Transitioning Youth with Special Health Care Needs to Adult Systems of Care: *The Role of Primary Care Providers*

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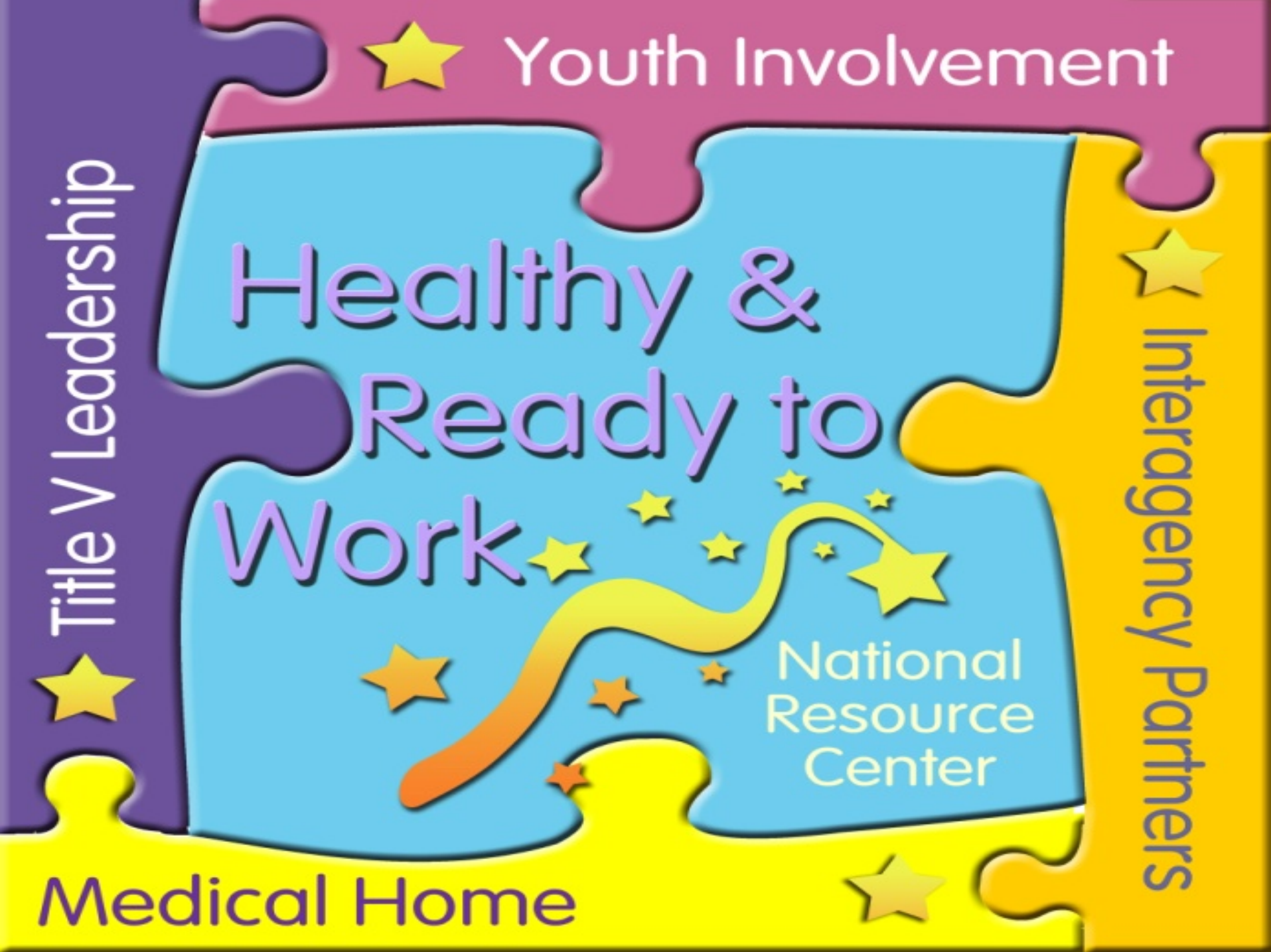
Youth Involvement
Title V Leadership
Healthy & Ready to Work
National Resource Center
Interagency Partners
Medical Home

Disclosure

- Neither Dr. Antonelli, nor any members of his immediate family has a financial relationship or interest with any proprietary entity producing health care goods or services related to the content of this CME activity.

