



# The Intersection of Research, Advocacy and Policy:

## *Florida Strategic Plan for Health Care Transition*

AMCHP 2010 Conference  
March 9, 2010



Presenter:

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# Agenda

- **Research**

*Background and Issues*

- **Advocacy**

*Florida SB 988 / HB 793*

- **Policy**

*Plan Implementation*

# Research

# Definition: Health Care Transition (HCT)

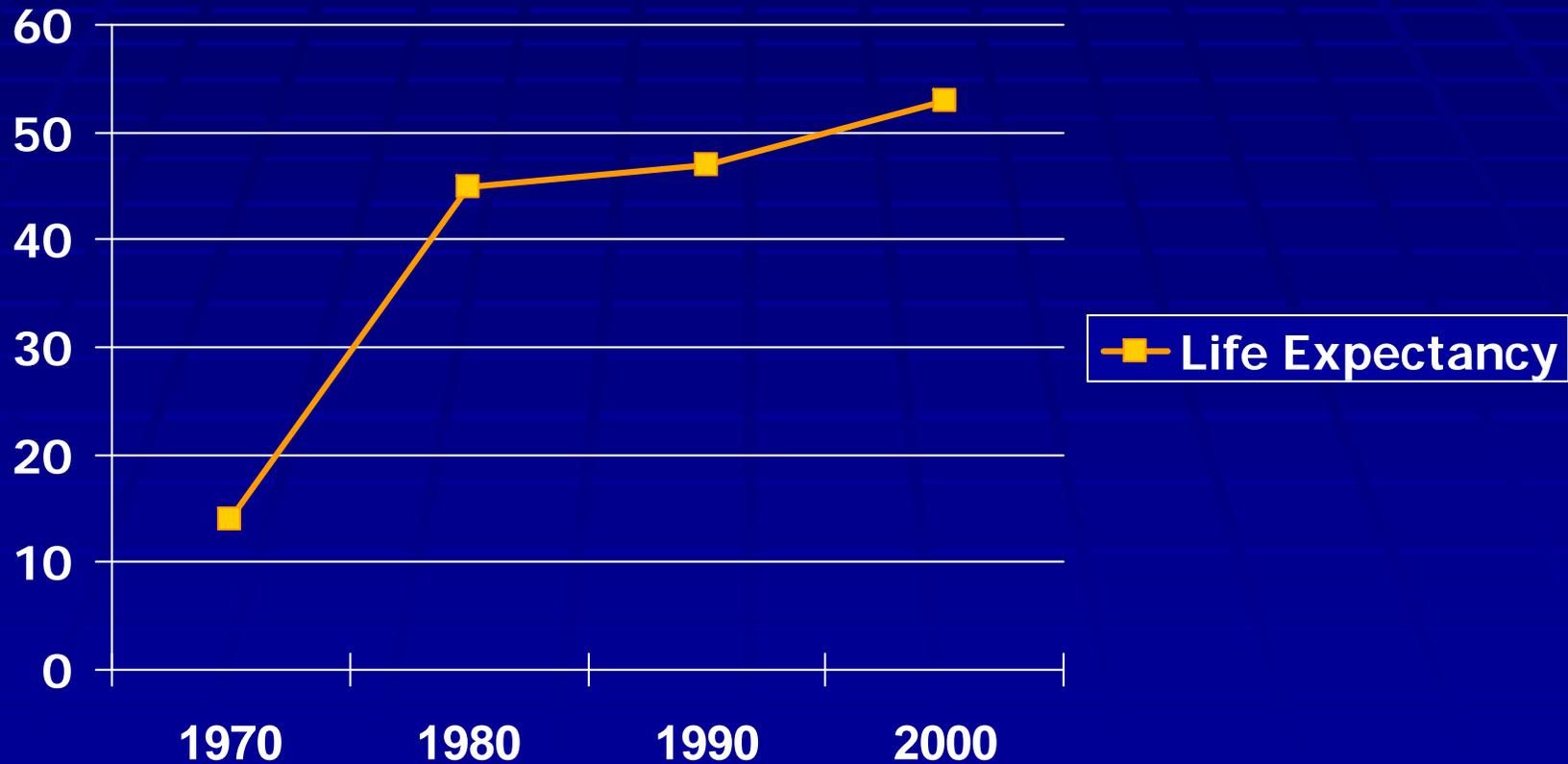
- Health care transition is the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to an adult-oriented care system.”

