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# Influence of Survey Design on Medical Home Prevalence

Excerpt from

## Measuring Medical Home: A Resource Manual for Researchers and Analysts

<http://medicalhomedata.org/ViewDocument.aspx?item=436>



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#### **IV. MEDICAL HOME FINDINGS FROM THE NS-CSHCN AND NSCH**

Although the methods and content addressing medical home differ in important ways, the NS-CSHCN and the NSCH share in common the “on every” scoring approach used to calculate the medical home composite measures derived from these surveys. Table 8 shows the crude results from using the “on every” approach to arrive at the prevalence of children with medical homes based on the various data elements available from the 2001 NS-CSHCN, 2005/06 NS-CSHCN, 2003 NSCH, and 2007 NSCH. National and state-specific results from all years of the NS-CSHCN and the NSCH are also available to query on the Data Resource Center for Child and Adolescent Health website ([www.childhealthdata.org](http://www.childhealthdata.org)).

##### ***4.1 Overall prevalence***

Despite differences in the methods and specific content involved, the medical home composite measure results across the surveys are remarkably consistent (Table 8). Regardless of health status, roughly one-half of the children in the United States (range: 44.0% to 57.5%) meet the AAP definition for having a medical home as operationalized through the NS-CSHCN and NSCH surveys. Although the overall medical home prevalence tends to be similar, there are substantial variations across the surveys in the proportion of children meeting the inclusion criteria for several medical home sub-components. In some cases, revisions to the questions and methods used to identify valid responders for a sub-component are the principal sources for this variation. For example, in the 2001 NS-CSHCN, nearly 90% of children did not meet the inclusion criteria for the coordinated care sub-component of medical home and subsequently were classified as “legitimate skips” on the basis of not needing such care (Table 8). Due to improvements to the questions used to assess need for care coordination, only 22% of children failed to meet the inclusion criteria for the 2005/06 NS-CSHCN coordinated care sub-component (Table 8).

Factors such as children’s health status and differential needs for health care also contribute to variation in sub-component denominator sizes for different groups. In the 2003 NSCH, over 50% of the children identified as having special health care needs required one or more of the specialized health care or services necessary for inclusion in the access to specialty care and services subcomponent topic denominator (Table 8; 11.5% + 42.7%). In contrast, in the same survey only 16% of children without special health care needs required the types of

specialized care or services that are the prerequisite for inclusion in the denominator of this subcomponent topic. Using different content and methods, the 2007 NSCH shows a similar pattern with about one third of CSHCN needing referrals for specialty or services compared to 16 percent of non-CSHCN.

These and other findings from the various administrations of the NS-CSHCN and the NSCH provide useful insights into the influence of question design and underlying population characteristics when assessing the complex and multi-factored medical home concept. Section 4.3 takes a closer look at the contribution of some of these factors to the overall medical home composite scores.

Appendix E provides a list of publications reporting on various analyses using the medical home composite measures or associated sub-components from the NS-CSHCN and NSCH. Several of these articles demonstrate state-specific applications of the medical home data from these surveys.

**TABLE 8:** Percent of children meeting the criteria for having a medical home overall and within each measured sub-component topic, by survey†

