

*A portion of the 2005 Illinois Needs Assessment (CSHCN) submitted to
Title V Maternal & Child Health Services
FY2004 Block Grant Report/Fiscal Year 2006 Application*

Conducted as part of Needs Assessment by:

UIC

UNIVERSITY
OF ILLINOIS
AT CHICAGO

**DIVISION OF SPECIALIZED
CARE FOR CHILDREN**

Partners:

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*This is an update of the earlier May and June versions and adds the final analysis (relationships to condition of child) to the September 22 version.

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INTRODUCTION, METHODOLOGY AND RESPONSE RATES

Introduction

The Division of Specialized Care for Children (DSCC) of the University of Illinois-Chicago (UIC) contracted with the Survey Research Office, located within the Center for State Policy and Leadership, of the University of Illinois at Springfield (UIS-SRO) to assist in conducting a Healthcare Needs Survey of families who have children with special healthcare needs. The survey was part of a broader needs assessment project conducted by UIC-DSCC.

The questionnaire was developed by DSCC staff, with the advice of UIS-SRO staff. The printing and distribution of the survey materials were the responsibility of UIC-DSCC staff (and other vendors hired by them). Completed surveys were returned to the UIS-SRO through postage-paid return envelopes. UIS-SRO staff were responsible for the input, cleaning and editing of completed survey data and for the preparation of descriptive tables and summaries of the results.

Methodology and Response Rates

The methodology was a mail-out survey of the population of DSCC households receiving services as of December 2004 (almost 8000) and the population of SSI households receiving benefits within the last three months of 2004 (nearly 900). Each household was sent an initial survey package consisting of a personalized cover letter, a questionnaire, and a postage-paid return envelope in late January 2005. Each household was then sent a postcard reminder about one week later. Follow-up survey packages similar in nature to the first were sent to non-respondents in late February 2005.

The cover letter made reference to the particular child who was receiving services/benefits, and respondents were instructed to complete the survey with reference to this child where applicable. When more than one child in a household was receiving services/benefits, the first child on the data base was the “focal child” for the survey. Respondents were also informed they could request an additional survey to complete for additional children who were receiving services/benefits.

Through the end of March, 4333 completed and unduplicated questionnaires had been received at the UIS-SRO. Nearly all of these (4286) were questionnaires that had been sent to respondents. The remaining 47 were those requested by respondents. Since the full population of DSCC and SSI households had been included in the survey – and all respondents were informed they could request an additional survey, it was decided to include the 47 additional questionnaires in the results. (However, in calculating response rates, these are excluded since they are in effect duplicate returns from particular households. In practice, the decision of whether to include/exclude these additional questionnaires makes virtually no difference in the results.)

Of the 4333 final questionnaires, 4140 were from the DSCC population (4095 sent to respondents, and 47 requested by respondents); 191 were from the SSI population; and 2 were unknown in this regard. The response rate for the DSCC population is about 52 percent while the response rate for the SSI population is about 22 percent.

Information relating to response rates, including the response rates for DSCC Regional Office areas, is presented in Table Intro-1. Generally, we find response rates for the DSCC population to be somewhat lower in the most urbanized areas of the state (i.e., Chicago metro area), a common finding across numerous types of statewide surveys. It is worth noting, however, that the final DSCC sample is very representative of the DSCC population by region, with the greatest difference between population and sample proportions for any single region at only about 1 percentage point.

Methodology and Response Rates
Response Rates, Regions of Populations and Final Samples

Regional Office	RO	Sent	Returned	Response Rate
Olney	8	534	313	58.6%
Springfield	12	603	346	57.4%
Marion	7	492	278	56.5%
St. Clair	6	526	292	55.5%
Rockford	10	1092	601	55.0%
Peoria	9	475	252	53.1%
Rock Island	11	417	220	52.8%
DuPage	13	913	454	49.7%
South Cook County	3	558	277	49.6%
Champaign	5	790	376	47.6%
North Cook County	1	599	279	46.6%
Chicago North	4	470	209	44.5%
Chicago South	2	465	198	42.6%
<i>Unknown (requested)</i>			<i>(47)</i>	
DSCC	Total	7934	4095	51.6%
SSI	Total	874	191	21.9%

Table Intro-1

Summary of Survey Results

The following is a summary of the results of the survey. The results are presented by section in question order.¹ For most questions (or sets of questions), the summary presents: the question; the tables (tabular results); and commentary.

