How to Use This Action Guide

This guide identifies strategies and action steps to address Health Care Transition. The goal is for youth to move from school to work, from Pediatric to adult health care and from living at home to independent living. The challenge is to identify and access adult services, to develop age/ability-appropriate support systems, and maximize independence - insuring that elements of a Medical Home Approach are in place.

This MCH Action Guide is divided into four sections:

- “How to Use”… the goal and the challenge
- “What’s at Stake”… background information and data
- “What Works”… best practices or promising strategies
- “Resources and Tools”… both State and National links - plus tips for writing SMART objectives

Maternal Child Health (MCH) Consultants can provide technical assistance to incorporate action guide information into local MCH operational plans. MCH Consultants are also ready to consult on specific content material. Resources regarding effective goals and SMART objectives can be found on the last page of this guide. To contact an MCH Consultant about Health Care Transition call: 303-692-2370. Also, please visit the HCP website at http://www.hcpcolorado.org.

What is at stake?

Previously, few children with chronic, debilitating health conditions survived to adulthood. Now, over 90% of youth with special health care needs (YSHCN) reach their 21st birthday.

Most existing transition services originate through the school system, but rarely are health care professionals consulted. Without addressing health care needs, successful transition is impossible.

About 70% of adults with disabilities (18-65) are unemployed.

Access to health care is a primary barrier keeping people with disabilities outside of the workforce.

The vast majority of YSHCN want to work and be active, productive participants in society.
Strategy #1: Leverage the Strengths and Assets of Community Partners.

The Colorado Department of Education along with local school districts assume the primary responsibility for transitioning youth from school to the next steps forward toward adult independence. For youth with special health care needs, many other State agencies, social service organizations, health care professionals and advocacy groups may be helpful or necessary partners.

As you provide referral and resource information, provide care coordination and promote community collaboration, consider these partners and brainstorm additions to this list:

- The youth themselves, along with the family and community members significant to them
- Educators, School Staff, School Nurses
- Family Practice Providers, Pediatricians
- Specialty Providers, Adult Practice Providers
- Mental Health Professionals
- Dental/Oral Health Professionals
- Youth Advisory and Family Groups
- Civic, Cultural, Business and Media Leaders
- Faith Communities
- Vocational Rehabilitation Partners
- Transportation/Mobility Experts
- Assistive Technology Partners
- Policy makers
- Insurance and Workforce Navigators
- Community Centered Boards (CCB)
- Nutrition, Occupational and Physical Therapists
- Post-Secondary Education Partners
- Leisure/Recreation Program Experts
- Assisted Living Partners

ACT!

- Assess the needs of your community – What do families need? What do providers want? What are the concerns of youth themselves? What resources currently exist and what resources are lacking? Are current services effective?
- Form an advisory group or use an existing coalition to develop community-specific strategies to address identified transition priorities.
- Develop or facilitate interagency agreements, memorandums of understanding or policy briefs that define and explain community partner roles and services.

* Remember: Transitioning youth to all aspects of adult life is an enormous task that involves many domains: education, employment, independent living, community involvement, recreation, leisure and more. The MCH role is to bring "health" to the table... to address health care concerns and promote a Medical Home Approach in all aspects of transition planning.

Questions to Ask:

- What transition services are currently in place? Is “health” appropriately acknowledged?
- What strategies will promote the inclusion of Medical Home concepts into transition planning?
- What will your group actually do to create and achieve health care transition outcomes?
Strategy #2: Establish MCH connections between both local schools and local health care providers.

Most youth with special health care needs attend school, and in most cases these students will have an Individualized Education Program (IEP) or a 504 Plan that addresses in some fashion their special health care needs. Transition issues should be an element of these plans as children approach adolescence. Hopefully, too, most youth with special health care needs have a primary care provider with whom transition concerns can be addressed. Typically, however, the school and the doctor do not have ongoing conversations. HCP Teams and their partners can provide strategies and tools to promote communication and promote a Medical Home Approach to transition planning.

