



Health Care Transition for Youth with Special Health Care Needs

An Analysis of National and State Performance

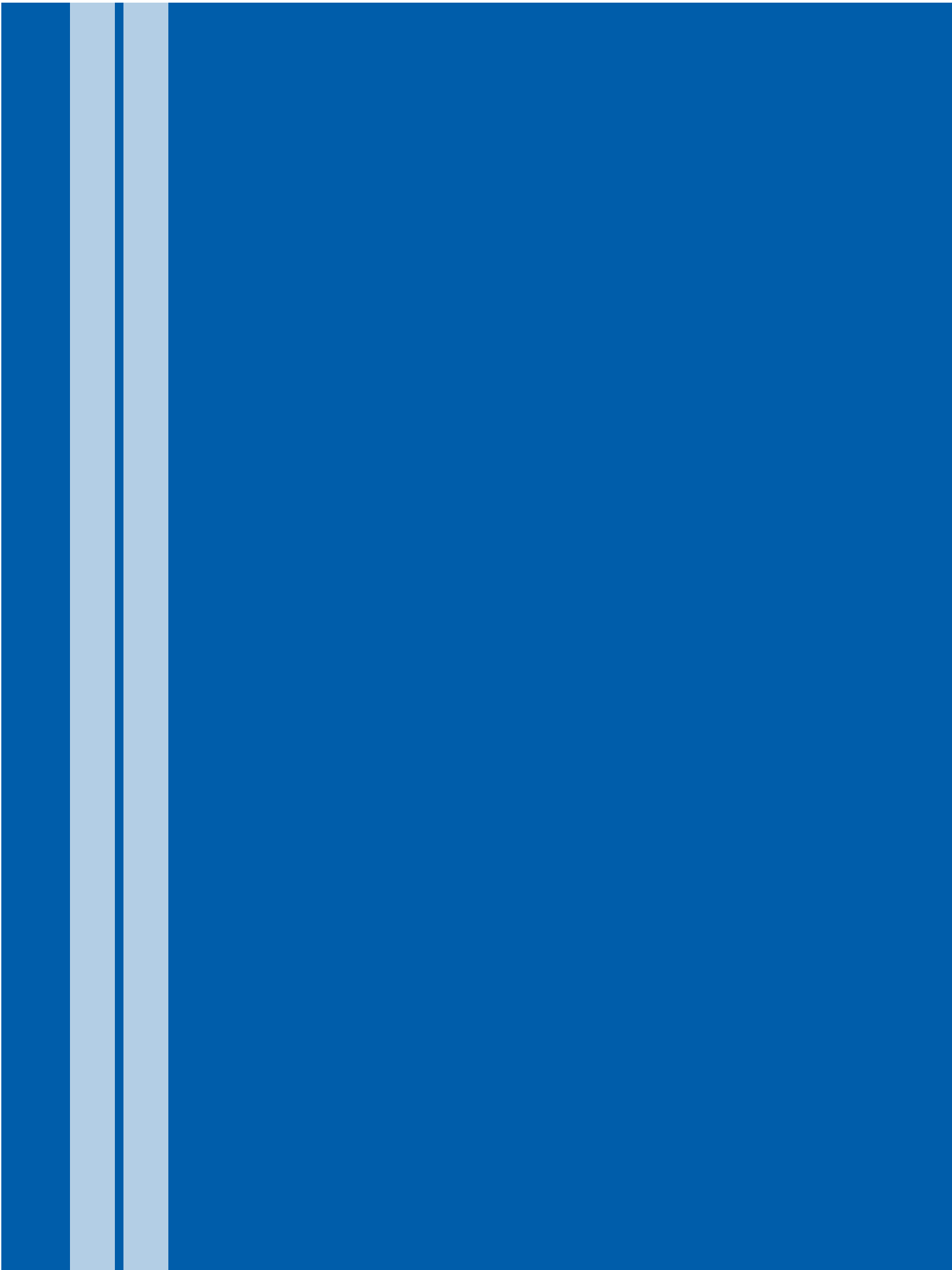
Prepared by:

Peggy McManus and Katherine Rogers
National Alliance to Advance Adolescent Health
for Got Transition?, the National Health Care Transition Center

January 2011



NATIONAL HEALTH CARE TRANSITION CENTER





Nationally, less than half of all youth with special health care needs, ages 12 through 17, successfully transition from pediatric to adult health care. This report provides new national and state information to establish a transition baseline, examine state variation in transition performance, and explore possible reasons for this variation. Information for this report was obtained from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the 2010 Current Population Survey (CPS).

