

***EVERY CHILD DESERVES A MEDICAL HOME***

# **Component Five: Medical Home and Transition**

*Participant Manual*



**In Collaboration With**  
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**Family Voices**  
**Healthy & Ready to Work National Center**  
**Maternal and Child Health Bureau**  
**National Association of Children's Hospitals and Related Institutions**  
**Shriners Hospitals for Children**

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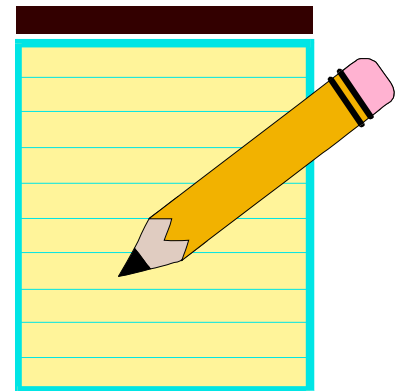
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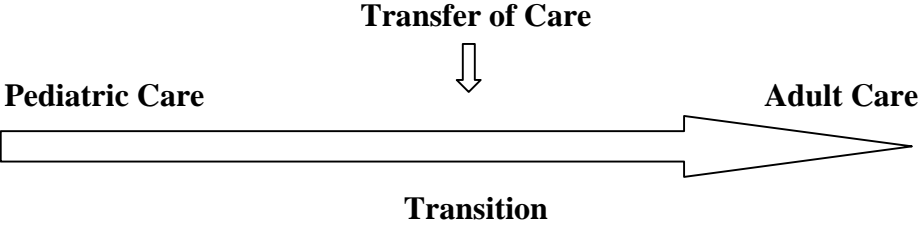
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## Component Five: Medical Home and Transition


<b>Slide 1</b>	<b>Section One: Medical Home and Transition: A Life-Span Process</b>
<b>Slide 2</b>	<b>Significance: What Does Health Have to Do With Transitions?</b>  If children and youth do not maintain optimal health <ul style="list-style-type: none"><li>• More emphasis on crisis and less on typical life, fun, and activities</li><li>• More on living as a patient, less as a kid</li><li>• Missed school with interruptions in learning</li><li>• Functional declines leading to social isolation</li></ul>
<b>Slide 3</b>	<b>Transition Realities</b> <ul style="list-style-type: none"><li>• 90% of YSHCN reach their 21st birthday.</li><li>• 45% of YSHCN lack access to a physician who is familiar with their health condition.</li><li>• 30% of 18 to 24-year-olds lack a payment source for needed health care.</li><li>• Many youth lack access to primary and specialty providers.</li></ul> <p>CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 2002</p>
<b>Slide 4</b>	<b>Transition Realities (cont'd)</b> <ul style="list-style-type: none"><li>• Increase use of emergency system of care: 40% versus 25% of typical youth annually.</li><li>• There are fewer work opportunities, and many are fearful of losing Medicaid eligibility.</li><li>• YSHCN are 3 times more likely to live on income under \$15,000.</li></ul> <p>NOD/Harris Poll Survey, 2000</p>


<p><b>Slide 5</b></p>	<p><b>Transition Realities (cont'd)</b></p> <p><b>Interruptions in</b></p> <ul style="list-style-type: none"> <li>• Social/recreational activities—<b>64%</b></li> <li>• Daily living activities—<b>59%</b></li> <li>• Work—<b>58%</b></li> <li>• School attendance and performance—<b>38%</b></li> </ul> <p>CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 1999–2002</p>
<p><b>Slide 6</b></p>	<p><b>What YSHCN Say</b></p> <ul style="list-style-type: none"> <li>• 90% want to live and work independently.</li> <li>• Many feel they are “treated like a child.”</li> <li>• Many feel a loss of control.</li> <li>• They feel they are not seen as unique individual, separate from their condition.</li> <li>• Health care providers defer to parent(s).</li> </ul> <p>NYLN Survey 2002; Rosen DS. Grand Rounds: all grown up and nowhere to go: transition from pediatric to adult health care for adolescents with chronic conditions. Presented at: Children’s Hospital of Philadelphia; 2003; Philadelphia, PA</p>
<p><b>Slide 7</b></p>	<p><b>What YSHCN and Families Say They Need</b></p> <ul style="list-style-type: none"> <li>• Information about resources</li> <li>• Referrals to services</li> <li>• A written health transition plan (who, what, when, and how)</li> <li>• An advocate to assist, explain, and encourage</li> <li>• Assistance from their medical home</li> </ul> <p>NYLN Survey, 2002</p>
<p><b>Slide 8</b></p>	<p><b>Learning Objectives</b></p> <ul style="list-style-type: none"> <li>• Describe the challenges inherent to the transition process.</li> <li>• Understand American Academy of Pediatrics (AAP) policy recommendations related to transition of youth with special health care needs (YSHCN).</li> <li>• Use clinical tools, communication strategies, and resources to facilitate a successful transition (pediatric to adult health care, school to work, and home to community).</li> <li>• Have increased expectations for YSHCN.</li> <li>• Initiate changes in practice that will support youth in transition.</li> </ul>

<b>Slide 9</b>	<b>Section Two: Transitions: From Policy to Practice</b>
<b>Slide 10</b>	<p><b>What Is Transition?</b></p> <ul style="list-style-type: none"> <li>• Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.</li> </ul> <p><b>To ensure successful transition to</b></p> <ul style="list-style-type: none"> <li>• Adult health care system</li> <li>• Work</li> <li>• Independence</li> <li>• Inclusion in community life</li> </ul>
<b>Slide 11</b>	<p><b>Transition to Adulthood: Critical Milestone</b></p> <p>The physician’s prime responsibility is the medical management of the young person’s disease, but the outcome of this medical intervention is irrelevant unless the young person acquires the required skills to manage their own condition and their lives.</p> <p>Ansell BM, Chamberlain MA. Children with chronic arthritis: the management of transition to adulthood. <i>Baillieres Clin Rheumatol.</i> 1998;12:363–373</p>
<b>Notes:</b>	

<p><b>Slide 12</b></p>	<p><b>Medical Home and Transition</b></p> <p>A medical home ensures continuity of care and successful transition for YSHCN</p> <ul style="list-style-type: none"> <li>• Across the developmental continuum</li> <li>• Among multiple providers</li> <li>• Into the adult health care system</li> <li>• In self-determination for informed decision making</li> </ul>
<p><b>Slide 13</b></p>	<p><b>The Transition Process</b></p>  <p>Rosen DS. Grand Rounds: all grown up and nowhere to go: transition from pediatric to adult health care for adolescents with chronic conditions. Presented at: Children’s Hospital of Philadelphia; 2003; Philadelphia, PA</p>
<p><b>Slide 14</b></p>	<p><b>Policy Recommendations</b></p> <p><b>Call on physicians to Take 6 Critical First Steps</b>  (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians—American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. <i>Pediatrics</i>. 2002; 110:1304–1306.) Available at:  <a href="http://pediatrics.aappublications.org/cgi/content/full/110/6/S1/1304">http://pediatrics.aappublications.org/cgi/content/full/110/6/S1/1304</a></p> <ol style="list-style-type: none"> <li>1. Ensure all YSHCN have an identified health care professional who attends to the unique challenges of transition.</li> <li>2. Identify knowledge and skills required to provide developmentally appropriate transition services, and include them in training for primary care residents and physicians.</li> <li>3. Maintain a portable, accessible, and current medical summary.</li> </ol>

<p><b>Slide 15</b></p>	<p><b>Policy Recommendations (cont'd)</b></p> <ol style="list-style-type: none"> <li>4. Create a written transition plan by age 14 with young person and family. Update it annually.</li> <li>5. Guidelines for primary and preventive care should be applied to all adolescents and young adults. Attention is given so YSHCN have access to more resources and services than their peers.</li> <li>6. Ensure affordable, continuous health insurance throughout adolescence and adulthood, including <ul style="list-style-type: none"> <li>• Health care transition planning</li> <li>• Care coordination</li> </ul> </li> </ol>
	<p>The AAP consensus statement on transitions is available in <b>Appendix A</b>.</p>
<p><b>Slide 16</b></p>	<p><b>From Policy to Practice: Assessment</b></p> <p>During each visit</p> <ul style="list-style-type: none"> <li>• Ask youth/families about their needs, concerns, and priorities.</li> <li>• Use assessment tools for youth, family, and/or provider.</li> </ul>
	<p>Copies of the following assessment forms are available in the appendices section of this component:</p> <ul style="list-style-type: none"> <li>• HRTW/CHOICES Developmental Pathways Checklist (<b>Appendix B</b>)</li> <li>• HRTW-KY Life Maps (<b>Appendix C</b>)</li> <li>• HRTW-MA Provider Checklist (<b>Appendix D</b>)</li> <li>• HRTW- CA Health Care Assessments (<b>Appendix E</b>)</li> <li>• PACER Health Care Skills Checklist (<b>Appendix F</b>)</li> <li>• Adolescent Autonomy Checklist (<b>Appendix G</b>)</li> <li>• WA - Transition Timeline for Children and Adolescents with Special Health Care Needs (<b>Appendix H</b>)</li> <li>• IL- DSCC Transition Checklist and Timeline for Medical Care Providers (<b>Appendix I</b>)</li> </ul>