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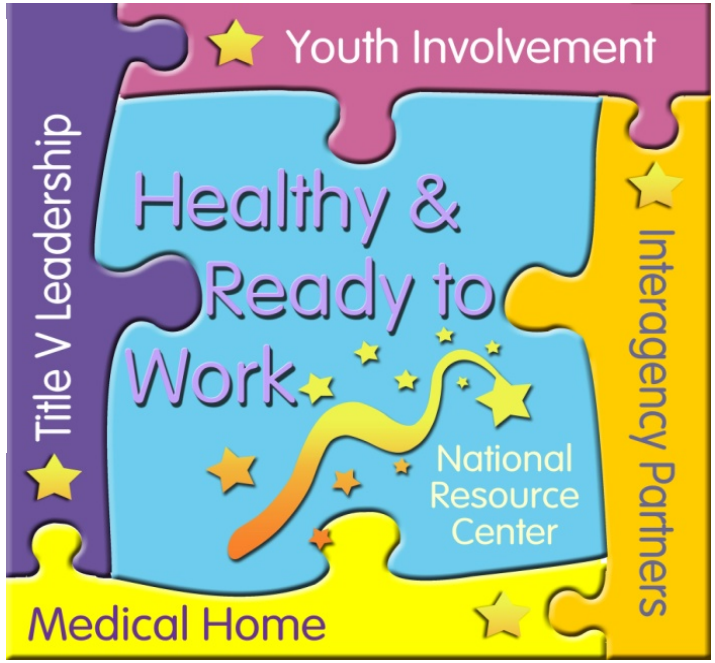

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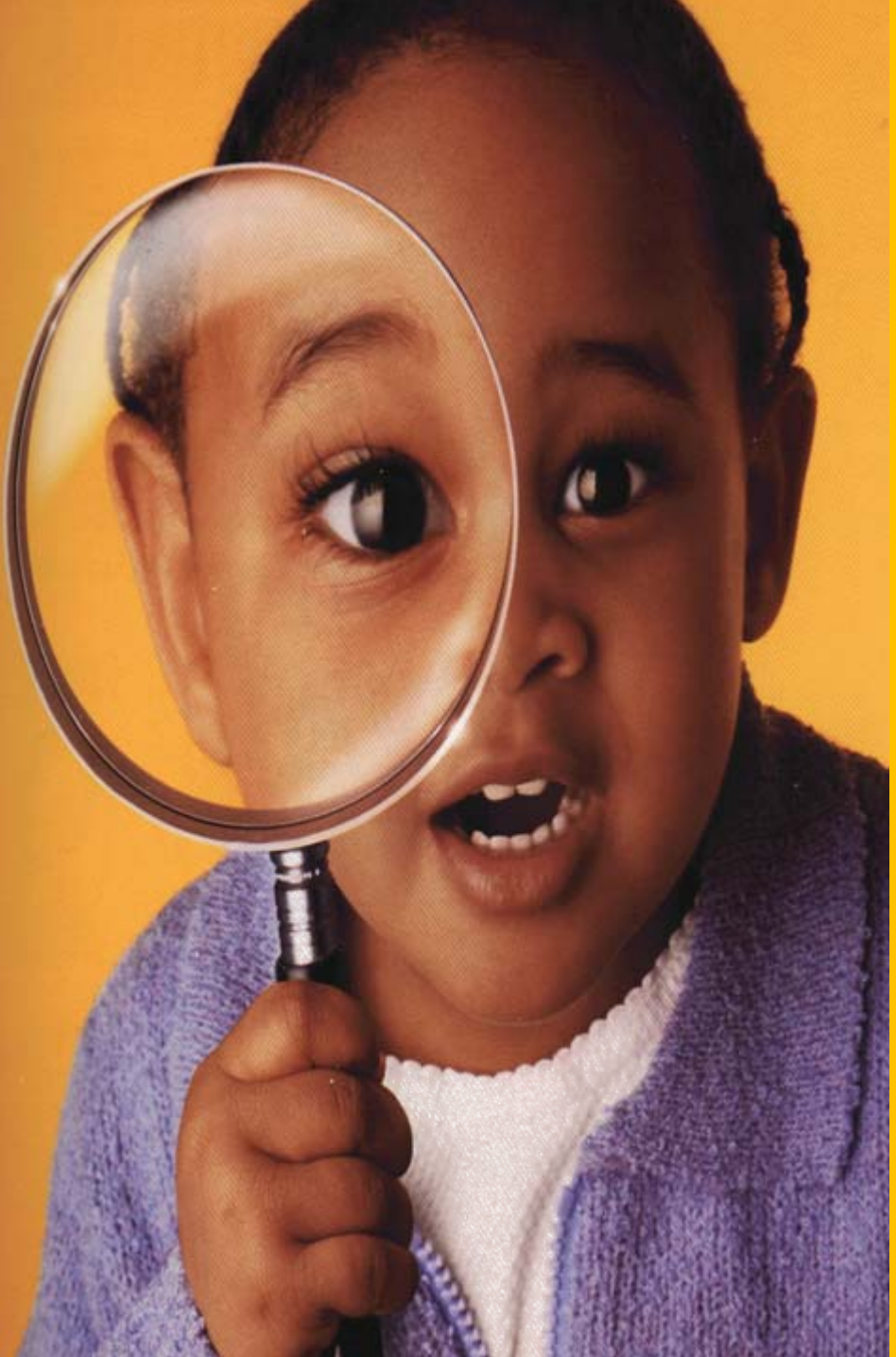


Health / Definition

Data

Prep for the Difference

Youth Involvement

Tools

Health Impacts All Aspects of Life

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

To stay healthy, young people need an **understanding** of their health and to **participate in their health care decisions**.