	<b>2001 NS-CSHCN</b>	<b>2005/06 NS-CSHCN</b>	<b>2003 NSCH</b>		<b>2007 NSCH</b>	
<b>Percent with MEDICAL HOME overall:†</b>	% (95% CI)	% (95% CI)	% (95% CI)		% (95% CI)	
<i>All children, ages 0-17</i>	--	--	46.1 (45.6 - 46.7)		57.5 (56.5 - 58.6)	
<i>CSHCN, ages 0-17</i>	52.6 (51.7 - 53.6)	47.1 (46.3 - 48.0)	44.2 (42.9 - 45.4)		49.8 (47.5 - 52.0)	
<i>Sub-component topics measured within each AAP Medical Home definitional component:</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>
<b>ESTABLISHED RELATIONSHIP WITH SPECIFIC PROVIDER</b>						
<u>Has at least one “personal doctor or nurse”</u>	89.0	93.5	83.3	90.0	92.2	94.7
<b>ACCESSIBLE</b>	--	--	--	--	--	--
<b>FAMILY-CENTERED</b>						
<u>Family-centered care(FCC) from ALL child’s doctors and other health care providers</u>						
<i>a) No, does not have FCC care</i>	31.9	32.5	--	--	31.6	34.1
<i>b) Yes, has FCC care</i>	64.2	62.4	--	--	65.1	64.8
<i>c) Legitimate skip</i>	3.9	5.1	--	--	3.3	1.1
<u>Family-centered care (FCC) from child’s personal doctor or nurse</u>						
<i>a) No, does not have FCC car</i>	--	--	17.7	16.3	--	--
<i>b) Yes, has FCC care</i>	--	--	65.2	73.4	--	--
<i>c) Legitimate skip</i>	--	--	17.1	10.3	--	--
<b>CONTINUOUS</b>	--	--	--	--	--	--

† All estimated percentages are weighted to represent the U.S. non-institutionalized child population ages 0-17; (95% CI) = 95% confidence interval

-- Not assessed by survey (See Table 2 for details)

**TABLE 8:** (continued)†

	<b>2001 NS-CSHCN</b>	<b>2005/06 NS-CSHCN</b>	<b>2003 NSCH</b>		<b>2007 NSCH</b>	
<i>Sub-component topics measured within each AAP Medical Home definitional component:</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>CSHCN, ages 0-17 (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>	<i>All children, ages 0-17 (%)</i>	<i>CSHCN, Only (%)</i>
<b>COMPREHENSIVE</b>						
<u>Getting needed referrals</u>						
<i>a) Needed, problems getting</i>	10.8	7.0	--	--	2.8	7.0
<i>b) Needed, no problem getting</i>	38.8	26.0	--	--	13.1	25.2
<i>c) Legitimate skip</i>	50.3	67.0	--	--	84.1	67.8
<u>Usual source(s) for both sick and well care</u>	90.5	92.9	--	--	93.1	94.8
<u>Preventive care visit during past 12 months</u>	--	--	77.8	86.5	--	--
<u>Consistent access to urgent care and/or phone advice from personal doctor or nurse</u>						
<i>a) Needed, did not consistently get</i>	--	--	3.6	6.3	--	--
<i>b) Needed, consistently got</i>	--	--	40.1	55.3	--	--
<i>c) Legitimate skip</i>	--	--	56.2	38.4	--	--
<u>Getting needed specialist care, and/or specialized health services or equipment</u>						
<i>a) Needed, problems getting</i>	--	--	3.5	11.5	--	--
<i>b) Needed, no problem getting</i>	--	--	19.2	42.7	--	--
<i>c) Legitimate skip</i>	--	--	77.3	45.9	--	--
<b>COORDINATED</b>						
<u>Getting effective care coordination when needed</u>						
<i>a) Did not get all help wanted</i>	6.7	31.8	--	--	12.9	29.7
<i>b) Got all help wanted</i>	4.5	46.0	--	--	28.3	43.4
<i>c) Legitimate skip(no report of getting or wanting more help with care coordination)</i>	88.8	22.2	--	--	58.8	26.9
<u>Follow up by personal doctor or nurse after child sees specialist care and/or gets specialized health services</u>						
<i>a) Needed, did not consistently get</i>	--	--	9.4	24.2	--	--
<i>b) Needed, consistently got</i>	--	--	12.9	29.4	--	--
<i>c) Legitimate skip</i>	--	--	77.6	46.4	--	--
<b>COMPASSIONATE</b>	<i>The concept of "compassionate care" is addressed in the context of the family-centered care questions</i>					
<b>CULTURALLY EFFECTIVE</b>	<i>For scoring purposes, questions addressing this topic are included in the Family-centered care sub-component</i>					

