



TITLE V PRACTICE BRIEF

TRANSITION FOR YOUTH WITH SPECIAL HEALTH CARE NEEDS: HOW DO WE GET THIS DONE?

Title V Practice Briefs focus on critical issues facing State Title V CYSHCN Programs. This brief summarizes findings and recommendations from an HRTW National Topical Call conducted on May 7, 2008, with Dr. Richard Antonelli and Dr. Patience White, HRTW Consultants, and Dr. Charles Onufer, Illinois Title V CSHCN Director. Toni G. Wall, Principal Investigator of the HRTW National Center grant and Director of the Maine Title V CSHCN Program moderated the call. (A written transcript, audio recording and resources for the call can be accessed at <http://www.hrtw.org/hrtwu/>.)

ISSUES IN TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE

According to the 2005-6 National Survey of Children with Special Health Care Needs, fewer than half of parents with teens with special needs reported that health care providers talked about meeting health care needs in adulthood. A 2008 American Academy of Pediatrics survey confirmed that fewer than half of pediatricians are providing transition support services such as discussing insurance options, making transition plans, or offering educational materials, and very few initiate transition planning early. A 2008 survey by New Hampshire Special Medical Services found that fewer than half of adult health care providers communicated with previous providers for young adults and 90% wanted written summaries and/or conversations with them. How can state CYSHCN agencies support health care providers to promote transition from pediatric to adult health care?

Think broadly about the role State Title V can play in assuring YSHCN access to adult health care. The importance of preparing YSHCN (and all youth) to transition from pediatric to adult health care cannot be overstated. Access to appropriate health care for young adults with special needs can be challenging. Without planning and preparation youth run the risk of

being without a medical home, insurance coverage, and sufficient knowledge of when, where, and how to access preventive/primary care, acute care, and emergency care.

State Title V programs are required to report their efforts in preparing YSHCN for transition from pediatric to adult health care as one of six National Performance Measures for the Maternal Child Health Block Grant. But how equipped is the adult health care system to receive them in light of the well-documented disparities in health status and access to care among persons with disabilities? What can Title V do to prepare the pediatric and adult medical communities to facilitate and support the transition?

Preparing YSHCN for transition, supporting them during the process, and assuring the adult system is available and accessible to them at the time of transition encompasses many of the **Ten Essential Services of Public Health** (see <http://www.cdc.gov/od/ocphp/nphpsp/essentialphservices.htm>).

State Title V agencies are dually charged with linking CYSHCN to needed personal health services and assuring the provision of care when otherwise unavailable. This requires availability and access to a competent personal health workforce—an essential public health service.

As Title V leadership confronts the budget crises facing many state and local governments, the challenge is how to move forward in our efforts to build systems of care that support transition. In many Title V CYSHCN programs, this requires no-cost or low-cost strategies. It also requires Title V programs to envision and actively seek more opportunities for collaboration with other publicly and privately funded programs and engage the adult medical community.

This Brief delineates a number of key issues facing YSHCN and the health care professionals who serve them as they make the transition from pediatric to adult health care. It offers strategies for Title V CYSHCN programs and their partners to use in supporting transition. Above all, this brief challenges Title V programs to reconsider the role that they can play in building access to and supporting the competency of adult health care providers to serve youth and young adults with special health care needs in today's turbulent fiscal environment.

UNDERSTANDING THE DIFFERENCES BETWEEN PEDIATRIC & ADULT MEDICINE

Different expectations. Different expectations about the roles of patients, families, and health care providers underlie pediatric and adult practices. Understanding these differences is important as we prepare youth to transition to adult health care and develop relationships with the adult-focused providers who will become their medical homes.

