



**Adequate Insurance and Financing for
CYSHCN and Their Families:
Maryland Data**

Why is a system of care important?

- Effective promotion of health and health services for children with special health care needs (CSHCN) requires a system of care that is integrated, comprehensive, coordinated, family centered and consistent across the life course (or lifespan).
- Ideally, families of CSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers

Why is a system of care important?

- Advancing integrated care systems for CSHCN and their families is a national mandate under Public Law 101-239 as well as a priority reflected in the Healthy People goals set forth by the U.S. Department of Health and Human Services from 2000 to 2020.
- It is the focus of Maryland's Title V CSHCN program, housed in OGCSHCN.

Measuring Progress

- To determine progress toward an integrated system of care for all CSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:
 - Partners in Decision-Making
 - Medical Home
 - **Adequate Health Insurance and Financing**
 - Early and Continuous Screening
 - Ease of Community-Based Service Use
 - Transition to Adulthood

reduce burden on families

OUTCOME 3: ADEQUATE INSURANCE

critical for lifelong health

affordable

reduce stress

consistent

accessible

equitable access to quality care

reliable

reduce disparities

good coverage

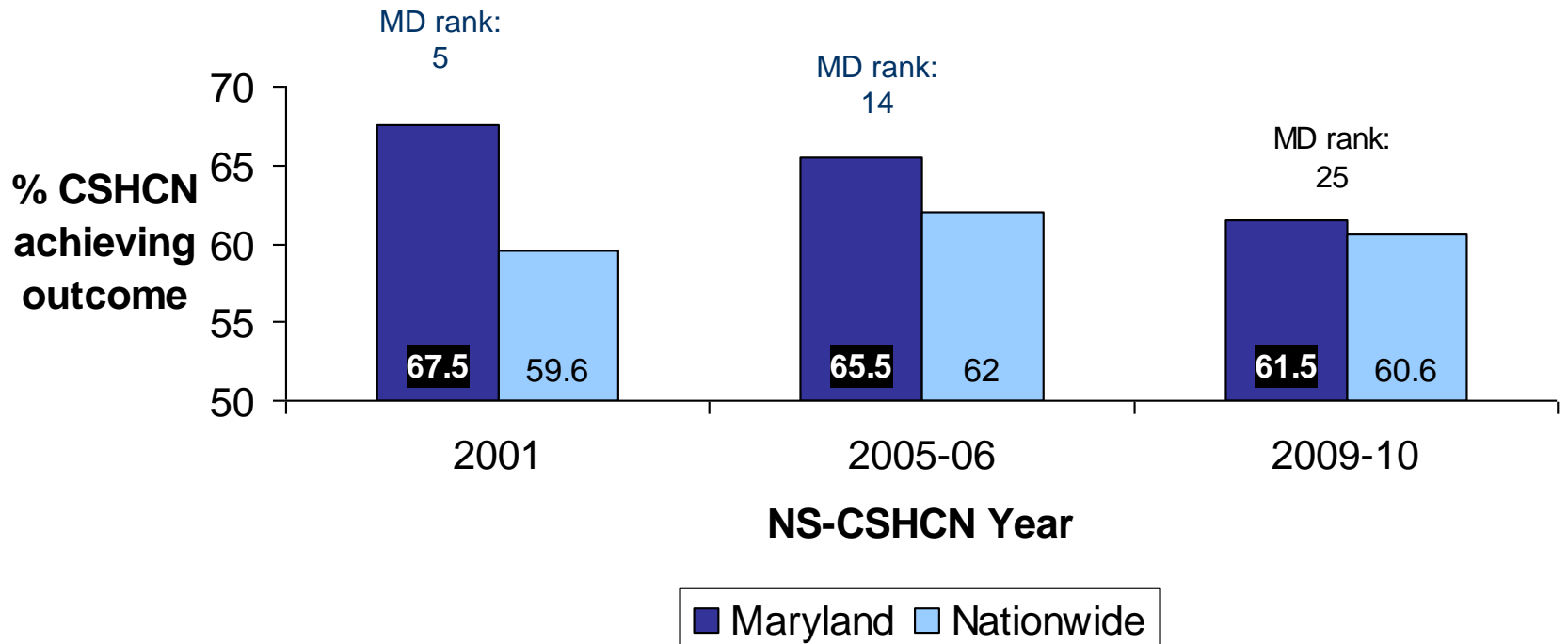
ability to get needed care



MARYLAND DATA

Time Trend- Insurance Adequacy in Maryland

% CSHCN whose families have adequate private and/or public insurance to pay for the services they need



Disparities in Maryland by Subgroup

By Demographics

46.3 Hispanic CSHCN	53.8 CSHCN 12- 17 years of age	61.5 All Maryland CSHCN	62.4 White non- Hispanic CSHCN	63.6 Other non- Hispanic CSHCN	65.2 Black, non- Hispanic CSHCN CSHCN 6-11 years of age	65.2 CSHCN 6-11 years of age	71.4 CSHCN 0-5 years of age
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By Specific Types of Health Needs

50.9 CSHCN qualified on functional limitations	53.1 CSHCN qualified on service use	54.4 One or more emotional, behavioral, or developmental issues	60.8 CSHCN qualified on Rx use AND service use	61.5 All Maryland CSHCN	65 No qualifying emotional, behavioral, or developmental issues	70.2 CSHCN qualified on Rx use
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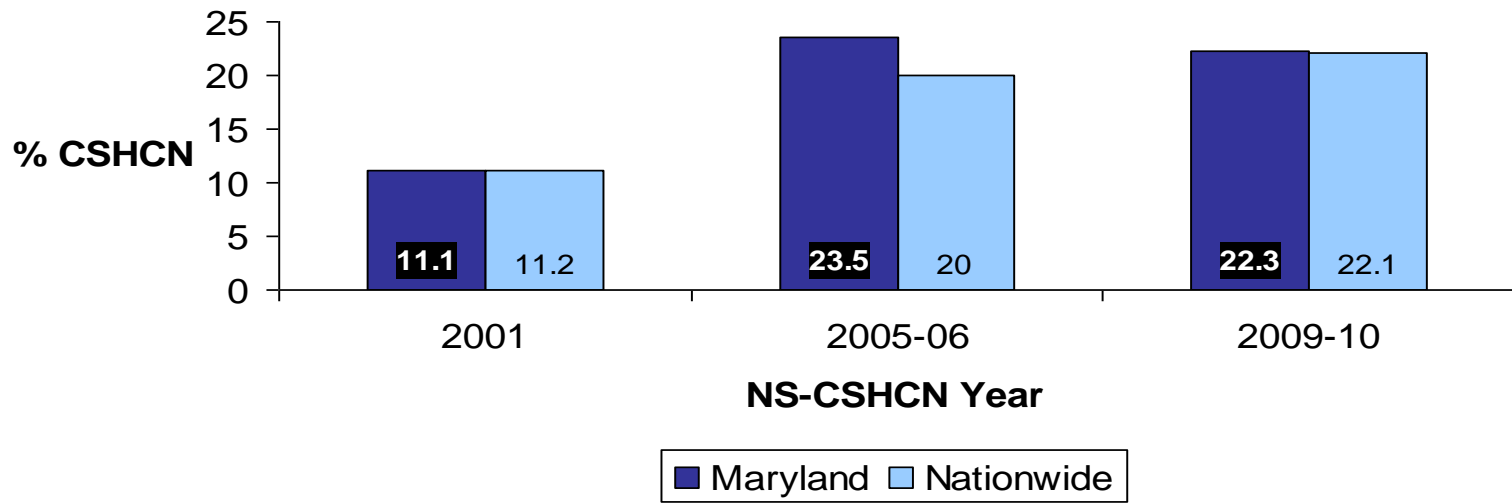
By Insurance Type and Presence of Medical Home

