What’s HEALTH Got to Do with Transition? EVERYTHING!

Healthy & Ready to Work
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NCSET
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Overview

- Federal Mandates
- The Health & Wellness Connection
- HRTW Tools & Resources
Disabled??
Special Health Care Needs?

HEALTH SERVICES
- Children & Youth with Special Health Care Needs (CYSHCN)
- Genetic
- Chronic Health Issues
- Acquired

EDUCATION SERVICES
- Youth with Disability
- Youth with Health Impairment

ADA & 504
- Disability & Health Impairment
Title V CYSHCN - Federal

HHS ➔ HRSA ➔ MCHB

1912 - The Children's Bureau
1935 - Title V of the Social Security Act
   Maternal and Child Health Services
   - STATE: Crippled Children's Services (CCS)

1989 – name change
   ➔ Maternal & Child Health Bureau
   www.mchb.hrsa.gov
   ➔ Title V CSHCN Programs
Title V CYSHCN – OBRA ‘89

- Family Centered
- Community Based
- Coordinated Care
- Culturally Competent
- Provide rehabilitation services to children under age 16 who receive SSI benefits
State Title V CSHCN Programs

- birth - 18 or 21
- varies from state to state
- may be limited by diagnosis, income, or age.
- Some programs provide direct services
- Some focus on assuring access to specialty services.

Directory of State Title V CSHCN Programs
www.championsforprogress.com
Who are CYSHCN??

“Children and youth with special health care needs are 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.”
Federal Mandates

- **Supreme Court decision - Olmstead** (1999)
  Affirmed the right of individuals with disabilities to live in the community rather than in institutions whenever possible.

- **President’s New Freedom Initiative** (2001)
  Responsibility given to HRSA for developing and implementing a community-based service system.
HRSA's MCHB will take the lead in developing and implementing a plan to achieve appropriate community-based services systems for CYSHCN and their families.

Barrier Addressed by Solution / Access to:
1. Comprehensive, family-centered care
2. Affordable insurance
3. Early and continuous screening for SHCN and
4. Transition services to adulthood
Transition to Adulthood

Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. (2002)
HRTW Phase II Projects

- **HRTW NATIONAL CENTER:** AED, Washington, DC
- **HRTW-AZ:** Southwest Institute for Families & OCSHCN
- **HRTW-IA:** Employment Policy Group, Ctr. for Disabilities & Development, Univ. of Iowa
- **HRTW-ME:** Maine Support Network, Western ME Partnership, Univ. of ME at Farmington
- **HRTW-MS:** Healthy Futures, Coalition for Citizens w/Disabilities
- **HRTW-WI:** Waisman Ctr., Univ. of WI – Madison
CYSHCN

9.4 million (13%) <18  www.cshcndata.org

Title V CYSHCN: 1,255,152 (0-18*)
SOURCE: Title V Block Grant FY 2005 Application
* Most State Title V CYSHCN Programs end at age 18

SSI Recipients:  959,379 (0-17)
321,114 (13-17)
243,689 (18-21)
460,019 (22-29)

SOURCE: SSA, Children Receiving SSI, December 2002, 2004
Transition & ......Screening
Health Impacts All Aspects of Life

Success in the classroom, within the community, and on the job requires that young people with special health care needs stay healthy.

To stay healthy, young people need an understanding of their health and to participate in their health care decisions.
Health & ....Life-Span

SECONDARY DISABILITIES
- Prevention/Monitor
- Mental Health, High Risk Behaviors

AGING & DETERIORATION
- Info long-term effects (wear & tear; Rx, health cx)
- New disability issues & adjustments
Screen for Life Areas

How does health affect:

- Employment
- Leisure, Recreation
- Community: transportation, housing, activities
- Higher Education or Training
Screen for ALL Health Needs

- Hygiene
- Nutrition
- Exercise (Fitness, Stamina)
- Sexuality Issues
- Mental Health
- Routine (Immunizations, Blood-work, Vision, etc.)
Transition & Medical Home
Consensus Statement: Health Care Transition (Sept. 2001)

American Academy of Pediatrics
American Academy of Family Physicians
American College of Physicians-American Society of Internal Medicine

CONSENSUS STATEMENT calls on physicians to:

• Maintain an up-to-date portable medical summary

• Create a written health care transition plan by age 14: what services, who provides, how financed

(Pediatrics 2002:110 (suppl) 1304-1306)
“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 the disease and his/her life.”

Allies: Medical Partnership

- Health & Wellness
- Health connection to performance?
- Rx for DME, AT
- Medical Evidence/Documentation to qualify for program eligibility
Transition & .... Health Care
Transition & ......Insurance

NO HEALTH INSURANCE

- 2 out of 5 college graduates (first year after grad)
- 1/2 of HS grads who don’t go to college
- 40% age 19 - 29 - uninsured during the year
- 2x rate for adults ages 30-64

SOURCE: Commonwealth Fund 2003
PUBLIC: Medicaid

**MAINTAIN MEDICAID**
- Passed SSI Redetermination - continue benefits.
- Emancipated Minor

**DROP FROM MEDICAID**
- Former childhood SSI recipient at age 18 did not qualify under SSI redetermination and loses benefits (income too high or does not meet disability criteria.)