Differences between Pediatric and Adult-Focused Health Care

	Pediatric	Adult
Age-related	Growth and development, future focused	Maintenance/ decline; Optimize the present
Focus	Family	Individual
Approach	Paternalistic Proactive	Collaborative Reactive
Shared decision-making	With parent	With patient who is a self-advocate
Services	Entitlement	Qualify/ eligibility
Non-adherence	More assistance	More tolerance
Procedural pain	Lower threshold of active input	Higher threshold for active input
Tolerance of immaturity	Higher	Lower
Coordination with federal systems	Greater interface with education	Greater interface with vocational rehabilitation and workforce development
Care provision	Interdisciplinary	Multidisciplinary
# of patients	Fewer	Greater
Transition definition	Transfer from pediatric to adult health care providers and the adult health care system	Transfer of patient from home or community setting into a hospital or other health care facility and vice versa

Patience White, MD, and Patti Hackett, MEd

The pediatric family-centered care model vs. the adult-focused disease management model. Differences in the family-centered model of care used by pediatric providers and the adult-focused disease management/chronic care model can

confound YSHCN when they enter the adult health care system. Unlike the pediatric model in which the child and family are the focus, the adult disease management model focuses its attention singularly on the young person with the expectation that he or she will take an active part in managing his/her own health—including consent for treatment. (See Appendix A)

In the typical pediatric practice, the patient population is healthy. Children and youth with one or more chronic conditions are exceptions and often accorded special treatment. In the internist/family physician's practice, a young person becomes one of many adults with chronic conditions (no longer special), and the family, which plays a central role in the pediatric practice, is supplanted by the expectation that young people act as self-advocates. The YSHCN is required to assume responsibility for establishing eligibility and securing and coordinating the services and supports that he or she receives, as eligibility for entitlement programs and service coordination often ends.

Differences in professional culture. When you look across societies, like Canada and Sweden with national health programs, the issue of transition doesn't go away even when payment is continuous. Cultural issues are the sub-context here. Pediatric and adult systems are very different. Physicians choose their disciplines early in their careers. Pediatricians want to treat children; internists elect to work with adults. A pediatrician may be concerned about the competence of adult-oriented providers to care for youth with pediatric onset conditions. An internist or subspecialist may create the medical home, but may not know the minute details about a pediatric on-set illness.

Even the word "transition" has different meaning. While the pediatric focus is on youth transition from pediatrics to adult care and services, transition among those in the "adult" world usually implies the transfer of a patient from a home or community setting into a hospital or other health care facility and vice versa.

Limited interaction between pediatric and adult health care. Families and pediatricians express difficulties in identifying physicians willing to be adult medical homes. The relationship that facilitates patient referral between physicians may not be in place. This can be problematic when it comes to finding an adult provider

willing to care for youth with pediatric onset conditions. The problem is compounded by the increasing shortage of primary care doctors. Limited reimbursement for care coordination presents yet another barrier. Navigating a fragmented health system and ensuring compatibility between the primary care physician/medical home, sub-specialists, hospital, and health plan further complicate the search.

Lack of incentives. Transition is a developmental milestone to be navigated by all youth. However, at present there is little incentive for pediatricians to transition youth to adult providers. While transition care plans are seen as important, lack of time and reimbursement issues often preclude their development. On the other hand, a demand for pediatric care may force pediatricians to transition youth to make room for new children transferring into their practices, or transition might be forced when children's hospitals refuse to accept young adults.

Change is normal. Everybody needs to come to agreement that change is going to happen and that it is natural. Unfortunately, not all youth and families and not all pediatricians see that young people *should* move into the adult healthcare system. Without planning and preparation for transition, families may be surprised when their children are refused care at a children's hospital because they have aged out. Without planning, an adult physician may be less willing to care for a youth with special needs. We want transition to happen when people are coping at their best, not when they are sick and showing up in an emergency room!

Every pediatric practice should have a policy, visibly posted, that gives the upper age-limit for youth served by the practice. For example: "We take care of young people until age 21 (18, 25, whatever it is)." This sets the expectation for transition. Likewise, patient activation and engagement needs to be a significant outcome measure of how the pediatric medical home is functioning.