Disability is……

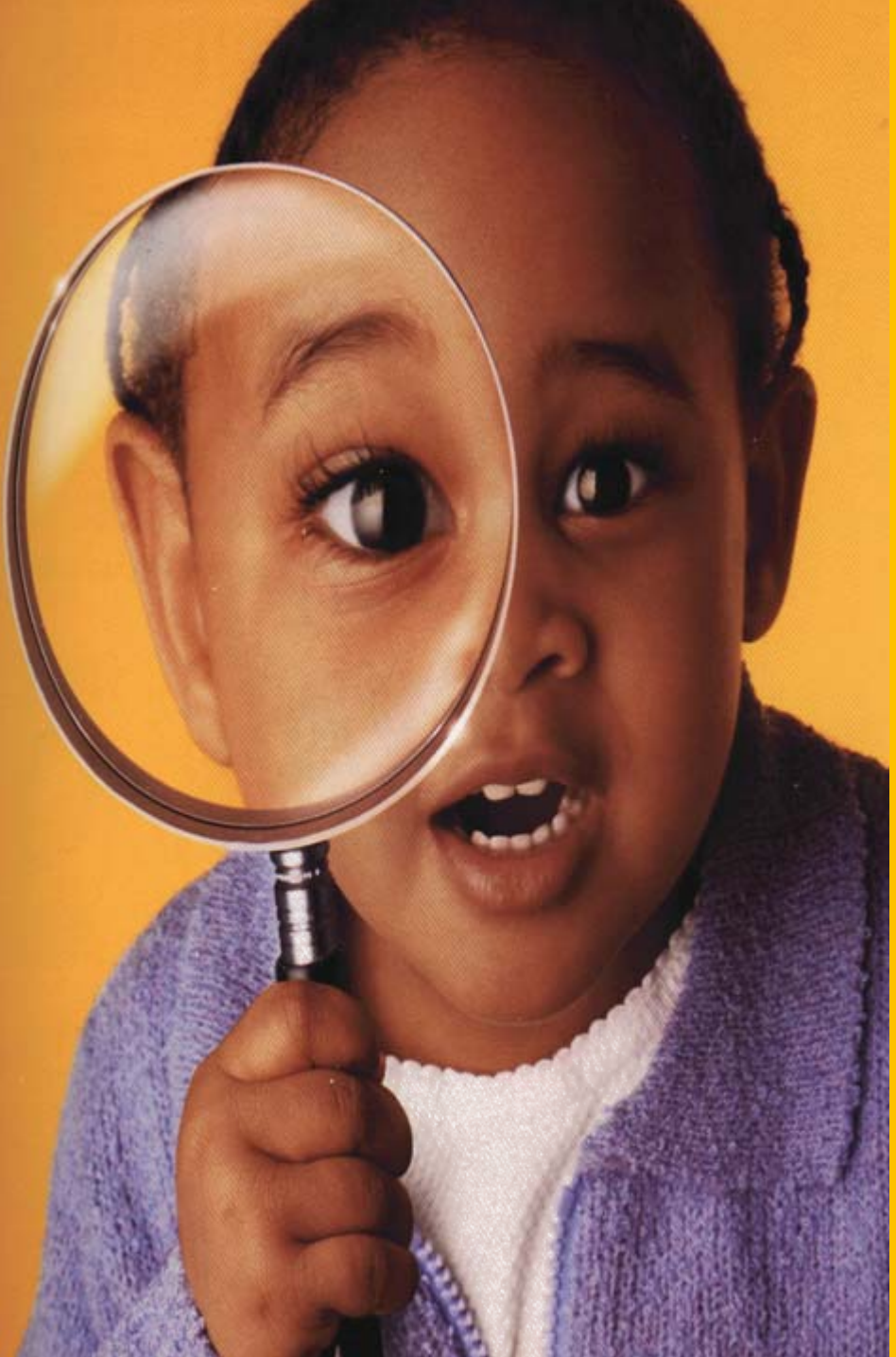
a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.

What is Health Care Transition?

Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.

Components of successful transition

- Self-Determination
- Person Centered Planning
- Prep for Adult health care
- Work /Independence
- Inclusion in community life
- **Start Early**