**NEW to MEDICAID**
- Child did not qualify for SSI under 18 due to family income. Age 18 may qualify for SSI and Medicaid as an adult single head of household.
NOT APPROVED - PROVISION TO CONTINUE RECEIVING SSI BENEFITS

- **SECTION 301** - Individuals found ineligible during redetermination may continue to receive SSI benefits **IF** they began receiving state vocational rehabilitation agency services **before their 18th birthday**. Section 301 allows the young adult to retain benefits while he/she participates in approved voc rehab program.

http://policy.ssa.gov/poms.nsf/lnx/0412515001
**Medicaid while Working**

**WORKING - Continued Medicaid Eligibility Section 1619(b)**
- still meets SSI criteria,
- needs Medicaid in order to work; and
- gross earned income is insufficient to pay for other public supports.

**MEDICAID BUY-IN via TICKET TO WORK**
- Worker could opt to buy-in and receive Medicaid benefits. Program is too new to assess if states are providing full benefit packages and at what level of sliding fee.
PRIVATE: Family, Employer or Solo

MAINTAIN BENEFITS via FAMILY PLAN

- Adult Disabled Dependent Child
- Student Status

Pays for health care benefits plan through:

- College - student plan
- Employed - group plan
- Self-pay: single plan
- Ticket to Work (Medicaid Buy-in)
- COBRA
Transition & ......Family & Youth
Transition to Adulthood is successful when ..... 

- Youth Leaders are partners in policy review and development

Youth have:
- voice and are heard in their own health care decisions
- Medical care that meets their needs and developmental issues
- insurance that is not in jeopardy due to getting older or working
Transition to Adulthood is successful when ..... 

Youth are

- supported in their aspirations and have the opportunity to try!
- financially supported to learn new skills for economic independence
- are working

Family members are working because services and supports are in place
Transition to Adulthood
Glen, age 30 - professional turf writer and thoroughbred racing analyst. One of only 6 people who provided Beyer Speed Figures for the Daily Racing Form.

Doctors predicted that he wouldn’t live to see his 2nd birthday due to SMA. He outlived his Doctor.

He used a motorized wheelchair to move, a portable ventilator to breathe and voice activated software to work at a computer, and acted as if these were minor inconveniences. “I’m just a person who needs more equipment.”

*Insurance:* Court ordered Private through Father & Step-mother
HRTW TEAM

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HRTW Projects
http://www.hrtw.org/about_us/projects.html
What's HEALTH Got To Do With Transition? EVERYTHING!

Health Impacts All Aspects of Life
Success in the classroom, within the community, and on the job requires that young people with special health care needs stay healthy. To stay healthy, young people need an understanding of their health and to participate in their health care decisions.

We provide information and connections to health and transition expertise nationwide – from those in the know, doing the work and living it!

This site focuses on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes provider preparation plus tools and resources needed to make more informed choices!
HRTW 2 GO: Information & Tools

Web-based resources that focuses on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes provider preparation plus tools and resources needed to make more informed choices!
Tips, Tools & Solutions

HRTW 2 GO Materials (developed by HRTW Projects)

Systems & Services
http://www.hrtw.org/tools/hrtw_go.php

Youth Involvement
http://www.hrtw.org/tools/hrtw_go_youth.php

Tools & Solutions
http://www.hrtw.org/tools/hrtw_go_tools.php

Health Care
http://www.hrtw.org/tools/hrtw_go_health.php
Tips, Tools & Solutions - 2

- Assessment Tools & Checklists
  http://www.hrtw.org/tools/check.html

- Youth Involvement
  http://www.hrtw.org/youth/index.html

- HRTW 2 Go - Youth Involvement
  http://www.hrtw.org/tools/hrtw_go_youth.php
**Tips, Tools & Solutions - 3**

- National Center for Medical Home Initiative
  [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

- Health Care Insurance Fact Sheets
  [http://www.hrtw.org/healthcare/hlth_ins.html](http://www.hrtw.org/healthcare/hlth_ins.html)

- HRTW Health Care Insurance Tools
Tips, Tools & Solutions - 4

- **A Primer on Insurance**
  [http://www.umaine.edu/cci/service/maine_works/primer.htm](http://www.umaine.edu/cci/service/maine_works/primer.htm)

- **Learning About Health Insurance: A Grade 5-12 Curriculum Aligned with Maine’s Learning Results**
  [http://www.umaine.edu/cci/service/maine_works/healthinsccurr/index.htm](http://www.umaine.edu/cci/service/maine_works/healthinsccurr/index.htm)
Transition to Adult Health Care:

A Training Guide (Two Parts)

http://www.waisman.wisc.edu/hrtw/Adult_Teen.pdf

This training guide is intended to serve as a framework for anyone interested in helping young people with special health care needs and their parents prepare for the transition to adult health care. Training has been divided into two parts: Part One, aimed at parents of children with special needs, and Part Two, aimed at the young people themselves. (94 pp, 2005)
HRTW Clinical Tools & Checklist
http://www.hrtw.org/tools/

- Guidelines/Policy
- Manuals/Brochures
- Screening
- Assessment
- Provider Checklist
- Health Care Plans / Forms
- Youth/Family Education
- Evaluation
- Portals
The LAWS
http://www.hrtw.org/tools/laws_leg.html

- Term Special Health Care Needs / Disability
- Disability Rights Portals
- Education Issues
- Employment & Disability
- Equal Opportunity Access (504, 508 & ADA)
- Family Medical Leave Act
- HRSA/MCHB – Title V Legislation
- Health Insurance Benefits
- SSI/SSDI