The "activated" patient. Successful transition requires that pediatric practices become very empowering. As HRTW pediatric consultant, Dr. Rich Antonelli says to his fellow pediatricians, "We have to make an 'offer' to the adult care providers that they can't refuse!" By the time they are ready to enter the front door of the

adult healthcare system via the medical home, transitioning youth come as a paragon of an integrated care system:

- ✓ Youth and their families understand their respective roles and the roles of adult providers;
- ✓ An integrated care plan is developed that goes beyond family and significant others to encompass the broader circle of support available to youth;
- ✓ Care coordination is in place;
- ✓ Literacy issues and cultural issues have been addressed;
- ✓ The pediatrician has encouraged the youth and family to search for adult physicians and communicates confidence in the receiving physician's ability to become the medical home for the young person and/or provide specialty care.
- ✓ Maintaining health insurance is discussed

STRATEGIES FOR TITLE V CYSHCN PROGRAMS TO SUPPORT HEALTH CARE TRANSITION

Consider the ways in which our three Topical Call panelists suggested Title V agencies could work with their partners to promote the successful transition of YSHC from pediatric to adult health care:

Assure competent personal health workforce. Touch base periodically with the personnel and programs that monitor and report on physician availability and oversee areas with health manpower shortage designation in your state. Some also may be involved in recruitment for medically underserved areas. Let them know your needs and enlist their support in identifying and communicating the need for adult providers. Look for ways to partner with them during the recruitment process and in linking incoming health care providers to information about the services and supports that are available in their new communities to help young adults with special health care needs.

Alert your state's medical schools and family practice and internal medicine residency programs about the difficulties YSHCN are facing in accessing adult health care. Consider ways to raise awareness and coordinate efforts with programs that share a similar mission in increasing access to health care, including those that address disparities in health care. Enlist the assistance of your

state's federally-funded Area Health Education Centers (AHECs), which link the resources of university health science centers with local planning and educational and clinical resources. Consider reaching out to your state's association of federally-funded primary care and rural health centers whose mission is to promote access to comprehensive, community oriented primary health care for the underserved.

If there are areas of your state in which there are difficulties in finding adult providers, consider a survey of adult practices in the area, perhaps done in conjunction with your state's Title V MCH Block Grant needs assessment.

A pediatrician in North Carolina sent out a survey that asked "Are you willing to take on patients who are transitioning out of our practice who have special health care needs? How many are you willing to take? What are some of your areas of interests or specialties? What are some of your limitations?" She made some phone calls, talked to people, and from this was able to develop a directory of adult providers in her area who are willing to care for youth transitioning out of her pediatric practice. She provides this directory to her patients to help them locate adult physicians.

Since finding adult care is often by word of mouth, ask around and find out "Who is a good provider for this or that? Encourage families to do the same and share the information.

Mobilize community partnerships. Work with agencies such as vocational rehabilitation and centers for independent living that serve persons with disabilities and special health needs about health care transition and ask them to assist youth and their families in identifying physicians who serve adults with similar needs. Enlist the support of existing physician referral services such as those operated by local medical societies and hospitals.

Expand dialogue beyond pediatricians to include the American College of Physicians, American Academy of Family Physicians, and medical associations at the state and community levels. Consider ways to bring pediatric and adult physicians together so that they can get to know one another and build relationships. Include other members of the medical team—social workers, care coordinators, office nurses or other staff, school nurses, public health nurses, for the roles that they can play in supporting transition.

Talk to your public health colleagues in chronic disease prevention. Many have a long history of working with health care providers and others at the community level to build systems of care that support adults with chronic conditions.

Inform, advocate, and empower people about health issues. Give presentations to local medical societies and write brief articles for state and local medical newsletters and journals about health care transition and the ways in which your Title V CYSHCN program is preparing youth and families to successfully transition to adult care. Invite pediatric nurses, social workers and other pediatric practice staff to workshops on transition and offer continuing education units whenever possible. Help them prepare youth to be "*activated patients*." Let adult practices know that the youth they receive will be "*activated patients*."

