Comparing States Using Survey Data on Health Care Services for Children with Special Health Care Needs (CSHCN)

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Presented at the Ninth Annual
Maternal and Child Health Epidemiology Conference
Tempe, Arizona • December 12, 2003

Centers for Disease Control and Prevention
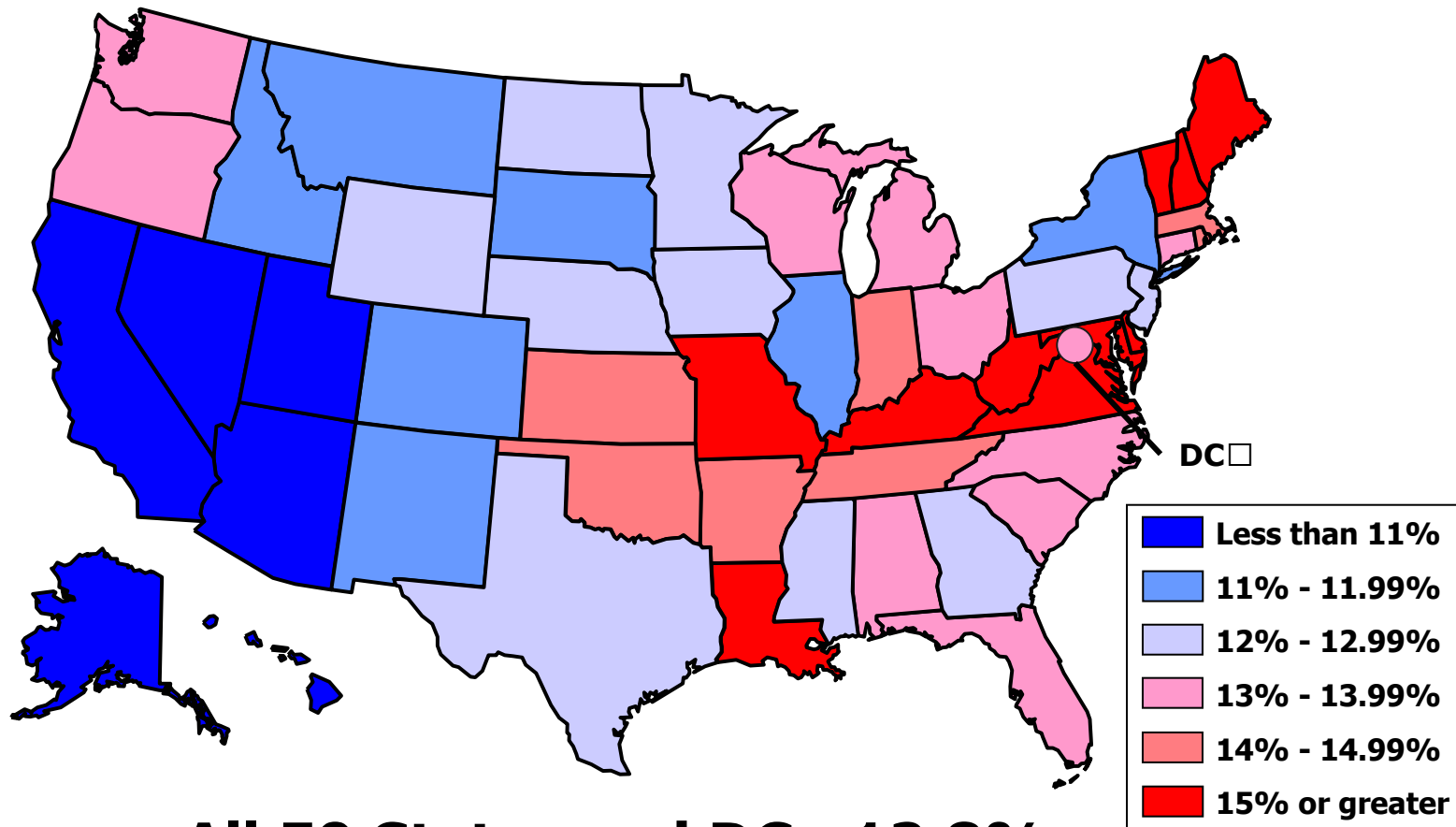**National Center for Health Statistics**

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National Survey of Children with Special Health Care Needs, 2001

- **Sponsor:** The Maternal and Child Health Bureau
- **Purpose:** To produce national and State-based estimates of the prevalence and impact of special health care needs among children 0-17 years of age
- **Sample:** Independent random-digit-dial samples for all 50 States and the District of Columbia (DC)
- **Screening:** From 196,888 households with children, 373,055 children were screened for special needs
- **Interviews:** Completed interviews for approximately 750 CSHCN in each State (38,866 CSHCN nationally)
- **Response Rate:** 61% (AAPOR Rate #3)

Prevalence of Children with Special Health Care Needs

All 50 States and DC: 12.8%

Legend:
- Less than 11%
- 11% - 11.99%
- 12% - 12.99%
- 13% - 13.99%
- 14% - 14.99%
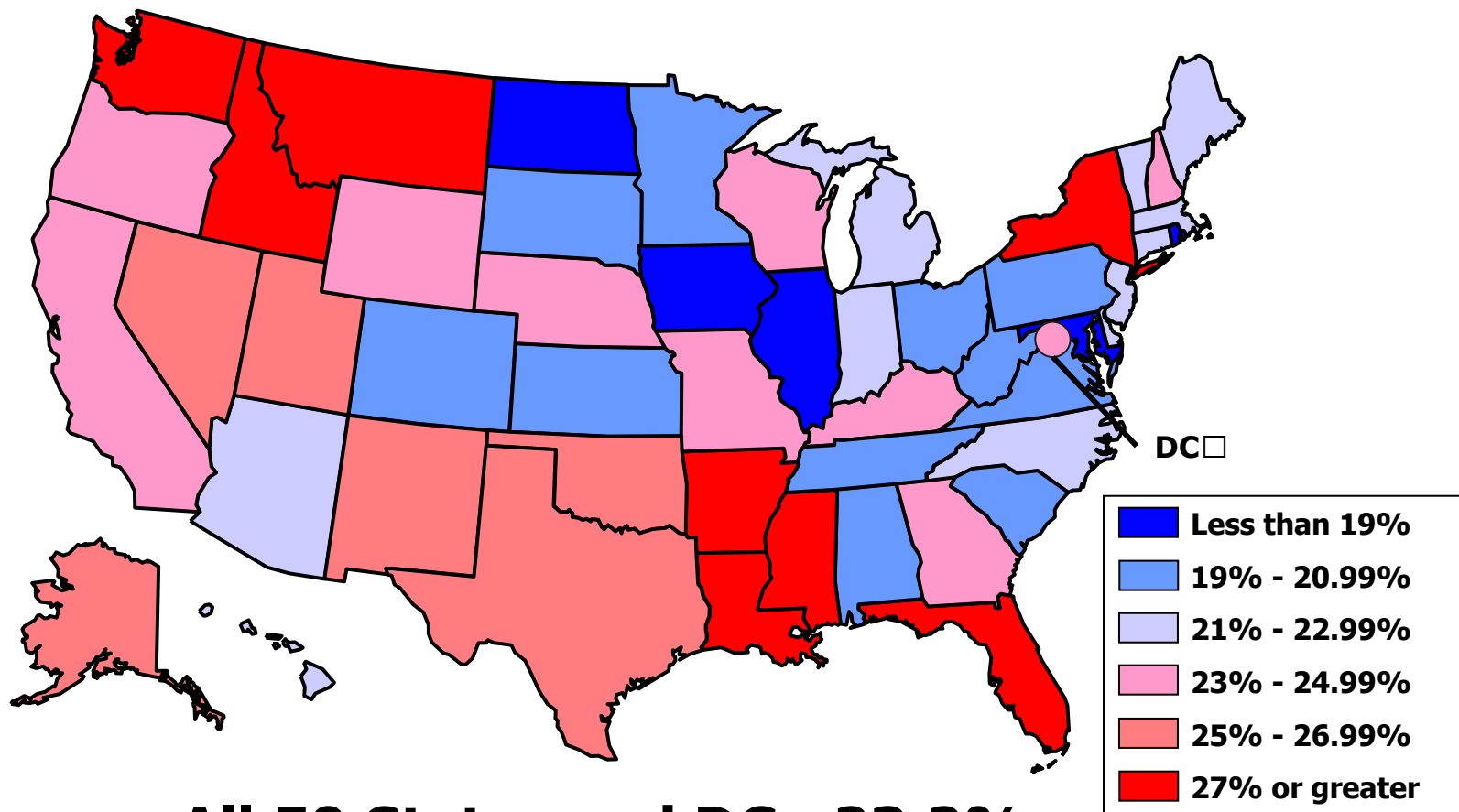- 15% or greater

