexico</td>
<td>34</td>
<td>56</td>
<td>31</td>
<td>42</td>
<td>25</td>
</tr>
<tr>
<td>Alaska</td>
<td>35</td>
<td>49</td>
<td>29</td>
<td>40</td>
<td>24</td>
</tr>
<tr>
<td>Mississippi</td>
<td>31</td>
<td>50</td>
<td>30</td>
<td>42</td>
<td>28</td>
</tr>
<tr>
<td>Idaho</td>
<td>31</td>
<td>77</td>
<td>37</td>
<td>34</td>
<td>26</td>
</tr>
</tbody>
</table>
What Are the Factors Affecting HCT?
Factors Impacting HCT

- Youth development & family support
- Health insurance
- Availability of developmentally appropriate care by adult providers
- Preparation by pediatricians
Transition to Adulthood

- Dependence ➔ Interdependence
  - Child in family ➔ Relationship/Marriage
  - Living household ➔ Independent living
  - High School ➔ College/Work
The Adolescent Brain

- 10-year NIH MRI study
- 5-20 y.o. participants
- Brain continues to change until mid 20s

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>Concrete thought</td>
<td>No future perspective</td>
<td>Abstraction</td>
<td>Established abstract thought</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Has future perspective; not always used</td>
<td>Future oriented</td>
</tr>
</tbody>
</table>
Emerging Adulthood
Developmental Milestones

- Cognitive development
  - Concrete to formal operational (late adolescence)
  - Future orientation

- Behavioral development
  - Other perspective, impact of behavior on self, others
  - Accepting responsibility, independent decisions

- Identity development
  - Separation from parents--independent beliefs, values
  - Longer term goals for work, relationships, starting own family

Emerging Adulthood 18-29

Secular Changes
- More youth pursuing higher education
  - 1940’s—14% post HS education vs 1990’s—60%
  - Mixed paths of education, vocation, independent living
- Age of marriage is increasing
  - 1940-1950’s—20; 1990’s—25-29

Increase in length of transition
- Up to late 20’s, early 30’s.

Social class differences in transition to adulthood

Source: U.S. Census Bureau, 1997
Racial Disparities in Median Age at Death of Persons With Down Syndrome, MMWR 2001 / 50(22);463-5.
High Risk Behaviors and Emerging Adulthood

Figure 3
Rates of Binge Drinking (Five or More Alcoholic Drinks in a Row) in the Past Two Weeks at Various Ages

Risk Taking in Adolescence

- Males and females 16-20 are at least 2X as likely to be in auto accidents than 20-50.
- Auto accidents are the leading cause of death among 15-to 20-year-olds
  - 31% of those killed had been drinking.
- 40% of adult alcoholics report having their first drinking problems between 15 and 19.

CDC, Surveillance Summaries, MMWR. 2008; Reyna & Farley. Psychological Science in the Public Interest. 2006
Factors Impacting HCT

- Youth development & family support
- Health insurance
- Availability of developmentally appropriate care by adult providers
- Preparation by pediatricians
Inadequate Health Insurance

- Y/YA aging out of health care plans/services
  - Medicaid—18
  - SCHIP/KidCare—19
  - CMS--21
- Benefits in temporary jobs often limited
- Change in eligibility rules for SSI
- Cost barriers for families to keep youth on insurance
Insurance Status ages 13-32

Adams SH, et. al. Pediatrics 2007;119;e1033-e1039
### 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 (0.8)</td>
</tr>
</tbody>
</table>

Data source was our analysis of the 2001 SIPP.*

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

---

Callahan and Cooper, Pediatrics. 2007:119;1175
Affordable Care Act Impact on Y/YA

Effective in 2010:

- Young adults up to age 26 can enroll in parents’ private insurance plan, regardless of marital status or living situation, if they aren’t eligible for any other employer-sponsored plan
- **2.5 million more YA on parents’ plan since 2010**

Effective in 2014:

