Newborn Screening, Long-Term Follow-Up, and Medical Home: Is Integration Possible?

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Every System is Perfectly Designed to Get the Results it Gets

- Institute for Healthcare Improvement
- National Initiative for Children's Healthcare Quality

Definition of Medical Home

- Care that is:
  - Accessible
  - Family-centered
  - Comprehensive
  - Continuous
  - Coordinated
  - Compassionate
  - Culturally-effective

Definition of Medical Home

- And for which the primary care provider shares responsibility with the family.

AAP/ AAFP/ NAPNAP/ ACP

Functional Definition of Medical Home

- Partnership between family and providers
- Commitment to continuous quality assessment and improvement
- Single point of entry to a “system” of care that facilitates access to medical and non-medical resources

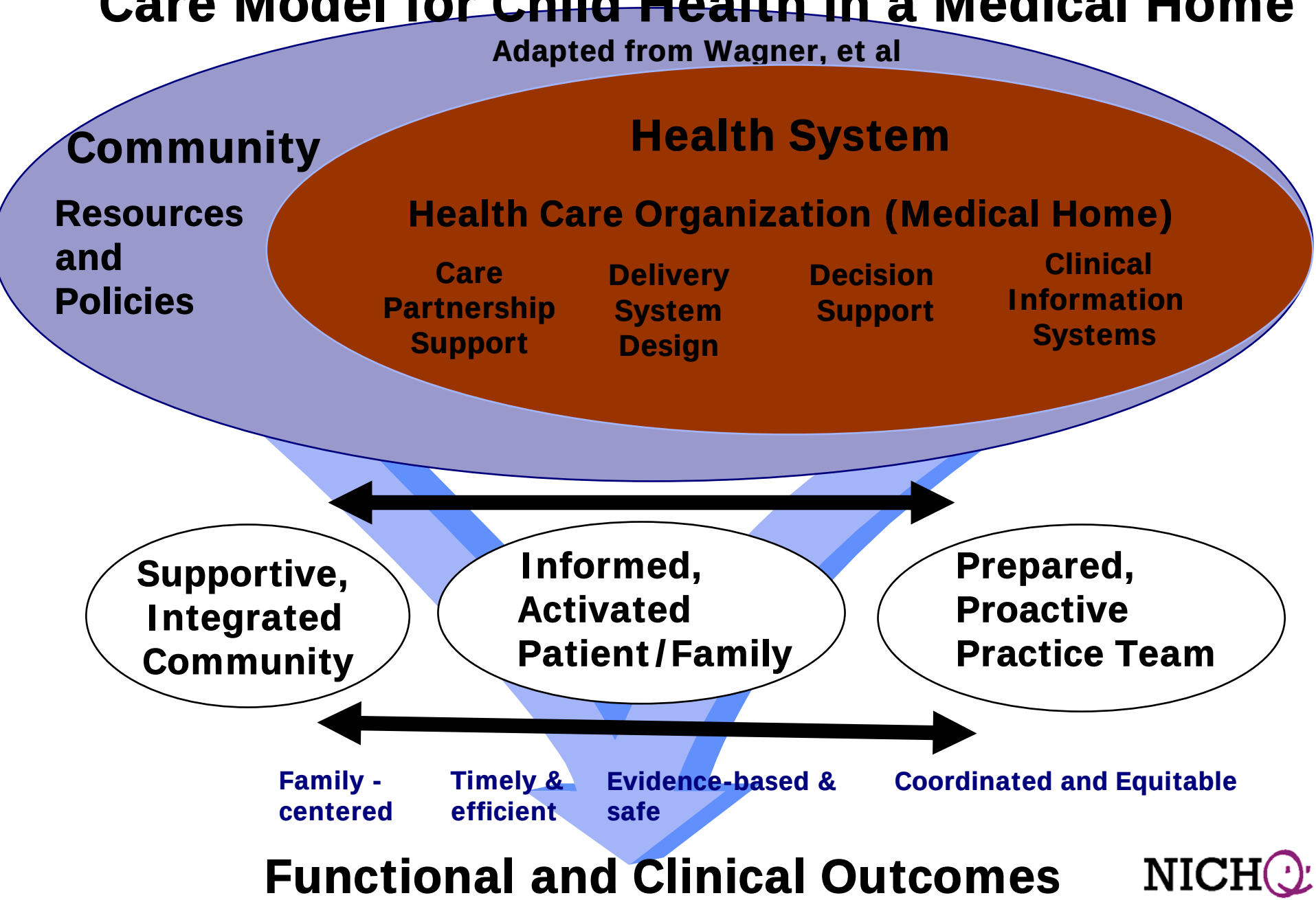
What Do Families Say a Medical Home Is?

