Transition to Adulthood:
Preparing for the Difference
from Entitlement to Eligibility for CYSHCN

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Transition to Adulthood: A Critical Milestone
Connecticut Department of Public Health
and the United Way of Connecticut
2-1-1 Child Development Infoline
December 6, 2007

During the next 60 min. we will .....

- **Affirm beliefs**
- **Ah Ha Moments!**
- **Make You Squirm**
- **Tools to Use**
- **Choose to Disagree**

LEARNER OBJECTIVES

- Review data

- Identify strategies and tools, to assist providers, youth and family with transition to adulthood

- Increase skill building in the areas of health care decision-making, self-determination and advocacy,

- Improve navigating the adult service delivery system.

Expectations & Who We Are

Expectations:
- What Qs do you want answered today?
- Experts in the room? What topics?

- **About YOU:**
  Teachers, Voc Rehab
  Families?? Youth??
  Others??

- **About Dr. White**

- **About Patti**

- **Special Thanks–**Lisa Davis & Kareena DuPlessis

Do you have “ICE” in your cell phone contact list?

To Program……

- **Space** or **Underscore** _____
  (this bumps listing to the top)
- **Type “ICE – 01”**
  – ADD Name of Person
  - include all ph #s
  - Note your allergies

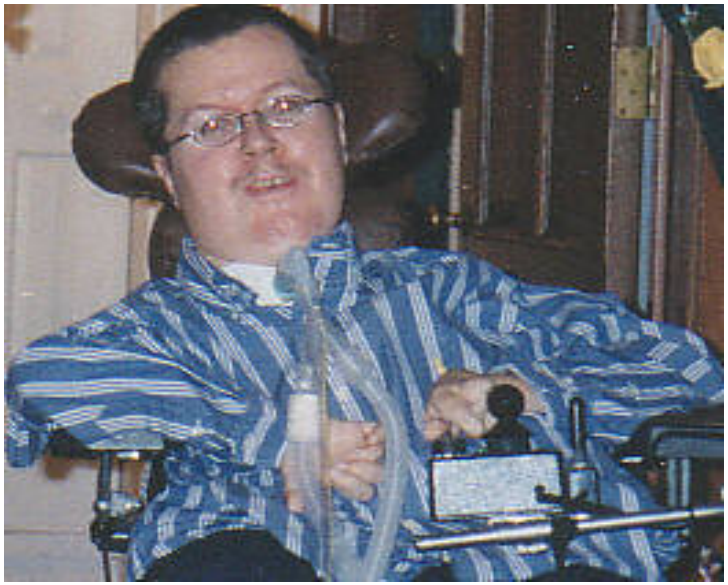
Alert Medics

icesticker.com
Contact Available
ICE
In Case of Emergency

Stick it on the back of your cell phone

You can have up to 3 ICE contacts (per EMS)

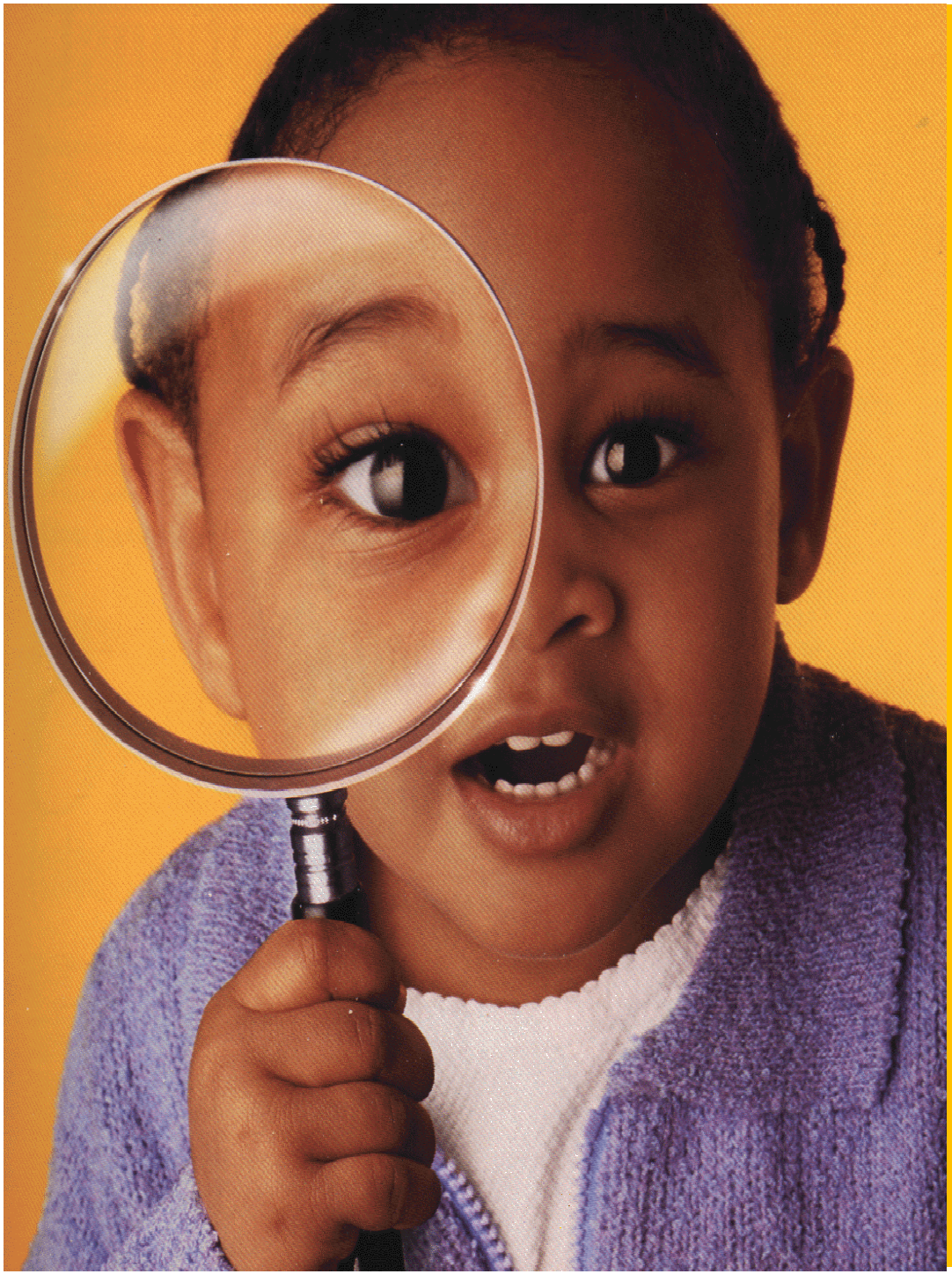
Growing Up Ready to LIVE!