The results for individual questions are generally presented for:

- a. The DSCC or SSI sample (i.e., the survey respondents, identified by initial population)
- b. DSCC and/or SSI services/benefits received (only DSCC; only SSI; both), *as reported in the questionnaire*

About What Families Wrote

The statistical survey provides data about families raising children with special healthcare needs. Families told a more personal story. After completing the eight-page survey, families wrote many comments. At the end of each section of this report, a few of these comments are included to honor the voices of these families who shared their thoughts about the joys, fears and challenges of parenting a child with special healthcare needs. (Please Note: Comments have been edited to remove identifying information.)

“My (child) is my life. We have a mild case of...(condition). We are very lucky and blessed that (it) is as mild as it is. He/she will always have trouble walking and doing things with his/her hands. He/she has an outstanding personality and smart as a tack when he/she wants to be. He/she can be very funny and attitude when he/she wants. He/she is not afraid to try or do anything. He/she is great. He/she is my life. Thank you everyone who helps him/her.”

¹ The exception here is race/ethnicity which is presented in the middle of the Demographic Section while it was among the last substantive questions asked in the questionnaire itself.



GENERAL INFORMATION AND DEMOGRAPHICS

General Information and Demographics

Questions concerning general information about the household and the child(ren) with a special healthcare need were included both at the very beginning and end of the questionnaire. The questions included at the beginning of the questionnaire solicited information about: number in household (adults and children); number of children who have special healthcare needs; number of children who receive DSCC services and SSI benefits; age of the child for whom the survey is being completed; the child's "most serious health condition"; and length of time the respondent has known their child has a special healthcare need. Race/ethnicity of the child with the special healthcare need was asked at the end of the questionnaire.

The following presents the actual questions found in the questionnaire.

Question 1 | ***How many persons are in your household?
_____ Adults _____ Children (under 21 years of age
including your family member with special
healthcare needs)***

Response to Question 1:

Number of Adults in Household

The average (median) number of adults per DSCC respondent household is two, reported by two-thirds (67%) of the DSCC sample. Just under one-quarter (24%) reported one adult while just under one-tenth (8%) reported three or more adults. The SSI sample contains far fewer respondents in two-adult households (44% vs. 67% for DSCC), more respondents in single adult households (41% vs. 24% for DSCC) and slightly more in households with three or more adults (12% vs. 8% for DSCC).

Question 1a - Number of Adults in Household

Number of adults in household	One	Two	Three or more	dk/na	n
DSCC surveys	23.5%	67.4%	8.1%	1.0%	4140
SSI surveys	40.8%	44.0%	12.0%	3.1%	191
As reported in survey:					
Only DSCC services	17.6%	74.4%	7.2%	0.9%	2556
Only SSI benefits	35.3%	49.1%	13.4%	2.2%	224
Both	37.6%	52.0%	9.2%	1.3%	1262

Table 1a

Number of Children in Household

The average (median) number of children in DSCC respondent households is two, reported by somewhat more than one-third (36%). Just over one-quarter (26%) reported one child, nearly one-quarter (24%) reported three children, and about one in eight (13%) reported four or more children. The largest difference between DSCC and SSI respondent households here is the somewhat greater percentage of SSI families who have four or more children (19% vs. 13% for DSCC).

Question 1b - Number of Children in Household

Number of children in household	One	Two	Three	Four or more	dk/na	n
DSCC surveys	26.0%	35.6%	23.6%	13.4%	1.5%	4140
SSI surveys	24.1%	33.0%	23.0%	18.8%	1.0%	191
As reported in survey:						
Only DSCC services	22.7%	37.9%	24.9%	13.7%	0.9%	2556
Only SSI benefits	34.8%	28.1%	17.0%	16.1%	4.0%	224
Both	29.2%	32.7%	22.3%	13.9%	1.8%	1262

*Table 1b***Question 2**

How many children in your household have special healthcare needs? How many receive DSCC services? How many receive SSI benefits?

Response to Question 2:*Number of Children with Special Healthcare Needs in Household*

Well over eight in ten (84%) of the DSCC respondents reported their family has one child with special healthcare needs while just over one in ten (11%) reported two children having such needs and a few (2%) reported more than two children. Far fewer SSI respondents reported one child with special healthcare needs (71%) and more of them reported two children having such needs (20%) and more than two children (4%). Among DSCC respondents, the incidence of having one child with special healthcare needs ranges from just over 80 percent to a high of 90 percent.