*Source: Blum et al., 1993*

# Why Is Health Care Transition Necessary?

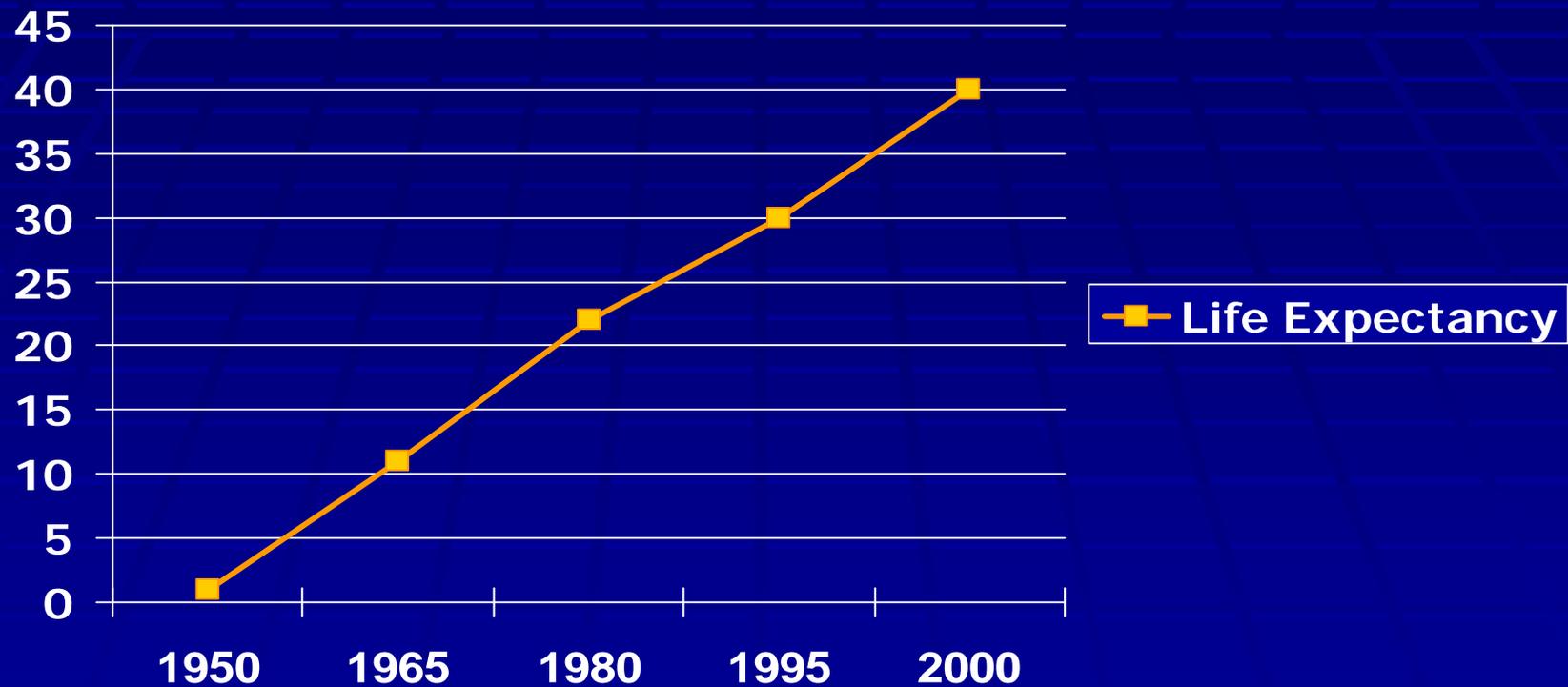


# Sickle Cell Disease



Platt OS, Brambilla DJ, Rosse WF, et al. Mortality in sickle cell disease. Life expectancy and risk factors for early death. *N Engl J Med* 1994;330:1639-44.

# Cystic Fibrosis



Adults with cystic fibrosis now account for 40 percent of the CF population.

*Reference: CF Foundation Website (accessed 5/15/06)*

# Changing Epidemiology of Childhood or Congenital Conditions

- Congenital Heart Disease
  - ~800,000 adults in the U.S. have CHD
    - 419,000 with moderate to severe complexity
    - At risk for re-operation, premature mortality
  - More adults than children
- Cerebral Palsy
  - In US ~800,000 people have CP
  - ~half or 400,000 are adults

*Warnes CA, et. Al. J Am Coll Cardiol. 2001;37:1170-1175*

*Murphy KP, et Al. Dev Med Child Neurol 1995;37:1075-84.*

*United Cerebral Palsy website ([www.ucp.org/ucp\\_generaldoc.cfm/1/9/37/37-37/447](http://www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447))*

# Youth with Chronic Health or Developmental Conditions

- 16-18% of youth have a SHCN
- 4-5% youth have disabling SHCN
  - Complex physical health conditions
  - Developmental disabilities
- 4-5% have serious mental illness

*Iryes H, et. al. Mathematica: 2004*

*Bethel C, et. al. Matern Child Health J (2008) 12:1-14*

# Significance

- Youth with SHCN are less likely to:
  - *finish high school*
  - *pursue postsecondary education*
  - *find a job*
  - *live independently*
- 3x more likely to live on income < \$15,000
- At risk for developing secondary disabling conditions, at great cost to individuals and communities

Source: USDHHS, 2001

# MCHB Core National Performance Measures

- #1. Families will participate in decision-making and be satisfied with services.
- #2. CSHCN will receive coordinated, comprehensive care within a medical home.
- #3. Families will have adequate health insurance.
- #4. CSHCN will be screened early and continuously.
- #5. Services will be organized so that families can use them easily.
- #6. YSHCN will receive the services necessary to make transitions to all aspects of adult life, including health care, work and independence.**

# **A Consensus Statement: 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*

1. Identify primary care provider
2. Identify core knowledge and skills
3. Knowledge of condition, prioritize health issues
4. Maintain an up-to-date medical summary that is portable and accessible
5. Apply preventive screening guidelines
6. Ensure affordable, continuous health insurance coverage

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

# Health System Issues

- Culture shift
- Preparation for transition by child health system
- Health insurance
- Adult system issues