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CSHCN, Select a State Profile - Windows Internet Explorer

http://cshcndata.org/Content/States.aspx?sid=2

National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data… Your story

Home | Tutorial | About Us | Contact Us | Search

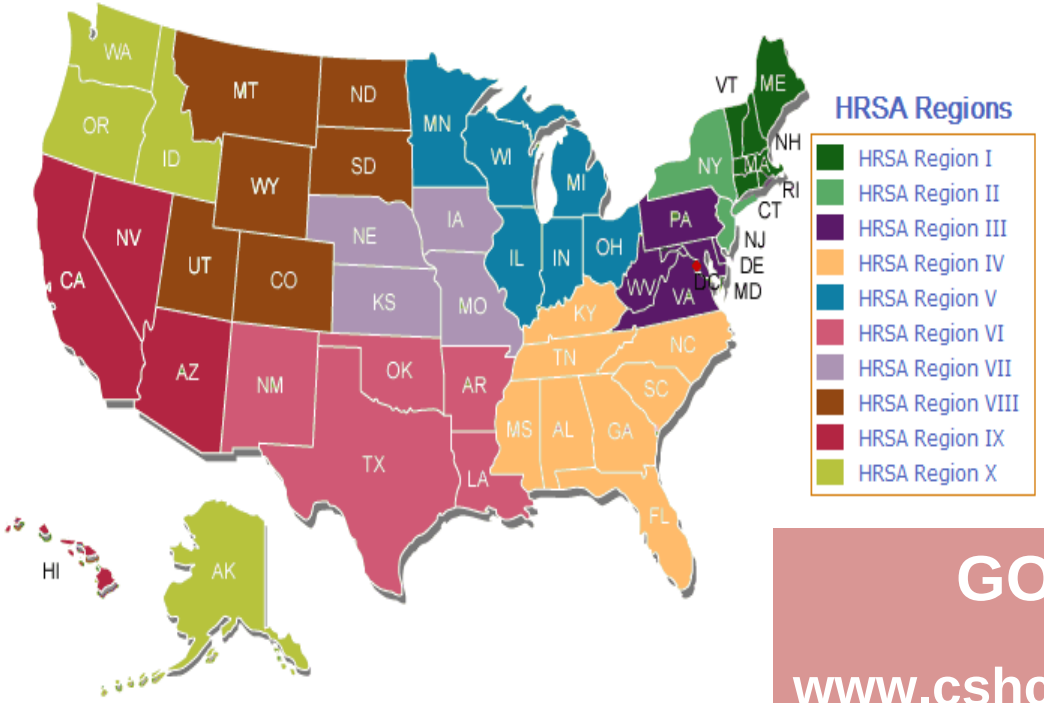
- Start a Data Query
- National & State Profiles
- How to Use This Site
- Presentations/Articles
- Survey Information
- FAQ
- Useful Resources

- SIGN UP FOR E-UPDATES
- ASK A QUESTION
- REQUEST A DATASET
- TELL A FRIEND
- YOUR BRIEFCASE

This site is a project of CAHMI The Child and Adolescent Health Measurement Initiative

2005/2006 NS-CSHCN National Chartbook State Pages

Click on a state (below) or HRSA Region (right) to see an interactive results page



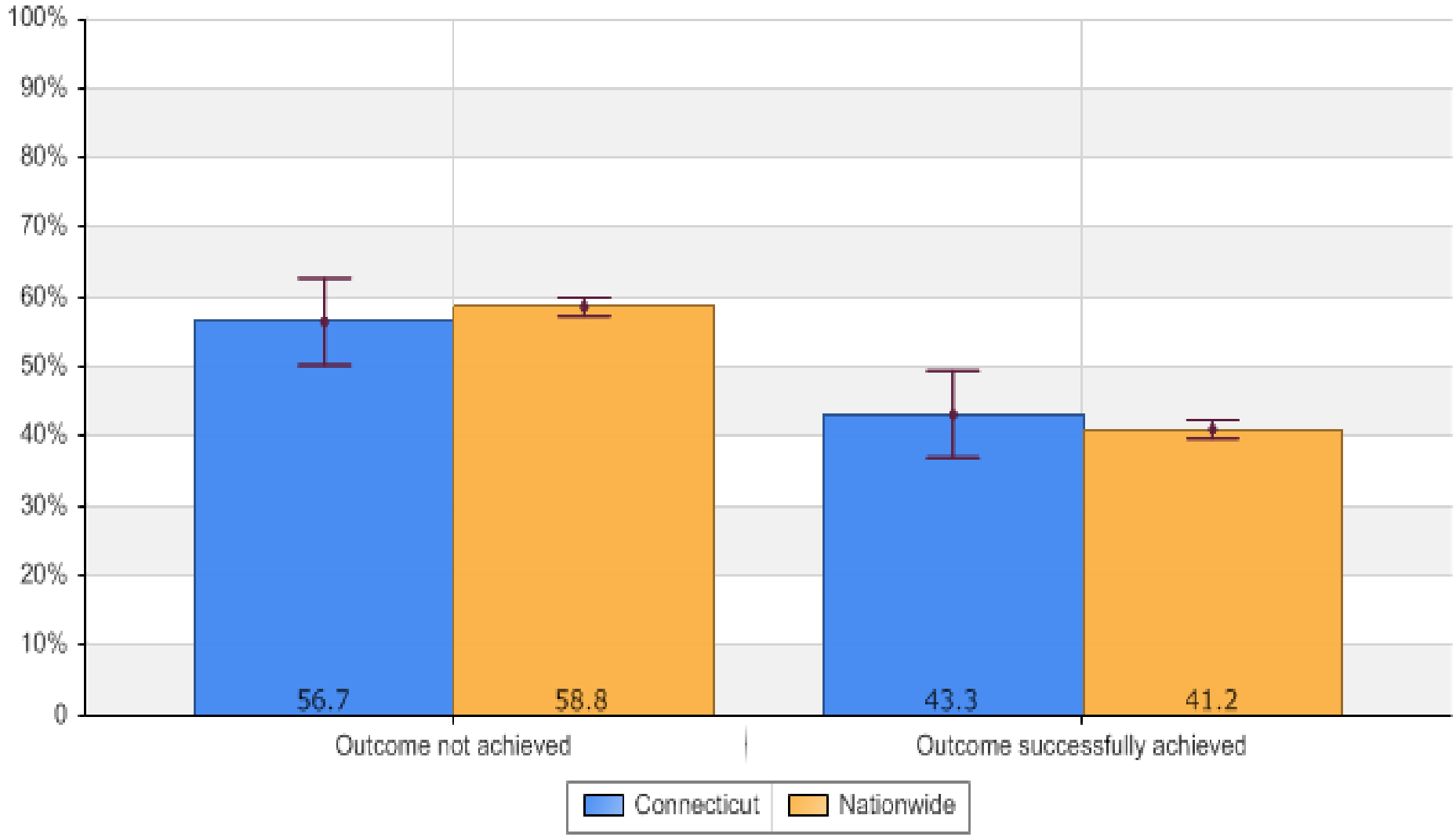
GOT DATA!