Our report analyzes the national transition outcome measure according to race/ethnicity, income, insurance, gender, and the presence of a medical home. It also summarizes each of the four questions that make up the transition measure. Due to small sample sizes, state transition outcomes are only analyzed by gender, presence of a medical home, and responses to individual questions that make up the composite transition measure. Multivariate analyses were conducted to examine why some states fare better than others on the transition measure. A set of tables and maps on pages 4–8 provide additional detail.

National Transition Outcome

Only 41% of youth with special health care needs in the US receive the services necessary to make transitions to adult health care, work, and independence, according to the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). This proportion is even lower among youth who are Hispanic or Black, with family incomes below 200% of poverty, and who are uninsured or publicly insured. In addition, males are less likely than females to transition successfully, and those without a medical home are at a significant disadvantage.

According to the NS-CSHCN, slightly more than a quarter of parents whose youth have a special need report that a discussion about transition to adult health care is needed but has not happened. About the same proportion report that their teen’s health care provider sometimes or never encourages the youth to take increased responsibility for their care. In addition, more than a third report that a discussion about the teen’s changing health care needs would be helpful but has not happened. As many as two thirds report that a discussion about health insurance is needed but has not happened.

State Transition Outcomes

There is great state variability in transition performance – in fact, there is a 30 percentage point difference in the outcome measure between the highest performing states of Missouri and Nebraska (54%) and the lowest performing District of Columbia (24%). The standard deviation for state performance is over six percentage points. As displayed in Figure A, 18 states fall between half a standard deviation (SD) above or below the mean national transition measure. Yet, 13 states fall between 0.5 to 1.5 SDs below the mean, and another two states perform at a level less than 1.5 SDs below the mean. States performing at half a standard deviation above the mean still have fewer than half of their youth with special needs transitioning to adult health care successfully.

Proportion of Youth Successfully Meeting the National Transition Outcome	
National average	41%
Race/ethnicity	
Hispanic	26%
Black	29%
White	47%
Income	
0-199% FPL	30%
200-299% FPL	41%
300-399% FPL	46%
400% FPL and above	54%
Insurance	
Uninsured	18%
Public Insurance	28%
Private Insurance	49%
Both public and private insurance	32%
Gender	
Males	39%
Females	44%
Medical home	
Without	29%
With	57%



When examining state transition differences by gender and the presence of a medical home, we found a substantial spread between states, as shown in Table 1. With respect to gender, DC males successfully transition at the lowest level (27%) compared to Nebraska males (57%), and DC females are even lower at 20% compared to North Dakota's females at 62%. With respect to the presence of a medical home, we found DC and New Mexico reporting the lowest transition success among youth without a medical home (18%) compared to the Minnesota's youth without a medical home (45%).

States also demonstrate significant variability on the four component measures that make up the transition outcome, as shown in Table 2. With respect to states' rankings on the extent to which discussions about transition to adult health care providers was needed but did not happen, we found that Nebraska was lowest ranked (39%), while Maine was highest ranked (12%). When parents were asked whether discussions about changing health needs as teens get older were needed but did not happen, Arkansas and Mississippi had the lowest ranking at 47% while Vermont had the highest at 26%. With respect to states' ranking on the extent to which health care providers sometimes or never encourage youth with special health care needs to take increased responsibility for care, we found Florida had the lowest ranking at 34%, and Nebraska had the highest at 21%. Finally, when asked whether discussions about health insurance were needed but had not happened, we found Rhode Island had the lowest ranking (75%) and Hawaii the highest (53%) -- two states with very low rates of uninsurance.

Multivariate Analyses

Based on state demographic data from the US Census and state transition performance data from the NS-CSHCN, we performed multivariate regressions to examine the factors most likely to affect transition results. We found significant and negative associations between state transition performance and uninsurance, poverty, and proportion of non-White youth.

In addition, we found significant and negative associations with the proportion of youth reporting their care is provided by a pediatrician. This latter response is likely the result of the fact that virtually all youth who receive their care from a pediatrician will have to transfer to an adult health care provider in contrast to youth seen by a family physician. Further, due to the structured responses provided within the NS-CSHCN, parents whose adolescent children see a provider serving both children and adults may respond differently regarding transition outcome component measures than parents of youth who see pediatricians for their care.