†All estimated percentages are weighted to represent the U.S. non-institutionalized child population ages 0-17

-- Not assessed by survey (See Table 2 for details)

#### ***4.2 Medical home prevalence by demographic characteristics***

Table 9 displays the medical home results again, this time by selected child demographic characteristics. As the results in the table show, the prevalence of having a medical home as measured by the NS-CSHCN and NSCH surveys rarely exceeds 60%, even when subgroups of children are considered. Notable exceptions include non-Hispanic White children and those with household incomes at or exceeding 400 percent of the federal poverty level. In the 2007, nearly 70 percent of children from these groups met the NSCH criteria for having a medical home (68.0% and 69.3%, respectively). Children from vulnerable groups are dramatically less likely to have a medical home (Table 9). In the same survey, medical home prevalence is 39% for children whose families have incomes at or below the poverty level, and 46% for those covered by public health insurance. Fewer than half of children who are lower-income, intermittently insured or uninsured children, or non-White or Hispanic had a medical home in 2007. Children with special health care needs, a group with even greater requirements for coordinated and comprehensive care, fared no better and often significantly worse than their non-special needs counterparts.

**TABLE 9:** Prevalence of Medical Home overall and by demographic characteristics -- U.S. non-institutionalized child population, ages 0-17†

	<b>2001 NS-CSHCN</b>	<b>2005-06 NS-CSHCN</b>	<b>2003 NSCH</b>		<b>2007 NSCH</b>	
	<i>CSHCN, ages 0-17</i>	<i>CSHCN, ages 0-17</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>
Number of children in sample (unweighted)	38,866	40,723	102,353	18,578	91,642	18,352
Percent meeting Medical Home criteria† (95% CI)	<b>52.6</b> (51.7 - 53.6)	<b>47.1</b> (46.3 - 48.0)	<b>46.1</b> (45.6 - 46.7)	<b>44.2</b> (42.9 - 45.4)	<b>57.5</b> (56.5 - 58.6)	<b>49.8</b> (47.5 - 52.0)
<b><i>Medical home prevalence by child characteristics</i></b>	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
<b><u>Age</u></b>						