www.cshcndata.org

CSHCN, Select a State Profile - Windows Internet Explorer | Internet | Protected Mode: On | 100%

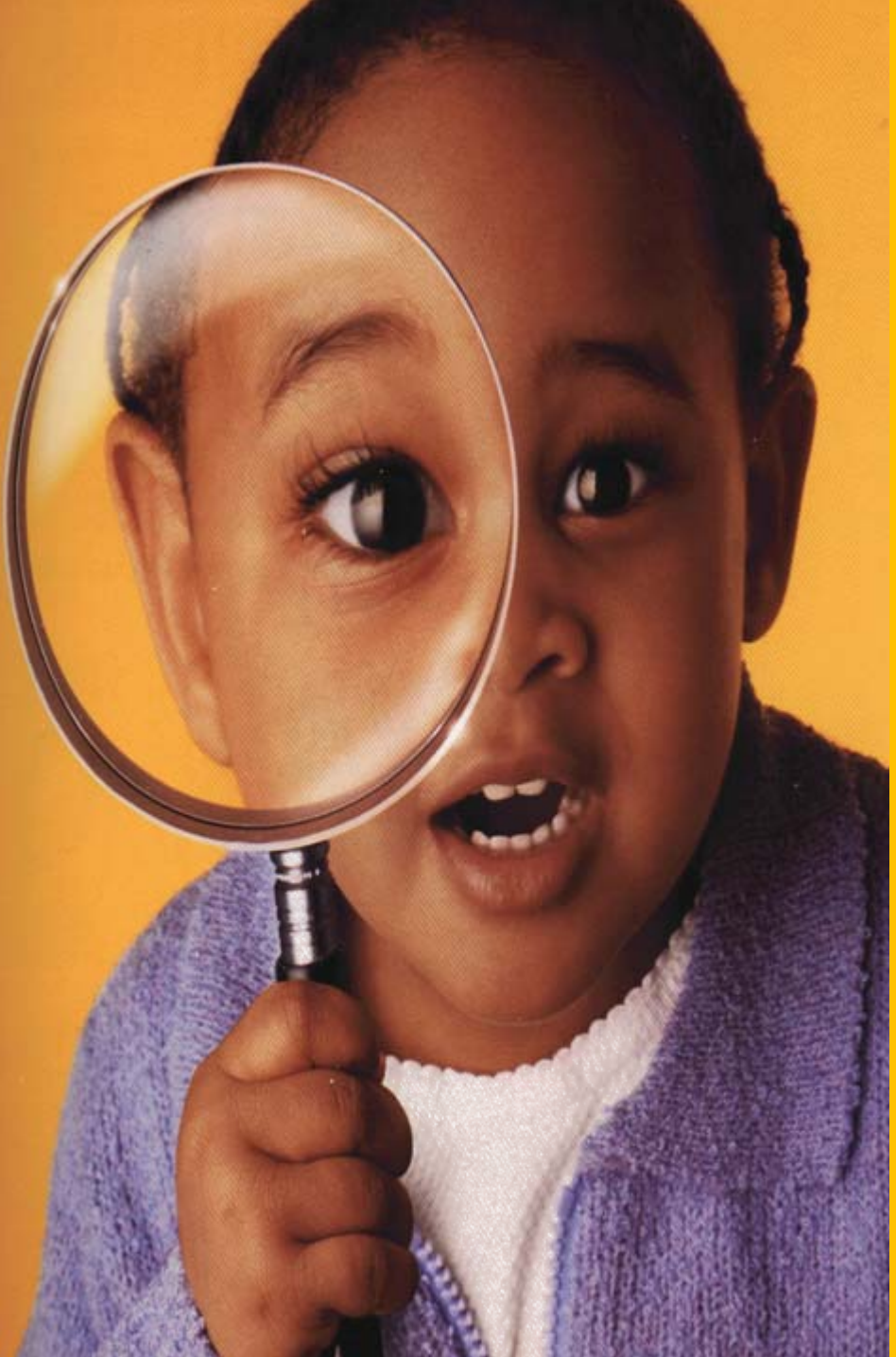
Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adult health care, work and independence

