

Health Advocacy Across the Lifespan: Part III Healthcare Transition

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*Statewide Parent
Advocacy Network*

Healthcare Transition

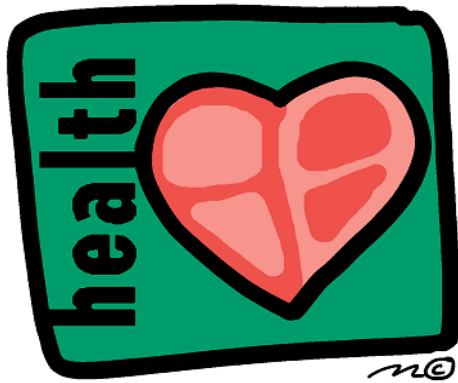
Transition to adult life is more than “school to work.” It includes changing to adult healthcare. But transition to adult life needs to start when children are young and be reinforced all along.

Even if the child may not be completely independent as an adult, families can help ensure that their child can reach their personal best potential, whatever that may be.

Photo www.fvkasa.org



Integrating Health into the Transition IEP



Eat your way to
5 A Day





Transition

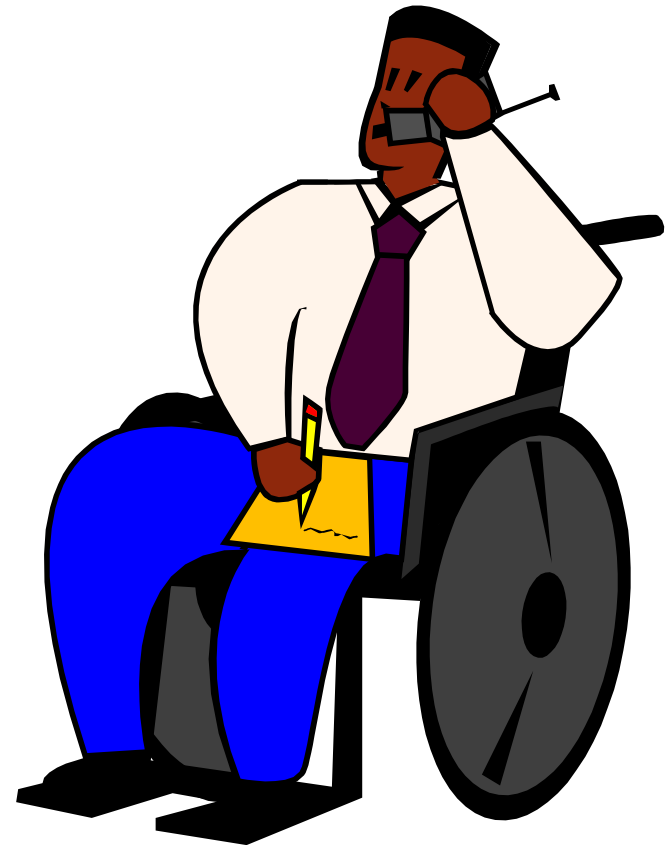


- *Intent & purpose*: preparation for & improving quality of adult life
- *Statement of transition service needs*: long range educational plan
- *Statement of needed transition services*: coordinated, long range plan for life
- *Linking* to needed programs, services & supports



Youth must learn how to...

- Manage their own health, health care, and health insurance/healthcare financing
- Interact with healthcare providers
- Advocate for their health and healthcare



Youth with special needs must:

- Understand their own condition & needed treatment
- Explain their condition & needed treatment to others
- Monitor their health status on an ongoing basis
- Ask for guidance from adults including healthcare providers
- Learn about the systems that will apply to them as adults
 - Health insurance
 - Social security
 - Guardianship & power of attorney for health care
- Understand formal and informal advocacy services and supports

Addressing Health in the IEP



- Present levels of academic achievement & functional performance
 - Current impact of student's health in relation to disability
 - Student's current knowledge & skills re: recognition & management of their health needs
 - Need for supports, equipment, accommodations, adaptations related to health issues

Examples of PLAAFP Statements



- Number of days of school missed due to health condition
- Impact of communication skills on ability to get needs met, e.g., “John cannot verbally indicate when he needs to be repositioned to avoid pressure sores.”
- Ability to self-administer medications, e.g., “Latesha needs reminders at lunch to access and take her medications.”
- Ability to recognize and take action on symptoms, e.g., “Latesha knows that when she sees sparkly lights, she is about to get a migraine and needs to go to the school nurse’s office and take her medication.”
- Need for accommodation because of symptoms, e.g., “Michael needs twice the usual time between classes due to pain and fatigue associated with his arthritis.”