We originally included a variable representing the proportion of a state's population reporting Hispanic origin, but in initial analyses the association between this variable and state performance was not statistically distinguishable from zero. This variable was not significant in any of a number of additional specifications tested. Our results suggest substantial collinearity between this variable and uninsurance. Our final model, as a result, includes a variable for uninsurance, but not one for Hispanic origin.

Variable	Coefficient
Uninsurance	- 0.40**
Poverty	- 0.25**
Non-White Race	- 0.17**
Proportion Seeing Pediatrician for Care	- 0.14*

* Significant at the 5% level.
** Significant at the 1% level.



Data limitations and Interpretation

It is important to note that, by using the state as the unit of analysis, we cannot identify associations between our variables and an individual adolescent's likelihood for success in transition. Our analysis demonstrates strong associations between a state's proportion of uninsurance, poverty, non-White race and the statewide performance on the transition indicator. Teasing apart these associations at a disaggregated level is an important next step for research, but one which requires further analysis of available data. Similarly, more in-depth analysis with NS-CSHCN data could further illuminate the relationship between an adolescent's provider type (i.e., pediatrician or family physician) and their access to necessary transition supports and services.

Implications

These baseline data on transition have several important implications. Most importantly, all states have significant improvements to make in ensuring that youth with special health care needs successfully transition from pediatric to adult health care. Much more needs to be done within primary care to assist youth with special needs in understanding their changing health needs, taking more responsibility for managing their own care, identifying an adult health care provider, and maintaining insurance coverage as they become a young adult.

Expanding the availability of medical homes¹⁻³ that meet the needs of youth will be critical to transition success along with enhancing medical home standards and qualifications to incorporate a consistent set of transition services and supports.⁴ In addition, reducing adolescent uninsurance rates will positively impact states' transition performance.

A critical next step is understanding racial and ethnic disparities in transition performance. It is apparent from our analysis that there is much yet to be learned about the factors associated with low levels of transition support for African American and other non-White youth with special health care needs. Is this the result of differences in access to or sources of primary care or may it be related to insurance status? Is it the result of parents' lack of awareness of transition services? Is cultural and/or linguistic competency a substantial barrier to care and transition support services? Is it the result of a lack of cultural competence among health care providers? Are there other cultural forces at work that require greater attention, such as the role of the family? In particular, Hispanic youth and their families may experience obstacles to successful transition beyond insurance gaps. Additional analysis of national survey data may provide insight into the unique transition experiences of these youth and their families.

Got Transition, the new National Health Care Transition Center – in partnership with the federal Maternal and Child Health Bureau and State Title V Programs for Children with Special Needs, have critical roles to play in guiding health care providers, youth and parents, and payers about promising transition approaches. In the spring/summer of 2011, Got Transition will have innovative tools, curricula, and other resource materials available on its website. For more information, see www.gottransition.org or find it on Facebook.

Endnotes

¹Medical Home Initiatives for Children with Special Health Care Needs Project Advisory Committee. The Medical Home Policy Statement. *Pediatrics*. 2002; 110: 184 – 186.

²American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association. *Joint Principles of the Patient-Centered Medical Home*, March, 2007.

³Tonniges TF, Palfrey JS (eds). The Medical Home. *Pediatrics Supplement*. 2004; 113, 1471 – 1548.

⁴Cooley WC, Sagerman PJ, and Transition Clinical Reports Authoring Group. Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics*. Forthcoming.

