



Champions for Inclusive Communities

Drilling Down to Understand Outcome 5: Services Organized so Families Can Use Them Easily

The National Survey of CSHCN gauges how well states and the nation as a whole are doing in achieving the 6 outcomes for children and youth with special health care needs and their families. The Data Resource Center (<http://childhealthdata.org/content/Default.aspx>) is a critical tool for analyzing and communicating the results of this survey. Based on the 2005/2006 National Survey of CSHCN, the following summary statistic was obtained for Outcome 5 via the Data Resource Center:

Outcome 5 was successfully achieved for 89.1% of families.

At first glance, it appears that Outcome 5 has been achieved for the vast majority of families. However, because this statistic is based on one primary question, there is a need to “drill down” through the data to understand other factors that pertain to 1) the ability of families to access all needed services, 2) reasons for why services were not received, 3) how well services are coordinated and who coordinates them, and 4) the impact on the family as they strive to get their needs met.

What else can we learn?

The purpose of this guide is to support states in using the Data Resource Center to investigate, or “drill down” through the survey data to gain a deeper understanding of the issues families face that impact the achievement of Outcome 5. This can be a valuable step in conducting a needs assessment, providing a richer picture of how well services are working – and where the challenges are – for families.

Below are examples of how to take a closer look at components related to Outcome 5 based on statistics for the nation. This same data is available for each state and HRSA region by choosing your area in drop-down boxes. You can set your state as the default once and get results from just your state for an entire session.

I. Did families get all the needed services?

In the 2005-2006 CSHCN survey, it was reported that 16% of CSHCN did not receive all the health care services or equipment that were needed.

To find this information:

1. From the DRC Homepage (<http://childhealthdata.org/content/Default.aspx>) choose "2005/06", choose your state or region, and choose "Health Care Needs and Access to Care" from the drop-down boxes. Click "Go."
2. Click "Indicator 6: CSHCN with any unmet need for specific health care services (derived)" and click "Next".
3. Add percentages for "1 unmet need for services/equip" and "2 or more unmet needs for services/equip" and record sum. You can also compare to nationwide percentages, state/regions, subgroups, and change the kind of chart that is displayed using the options at the bottom of the page.

II. What were the unmet family support service needs?

Family support service:	% of all families with support service need(s)	% of families who needed the service and that need was unmet
Respite care	17.5	48.1
Genetic counseling		23.8
Family counseling		19.4

To find this information:

1. From the DRC Homepage (<http://childhealthdata.org/content/Default.aspx>) choose "2005/06", choose your state or region, and choose "Health Care Needs and Access to Care" from the drop-down boxes. Click "Go."
2. Click "Number of family support services needed by CSHCN (derived)" and click "Next".
3. Add percentages of "CSHCN needing 1 or 3 family support services" and "CSHCN needing 2 or 3 family support services". Record number in first column.
4. Click browser's back button or blue "New Question" button.
5. Scroll to bottom of list of options.
6. Click "Unmet needs for family respite care" and "Next".
7. Click "Unmet needs for respite care among CSHCN needing this care" and "Next".
8. Record number in right column, top row. Click browser back button twice and scroll to bottom of list.

9. Click "Unmet needs for family genetic testing or counseling among CSHCN needing this care" and "Next". Record number in right column. Click browser back button twice and scroll to bottom of list.
10. Repeat steps to obtain and record percentage for "Unmet needs for family mental health care or counseling among CSHCN needing this care".

III. What were the unmet health care needs of CSHCN?

Health service	% who needed service	% who needed service but did not receive
Routine preventive care	1.9	2.5
Specialist care	2.8	5.4
Preventive dental care	6.3	7.7
Other dental care	2.6	10.2
Prescription medications	1.6	1.8
Physical, occupational, or speech therapy	3.1	13.5
Mental health care or counseling	3.7	14.9
Substance abuse treatment or counseling	0.6	20.6
Home health care	0.5	10.6
Eyeglasses or vision care	1.4	4.3
Hearing aids or hearing care	0.4	8.0
Mobility aids or devices	0.3	7.1
Communication aids or devices	0.5	23.9
Medical supplies (disposable)	0.5	2.5
Durable medical equipment	0.4	3.9

* % of all CSHCN 05-06 who needed service

** % of those who needed service but did not receive all needed care; n varies

To find this information:

Column for % who needed service:

1. From the DRC Homepage (<http://childhealthdata.org/content/Default.aspx>) choose "2005/06", choose your state or region, and choose "Health Care Needs and Access to Care" from the drop-down boxes. Click Go.
2. Click "Unmet need for each of 15 specific health care services - for all CSHCN" and "Next".
3. Choose the type of need from list. Use the scroll bar just to the right of the list of needs to see the lower half of the list.
4. Click on the type of service and "Next". Record percent of CSHCN with unmet needs for that type of health care service.