Develop policies and plans that support individual and community health efforts. Consider the ways in which you might encourage the sending pediatricians to talk to the receiving adult physicians before an actual transfer takes place and to follow-up. If a pediatrician agrees to look over their shoulders, many adult colleagues are happy to take on YSHCN. If you contract with physicians for direct services, consider how you might include transition as a contract stipulation under the required scope of work. If you provide (or contract for) care coordination, consider having the care coordinator sit in on the first meeting with the adult provider to act as a bridge between the pediatric and adult providers and to offer support to the youth and family.

Many Title V programs maintain active relationships with their state medical schools and residency training programs, especially in regards to pediatric and women's health. Consider expanding this relationship to include family practice and internal medicine. Grand Rounds and other venues can be used to present programs related to health care transition. Young people can participate and describe important issues.

States often find it difficult to engage physicians in medical home/transition training and there are no great incentives for family practice physicians to do so. However, the Pennsylvania Medical Home Project has created a winning model. Unique

situations have been created in the residency programs for pediatric and family physicians within the hospital to work together. A coordinator introduces pediatric patients to family practice residents who then assume responsibility for their care. Later, when they go out on their own or into a private group practice, these physicians are familiar with the medical home concept as well as accustomed to working with CYSHCN. For more information see www.pamedicalhome.org.

Title V CYSHCN programs can play an important role in helping pediatric practices to develop a transition policy, identify and access community resources, and jointly develop care plans that include transition. Link pediatric providers to transition resources on the Internet through www.hrtw.org and other reputable sites. Consider how new electronics can help, such as encouraging people to use jump/flash drives to carry medical summaries or using web-based care plans. Some pediatric practices have few YSHCN so they see no need to develop a protocol. CYSHCN agencies can develop websites with template protocols, healthcare checklists, portable medical summaries, transition timelines, teaching sheets, and lists of local resources. A good example of what a state agency can do is the Illinois CYSHCN program at <http://www.uic.edu/hsc/dscc>.

Link people to needed personal health services and assure the provision of care when otherwise unavailable. Contracts and other agreements that your Title V CYSHCN agency executes with private and public providers are important mechanisms for promoting the expectation that youth and their families will receive preparation and support for transition. Make sure that contractors and their staff understand why transition is important, what is required for it to be successful, and have access to tools, resources, and other supports.

Title V agencies can focus on building relationships with primary care physicians especially in the regional offices (local staff with local physicians and their office staffs). Agencies can promote participation of offices in medical home projects and other grant activities such as with developmental disabilities, supported employment, or independent living agencies. Most states have interagency transition councils that would welcome health professionals. When health care providers don't have the time to

serve on interagency transition councils, consider the ways in which you can keep them informed and up to-date on transition issues, including services and supports available to YSHCN and their families. Also, don't forget to seek their input when planning and designing transition strategies. Remember, too, that many physician offices and group practice sites have a "gatekeeper"—or staff member who is the *go to* for families with questions or problems. Ask around and find out who these people are and contact them. They may welcome the opportunity to work more directly with you.

Title V CYSHCN programs can network with their education colleagues to promote the inclusion of personal competencies that support successful health care transition in the student's Individual Education Plan (IEP) and/or graduation plan and through health education curricula. Many states have interdisciplinary transition coordination efforts that promote transition planning across agencies. School nurses and school social workers also can be excellent allies in preparing youth to manage their health and successfully plan and negotiate the transition to adult health care.

All states have or will soon have MCHB-funded Family to Family Health Information Centers which can help to prepare families early for transitions. These can be a resource to CYSHCN staff and medical homes through their mentoring programs, educational offerings and leadership development for youth and families to help them become informed, activated patients. For more information see www.familyvoices.org/projects/f2f.

Remove administrative barriers. Legally, families cannot be in the room with young adults age 18 and older without their permission or with guardianship. It isn't a very good start for an adult-oriented physician to ask families to leave on the first visit if they have never done that. Prepare youth and families for legal adulthood at age 18 by giving youth opportunities to give assent/consent for procedures, discuss options for care, and learn to gather information.