49.3 CSHCN without a medical home	61.5 All Maryland CSHCN	62.1 CSHCN with private insurance only	67.3 CSHCN with public insurance only	74.3 Both public and private insurance	76.5 CSHCN with a medical home
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Source: 2009-10 NS-CSHCN

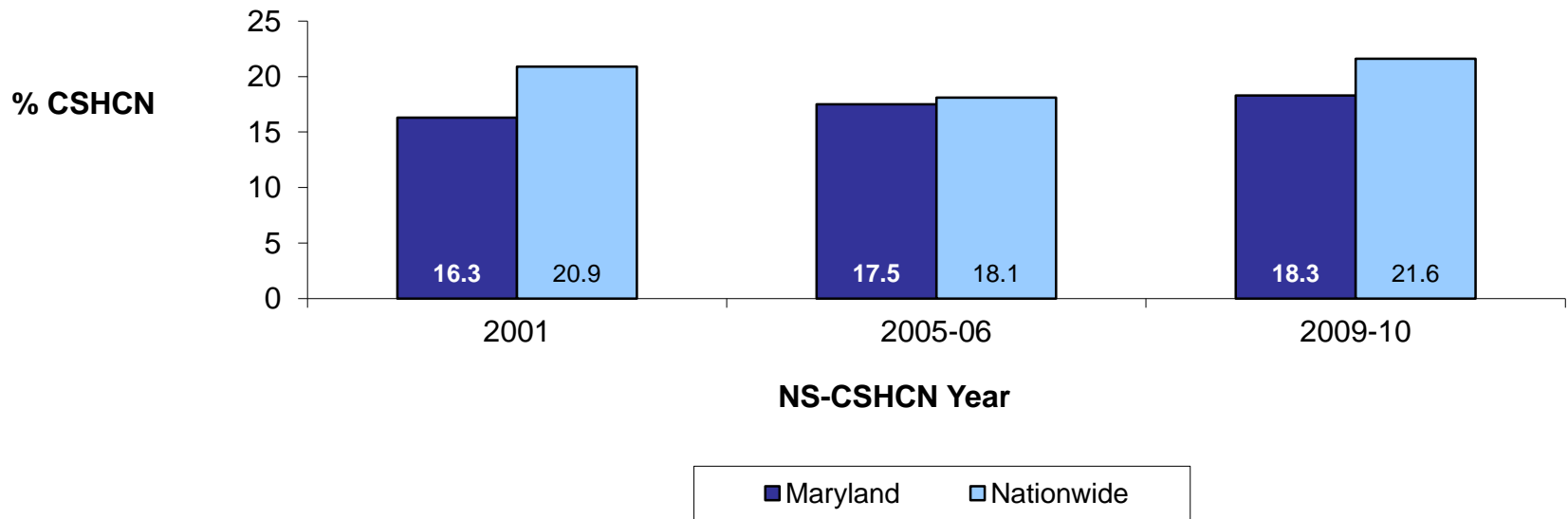
Impact on Families

% CSHCN whose families spend \$1000 or more on out-of-pocket medical expenses in the past 12 months