Question 2a - Number of Children with Special Healthcare Needs in Household

Number of children w/special healthcare needs	None	One	Two	More than two	dk/na	n
DSCC surveys	0.4%	84.2%	11.1%	2.1%	2.1%	4140
SSI surveys	1.0%	70.7%	19.9%	3.7%	4.7%	191
As reported in survey:						
Only DSCC services	0.3%	85.1%	11.1%	1.8%	1.7%	2556
Only SSI benefits	0.4%	77.7%	13.4%	3.1%	5.4%	224
Both	0.2%	83.2%	12.8%	2.8%	1.0%	1262

*Table 2a**Number of Children Who Receive DSCC Services and/or SSI Benefits*

Respondents were asked how many of their children receive DSCC services and how many of their children receive SSI benefits.

From these two questions, a single measure (i.e., a combined response measure) was developed that put respondents into the following categories.

- Those who reported receiving neither DSCC nor SSI
- Those who only receive DSCC services
- Those who only receive SSI benefits
- Those who receive both services/benefits

The results are demonstrated in Table 2b (for DSCC services) and in Table 2c (for SSI benefits). The combined response measure results are found in Table 2d. Based on this measure, one of the analysis characteristics used in tables throughout the summary report uses all but the first of these four categories (indicated with “*” above).

Question 2b - Number of Children Receiving DSCC Services

Number of children receiving DSCC services	None	One	Two or more	dk/na	n
DSCC surveys	6.3%	83.4%	7.1%	3.3%	4140
SSI surveys	59.7%	33.0%	5.2%	2.1%	191
As reported in survey:					
Only DSCC services	0.0%	91.6%	8.4%	0.0%	2556
Only SSI benefits	100.0%	0.0%	0.0%	0.0%	224
Both	0.0%	92.9%	7.1%	0.0%	1262

Table 2b

Question 2c - Number of Children Receiving SSI Benefits

Number of children receiving SSI benefits	None	One	Two or more	dk/na	n
DSCC surveys	65.0%	27.4%	4.3%	3.3%	4140
SSI surveys	7.3%	75.9%	14.7%	2.1%	191
As reported in survey:					
Only DSCC services	100.0%	0.0%	0.0%	0.0%	2556
Only SSI benefits	0.0%	84.8%	15.2%	0.0%	224
Both	0.0%	86.4%	13.6%	0.0%	1262

Table 2c

Question 2d - Families Receiving Both DSCC Services and SSI Benefits

Receiving DSCC services and SSI benefits	Neither	DSCC Services Only	SSI Benefits Only	Both	dk/na	n
DSCC surveys	3.0%	61.6%	2.8%	28.9%	3.7%	4140
SSI surveys	2.6%	3.7%	56.0%	34.6%	3.1%	191

Table 2d

Not surprisingly, reports of the number of children receiving DSCC services and SSI benefits are related to which sample respondents are part of (DSCC or SSI). About 90 percent of the DSCC sample reported receiving DSCC services (83% for one child and 7% for two or more children) while nearly 40 percent of SSI reported such (33% for one child and 5% for two or more children). In contrast, just over 90 percent of the SSI sample reported receiving SSI benefits (76% for one child and 15% for two or more children) while just over 30 percent of the DSCC sample reported receiving such (27% for one child and 4% for more than one child). (See Table 2a.)

When we combine the two sets of reports (i.e., receipt of DSCC services and receipt of SSI benefits), we find that just over 60 percent (62%) of the DSCC sample reported receiving DSCC services only while nearly 30 percent (29%) reported receiving both DSCC services and SSI benefits. The SSI sample is nearly a mirror image, with somewhat fewer than 60 percent (56%) reporting receiving only SSI benefits while just

over one-third (35%) reported receiving both. Across DSCC regions, a decrease in the percent that reported receiving only DSCC services is generally associated with an increase in the percent that reported both DSCC services and SSI benefits.

Question 3

What is the age of the child for which you are completing this survey? (Years and Months)

Response to Question 3:

The median age of the “focal child” for DSCC respondents is nearly 10 years old – with 13 percent reporting a child under 3 years old; 16 percent reporting a child 3 to 5 years old; nearly four in ten (39%) reporting a child 6 to 12 years old; just over one-quarter (27%) reporting a child 13 to 18 years old; and 6 percent reporting a child over 18 years old.

