



## What's HEALTH Got to Do with Transition? EVERYTHING!

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## Health Impacts All Aspects of Life

Success in the classroom, community, and on the job requires that young people are healthy.

- Increased understanding of health issues
- Participate in health care decisions
- Ultimate – Manage health & wellness

## Overview

- Definitions
- Federal Mandates (follow \$)
- Health Insurance Options
- Health & Wellness
- Advice with Hindsight (Lessons learned)
- Take Away Messages

## Definition: Health? More than a Payor

### HEALTH

- Wellness (Maintain, Improve)

### HEALTH CARE SERVICES

- Medical Home - Primary Care
- Care Coordination

### HEALTH INSURANCE

- Public (Medicaid to Medicare)
- Private (Family Plan/Self)

## 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 that impacts learning (IEP)
- Youth w/ Health Impairment that needs support (504)

### FEDERAL LAWS: ADA & Section 504

- Disability and/or Health Impairment

## 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.”

McPherson, M., et al. (1998). A New Definition of Children with Special Health Care Needs. *Pediatrics*. 102(1);137-139.  
<http://www.pediatrics.org/search.dtl>

## Data: Children & Youth with disabilities and health needs

Nationwide	9.4 million (13%) <18
Title V CYSHCN	963,634 (0-18*)
SSI Recipients	1,036,990 (0-17) 386,360 (13-17)

1. [www.cshcndata.org](http://www.cshcndata.org)
2. Title V Block Grant FY 2006, [www.mchb.hrsa.gov](http://www.mchb.hrsa.gov)  
\* Most State Title V CSHCN Programs end at age 18
3. SSA, Children Receiving SSI, December 2005, [www.ssa.gov](http://www.ssa.gov)

## SSI Recipients Who Work: 18-29

### Youth & Young Adults

	PASS	IWRE	BEW
under 18	3,314		1.0%
18-21	32,658		9.7%
22-29	79,819		23.7%
<b>National total</b>	<b>1,582</b>	<b>6,310</b>	<b>2,552</b>
under 18	3	4	5
18-21	65	312	111
22-29	321	2,042	619

SOURCE: SSA, SSI Disabled Recipients Who Work, 2005

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## Federal Mandates – Health Connection

### The President's New Freedom Initiative

HRSA/MCHB: develop and implement a community-based service system

1. Comprehensive, family-centered care
2. Affordable insurance
3. Early and continuous screening for SHCN
4. **Transition services to adulthood (Health)**

Surgeon General's Call for Action  
Improve the Health and Wellness  
of Persons with Disabilities 2005

1. Persons with disabilities can lead long, healthy, productive lives;
2. Health care providers have knowledge and tools to treat the whole person with a disability with dignity;

<http://www.surgeongeneral.gov/library/disabilities/calltoaction/whatitmeanstoyou.html>

Surgeon General's Call for Action  
Improve the Health and Wellness  
of Persons with Disabilities 2005

3. Promote good health by developing and maintaining healthy lifestyles;
4. Accessible health care and support services promote independence for persons with disabilities.

<http://www.surgeongeneral.gov/library/disabilities/calltoaction/whatitmeanstoyou.html>

State Title V CSHCN Block Grant

National Performance Measures

To help states develop effective mechanisms to achieve a system of care for all children with special health needs and their families by 2010, six national performance measures (NPM) will serve as a guide to states in meeting this goal.

SOURCE: BLOCK GRANT GUIDANCE  
New Performance Measures See p.43  
<ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf>

HRSA/MCHB

CORE National Performance Measures

1. Screening
2. Family
3. Medical Home
4. Health Insurance
5. Community Services
6. Transition

BLOCK GRANT GUIDANCE

Screening

**SECONDARY DISABILITIES**

- Prevention/Monitor
- Mental Health
- High Risk Behaviors

**AGING & DETERIORATION**

- Info long-term effects (wear & tear; Rx, health cx)
- New disability issues & adjustments



Family

**Aspirations & Expectations**

- Aspirations → Youth (Opportunity to Try)
- Expectations → Adults (Raising the bar)
- HEALTHY - How to stay well for longer periods

## Medical Home

Not a building, house or hospital

- It is an approach..... providing comprehensive primary care
- Consensus Statement: Health Care Transition (Sept. 2001)
- Maintain portable medical summary



## Tool: Portable Medical

Summary see HRTW Tool

- Medical Evidence/Documentation
  - qualify for program eligibility
  - obtain funding/reimbursement
- One page – Reference Sheet
  - contact info (person, health surrogate, doctors, vendors)
  - communication / learning
  - prioritize health issues
  - medications
  - equipment

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## Health Insurance: Plan Ahead

No Health Insurance - Ages 20-29, 2x rate – adults 30-64

- 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



## Prepare for the Realities of Health Care Funding

### Insurance

- Aging out of health care plans and services (private insurance, EPSTD, state Title V)
- Temporary jobs often do not include insurance or premiums are too high compared to the starting pay