<p><b>Slide 17</b></p>	<p><b>From Policy to Practice: Care Planning</b></p> <p>In collaboration with youth and family, develop a plan of care that includes</p> <ul style="list-style-type: none"> <li>• Major concerns</li> <li>• Relevant data</li> <li>• What will be done</li> <li>• Who will do it</li> <li>• When it will be done</li> </ul>
<p><b>Slide 18</b></p>	<p><b>From Policy to Practice: Portable Medical Summary</b></p> <p>There are 4 main types of medical summaries that one can choose to use based on his or her need and preference</p> <ul style="list-style-type: none"> <li>• Emergency department care plan (emergency medical services transport)</li> <li>• HRTW, portable medical summary, 1-page</li> <li>• 3-fold, wallet-sized medical information summary</li> <li>• Transitional care summary</li> </ul>
	<p>Copies of each type of portable medical summary are available in the appendices:</p> <p>A copy of an emergency department care plan is located in the appendices of the Comprehensive, Coordinated, Collaborative Care component,</p> <p>HRTW, Portable Medical Summary (1 page): <b>Appendix J</b></p> <p>Medical Information Summary (3-fold, wallet-sized): <b>Appendix K</b></p> <p>Transition Summary: <b>Appendix L</b></p>

<p><b>Slide 19</b></p>	<p><b>From Policy to Practice: Transition Plan</b></p> <p>At age 14, develop a written health transition plan that includes</p> <ul style="list-style-type: none"> <li>• Proactive wellness (diet, safety, risk reduction)</li> <li>• Increasing responsibility for self-care and health</li> <li>• Transition to adult health care</li> <li>• Health care funding options</li> <li>• Future plans that may be influenced by health (work, school, recreation, community involvement)</li> <li>• Preventive care; secondary disabilities</li> </ul>
	<p>A copy of a transition action care plan is located in <b>Appendix M</b>.</p>
<p><b>Slide 20</b></p>	<p><b>From Policy to Practice: Preventive Guidelines</b></p> <ul style="list-style-type: none"> <li>• Follow approved guidelines <ul style="list-style-type: none"> <li>- Bright Futures: <i>HTTP://BRIGHTFUTURES.AAP.ORG/WEB/</i></li> <li>- Guidelines for Adolescent Preventive Services: <i>WWW.AMA-ASSN.ORG/AMA/UPLOAD/MM/39/GAPSMONO.PDF</i></li> </ul> </li> <li>• Schedule routine well-child visits to promote optimal health and wellness</li> <li>• Schedule periodic visits to manage chronic health/disability issues</li> </ul>
<p><b>Slide 21</b></p>	<p><b>From Policy to Practice: Care Coordination</b></p> <p>Develop a system of office-based coordination to effectively</p> <ul style="list-style-type: none"> <li>• Refer youth/families to resources</li> <li>• Facilitate communication among medical home and specialty providers</li> <li>• Coordinate care</li> <li>• Mentor/educate youth/families</li> </ul> <p>Develop the role of a care coordinator within a practice</p>

<p><b>Slide 22</b></p>	<p><b>From Policy to Practice: Teaching</b></p> <p>Continuously educate and mentor children, youth, and families as they learn essential lifelong transition skills</p> <ul style="list-style-type: none"> <li>• Proactive planning</li> <li>• Problem solving</li> <li>• Self- advocacy</li> <li>• Negotiation</li> </ul>
<p><b>Notes:</b></p>	
<p><b>Slide 23</b></p>	<p><b>From Policy to Practice: Evaluation</b></p> <p>Evaluate plan of care</p> <ul style="list-style-type: none"> <li>• Progress being made toward outcomes?</li> <li>• Everyone on task?</li> <li>• Who’s in charge?</li> <li>• Anyone need support?</li> <li>• Unexpected outcomes?</li> <li>• Revision of plan needed?</li> </ul>
<p><b>Slide 24</b></p>	<p><b>Section Three: Starting Early</b></p>
<p><b>Slide 25</b></p>	<p><b>Starting Early: Tips for Providers</b></p> <ul style="list-style-type: none"> <li>• Be honest and support hope at diagnosis/prognosis</li> <li>• Refer immediately to supportive resources</li> <li>• Celebrate the positive—What is working!</li> <li>• Talk about the future—What is possible!</li> </ul>

<b>Slide 26</b>	<b>Starting Early: How to Support Caregivers</b> <ul style="list-style-type: none"><li>• Refer to parent-to-parent support/AARP grandparent resource center</li><li>• Facilitate access to respite services</li><li>• Affirm and encourage efforts</li><li>• Provide practical help with care coordination</li></ul>
<b>Slide 27</b>	<b>Starting Early: Tips for Families</b> <ul style="list-style-type: none"><li>• View the child as a child, not by the condition</li><li>• Avoid “special treatment”; establish family role(s)</li><li>• Encourage learning new skills (self-care, involvement in medical therapies, etc)</li><li>• Have expectations and push the limits</li><li>• Support child’s/youth’s aspirations</li></ul>

**Role Playing:  
Snecia  
Scenario 1**

**Age:** 12 months

**Diagnosis:**  
Cerebral palsy

**Family:**  
Lives with her  
mother, Miranda

**Concerns:**  
Understanding  
diagnosis; linking  
with necessary  
resources  
(insurance/financial,  
specialists, family  
support groups)

Snecia is in today for a follow-up visit. She has just recently had magnetic resonance imaging (MRI) and the neurologist told Miranda, Snecia's mother, that the MRI confirms that she has cerebral palsy (CP). Snecia's mother had called the office and requested to see Dr Pat to discuss the findings of the MRI and to find out more about her diagnosis. Dr Pat has reviewed the note from the neurologist and the radiologist report and is prepared for the visit. In addition, (s)he has reviewed the most recent Individualized Family Service Plan (IFSP) from Snecia's early intervention program. Miranda and her mother have just completed a needs assessment designed to help identify their major needs and concerns that should be addressed during today's visit.

Dr Pat enters the room where Miranda is holding Snecia. Miranda's mother, Snecia's grandmother, is present as well. Both look tense and worried. Dr Pat gives greetings to Miranda and her mother and walks over and touches Snecia. (S)He pulls his chair up and sits down next to Miranda and Snecia. Dr Pat begins the conversation by asking Miranda to share her questions and concerns.

Miranda describes her recent visit to the neurologist and being told that Snecia has CP. She tells Dr Pat that she was so upset that she just shut down and really did not comprehend anything that was said after the words "cerebral palsy" were used. Miranda's mother interjects that she does not know much about CP but a niece has CP and she is unable to do anything for herself. Miranda and her mother are both tearful. Miranda asks, "What does CP really mean?" Snecia's grandmother asks, "Are there different degrees of CP and does it get worse over time?" Dr Pat provides Miranda and her mother with an overview of CP and answers their questions. They are relieved to find out that CP is not progressive and that CP is a label that describes abnormal movement or muscle tone. They then ask Dr Pat what (s)he thinks the future holds for Snecia. They wonder aloud, "Will she be mentally retarded? Will she always have to live at home? Will she need someone to take care of her all of her life?" Dr Pat answers each question providing a realistic, yet hopeful view of the future. (S)He explains that there are many treatments that can improve the problems with muscles and states that he will refer them to specialists as needed. (S)He encourages them to have hopes and dreams for Snecia's future. With good medical management and support at home and school, Snecia should be able to live independently and have a job. (S)He reassures them that (s)he will be checking everything carefully: development, vision, hearing, feeding and nutrition, constipation, muscle tone, and orthopedic status. (S)He emphasizes to Miranda and her mother that their input is critical. They are the ones that know Snecia best and if they have questions or concerns they should let him/her know right away. No question is too trivial to ask. Dr Pat states that (s)he will continue to work with the neurologist to ensure that Snecia's seizures remain well controlled. (S)He emphasizes that the goal is for Snecia to live as fully and normally as possible. She should be treated like any other child with expectations for independence and consistent love and discipline. Dr Pat then asks if they have additional questions about CP. Neither Miranda nor her mother can think of any at this time.