0 – 5 years old	<b>53.5</b> (51.3 - 55.7)	<b>50.4</b> (48.4 - 52.3)	<b>55.9</b> (54.9 - 56.9)	<b>48.7</b> (45.7 - 51.6)	<b>64.0</b> (62.1 - 65.8)	<b>55.4</b> (50.2 - 60.4)
6 – 11 years old	<b>53.8</b> (52.4 - 55.3)	<b>47.4</b> (46.1 - 48.8)	<b>42.7</b> (41.7 - 43.6)	<b>43.9</b> (41.8 - 46.0)	<b>55.2</b> (53.3 - 57.0)	<b>47.2</b> (43.6 - 50.8)
12 – 17 years old	<b>51.1</b> (49.6 - 52.6)	<b>45.2</b> (44.0 - 46.5)	<b>40.2</b> (39.3 - 41.0)	<b>42.2</b> (40.4 - 44.1)	<b>53.4</b> (51.7 - 55.1)	<b>49.4</b> (45.9 - 52.9)
<b><u>Race/ethnicity</u></b>						
White/non-Hisp	<b>56.9</b> (55.9 - 58.0)	<b>52.8</b> (51.8 - 53.8)	<b>52.8</b> (52.2 - 53.4)	<b>47.2</b> (45.8 - 48.6)	<b>68.0</b> (66.8 - 69.1)	<b>57.0</b> (54.4 - 59.6)
Hispanic	<b>40.7</b> (37.5 - 44.0)	<b>32.2</b> (29.5 - 35.0)	<b>30.3</b> (28.9 - 31.7)	<b>34.9</b> (30.5 - 39.6)	<b>38.5</b> (35.5 - 41.7)	<b>31.8</b> (25.3 - 39.2)
Black/non Hisp	<b>44.3</b> (41.5 - 47.2)	<b>36.6</b> (34.3 - 38.9)	<b>39.4</b> (37.8 - 40.9)	<b>40.9</b> (37.2 - 44.8)	<b>44.2</b> (41.6 - 46.8)	<b>39.6</b> (34.2 - 45.2)
Multi racial/non-Hisp	<b>49.7</b> (44.4 - 55.0)	<b>46.8</b> (42.3 - 51.3)	<b>46.0</b> (43.1 - 48.9)	<b>38.0</b> (32.2 - 44.3)	<b>63.0</b> (58.0 - 67.8)	<b>49.9</b> (41.2 - 58.7)
Other/non-Hisp	<b>38.3</b> (31.9 - 45.1)	<b>40.0</b> (35.2 - 44.8)	<b>41.5</b> (37.7 - 45.3)	<b>39.2</b> (30.0 - 49.2)	<b>48.6</b> (44.0 - 53.2)	<b>42.7</b> (30.7 - 55.7)
<b><u>Household Income as percentage of Federal poverty level (FPL)</u></b>						
0- 99% FPL	<b>37.9</b> (35.3 - 40.5)	<b>34.0</b> (32.0 - 36.0)	<b>31.2</b> (29.5 - 32.9)	<b>34.6</b> (30.8 - 38.6)	<b>39.4</b> (37.3 - 41.5)	<b>37.1</b> (33.4 - 41.0)
100% - 199% FPL	<b>48.7</b> (46.5 - 50.9)	<b>41.2</b> (39.3 - 43.0)	<b>39.6</b> (38.2 - 41.0)	<b>42.2</b> (38.9 - 45.7)	<b>49.4</b> (47.5 - 51.3)	<b>44.5</b> (40.8 - 48.3)
200% - 399% FPL	<b>56.2</b> (54.5 - 57.9)	<b>51.1</b> (49.6 - 52.6)	<b>50.1</b> (49.0 - 51.1)	<b>46.7</b> (44.3 - 49.2)	<b>62.5</b> (61.0 - 63.9)	<b>55.4</b> (52.0 - 58.7)
400% FPL or greater	<b>59.7</b> (57.8 - 61.5)	<b>56.3</b> (54.8 - 57.8)	<b>56.9</b> † (55.8 - 58.0)	<b>49.4</b> (46.9 - 51.9)	<b>69.3</b> (68.0 - 70.6)	<b>56.4</b> (53.1 - 59.6)
Income not reported	<b>50.3</b> (47.3 - 53.2)	††	††	††	††	††

(CONTINUED)