## Prepare for the Realities of Health Care Funding

### Jeopardy

- Desire to work and be independent may jeopardize dependent status to remain on health plan.
- Increased salary may affect SSI payments (lower or eliminate which then may cause to lose Medicaid)

**Health Insurance: SSI  
GATEWAY to Medicaid Benefits**

Medicaid is automatic in all but 11 states known as "209B States"

CT, HI, IN, IL, MN, MO, ND, NH, OK, OH, and VA

- State requires separate application to Medicaid
- State has at least one more stringent requirement than the SSI rules for Medicaid eligibility

**Health Insurance:  
SSI GATEWAY to COBRA**

- Individuals applying for COBRA disability determinations do NOT have to meet the nondisability requirements (income) for SSDI (Title II) or SSI (Title XVI) to qualify for the extended coverage.
- EXTENDS COBRA → 11-mo. disability extension

[http://www.cms.hhs.gov/COBRAContinuationofCov/09\\_NoticesRequiredofQualifiedBeneficiaries.asp](http://www.cms.hhs.gov/COBRAContinuationofCov/09_NoticesRequiredofQualifiedBeneficiaries.asp)

**Health Insurance:  
Public/Medicaid**

**Maintain Medicaid**

- Passed SSI Redetermination cont. benefits.

**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.

**Health Insurance: Public**

- "STUDENT CHILD" up to age 22

Effective April 1, 2005 Section 432 of the Social Security Protection Act extended the student earned income exclusion (SEIE) to any individual under the age of 22 regularly attending school, college, or training designed to prepare him/her for a paying job, this includes students who have IEPs.

<https://s044a90.ssa.gov/apps10/poms.nsf/lnx/0500501020>

→ REMEMBER SSI GATEWAY TO MEDICAID!!

**Health Insurance: Private**

**Maintain Benefits via Family Plan**

- Adult Disabled Dependent Child 40+ states
- Student Status
- New State Laws: extend age regardless of Dx (ie NJ: Youth stays on family plan until age 30)
- ERISA plans can change age limitations

**Health Insurance: Private**

Youth Pays for health care benefits via:

- COBRA
- College - student plan
- Employed - group plan
- Self-pay: single plan
- Ticket to Work (Medicaid Buy-in)

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## Health Care providers as Allies

- **Develop a Transition Plan** – Wellness, Care, Productivity, Insurance
- **Identify Medical supports:** at school, nearby campus, and plans for emergency and inpatient events.
- **Teach Wellness** – Proactive Wellness, beyond the diagnosis, know about the disability.
- **Assess for Modifications** - Work Load, and equipments/assistive technology.

## Healthy & Ready... Legal Impact Informed Decision Making

1. Privacy - HIPAA - Health Records
2. Consent – Signature Treatments (signature stamp)
  - Assent to Consent
  - Varying levels of support (varies due to health)
  - Stand-by (health surrogate)
  - Guardianship (limited → full)

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## Prepare for the Realities of Health Care Services

### Difference in System Practices

- Pediatric Services: Family Driven
- Adult Services: Consumer Driven

The youth and family finds themselves between two medical worlds...that often do not communicate.

Issue	Pediatric	Adult
Age-related	Growth& development, future focussed	Maintenance/decline: Optimize the present
Focus	Family	Individual
Approach	Paternalistic Proactive	Collaborative, Reactive
Shared decision-making	With parent	With patient
Management	Prescriptive	Collaborative
Non-adherence	>Assistance	< 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 employment
Care provision	Interdisciplinary	Multidisciplinary
# of patients	Fewer	Greater

## Health Care Transition Consensus Statement

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

Pediatrics 2002;110 (suppl) 1304-1306

Calls on physicians to:

1. Understand the rationale for transition from child-oriented health care
2. Have the knowledge and skills to facilitate that process

## Health Care Transition Consensus Statement

3. Know if, how, and when transfer of care is indicated
4. Maintain an up-to-date portable medical summary
5. Create a written health care transition plan by age 14: what services, who provides, how financed

## Lessons Learned: AERC

Participants – DC 12 -18 years

- SSI Qualify Diagnosis: 80% MR,LR, CP
- Dual conditions: 40%  
emotional issues, ADHD, asthma, obesity, diabetes, musculoskeletal

Tip: If youth needs prescription medications, other medical conditions likely and can derail progress to independence if not attended to.