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15 Key Indicators for CSHCN

- **Child health** (2 indicators)
  - Impact on activities, school absences
- **Health insurance coverage** (3 indicators)
  - Uninsurance (past year, point in time), adequacy
- **Access to care** (5 indicators)
  - Unmet needs, unmet support needs, problems with referrals, no usual source of care, no personal doctor or nurse
- **Family-centered care** (1 indicator)
- **Impact on family** (4 indicators)
  - Out-of-pocket expenses, family financial problems, time spent on care, impact on employment for family members

Percent of CSHCN whose Conditions Affect their Activities Usually, Always, or a Great Deal
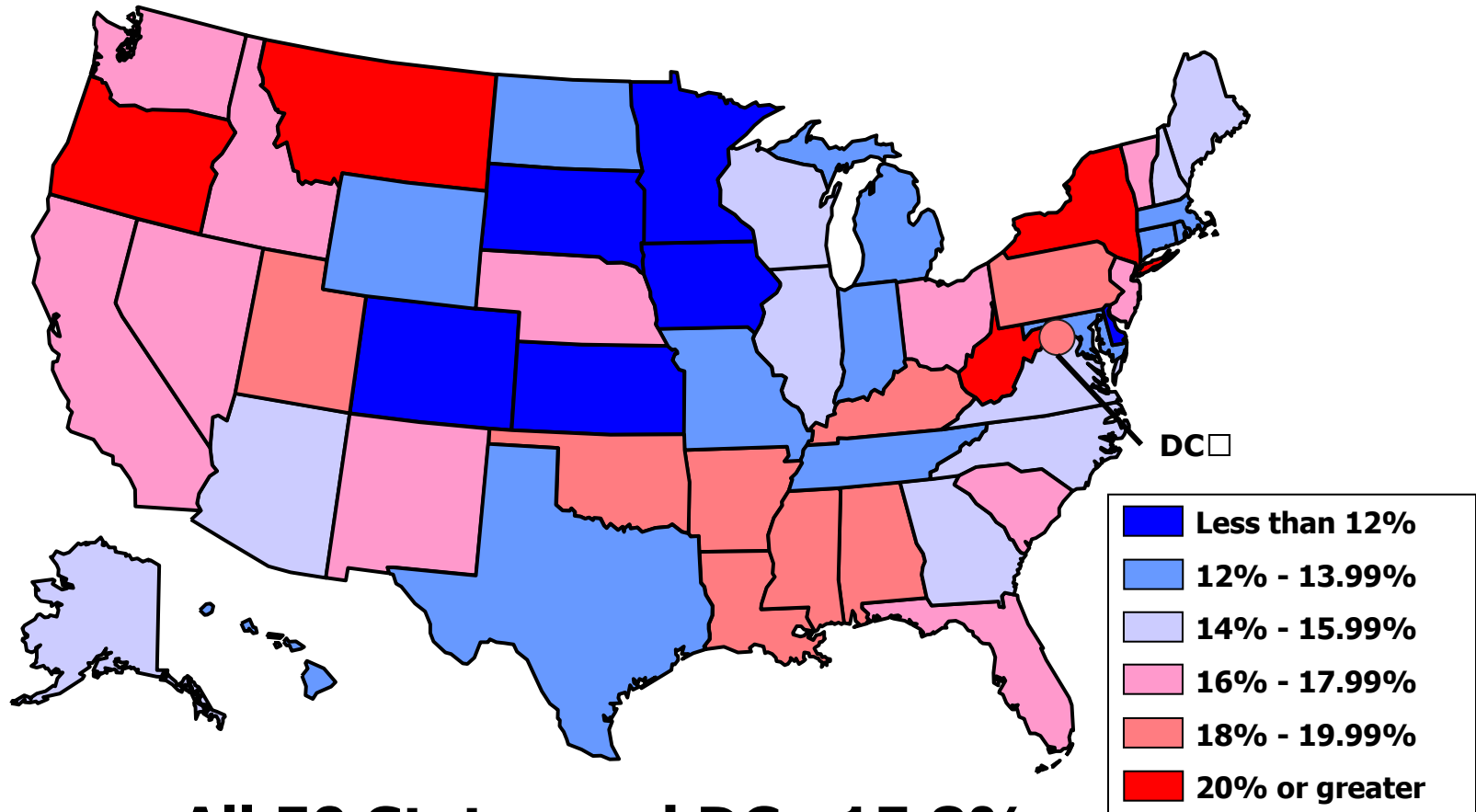

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Less than 19%

19% - 20.99%

21% - 22.99%

23% - 24.99%

25% - 26.99%

27% or greater

All 50 States and DC: 23.2%

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Percent of School-Aged CSHCN with 11 or More Days of School Absences Due to Illness

All 50 States and DC: 15.8%

Legend:
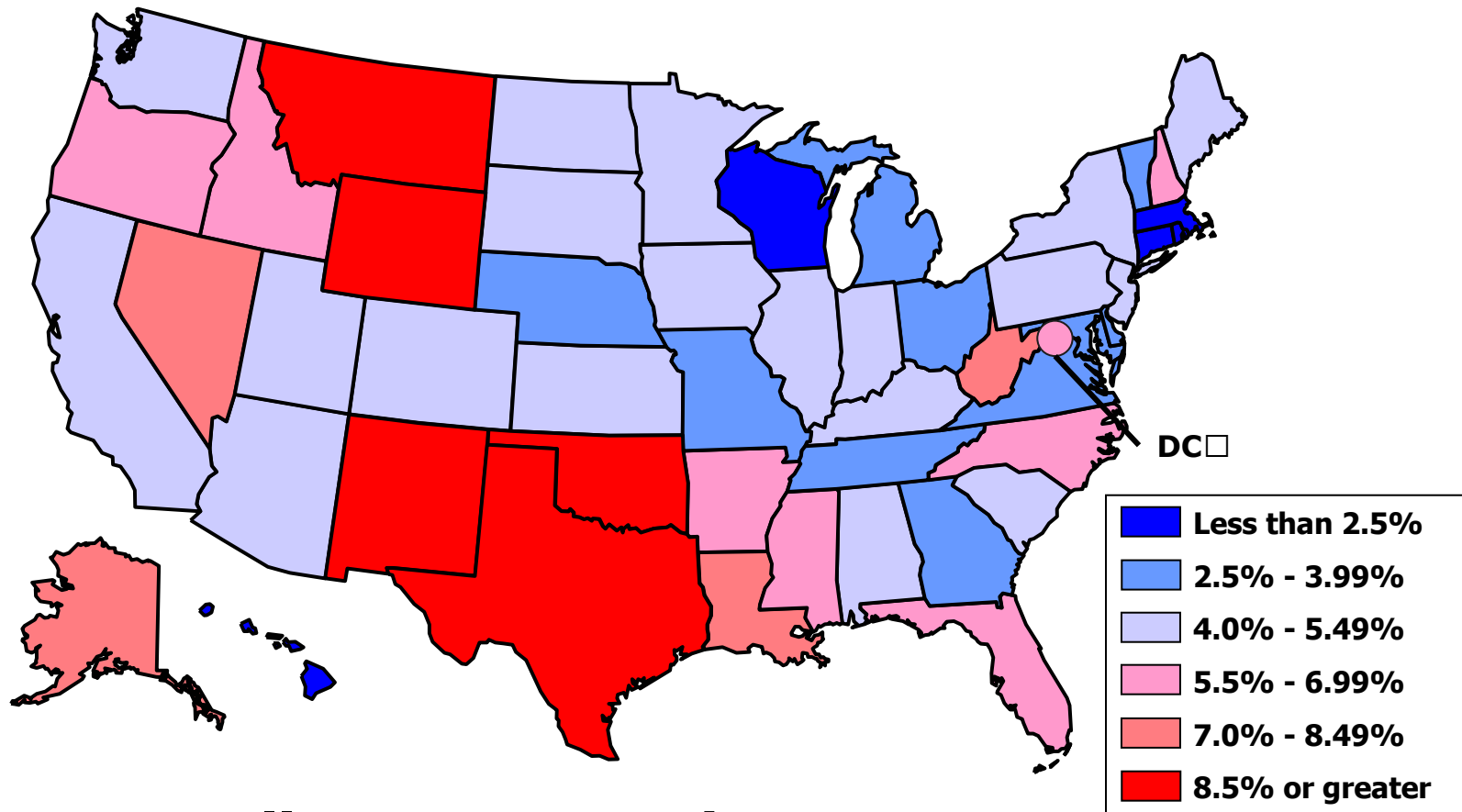- **Less than 12%**
- **12% - 13.99%**
- **14% - 15.99%**
- **16% - 17.99%**
- **18% - 19.99%**
- **20% or greater**