Table 1

STATES	Proportion of Adolescents with Special Health Care Needs Meeting the National Transition Outcome, Overall and by Selected Characteristics					Demographic Characteristics of States' Adolescent Populations		
	Overall	Gender		Medical home ¹		Under 200% FPL	Uninsured	Non-white Race
		Male	Female	With	w/out			
NATIONAL AVERAGE	41%	39%	44%	57%	29%	38.2%	11.2%	21.5%
Alabama	38	32	46	57	23	52.6	8.0	27.3
Alaska	42	41	45	60	32	26.2	12.2	19.8
Arizona	39	36	43	59	26	46.9	15.8	15.8
Arkansas	33	31	36	47	23	43.6	14.1	21.2
California	37	33	42	53	27	42.2	13.1	19.5
Colorado	47	41	55	63	31	31.1	11.7	7.6
Connecticut	43	41	46	58	31	19.5	8.7	18.4
Delaware	42	43	41	58	27	31.8	10.8	25.8
District of Columbia	24	27	20	40	18	55.2	9.9	78.2
Florida	34	30	39	53	23	43.3	21.2	26.6
Georgia	37	38	36	44	31	40.4	16.0	38.8
Hawaii	39	40	39	48	34	39.5	3.1	52.1
Idaho	46	45	48	57	38	35.6	10.1	3.2
Illinois	44	46	42	69	25	37.5	10.0	21.5
Indiana	41	39	43	47	35	37.3	9.3	12.3
Iowa	47	45	50	58	33	28.4	6.5	6.0
Kansas	50	51	49	67	35	35.7	9.2	9.4
Kentucky	43	39	47	64	29	38.2	10.6	9.9
Louisiana	41	45	35	59	27	40.9	10.9	46.5
Maine	49	46	53	58	40	34.3	4.1	2.8
Maryland	37	33	43	56	26	24.6	8.8	39.0
Massachusetts	47	45	50	61	30	31.1	2.5	15.9
Michigan	41	35	49	58	29	36.9	5.6	21.8
Minnesota	53	48	59	62	45	26.5	6.5	9.4
Mississippi	31	22	42	42	22	56.0	11.3	47.6
Missouri	54	54	55	73	36	36.8	11.4	14.9
Montana	46	42	52	61	34	40.5	10.4	8.7
Nebraska	54	57	51	72	35	31.2	6.8	8.9
Nevada	42	42	42	59	28	37.6	15.8	20.6
New Hampshire	52	52	51	69	36	22.1	4.5	3.5
New Jersey	38	33	46	54	29	30.7	7.5	26.3
New Mexico	34	36	31	56	18	48.0	18.4	18.8
New York	38	34	43	55	25	41.0	6.8	26.5
North Carolina	40	34	49	60	27	40.6	11.6	33.7
North Dakota	51	44	62	67	35	30.0	7.1	17.9
Ohio	49	48	50	59	35	36.3	7.9	17.8
Oklahoma	44	41	47	55	31	34.4	16.5	24.3
Oregon	44	49	39	62	31	38.9	13.6	10.0
Pennsylvania	46	47	45	59	35	34.1	8.3	18.5
Rhode Island	38	37	39	52	24	39.5	7.0	13.1
South Carolina	37	35	41	47	31	36.2	13.3	33.1
South Dakota	51	49	52	62	37	33.3	9.1	12.0
Tennessee	40	42	37	53	27	42.7	8.0	18.0
Texas	37	34	32	51	24	46.0	19.3	20.4
Utah	43	39	47	58	30	24.8	10.8	5.4
Vermont	52	44	60	60	43	33.9	6.4	3.8
Virginia	38	34	44	55	24	30.7	7.5	27.8
Washington	47	45	51	61	36	29.5	5.7	14.7
West Virginia	41	38	45	54	27	39.6	7.6	5.2
Wisconsin	45	45	44	57	38	28.7	5.5	12.3
Wyoming	47	46	48	57	39	29.4	7.5	2.8

Source: Analysis of the 2005 - 2006 National Survey of Children with Special Health Care Needs and U.S. Census 2010 Current Population Survey data, prepared by The National Alliance to Advance Adolescent Health for the National Health Care Transition Center. Data based on parental report.

Bold: n<50; **Red and italicized:** n<20.

¹Medical home: These data indicate the proportion of adolescents who transition successfully who do or do not meet the criteria indicating their care is delivered within a medical home.