**“When we left pediatric care it was as if someone flipped the switch and turned the lights off.”**

- Parent of child with cerebral palsy

# What Are the Issues?

- Professional culture and traditions

## Pediatricians

*Child- friendly*

*Family-centered*

*Interact primarily  
with parents*

*Nurturing*

*Prescription*

*Developmental Focus*

## Adult Physicians

*Cognitive*

*Patient-centered*

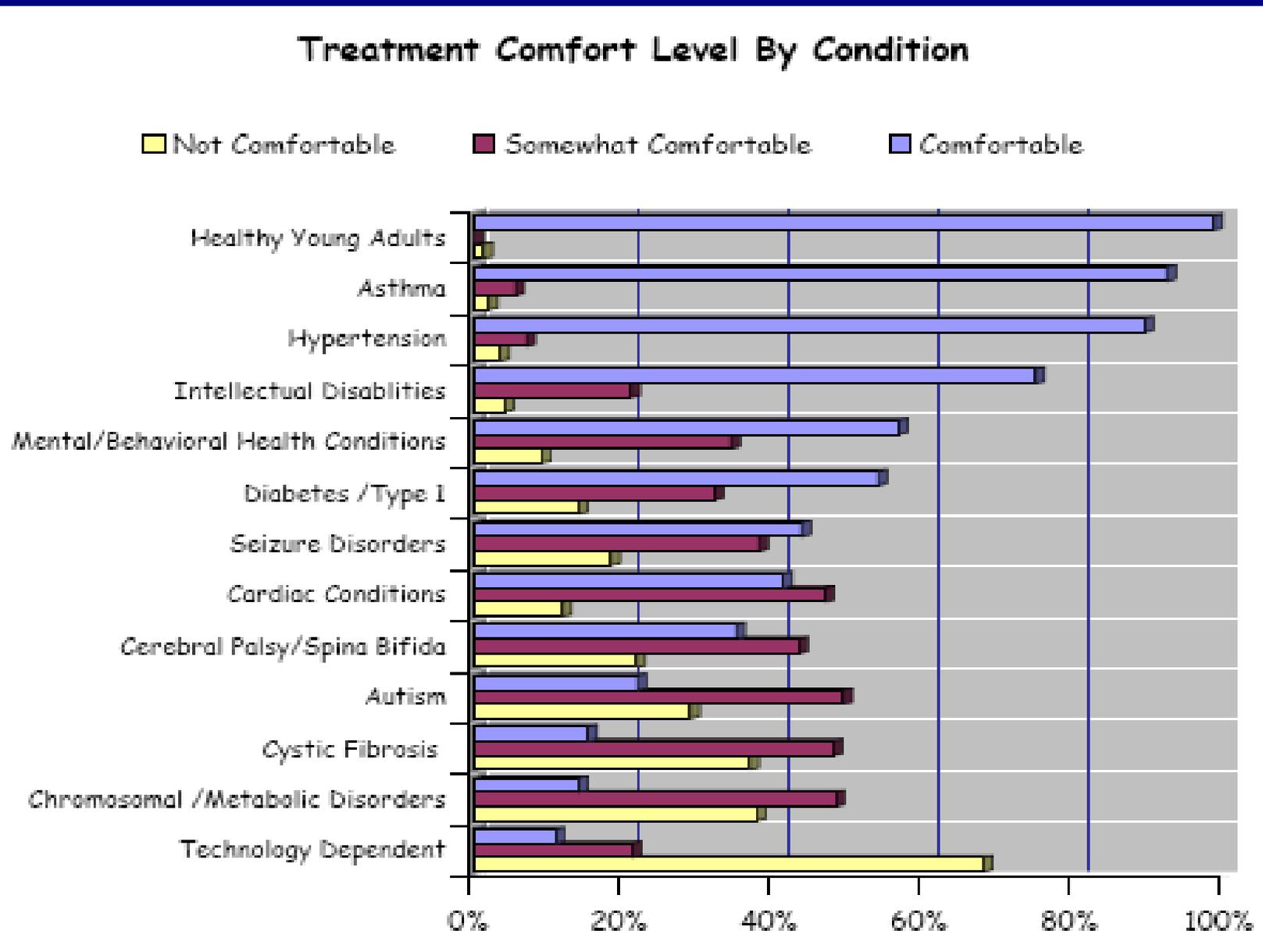
*Interact with patient*

*Empower individual*

*Collaborative*

*Disease Focus*

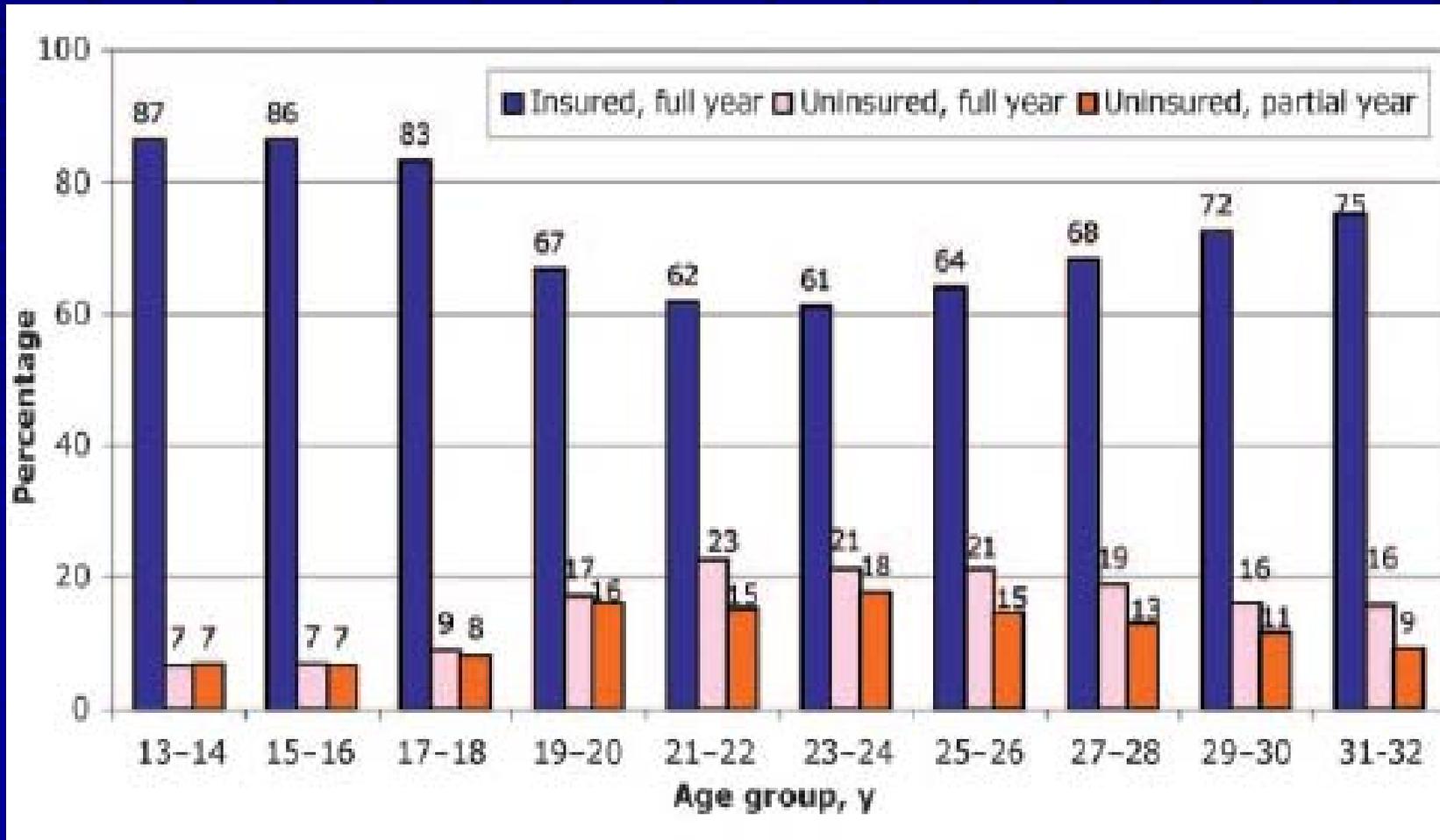
# Comfort of Adult Providers: 2008 NH Survey



# Insurance Barriers

- Young adults have the lowest insurance rate of any age group 0–64 years
  - ~34% ages 18–24 years were uninsured during the past year
  - > 50% for poor, minority, low educational attainment
- Reasons for loss of insurance
  - Ineligibility for parents' insurance
  - Coverage for public insurance ends at 18, 19 or 22
  - SSI rules change at 18
    - “any gainful activity” vs. “causes marked and severe functional limitations”

# Insurance Status: Ages 13-32



# A Framework for Health Care Transition

- Ongoing access to age and disease-appropriate primary and specialty care providers
- Access to uninterrupted, affordable health insurance
- Development of disease self-management skills
- Access to age appropriate educational and vocational opportunities to allow economic self-sufficiency

Source: Lotstein DS, et. al *J Adol Med.* 2008;43:23-29.