Medical Home

- It is an “Attitude”.
- Care Coordination addressing medical as well as non-medical issues.
- Referrals to specialists who embrace similar philosophies.
- Parent- Professional Partnership.

Parent Advisory Group, Nashaway Pediatrics

Care Model for Child Health in a Medical Home



Community of Care Model Building MH Systems

Family to Family Supports

Pediatric PCP's and specialists

Including mental health

Adult PCP's and specialists and transition advisors

Educational Systems:

Birth to 22 Years

Quality Advocates
Leapfrog, NQF

CSHCN, YSHCN and Family

State and Federal Agencies

Title V

PCOC

AAP**/AAFP**

NAPNAP/ ACP

CBO's

Grantsmakers

MCO's

public/private

Employers/ Purchasers

Antonelli AHRQ Conf, 2002

2006

Crossing the Quality Chasm (IOM): How Do We Fix the System?

- “Current care systems cannot do the job. Trying harder will not work. Changing systems of care will.”

Priority Areas for National Action: Transforming Health Care Quality

- Priorities Relating to Children and Youth
  - Care Coordination- across paradigms of care
  - Self-management/ health literacy
  - CYSHCN
  - Immunizations
  - Depression
  - Medication Management

Chain of Effect Framework

(Berwick, Health Affairs, 2002)

- Level A: experience of patients
- Level B: “microsystems” (eg, the team that provides the care)
  - Knowledge-based care
  - Patient-centered care
  - Systems-minded care (emphasis on coordination of care; chronic condition management)

Chain of Effect Framework

(Berwick, Health Affairs, 2002) continued

- Level C: Health care organizations
  - Finding and adopting evidence-based, best practices
  - IT
  - Education of staff
  - Coordination of care across settings
  - Outcome and performance assessment

Chain of Effect Framework

(Berwick, Health Affairs, 2002) continued

- Level D: health care environment
  - Policy
  - Reimbursement
  - Regulation
  - Accreditation
  - Etc.

1/3 of US patients with health problems had experienced medical errors. Americans were more likely to experience inefficient coordination of care, and high out-of-pocket expenses deterring them from seeking treatment for chronic diseases compared to other developed countries.

Commonwealth Fund,

Health Affairs, Nov 2005

What is Care Coordination?

A process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health.

AAP 2005

Stakeholders

- Families
- Employers (Leapfrog Group, National Quality Forum)
- Providers
- Community-Based Organizations
- Payers: Medicaid and Commercial
- State and Federal Agencies
- Legislators

Metanoia: Thinking About Medical Outcomes: Results-Based Accountability (Friedman)

- Born Optimally Healthy
- Healthy and Developing Well
- Healthy and Ready to Learn (school entry)
- Healthy and Ready to Work (adolescence into young adulthood)

Comments from the “Trenches” of Primary Care Across the US about NBS, LTFU, and Medical Home

- In some regions, referral across state lines is possible
- Problems with CC in MH are NOT unique to metabolic and genetic conditions; they apply to any chronic conditions
- Even when some services available (eg, metabolism SP), allied services (eg, nutrition) not linked

Comments from the Trenches

- Ensure prenatally identified PCP in MH
- Reimburse for the visit (consider it a standard of care) with agenda to include NBS and options for outcomes
- Develop care coordination as a discipline, linked to MH

What Needs to Be Done Now?

- Choose an Option:
  - NBS program requires multiple paradigms for F/U that are diagnosis specific
  - Integrated model that builds on the strength of MH and collaborative, coordinated care
- Guess which one I recommend?

Integrated, Coordinated MH Model of Care for NBS and LTFU

- What are the barriers?

Barriers to Care Coordination

AAP Periodic Survey #44

August 2000

	Always	Never	Barriers
Primary Care Coordinator	71%	5%	1. Time
Discuss non-medical needs	41%	14%	2. Staff
Assist with discharge plan	24%	41%	
Contact with school	24%	16%	1. Time 2. Communic.
Post-specialist appointment	19%	28%	1. Time 2. Reimburs.