Health-Related Post-Secondary Goals

- Independent living skills
 - skills or tasks that contribute to the successful independent functioning of an individual in adulthood in the domains of leisure/recreation, home maintenance, personal care, and community participation



Measurable Annual Goals

- Measurable Annual Goals:
 - Goals related to progress in the general curriculum
 - Goals related to other needs that result from the student's disability
- Include as much self-care and independent management of health conditions as possible to optimize adulthood employment, independent living and community participation



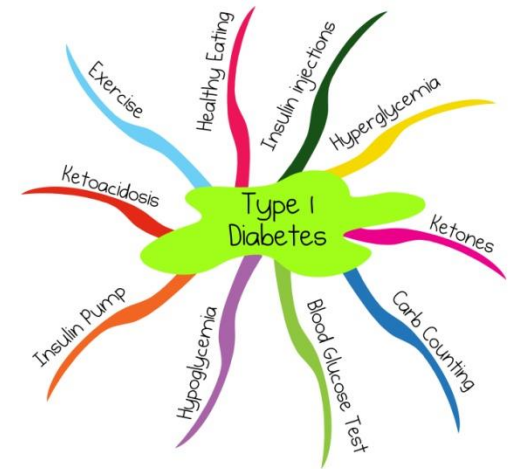
Goal Examples

- John will learn self-catheterization so he can independently take care of his toileting needs while attending culinary school.
- Monique will contact two adult health care providers to interview during the first semester so she can choose a provider who will care for her before she turns 21.
- Yuri will learn to order and pay for his medicines so he can live independently in the community
- Keisha will identify symptoms that need urgent and emergent care and will develop a plan for emergency care.



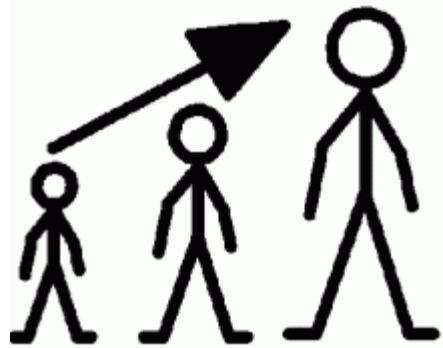
Goal Examples

- James will learn how his oral care habits, medications and diabetes affect his teeth and oral health and identify a dentist to care for him.
- Jo will understand how alcohol and other drugs interact with her seizure medications so she can live safely in the community.
- Makeala will create a health organizer to track medications and appointments with her physicians.



Sample of Daily Log

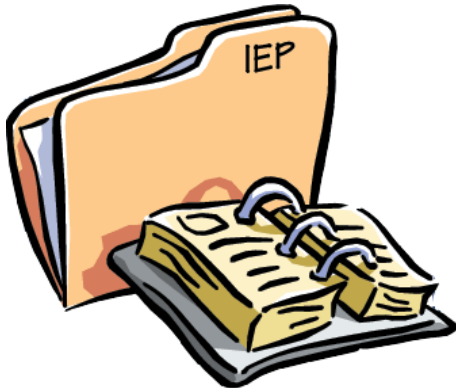
Time	Activity	Special Reminders or Notes
6:00 am	Get up by 6:15, take shower, wash hair	Do some stretching exercises before breakfast
7:00 am	Eat breakfast, take medication, brush teeth use mouthwash	Hot or cold cereal during week, Pack lunch and put it in carry case by front door
8:00 am	Leave for bus stop by 8:15	Be sure to check weather before leaving
9:00 am	Punch in at work	Put lunch in refrigerator
10:00 am	Break time—eat fruit and something to drink	Milk or water—not soda
11:00 am		
12 noon	Eat lunch, take medication	No orange juice with this medication



Transition services...

- Coordinated set of activities
- Designed within an outcome-oriented process
- Promotes movement from school to post-school activities including postsecondary education, vocational training, integrated employment (including supported employment), continuing education, adult services, independent living, community participation
- Based on youth's needs
- Take into account strengths, preferences, interests

- Services shall include: instruction, related services, community experiences, employment and other post-school adult living objectives, activities of daily living, and functional vocational assessment



- Three years before the student turns 18 (at 15) a statement that the student has been informed of the rights that will transfer to the student on reaching the age of majority. This also impacts health decisions.