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Percent of CSHCN Without Insurance at Some Point in Past Year

DC □

Legend:
- **Less than 7%** (dark blue)
- **7.0% - 9.49%** (medium blue)
- **9.5% - 11.99%** (light blue/lavender)
- **12.0% - 14.49%** (pink)
- **14.5% - 17.99%** (light red)
- **18% or greater** (red)
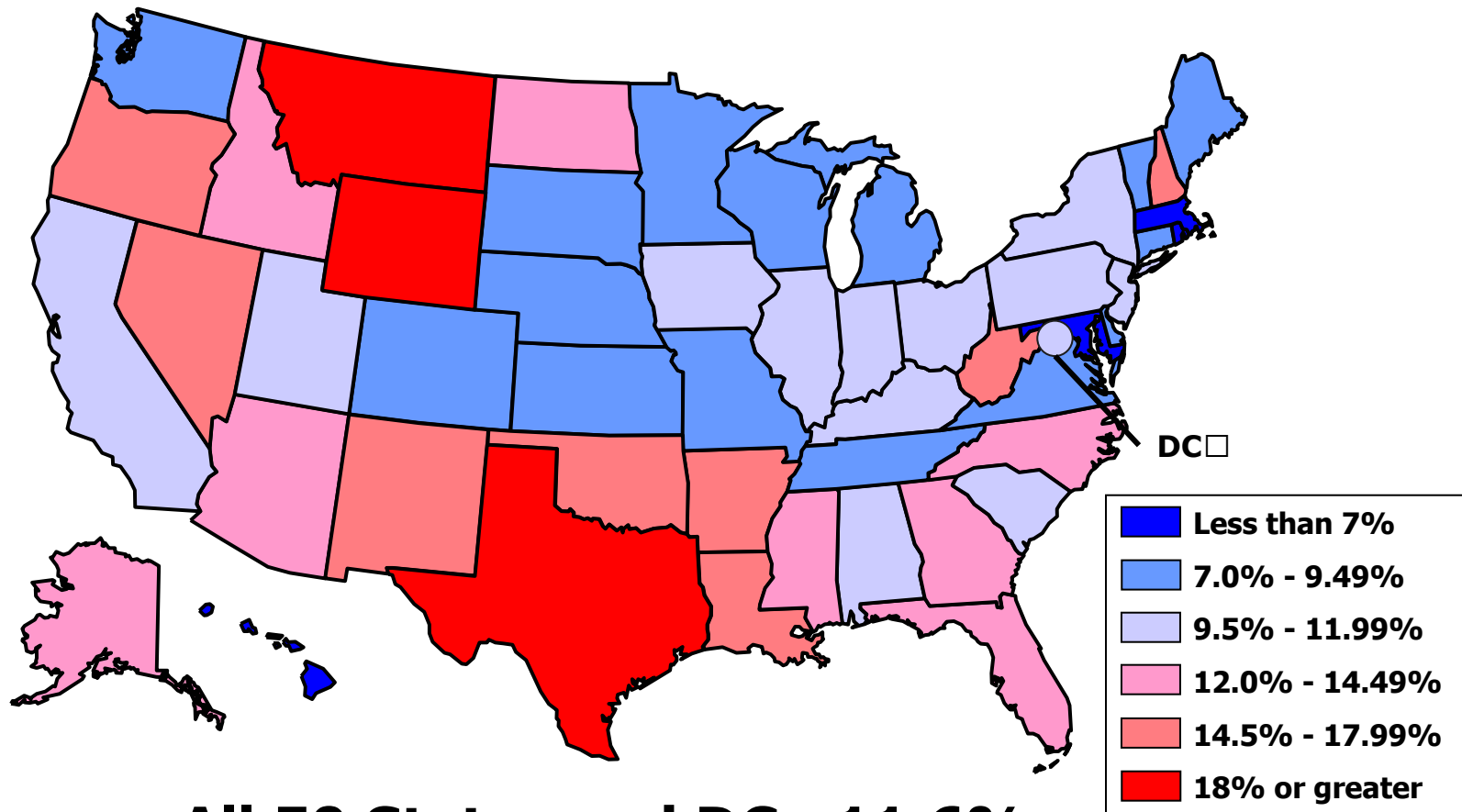
All 50 States and DC: 11.6%

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Percent of CSHCN Without Insurance At the Time of the Survey

All 50 States and DC: 5.2%

DC☐

Legend:
- ☐ Less than 2.5%
- ☐ 2.5% - 3.99%
- ☐ 4.0% - 5.49%
- ☐ 5.5% - 6.99%
- ☐ 7.0% - 8.49%
- ☐ 8.5% or greater

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Percent of Currently Insured CSHCN with Insurance that is Not Adequate

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All 50 States and DC: 33.5%

■	Less than 30%
■	30% - 31.99%
■	32% - 33.99%
■	34% - 35.99%
■	36% - 37.99%
■	38% or greater

Percent of CSHCN with Any Unmet Need for Specific Health Care Services

Legend:
- Less than 14%
- 14% - 15.99%
- 16% - 17.99%
- 18% - 19.99%
- 20% - 21.99%
- 22% or greater