Connecticut vs. Nationwide



Barriers to Transition * rated *extremely important or very important (combined)* HRTW Questionnaire 2006-2007	Medical Homes N=52 in 26 states	NACHRI Hospitals N=19 in 18 states	States N=42 of 59 States/ Territories
Lack of **capacity of adult providers** to care for youth/adults with SHCN	**83%**	**85%**	**95%**
Lack of understanding of **reimbursement** eligibility differences between adults and children with special health care needs	**65%**	**63%**	Not Asked
Fragmentation of care among systems providers	**87%**	**73%**	**89%**
Lack of **knowledge about or linkages** to community resources that support youth in transition	**85%**	**58%**	**50%**

Health Care Transition Activities	Medical Homes N=52 26 states	NACHRI Hospitals N=19 18 states (12%)	Shriners Hospitals N=20 15 states & Canada (91%)	State Title V Agencies N=42 of 59 States/ Territories (71%)
Create an individualized health transition plan	**34%**	**43%**	**25%**	**50%**
Promote health management, self care, and prevention of secondary disab.	**63%**	**79%**	**95%**	**72%**
Discuss legal responsibility for medical decisions and health records <18.	**21%** Written 81% assent	**58%**	**100%**	**62%**
Recruit adult primary /specialty providers to assume care of youth with special needs	**56%**	**58%**	**35%**	**53%**



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Outcome Realities

- Nearly 40% cannot identify a primary care physician
- 20% consider their pediatric specialist to be their ‘regular’ physician
- Primary health concerns that are not being met
- Fewer work opportunities, lower high school grad rates and high drop out from college
- YSHCN are 3 X more likely to live on income < $15,000

SOURCES: CHOICES Survey, 1997;
NOD/Harris Poll, 2000; KY TEACH, 2002

Health Care Processes Should Have:

- Care based on continuing healing relationships
- Customization based on patient needs and values
- Patient as source of control
- Shared knowledge and free flow of information
- Safety
- Transparency
- Anticipation of needs

SOURCE: Crossing the Quality Chasm 2001

How Do We Achieve

That Type of System?

National Center of Medical Home Initiatives

Elements of Medical Home

Care that is:

- **Accessible**
- **Family-centered**
- **Comprehensive**
- **Continuous**
- **Coordinated**
- **Compassionate**
- **Culturally-effective**

and for which the primary care provider shares responsibility with the family.

CSHCN, YSHCN and Family

What is Medical Home Really? 01

A **Medical Home** is a …….