Dr Pat asks if written information about CP would be helpful saying that the written information may trigger them to think of additional questions. Miranda and her mother agree that it would be helpful to have something in writing. Dr Pat provides them with handouts from the local and national United Cerebral Palsy chapters. Dr Pat also asks if they would like to talk with other families who have children with CP. Miranda and her mother are enthusiastic. Two families in his practice have agreed to provide information and support to families who have a child with CP. (S)He provides Miranda with their phone numbers. These mentor families will provide Miranda with information about parent support groups and if she is interested, will attend a meeting with Miranda and her mother. (S)He reflects to himself/herself how lucky (s)he is to have a parent advisory council and families willing to help provide support to and for each other.

Dr Pat reviews the needs assessment completed by Miranda. (S)He notes that problem areas include gagging on foods with texture and constipation, and talks with Miranda more about these problems areas. (S)He then places Snecia on the examination table and does a comprehensive physical. During the physical he points out the things that Snecia can do and how well she is growing and developing. Dr Pat compliments Miranda and her mother for the good care she is getting.

Dr Pat then asks Miranda if there is anything else she would like to discuss before they develop the plan of care. Miranda mentions her problem in getting Supplemental Security Income (SSI) and the fatigue she is experiencing trying to work full time and take care of a baby with special needs. Dr Pat, Miranda, and Snecia's grandmother then begin developing an action care plan to address each of these needs and concerns. The treatment plan for constipation includes dietary management as well as a daily dose of Milk of Magnesia. Miranda is to check back with Dr Pat in 2 weeks to see if the plan is working. The treatment plan for choking on textured foods includes a referral to a speech therapist to evaluate for oral sensitivity and swallowing difficulties. Because Snecia has a definitive diagnosis of CP, Dr Pat asks Miranda about making a referral to Shriners Hospitals for an orthopedic evaluation and follow-up. (S)He explains that problems with muscles can lead to problems with bones and that an orthopedist would make a nice addition to Snecia's team.

Dr Pat then addresses the SSI and Medicaid dilemma. Medically Snecia has a good chance to qualify for SSI benefits, but Miranda's monthly paychecks exceed the income limits. In their state, receiving SSI has the added benefit of making Snecia automatically eligible for Medicaid. Medicaid has better benefits than SCHIP, particularly in terms of therapy and durable medical equipment, which may be important in the future.

To qualify Miranda could consider reducing her weekly hours thereby reducing her monthly income. She needs to evaluate what will give her and her child the best quality of life from the perspective of working full-time, being stressed and exhausted as the solo caregiver versus cutting back hours to qualify for SSI (which would provide a small cash benefit) and getting better health care benefits through Medicaid (maybe both would qualify). In addition, Snecia would likely be eligible for services and support from their state's CSHCN program. He provides her with a brochure that has a contact name and number. With a combination of coverage from Medicaid or SCHIP, CSCHN, and Shriners, Snecia's needs most likely would be met. Dr Pat emphasizes that knowing what is available and putting the best package of benefits together for Snecia with or without SSI is a complex process. He emphasizes that he and the care coordinator are willing to answer questions and help with the application process and documentation.

These are not easy choices for a solo caregiver and wage earner. Working full time allows her to pay bills and provides a stable residence, which prevents them from being homeless, plus gives her needed health benefits. Reducing her hours to meet the income criteria for SSI may lead to their family living at or near poverty and she may be left with no health care benefits for herself. Only Miranda can decide what will be best for the family.

Dr. Pat gives a copy of the care plan to Miranda and gets a release of information to allow him/her to send a copy to her early intervention coordinator. (S)He also gets a release of information to send medical records to Shriners Hospitals. (S)He schedules a follow-up visit at 15 months for Snecia's well-child check and immunizations, as well as to do a follow-up on the current plan of care. Miranda is encouraged to call with questions and concerns. The care coordinator will follow up via phone as well and work to get the appointments scheduled with the speech therapist and Shriners Hospitals.

<p><b>Instructions</b></p>	<p>This is the second role-playing scenario that explores another child with special health care needs, Jeremy, and his family’s transition process.</p>
<p><b>Role Playing: Jeremy Scenario 1</b></p> <p><b>Age:</b> 4 years old</p> <p><b>Diagnosis:</b> Spinal muscular atrophy type 2</p> <p><b>Family:</b> Lives with both parents, Patti and Herb. Recently relocated.</p> <p><b>Concerns:</b> Connecting with community resources; school</p>	<p>Jeremy is in today for his first visit with Dr Pat. He has recently moved with his parents from Boston to Cincinnati.</p> <p>Dr Pat introduces himself/herself to Patti and Herb, walks over to Jeremy’s chair, and kneels down to establish eye contact. (S)He spends a minute or two talking with Jeremy about a toy that he is playing with and his “snazzy” power chair. Then Dr Pat addresses Patti, Herb, and Jeremy telling them that (s)he wants to use the office visit today to learn more about Jeremy’s health condition and to focus on their major concerns and priorities at this time. Dr Pat provides Jeremy with some additional toys and tells Jeremy that he can listen while he plays and chime into the conversation at any time.</p> <p>Patti provides Dr Pat with Jeremy’s portable medical summary complete with details about hospitalizations, serious illnesses, medications, therapies, and resources. She carries copies of all the hospital discharge summaries in a file, just in case there is a question she can look up the information. She tears up when she says that it has taken years of hard work to get Jeremy what he needs and expresses that the move has disrupted their support services. She explains that the doctors originally did not give them much hope for Jeremy’s future. However, she and Herb decided early to make the most of every day and to think of the future in terms of what needs to happen “this” year. Herb adds that sometimes it is confusing to know what is best to do today or this year and explains that they are struggling with the decision of whether to send him to preschool. Herb and Patti are in agreement that they want him to have the opportunity, but from past experiences they know the cost can be high with Jeremy getting frequent colds and pneumonia. Patti explains that she and Herb are constantly trying to balance meeting Jeremy’s health needs, with letting him be a “little boy.”</p> <p>Dr Pat acknowledges that (s)he has heard 2 major concerns, the need to be connected to resources in their new “home town” and the need to make a decision regarding preschool. Dr Pat tells Patti and Herb that part of providing a good medical home is helping families connect to needed providers and resources. (S)He reassures Patti and Herb that he will help them find what they need and also gave them the number for the Title V CSHCN agency that provides community-based information and referral services and the name of a staff member who will guide them in the process. Dr Pat tells Patti and Herb that the practice has a part-time care coordinator who will be calling them in the near future and obtains a time and number for that call to be placed. (S)He asks if they would like to be referred to a parent support group stating that parents are usually the experts about what is really available and helpful.</p> <p>Dr Pat then addresses Jeremy and asks, “What would you like to do when you grow up?” Jeremy responds that he wants to be a fireman, ride in a fire truck, and wear a fireman’s hat. Dr .Pat tells Jeremy that there are many important jobs to do at the fire station and that everyone who works at the fire station gets to ride the fire truck and wear a fireman’s hat. (S)He lets Jeremy know that working at the fire station is a future possibility, and that there are many other possibilities open to him. Dr Pat states that learning to be a good worker is very important, and that Jeremy can learn to be a good worker at home. (S)He then asks what kinds of family chores Jeremy has. Jeremy proudly announces that he gets to answer the phone and feed the dog. Dr Pat reinforces the importance of his jobs to the family and asks what he would like to learn to do next to help Mom and Dad. Jeremy thinks for a minute and says he would like to fold the clean cloths and help match the socks. A brief discussion about how to make this happen follows. He then asks Jeremy what he thinks about going to preschool. Jeremy tells Dr Pat that he would like to go to school and play with the other kids.</p>

Dr Pat then addresses Patti, Herb, and Jeremy saying that going to preschool is important, not just to make friends but to prepare for kindergarten and first grade. (S)He emphasizes that going to school, learning, and helping out at home are the most important jobs for Jeremy right now. (S)He asks Patti and Herb to tell him more about their concerns related to Jeremy’s health and preschool.

Patti and Herb review the persistent problems with recurrent pneumonia, eating, and weight maintenance. They explain that during the most recent hospitalization the pulmonologist had requested a swallowing study to rule out aspiration. Due to insurance this request has to be initiated by the primary doctor. They state that the x-ray reports state possible aspiration and that they would like to understand the relationship between choking on foods, aspiration, and pneumonia better.

Dr Pat explains the relationship between having a neuromuscular disease and problems with chewing and swallowing leading to aspiration and then pneumonia. (S)He offers to set up the study and coordinate an appointment with the new pulmonologist. (S)He notes that working with the pulmonologist and getting the results of this study quickly will be part of the plan to keep Jeremy healthy and in school. Patti and Herb are visibly relieved.