	<b>2001 NS-CSHCN</b>	<b>2005-06 NS-CSHCN</b>	<b>2003 NSCH</b>		<b>2007 NSCH</b>	
	<i>CSHCN, ages 0-17</i>	<i>CSHCN, ages 0-17</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>	<i>All children, ages 0-17</i>	<i>CSHCN only</i>
<b><u>Health insurance status, past 12 months</u></b>						
Insured full year; no gaps	<b>54.4</b> (53.4 - 55.4)	<b>47.9</b> (47.0 - 48.8)	<b>49.3</b> (48.7 - 49.9)	<b>45.9</b> (44.5 - 47.2)	<b>60.9</b> (59.8 - 62.0)	<b>52.5</b> (50.1 - 54.9)
Uninsured for some period of time	<b>40.0</b> (36.9 - 43.2)	<b>26.5</b> (22.8 - 30.2)	<b>28.3</b> (27.0 - 29.7)	<b>32.3</b> (28.8 - 36.0)	<b>38.4</b> (35.4 - 41.4)	<b>29.9</b> (24.5 - 36.0)
<b><u>Type of health insurance</u></b>						
Private or employer-based coverage	<b>58.2</b> (57.0 - 59.3)	<b>53.3</b> (52.2 - 54.3)	<b>52.6</b> (52.0 - 53.3)	<b>47.7</b> (46.2 - 49.2)	<b>66.5</b> (65.3 - 67.8)	<b>56.6</b> (53.6 - 59.6)
Publicly insured (Medicaid; SCHIP)	<b>43.7</b> (41.6 - 45.9)	<b>38.9</b> (37.2 - 40.6)	<b>38.9</b> (37.7 - 40.0)	<b>40.2</b> (37.8 - 42.7)	<b>45.4</b> (43.3 - 47.6)	<b>42.1</b> (38.6 - 45.7)
Uninsured at time of survey	<b>36.4</b> (32.5 - 40.5)	<b>26.5</b> (22.8 - 30.2)	<b>23.1</b> (21.6 - 24.6)	<b>30.2</b> (25.4 - 35.6)	<b>35.7</b> (32.1 - 39.5)	<b>28.9</b> (21.8 - 37.4)
<b><u>Primary household language</u></b>						
English	n/a	<b>48.3</b> (47.4 - 49.3)	<b>49.3</b> (48.8 - 49.9)	<b>45.4</b> (44.1 - 46.6)	<b>61.7</b> (60.7 - 62.8)	<b>51.8</b> (49.5 - 54.1)
Other than English	n/a	<b>22.1</b> (46.2 - 48.1)	<b>23.8</b> (22.2 - 25.5)	<b>22.7</b> (17.3 - 29.3)	<b>28.8</b> (25.2 - 32.6)	<b>16.8</b> (11.2 - 24.5)
<b><u>Language of the interview</u></b>						
English	<b>53.6</b> (52.7 - 54.6)	n/a	n/a	n/a	n/a	n/a
Other than English	<b>23.1</b> (18.5 - 28.4)	n/a	n/a	n/a	n/a	n/a
<b><u>Qualifying special health care needs criteria</u></b>						
Managed by Rx meds only	<b>63.9</b> (62.5 - 65.4)	<b>58.9</b> (57.6 - 60.2)	n/a	<b>54.3</b> (52.3 - 56.3)	n/a	<b>62.5</b> (58.6 - 66.1)
Elevated services use/need only	<b>41.1</b> (38.7 - 43.6)	<b>35.8</b> (33.5 - 38.1)	n/a	<b>31.5</b> (28.5 - 34.8)	n/a	<b>39.3</b> (34.1 - 44.6)
Elevated service need AND Rx meds	<b>53.6</b> (51.7 - 55.6)	<b>45.2</b> (43.4 - 47.0)	n/a	<b>45.5</b> (43.0 - 48.1)	n/a	<b>50.1</b> (45.6 - 54.6)
Functional limitations -- alone or with any services or Rx meds use	<b>41.2</b> (39.3 - 43.2)	<b>32.2</b> (30.4 - 33.9)	n/a	<b>33.2</b> (30.7 - 35.9)	n/a	<b>34.6</b> (30.2 - 39.2)

† All estimates are weighted to represent the U.S. non-institutionalized child population ages 0-17; (95% CI) = 95% confidence interval

†† When income and/or number of persons in household were not reported, Federal Poverty Level (FPL) of household was estimated using single imputation methods