Health & Wellness + Humor

What would you do,

if you thought you could not fail?



Just the Facts

about HRTW

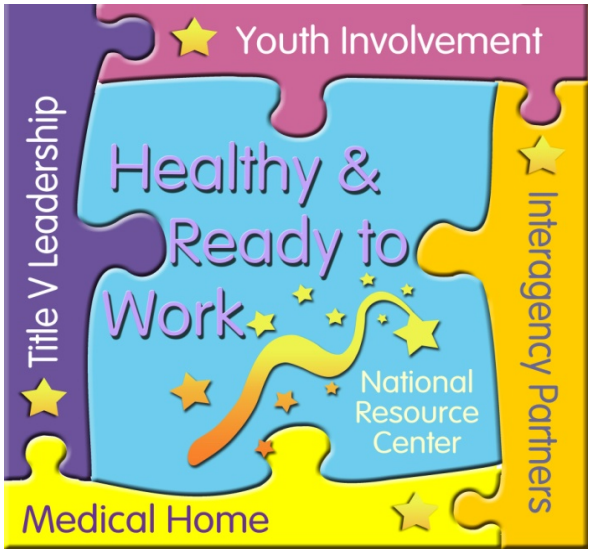
Data

Skills & Tools

Insurance

What to Do What
By When

HRTW TEAM



HRSA/MCHB Project Officer
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Federal Policy

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Healthy & Ready to Work - Microsoft Internet Explorer

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About Us Site Map site search GO

Systems & Services | Youth Involvement | Tools & Solutions | Health Care | HRTW-U

HRTW National Resource Center

- Questionnaire Transition

508 Bobby APPROVED

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!

site by eostudios

The HRTW Center is headquartered at the Maine State Title V CSHN Program. Activities are coordinated through the Maine Support Network's Center for Self-Determination, Health and Policy. The Center is funded through a cooperative agreement (U39MC06899-01-00) from the Integrated Services Branch, Division of Services for Children with Special Health Care Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Service Administration (HRSA), Department of Health and Human Services (DHHS).
Monique Fountain-Hanna, MD, HRSA/MCHB Project Officer.

Internet

start (11 unread) Yahoo... Healthy & Ready t... Document2 - Micro... HRTW-RENAL-SD-... HRTW-Questionnai... HRTW-RENAL-SD-... 2006.HRTW-ILL TR... 9:03 PM

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**.

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**." * HRTW initiative has added YOUTH to CSHCN/CYSHCN since 1996.

Source: 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

CORE National Performance Measures

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

SOURCE: BLOCK GRANT GUIDANCE

New Performance Measures See p.43

ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf

Title V Block Grant:
National 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)

New World: New Lingo

1. Moving Up from Powerless

2. Transferring Skills

Doc/RN➔parent ➔family & friends

Family ➔ child/youth

Youth ➔ friends

3. Strengthening Families

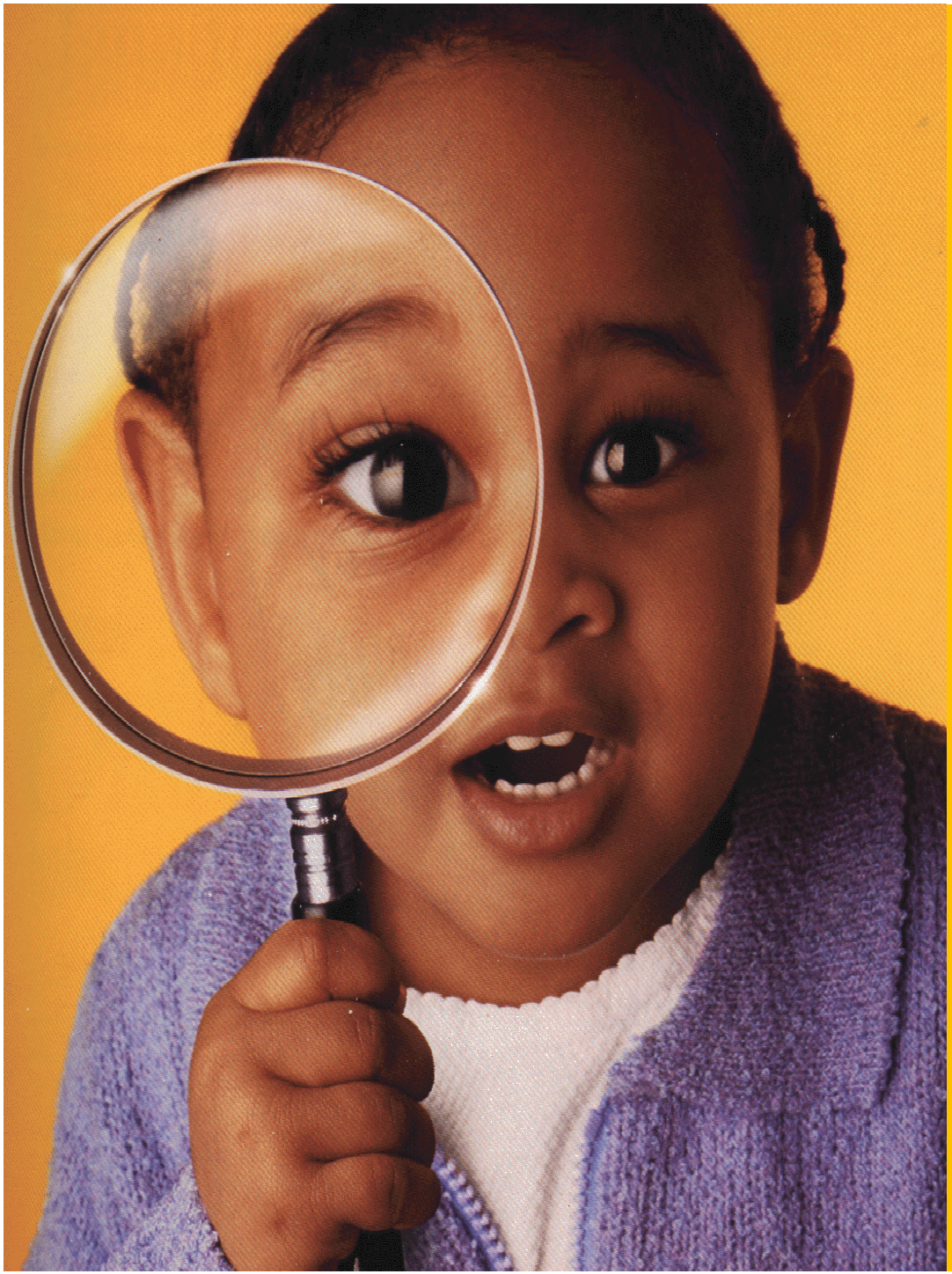
- Support (Family to Family)
- Mentor (Life Coach)
- Counseling (Getting thru the hard patch)
- Financial Planning