Together they develop a plan of care using the action care plan. The plan includes referrals to an orthopedist, a nutritionist, and the local medical center diagnostic center for the recommended swallowing study. Assignments are mutually negotiated between Patti, Herb, Jeremy, and Dr Pat. Jeremy’s job is to think of questions he wants answered about his new school. Patti and Herb will investigate schools and explore services available through Individuals with Disability Act (IDEA) and 504. They will think carefully about what supports Jeremy needs at school and select the support services that are the most helpful and the least intrusive. The office care coordinator will contact Patti and Herb and coordinate referrals, with the expectation that the plan will be reviewed and evaluated at each visit. Patti and Herb will work on updating the portable medical summary with information relative to new providers on Jeremy’s team. A new chronic condition appointment is made in 8 weeks to discuss the results of the swallowing study and review the plan of care. A copy is placed in the chart and a copy sent home with Patti and Herb. A copy is also forwarded to the part-time care coordinator, who will call the family and work with them to find resources and follow up to evaluate the effectiveness of the plan of care. The visit ends with Dr Pat emphasizing his/her desire to work with the family and Jeremy to optimize health, inclusion, and planning for the future. Dr Pat touches Jeremy’s hand and says goodbye to the family.

## **Section Four: School-aged Children and Teens**

<p><b>Slide 28</b></p>	<p><b>Provider’s Role in Supporting Elementary School-aged Child</b></p> <ul style="list-style-type: none"> <li>• Increase expectations and responsibilities for self-care.</li> <li>• Encourage role and responsibilities in family’s home (answering phone, pet care, etc).</li> <li>• Increase involvement in decision making</li> <li>• Ask child what he or she wants to do when grown up (dreams, jobs, relationships, etc).</li> <li>• Support his or her aspirations.</li> </ul>
<p><b>Slide 29</b></p>	<p><b>Physician’s Role in Achieving Success in School</b></p> <ul style="list-style-type: none"> <li>• Encourage peer socialization and inclusion in opportunities.</li> <li>• Encourage students to be aware of their needs and to seek help when needed.</li> <li>• Advocate to ensure health issues are addressed in school; are not interfering in learning.</li> </ul>
<p><b>Slide 30</b></p>	<p><b>Physician’s Role in Achieving Success in School (cont’d)</b></p> <ul style="list-style-type: none"> <li>• Attend Individualized Education Plan (IEP) meeting in person or via speakerphone.</li> <li>• When medically safe, attempt to minimize intrusive health-related procedures/needs during school hours.</li> <li>• Help families negotiate the education maze (Individuals with Disabilities Education Act/IEP special education, 504, and regular education and accommodation plan).</li> <li>• Help families learn how to advocate for services.</li> </ul>
<p><b>Slide 31</b></p>	<p><b>Office Strategies to Assist in Achieving Success With Youth</b></p> <ul style="list-style-type: none"> <li>• Create “disability-cool” environment (age-appropriate disability-cool posters, magazines, etc, in waiting room).</li> <li>• Schedule well appointments that do not conflict with school and social activities.</li> <li>• Encourage youth to cosign (or use signature stamp) to become involved in health care process (assent/consent).</li> <li>• Schedule youth in cohorts to provide opportunities for group education and socialization.</li> </ul>

<b>Notes:</b>	
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<b>Slide 32</b>	<p><b>Communication Strategies to Assist in Achieving Success With Youth</b></p> <ul style="list-style-type: none"> <li>• Be “askable”; avoid rushing.</li> <li>• Listen more; talk less.</li> <li>• Show that you care.</li> <li>• Use open-ended questions to engage conversation.</li> <li>• Move from less sensitive to more sensitive questions.</li> <li>• Address unspoken concerns (pimples, sex, looks, masturbation, etc).</li> <li>• Spend more time alone with youth while the family is in waiting area (if developmentally appropriate).</li> </ul>
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<b>Slide 33</b>	<p><b>Focus on Health Care for Tweens/Teens</b></p> <ul style="list-style-type: none"> <li>• Focus on health promotion.</li> <li>• Involve youth in prevention of secondary disabilities.</li> <li>• Prevent self-destruction. <ul style="list-style-type: none"> <li>- Adherence issues</li> <li>- Risk taking (alcohol, sex, drugs)</li> <li>- Unrecognized mental health issues</li> </ul> </li> </ul>
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<p><b>Slide 34</b></p>	<p><b>Mental Health Concerns for YSHCN</b></p> <ul style="list-style-type: none"> <li>• Under-identification because the condition <ul style="list-style-type: none"> <li>- Masks aberrant behavior</li> <li>- Distorts the presentation of signs and symptoms</li> <li>- Makes typical testing procedures difficult</li> </ul> </li> <li>• Significant adjustment difficulties, delay in social maturation, unnecessary dependency</li> <li>• Prominent social isolation</li> </ul>
<p><b>Slide 35</b></p>	<p><b>Focus on Self-care for Tweens/Teens</b></p> <ul style="list-style-type: none"> <li>• Increase expectations for <ul style="list-style-type: none"> <li>- Communicating feelings and needs</li> <li>- Providing interim history</li> <li>- Developing plan of care</li> <li>- Coordinating care</li> <li>- Scheduling appointments that do not interfere with school</li> </ul> </li> </ul>
<p><b>Slide 36</b></p>	<p><b>Focus on Sexuality for Tweens/Teens</b></p> <ul style="list-style-type: none"> <li>• Discuss the physical changes of puberty and the effect of chronic illness or disabilities on physical and sexual development.</li> <li>• Try to put the questions regarding sexual health in the context of a general review of systems.</li> <li>• Direct the conversation accordingly to positive responses.</li> <li>• Discuss how to recognize, report, and/or prevent violence, such as assault, rape, and incest.</li> <li>• Offer resources to build further awareness on safe and educated sexual behavior.</li> </ul>
<p><b>Slide 37</b></p>	<p><b>Focus on Work for Tweens/Teens</b></p> <ul style="list-style-type: none"> <li>• Listen and support goals. Locate and connect to “out of box” thinkers.</li> <li>• Talk about volunteering opportunities.</li> <li>• Collaborate in the development of an IEP or 504 plan.</li> <li>• Talk about agencies and supportive services (scholarships, Vocational Rehabilitation, Supplemental Security Income (SSI), school to work, ticket to work, centers for independent living).</li> </ul>



More information on SSI can be found at

**[HTTP://WWW.SOCIALSECURITY.GOV/](http://www.socialsecurity.gov/)**

**[HTTP://WWW.HRTW.ORG/](http://www.hrtw.org/)**

**Role Playing:  
Snechia Scenario  
2**

**Age:** 11 years old

**Diagnosis:**  
Cerebral palsy

**Family:**  
Lives with her  
mother, Miranda

**Concerns:**  
Level of activity;  
nutrition; puberty

Snechia is now 11 years old and will be going to middle school in the fall. She is doing well. She is primarily in special education classes. She is in today for her annual well-child visit. Miranda has completed a needs assessment and Snechia has worked with her mother to answer some of the questions. She is very proud of her accomplishment. Miranda is now in school, and hopes to become a computer programmer. Her life is quite busy between school and work.

Dr Pat walks in and greets Snechia and Miranda. (S)He spends some time talking with Snechia about going to middle school. Snechia seems very excited about going to a new school. Miranda is more reserved saying, "There is a lot to think about at this time in Snechia's life." Dr Pat then reviews the needs assessment. Weight management, onset of puberty, and mobility at home and school are the major issues identified on the needs assessment.

Dr Pat probes the issues identified on the needs assessment first. (S)He notes that Snechia has completed part of the needs assessment and congratulates her for her effort. (S)He tells Snechia that she is almost a teenager and that he wants her to be fully involved in this visit. (S)He encourages her to ask questions. (S)He then plots Snechia's height and weight and notes that she is in the 90th percentile for weight and the 50th percentile for height. Miranda tells Dr Pat that for the past few months, Snechia has been gaining weight and that the weight has impaired her mobility. She gets tired easier and is spending less time trying to walk and crawl and more time in her chair. She does not like to wear her orthotics, she says, "They hurt." When Miranda tries to get Snechia to wear her braces and be more active, Snechia gets upset. Miranda says, "It is hard to believe that that little baby that was so hard to feed has grown up into such a hearty eater and has gotten so big!" She asks Dr Pat what to do. Dr Pat takes a complete dietary history and makes appropriate recommendations. Snechia does consume a large quantity of soda pop and juices. She does not like water. Also, she likes to snack while she watches TV. He emphasizes that the goal is not weight loss, but to curtail the weight gain so that her height and weight are more proportional. They then explore how to increase activity. Snechia loves to swim. Mom cannot afford a membership to the YMCA, but does take Snechia swimming for special events. Dr Pat tells Mom about a special program for CYSHCN at the YMCA. Miranda and Snechia were excited to learn about this opportunity.