5. Click blue "New Question" button at top right or click your browser's "Back" button to see the list of services again. Continue for each health care service type.

Column for % with Unmet Need

1. After recording the percentage with unmet need for Durable Medical Equipment, either click blue "New Topic" button at top right and choose "Health Care Needs and Access to Care" and "Next" or click your browser's back button twice.
2. Click "Level of unmet need for CSHCN needing each of 15 specific health care services" and "Next".
3. Choose the type of health care service and "Next". Move scroll bar down to see lower half of list.
4. Add percentage who received "some" and percentage who "Did not receive any of the care needed", record number.
5. Click blue "New Question" button at top right to return to the list of health care services and continue.

IV. What were the reasons families had difficulties using services?

Reason for Difficulty	Percent Reporting Difficulty
Could not get needed information	6.7
Too much paperwork required	2.7
Not able to pay for services	4.3
Problems with transportation	2.2
Could not get services when needed	7.2
Long waiting lists	3.3
Problems with communication between service providers	5.5
Language or cultural problems	1.4
Could not find providers with necessary skills	4.5
Services unavailable in area	4.4
Child not eligible	4.8
Used up all eligible benefits	1.5
Did not have time to figure it out	2.7

To find this information:

1. From CSHCN Survey homepage (<http://cshcndata.org/Content/Default.aspx>), click "Start a Data Query" and "2005/06 NS-CSHCN" at far top right.

2. Choose your state or region from the geographic area drop-down box.
3. Click on "2005/06 CSHCN Survey Sections" and "Next".
4. Click on "CSHCN Ease of Service Use (Survey Section 6c)" and "Next".
5. Click on "Type of difficulties experienced -- for all" and "Next".
6. Click on "Could not get needed information" and "Next".
7. Record percentage who had this trouble.
8. Continue through list by clicking blue New Question button to return to list and choosing each difficulty from the list. Scroll down to see entire list.

V. What did families say about their care coordination?

In the 2005-2006 National Survey of CSHCN, all components of care coordination were in place for 59.2% of children who needed care coordination; one or more element of effective care coordination was missing for 40.8%.

To find this information:

1. From CSHCN Survey homepage (<http://cshcndata.org/Content/Default.aspx>), click "Start a Data Query" and "2005/06 NS-CSHCN" at far top right.
2. Click "2005/06 CSHCN Survey Sections" and choose State/Region from drop-down box. Click "Next".
3. Click "CSHCN Care Coordination (Survey Section 5)" and "Next".
4. Click "Medical Home Part E: Receives effective care coordination, only children who needed care coordination (derived)" and "Next".
5. Record percent who met all components and percent who did not into the statement.

NOTE: Families were not asked directly about the effectiveness of their care coordination. Instead, DRC and their partners developed criteria and derived this finding from several specific questions that families did answer. You may want to insert a note from DRC with specifics about how they defined "effective care coordination" – details of how to find the definition are below.

To insert note with specifics about how effective care coordination was derived: Click on "(derived)" link on the page with statistic (in the Question wording section at top). Copy and paste into your document. To be sure to give DRC appropriate credit, fill-in values for month, day and year in this citation:

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*. Data Resource Center for Child and Adolescent Health website. Retrieved [mm/dd/yy] from <http://childhealthdata.org/content/Default.aspx>

VI. Who helped families coordinate care?

Care coordinated by:	% of CSHCN families receiving 2 or more services
Doctor or office staff	24.3
Someone other than doctor or office staff	8.8
No one helps this family coordinate care	66.8

To find this information:

1. From CSHCN Survey homepage (<http://cshcndata.org/Content/Default.aspx>), click "Start a Data Query" and "2005/06 NS-CSHCN" at far top right.
 2. Click "2005/06 CSHCN Survey Sections", choose State/Region, and click "Next".
 3. Click "CSHCN Care Coordination Survey (Survey Section 5)" and "Next"
 4. Click "Does child's doctor help with care coordination?" and "Next".
 5. Record percentages.
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VII. Did families get enough extra help coordinating care?