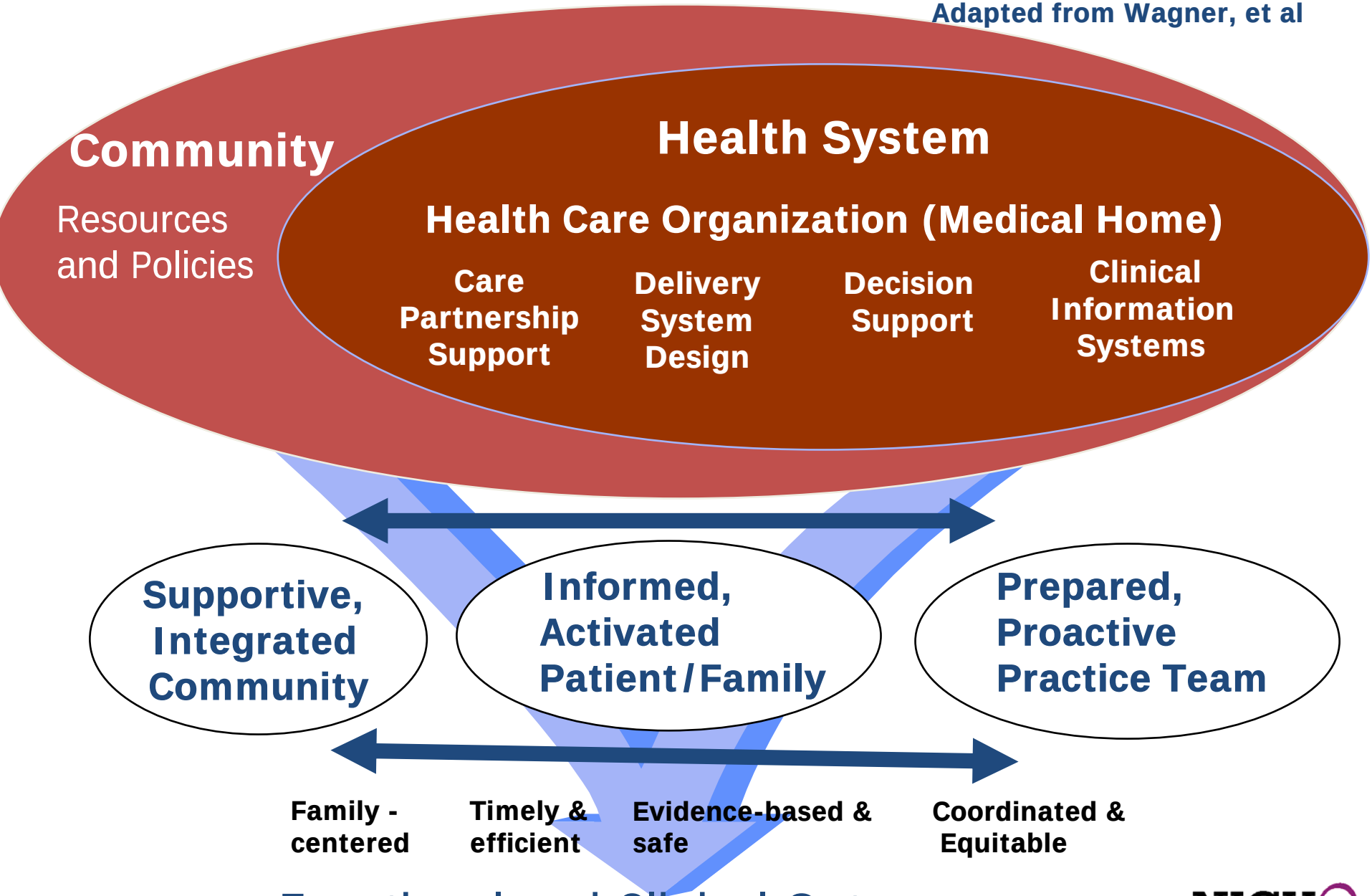
community-based, primary care setting that integrates high quality, evidence-based standards in providing and coordinating family-centered health promotion as well as acute and chronic condition management.

What is Medical Home Really?

A **subspecialist** can provide a Medical Home as long as all elements of the care needs of the patient are addressed.

Care Model for Child Health in a Medical Home

Adapted from Wagner, et al



NICHQ

Shared Decision Making

Provider	Parent	Young Person
Major responsibility	Provides care	Receives care
Support to parent and child	Manages	Participates
Consultant	Supervisor	Manager
Resource	Consultant	Supervisor

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....

A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs

- American Academy of Pediatrics
- American Academy of Family Physicians
- American College of Physicians -

  American Society of Internal Medicine

Pediatrics 2002:110 (suppl) 1304-1306

Results of Pediatric Practice Survey

- **38%** had a stated policy in their practice for when a YSHCN should transfer to an adult physician

  0% had policy posted for families to see

- **66%** had identified adult practices for referral.
- **19%** had a policy to discuss legal issues for adulthood before age 18.
- **33%** had identified a transition coordinator in the office
- **29%** had care plans for YSHCN supporting transition

Core Knowledge & Skills: MEDICAL HOME

1. Practice provides care coordination for youth with complex conditions
2. Practice creates an individualized health transition plan before age 14
3. Practice refers youth to specific primary care physicians
4. Practice provides support and confers with adult providers post transfer
5. Practice actively recruits adult primary care /specialty providers for referral

Core Knowledge & Skills: FAMILY & YOUTH

1. Practice discusses transition after diagnosis, and planning with families/youth begins early (ped practice) or when youth are transferred to the practice (adult practice)

2. Practice provides educational packet or handouts on expectations and information about transition

3. Youth participate in shared care management and self care (call for appt/ Rx refills)

4. Practice assists families/youth to develop an emergency plan (health crisis and weather or other environmental disasters)

Transition & ……Insurance

NO HEALTH INSURANCE

40% 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

Transition to Adulthood

FACTORS ASSOCIATED WITH RESILIENCE for youth with disabilities: Which is MOST important?

- Self-perception as not “handicapped”
- Involvement with household chores
- Having a network of friends
- Having non-disabled and disabled friends
- Family and peer support
- Parental support w/out over protectiveness

Source: Weiner, 1992

FACTORS ASSOCIATED WITH RESILIENCE for youth with disabilities: Which is MOST important?