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**



What the Data Tells Us

Youth are Talking: Health Concerns

Main concerns for health:

- **What to do in an emergency**
- **How to get health insurance**
- **Learn how to stay healthy**
- **What could happen if condition gets worse**

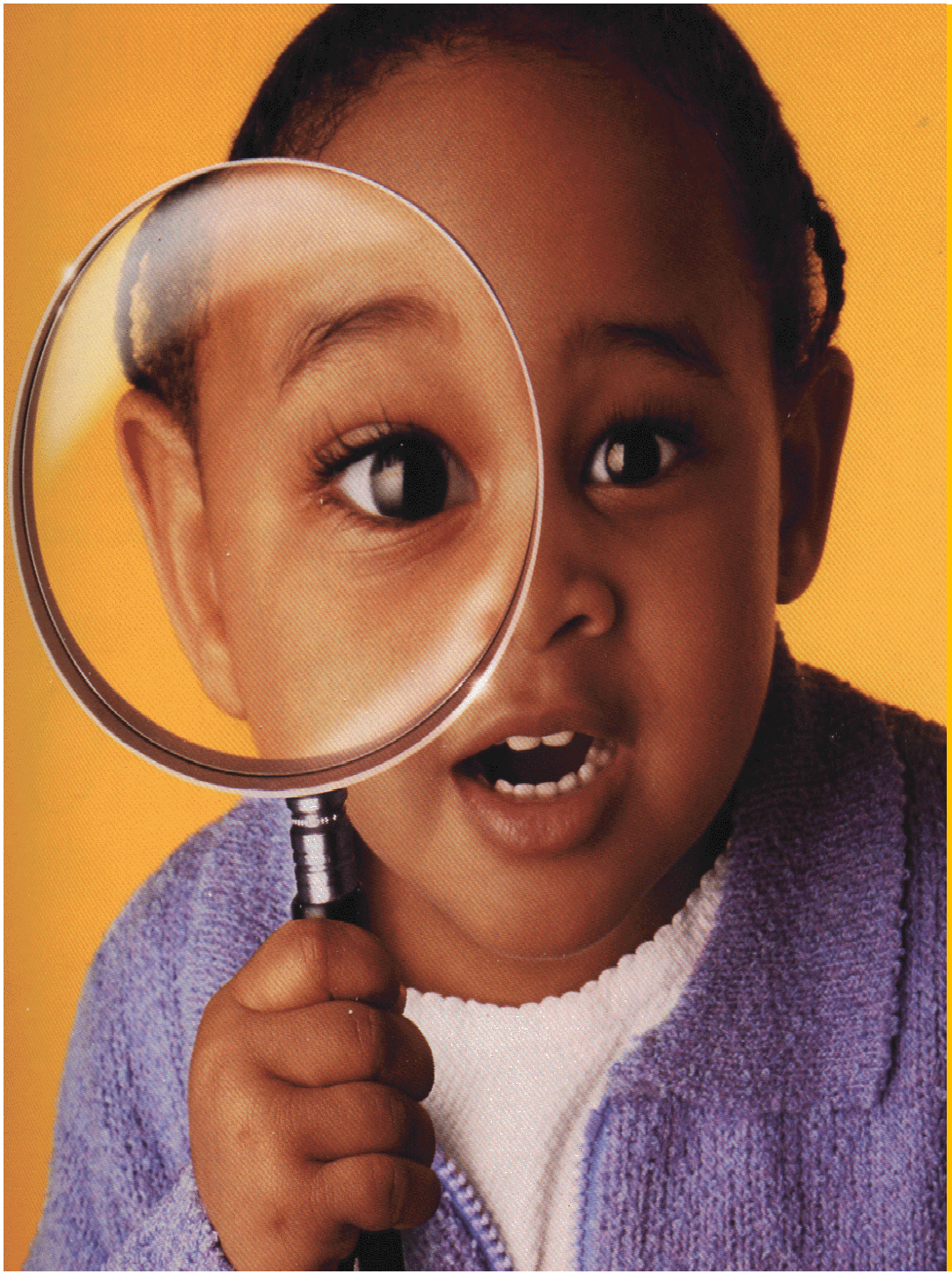
SOURCE: Joint survey: Minnesota Title V CSHCN Program and the PACER Center, 1995
Survey - 1300 YOUTH with SHCN / disabilities
- AND -
National Youth Leadership Network Survey 2001,
300 youth leaders disabilities