Family response:	% of all CSHCN families
Did not need extra help	80.6
Needed extra help and did not get it (never/sometimes)	15.3
Needed extra help and usually got it	4.1

To find this information:

6. Starting on same page as in the above table, Click browser's back button.
 7. Click "Received extra help with care coordination?" and "Next". Record percentages.
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VIII. How did families rate the communication among providers?

Type of communication:	% of all CSHCN families "Very satisfied"	% CSHCN who needed care coordination and were "Very satisfied"
Among child's doctors & other health care providers (34.5% said not needed)	41.8	63.8
Between health providers & school, EI, others (71.9% said not needed)	14.7	52.1

To find this information:

1. From CSHCN Survey homepage (<http://cshcndata.org/Content/Default.aspx>), click "Start a Data Query" and "2005/06 NS-CSHCN" at far top right.
 2. Choose your state or region from the geographic area drop-down box. Check the box below that if you want all of your statistics to be for this state/region (the geographic area will reset when you visit the site again).
 3. Click "CSHCN Chartbook Indicators and MCHB Core Outcomes" and "Next".
 4. Click "Care Coordination and Family Centered Care" and "Next".
 5. Click "Individual components of care coordination" and "Next".
 6. Click "Communication between child's doctors (derived)" and "Next".
 7. Record percentage "Very satisfied" and record percent who did not need this type. Click browser's back button.
 8. Click "Satisfied with communication among child's doctors when needed for care coordination (details)" and "Next".
 9. Record percentage who were "Very satisfied ... when needed". Click back.
 10. Click "Communication by doctors with child's schools and other programs (derived)" and "Next".
 11. Record percentage Very satisfied and record percent who did not need this type. Click browser's back.
 12. Click "Satisfied with doctors' communication with school or other programs when needed (derived)" and "Next".
 13. Record percentage "Very satisfied with communication when needed" in right column.
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IX. What has been the impact on families?

Impact	% of all CSHCN families 05-06
Time spent providing care –providing healthcare at home	0 = 54.1; 1 hr or less = 25.9; 2-7 hrs = 11.8; 8-20 hrs = 3.7; 21 hrs or more = 4.6
Time spent providing care –arranging or coordinating care	less than 1 hr = 54.8; 1-2 hrs = 30.7; 3-10 hrs = 11.6; 11 hrs or more = 2.9
Percent who cut back and/or stopped working	23.8

To find this information:

1. From CSHCN Survey homepage (<http://cshcndata.org/Content/Default.aspx>), click "Start a Data Query" and "2005/06 NS-CSHCN" at far top right.
 2. Choose your state or region from the geographic area drop-down box.
 3. Click on "2005/06 CSHCN Survey Sections" and "Next".
 4. Click "CSHCN Impact on the Family (Survey Section 9)" and "Next".
 5. Choose "How many hours per week does family spend providing health care at home for child?" and "Next".
 6. Record percentages. Click browser's back button or blue New Question button.
 7. Choose "How many hours per week does family spend coordinating child's health care?" and "Next".
 8. Record percentages.
 9. From near the top of the page, choose green "Home" box and "DRC Home".
 10. From the DRC Homepage (<http://childhealthdata.org/content/Default.aspx>) choose "2005/06", choose your state or region, and choose "Impact on Families" and "Go".
 11. Click "Indicator 15: CSHCN whose conditions cause family members cut back or stopped working" and "Next".
 12. Record percentage.
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Developed by Cora L. Price, Research Associate at Champions For Inclusive Communities, Early Intervention Research Institute, Utah State University, Logan, UT. Champions for Inclusive Communities wishes to thank those at the Child and Adolescent Health Measurement Initiative, the developers of the Data Resource Center, for their assistance in helping develop this tool. Contact cora.price@usu.edu.

Data Source:

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*. Data Resource Center for Child and Adolescent Health website. Retrieved [10/18/09] from <http://childhealthdata.org/content/Default.aspx>



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