## Lessons Learned: AERC

After 1 Yr in the AERC,  
active\* 13 yr olds:

- **AGE 13-- more engaged** (3x as many 13 yo wanted to join AERC program than other ages)
- **LESS DIFFERENCES** in measurements compared to age mates w/o disabilities;
- **SIGNIFICANT IMPROVEMENT** compared to other ages in outcome measures

## Lessons Learned: AERC

After 3 years in AERC,  
participants had:

- More education
- More paid work experience
- Improved health - youth's point of view
- More likely - have adult primary care physician

## Lessons Learned

- **RESPOND** -- to young person's and family's needs/ resolve immediate problem first (health issues)
- **FLEXIBILITY** -- in programming
  - Interventions may change
- **CULTURAL COMPETENT**
  - Diversity of staff important
  - Know and honor beliefs of family/youth

## Lessons Learned

- **Program Advisors**
  - Youth need skills to interface between cultures (ethnic, work-based, urban/suburban)
  - Need to serve like “Life Coaches”
- **Provide training understand role**
  - dependent
  - co-dependent
  - Interdependent → more areas
  - independent → as possible

## Lessons Learned

### **BUILD TRUST**

- Worry about losing benefits
- Increasing independence and income

### **MEDICAL**

- Wellness affects performance & productivity
- Teach youth skills
  - how to find adult providers
  - how to manage their health
  - how to disclose disability/health issues
  - how to ask for accommodations

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### Take Home Messages:

## **HEALTH & WELLNESS**

### Health Impacts Performance

- WELLNESS BASELINE: What's the norm?
- HEALTH CARE: Primary Care
- SECONDARY CONDITIONS- Refer for help
- HEALTH INFO - Portable Medical Summary
- Rx MEDICATIONS: indicate health issues

### Take Home Messages:

## **POLICY & PRACTICES**

There are policies and practices that support transition and health!

- **FEDERAL:** Policies become laws/mandates  
Often grant \$\$ follows
- **STATE:** Title V CSHCN Health Programs
- **MEDICAL:** They are ALLIES!

### Title V Block Grant:

## **Nat'l Performance Measure #6**

### 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)

[www.hrtw.org](http://www.hrtw.org)



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## Resources-01

HRSA/MCHB funded Nat'l Centers (6)

1. **HEALTH & TRANSITION**, [www.hrtw.org](http://www.hrtw.org)  
Healthy & Ready to Work National Resource Center
2. **MEDICAL HOME** [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)  
National Center on Medical Home Initiatives
3. **FAMILY PARTNERSHIP** [www.familyvoices.org](http://www.familyvoices.org)  
National Center on Family and Professional Partnerships

## Resources-02

HRSA/MCHB funded National Centers (6)

4. **CULTURAL COMPETENCE**  
<http://www11.georgetown.edu/research/gucchd/nccc/>  
National Center for Cultural Competence
5. **HEALTH INSURANCE** <http://www.hdwg.org/cc/>  
Catalyst Center – for Improving Financing of Care for CYSHCN
6. **DATA** [www.cshcndata.org](http://www.cshcndata.org)  
Data Resource Center National Survey for CSHCN

## Resources-03

**HEALTHY & READY TO WORK**

[www.hrtw.org](http://www.hrtw.org)

- **HRTW Portable Medical Summary** - One page summary of health needs that youth or others can carry. Information contains medical history, current medication, name of health surrogate, health insurance numbers, contact information for treating doctors, pharmacy, home health and other vendors.

## Resources-03

**HEALTHY & READY TO WORK**

[www.hrtw.org](http://www.hrtw.org)

- Understanding Health Insurance - Web links to Choosing a Plan, Paying for Care, Public Insurance, Private Insurance, Policy / Advocacy Centers and Insurance Regulations, Laws and Statutes.

## Resources-03

**HEALTHY & READY TO WORK**

[www.hrtw.org](http://www.hrtw.org)

- Decisions & Making Choices - Web section contains information of Informed Decision Making, Assent-Consent, Guardianship, Living Wills and Advance Directives.

## Resources-04

### HRTW Portal - Laws that Affect CYSHCN

[http://www.hrtw.org/tools/laws\\_leg.html](http://www.hrtw.org/tools/laws_leg.html)

- The Term Special Health Care Needs or 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

## Resources-05

- ADOLESCENT HEALTH  
Transition Project Washington  
<http://depts.washington.edu/healthtr/index.html>
- **Transition Timeline for Children and Adolescents with Special Health Care Needs.**  
Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go of others. The Timeline for Children may help you think about the future.

## Resources-05

- **Working Together for Successful Transition:**  
Washington State Adolescent Transition Resource Notebook - Great example to replicate.
- **Adolescent Autonomy Checklists**

## Resources-06

- Health and Healthcare in Schools  
<http://www.healthinschools.org/ejournal/2003/privacy.htm>  
  
The Impact of FERPA and HIPAA on Privacy Protections for Health Information at School. Sampling of the questions from school nurses and teachers.

## Resources-06

- NICHCY - National Dissemination Center for Children with Disabilities  
[www.nichcy.org](http://www.nichcy.org)  
Materials for families and providers on: IDEA, Related Services and education issues – in English/Spanish
- Section 504  
<http://www.ed.gov/about/offices/list/ocr/504faq.html>