- Extends Medicaid coverage up to age 26 to foster care children
- **Expands Medicaid eligibility to all legal residents up to 133% FPL**
- Increase Medicaid reimbursements for some PCPs to Medicare level
- Creates state-based health insurance Exchanges to provide more private options
- Pre-existing conditions covered

Factors Impacting HCT

- Youth development & Family Support
- Health insurance
- Availability of developmentally appropriate care by adult providers
- Preparation by pediatricians
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

Rosen D. J Adolesc Health 1995;17:10
<table>
<thead>
<tr>
<th>Internists Receptivity of YSHCN</th>
<th>1 doesn’t impact care</th>
<th>4 impacts care greatly</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of training in congenital and childhood chronic illnesses</td>
<td>2.86</td>
<td></td>
</tr>
<tr>
<td>Difficulty caring for patients with CP, intellectual disabilities if parents don’t stay involved</td>
<td>2.86</td>
<td></td>
</tr>
<tr>
<td>Patients often need superspecialists—hard to access—e.g., cardiologist with experience in adult congenital heart disease</td>
<td>2.77</td>
<td></td>
</tr>
<tr>
<td>Difficulty meeting psychosocial needs of YSHCN</td>
<td>2.77</td>
<td></td>
</tr>
<tr>
<td>Lack of training in adolescent medicine, adolescent development/behavior</td>
<td>2.63</td>
<td></td>
</tr>
<tr>
<td>Difficult to face disability and end-of-life issues at such an early age</td>
<td>2.63</td>
<td></td>
</tr>
</tbody>
</table>

Peter et al. Pediatrics 2009;123; 417
Comfort of Adult Providers: 2008 NH Survey

![Treatment Comfort Level By Condition](https://www.wadsworth.org/newborn/nymac/docs/survey_AdultHealthCareProviders.pdf)
Availability of Adult Providers

- Trained in pediatric onset conditions
  - Primary care
  - Specialty care

- Willing to take primary responsibility for care

- Support ongoing transition process

- Provide developmentally appropriate services for youth and family
Deliver Care to Young Adults with Pediatric-Onset Special Needs

- Cancer Survivors
- Down Syndrome
- Autism
- Congenital Heart Disease
- Adolescent Maturity
- Spina Bifida
- Cerebral Palsy
- Sickle Cell Disease
- Adult ADHD
- Cystic Fibrosis
Factors Impacting HCT

- Youth development & Family Support
- Health insurance
- Availability of developmentally appropriate care by adult providers
- Preparation by pediatricians
<table>
<thead>
<tr>
<th>Transition services</th>
<th>For nearly all or most</th>
<th>For some</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assist with referral to specific family or internal medicine physicians</td>
<td>47</td>
<td>33</td>
</tr>
<tr>
<td>Assist with establishing referral to specific adult specialists</td>
<td>45</td>
<td>32</td>
</tr>
<tr>
<td>Discuss consent and confidentiality issues prior to age 18</td>
<td>33</td>
<td>27</td>
</tr>
<tr>
<td>Assist with medical documentation for program eligibility (e.g., Supplemental Security Income, vocational rehabilitation, college)</td>
<td>32</td>
<td>34</td>
</tr>
<tr>
<td>Discuss assent to care issues prior to age 18</td>
<td>31</td>
<td>27</td>
</tr>
<tr>
<td>Assist in creating a portable medical summary</td>
<td>27</td>
<td>26</td>
</tr>
<tr>
<td>Support family or internal medicine physicians with education and consultation</td>
<td>23</td>
<td>30</td>
</tr>
<tr>
<td>Assist with identifying options to maintain health care insurance after age 18</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>Create an individualized health care transition plan</td>
<td>12</td>
<td>26</td>
</tr>
<tr>
<td>Provide adolescents/parents with an educational packet or handouts</td>
<td>11</td>
<td>14</td>
</tr>
</tbody>
</table>

*Source: AAP Periodic Survey of Fellows #71, 2008*
Goals for Transition

- Manage their own health
  - Disease self-management
  - Prevention, substance use, safety, sexuality

- Appropriately access adult primary care, specialists, therapies, equipment, supplies, etc.