Dr Pat then explores mobility issues at school. In middle school Snechia's classes will be more spread out. She spends substantial time in the special education class, but will start the day in her homeroom and take keyboarding and music in another area of the school. The school will provide Snechia with an aide to ensure that she can navigate to and from her classes and provide assistance in toileting. They want her to use a wheel chair because it is quicker and safer. She is provided 30 minutes of physical therapy weekly. Dr Pat notes that Snechia has had a growth spurt and her spasticity has increased. She takes a small dose of oral baclofen, but has not had a dose increase during this most recent growth spurt. Dr Pat asks Miranda when they last saw Snechia's orthopedist. Miranda confesses that she has missed 2 appointments because she was so busy with school and work. Dr Pat encourages Miranda to reschedule the appointment with Shriners as soon as possible. (S) He explains to Miranda and Snechia that if Snechia's muscles were not so tight her orthotics would probably fit better and it would be easier to walk. Dr Pat states that (s) he will send a copy of his note with his/her concerns relating to increased tone and the problem with the orthotics to Shriners.

Dr Pat turns to Miranda and asks what her concerns are related to puberty. Miranda says that changes are starting and she just does not know how to explain it all to Snechia. Dr Pat asks Miranda if she would like for him/her to help. She nods emphatically. Dr Pat then addresses Snechia and asks if she has noticed changes in her body. Snechia does not look at Dr Pat, but with a little prompting from her mother says that she is now wearing a bra. Dr Pat uses this opportunity to explain the basics of pubertal development and the probability that Snechia will start her period with the next few months.

Then at a very basic level Dr Pat discusses the relationship between having a period and being able to have a baby. This leads to a discussion of “good touch” and “bad touch” and the importance of telling her mother or teacher if anyone tries to touch her body inappropriately. Dr Pat concludes by asking Snecia if she has any questions.

Snecia shakes her head no and does not make eye contact. Dr Pat tells Snecia that she may think of some questions to ask her mother. He gives Snecia and Miranda a pamphlet “When Girls Grow Up” to review at home and continue the discussion. Miranda thanks Dr Pat for his help. (S) He also provides Miranda with a pamphlet regarding teaching girls with developmental delays the basics of managing menstrual hygiene. Miranda’s mother says, “I’ve been dreading this, but you have made me feel a lot better about it all today.”

Dr Pat then completes a routine well-child history and physical. Snecia’s mother stays in the room. Dr Pat points out to Snecia some of the changes that are occurring in her body and emphasizes that they are normal. (S) He once again provides her with the opportunity to ask questions.

After completing the examination, he then develops a plan of care that addresses the concerns identified during today’s visit. The plan includes action items for Snecia. She is to give herself a sticker every time she drinks water rather than pop and eats a healthy snack rather than “junk food.” After her trip to Shriners she is to begin wearing her orthotics and walking in the house after school. The stickers will add up to a special reward that Miranda and Snecia will negotiate. Dr Pat uses this opportunity to ask Miranda what chores and responsibilities Snecia has at home. Snecia proudly announces that she helps set the table, does the dishes, and is responsible for cleaning her room. Dr Pat gives both Snecia and Miranda positive feedback and encourages Miranda to continue helping Snecia become increasingly independent in self-care and home management skills.

As the office visit concludes, (s) he offers to participate in the IEP by speakerphone and schedules a follow-up visit in 3 months to follow-up. Miranda states that she will call him/her with the date of the IEP meeting. Dr Pat tells Snecia that she can help mom and be the one to call with the date. (S)He tells her that when she calls all she needs to say is that she needs to talk with Dr Pat. Snecia smiles and says she will.

**Role Playing:  
Jeremy  
Scenario 2**

**Age:** 14 years old

**Diagnosis:** Spinal muscular atrophy type 2

**Family:**  
Lives with parents, Patti and Herb

**Concerns:**  
Functional decline; sexual health; risk-taking behavior; IEP

Jeremy is in today for a chronic condition visit and well-teen check. He has just completed the transition assessment form, Planning for My Future. An hour has been planned for the encounter.

Dr Pat gives greetings to Jeremy, Patti, and Herb, and tells Patti and Herb that (s)he will see Jeremy first and then call them back for a discussion. Jeremy wheels back to the examination room with Dr Pat, while his parents wait in the waiting room. Dr Pat asks about school. Jeremy reports that he has just completed middle school and is getting ready to go to a very large high school. He has done well academically and has been the statistician for the athletic department during middle school and a writer for the school newspaper. He expresses some concerns about how big his new high school is and wonders if he will be able to keep up the pace of his extracurricular activities with the new demands of high school. He tells Dr Pat that it is getting a little harder to do some of his daily activities including using his laptop computer. He also has noticed that he seems to get tired more easily and sometimes gets a little short of breath when he is talking for a long period. He laughs and says, "I'm always talking."

Dr Pat begins by addressing Jeremy's health concerns. (S)He reviews recent encounters and the notes from specialists involved in Jeremy's care. The orthopedist has recommended surgery for scoliosis over the summer break and the pulmonologist is recommending use of the Vest. Dr Pat talks with Jeremy about these 2 recommendations. Jeremy says that a representative from the company that distributes the Vest has already been out to the house and is working on getting prior authorization through insurance. He is willing to try it, and says it is even kind of fun "getting all shook up." Jeremy is less enthusiastic about the upcoming surgery for his scoliosis. They talk about risks and benefits, and Jeremy acknowledges that he really does not have an option. He recognizes that if his curve is not stabilized it will only get worse and further impair his lung function. Dr Pat then asks Jeremy what would help in terms of improving his endurance and lessening fatigue. Jeremy tells Dr Pat that he and his mom and dad have thought this question through. They are all in agreement that Jeremy could benefit from a voice-activated computer and adaptations to the controls on his wheel chair.

Dr Pat then requests that Patti and Herb come into the examination room. Dr Pat then begins a review of systems, and asks Jeremy about his self-care of his penis. As Dr Pat is reviewing how to conduct a testicular examination, Jeremy struggles a bit to let Dr Pat know that he feels awkward about how girls perceive him physically. He says that he does not have a girlfriend now, but would sure like to have one or, "at least someone who flirted a little with me." He laments that most girls are just not interested in guys in a chair. Dr Pat spends time discussing Jeremy's concerns, including healthy ways to express sexual feelings, acne, and his weight.

Dr Pat expands the discussion to include drugs, alcohol, and smoking. (S)He assesses Jeremy's current use and his risk for future use. (S)He is up front with Jeremy about the opportunities and temptations that will come in high school. Jeremy emphatically says that he does not plan to smoke, drink, or use drugs. Dr Pat does some role rehearsal with Jeremy regarding how to say no and not appear to be a "nerd."

Dr Pat gives Jeremy a lot of positive feedback about how well is doing academically and socially. (S)He emphasizes to Jeremy that if he feels that he is developing a health problem or has other concerns, (s)he would like for Jeremy to call him/her right away. (S)He and his staff have implemented office procedures to assist in maintaining efficient communication with teens. There will be no hassle and no questions at the front desk level.

Dr Pat then asks Jeremy if (s)he could call his parents back in and together they could develop a plan to ensure a successful transition from middle school to high school. Dr Pat begins by asking Jeremy to share his major concerns. Jeremy reiterates that he is concerned about endurance, voice fatigue, and missing school secondary to respiratory infections. He adds that he would love to go to high school without an aide if at all possible. The major need for an aide is to have someone to help him with his toileting needs. Patti voices that she is concerned about Jeremy's functional declines and is interested in a referral to the technology center for a comprehensive evaluation. She reinforces that a voice-activated computer would be helpful so that Jeremy does not have to spend so much energy trying to type everything for his assignments. She notes that he is taking accelerated courses with high homework demands. Herb shares his concerns about seating explaining that the orthopedist is planning to stabilize Jeremy's scoliosis with surgery this summer. He thinks that Jeremy may benefit from a new power chair after that surgery. In the meantime, he would like the hand controls on the old power chair adjusted to make it easier for Jeremy to maneuver.