# How Are We Doing?

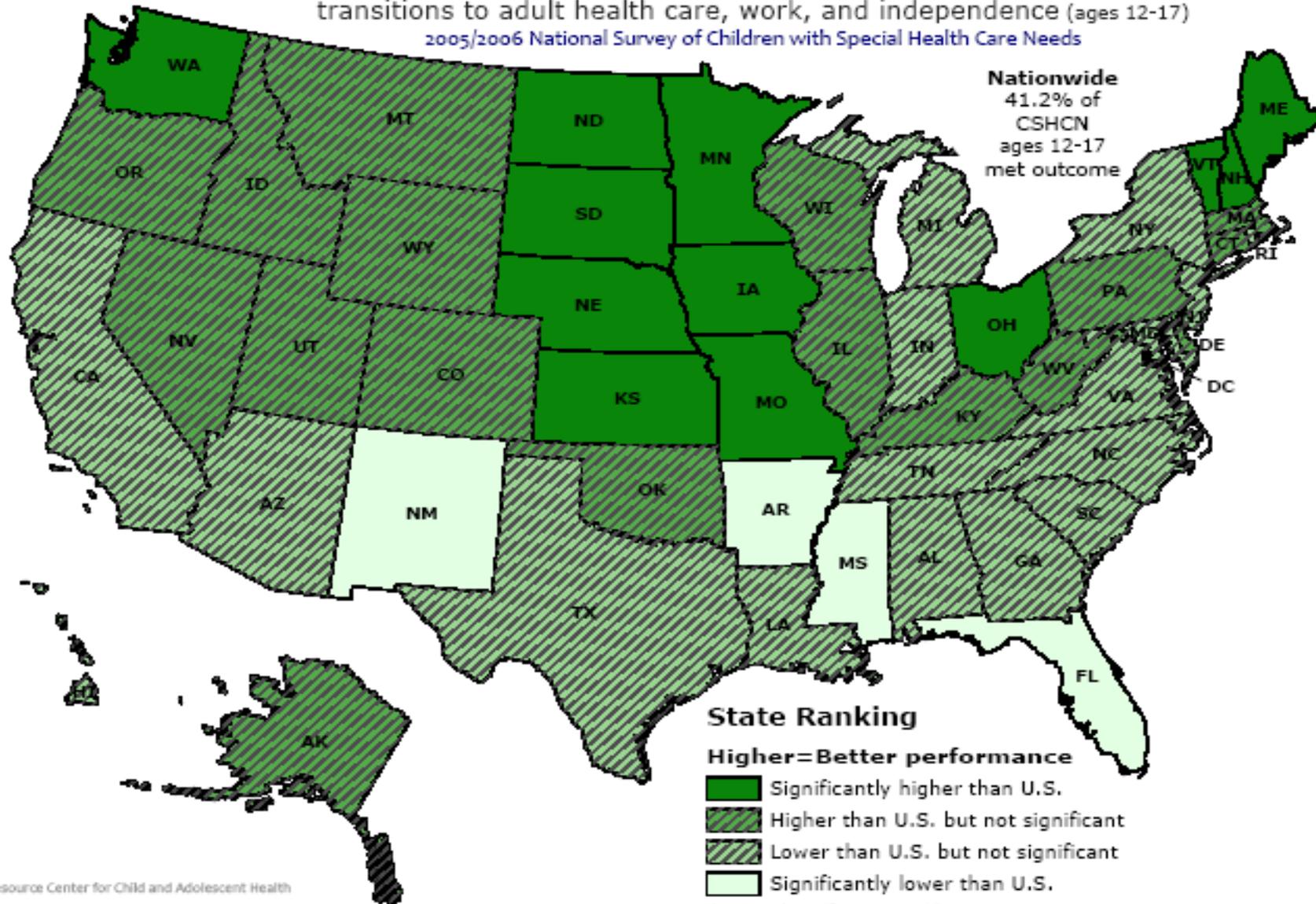
## In the 2005/2006 National Survey of CSHCN:

- 41% among ages 12-17 met core transition outcome
  - Only 34% had discussed upcoming changes in insurance, and 42% had discussed shifting to an adult care provider
  - 62% discussed adult health care needs
  - 78% were encouraged to take responsibility for health
- Greater likelihood of transition if the youth was cared for in a medical home and had insurance
- Less likely if youth was in lower income level, didn't speak English, and was black or Hispanic

Source: Lotstein et. Al. Pediatrics 2009;123: e145-e152.