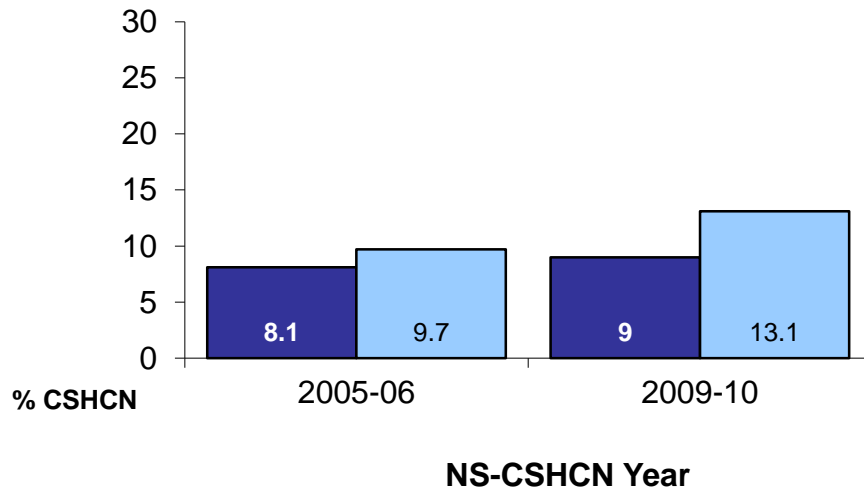
Impact on Families

% CSHCN whose health conditions cause financial problems for the family

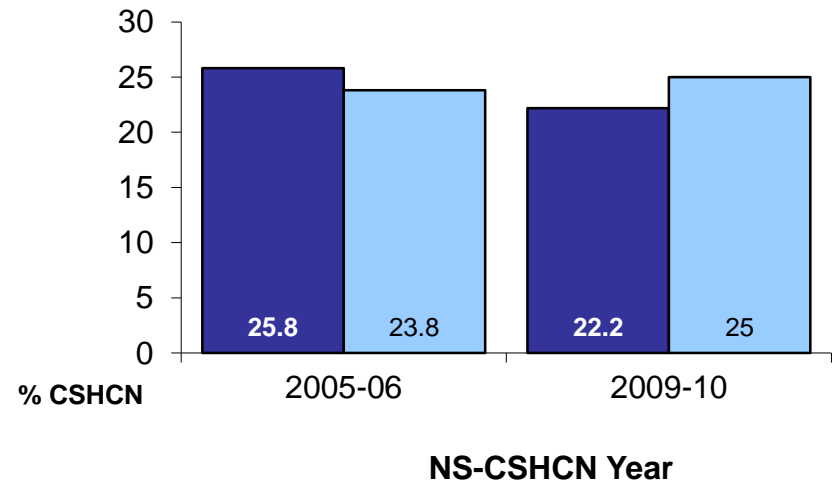


Impact on Families

% CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's care



% CSHCN whose health conditions cause family members to cut back or stop working



■ Maryland
■ Nationwide

■ Maryland
■ Nationwide

Impact on Families

- % parents/caregivers of CSHCN who have avoided changing jobs because of concerns about maintaining health insurance for their CSHCN:

16.9%

Source: 2009-10 NS-CSHCN

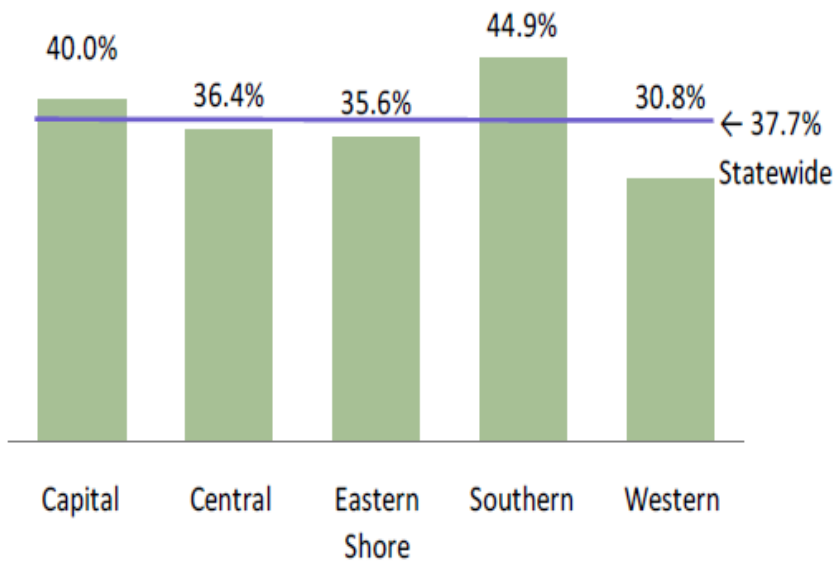
Impact on the Family

% of CYSHCN

<i>CYSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child</i>	42.5
<i>Families who report that their child's insurance does not pay for all health services needed</i>	54.5
<i>CYSHCN who were uninsured at some point in the last 12 months</i>	12.7
<i>CYSHCN whose conditions cause family members to cut back or stop working</i>	37.7