Internal Medicine Nephrologists (n=35)

Survey Components	Percentages
Percent of transitioned patients	**< 2% in 95% of practices**
Transitioned pats. came with an introduction	**75%**
Transitioned patients know their meds	**45%**
Transitioned patients know their disease	**30%**
Transitioned patients ask questions	**20%**
Parents of transitioned patients ask questions	**69%**
Transitioned Adults believed they had a difficult transition	**40%**

Maria Ferris, MD, PhD, MPH, UNC Kidney Center

Barriers to Transition * Pediatric Viewpoint * HRTW Questionnaire 2006-2007	Peds. Medical Homes N=52 in 26 states	Children Hosp Hospitals N=19 in 18 states	State Title V 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

Takes Time & Skills

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

6 Critical First Steps to Ensuring Successful Transitioning To Adult-Oriented Health Care

1. Identify primary care provider

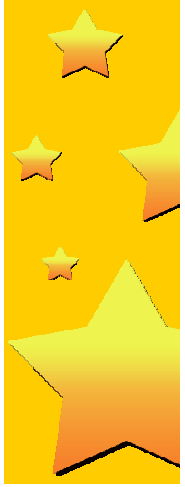
- Peds to adult
- Specialty providers
- Other providers

Pediatrics 2002:110 (suppl) 1304-1306

6 Critical First Steps
to Ensuring Successful Transitioning To Adult-Oriented Health Care

2. **Identify core knowledge and skills**

- Encounter checklists
- Outcome lists
- Teaching tools



6 Critical First Steps
to Ensuring Successful Transitioning To Adult-Oriented Health Care

3. **Maintain an up-to-date medical summary that is portable and accessible**

- Knowledge of condition, prioritize health issues
- Communication / learning / culture
- Medications and equipment
- Provider contact information
- Emergency planning
- Insurance information, health surrogate

Pediatrics 2002:110 (suppl) 1304-1306

6 Critical First Steps
to Ensuring Successful Transitioning To Adult-Oriented Health Care

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

- Expecting, anticipating and planning
- Experiences and exposures
- Skills: practice, practice, practice
- Collaboration with schools (add health skills to IEP) and community resources

Pediatrics 2002:110 (suppl) 1304-1306

6 Critical First Steps
to Ensuring Successful Transitioning To Adult-Oriented Health Care

5. Apply preventive screening guidelines

- Stay healthy
- Prevent secondary disabilities
- Catch problems early

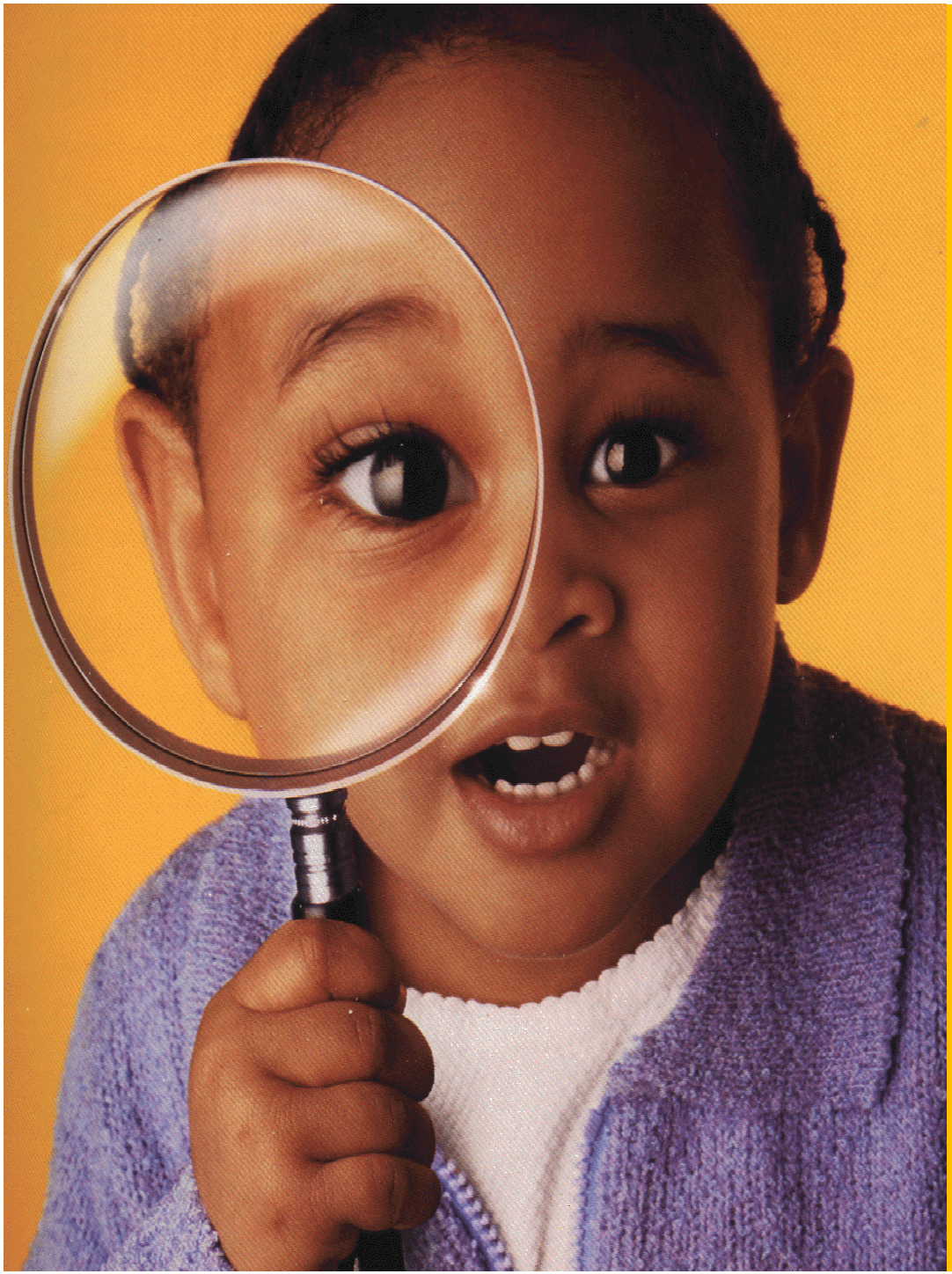
Source: Pediatrics 2002:110 (suppl) 1304-1306

6 Critical First Steps
to Ensuring Successful Transitioning To Adult-Oriented Health Care

6. **Ensure affordable, continuous health insurance coverage**

- Payment for services
- Learn responsible use of resources

Pediatrics 2002:110 (suppl) 1304-1306



If

Transition

Preparation

or Planning

does NOT occur

what happens?