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All 50 States and DC: 17.7%

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Percent of CSHCN with Any Unmet Need for Family Support Services
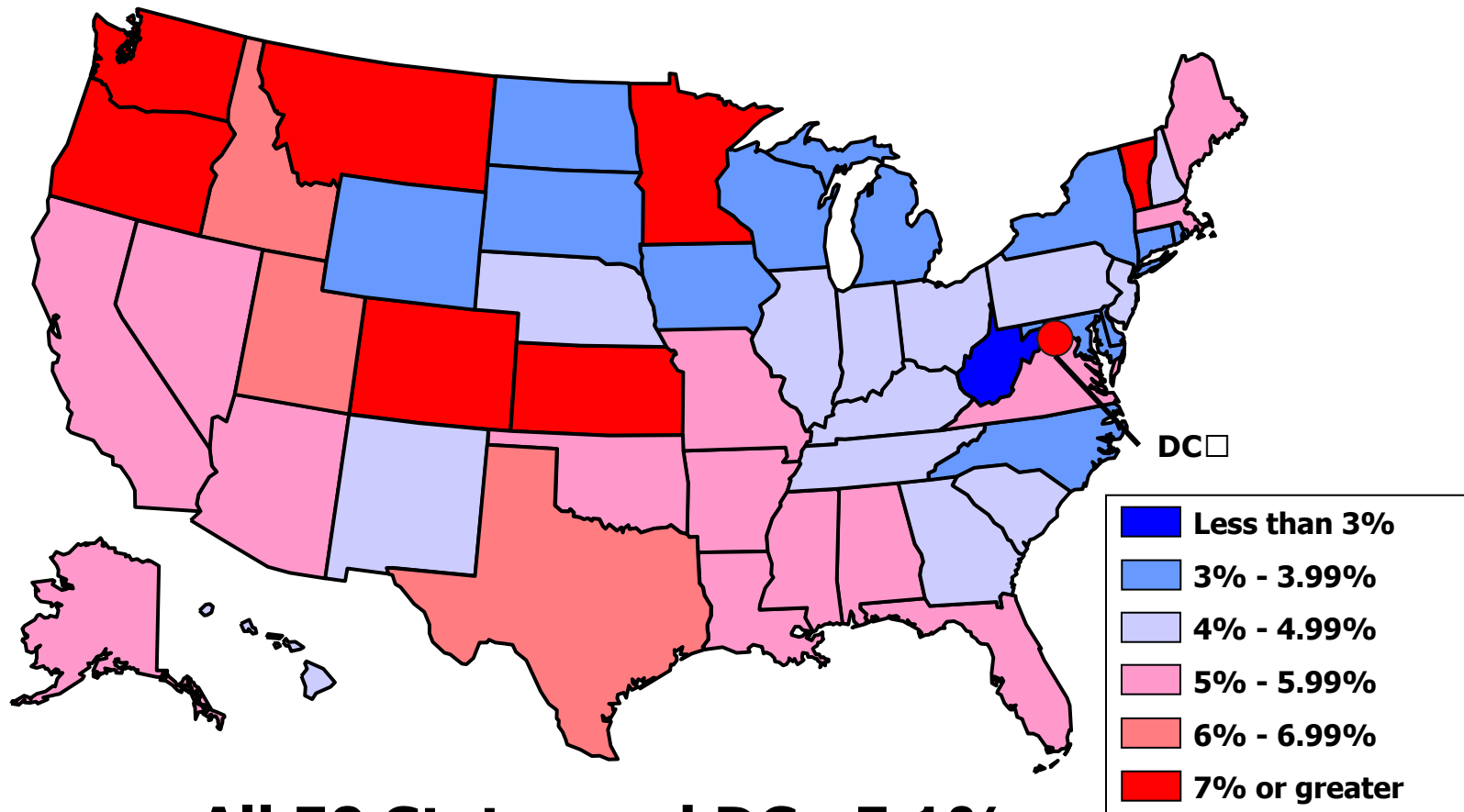
All 50 States and DC: 5.1%

Legend:
- **Less than 3%**
- **3% - 3.99%**
- **4% - 4.99%**
- **5% - 5.99%**
- **6% - 6.99%**
- **7% or greater**

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Percent of CSHCN Needing Specialty Care Who Had Difficulty Getting a Referral

DC☐

Legend:
- Less than 16%
- 16% - 18.99%
- 19% - 21.99%
- 22% - 24.99%
- 25% - 27.99%
- 28% or greater
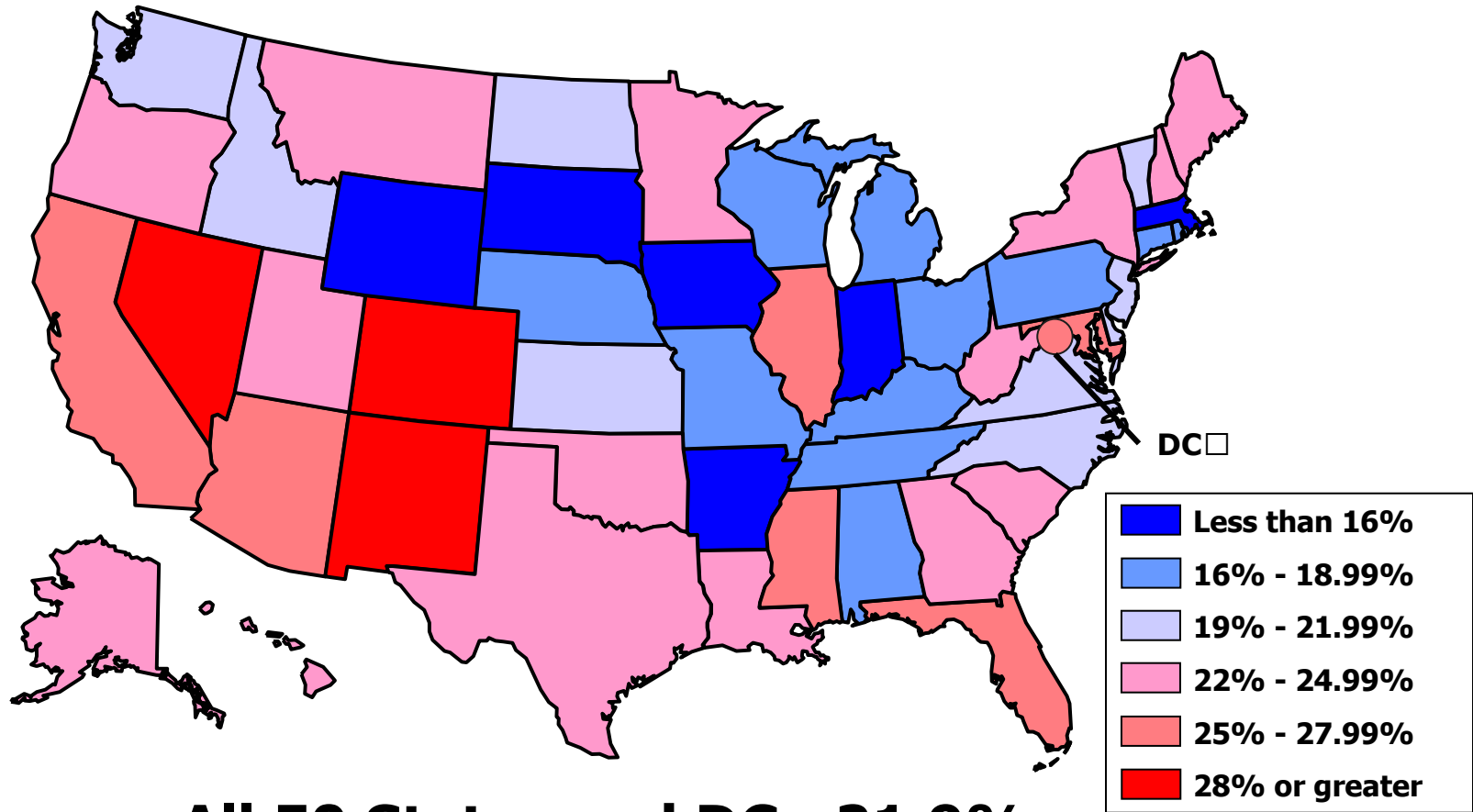
All 50 States and DC: 21.9%

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Percent of CSHCN Without a Usual Source of Care (or Who Rely on the Emergency Room)

DC □

Legend:
- Less than 7.5%
- 7.5% - 8.49%
- 8.5% - 9.49%
- 9.5% - 10.49%
- 10.5% - 11.49%
- 11.5% or greater

