Transitioning to Adult Services and Independent Living

Adolescence is a time of many changes, many questions about the future and for some youth much uncertainty. A typical teenager will transition from high school to college or employment, living at home to living independently and from pediatric health care to adult health care. This process can be a very bumpy road for some teenagers with disabilities and chronic conditions. Health care professionals can play an important role in assisting these youth and their families.

The process begins early in childhood by a focus on health promotion and the prevention of secondary disabilities. Health promotion includes encouraging self-care, independence, social skills and community involvement. The American Academy of Pediatrics has published a Clinical Report on Transition, pediatrics.aappublications.org/content/128/1/182.full.pdf+html. The AAP report recommends initiating a conversation about transition at 12-13 years of age and jointly developing an initial transition plan with youth and families at 14-15 years of age.

The goals of youth transition are to support:

1. optimal health, wellness and function of the individual,
2. self-determination of the individual to the greatest extent possible, and
3. maximum independence and inclusion based on his or her choices.

Self-determination is important for everyone, and especially adolescents and young adults with disabilities. Important skills that contribute to self-determination are the youth's ability to speak up or advocate for themselves, to set goals, to solve problems and to make decisions. More information on self-determination is available at www.waisman.wisc.edu/naturalsupports/pdfs/FosteringSelfDetermination.pdf, www.cec.sped.org/AM/Template.cfm?Section=Home&CONTENTID=2337&TEMPLATE=/CM/ContentDisplay.cfm&CAT=none and www.ohsu.edu/oidd/CSD/

Another critical concept is Person-centered planning. Person-centered planning is an ongoing process used to help youth with disabilities plan for their future. The youth and their family are the center of planning. Planning is based on respect for the rights of youth to set their own goals, on his or her own vision (what's important TO the person) and strengths as well as his or her needs (what's important FOR the person). Person-centered planning involves a committed circle of people and results in an action plan that will include the skills and resources needed to achieve those goals. More information on person-centered planning is

available at www.pacer.org/tatra/resources/personal.asp, www.ilr.cornell.edu/edi/pcp/ and www.ncset.org/about/default.html

Schools, the Department of Vocational Rehabilitation (DVR) and Developmental Disability services are key partners with families and health care providers in transition planning. School staff must include transition services on a child's Individual Education Plan (IEP) by age 16 years and update services every year thereafter (for information from the Oregon Department of Education, see www.ode.state.or.us/search/page/?=1279). The DVR is a state and federally funded program that helps individuals with disabilities find a job. An individual must have a disability that interferes with his or her ability to get or maintain employment (more information from the Oregon Department of Vocational Rehabilitation including the Ticket to Work program is at, www.oregon.gov/DHS/vr/). Staff from Developmental Disability services assist youth with intellectual disabilities and autism and their families to identify appropriate supports for the transition from adolescent to adult services. In Oregon, adolescents with developmental disabilities are eligible for assistance from a Broker. The Brokerage system assists individuals and families find resources so the individual can fully participate in community life based on his or her choices. For more information on the Brokerage system, see www.oregon.gov/DHS/dd/adults/supports.shtml

Youth transition has captured the national spotlight and a great deal of resource material is available for both health care professionals and families. How can you help? What follows is a health care provider "To Do" list and links to representative tools and resources to support those activities.

Health Care Provider "To Do" list (adapted in part from the AAP Report):

1. Develop a formal youth transition policy for the primary care office and notify families about the policy, for example, through adaptation of the template for the *Medical Home Practice Brochure for Parents* www.pediatricmedhome.org/pdfs/1_Brochure_Sample.pdf. The policy may include the expected age to transition to adult health care and examples of transition activities such as those described in the "To Do" list for health professionals.

2. Initiate a conversation about transition with youth and family at 12-13 years of age, and continue to prepare youth and families for the transition process,

3. Develop an initial health transition plan beginning at 14-15 years of age,

4. Provide on-going support to the youth and family in managing their own health care (self-management supports),

5. Identify external care coordination/care management supports as needed, for example, the public health nurses of the Child Development and Rehabilitation Center's (CDRC) CaCoon program, www.ohsu.edu/xd/outreach/occyshn/programs-projects/cacoon.cfm

6. Support youth in building self-advocacy (speaking up), self-determination (decision-making, goal-setting and developing an action plan), self-care and independence. Representative resources to share with youth and families are:

   Transition to Adult Care: Developmental Activities Checklist, www.syntiro.org/hrtw/tools/pdfs/PC1SHC_Chicago_Provider_transition_checklist.pdf

   Transition Timeline from Shriners Hospitals at, www.floridahats.org/wp-content/uploads/2010/03/Transition-Timeline1.pdf

   Transition Health Care Checklist: Preparing for Life as an Adult. This is a comprehensive guide for youth and their families that includes basic information on transition, a skills checklist as well as specific information on a number of subjects such as financial and legal concerns, www.waisman.wisc.edu/wrc/pdf/pubs/THCL.pdf