Outcome Realities for YSHCN

- Nearly 40% cannot identify a primary care physician
- 20% consider their pediatric specialist to be their "regular" physician
- Primary health concerns 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, 2000 and NCD Lou Harris Poll, 2000

Time

Jan 2004

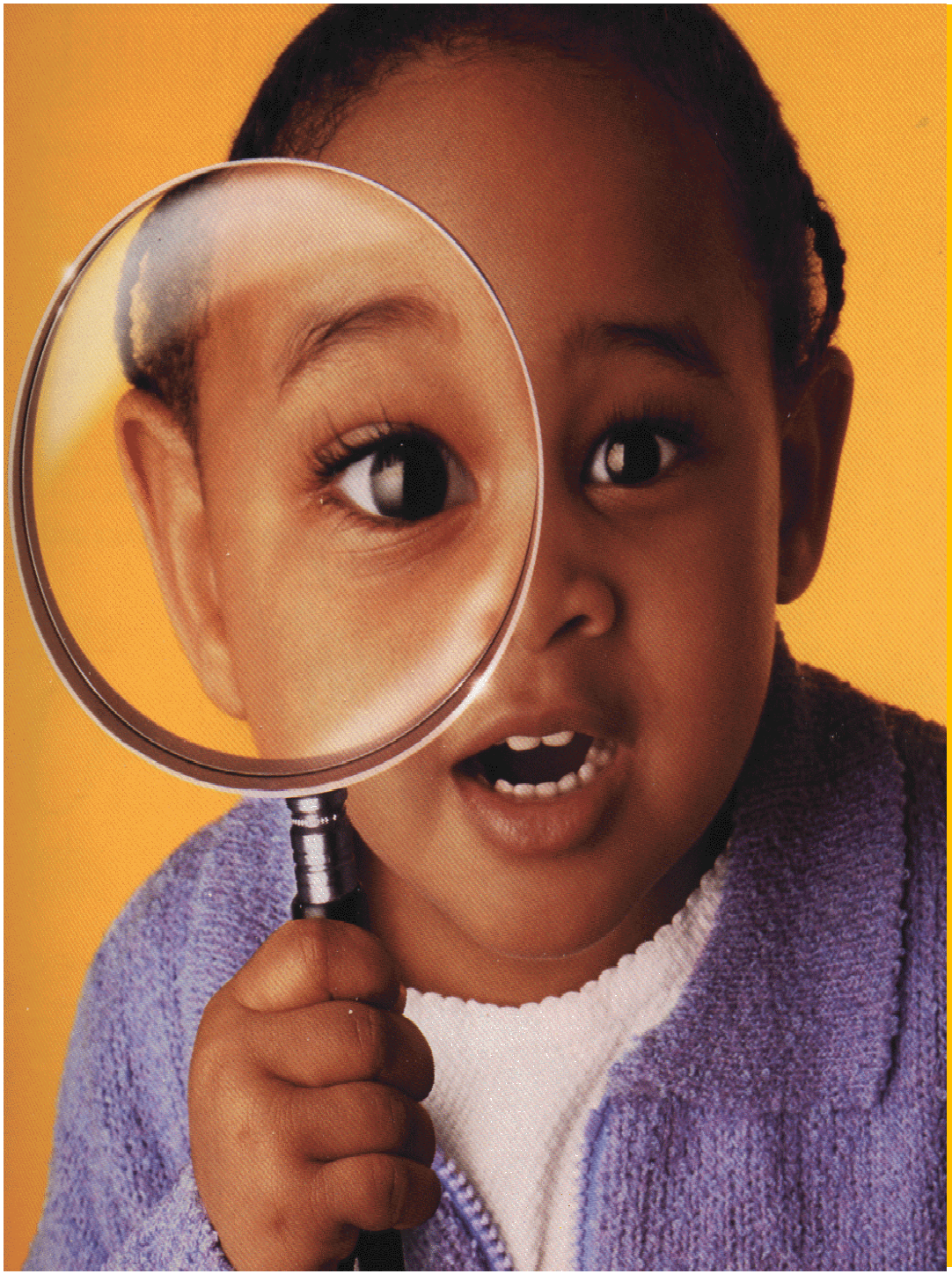
Societal Context for Youth without Diagnoses in Transition

- **Parents are more involved - dependency**
  "Helicopter Parents"

- **Twixters = 18-29**
  - live with their parents / not independent
  - cultural shift in Western households - when members of the nuclear family become adults, are expected to become independent

- **How they describe themselves (ages 18-29)**
  61% an adult
  29% entering adulthood
  10% not there yet

(Time Poll, 2004)



Health

Care

Transition

Preparing

for the

Difference

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**."