All 50 States and DC: 9.3%

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Percent of CSHCN Without a Personal Doctor or Nurse

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Legend:
- Less than 7%
- 7% - 8.99%
- 9% - 10.99%
- 11% - 12.99%
- 13% - 14.99%
- 15% or greater
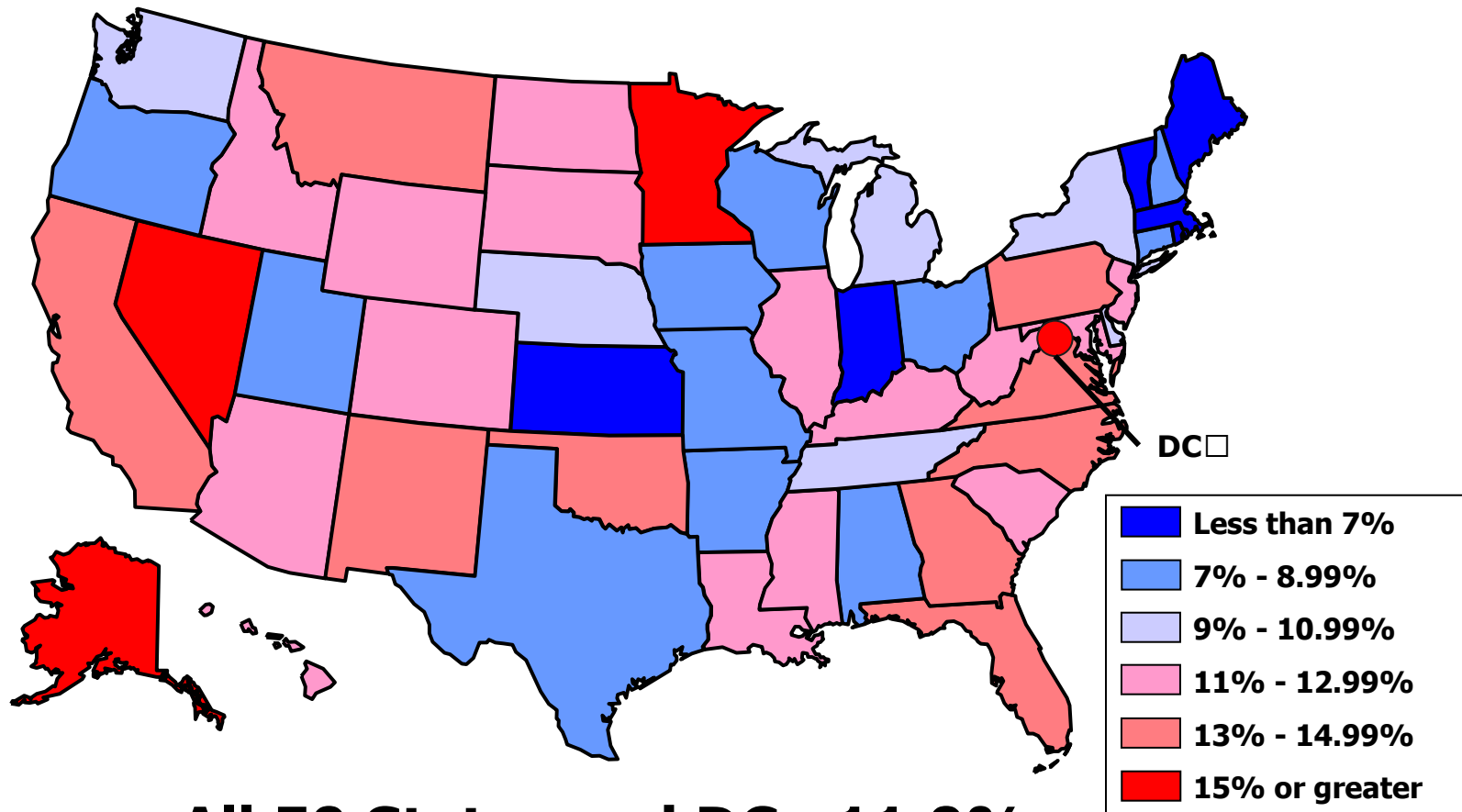
All 50 States and DC: 11.0%

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Percent of CSHCN Without Family-Centered Care

DC☐

Less than 29%

29% - 30.99%

31% - 32.99%

33% - 34.99%

35% - 36.99%

37% or greater

All 50 States and DC: 33.5%

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Percent of CSHCN whose Families Paid $1,000 or More for their Medical Expenses in Past Year

DC ☐

Legend:
- Less than 8%
- 8.0% - 9.49%
- 9.5% - 10.99%
- 11.0% - 12.49%
- 12.5% - 13.99%
- 14% or greater

All 50 States and DC: 11.2%

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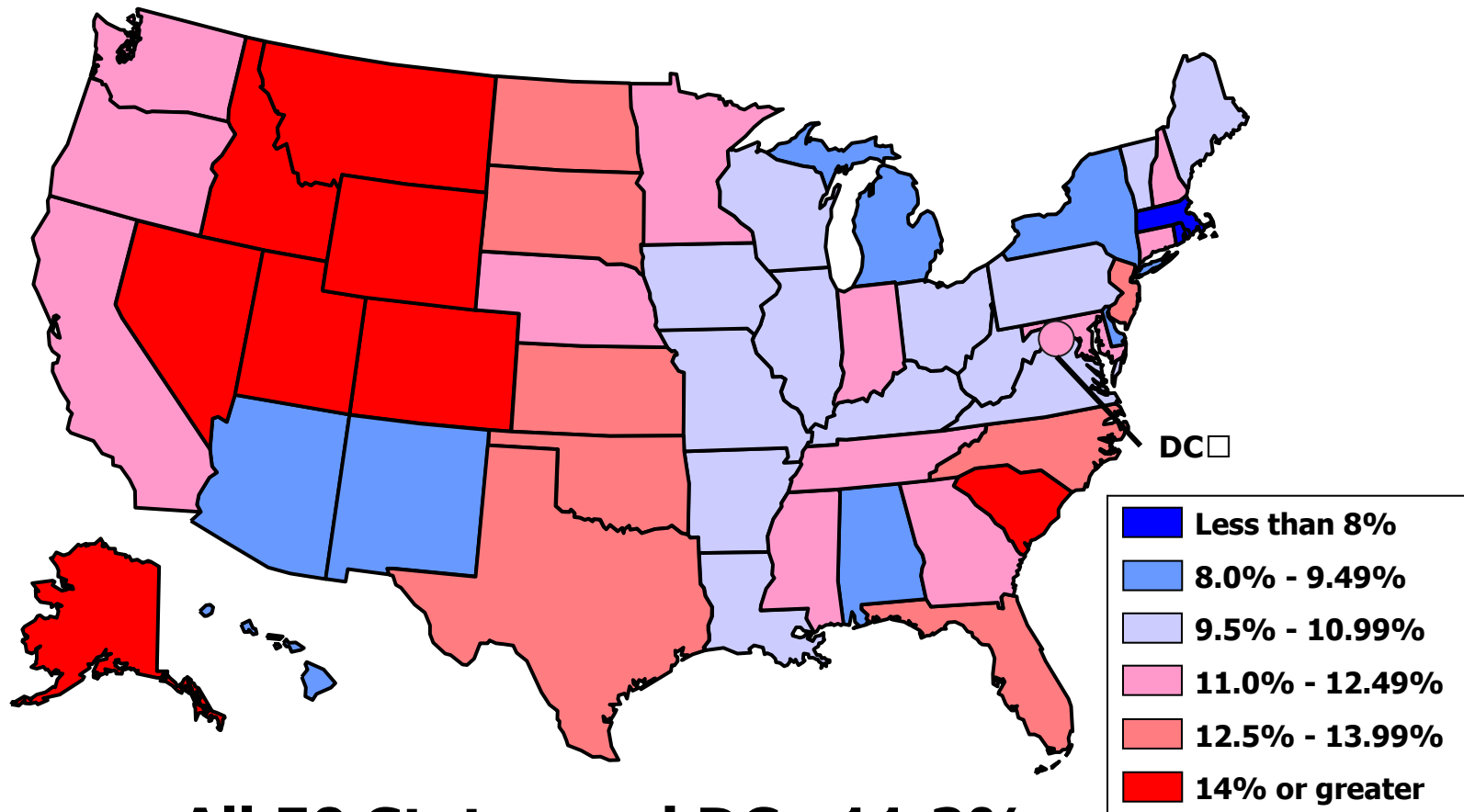
Percent of CSHCN whose Condition Caused Financial Problems for the Family