- Access to adequate and continuous health insurance

- Implement education and vocational goals

Scal et. al. Pediatrics 2002
Integrated Model of Health Care Transition

Parent/Family

Youth

Personal growth and development

Role of parent/carer

Professional transition

Connecting structures

Paediatric services

Adult services

National Coordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO); www.sdo.lshtm.ac.uk
AAP/ACP/AAFP
Transitions Clinical Report

- Published in Pediatrics, July 2011
- Provides framework for developmentally appropriate transition services:
  - For all youth
  - Enhanced planning activities for YSHCN
  - Move from pediatric to adult model of care at age 18, even if there is no transfer (e.g., Med Peds practice)
  - Within context of a medical home
Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction

1. Medical Home Interaction for Patients ≥ 12 Years of Age

2. Age Ranges

3. Action Steps for Specific Age Ranges

4. Determination of Special Needs

5. Incorporate Transition Planning in Chronic Condition Management

6. Transition Complete

---

**Legend**

- Start
- Action/Process
- Decision
- Stop

---

**Notes:**

- The term "Special Needs" as used herein includes children with special health care needs as defined in the Healthy Children, Healthy Youth Act of 2009, which includes children who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services or support services that are not available through the regular education system alone. (For a list of health and related services, see children.gov/healthy-youth-

---

**Steps:**

1. **Initiate first step in the health care transition planning process at age 12.**
2a, 2b, 2c, 2d. **Age Ranges.** By age 12, conduct surveillance to assess any special health care needs. Start actual transition planning by age 14. By ages 16-17, transition planning should be well established. At age 18, initiate an adult model of care for most youth, even if there is no transfer of care. If transition planning does not occur on the schedule described by the algorithm, a concentrated effort is required (eg, special visits) to successfully complete the process.

3a. Every practice should have a written transition policy that is prominently displayed and discussed with youth and families. The policy should explicitly state the practice's expectations and care process for the health care transition of their adolescent patients to an adult model of care.

3b. The practice should utilize a standard transition plan that can be adapted for each patient's needs. This tool should include components to obtain an accurate assessment of the patient's ability to successfully transition. Providers should interview youth and family members to identify needs and to assess the intentions and motivations for youth independence.

3c. Transitions plans must be reviewed regularly and updated as necessary. The provider must also perform surveillance for changes in the youth's medical status and address youth and family concerns that may warrant changes in transition goals. Failure to achieve transition readiness goals warrants revocation of the existing plan, and increased frequency of medical home interventions/visits. A "pretransfer" visit to the adult medical home could be conducted during the year before the transfer.

3d. Transition to an adult model of care occurs appropriate for youth's developmental level. This is followed as appropriate by transfer to an adult medical home. Complete medical records should be delivered to the adult provider, along with a portable summary, which is then provided to the patient or guardian. For children and youth with special health care needs, direct communication between pediatric and adult providers is essential, as adult medical personnel may be unfamiliar with certain pediatric conditions.

4. Transition planning for children and youth with special health care needs should include specific chronic condition management (CCM) activities such as: use of registries; care plans; care coordination; CCM office visits, and involvement with medical specialists. Transition goals must be individualized to account for variations in the complexity of a youth's condition and in the youth's intellectual ability and guardianship status.

5a. Youth with special health care needs require an expanded transition planning process. Transition planning in CCM includes addressing the exchange of complex health information; responsibilities for self-care and transfers of specialty care, and issues related to insurance, entitlements, guardianship, and eligibility for adult services. In a medical home, such youth may have a written care plan as part of the medical record. At age 14, this plan should include a section titled "transition plan," which should be expanded and developed as the youth approaches age 14 and beyond.

5b. Use of transition tools and readiness checklists facilitate the provider's ability to ensure that all age-appropriate transition issues have been addressed. Each action step must be completed in order, even if it means the provider has to schedule specific visits to initiate and complete steps missed earlier in the process in order to catch up before the next visit.

5c. Focused tasks involving little detail or complexity can be addressed by the medical home care coordinator, medical provider, or other appropriate staff through telephone or electronic media. More complex issues may necessitate face-to-face office visits.