- Communicate with Special Education Directors, Transition Coordinators and/or individual school building personnel to explain the role Public Health plays in "connecting kids with care" and building community systems.
- Empower youth and families to advocate for a Medical Home Approach.
- Communicate with both pediatric and adult medical providers to explain how Public Health can assist in expanding a Medical Home Approach for youth with special health care needs.
- Raise awareness of the importance of a Medical Home Approach among non-health care professionals.
- Provide training to promote transition planning and a Medical Home Approach.

Questions to Ask:

- Are you able to clearly explain how transition planning is an essential element of a Medical Home Approach?
- Do you have the "marketing materials" necessary to share/explain your role?
- What connections currently exist that would facilitate communication with school personnel? Parents? School Nurses? Speech Clinicians? Social Workers?
- Are you able to clearly explain to providers how your services can help them expand their own capacity and increase family satisfaction?
- How can you promote a Medical Home Approach and transition planning consultation within your current capacity?
Strategy #3: Provide transition planning and consultation through HCP Care Coordination and Specialty Clinic Service.

Much of what follows reflects standard practice for local HCP Teams and County Nursing Services. The work involved in these "enabling services" does help to establish interagency collaboration, to build and strengthen service infrastructure and, in many cases, may lead to policy initiatives and change. As you engage in these activities, always keep this infrastructure and systems-building potential in mind!

- Assemble materials that are helpful to youth, families and community partners... Tool Kits, Guides, Check Lists, Medical Summary Templates, Workbooks and Resource Lists.
- Empower youth and families to include primary care providers in transition planning and to advocate for a Medical Home Approach.
- Develop and expand directories of local services.
- Provide "outreach" to targeted populations for whom health care transition is judged to be an area of need.
- Utilize other agencies and partners who may provide services such as navigating insurance options, applying for public assistance, developing workforce readiness skills, continuing education and job training programs.
- Utilize MCH Consultants for strategic planning and resource development.

Questions to Ask:

- What transition planning services do you currently provide to primary care providers utilizing HCP Care Coordination? What level of satisfaction do providers report?
- Which resource materials need revision? What needs to be developed?
- How well are schools and other facilities addressing transition needs? What percent of YSHCN have transition plans?
- Might training opportunities or connections to more distant resources expand the capacity of local providers to serve youth in transition?
- Are youth and families currently receiving appropriate and adequate information about transition planning through Care Coordination and Specialty Clinic Services?
Resources and Tools

From Children's Services to Adult Systems of Care

State Resources

Colorado Department of Public Health and Environment Prevention Services Division – Health Care Program for Children with Special Needs (HCP)
www.hcpcolorado.org

Colorado Department of Education Exceptional Student Leadership Unit
http://www.cde.state.co.us/cdesped/TransResources.asp

Colorado Division of Labor and Employment Workforce Centers
www.coworkforce.com

Colorado Division for Developmental Disabilities Statewide Community Centered Boards
www.cdhs.state.co.us/ddd/CCB_Main.htm

National Resources

Healthy and Ready to Work National Resource Center
http://www.hrtw.org/index.html

Health Care Transitions
http://hctransitions.ichp.ufl.edu/

American Academy of Pediatric Medical Home
www.medicalhomeinfo.org

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

National Alliance for Secondary Education and Transition
http://www.nasetalliance.org/about/index.htm

Fact Sheets and Tool Kits

A Guide to Transition Services for Youth with Special Health Care Needs
http://www.cdphe.state.co.us/ps/hcp/transition/transitionguide.pdf

It's Time to Transition!
A Workbook for Young Adults, Their Families and Their Providers
http://www.cdphe.state.co.us/ps/hcp/transition/workbook.pdf

Charting a Course for the Future - A Transition Tool Kit
http://www.cde.state.co.us/cdesped/TK.asp

Transition PowerPoint Sets - Adolescent Health Transition Project – Washington State
http://depts.washington.edu/healthtr/powerpoint/default.html

Transition Fast Facts- Colorado Department of Education
http://www.cde.state.co.us/cdesped/TransResources_FF.asp

Technical Assistance

To develop goals and S.M.A.R.T. objectives visit this interactive website:
http://apps.nccd.cdc.gov/dashoet/writing_good_goals/page002.html

For technical assistance, contact an MCH Specialist on Health Care Transition: 303-692-2370.