The SSI sample reported a far younger group of children as a whole, with the median age being just over 3 years old. Over 40 percent (45%) of the SSI sample reported a child under 3 years old, one-fifth (20%) reported a child 3 to 5 years old, one-quarter (25%) reported a child 6 to 12 years old, and about 10 percent reported a teenager. Virtually no SSI respondent reported a child more than 18 years old.

Across the DSCC regions, the median age for eleven of the thirteen regions is about 10 years old, ranging from 9.2 years to 10.8 years.

Question 3 - Age of “Focal Child”

Age of child	Under 3 yrs	3 - 5 yrs	6 - 12 yrs	13 - 18 yrs	Over 18 yrs	<i>n</i>	Mean	Median
DSCC surveys	12.6%	15.8%	38.6%	26.9%	6.1%	4119	10.0	9.9
SSI surveys	44.7%	20.2%	25.0%	9.6%	0.5%	188	5.2	3.2
As reported in survey:								
Only DSCC services	12.5%	17.1%	40.8%	26.4%	3.2%	2546	9.6	9.5
Only SSI benefits	25.4%	13.4%	31.7%	16.1%	13.4%	224	9.0	8.0
Both	14.2%	14.8%	34.6%	26.8%	9.7%	1253	10.3	10.0

Table 3

Question 4

What do you believe is your child’s most serious health condition?

Response to Question 4:

The coding scheme for these responses is based on DSCC codes but expanded to include health conditions that do not, by themselves, make a child eligible for DSCC services. It must be remembered that the question asks for respondents’ identification of the child’s most serious health condition, and not for the health condition that makes a child eligible

for services/benefits. It should also be remembered that the codes are based on the descriptions that respondents supply. Multiple conditions were coded if given by respondents; thus, the percentages will add to more than 100 percent. Some responses were too general in nature to code (labeled “general” in the tables below).

Tables for most serious health condition: The results for the two samples and by reported source of DSCC/SSI services/benefits are presented in Table 4. Health conditions are ordered by most to least frequent for the DSCC sample as a whole. By far, the most frequently-identified health conditions by DSCC sample respondents are those relating to the nervous system (33%), followed distantly by those relating to hearing (15%) and external body (13%). Next in frequency are those relating to cardiovascular conditions (10%) and orthopedic conditions (9%). For SSI respondents, the most frequently identified conditions are: nervous system (23%); mental disorders (15%); and respiratory (14%). Just over one-quarter (27%) of SSI sample respondents gave a description too general to code, and just under one-tenth (8%) of DSCC sample respondents did so as well.

*Question 4 - Most Serious Health Condition of Child
by Sample Type and by Reported Source of Services/Benefits*

Condition	Sample		As Reported in Survey		
	DSCC Sample	SSI Sample	Only DSCC Services	Only SSI Benefits	Both DSCC and SSI
Nervous system	33.1%	23.1%	27.0%	34.0%	45.3%
Hearing	15.1%	4.0%	17.8%	5.3%	8.7%
External body	12.7%	2.3%	14.8%	4.8%	8.2%
Cardiovascular	10.1%	5.8%	11.2%	6.2%	8.1%
Orthopedic	9.4%	4.0%	8.8%	6.7%	10.0%
Respiratory	6.6%	13.9%	5.8%	11.5%	9.0%
Eye	5.7%	6.9%	6.0%	5.3%	4.8%
Mental disorders	5.1%	15.0%	4.1%	12.4%	6.7%
Inborn error	4.0%	2.9%	4.1%	2.9%	3.6%
Urinary	2.6%	1.7%	3.0%	1.4%	1.9%
Hemophilia	1.4%	1.2%	1.5%	1.4%	1.0%
Cystic fibrosis	1.3%	0.0%	1.6%	1.4%	0.7%
Other specific	4.8%	13.3%	4.5%	8.6%	5.7%
General	8.2%	26.6%	7.2%	23.0%	10.5%
<i>number responding</i>	<i>3877</i>	<i>173</i>	<i>2399</i>	<i>209</i>	<i>1177</i>

Table 4

Question 5

How long have you known that your child has special healthcare needs? (Less than one year, One year to three years, More than three years)

Response to Question 5:

About three-quarters (75%) of the DSCC sample reported they have known about their child’s special health needs for more than three years, with another one in six (18%)

reporting one-to-three years and 7 percent reporting less than one year. Greater percentages of SSI than DSCC respondents reported knowing about their child's special health needs less than one year (34%) and one-to-three years (34%) and fewer reported knowing about their child's needs more than three years (29%). See Table 5a. This is not surprising, given the fact that the SSI sample children are far younger as a group (previous section), and the relationship between the age of the child and the length of time the respondent has known about the child's special health needs, as seen in Table 5b.