6. The provider is finished with the transition tasks for that specific interaction or visit, transition planning is an ongoing activity that occurs at every interaction.
Incorporate new clinical care guidelines in training Peds and Med/Peds residents

Develop an education intervention that utilizes EHR as an experiential teaching tool
Program Components

- Pilot started Summer 2012
- Introductory PPT and video
- EHR prompts in Allscripts and Epic
  - Continuity clinics – 17 Davis, HealthPark, STC (Med-Peds)
  - Adapted from AAP Medical Home templates, Children’s Hospital Boston
  - Age-appropriate; well child visits
  - Accompanying patient handouts
- Modified GAPS, Bright Futures materials
Florida’s clearinghouse for health care transition information at www.FloridaHATS.org
Florida HATS

- Program established in 2009
- Positioned in the Department of Health, Children’s Medical Services (state Title V program)
- Administered by USF Peds
- Implement a state HCT plan
For Health Care Providers

If you provide health-related services to young adults with chronic health conditions or disabilities, please be sure you are listed in our Health Services Directory for Young Adults. Visit Submission Instructions to add or update your program information.

Training for Professionals

FREE CME/CEU Credits!

A new training program is now available for free CME/CEU credits through Florida Gulfcoast AHEC. See our brochure on the Health Care Transition Training Program developed by the Institute on Child Health Policy at the University of Florida, and get started today by visiting www.aheceducation.com.

Transition Assessment

- TRAQ 4.1 (JaxHATS transition readiness tool)

Medical Summary Forms

- Health Care Transition Summary (2 page summary to carry at all times)
- Electronic Care Plan (University of Wisconsin)
- Electronic Transition Information Form (HealthyTransitionsNY)
- My Health Passport (SickKids Good 2 Go Transition Program)

General Checklists & Care Plans

- Transition Timeline (from Shriners Hospitals and University of Washington)

Workbooks from the Institute of Child Health Policy at University of Florida and CMS:

- Workbook for Ages 12-14 (English)
- Workbook for Ages 12-14 (Spanish)
- Workbook for Ages 15-17 (English)
- Workbook Ages 15-17 (Spanish)
- Workbook for Ages 18+ (English)
- Workbook for Ages 18+ (Spanish)
- Workbook for Ages 18+ (Spanish)

www.FloridaHATS.org
Welcome

This Transition Toolkit was designed to provide a step-by-step approach to accessing resources that will help you with transition from pediatric care to adult care. The toolkit is designed for pediatric providers, other health care personnel (e.g., social workers, nurse care coordinators) and patients & families. The resources provide guidance or information to support youth and families during transition to adulthood and to adult health care. You will be asked a series of questions that will help determine which resources be most useful to you (depending on your role) to support the transition process.

Let's Get Started!

If you are a returning user, please use the login form at the right to complete and/or review your Transition Toolkit. If you are a first time user, please register to create a new account.
Florida HATS

- Health Services Directory for Young Adults
  - Search online by location, or
  - Type of service
Health Services Directory for Young Adults

Use the form below to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

Providers: For instructions on adding a service to our service directory or updating an existing entry, please visit our Submission Instructions page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Florida Developmental Disabilities Council, Florida Department of Health, or Children’s Medical Services. The information is solely for your convenience in locating services from those available in your area. Individuals should perform their own research of any organization they choose. If the service is covered on an insurance plan, first check the plan’s provider network. However, if you believe a particular listing in this directory does not meet our criteria of serving young adults with chronic health conditions or disabilities, please contact us here.