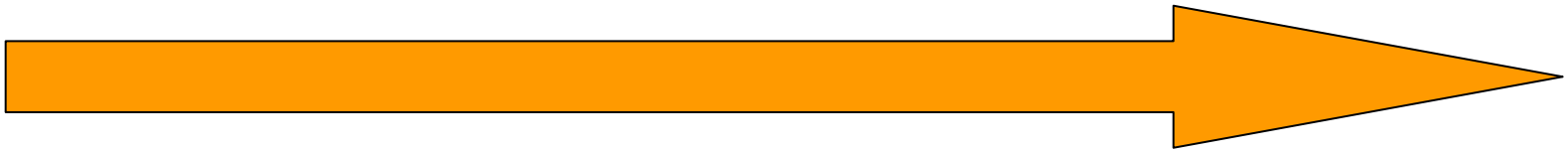
SOURCE: Ansell BM & Chamberlain MA

The Transition Process

Referral & Transfer of Care

Pediatric Care

Adult Care



Transition

SOURCE: Rosen DS. Grand Rounds: All Grown up and Nowhere to Go: Transition From Pediatric to Adult Health Care for Adolescents With Chronic Conditions. Presented at: Children's Hospital of Philadelphia; Philadelphia, PA, 2003

Prepare for the Realities of Health Care Services

Difference in System Practices

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

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

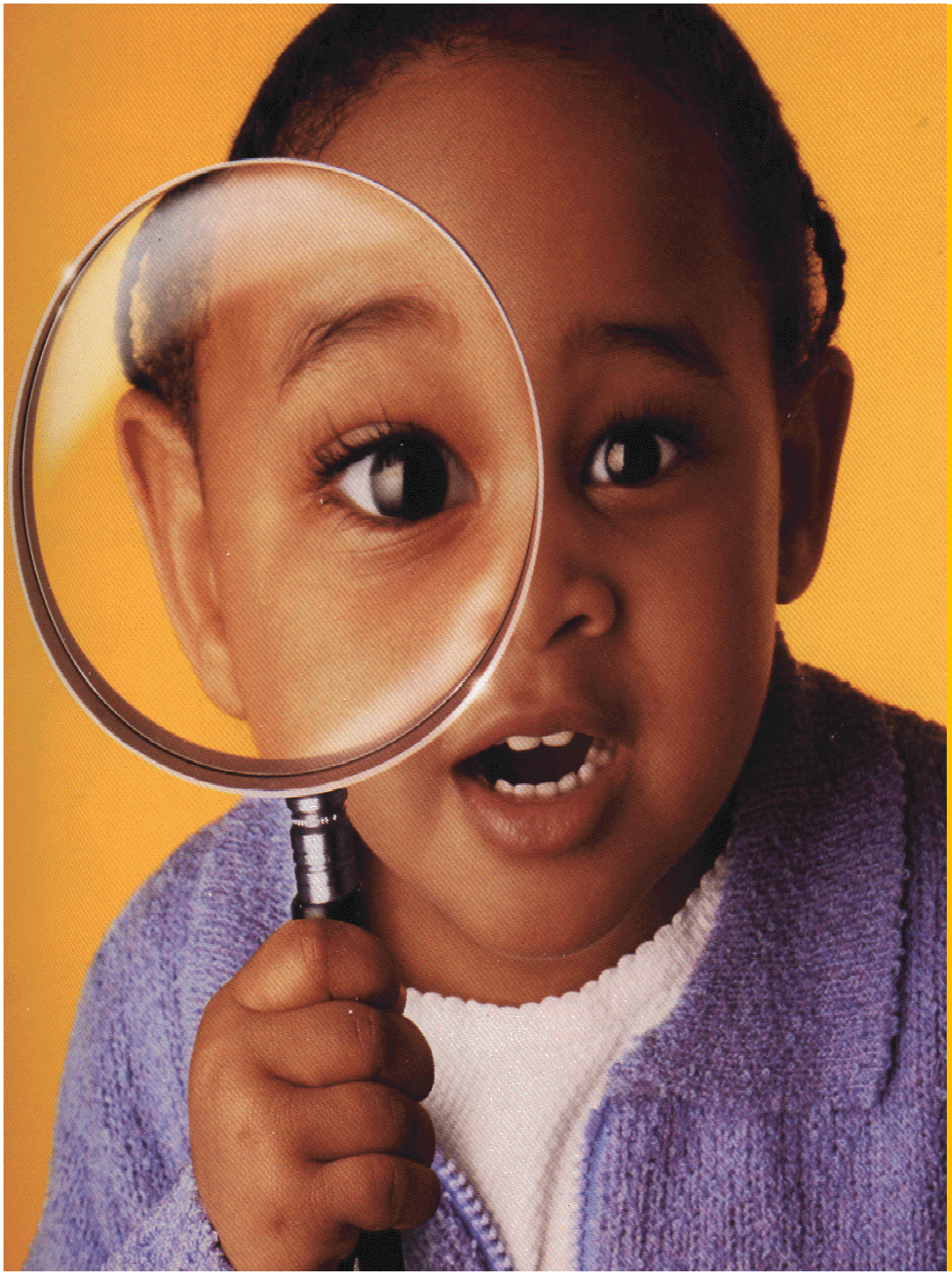
	Pediatric	Adult
Age-related	Growth& development, future focussed	Maintenance / decline: Optimize the present
Focus	Family	Individual
Approach	Paternalistic Proactive	Collaborative, Reactive
Shared decision-making	With parent	With patient
Services	Entitlement	Qualify / eligibility
Non-adherence	>Assistance	> 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

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

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



HRTW

Tips & Tools

Know Your Health & Wellness Baseline

- How does your body feel on a good day?
- What is your typical
  - body temperature
  - respiration count
  - elimination habits?
  - quality of skin (front and back)

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 All Health Needs

- **Hygiene**
- **Nutrition** (Stamina)
- **Exercise**
- **Sexuality Issues**
- **Mental Health**
- **Routine** (Immunizations, Blood-work, Vision, etc.)