n/a = information not collected by survey

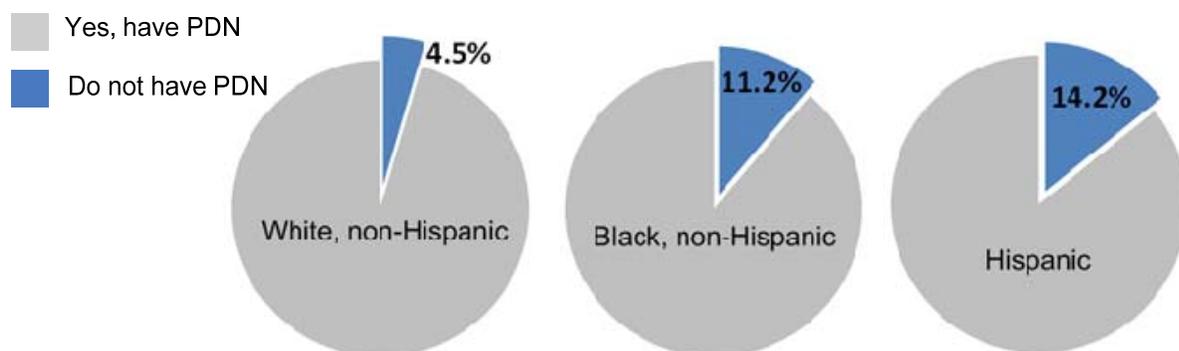
### 4.3 Influence of survey design on medical home prevalence

**Personal doctor or nurse criterion:** Prior to the availability of data from the NS-CSHCN and NSCH, States and others often relied upon the proportion of children with a primary care provider, or as it is sometimes termed; “a personal doctor or nurse,” as the sole indicator of whether children have a medical home. The advent of more robust assessments, such as those from the NS-CSHCN and NSCH, demonstrated that having a personal doctor or nurse alone is not sufficient for having a medical home as defined by the AAP. At the same time, whether or not children have affirmative responses indicating the presence of a PDN continues to be a significant factor in determining the medical home prevalence estimates generated by these surveys.

Both the NS-CSHCN and NSCH include having a personal doctor or nurse (PDN) as one of several basic or minimum criteria for having a medical home. Children with response of NO to the survey question about having one or more personal doctors or nurses are classified from the outset as not having a medical home, regardless of whether they achieve thresholds scores on all other components of the medical home measure.

In the 2007 NSCH, about 8 percent of children overall were without any PDN. Some groups of children, however, have a disproportionately higher risk. Black, non-Hispanic children are twice as likely and Hispanic children are three times more likely to not have any PDN compared to white, non-Hispanic children (Fig. 5). Similar disparities in meeting the baseline criterion of having at least one PDN strongly contribute to the lower prevalence of medical home among non-white and Hispanic children found in the 2003 NSCH and NS-CSHCN surveys (Table 9).

**Figure 5: Children age 0-17 years with at least one personal doctor or nurse (PDN), by race/ethnicity – U.S. non-institutionalized child population, 2007**