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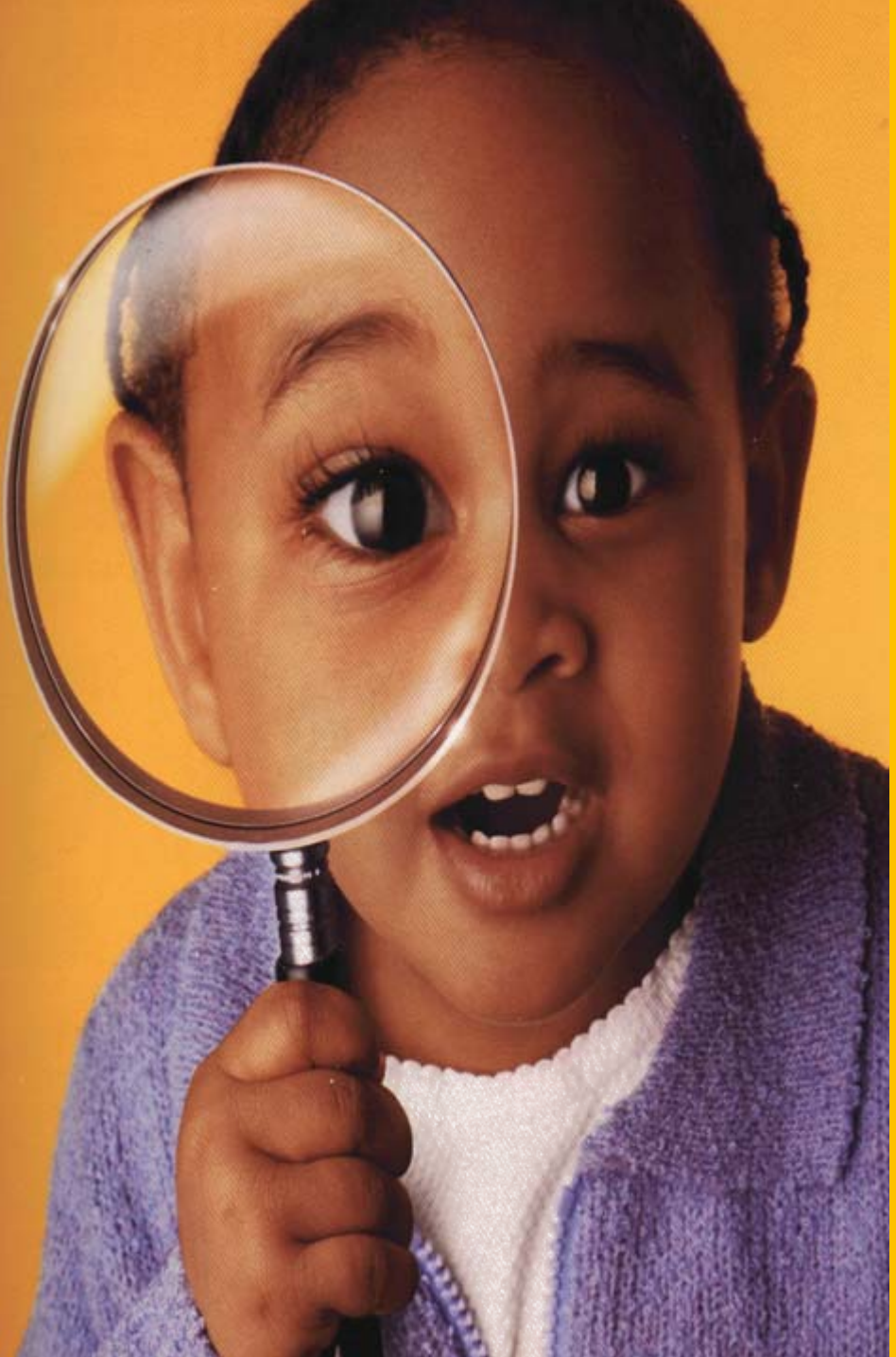
Health & Wellness: Being Informed

"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**."

SOURCE: Ansell BM & Chamberlain MA



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Levels of Support

Levels of Support	Family Role	Young Person
Independent	**Coach**	**Can do or can direct others**
Interdependent	**Consultant Coordinates**	**Can do or can direct others** May need support in some areas
Dependent	**Manages Coordinates** expand circle of support	**Needs support full-time -all areas** expand circle of support

The Ultimate Outcome: Transition to Adulthood

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Resources

HRSA/MCHB funded National Centers (6)

1. HEALTH & TRANSITION **www.hrtw.org**

Healthy & Ready to Work National Resource Center

2. MEDICAL HOME **www.medicalhomeinfo.org**

National Center on Medical Home Initiatives

3. FAMILY PARTNERSHIP **www.familyvoices.org**

National Center on Family and Professional Partnerships

Resources

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

Data Resource Center National Survey for CSHCN

Resources

HRTW Portal - Laws that Affect CYSHCN
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

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.

- **Working Together for Successful Transition**: Washington State Adolescent Transition Resource Notebook

  - Great example to replicate.

- **Adolescent Autonomy Checklists**

Resources

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.

NICHCY - National Dissemination Center for Children with Disabilities 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

Useful Websites for Medical Home

AAP Medical Home

- http://www.medicalhomeinfo.org:
  useful tools and resources for families and providers

- http://www.medicalhomeimprovement.org:
  tools for assessing and improving quality of care delivery, including the Medical Home Index, and Medical Home Family Index

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