- Instruction
 - Courses of study
 - Skill development



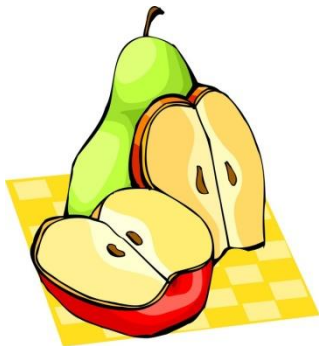
- Related services
- Community experiences
- Adult living objectives
- Adult living
- Daily Living skills
- Functional vocational assessment



Instruction

Teaching student how to...

- Use smart phone or alarm watch to track medication schedule
- Ask for snack when recognizing signs of low blood sugar
- Ask questions of the primary care provider & specialists



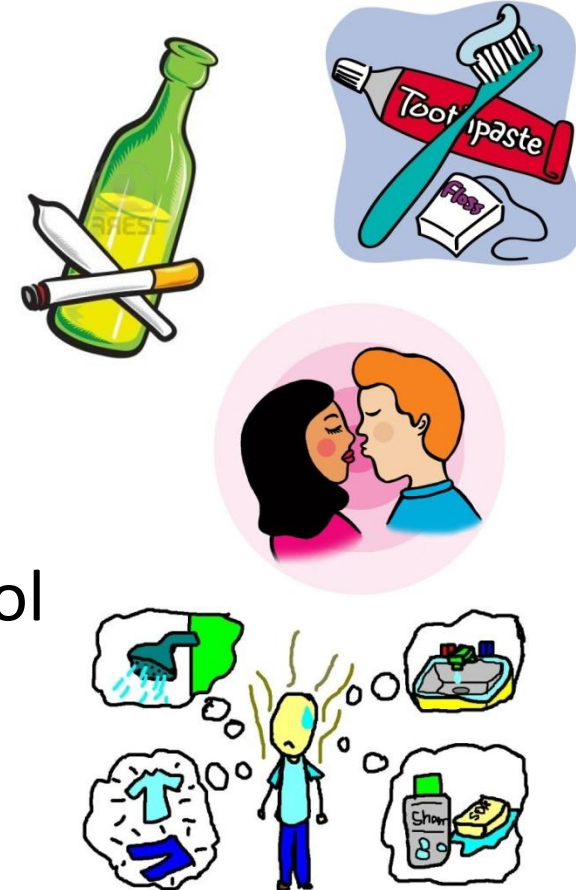
Self Advocacy in Health Arena

- Knowledge of the laws (HIPAA)
- Age of majority
 - Health power of attorney
- Self-disclosure/self-identification
- Health advocacy skills



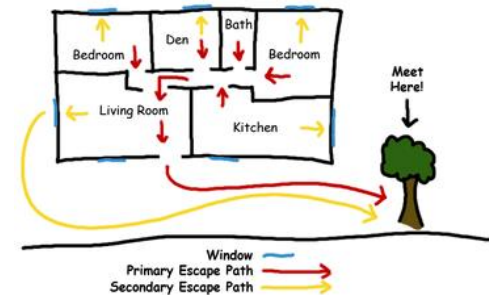
Health Choices in Daily Life

- Nutrition
 - Food choices (healthy, limitations, parameters)
 - Basic cooking skills including safety
 - Shopping
- Personal hygiene & emotional health
- Physical activity/exercise
- Safety at home & in the community
- Understanding effects of drugs, alcohol
- Relationships & sexuality



Managing Health Conditions

- Developing personal health history & care plan for health conditions
- Understanding & managing medications; accessing pharmacy
- Learning how to self-advocate with doctors
- What to do in an emergency (knowing signs & needs for personal emergency care & how to access that care)
- What to do in a disaster



Health & Employment

- Are work accommodations required?
 - Physical environment
 - Work hours
 - Medication administration
- Is skill development required?
 - Self-care activities
 - Self advocacy for health needs