DC☐

Legend:
- Less than 17%
- 17% - 18.99%
- 19% - 20.99%
- 21% - 22.99%
- 23% - 24.99%
- 25% or greater

All 50 States and DC: 20.9%

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Percent of CSHCN whose Families Spend 11+ Hours per Week Providing or Coordinating Care

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Less than 10%

10% - 11.99%

12% - 13.99%

14% - 15.99%

16% - 17.99%

18% or greater
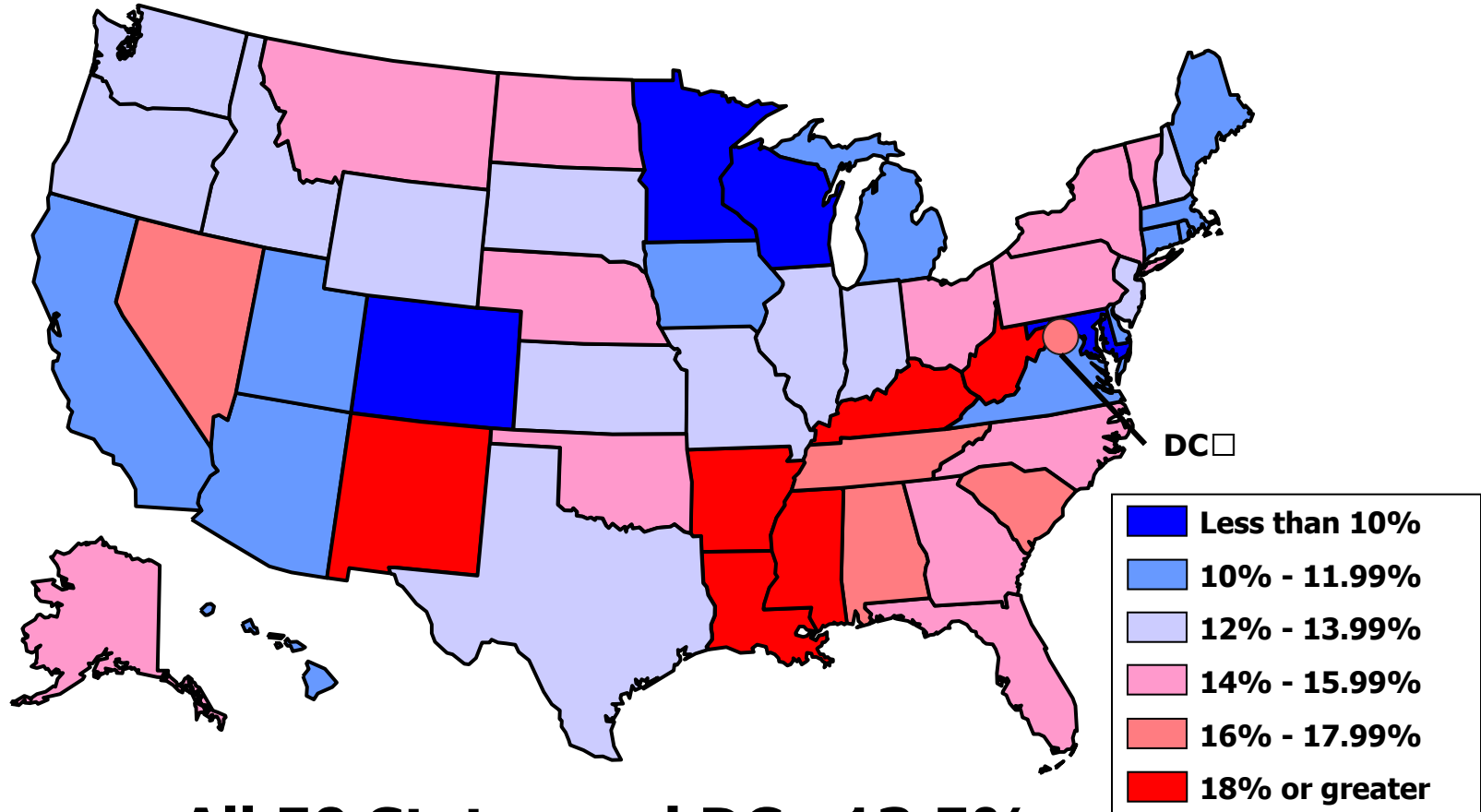
All 50 States and DC: 13.5%