Handout: Portable Medical Summary

Carry in your wallet

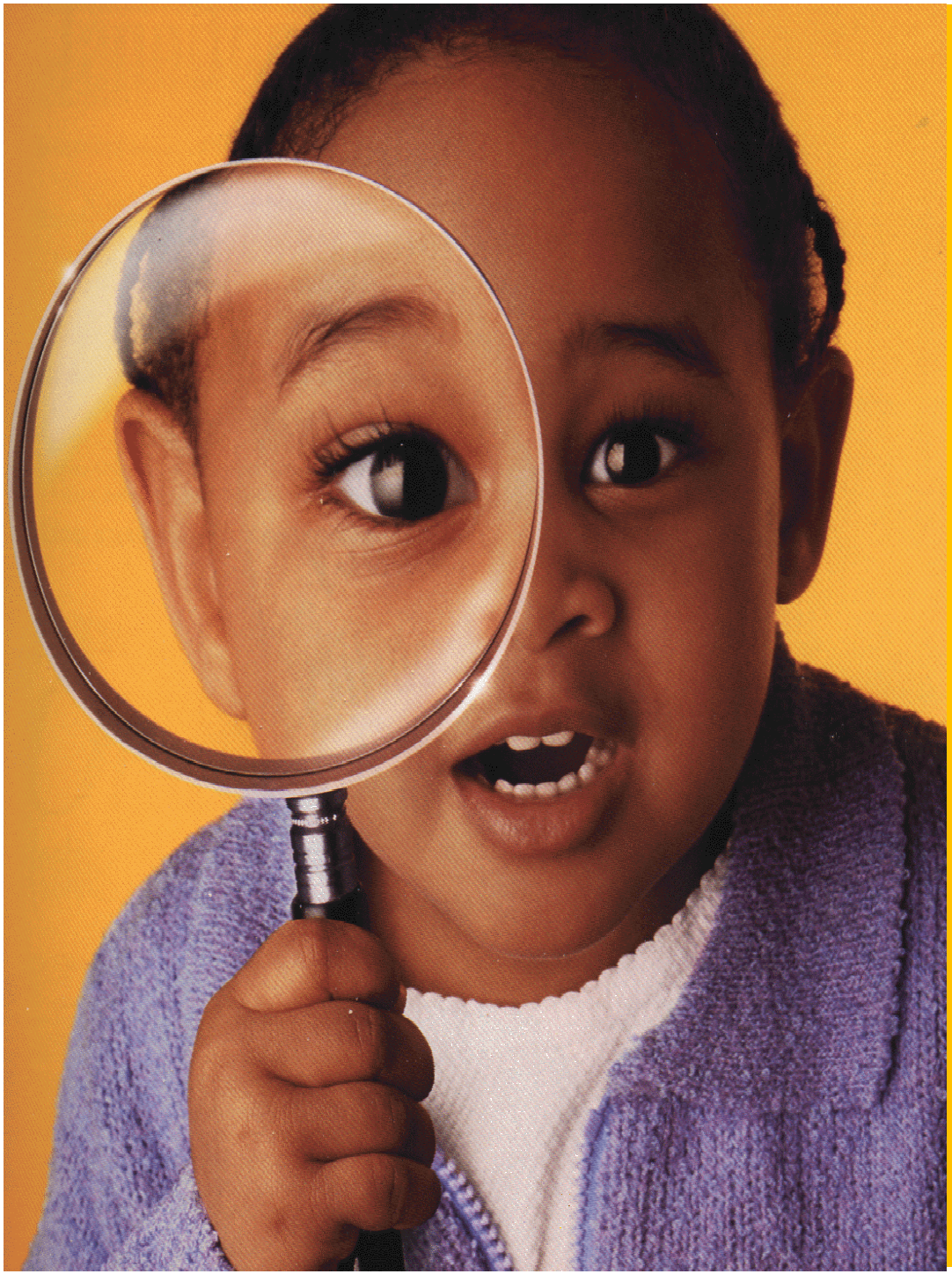
Good Days

- *Cheat Sheet:* **Use as a reference tool**

- **Accurate medical history**
- **Correct contact #s**
- **Document disability**

Health Crisis

- **Expedite EMS transport & ER/ED care**
- **Paper talks when you can not**



Maintaining Health Care Insurance

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

Source: Commonwealth, 2003, 2005

Extended Coverage – For ALL Youth and Young Adults

Public Act 07-185 (Formerly S.B. 1484)

This act requires that group comprehensive and **public** health insurance policies extend coverage to children until the age of 26.

Signed by Governor (7/10/07)

Extended Coverage – Family Plan

- **Adult Disabled Dependent Care**

  Incapable of self-sustaining employment by reason of mental or physical handicap, as certified by the child's physician on a form provided by the insurer, hospital or medical service corporation or health care center

- **Adult, childless continued on Family Plan**

  Increasing age limit to 25-30

  CO, CT, DE, ID, IN, IL, ME, **MD**, MA, MI, MT, NH, **NJ**, NM, OR, PA, RI, SD, TX, VT, VA, WA, WV

Extended Coverage – Family Plan

Adult Disabled Dependent Care

Sec. 38a-489

Continuation of coverage of mentally or physically handicapped children.

- **Youth must be on plan 120 days**

(1) **Incapable of self-sustaining employment by reason of mental or physical handicap, as certified by the child's physician on a form provided by the insurer**, hospital or medical service corporation or health care center, and

Extended Coverage – Family Plan

(2) chiefly **dependent upon the policyholder** or subscriber for support and maintenance.

(b) **Proof of the incapacity and dependency** shall be furnished to the insurer, hospital or medical service plan corporation or health care center by the policyholder or subscriber **within thirty-one days of the child's attainment of the limiting age.**

Extended Coverage – Family Plan

The insurer, corporation or health care center may at any time require proof of the child's continuing incapacity and dependency.