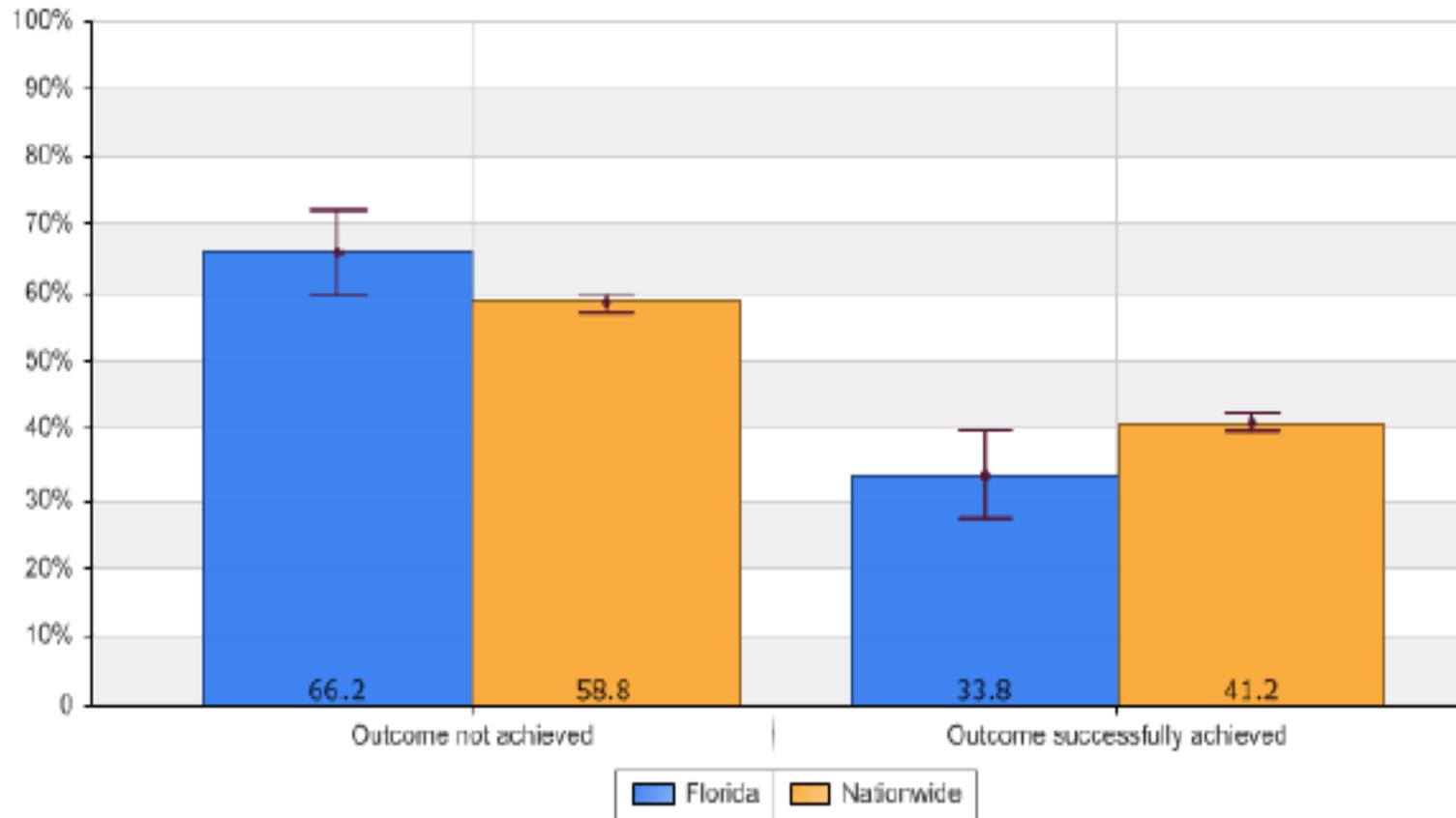


### MCHB Core Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence (ages 12-17) 2005/2006 National Survey of Children with Special Health Care Needs



# How Are We Doing in Florida?

*Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adult health care, work at independence*  
**Florida vs. Nationwide**



Citation format: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved [mm/dd/yy] from [www.cshcndata.org](http://www.cshcndata.org)

# Advocacy

# Florida SB 988 / HB 793

- Florida advocates identified a legislative champion, Senator Stephen Wise, for proposed bill
- Passed in the 2008 Legislative Session (eff 7/08)
- Mandate to assemble a multi-agency Task Force and obtain input from stakeholders, including youth/young adults (Y/YA)
  - Chaired by Title V Director, Children's Medical Services (CMS)
  - Participation of key agency leaders required: Department of Education, Department of Children and Families, Agency for Health Care Administration, Agency for Persons with Disabilities, Division of Vocational Rehabilitation, and other legislatively appointed representatives

# Florida SB 988 / HB 793

- Develop a statewide plan for health care transition
  - Assess and document need
  - Identify strategies/best practices
  - Present range of different models
    - *To accommodate geographic and cultural diversity*
    - *To adapt to the local needs, health system*
    - *Integrate with education, vocation, independent living programs*
  - Identify existing and potential funding sources
- Submit report to Governor and Legislature by 1/1/09

# Plan Development

- Florida Developmental Disabilities Council (FDDC) supported initiative with approximately \$65K; no legislative budget allocation
- Hired Project Facilitator through competitive bid
- Task Force comprised of 14 legislative appointees and 21 additional stakeholders; total 35-member Workgroup
- First Task Force meeting held 8/08
  - 28 participants (21 in attendance, 7 via teleconference)
  - Subcommittee members identified for Financing, Services & Models of Care, and Education & Training