Dr Pat asks if they have had an IEP meeting yet. While Jeremy's classes are all in regular inclusive classes, he does receive specialized transportation through his IEP. Health-related services are also included in IEP, and Dr Pat asks if the IEP needs to be updated. Patti and Herb state that with a little preplanning, the class schedule could be arranged so there would be reduced travel distance from class to class. Dr Pat asks Jeremy, Patti, and Herb to think about reviewing a fire and emergency evacuation plan for the school. Although the school may be well-intentioned, (s)he notes that they may not be aware of the solutions that families have developed as they live daily with adapting to the world. Also Dr Pat notes that with increasing respiratory problems and occasional mucous plugs there needs to be an emergency care plan as well and offers a sample plan as well. Dr Pat asks Jeremy to start the emergency care plan and have it ready for their review at their next clinic appointment.

Patti and Herb tell Dr Pat that Jeremy plans to lead his IEP meeting and that they will be their to support him. Dr Pat consults his/her calendar and tells Jeremy that (s)he will be glad to participate in part of the meeting via speakerphone. Everyone agrees that Dr Pat's participation would be helpful. (S)He can support Jeremy in his request for simple adaptations that will conserve energy and promote inclusion. Dr Pat reminds Jeremy to take his signature stamp to school so that he can sign his IEP.

They brainstorm together for a few minutes and make a list of ideas to present at the IEP meeting. They will share this with school personnel prior to that meeting to give them time to research solutions that can be discussed at the meeting and entered on the plan. Jeremy would like an extra set of books, one for school and one for home, so that he will not have to carry so much in his backpack. He also wants to be sure the toileting issue is taken care of. He said that on days his aide was sick during middle school he would just hold it all day rather than try to teach someone new how to help with the transfer. Dr Pat asks if (s)he would rather wear a Texas catheter than depend on an aide. Jeremy says that he will think about it. If he decides yes, Dr Pat will write the prescription for supplies. Herb wants to ask the school about finding a student note taker in each class who would be willing to take their notes on carbon paper and give a copy to Jeremy. Jeremy reflects out loud that he may have to choose between being the sports department statistician or on the newspaper staff. Both are more demanding than in middle school. Although he loves to write, he is leaning toward staying with the athletic department. Many of his friends are the school "jocks" and have requested that he continue to be the statistician for the athletic department. These friendships and this job are important to Jeremy.

Dr Pat inquires about nutritional needs at school. Jeremy reports that all of his nutritional needs are met through continuous nighttime gastrostomy tube feedings. He eats a little during the day just to be social. Maintaining his weight continues to be a problem. Dr Pat asks what they think would help the most. All agree that a reduction in expenditure of calories would be helpful. Also they would like to increase the rate of the nighttime feeds and try to get his weight up prior to surgery.

	<p>They discuss a plan to slowly increase the volume of his feedings.</p> <p>Dr Pat, Jeremy, Patti, and Herb then develop a care plan that addresses the immediate issue including the respiratory issues, his upcoming orthopedic surgery, the IEP meeting, and the referral for the technology evaluation. They talk about the transition services and resources that will become available at school and the importance of including transition planning in the IEP planning process. Dr Pat ends this part of the dialogue by introducing the concept of comprehensive, continuous transition planning, noting that it is not too early to be thinking about what will happen when Jeremy goes to college. He very briefly introduces resources that will be available such as vocational rehabilitation funding, attendant care if needed, changes in SSI at age 18, school to work incentives, and scholarships. (S)He states that every year they will need to look at what needs to happen next in terms of transition planning so that Jeremy can go to college and live independently from Patti and Herb. (S)He also lets Jeremy know that someday (s)he will transition from his care as well. Dr Pat gives Jeremy a blank copy of a transition plan and requests that the family review their transition goals and begin filling out the plan prior to their next return to clinic appointment. They will review it, and the emergency plan in 6 weeks when Jeremy returns to the clinic. His orthopedic surgery will be behind him, and they can evaluate the need for a referral for a wheelchair evaluation.</p>
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<b>Slide 38</b>	<b>Section Five: Transitioning to Adult Systems</b>										
<b>Slide 39</b>	<p><b>Pediatric and Adult Medicine Really <i>Are</i> Different</b></p> <table border="1"> <thead> <tr> <th data-bbox="500 310 1023 348"><u>Pediatrics</u></th> <th data-bbox="1023 310 1458 348"><u>Adult Medicine</u></th> </tr> </thead> <tbody> <tr> <td data-bbox="500 348 1023 390">- Family-centered</td> <td data-bbox="1023 348 1458 390">- Individual autonomy</td> </tr> <tr> <td data-bbox="500 390 1023 432">- Developmental focus</td> <td data-bbox="1023 390 1458 432">- Disease focus</td> </tr> <tr> <td data-bbox="500 432 1023 474">- Nurturing</td> <td data-bbox="1023 432 1458 474">- “Cognitive”</td> </tr> <tr> <td data-bbox="500 474 1023 516">- Interdisciplinary</td> <td data-bbox="1023 474 1458 516">- Multidisciplinary</td> </tr> </tbody> </table> <p>Eiser C, Flynn M, Green E, et al. Coming of age with diabetes: patients’ views of a clinic for under-25 year olds. <i>Diabet Med.</i> 1993; 10:285–259</p>	<u>Pediatrics</u>	<u>Adult Medicine</u>	- Family-centered	- Individual autonomy	- Developmental focus	- Disease focus	- Nurturing	- “Cognitive”	- Interdisciplinary	- Multidisciplinary
<u>Pediatrics</u>	<u>Adult Medicine</u>										
- Family-centered	- Individual autonomy										
- Developmental focus	- Disease focus										
- Nurturing	- “Cognitive”										
- Interdisciplinary	- Multidisciplinary										
<b>Slide 40</b>	<p><b>Practical Barriers to Health Care Transition</b></p> <ul style="list-style-type: none"> <li>• Difficulty in “letting go”</li> <li>• Limited access to adult providers</li> <li>• Focus on disease management rather than functional outcomes</li> <li>• Lack of supportive outcomes data</li> <li>• No proven model</li> </ul> <p>Youth are less interested in any transition organized around medical issues and more interested in a transition to financial and social independence.</p>										
<b>Notes:</b>											

<b>Slide 41</b>	<b>Strategies for Health Care Providers</b> <ul style="list-style-type: none"><li>• Define your role early and the expectations associated with transitions.</li><li>• Provide strategies to select adult health care provider(s).</li><li>• Encourage youth/family to visit and interview physician/office staff.</li><li>• In compliance with the Health Insurance Portability and Accountability Act of 1996, send records to adult health care provider(s); ensure youth has a copy.</li><li>• Update portable medical summary and care plans.</li></ul>
<b>Slide 42</b>	<b>Strategies for YSCHN</b> <ul style="list-style-type: none"><li>• Move from assent to consent.</li><li>• Review insurance benefit package to ensure continuity of care.</li><li>• Update medical information documentation of disability – Helpful at annual recertification.</li><li>• Discuss legal transition at 18 years from minor to adult rights without support/with support.</li><li>• Review guardianship options (full, partial, or total independence).</li></ul>

## Strategies for Maintaining Funding

Reality of adult health care funding for young adults is complex.

- Lack of job benefits with entry-level/part-time jobs
- SSI/Medicaid cutoff
- Age caps
- Two types of insurance to navigate: public or private

### Public

- EPSDT
- SCHIP\*
- SSI
- Medicaid
- State Title V: CSCHN Program

### Private

- Family plan (adult disabled, dependent status; student status)
- YSCHCN pays own premium (college student plan; employment group plan; self-pay plan; Ticket to Work; COBRA)

\*Excluding residents in Maine. They have expanded SCHIP to cover adults with disabilities.



There is a fact sheet available in **Appendix N** that gives more information on public and private insurance options.

**Strategies for Ensuring Benefits and Services**

- Review program guidelines to ensure continuity into adult system.
- Discuss legal transition from minor to adult, rights of minor to adult, guardianship.
- Review SSI as an adult (re-determination or applying for first time).
- Discuss upcoming changes with SSI.
  - Apply 6 months prior to 18th birthday.
  - Gather medical documentation.
  - Review work incentives, PASS, ticket to work.

**Notes:**

**Role Playing:  
Snechia  
Scenario 3**

**Age:** 17 years old

**Diagnosis:**  
Cerebral palsy

**Family:**  
Lives with her  
mother, Miranda;  
considering living  
independently

**Concerns:**  
Living  
independently; urge  
incontinence;  
reproductive health;  
guardianship;  
transition to adult  
health care provider

Snechia is now 17 years old and a junior in high school. She is in today for her yearly well-youth checkup. Dr Pat greets Miranda and Snechia in the waiting room and asks Miranda if (s)he can see Snechia alone for the first part of the visit. (S)He explains that he will invite Miranda back for her input before they start developing the plan of care. This is acceptable to Miranda and Snechia. Snechia has completed the needs assessment and takes it with her as she walks with her walker to the examination area.