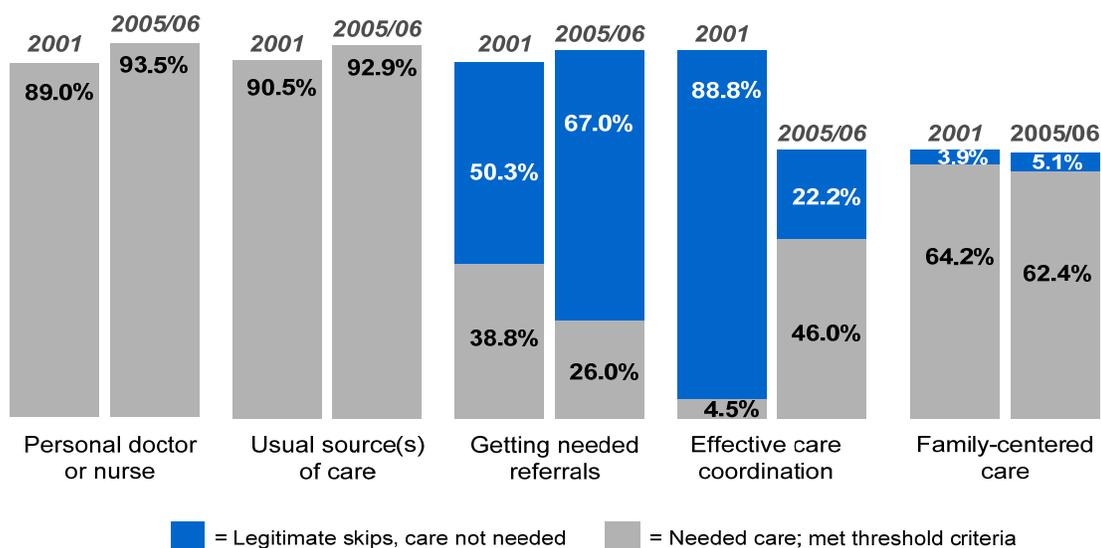


Source: National Survey of Children's Health, 2003

***Influence of question changes:*** In response to issues identified during the first administration of the NS-CSHCN, the Effective Care Coordination and Getting Needed Referrals sub-components of the medical home measure were revised prior to the survey’s second administration in 2005/06 (see Sections 2.1 and 3.3). The questions for assessing these sub-components underwent substantial changes in wording, design and content. Included were significant modifications in the criteria used for identifying valid responders and legitimate skips in each of these sub-components. Comparing the medical home results prior to and after these types of revisions provides an opportunity to observe the effect of changes in question design and content on the medical home composite score, and potentially, the estimates of medical home prevalence overall.

Figure 6 compares the 2001 and 2005/06 NS-CSHCN distributions on each of the five medical home sub-component topics for children meeting either the threshold criteria for getting needed care or classified as “legitimate skips” because care was assumed and/or reported to not be needed. The proportion of children either meeting threshold criteria or classified as legitimate skips varies substantially across the five medical home sub-component topics within each and across the two survey administrations. In 2001, Effective Care Coordination was the sub-component topic with the highest combined proportion of threshold achievers and legitimate skips (93.3%) and the Family-Centered Care sub-component topic was the lowest (68.1%).

**Figure 6: Proportion of CSHCN receiving care that meets the threshold criteria or classified as “legitimate skips” within each medical home sub-component topic, by NS-CSHCN survey year**



In 2005/06, the changes made to the care coordination questions greatly altered the proportions of children either meeting the threshold criteria or classified as legitimate skips within that sub-component topic. As Figure 6 illustrates, Effective Care Coordination went from being the sub-component with the highest combined proportion of threshold achievers and legitimate skips in 2001 to essentially tying with Family-Centered Care sub-component for the lowest proportion in 2005/06 (68.2 % and 67.5%, respectively).

Although changes to the care coordination questions also dramatically changed the individual proportions of children who were classified as needing care coordination and met the threshold criteria or who were classified as not needing care coordination (legitimate skip) in the 2005/06 survey, it is actually the combined proportion of these two categories that has potential to influence the overall medical home score. This is because the overall medical home results are based on the proportion of children who either meet the threshold criteria or qualify as legitimate skips on every one of the five sub-components topics. As such, the proportion of children meeting the overall medical home composite measure cannot exceed the results for the sub-component with the lowest combined proportion of threshold achievers and legitimate skips.

In 2001, the Family-Centered Care sub-component anchored the medical home composite score by having the lowest combined proportion of threshold achievers and legitimate skips. As a result of questions changes in the 2005/06, the Effective Care Coordination sub-component tied with the Family-Centered Care sub-component for the lowest combined proportion of threshold achievers and legitimate skips. Because of this tie, it was the 52 percent of cases that either met the threshold criteria or were legitimates skips across both these of sub-components that formed the new baseline proportion for the overall medical home score, rather than 67.5 percent result for the Family-Centered Care sub-component.

From a question design perspective, it is interesting to note that changes in question content and skip patterns do not always influence a composite measure. The 2005/06 questions for the Getting Needed Referrals sub-component also underwent substantial revision. Although these revisions changed the relative distributions of legitimate skips and threshold achievers within the sub-component, the net effect was only a slight increase over the 2001 results for the combined proportion of these cases (See Fig. 6). As a result, the question changes for this sub-component had minimal, if any, effect on the overall medical home composite score in 2005/06.