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics,
State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001
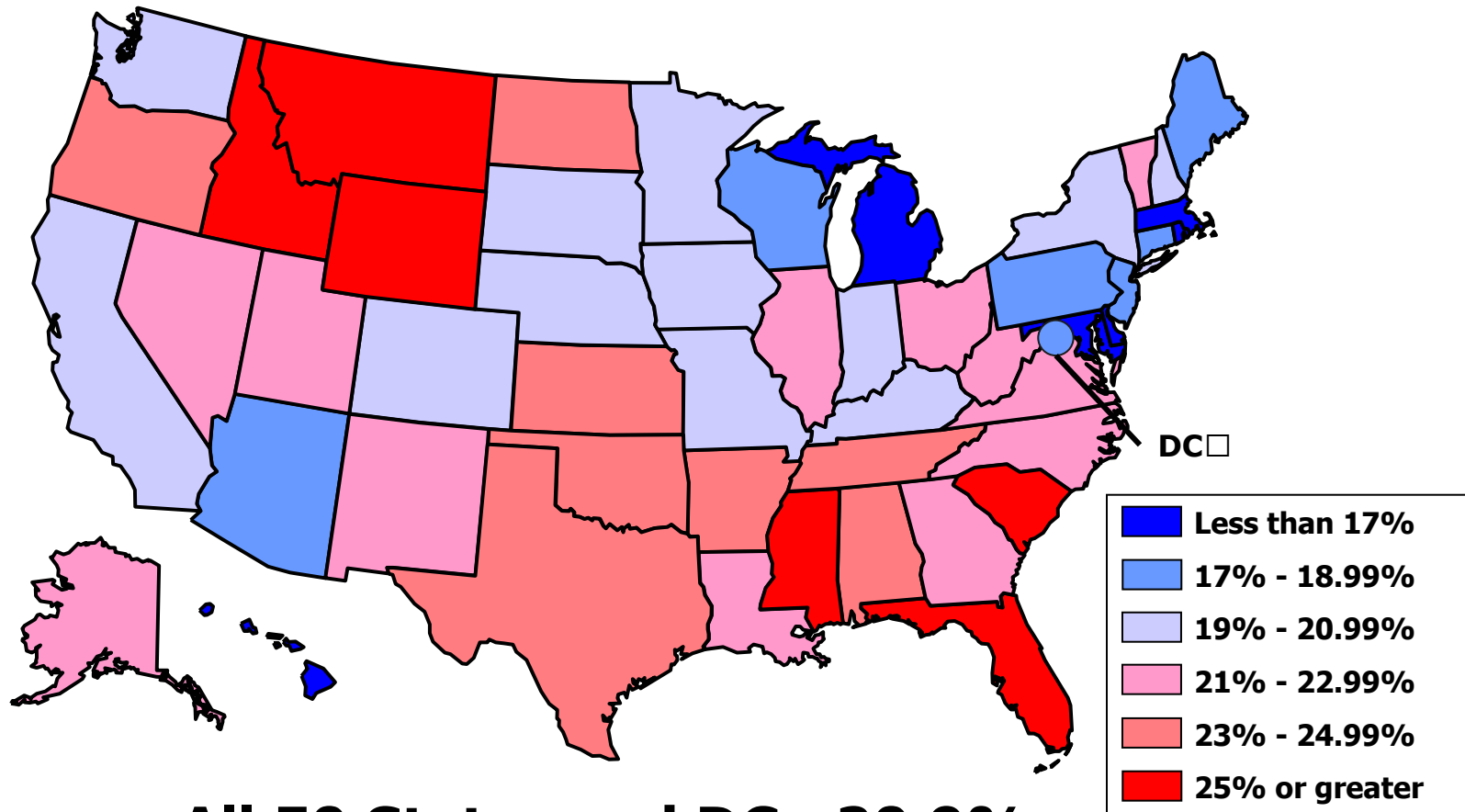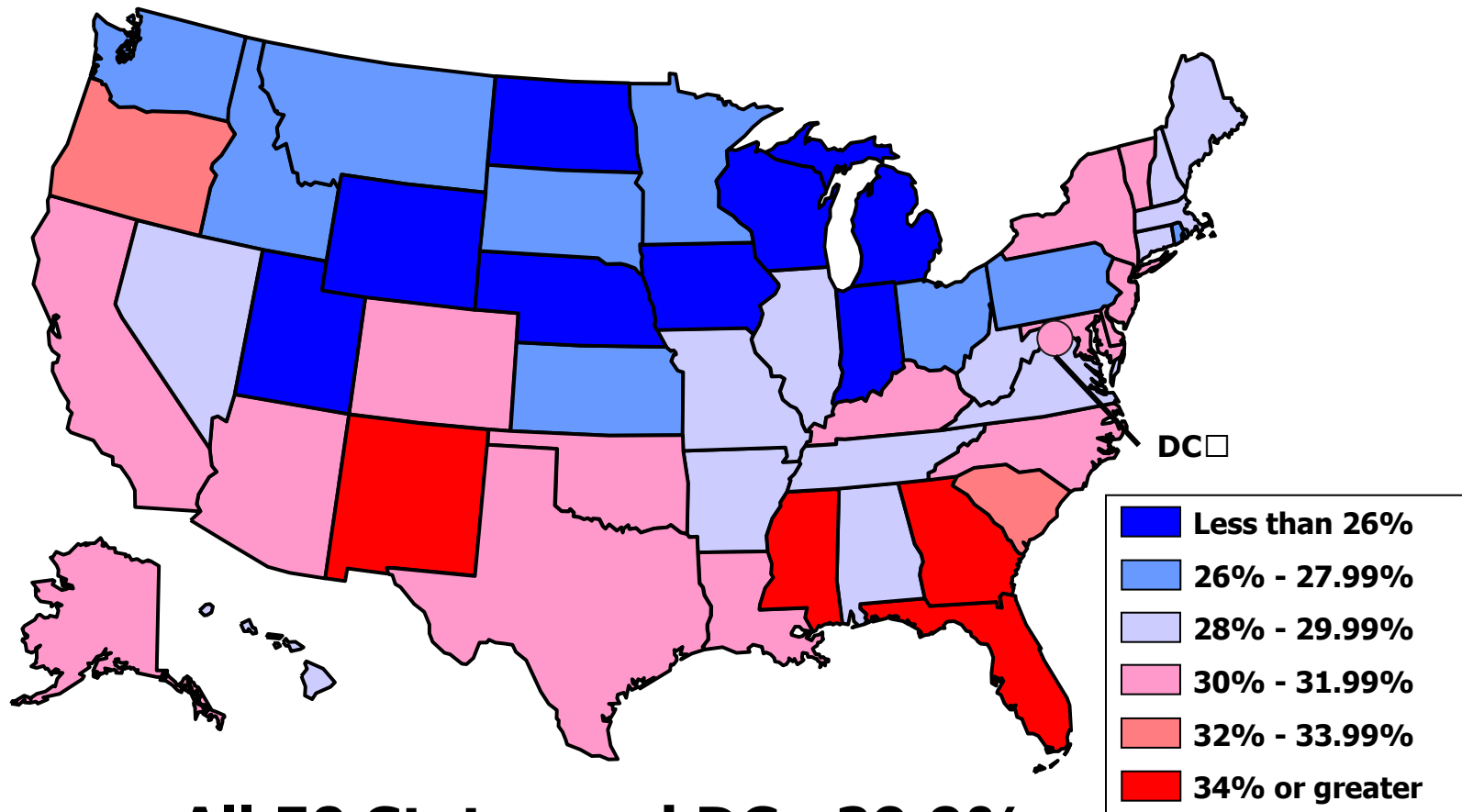
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Percent of CSHCN whose Condition Affected the Employment of Family Members

DC □

Legend:
- Less than 26%
- 26% - 27.99%
- 28% - 29.99%
- 30% - 31.99%
- 32% - 33.99%
- 34% or greater

All 50 States and DC: 29.9%

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Issues in Development of a Composite Indicator

- Is a composite indicator useful?

- Which indicators should be used as components of the composite?

- Should some indicators be more important than others?

- Are relatively small differences between States on particular indicators meaningful?

- Are extreme values ("outliers") meaningful when comparing States?

Percent of CSHCN without insurance at some point in past year

State	Percent	Rank
State A	11.81	31
State B	11.85	32
State C	19.80	50
State D	22.78	51

Because (32 – 31 = 51 – 50), composite indicators based on ranks can exaggerate small differences in percents and minimize large differences in percents.

Composite Indicator was Developed by Converting the Percents from Each Key Indicator to Standard Scores and then Averaging the Scores

- Maximizes the impact of extreme percentage scores on a particular indicator
- Minimizes the impact of small differences between States on a particular indicator
- Each indicator has an equivalent impact on the composite indicator

This is the approach used in the Casey Foundation's annual KIDS COUNT Data Books.

State A	Standard Score
Impact on activities	-1.06
School absences	0.95
Uninsured (past year)	0.10
Uninsured (now)	-0.43
Inadequate insurance	0.30
Unmet need	0.46
.	.
.	.
.	.
Average	0.32