   Healthcare Transition Planning Guides for youth 12-14 years, 15-17 years and 18 years and older. These guides include information on necessary skills and a structure for planning, goal-setting and related activities for youth and their families, www.floridahats.org/?page_id=608

   Goal Setting for youth with developmental disabilities, go to Healthy Transitions NY, www.healthytransitionsny.org/skills_media/tool_show/9

   Parent-Child Self-management, a model for the transfer of the responsibility for management of the child's chronic condition from parents to youth, depts.washington.edu/healthtr/documents/sharedmanage.pdf

7. Assist the youth and family identify supports needed for independent living and work (participate in person-centered planning when asked),

8. Assist the youth and family identify an adult health care provider,

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9. In collaboration with the youth and family, formulate a medical summary for the adult health care provider and consider initial co-management of the young adult with the adult health care provider. One example of a template for a Transition summary is, www.floridahats.org/wp-content/uploads/2010/03/HCT-Summary.pdf

10. Introduce the adult health care provider to appropriate pediatric specialist(s) as needed, for example Developmental and Behavioral Pediatricians and Child Psychiatrists for youth with autism spectrum disorder or intellectual disability,

11. Assist the youth and family identify on-going health insurance (public and/or private),

    Information on health care financing from the Healthy and Ready to Work program of the MCHB, Youth with Disabilities in Transition, www.hrtw.org/tools/index.html

    Fact Sheets on financial and legal concerns, work and disability benefits included in, Transition Health Care Checklist: Preparing for Life as an Adult (Waisman Center), www.waisman.wisc.edu/wrc/pdf/pubs/THCL.pdf

12. Coordinate planning with adult health care providers, transition specialists at schools, Developmental Disability services/Brokerages, DVR and other community partners, and

13. Advocate with the youth and family for needed services.

General Internet sites on the transition of youth to adult services:

The Youthhood web site, www.youthhood.org/, is a "dynamic, curriculum-based tool that can help young adults plan for life after high school." It was developed by staff at the National Center on Secondary Education and Transition, University of Minnesota.

The Oregon Youth Transition Program (YTP) is a comprehensive transition program for youth with disabilities operated collaboratively by the Oregon Office of Vocational Rehabilitation Services (OVRS), the Oregon Department of Education (ODE), the University of Oregon (U of O), and local school districts statewide in Oregon. The purpose of the program is to prepare youth with disabilities for employment or career related post-secondary education or training, www.ytporegon.org/

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The National Health Care Transition Center, www.gottransition.org, supported by a cooperative agreement between the US Maternal and Child Bureau and the Center for Medical Home Improvement, includes link to Clinical Practice Guidance and Algorithm on transition jointly developed by the AAP, the American Association of Family Physicians and the American College of Physicians.

Adolescent Health Transition Project at University of Washington, depts.washington.edu/healthtr, practical tips for health professionals, parents and teens, checklists and links to other resources, and the workbook, *Planning for a Healthy Transition: A Family Transition Plan*, here.doh.wa.gov/materials/healthy-transition-plan/13_CSHCN-parent_E11L.pdf

Florida Health and Transition Services (HATS), a comprehensive transition resource site that links to documents from a number of other transition sites, www.floridaHATS.org

Healthy and Ready to Work (HRTW) National Center, variety of tools and checklists for providers including transition checklist and templates for care plan, medical summary and emergency management plan web.syntiro.org/hrtw//tools/index.html

Healthy Transition NY, a comprehensive transition resource site for youth with developmental disabilities that includes tools for scheduling an appointment, managing medications, speaking up at the doctor's office and setting health goals www.healthytransitionsNY.org

Transition resources from the Waisman Center, Transition to Adult Health Care: Training Guide in Three Parts, www.waisman.wisc.edu/cedd/pdfs/products/health/TAHC_2.pdf and the Transition to Health Care Checklist: Preparing for Life as an Adult, www.waisman.wisc.edu/cedd/pdfs/products/health/THCL.pdf

Additional links to Internet Transition resources, www.familyvillage.wisc.edu/sp/trans.html

Other resources for providers and parents:

Autism Speaks Transition Tool Kit, www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

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General information on adolescent health promotion:

Bright Futures, www.brightfutures.org

Guidelines for Adolescent Prevention (GAPS), www.ama-assn.org/ama/pub/category/1980.html

Internet sites for teens with disabilities:

Ability OnLine, www.ablelink.org/public/default.htm

Kids as Self Advocates (part of Family Voices), www.fvkasa.org

LD OnLine, a web site on learning disabilities that includes chat rooms for students, teachers and parents, www.ldonline.org

Do It, a program to support high school students with disabilities in post-secondary education using technology from the University of Washington, www.washington.edu/doit/