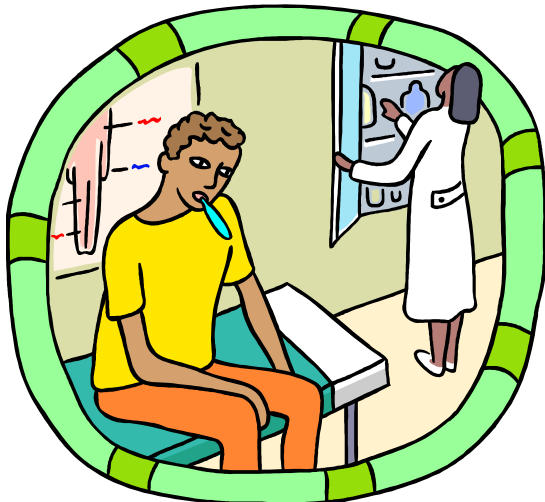


STANDING UP 
for your health

Nuts & Bolts of the Health System



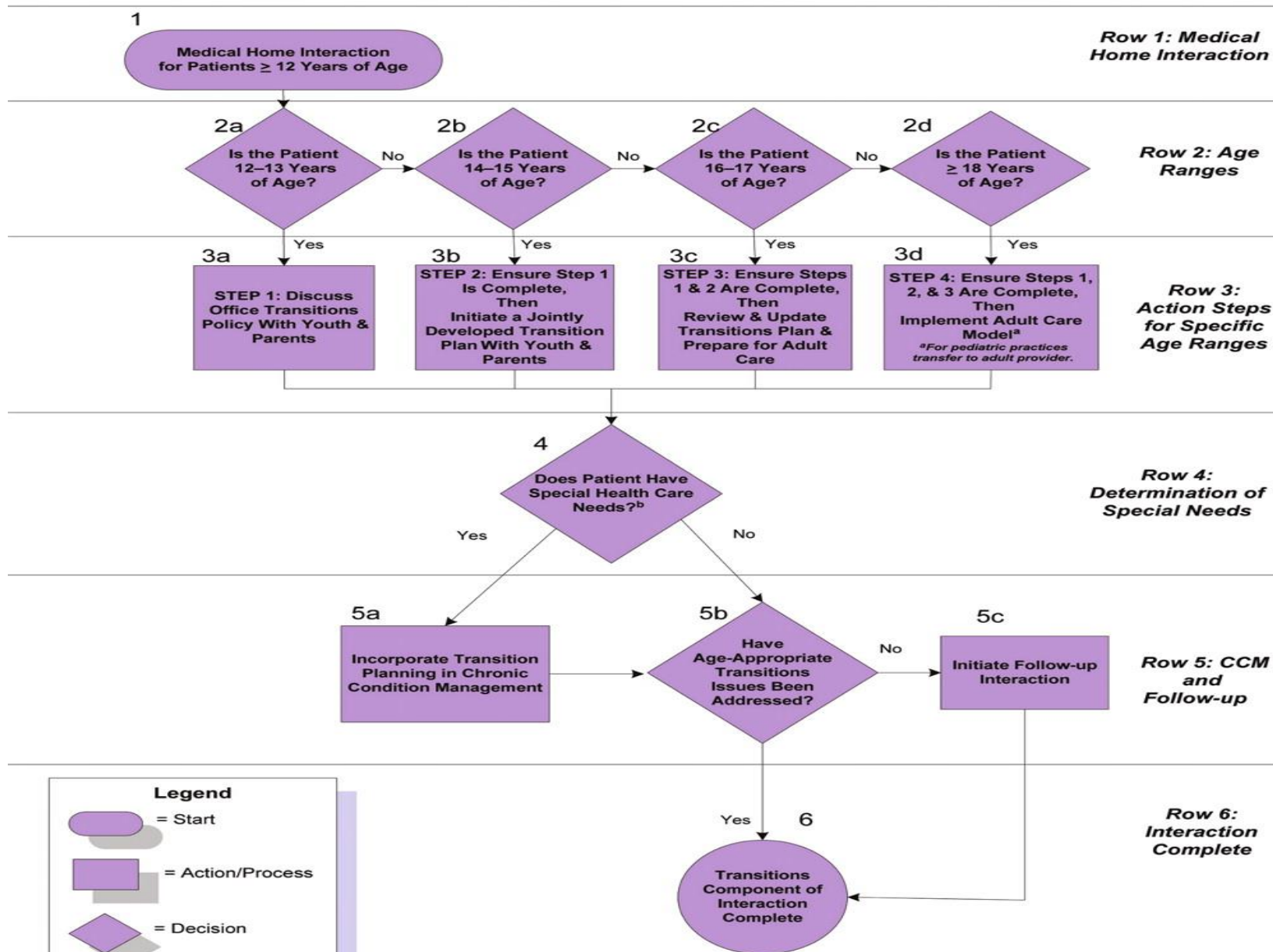
- How to get health insurance
 - Private? Medicaid?
 - Managed care?
 - Fee for service?
- Health care
 - Who makes decisions?
 - Changing/choosing health care providers
 - Primary care physicians
 - Specialists
 - Getting to appointments
- Keeping accurate, up-to-date medical history