Rank after Averaging the Standard Scores for Each of the 15 Key Indicators

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Legend:
- Top 5 (best)
- 6 - 15
- 16 - 25
- 26 - 35
- 36 - 46
- Bottom 5 (worst)
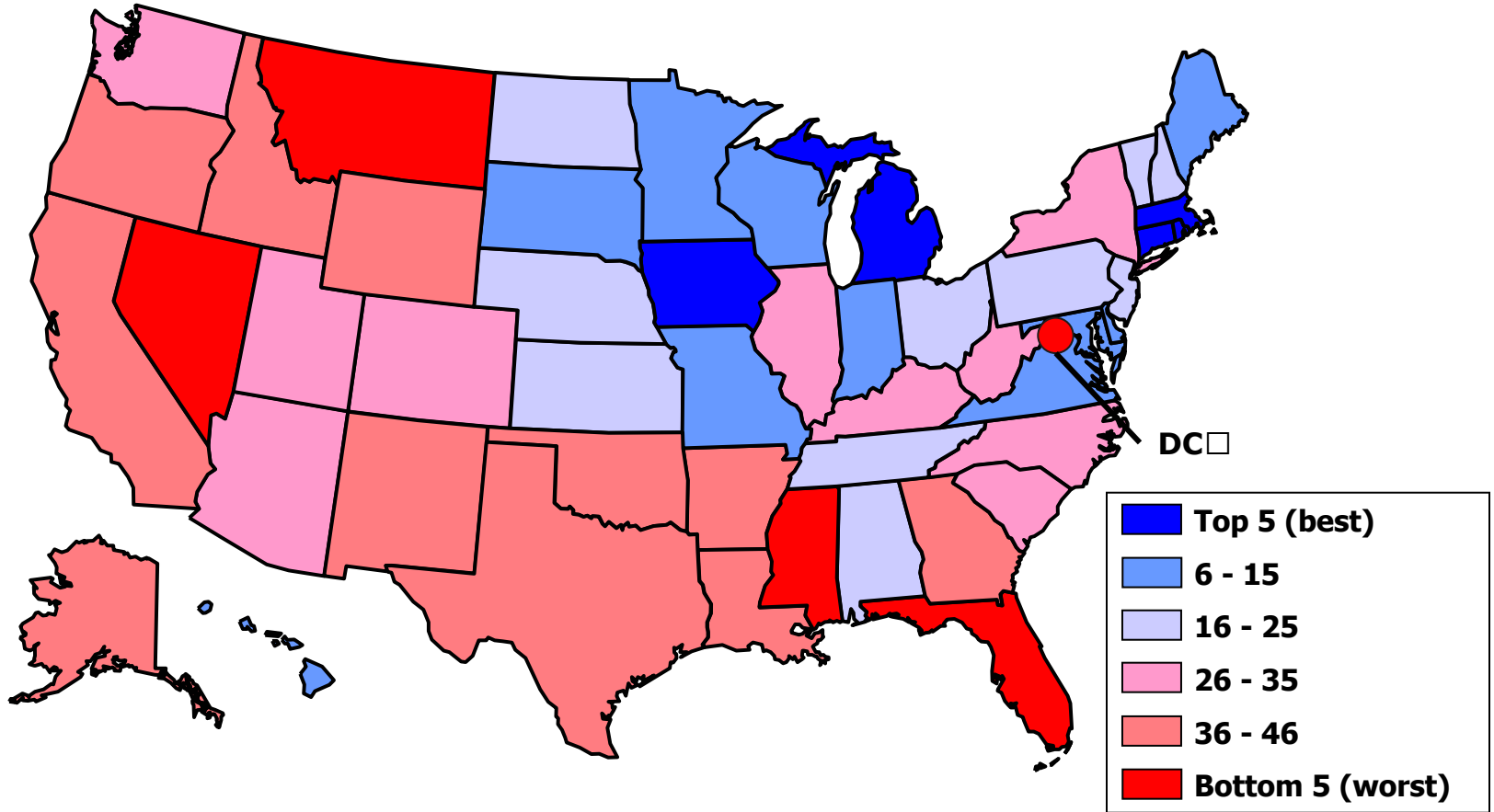
Average of the Standard Scores for Each of the 15 Key Indicators, by State
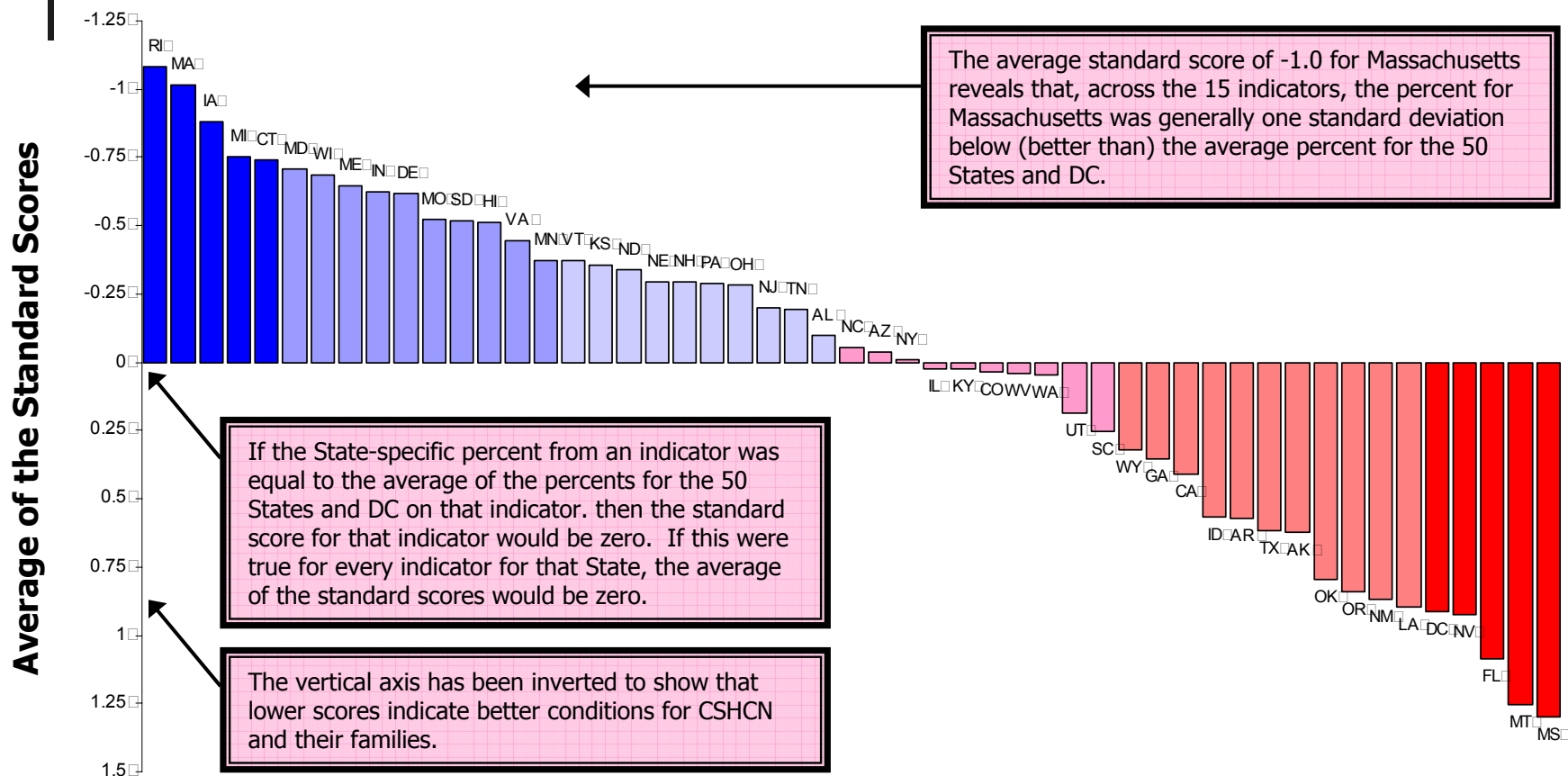
The average standard score of -1.0 for Massachusetts reveals that, across the 15 indicators, the percent for Massachusetts was generally one standard deviation below (better than) the average percent for the 50 States and DC.

If the State-specific percent from an indicator was equal to the average of the percents for the 50 States and DC on that indicator. then the standard score for that indicator would be zero. If this were true for every indicator for that State, the average of the standard scores would be zero.

The vertical axis has been inverted to show that lower scores indicate better conditions for CSHCN and their families.

Concluding Thoughts

- Composite indicators are strongly influenced by the choice of indicators that are used in the composite

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- These 15 indicators may not be the most appropriate indicators for comparing States.

Concluding Thoughts

- The composite indicator is correlated with the percent of children in each State who lived in households with income below 200% of the Federal Poverty Level
  - Pearson's correlation coefficient = .71

- A composite indicator unrelated to income may be desirable

For more information…

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- http://www.cdc.gov/nchs/slaits.htm