Remove administrative and financing barriers for cross-specialty co-management to support education, capacity-building, and sustainability. Insurance and Medicaid barriers currently do not provide compensation for pediatric and adult primary care

physicians to be able to communicate and co-manage young adults. State agencies can promote policies that encourage providers to be able to reach out to their colleagues across the age threshold for ongoing co-management and promote reimbursement for care coordination and transition planning through Medicaid and private insurance

Help pediatric practices to use Care Plan Oversight CPT Codes; these can be used as administrative data to track progress and may lead to reimbursement.

Evaluate effectiveness, accessibility, and quality. The National Committee on Quality Assurance (NCQA, see www.ncqa.org), and others are developing assessment tools for the medical home. The corporations that buy health insurance for their employees are demanding improved access to care, improved quality of care, and linking reimbursement to high performing community-based systems of care. State agencies can stay abreast of these changes with the state's medical community. Moreover, in their advocacy roles, Title V and other policy makers can promote links with payers and incentives, including pay for performance.

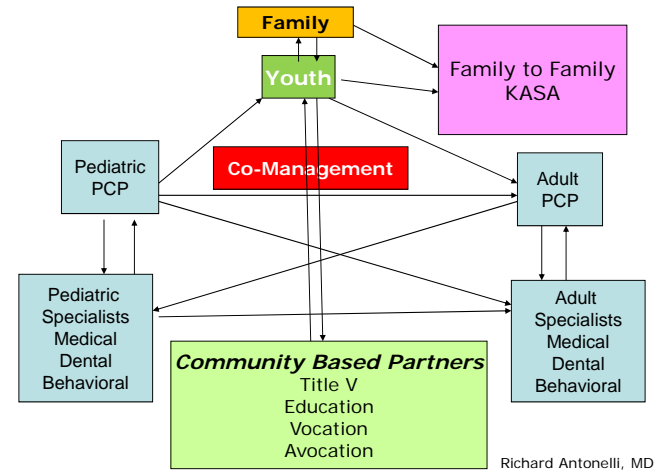
Use data and other information to educate policymakers about the importance of healthcare transition. As states work on the Five Year Needs Assessment required for the Maternal Health Block Grant, consider how data and other information that you collect can be widely disseminated to state and local policymakers, health care providers, YSHCN and their families, and other stakeholders. Use data and other findings to make the case for transition programming and to document your progress. State and national data from the Behavioral Risk Factor Survey, (<http://www.cdc.gov/BRFSS/>) and Kids Count, <http://www.kidscount.org/datacenter/databook.jsp> can be used along with the National Survey of CSHCN.

Build a system of care that supports transition. In exercising its public health role, Title V has a long tradition of mobilizing public and private sector pediatric health care providers, medical training programs, government policy makers, YSHCN and their families, and other stakeholders in building pediatric systems of care. Now that CYSHCN are surviving into adulthood and in

need of adult health care, Title V is charged with expanding its definition of the system of care to include the adult medical community and other adult-focused community resources. The challenge is to prepare youth and their families, facilitate cross-system collaboration between pediatric and adult providers, and ensure on-going access to community services and supports as YSHCN exit the pediatric system and enter into the adult system.

Start early. Transition is part of the natural developmental process for all children. Transition planning should start at diagnosis for children with special needs. The system of care can build a sense of the future for families. State CYSHCN agencies can support families, physicians, and health and social service professionals to envision and plan for the future.