How the Doctor Can Help

- AAP, AAFP, ACP 2002 joint statement calls for:
 - PCP responsible for transition planning
 - Having knowledge & skills needed for HCT services
 - Maintaining up-to-date portable medical summary
 - Creating written HC transition plan by age 14
 - Implementing recommended preventive services guidelines
 - Ensuring continuous health insurance coverage
- Society for Adolescent Medicine endorsed (2003)

Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction



Legend

- = Start
- = Action/Process
- = Decision
- = Stop

^bThe federal Maternal and Child Health Bureau defines children with special health care needs as: "Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 pt 1):137-140.)

<p>Medical Home Interaction for Patients ≥ 12 Years of Age</p>		<p>1. Initiate first step in the health care transition planning process at age 12.</p>
<p>Is the Patient 12-13 Years of Age? Is the Patient 14-15 Years of Age? Is the Patient 16-17 Years of Age? Is the Patient ≥ 18 Years of Age?</p>		<p>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.</p>
<p>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.</p>		<p>STEP 1: Discuss Office Transitions Policy with Youth & Parents</p>
<p>STEP 2: Ensure Step 1 Is Complete Then Initiate a Jointly Developed Transition Plan With Youth & Parents</p>	<p>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.</p>	
<p>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 reevaluation 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.</p>		<p>STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care</p>
<p>STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model* <i>*For pediatric practices transfer to adult provider</i></p>	<p>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 also 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.</p>	
<p>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 comanagement with medical subspecialists. 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.</p>		<p>Does Patient Have Special Health Care Needs?</p>
<p>Incorporate Transition Planning in Chronic Condition Management</p>	<p>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; competencies for self-care; 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 18 and beyond.</p>	
<p>5b. Use of transition planning 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 this 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.</p>		<p>Have Age-Appropriate Transitions Issues Been Addressed?</p>
<p>Initiate Follow-up Interaction</p>	<p>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.</p>	
<p>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.</p>		<p>Transitions Component of Interaction Complete</p>

Transition to Adult Life

- ❖ Family Voices Kids as Self Advocates (KASA) which is run by youth at <http://fvkasa.org/resources/health.php>
- ❖ Centers for Independent Living (CILs) help people with disabilities with activities of daily living and independent living skills www.njsilc.org/
- ❖ The National Center for Healthcare Transition (Got Transition?) can be found at www.gottransition.org/
- ❖ SPAN has a Youth Resources for Empowerment webpage at www.spanadvocacy.org/content/youth-resources-empowerment and a Transition webpage at www.spanadvocacy.org/content/transition-school-adult-life
- Transition to Adult Life On-Line Resource Guide, www.spanadvocacy.org/content/transition-adult-life-line-resource-guide
- Being a Healthy Adult: How to Advocate for Your Health & Healthcare, <http://rwjms.rutgers.edu/boggscenter/products/BeingaHealthyAdultHowtoAdvocateforYourHealthandHealthCare.html>
- Transition Checklist for Teens, www.spanadvocacy.org/sites/startingpointstemplate.drupalgardens.com/files/files/ChecklistTeensRE_0.pdf
- Transition Checklist for Parents/Caregivers, www.spanadvocacy.org/sites/startingpointstemplate.drupalgardens.com/files/files/CaregiverChecklist_RE_0.pdf

Adult Advocacy Resources

- NJ Statewide Independent Living Council & County Centers for Independent Living (www.state.nj.us/humanservices/dds/home/cntrindlivindex.html)
- NJ Council on Developmental Disabilities (www.njcdd.org/)
 - Partners in Policymaking
 - People First NJ
 - Youth Leadership Project
- Arc of NJ (www.arcnj.org)
 - Mainstreaming Medical Care
 - NJ Self-Advocacy Project