# Plan Development

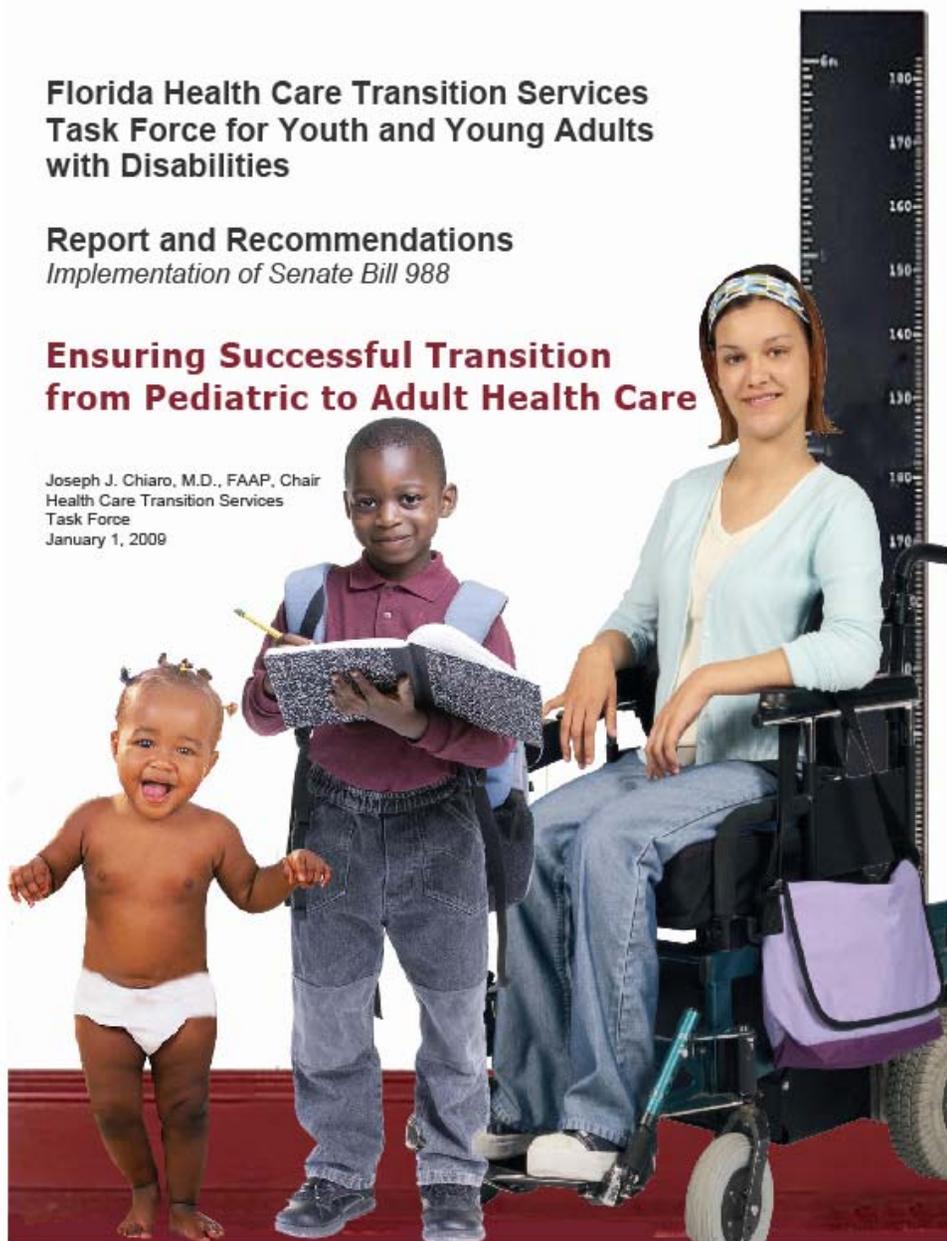
- Created [www.healthcaretransition.org](http://www.healthcaretransition.org) and Task Force email distribution list
- Facilitated 13 subcommittee teleconferences (4-5 per subcommittee)
- Compiled “stories” from young adults, families, providers
- Second Task Force meeting held 11/08
  - 24 participants (20 in attendance, 4 via teleconference)
- Final report completed 12/08
  - Entitled *Ensuring Successful Transition from Pediatric to Adult Health Care*
  - Available in print and online

**Florida Health Care Transition Services  
Task Force for Youth and Young Adults  
with Disabilities**

**Report and Recommendations**  
*Implementation of Senate Bill 988*

**Ensuring Successful Transition  
from Pediatric to Adult Health Care**

Joseph J. Chiaro, M.D., FAAP, Chair  
Health Care Transition Services  
Task Force  
January 1, 2009



# Legislative Report

# Key Strategies

- Services and Models of Care
  - Establish a state Office of Health Care Transition
    - Support local public/private HCT coalitions in building regional service systems
    - Locate within CMS; provide oversight and technical assistance
- Health Care Financing
  - Create an Insurance Resource Guide for YSHCN
  - Work with insurers to develop policies that support medical homes, care coordination, co-management of YSHCN
  - Advocate for a Medicaid Buy-In program
  - Advocate for insurance payments to reflect the time and resources required for appropriate care of YSHCN

# Key Strategies

- Education and Training
  - Disseminate HCT educational materials to YSHCN, families, and providers
  - Provide training for professionals (CME/CE credit)
  - Create an online toolkit and clearinghouse of information
- Infrastructure
  - Secure legislation and funding to support the Office of Health Care Transition in building regional service systems
  - Establish operational and oversight systems for the Office

# Florida Strategic Plan for Health Care Transition

10/20/2009

## Foundation

### Our Mission

To ensure successful transition from pediatric to adult health care for all youth and young adults (YYA) in Florida, including those with disabilities or special health care needs.

### Our Core Values

- YYA and their families will participate in decision-making at all levels, and be satisfied with the services they receive.
- YYA will receive coordinated, ongoing, comprehensive care within a medical home.
- YYA will have adequate private and/or public insurance to pay for the services they need.
- YYA will be continuously screened to detect other conditions and prevent secondary disabilities.
- Community-based systems will be integrated, collaborative, and organized so YYA and their families can use them easily.
- YYA will receive services that meet their physical, social, and developmental needs.

## Strengths

### What we do best

Florida leaders have been at the forefront in recognizing challenges faced by youth as they age out of pediatric health care and developing innovative programs to meet the needs of emerging adults with disabilities or special health care needs.

## Key Strategies

### How we will get there

Leverage the infrastructure of Children's Medical Services (CMS) and its federally mandated responsibility for health care transition planning to establish a state Office of Health Care Transition within CMS that:

- Provides leadership, expertise, and resources to create and sustain a statewide comprehensive system of care.
- Supports and monitors local public/private transition coalitions.
- Is guided by a statewide Advisory Council comprised of YYA, families, key state agencies, advocacy organizations, professional associations, and other stakeholders.

## Goals and Statewide Objectives

### Health Care Financing

**1 Health Care Benefits.** YYA obtain and maintain adequate, affordable health insurance.

- Develop a technical assistance guide to help identify insurance options available to YYA.
- Implement a Medicaid Buy-In option.