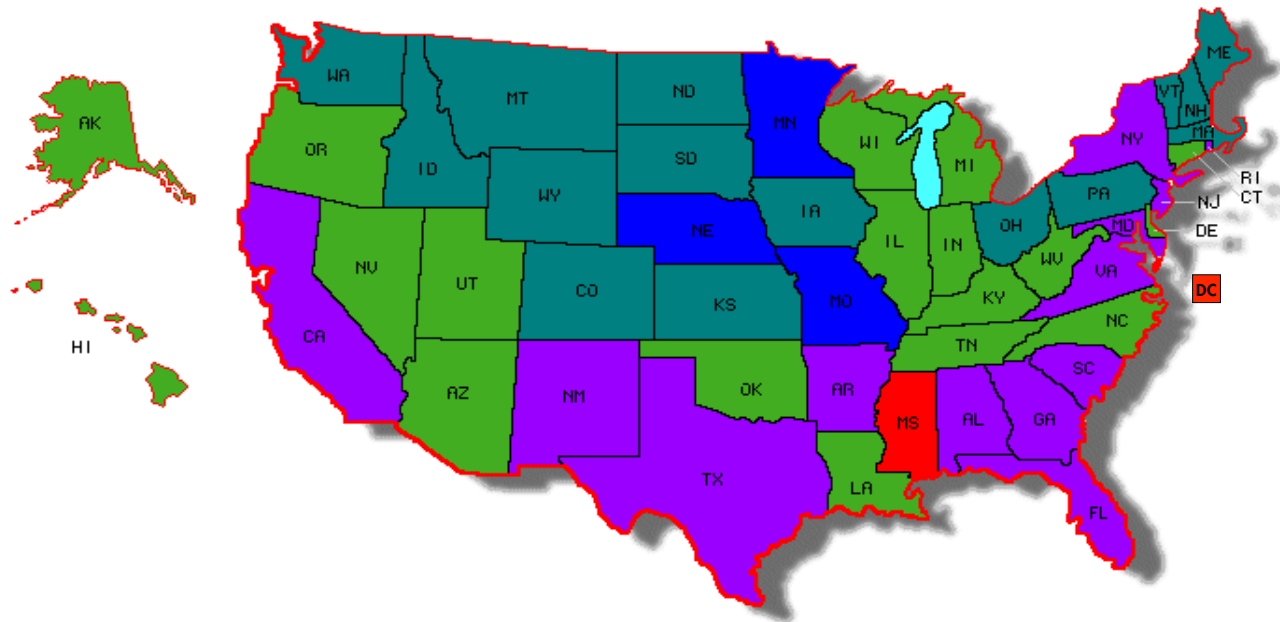
Table 2

STATES	Meeting National Transition Outcome	Pediatrician as Teen Primary Care Provider	Discussion About Transition to Adult HCP Needed but Not Happened	Discussion about Changing Health Needs Needed but Not Happened	HCPs “sometimes” or “never” encourage YSHCN to Take Increased Responsibility for Care ¹	Discussion About Insurance Needed but Not Happened
NATIONAL	41%	61%	27%	38%	28%	66%
Missouri	54	59	21	29	24	58
Nebraska	54	44	39	30	21	58
Minnesota	53	52	21	23	24	61
Vermont	52	62	17	26	22	63
New Hampshire	52	60	20	27	24	62
North Dakota	51	41	24	29	25	56
South Dakota	51	32	18	32	33	58
Kansas	50	40	23	30	25	56
Maine	49	51	12	26	27	67
Ohio	49	61	30	33	26	66
Iowa	47	38	26	36	28	59
Washington	47	56	24	30	25	66
Colorado	47	57	17	40	25	64
Wyoming	47	59	24	33	24	61
Massachusetts	47	80	20	30	28	62
Montana	46	44	26	37	24	64
Pennsylvania	46	61	20	34	29	64
Idaho	46	37	21	34	29	65
Wisconsin	45	55	24	36	26	68
Illinois	44	58	32	37	31	63
Oklahoma	44	48	25	41	28	64
Oregon	44	56	21	32	29	64
Connecticut	43	77	21	41	25	70
Kentucky	43	53	30	36	28	65
Utah	43	57	22	38	28	66
Delaware	42	63	23	42	28	65
Alaska	42	48	23	33	30	67
Nevada	42	54	20	34	32	66
West Virginia	41	46	31	29	27	61
Indiana	41	44	27	35	27	62
Louisiana	41	58	27	33	27	57
Michigan	41	58	26	41	26	63
North Carolina	40	61	34	42	29	63
Tennessee	40	66	26	40	30	59
Arizona	39	56	28	43	30	66
Hawaii	39	67	32	38	28	53
New York	38	75	35	34	24	63
Alabama	38	69	34	37	25	65
New Jersey	38	79	24	42	33	69
Virginia	38	64	25	43	30	73
Rhode Island	38	71	25	36	33	75
Maryland	37	78	31	39	31	71
South Carolina	37	54	29	39	25	59
California	37	67	28	40	33	71
Texas	37	54	25	43	27	70
Georgia	37	64	28	42	29	69
Florida	34	73	32	41	34	73
New Mexico	34	56	31	42	29	68
Arkansas	33	49	29	47	31	67
Mississippi	31	50	30	47	31	64
Dist of Columbia	24	77	37	34	32	70

Source: Analysis of the 2005 - 2006 National Survey of Children with Special Health Care Needs, prepared by The National Alliance to Advance Adolescent Health for the National Health Care Transition Center.
¹Data on the subcomponent measure regarding responsibility for self care is reported for all children ages 5 – 17, rather than adolescents only.