Related Service Directories in Florida:
- Project 10’s Florida District Resource Directory
- Health Resource Directory for Persons with Intellectual Disabilities in Florida
- Find-a-Ride Florida Resource Directory
- CMS Provider Search
- Where To Find Help in Florida

More Info >

Search by: Categories AND/OR Keyword(s)

City, State, County:  -- Any City --
County:  -- Any County --
Health Category:  -- Any Health Category --

Search by Keyword(s):  

Submit Query  Reset
Resources

Insurance

Guardianship

Adapted Bright Futures
Patient Handout

Links:
www.FloridaHATS.org
www.Project10.org
www.GotTransition.org
www.RehabWorks.org
www.211AtYourFingertips.org

Just the Facts:
The 411 on Health Insurance for Young Adults Ages 18-30 in Florida

Including Those with Chronic Health Conditions or Disabilities

Version 1.3, updated July 2011

Health Care Transition and Decision Making

For a youth or young adult who has intellectual disabilities, or her health care transition often raises questions for care providers and families about guardianship. This brief provides a high level look at guardianship and other decision-making supports as well as resources that will provide more in-depth information.

Guardianship Issues

Reaching the Age of 18 — Opportunities and Challenges for Young Adults with Disabilities

Reaching the age of majority (18 years, in most states and jurisdictions) means, under other law, that individuals are no longer a “minor.” A “minor,” the person has the right and responsibility to make certain legal choices that he or she makes. For young adults with intellectual disabilities, this may be a challenging period for increased independence. Indeed, however, there are also many concerns about how to best support the person in self-determination in making the decisions such as health care in financial management.

The brief provides a broad outline of decision-making support options, both informal and legal, that may assist a young adult with an intellectual disability. States and jurisdictions may have different laws and options. Each state defines the categories and criteria for guardianship in relation to important health and educational decisions that a young adult may pursue since every young person has unique strengths and individual needs for support.

Decision Making — A Skill that Requires Practice and a Variety of Experiences

Decision-making is a learned skill. Children and youth who have support and experience in making what they view as important life choices will be better prepared as adults having exercised this skill early on. Over time, based on making experiences related to health and self-management, “what an adult decides” that state requires. When young adult or young adult who doesn’t have the opportunity to make decisions of importance in the life and to participate in a shared decision-making process, the lack of skill building may need to be practiced in “mock situations” either by the family or by their young person. By themselves, the young adult or the young adult with intellectual disability are able to make all decisions, especially those choices with

HEALTHY AND SAFE HABITS:
- Get enough sleep—teens need between 8-12 hours of sleep each night.
- Physical activity—get at least 30 minutes of activity (walking or playing a sport).
- Limit TV and computer time—no more than 2 hours a day.

INJURY AND VIOLENCE PREVENTION:
- Always wear a seat belt—can save your life and the lives of others.
- Play attention to speed limits.
- Never drink and drive or ride in a car with someone who has been drinking. Designate a driver who does not drink or call someone for a ride if you feel unsafe.
- Use helmets while riding your bike or collecting skateboard.
- Guns are never for play and should not be handled by anyone.

NUTRITION:
- Drink at least 8 glasses (8 ounces) of water each day.
- Eat meals as a family—catch up on the day and keep your family talking.
- Limit added sugars (such as French fries and chips) and high sugar foods (such as soda and candy) to improve your energy and keep your weight under control.

DENTAL HEALTH:
- Brush your teeth twice a day and floss once a day.
- See your dentist at least once a year.
- Smoking and chewing tobacco can cause cancer, tooth decay and mouth cancer.

SEXUALITY:
- Talking to your child about sex is the only way to prevent sexually transmitted infections like gonorrhea, chlamydia, herpes, and HIV.
- You do not have sex, use a condom and other effective birth control prevent pregnancy and some of the STIs.
- Sexual violence is common—communicate clearly with your partner.

PREVENTION OF SUBSTANCE USE/ABUSE:
- Smoking is dangerous to your health—it causes cancer, heart disease and stroke, and premature aging.
- If you smoke, drink or use illegal drugs, talk to your parents or doctor about ways to get help.
You can talk to your doctor or

SCHOOL ACHIEVEMENT:
- High school can be demanding and frustrating. Graduating high school is the only guarantee to higher wages and a chance at a good job.
- Talk to your guidance counselor about which courses are right for you.
- Getting involved in school activities can make school more fun and enjoyable.