Dr Pat begins by asking Snechia how school is going. Snechia excitedly tells Dr Pat about her work-study program and her life skills classes. She is very pleased with the things she can do for herself such as cooking, shopping, and paying for purchased items. She frowns and tells Dr Pat that she can't seem to learn how to balance a checkbook. She tells Dr Pat about her job at the veterinary clinic and says that when she gets out of high school, this is the job she hopes to get. She spends a few minutes describing her duties at the clinic and some of her favorite animals.

Dr Pat then reviews the needs assessment. Snechia has identified 2 concerns. The first is problems with urge incontinence. Snechia says that sometimes she just can't help it and wets herself on the way to the bathroom. She says, "I just can't get there fast enough." The second concern is related to planning for the future. Snechia says that she is learning about her options for living independently from her mother. Her counselor has suggested living in a group home and has encouraged Miranda to place Snechia's name on a waiting list. Snechia tells Dr Pat that she does not want to live in a group home. She confides, "I have a boyfriend and someday we are going to get married and live together. I don't think they let you live together in a group home."

Dr Pat addresses these 2 concerns before he begins the history and physical. (S)He does a careful review of her urinary symptoms and will order a clean catch before Snechia leaves the office. He then tells Snechia that there are other housing options available and that (s)he will refer to the care coordinator for more details.

Dr Pat then completes a routine well-youth check combining Bright Futures guidelines for early and mid-adolescence as developmentally appropriate for Snechia. (S)He discusses a range of topics including smoking, drug and alcohol use, and sexual exploitation. (S)He asks Snechia if she and her boyfriend have ever had sex and simply, but explicitly, defines what he means by "having sex." At first Snechia says that she has not had sex, and then she says, "Maybe one time we did." She asks Dr Pat to keep it a secret from her mother. Dr Pat then explains to Snechia that having sex could lead to having a baby, and that most 17-year-olds are not ready to be parents. Snechia nodded her head and told Dr Pat that she did not want a baby. Dr Pat then talked with Snechia about birth control options. Snechia told Dr Pat that she would never have sex again until she was ready to have a baby. Dr Pat reinforced her decision for waiting, but said that sometimes it is hard to wait, and many young women use birth control just in case they change their minds. (S)He asked Snechia what she thought about this idea. Snechia was quiet for a few minutes and then said, "Maybe I should do that too, but I don't want my mother to know it." Dr Pat explains that it is important to let her mother know, as she would need to be involved in getting the pill or bringing her to the office for an injection. Snechia asks Dr Pat if he would talk to her mother about it when she comes in.

Dr Pat calls the nurse to assist Snechia in getting prepared for the physical examination. Dr Pat explains that because she has been having urinary symptoms, (s)he wants to check her vaginal secretions during the examination and explains how it is done. Snechia asks Dr Pat if her mother can come back. Miranda joins Snechia after the examination. The nurse assists Snechia in getting clean catch urine and in getting dressed.

Dr Pat gives a brief overview of the concerns that Snecia had identified and the anticipatory guidance provided. (S)He tells Miranda of Snecia's desire to start using contraceptives and explains why. Dr Pat praises Snecia for being honest and telling him/her that she has had sex. Dr Pat then asks Miranda for her input. Miranda tells Snecia that she would rather she wait to have sex until she is married. She ponders out loud to herself saying, "If it happened once it could happen again, and none of us are ready for a baby." They talk a few more minutes and decided that Snecia should start on Depo Provera. Dr Pat provides extensive teaching, as well as printed information. Because of Snecia's past problems with her weight, (s)he plans to monitor weight gain closely. In addition, (s)he recommends that Snecia start on calcium pills because contraception plus limited mobility places her at double risk for osteoporosis.

Dr Pat, Snecia, and Miranda then develop a care plan. The results of the dipstick are negative. (S)He will send the urine to the lab for a microscopic and culture and sensitivity pending outcomes of the microscopic. Dr Pat prescribes Ditropan LA to see if that will relieve the episodes of urge incontinence. (S)He encourages Snecia and her mother to keep track of how often Snecia voids and how much for the first week. They are to call him/her if she goes longer than 8 to 10 hours without voiding or voids in amounts of greater than 400 cc. In addition they are to watch for signs and symptoms of a urinary tract infection. Dr Pat will call if the urinalysis is positive and the plan needs to be altered.

Dr Pat then brings up Snecia's concerns about independent living. (S)He asks Miranda what she and Snecia have discussed and what is being considered on her transition plan at school. Miranda laughs and says that she would prefer that Snecia live with her and forget about getting married. She recalls her concerns when Snecia was a baby. She asks Dr Pat if (s)he remembered how worried she was that Snecia would not grow up and become independent. Dr Pat nods that (s)he remembers. Miranda volunteers that the school transition counselor has been very helpful and has provided them information about several options, including Section 8 housing.

Miranda tells Dr Pat that one of the most challenging transition issues for her is what to do about guardianship. She does not want total guardianship because that would take away Snecia's ability to make her own decisions. She tells Dr Pat, "We have worked hard to help Snecia become ready to make her own decisions." She acknowledges that there are some areas where Snecia will need some ongoing help such as financial management and medical decision making. Dr Pat suggests that she explore a limited guardianship related to financial matters and consider becoming Snecia's medical surrogate. Miranda tells Dr Pat that she thought guardianship was an all or nothing proposition and is relieved that it can be individualized to meet Snecia's needs.

Dr Pat concludes the visit with a discussion regarding health care transition issues. (S)He reminds Snecia and her mother that before Snecia turns 21 they will need to find adult health care physicians. Dr Pat recommends a family physician, plus a physiatrist who would monitor and treat Snecia's spasticity, evaluate for therapy and equipment needs, and refer to an orthopedist as needed. (S)He provides Snecia and Miranda with a handout outlining things to consider when searching for an adult health care provider. (S)He recommends that when Snecia transitions from Shriners at age 18 that they work together to find a physiatrist. Dr Pat could then work with the physiatrist for a year or 2 before Snecia transitions to an adult primary care physician. This plan would keep Snecia from having to get used to 2 new physicians at the same time. Miranda and Snecia like that idea.

Snecia is to return in 3 months for her Depo Provera and a weight check. Dr Pat will also evaluate the effectiveness of the Ditropan.

**Role Playing:  
Jeremy  
Scenario 3**

**Age:** 18 years old

**Diagnosis:** Spinal muscular atrophy type 2

**Family:**  
Lives with parents, Patti and Herb; about to go away to college

**Concerns:**  
Continuity of insurance; transitioning to adult health care provider; developing an emergency care plan for while living at college

Jeremy drives his power chair back to the examination room unaccompanied by his mother or father. His mother dropped him off for his visit and is running an errand. In preparation for this visit, Jeremy has brought a long a short list of questions and issues he would like to talk with Dr Pat about. Sometimes he e-mails these before his appointment, so Dr Pat has time to research new issues. He also has copies of his portable medical summary and transition care plan ready for review and revision.

Dr Pat begins the conversation by asking Jeremy to catch him/her up on what is happening in terms of college planning. Jeremy reports that he did well on his ACT and that lots of colleges are recruiting him. He is interviewing his top prospects to determine which colleges have the best disability support services, including attendant care. He is also evaluating which communities can provide him with the level of medical support he needs. He would like ready access to a gastroenterologist to manage feeding issues, pulmonologist for emergency respiratory issues, and a physiatrist (physical medicine and rehabilitation) to look at ongoing seating and technology challenges.

In selecting possible colleges, Jeremy also explored health care resources of the area and distances. His family always tried to live within a 15-minute response time circle (work/school, home and hospital) and would accept a 30-minute response time from work/school, home and hospital. This seemed to work, and he is applying the same "travel to care comfort zone" rule when choosing a college.

He has been to vocational rehabilitation to explore getting funding for college tuition and related expenses. Vocational rehabilitation will pay 75% of the tuition to an in-state school. He can take this lump sum and apply it to out-of-state tuition if he chooses. Jeremy still wants to do computer programming and is seriously weighing the merits of 2 in-state schools. Even with the out-of-state offers, he would like to stay within a 2-hour drive of his parents. He laughs and tells Dr Pat that in spite of all the planning they have done, his mother is a little anxious about him going out of state. He reports that her major concern is making sure that he has good health care. His Dad's concern is being sure that Jeremy keeps good health insurance. Jeremy confides that his major concern is how to manage an emergency. Although he is very independent in managing his health, when a serious respiratory crisis occurs, it is nice to have backup from his family, who can quickly assess the situation and get him the help he needs. Dr Pat reassures Jeremy that (s)he will help him find specialists and communicate with them once he has decided on school location. (S)He commends Jeremy for including adequacy of medical support as a major criterion for school selection.