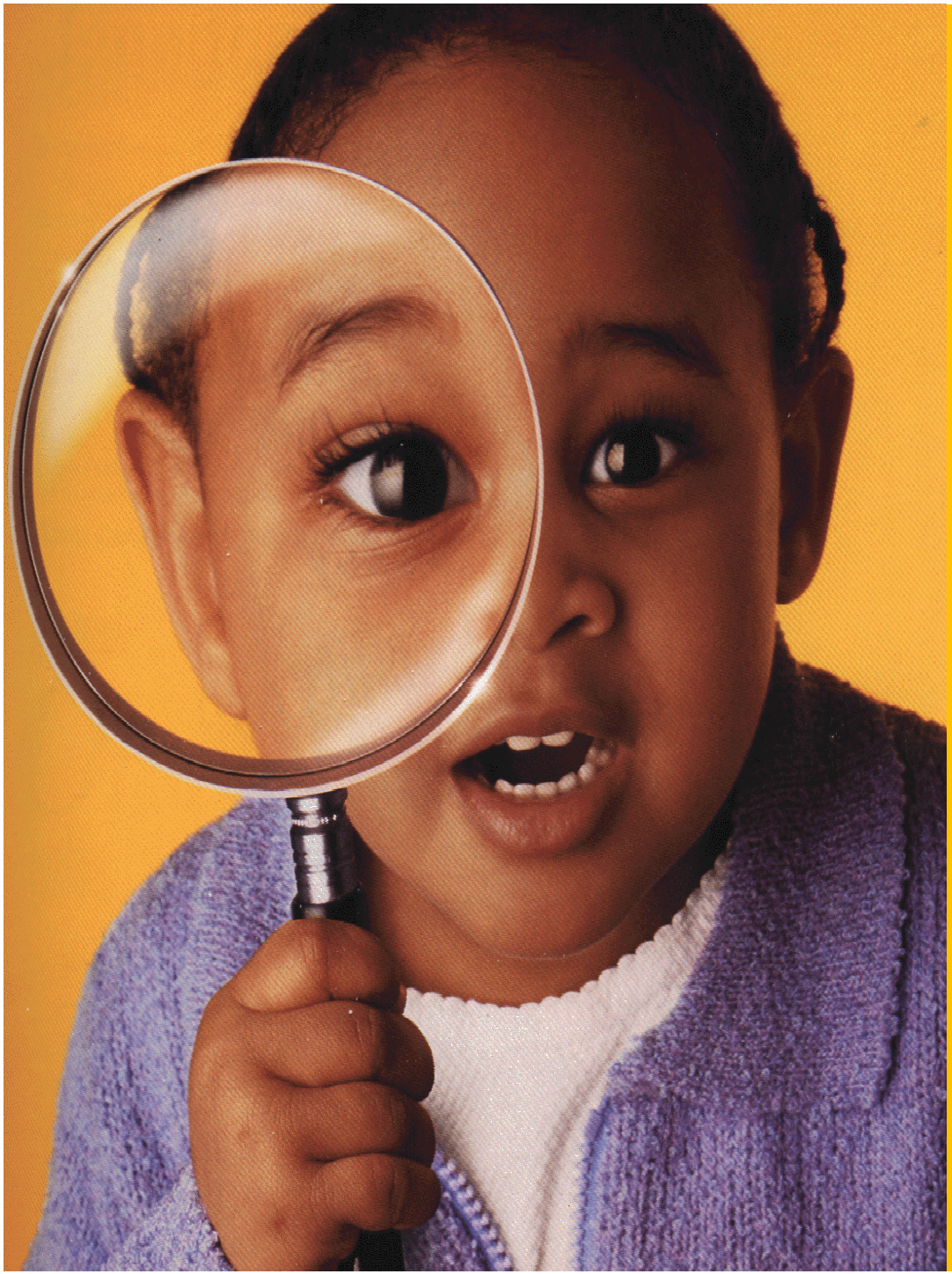
After a period of two years has elapsed following the child's attainment of the limiting age the insurer, corporation or health care center may require periodic proof of the child's continuing incapacity and dependency but in no case more frequently than once every year.

Private Health Insurance

Requires

An insurer may require, as a condition of eligibility for continued coverage in accordance with this section, that a covered person seeking continued coverage for a dependent child **provide written documentation on an annual basis** that the dependent child meets or continues to meet the requirements

Celebrate Annual Documentation!



What to do

By Age 10

Before Age 18

Families: Prepare for Changing Roles

- **Temporary spokesperson on behalf of minor child**

  (until age 18, or declared by the court)

  - 2 voices to be heard: families and CY

ASSENT to CONSENT

Eastern Maine Medical Center

A parent or guardian is generally required to sign for a patient under the age of 18. Patients aged 14-17 should also sign.
See IDD 20.041.

If an adult is unable to make or communicate medical decisions, then the following may sign in the priority given: agent under healthcare power of attorney, guardian, spouse, domestic partner, next-of-kin.
See IDD 20.060 Indicate capacity of representative.

Informed Decision Makers

FERPA Family Education Rights & Privacy Act

HIPAA Health Insurance Portability and Accountability Act

1. **Privacy ➔ Records**
2. **Consent ➔ Signature** (signature stamp)
   - Assent to Consent
   - Varying levels of support
   - Stand-by (health surrogate)
   - Guardianship (limited to full)

FAMILIES: To Do Before Age 10 (child/youth)

Start early - Routine Habits

1. Carry insurance card
2. Present insurance card
3. Present Co-pay
4. Prepare for Doc visit: 5 Qs
5. Begin to know wellness baseline
6. Teach decision making
7. Offer choices during treatment

FAMILIES/YOUTH: TO DO - Before age 18

1. Create/Update Portable Med Record
2. Prepare for Doc visit: 5 Qs
3. Know wellness baseline, Dx, Meds
4. Practice calling for Rx
5. Make own Doctor appts
6. Decision making / Learning choice
7. Assess: Insurance, SSI, VR

Just the Facts: Private Health Insurance

Physicians, Care Coordinators

- More than letter from God
- Discuss before age 17, 26

Families & Youth

- Transition of Care Notebook

  ➔concise thin files - sample documentation

Don’t wait to be informed – get forms early

Bottom line: with or without us - youth and families get older and will move on…Think what can make it easier; do what's in your control and support youth to tackle what's their control.

1. **Start early!!!!!**

2. **Reinforce life span skills**
   Prepare for the marathon

3. **Assist youth to learn how to extend wellness**

4. ***Reality check:*** **Have all of us done the prep work for the send off before the hand off?**

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