Question 5a - Length of Time Known about Child's Special Health Needs

How long known about child's special healthcare needs?	Less than 1 yr	1 – 3 yrs	More than 3 yrs	dk/na	n
DSCC surveys	7.2%	16.8%	75.4%	0.7%	4140
SSI surveys	34.0%	33.5%	29.3%	3.1%	191
As reported in survey:					
Only DSCC services	7.2%	17.0%	75.0%	0.4%	2556
Only SSI benefits	18.8%	19.6%	59.4%	2.2%	224
Both	8.2%	16.6%	74.9%	0.3%	1262

Table 5a

*Question 5b - Length of Time Known about Child's Special Health Needs
By Age Group*

How long known about child's special healthcare needs?	Less than 1 yr	1 – 3 yrs	More than 3 yrs	dk/na	n
By age of child:					
Less than 3 yrs	35.3%	62.1%	1.5%	1.2%	604
3 to 5 yrs	6.5%	27.0%	66.1%	0.3%	688
6 to 12 yrs	3.9%	8.5%	87.2%	0.4%	1637
13 to 18 yrs	2.9%	4.4%	91.7%	0.9%	1127
Over 18 yrs	2.8%	1.6%	94.5%	1.2%	253

Table 5b

Race/ethnicity of child with special healthcare needs? (Please circle ALL number(s) that apply)

Question 21

- | | |
|--------------------|-------------------|
| 1 African-American | 2 American Indian |
| 3 Asian | 4 Hispanic |
| 5 White | 6 Other |

Response to Question 21:

At the end of the questionnaire, respondents were asked to identify the race/ethnic background of their child with special healthcare needs. Those coded “white,” “African-

American” (or “black”) and “Asian” are those whose sole race/ethnicity is white, black or Asian, respectively. Hispanics are those who checked only Hispanic or Hispanic in combination with another race category (generally either white or black). Most (but certainly not all) of the “other/mixed” respondents are a combination of white and black. The results are presented in Table 21. (Those who did not answer are omitted from the results.)

Nearly seven in ten DSCC respondents are white while 15 percent are Hispanic, 11 percent are African-American, 2 percent are Asian, and 2 percent are “other/mixed.” This distribution is not far from the 2000 Illinois census distribution.² The SSI sample is more diverse, split about equally between African-Americans (38%) and whites (35%) and with about one in five being Hispanic (21%).

Question 21 - Race/ethnicity of Child's Race/Ethnic Background

Race/ethnicity	White	Black	Hispanic	Asian	Other / Mixed	n
DSCC surveys	69.4%	11.0%	15.2%	2.3%	2.2%	4078
SSI surveys	35.5%	37.6%	21.0%	1.6%	4.3%	186
As reported in survey:						
Only DSCC services	76.3%	6.0%	13.4%	2.4%	1.9%	2529
Only SSI benefits	44.7%	28.3%	22.8%	1.4%	2.7%	219
Both	53.8%	22.7%	18.4%	1.9%	3.2%	1237

Table 21

² The 2000 Illinois census shows: 68 percent white only; 15 percent black only; 3 percent Asian only; and 12 percent Hispanic (alone or in combination).

What Families Wrote . . .

About Their Children and Their Lives

“When you have a special circumstance child, you learn a lot about the system. You find that some schools know what they are doing and some have to be taught by you and that’s the most frustration. I wish schools would be more open and willing to try different approaches (not all kids fit in square pegs).”

“My child is a child with many special needs (who) is unable to do much on his/her own without the help of someone. He/she is a loveable child and our plan is to have him/her live with us always. We cannot imagine our lives any different. He/she cannot understand much . . . read, write or make any decisions . . . (and) . . . depends on me for total hygiene, bathing, shaving, brushing teeth. He/she is a very happy child and shows emotions . . . does sign . . . and loves basketball, long rides and going to the park.”