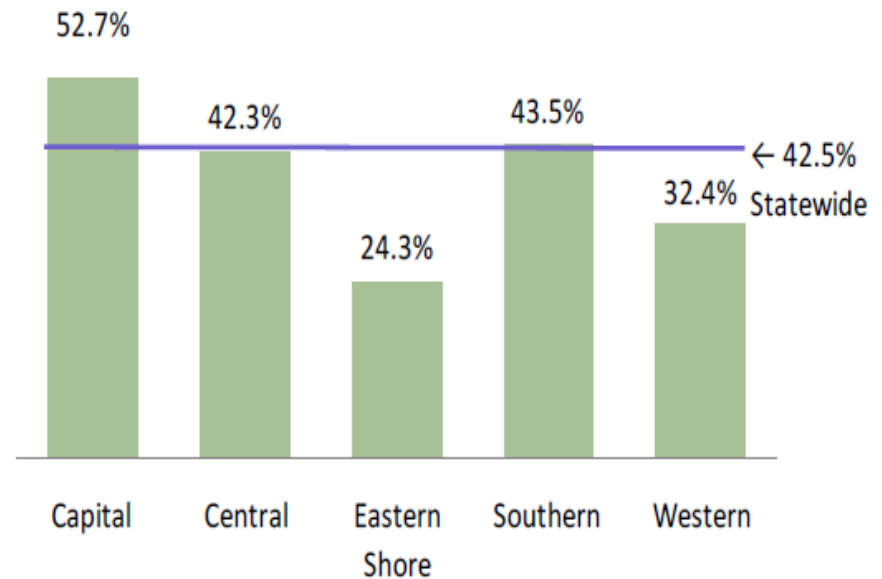
Impact on the Family:

Families whose CYSHCN conditions cause family to cut back or stop working



Impact on the Family:

Families who paid \$1000 or more out of pocket in medical expenses per year per child



Source: 2010 Maryland Parent Survey

Adequate Insurance and Financing- a Priority in Maryland

- In a 2010 poll conducted by OGCSHCN, stakeholders ranked AIF as the #1 (out of 18) statewide priority for Maryland CYSHCN
- In a 2011-12 poll conducted by OGCSHCN, stakeholders ranked AIF #5 out of 21 priorities for CYSHCN with ASD and other DD

#1: Access to needed therapies

#2: Youth transition to adulthood

#3: Training for school personnel

#4: Community-based, easy-to-use services

#5: Adequate health insurance and financing

#6: Family support and advocacy

#7: Access to child care and respite care

#8: Recreation and leisure opportunities

#9: Effective local-level cross-sector collaboration

#10: Family training and education

Other priorities: Family/professional partnerships (#11); Developmental screening and diagnostic services (#12); Mental health treatment and services (#13); Effective information dissemination (#14); Effective state-level cross-sector collaboration (#15); Access to primary and specialty health care (#16); Training for medical and related services professionals (#17); Medical home (#18); Access to transportation (#19); Training for other public servants (#20); Other needs (#21); and Reducing disparities (#22).

Top 10 rankings by regions or stakeholder groups (2011; ASD and other DD):

- #2 among medical center/health care provider stakeholders
- #3 in western, capital area, and central regions of Maryland
- #4 among local government agency stakeholders
- #5 among community-based agency stakeholders and among parent/family stakeholders
- #7 among advocacy organization stakeholders
- #9 among state government agency stakeholders
- #10 in eastern shore region of Maryland

Questions?

- Find NS-CSHCN and NSCH Survey data online at

<http://childhealthdata.org/learn/NS-CSHCN>

THANK YOU