What Are Barriers to NBS and LTFU and Coordination in MH?

- Technical Knowledge and Skills of Providers
- Definition and Role Responsibility
  - Who will coordinate care across systems?
- Availability of Resources (for consultation, support, long term management)

What Are the Opportunities?

- Care Coordination (CC) that is evidence-based and reimbursed and available directly to families at the community and MH level
- CC that is auditable and integrated as a standard of care (eg, use of written care plans)

What Are Facilitators?

- P4P
- Bright Futures
- Develop Chronic Condition Management in MH

Mechanism for Shared Care

- Co-Management: evidence-based to enhance access
- Distinguish from consultative model since it emphasizes mutual education, shared and delineated responsibilities
- Optimizes utilization of subspecialist (SP) resources
- Reimburses both PCP and SP
- CC is reimbursed
- Builds on existing relationships
- Enhanced access and sustainability are goals

What About Transition into Adulthood for Youth with SHCN?

The Ultimate Outcome:Transition to Adulthood

Health Care
Transition
Requires
Time & Skills

for children,
youth, families
and
their Doctors too!

How Many CYSHCN?

13-40% of Pediatric Population in US

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

Sources:

1. www.cshcndata.org
2. Title V Block Grant FY 2006, www.mchb.hrsa.gov

   * Most State Title V CSHCN Programs end at age 18
3. SSA, Children Receiving SSI, December 2005, www.ssa.gov

Outcome Realities

- 90% of YSHCN reach their 21st birthday
- Nearly 40% cannot identify a primary care physician
- 20% consider their pediatric specialist to be their ‘regular’ physician
- Significant numbers have extensive primary health concerns that are not being met
- Fewer work opportunities, lower high school grad rates and high drop out from college

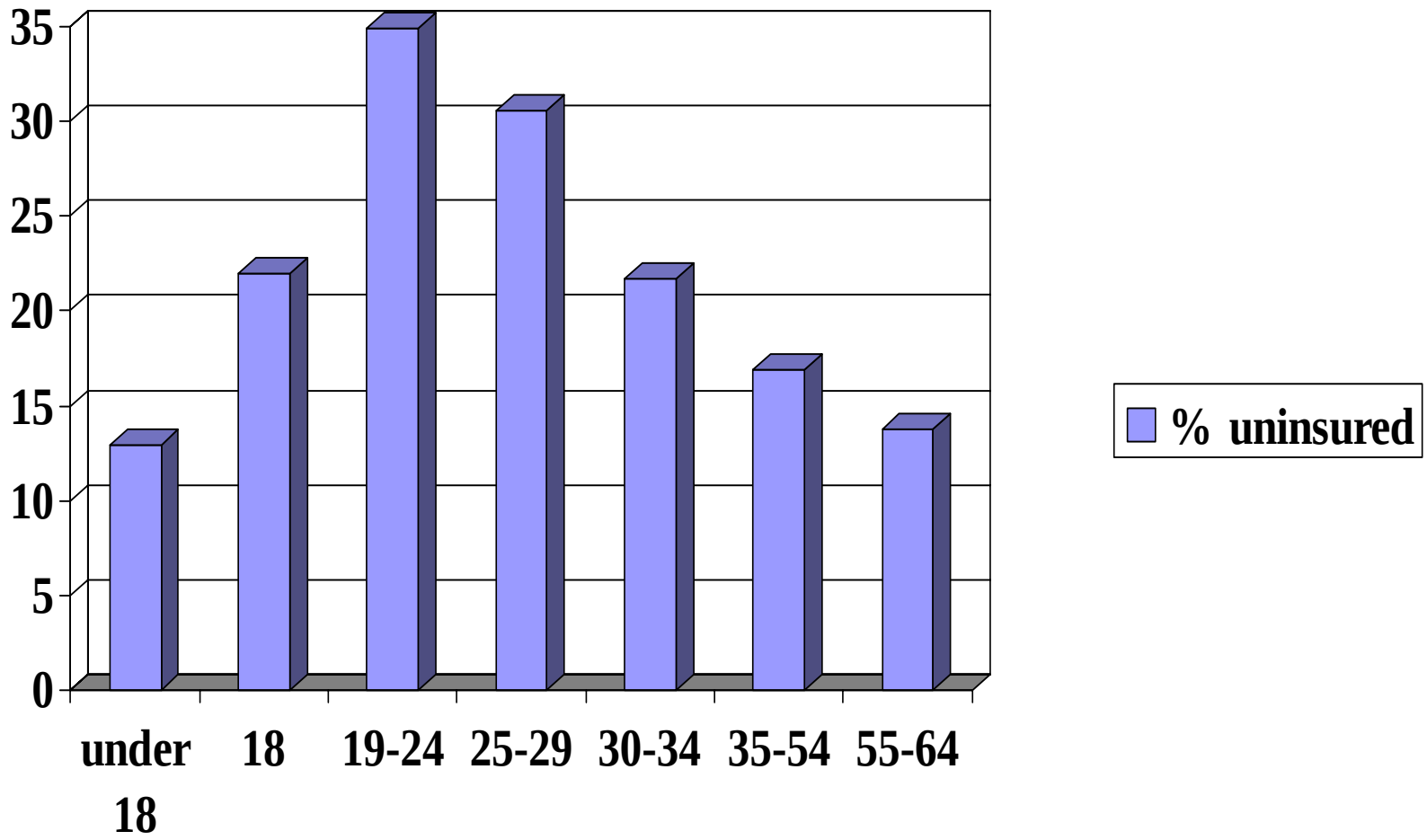
CHOICES Survey, 1997; NOD/Harris Poll, 2000; KY TEACH, 2002