Dr Pat then asks Jeremy what is being worked out about health insurance. Jeremy shakes his head. He tells Dr Pat how difficult it has been to figure everything out. His dad's health insurance benefits are decreasing, with larger deductions and co-pays. He tells Dr Pat that he has already applied for SSI as it is just 6 months until he is 18. He is hoping that he will get SSI and then a medical card. He tells Dr Pat, "A medical card will work until I start bringing in an income. If I make too much, I will lose my benefits. The SSI Medicaid route only works if you don't make much money." He laughs and says, "It will take more than SSI to support my expensive tastes." His dad's insurance has the option to declare Jeremy an adult dependent child, enabling Jeremy to retain his insurance through his father's job. He has a 2-week period to sign up for this benefit right after he turns 18, and the insurance company expects yearly verification that Jeremy is not employed and independent. Jeremy lets Dr Pat know that he does not want the label of an adult child, but that this may be their best option. In addition, he recognizes that in an unstable job market his dad could get laid off and that COBRA options are very expensive. He could get student health, but that does not cover summer break time or if he has to drop back to part-time student status. He tells Dr Pat that when he gets a 6-figure job with IBM, he would like to think that he could get employer-based insurance, but that if he had to work part-time due to health problems he could lose his employer-based insurance as well.

Jeremy reflects a minute and says, “There is just no good option for the long term, and so I just have to decide which is best for now.” He has decided that being an adult dependent on his father’s policy with a Medicaid backup until his income kicks him off is the best plan for now.

Dr Pat then addresses Jeremy’s concern about emergency management. (S)He asks Jeremy what concerns him the most. Jeremy tells Dr Pat that developing a mucous plug and having respiratory distress is the most frightening aspect of being alone. They talk for a few minutes about how Jeremy could summon help. One solution is to have a pager that connects to both 911 and home, or a medical alert device that many seniors also use. Jeremy will discuss this issue further with his parents and will call Dr Pat if his assistance is needed.

Jeremy then tells Dr Pat that one of the colleges has offered him a student work-study opportunity. Jeremy has not applied for SSI; however, he is wondering if he should decline the work offer to prevent reduction in his benefits. Dr Pat tells Jeremy that (s)he is going to schedule him to see the care coordinator, who can answer those questions easily. During that encounter, the care coordinator tells Jeremy about the PASS program and the Student Earned Income Exclusion SSI work incentive. Both programs enable Jeremy to work and keep his SSI.

Jeremy and Dr Pat update Jeremy’s portable medical summary and emergency care plan. They also review and revise his transition plan in preparation for college. Because Jeremy will be living away from home, he will need attendant care for the first time, someone to help him get into bed for the night, up in the morning and dressed for classes, hook up his gastrointestinal tube feedings at night, and assist with the Texas catheter. Jeremy will work with disability support services to arrange transportation to medical specialists as needed and to arrange for a note taker and voice-activated computerized testing. Jeremy tells Dr Pat that he is excited, but that it will seem weird to have an attendant. Dr Pat provides Jeremy with some information about hiring, training, and evaluating an attendant. Another issue they discuss is naming a designated health surrogate and getting the form signed with copies for Jeremy, his designee, alternates, and his medical file at Dr Pat’s office.

Plans are made for Jeremy to call Dr Pat once he has decided on a college. Dr Pat will then help Jeremy find the medical specialists he needs to be on his team. Dr Pat has agreed to remain Jeremy’s medical home until he has graduated from college. Jeremy is relieved to not have to do all of the medical transitioning at once!

**Slide 44** **Section Six: Take-Home Messages**

- Slide 45** **What to Do on Tuesday for Providers**
- Hang up a disability-cool poster in the waiting room.
  - Ask a parent to leave the examination room so you can talk directly to the youth.
  - Train staff to make YSHCN appointments after school.
  - Call a family physician to consult about a transitioning youth.

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**Slide 46****What to Do on Tuesday for Children and Youth**

- Become responsible for a new household chore.
  - Make a list of questions/concerns you have about your health that you can give to your pediatrician.
  - Call your pediatrician to make your own appointment.
  - Call in your refill prescriptions.
  - Draft your portable medical summary.
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## Appendices

A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs	A
HRTW CHOICES Transition Developmental Pathways Checklist	B
HRTW-KY Life Maps	C
Provider Transition Checklist and Timeline	D
HRTW -CA Transition Health Care Assessment (Adolescent Version)	E
HRTW -CA Transition Health Care Assessment (Professional Version)	
PACER Health Care Skills Checklist	F
Adolescent Autonomy Checklist	G
Washington Transition Timeline for Children and Adolescents with Special Health Care Needs: Developmental Disabilities for Medical Care Providers	H
IL- DSCC Transition Checklist and Timeline for Medical Care Providers	I
HRTW, Portable Medical Summary (1 page)	J
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Public & Private Insurance Plans: Understanding the Options for YSHCN	N
Transition-Related Resources and Services Fact Sheet	O
Additional Resources: Healthy & Ready to Work Web site	P
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## Additional Resources

### Books

**Search the Medical Home Bibliography at:** [www.medicalhomeinfo.org/publications/bibliography.html](http://www.medicalhomeinfo.org/publications/bibliography.html)

### AAP Policy Statements

**Search for any AAP Policy Statement at:** <http://aappolicy.aappublications.org/>

### Transition Web Sites:

- **American Academy of Pediatrics:** [www.aap.org/](http://www.aap.org/)
- **American Medical Association Adolescent Clinical Preventive Services:** [www.ama-assn.org/ama/pub/category/1980.html](http://www.ama-assn.org/ama/pub/category/1980.html)
- **Centers for Independent Living:** [www.ilru.org/jump1.htm](http://www.ilru.org/jump1.htm)
- **Federal government services and information sites:** [www.disabilityinfo.gov/](http://www.disabilityinfo.gov/)
- **Healthy & Ready to Work National Center:** [www.hrtw.org/](http://www.hrtw.org/)
- **Housing:** [www.hud.gov/](http://www.hud.gov/)
- **Information, resources, and research about work and disability issues:** [www.worksupport.com/](http://www.worksupport.com/)
- **Kentucky Cabinet for Health Services Commission for CSHCN:** <http://chs.ky.gov/commissionkids>
- **Louisiana HRTW:** [www.hdc.lsuhs.edu/Programs/CDP/ashstprd.htm](http://www.hdc.lsuhs.edu/Programs/CDP/ashstprd.htm)
- **Massachusetts HRTW:** [archives.communityinclusion.org/transition/](http://archives.communityinclusion.org/transition/)
- **National Collaborative on Workforce and Disability for Youth:** [www.ncwd-youth.info/](http://www.ncwd-youth.info/)
- **National Center for Medical Home Initiatives:** [www.medicalhomeinfo.org/](http://www.medicalhomeinfo.org/)
- **National Institute on Disability and Rehabilitation Research's site on assistive technology:** [www.abledata.com/](http://www.abledata.com/)
- **National Mental Health Information Center:** [www.mentalhealth.org/](http://www.mentalhealth.org/)
- **National Organization on Disability:** [www.nod.org/](http://www.nod.org/)
- **PACER Center:** [www.pacer.org](http://www.pacer.org)
- **Shriners Hospitals CHOICES project materials:** [www.shrinershq.org/choices](http://www.shrinershq.org/choices)
- **State transportation Web sites:** [www.fhwa.dot.gov/webstate.htm](http://www.fhwa.dot.gov/webstate.htm)
- **TelAbility:** [www.TelAbility.org](http://www.TelAbility.org)
- **University of Washington Adolescent Health Transition Project:** <http://depts.washington.edu/healthtr>

Please note: Inclusion in this publication does not imply endorsement by the American Academy of Pediatrics (AAP). The AAP is not responsible for the content of the resources mentioned.

# How to Find Disability -Cool Posters and Other Images

Have you checked your:

- Local Vocational Rehabilitation Office
- Rehabilitation hospital or Shriners Hospital
- Social Security Administration office
- Special Olympics
- Winners on Wheels
- Workforce Development office
- College Disability Services offices
- Departments of Special Education at state or local levels
- Healthy & Ready to Work Project in your area
- Durable Medical Equipment or pharmaceutical providers

Have you searched on the Internet browser to Google ([www.google.com](http://www.google.com)) and click on the Images tab along the top of the search area? Try some of these search terms to generate "disability cool" images:

- "wheelchairs + sports"
- "disability + games" or
- "disability + friends"

Have fun with it! By utilizing these images or posters, you will be communicating to the CYSHCN in your life that success, fun and a full life is possible!