Figure A. State Transition Performance* and Variance from National Mean



National mean: 42.6%

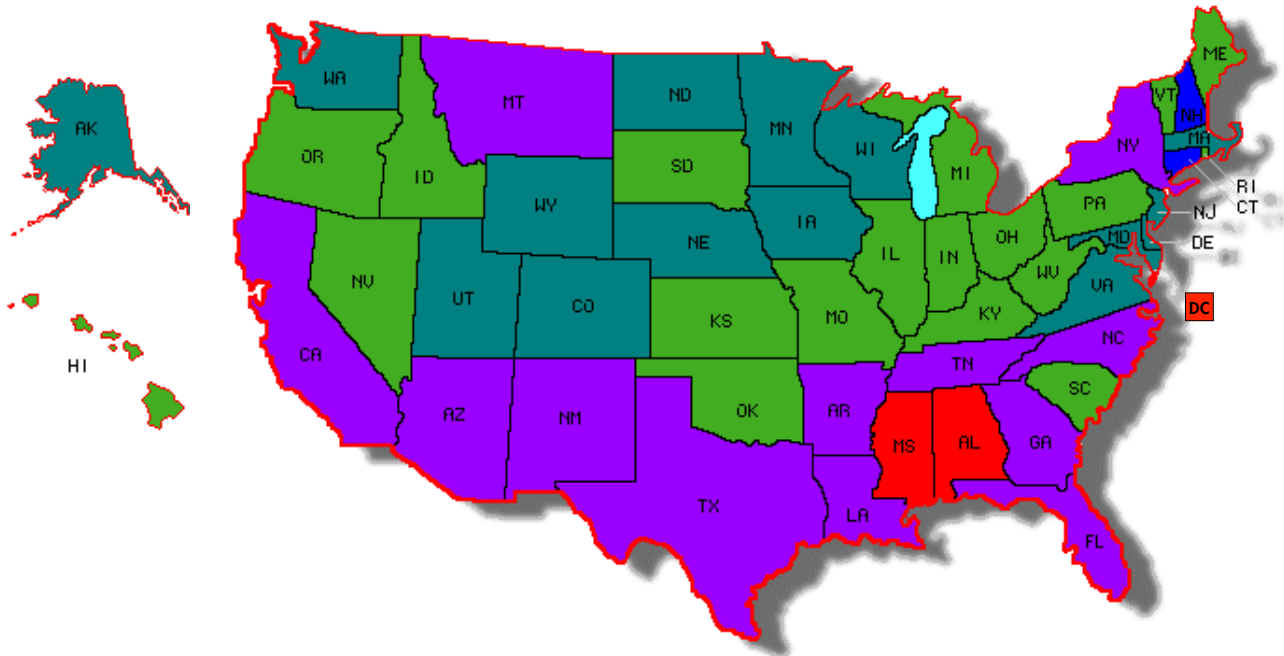
- More than 1.5 standard deviations (SD) above the mean
- Between 0.5 and 1.5 SD above the mean
- Between 0.5 SD above and 0.5 SD below the mean
- Between 0.5 and 1.5 SD below the mean
- More than 1.5 SD below the mean

*State performance on the Transition Performance Measure is assessed via parental report on several component questions in the National Survey of Children with Special Health Care Needs and is defined as the proportion of adolescents receiving the support necessary to transition successfully to adult life, health care, and work.

Source: Prepared by Katherine Rogers of the National Alliance to Advance Adolescent Health for the National Health Care Transition Center based on data from the 2005-2006 National Survey of Children with Special Health Care Needs; November, 2010.