Pediatric to Adult Systems of Care: Possibilities



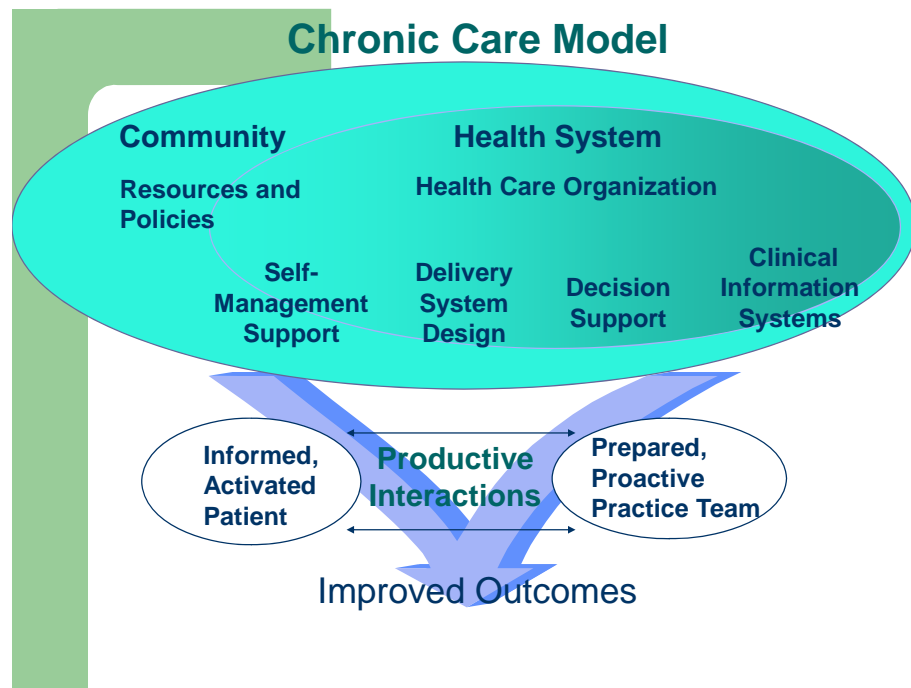
Issues: Capacity, training, communication, changing roles of youth, financing mechanisms, professional culture and traditions

Strategies: Outreach and education (youth, families, pediatric and adult providers, primary care and subspecialty.) Remove administrative and financing barriers for cross-specialty co-management

Appendix A

The Chronic Care Model: A System of Care for Chronic Illness

The Chronic Care Model is an organizational approach to caring for people with chronic disease in a primary care setting. The system is population-based and creates practical, supportive, evidenced-based interactions between an informed, activated patient and a prepared, proactive practice team (Wagner, et al). The model predicts that improving its six interrelated parts—self-management support, clinical information systems, delivery system redesign, decision support, health care organization, and community resources—can reform systems. The model also highlights the key role of organizational leadership, and the importance of linking health services and community resources.



Developed by The MacColl Institute
ACP-ASIM Journals & Books
<http://www.improvingchroniccare.org/>

Resources:

For more materials, see www.hrtw.org/tools and www.hrtw.org/healthcare

American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP), American Osteopathic Association (AOA). Joint Principles of the Patient-Centered Medical Home 2007 <http://www.pcpc.net/node/14>

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. Pediatrics. 2002;110: 1301-1335 Supplement <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/6/S1/1304>

American College of Physicians. The Advanced Medical Home: A Patient-Centered, Physician-Guided Model of Health Care: A Policy Monograph 2006 http://www.acponline.org/advocacy/where_we_stand/medical_home/

Catalyst Center – MCHB-funded National Center for insurance <http://hdwg.org/catalyst/>

Champions, Inc. – MCHB-funded National Center for community organization <http://www.championsinc.org/>

Kids As Self Advocates (KASA) www.fvkasa.org Youth involvement

McManus M, Fox H, O'Connor K, Chapman T & MacKinnon J (2008) Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care. National Alliance to Advance Adolescent Health. <http://www.incenterstrategies.org/jan07/factsheet6.pdf>

Medical Home Learning Collaboratives and Chronic Care Model: <http://www.medicalhomeinfo.org/model/learning.html>

Medical Home Training modules – includes comprehensive coordinated care and transition; curriculum developed with Title V participation: <http://www.medicalhomeinfo.org/training/index.html>