Outcome Realities

- YSHCN are 3 times more likely to live on income under $15,000
- The National Survey of CSHCN, 2001 revealed that only 6.3% of YSHCN ages 13-17 perceived they had received preparation for transition to adulthood.
- 35% of 18 – 24 year-olds lack a payment source for health care

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

Percent Uninsured by Age:
People under age 65, first half of 2002
Center for Cost and Financing Studies, AHRQ, Medical Expenditure Panel survey,
2002 Point-in-time File



What is the System Level Problem?

It’s the Culture and Design of the System!!

Issue (White, adapted from Rosen)	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

Shared Decision Making

Adapted by P. White, from G. Kieckhefer, 2005

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

Providers' Self-Rating of Transition Processes

04% Not interested

25% No processes, but interested

32% Beginning stages

18% Working on; about halfway to where want to be

11% Have transition policy and processes integrated into practice

Models for Transition of Health Care

- **Co-Management between primary care and subspecialists** (both pediatric & adult neph):

  - shared letters

  - shared visits

Models for Transition of Health Care

- **CME opportunities**
- **Encourage patient “get acquainted visits with adult providers”**
- **Facilitation by physicians, nursing or office staff, care coordinators, and youth themselves**

www.hrtw.org

Transition to Adulthood

Useful Websites for Medical Home

- http://www.medicalhomeinfo.org: American Academy of Pediatrics hosted site that provides many 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

References for MH and CC

- McPherson, M., Arango, P., Fox, H., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*,137–140
- U.S. Department of HHS, New Freedom Initiative. www.hhs.gov/newfreedom
- Committee on Children with Disabilities, American Academy of Pediatrics. Care coordination policy statement. *Pediatrics*, 2005
- Committee on Quality of Health Care in America, Institute of Medicine. (2001). Crossing the quality chasm: A new health system for the 21st century

References for MH and CC

- Committee on Identifying Priority Areas for Quality Improvement, Institute of Medicine. (2003). Priority areas for national action: Transforming health care quality.

  Adams, K. and Corrigan, J. Editors.
- Antonelli, R. and Antonelli, D., Providing a Medical Home:The Cost of Care Coordination Services in a Community-Based, General Pediatric Practice, *Pediatrics, Supplement*, May, 2004.
- Antonelli, R., Stille, C. and Freeman, L., Enhancing Collaboration Between Primary and Subspecialty Care Providers for CYSHCN, Georgetown Univ. Center for Child and Human Development, 2005

Other Evidence that CC Makes an Impact

- Reduction in Neonatal Intensive Care Unit Admission Rates in a Medicaid Managed Care Program *Stankaitis, et al. Amer J Man Care, March, 2005*
- Use of Asthma Guidelines by PCP's to Reduce Hospitalizations and ED Visits in Poor, Minority, Urban Children, *Cloutier, M, Hall, C, Wakefield, D, Bailit, H. J Pediatrics, 2005*

Resources: Transition

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: Transition

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: Transition

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

Resources: Transition

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: Transition

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: Transition

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