Figure B. State Adolescent Population with Family Incomes Below 200% of Federal Poverty Level and Variance from National Mean



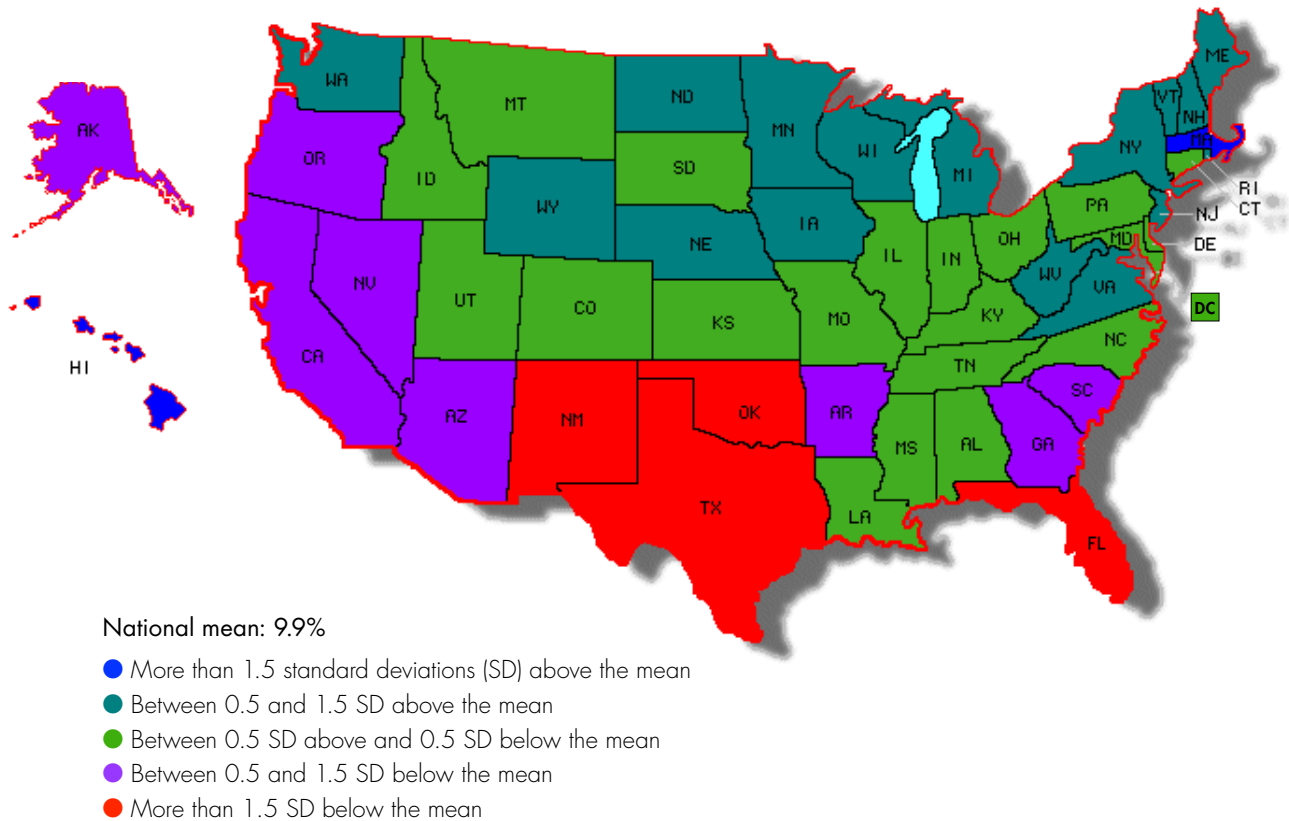
National mean: 36.3%

- More than 1.5 standard deviations (SD) above the mean
- Between 0.5 and 1.5 SD above the mean
- Between 0.5 SD above and 0.5 SD below the mean
- Between 0.5 and 1.5 SD below the mean
- More than 1.5 SD below the mean