National Survey of Children with Special Health Care Needs www.cshcndata.org

Survey of Adult Health Care Providers (2008) about Health Care Transition for Youth with Special Health Care Needs by New Hampshire Special Medical Services Title V /CSHCN. See <http://www.nhps.org/default.htm> or contact Kathy Higgins Cahill at kcahill@dhhs.state.nh.us

Book: Betz, CL & Nehring, WM (2008). Promoting Health Care Transitions for Adolescents with Special Health Care Needs and Disabilities. Brookes Publishing, <http://www.brookespublishing.com/store/books/betz-68608/index.htm> for table of contents and ordering information

Transition Resources from State Title V programs:

Alabama: Transition resources and youth involvement in Title V
<http://www.rehab.alabama.gov/Home/default.aspx?url=/Home/Services/CRS/Main>

Arizona: Parent-Youth Leadership Curriculum:
<http://www.azdhs.gov/phs/ocshcn/index.htm>

Arkansas: Teen Transition brochure:
<http://www.medicalhomear.org/publications.html>

Colorado: Transition Guide and Transition Workbook at:
<http://www.cdphe.state.co.us/ps/hcp/outcomes/six.html>

Florida: <http://www.cms-kids.com/kids/teens/transitions.html>

JaxHATS: <http://jaxhats.ufl.edu/> Assessment forms

ICHP Transition project: <http://hctransitions.ichp.edu/> Site has some streaming videos.

Hawaii: <http://hawaii.gov/health/family-child-health/cshcn/cshcnoutcomes.html>
Personal health record; workbook

Illinois: <http://www.uic.edu/hsc/dscc/>; provider information at
<http://internet.dscc.uic.edu/dsccroot/providers/providers.asp#transition>

Kansas: A transition poster (in English or Spanish) that can be used in offices; contact Mary Ann Bechtold at MBechtol@Kdhe.state.ks.us

Kentucky: Transition education materials
<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>
also, www.transitiononestop.org

Maine: <http://www.servicesforme.org/> YouthSpeak and other youth involvement and transition materials developed in HRTW projects

Maryland: http://www.fha.state.md.us/genetics/healthcare_transition.cfm
10 steps to health care transition

Massachusetts: <http://www.mass.gov/dph/fch/dpech.htm> *We are Able* video;
<http://www.communityinclusion.org/page.php?id=2&page=pubs&type=topic>;
Center for Community Inclusion booklet from HRTW

Michigan: http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_35698-135030--,00.html; newsletters from YAC and transition resource manual

Minnesota: <http://www.health.state.mn.us/divs/fh/mcshn/transition.htm>

Nebraska: <http://www.answers4families.org/family/youth-transition> CMS-funded Portals Medical Transition Project

New Mexico: <http://www.nmtransition.org/> Transition video, "What Comes Next" with discussion guide. Contact Elaine Abhold at Elaine.abhold@state.nm.us

New York: http://www.health.state.ny.us/community/special_needs/index.htm
4-page health summary

Oregon: <http://www.ohsu.edu/outreach/cdrc/occyshn/resources/materials.html>
Oregon's Medical Home project transition materials:
<http://www.ohsu.edu/outreach/cdrc/medicalhome/providers/transition.html>

Pennsylvania:
<http://www.dsf.health.state.pa.us/health/cwp/view.asp?A=179&O=243876>
39 page transition checklist

Texas: <http://www.dshs.state.tx.us/cshcn/transinfo.shtm>

Utah Medical Home Project transition materials:
http://www.medhomeportal.org/sections/index.cfm?section_id=4§ion_content_id=67 and **Becoming Leaders for Tomorrow** <http://blt.cpd.usu.edu/>

Washington Adolescent Health Transition Project:
<http://depts.washington.edu/healthtr/>

Wisconsin Medical Home project (Title V collaborated)
<http://wimedicalhometoolkit.aap.org/transitions>

Wisconsin HRTW project: <http://www.waisman.wisc.edu/hrtw/>

Wyoming: Care Coordination manual has transitioning (see last appendix)
<http://wdh.state.wy.us/familyhealth/csh/carecoord.html>



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