ADAPTATION TO ADULTHOOD:
- Take responsibility for your health care. Become more independent in making medical treatment, filling prescriptions, making doctors’ appointments, and communicating with your doctor. Talk to your parents, teachers, and doctors about what you need in order to be successful in your activities that’s called self-advocacy.
- Know your rights and responsibilities when you turn age 18, including making decisions about medical care, finances, and other legal matters.
- Know how your health insurance and health care needs will change in adulthood.

Adapted Bright Futures
Patient Handout
Health Insurance

This is the first in a series of informational articles called Transition 2 Go. This series will include tips and resources about highlighted health care transition issues that you can share with you and one, wherever you are.

The first issue of Transition 2 Go focuses on health care coverage for transitioning adolescents and young adults. It’s a timely topic given the U.S. Supreme Court’s recent decision to uphold major portions of the Affordable Care Act (ACA).

One of the biggest barriers to receiving appropriate health care among young adults is access to adequate health care coverage. Enrolling out of childhood insurance plans, lack of preparation and knowledge about available insurance options can contribute to critical lapses in coverage during early adulthood. The ACA emphasizes the important role of medical homes in assisting patients to plan and access health insurance. This assistance is essential for patients preparing to transition to adult systems, especially for youth with special health care needs.

Justthe Facts: The Affordable Care Act (ACA) requires health insurers for Young Adult Ages 19-26 in Florida to provide comprehensive, Florida-specific information about insurance options. In the case of young adults, the 4-page guide outlines coverage options for individuals of all ages, including those with disabilities or chronic health conditions. It is available in hard copy (English only), or can be downloaded in English, Spanish, and Haitian Creole from the Florida DMH website at www.FloridaDMH.org/Pages/AHSC.

In addition to descriptions of various private and public insurance plans, the guide identifies locally available programs for low-income residents, such as those offered in Hillsborough, Pinellas, Osceola, Brevard, and Polk Counties. The map on the inside back cover gives a brief snapshot of the range of options currently available.

School to Work Transition Vocational Rehabilitation

Most teens and young adults look forward to having a job and being independent. For young Floridians with disabilities whose goals include employment, the Florida Department of Education’s Division of Vocational Rehabilitation (VR) can provide critical support services. This federal-state program works with people who have physical or mental disabilities to prepare for, gain and/or retain employment.

Transition planning for individuals whose health conditions interfere with their ability to work should address eligibility for an array of VR programs, including the School to Work Transition program. The School to Work Transition program specifically helps students ages 16-22 prepare for employment and adult life. VR transition activities can help students enter training, continue education, and/or find a job after leaving high school.

Any student with a disability may be eligible for VR services starting at age 16. For students who receive special education services, schools often take the lead in referral to VR as part of the student’s transition Individualized Education Plan (IEP). However, having an IEP is not a VR eligibility requirement. Health care professionals can help assure that all young people with disabilities and their families are aware of VR as a potential source of services and supports, and facilitate access by making referrals as needed.

Students who may benefit from VR services should apply at least 2 years before leaving high school, e.g., apply at age 16 if leaving high school at age 18. VR can also assist students with community work experience while they are still in high school. Applications can be downloaded at http://rehabworks.org/docs/VRapplication.pdf.

VR referrals can be made by anyone by contacting the local VR office at www.rehabworks.org (click on VR Office Directory). To learn more about the School to Work Transition program, visit www.rehabworks.org/docs/School2Work.pdf.

For more information about this topic, contact Janet Hess at jhess@health.usf.edu or (813) 259-6604.
Florida HATS

- Regional HCT coalitions in Hillsborough County, NE Florida, Panhandle area; South Florida and Orlando in the planning stage
  - Public health strategic planning process (MAPP)
  - Workgroup updates posted regularly on www.FloridaHATS.org (under “Regional Coalitions”)
What You Can Do

- Be willing to accept Y/YA as patients

- Encourage self-determination and independence in managing care among Y/YA
  
  - Fill prescriptions, take medication, schedule appointments, decision-making, etc

- Encourage Y/YA to maintain an up-to-date health summary that is portable and accessible

- Identify and help Y/YA access adult specialty care providers

- Help Y/YA identify & access adult health insurance

- Assist with links to adult social/support services