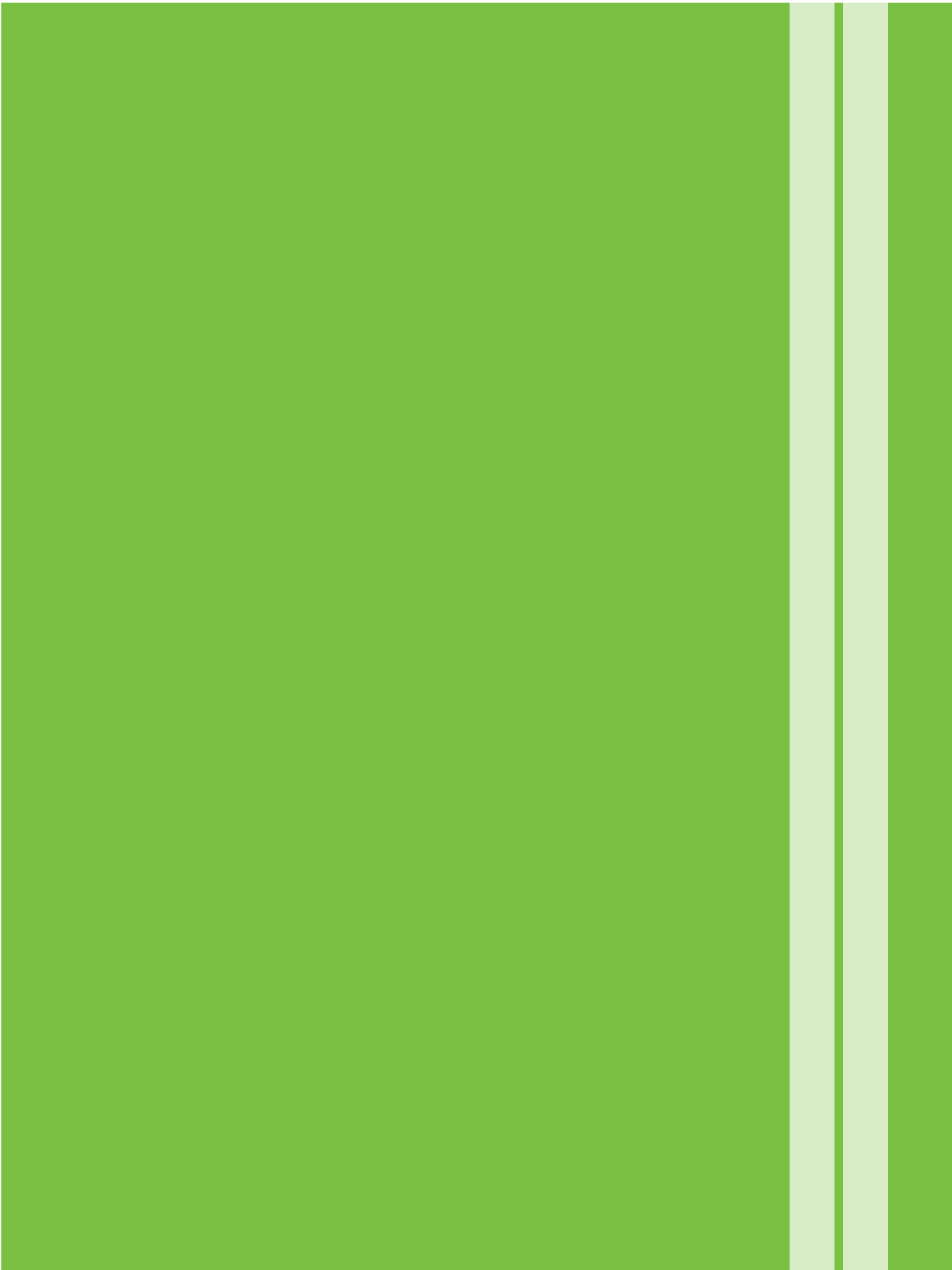
Source: Prepared by Katherine Rogers of the National Alliance to Advance Adolescent Health for the National Health Care Transition Center based on U.S. Census Current Population Survey estimates, 2010 data; November, 2010.



Figure C. State Uninsured Adolescent Population and Variance from National Mean



Source: Prepared by Katherine Rogers of the National Alliance to Advance Adolescent Health for the National Health Care Transition Center based on U.S. Census Current Population Survey estimates, 2010 data; November, 2010.





NATIONAL HEALTH CARE TRANSITION CENTER

Center for Medical Home Improvement (CMHI)
18 Low Avenue, Suite 1 | Concord, New Hampshire 03301 | 603.228.8811

NHCTC is supported by cooperative agreement U39MC18176 HRSA/US MCHB
Got Transition? is a program of CMHI at Crotched Mountain Foundation.



*THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH*

750 17th Street NW, Suite 1100 | Washington, DC 20006
202.223.1500 | www.TheNationalAlliance.org