**2 Service Compensation.** Insurers reimburse providers for services needed to effectively care for YYA.

- Work with Medicaid program to implement medical homes for YYA.
- Work with Medicaid program and private insurers to develop policies relating to co-management of YYA.
- Advocate for insurance payments to reflect the time and resources required for appropriate care of YYA.
- Accept federal Medicaid matching funds for education and outreach to adults with Sickle Cell Disease.
- Extend CMS Network coverage for YYA to age 25 or 29.

### Education and Training

*Policy Makers and Funders*      *Education/Allied Professionals*

**3 Material Development.** Develop, adapt, and disseminate health care transition educational and training materials.

- Identify educational and training needs.
- Coordinate development or adaptation of education and training materials for each target market.
- Utilize existing state and community networks and organizations to assist in production and dissemination of materials.

*Health Care Professionals*      *YYA and Families*

**4 Accredited Training.** Provide multi-modal training approved for CME/CEU credit at no cost to the individual.

- Provide accredited health care transition-specific training for professionals and families.
- Advocate for mandatory disability-related training for health care professionals.

*Students in Training*

**5 Outreach and Promotion.** Engage high visibility spokespersons to communicate messages related to health care transition.

- Engage a physician champion for outreach to the health care community; explore feasibility of Surgeon General.
- Engage a YYA for outreach to his/her peers and families.

### Services and Models of Care

**6 Regional Coalitions.** Organize local public/private health care transition coalitions.

- Develop planning guidelines to assist in local coalition-building.
- Identify geographic regions for local coalitions.
- Pilot local coalition development in 3 selected regions, 2 urban and 1 rural.
- Identify external funding sources to support expansion of local coalition development; see Infrastructure.

**7 Information Clearinghouse.** Establish a centralized, searchable database of providers, best practices, and resources.

- Collect clinical guidelines in treatment of chronic disease and pediatric onset conditions.
- Collect patient-centered health care tools.
- Identify model health care transition programs that local coalitions can replicate based on their needs and resources.
- Identify resources to assist YYA with employment, benefits, independent living, decision-making options, housing.
- Create and maintain database of adult primary care physicians and specialists.

**8 Evaluation.** Develop and monitor performance measures at the state and local levels.

- Identify process, impact, and outcome measures for the state, local coalitions, organizations, and YYA.
- Consider MCHB core outcomes for CYSHCN as well as current CMS health care transition indicators.

### Infrastructure

**9 Funding and Policy.** Identify policy and secure funds for plan implementation.

- Advocate for increased state funding from general revenue.
- Advocate for increased federal funding of Title V Block Grant.
- Recommend new health care transition objective in HP2020 Plan.
- Identify external funding to support expansion of local coalitions.

**10 Stakeholder Collaboration.** Coordinate plan development and implementation across agency and stakeholder groups.

- Share legislative report and solicit participation from key agencies and organizations.
- Coordinate cross-organization advocacy for improved systems and quality of life for YYA.
- Increase participation of YYA and families in planning and implementation.

**11 Governance.** Establish operational and oversight systems for State Office of Health Care Transition.

- Identify and hire program staff.
- Establish a statewide Advisory Council.

## Vision

### What our State will look like

All youth in Florida, including those with disabilities or special health care needs, will successfully transition to all aspects of adult life, including adult health care, work, and independence.

## Implementation

### How we make strategy a habit

The Task Force, CMS's Office of Health Care Transition, FDCC, and other partners will:

- Communicate the Strategic Plan to all stakeholders throughout the state.
- Involve stakeholders in the creation of objectives and action items to support goals.
- Hold parties responsible for achievement of assigned objectives.
- Monitor the plan quarterly.
- Hold regularly scheduled teleconference calls to report on progress.
- Change the plan if something is not working; take corrective action or move to build on success.
- Link strategy to performance.
- Celebrate when goals are reached.



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

# Challenges

- Timeframe
  - Short period of time to develop legislative report
- Difficulty engaging youth/young adults in the planning process
  - Amount of time required
  - Meeting schedule conflicts
- Identifying participant availability for large group meetings
- Diverse group of participants had limited opportunities for face-to-face networking and relationship-building

**Policy**

# Implementation in 2009-2010

- Proposed 2010 state legislation formalizes key strategies from legislative report
- Current activities jointly funded by FDDC and CMS; administered through USF
- Enhanced Web site
  - Searchable toolkit and resources
- Cross-disciplinary training for professionals
  - In development by University of Florida
  - Available for free CME/CE in 2nd quarter '10

# Implementation in 2009-2010

- Insurance Resource Guide
  - Online and in print
  - Available in 2<sup>nd</sup> quarter '10
- Launched local coalition development
  - Developed *Strategic Planning Guide for Regional Coalitions*
  - Provided county-level data for YSHCN
  - Piloting in Tampa and Jacksonville (urban) and Panhandle area (rural) from Jan-May '10
- Adopted new program name:  
**FloridaHATS (Health And Transition Services)**

# Looking Forward

- Monitor federal and state legislative activity
- Formalize Task Force as state advisory body for Office of Health Care Transition
- Continue local coalition development, with leadership from CMS area offices
- Coordinate HCT-related activities across agencies at both state and local area levels
- Develop indicators and benchmarks to evaluate progress, by state and by local area