“Since the surgery my child is undergoing is relatively new, it is hard to say how much if any special needs my child will have in the future. The other thing I would like to add is about how many times I have to explain my child’s diagnosis to healthcare providers that we do not regularly see. I carry a stylized picture of what is wrong that I found on the Internet so that it is easier to explain...”

“Well, it’s hard sometimes for my husband and I, and maybe in the future for our child. We don’t go out much, and when we do it seems our child gets sick right away. So now we’d rather stay home all winter than being in the hospital for one week. Now, having a new addition to our family, it is hard spending time with our child in the hospital. . . . But for now, we’ve been able to manage with the necessities. As the years go by it seems to get harder, but for now, we are making things work. . . . Thank you from the heart of the children whose lives you help to improve through your support.”

“Taking care of a medically complex, chronically ill child is extremely challenging. The most difficult aspect of this life is getting all the caregivers on the same page when an acute or even a planned surgery or procedure is done . . . The coordination of care between specialties is difficult. Everyone cares but time is so sparse for the doctors as well as the families. I would love to see a specialty developed just for the medically complex child/adult so there could be a central location where specialists and families could go to keep current. . . .”



COMMUNITY HEALTH ACCESS

Community Health Access (CHA)

A section of the questionnaire titled “**Community Health Access**” focused on the need for and use of 21 different kinds of health-related services. For 19 of the 21 services, the following three questions were asked. For the additional two services, all but the third question was asked.³

Question 6

For the services listed below, please circle “yes” or “no” whether your child needed the service within the last twelve months.

If the service was needed, did you use it?

For any services that you used, please tell us how much time you traveled one way to get that service.

- *Well child care (routine checkups)*
- *Primary care (minor illness, injury)*
- *Specialty care (such as neurologist/ cardiologist)*
- *Dental care (checkups, fillings)*
- *Specialty dental care (orthodontia)*
- *Emergency room services*
- *Hospital care for children (inpatient or outpatient)*
- *Immunizations*
- *Physical therapy (PT)*
- *Occupational therapy (OT)*
- *Speech therapy (ST)*
- *Early intervention services (birth to age three)*
- *Genetic testing and counseling*
- *Mental health and/or counseling services*
- *Prescription medications*
- *Medical equipment/supplies*
- *Special dietary products*

³Travel time was not asked for “in-home nursing care” nor for “home health aide.” The full list is provided below.

Question 6
continued

- *In-home nursing care - [no mileage asked]*
- *Home health aide (personal attendant) – [no mileage asked]*
- *Respite care (A break for caregivers and families. A service in which temporary care is provided to a child or adult with disabilities or chronic illness.)*

The following are several indicators of need that can be calculated from the questions asked.

Total Need: The percent of *all respondents* who expressed a need for the service in the past 12 months.

Unmet Need (i.e., “need but not use”): The percent of *all respondents* who indicated needing but not using a service. This is useful in examining the actual proportion of all respondents who have a potential unmet need.⁴

Travel Time: A need percentage based on responses to travel time when categorized into: up to 30 minutes; 31 to 60 minutes; and over 1 hour (and categorized further for some items). (The need indicator here is that which focuses on the travel time deemed to be too long for particular services.)

Response to Question 6:

The results for the Total Need percentages and for the Unmet Need percentages are presented in Table 6a for the DSCC sample and in Table 6b for the SSI sample.

The Total Need percentages for DSCC sample members range from a low of 10 percent for home health aide to a high of 74 percent for well child care. The range for SSI sample members is even greater, with a low of 8 percent for home health aide and a high of 82 percent for well child care.

Of greater importance is the percent who have a need but who did not utilize services for it (the Unmet Need percentage). The percentages here are, of course, lower, and the range is narrower.

For DSCC sample members, this Unmet Need percentage ranges from a low of 2.5 percent to a high of 8.6 percent. Showing the most unmet need is dental care (8.6%) followed by respite care (6.6%) and then specialty dental care (5.9%) and speech therapy (5.3%). The remaining items have Unmet Need percentages less than 5 percent, and the order can be seen in Table 6a.

⁴ Another measure is that of looking at the unmet need proportion, relative to the total number *expressing* a need. It was decided to focus on unmet need as a percentage of all respondents in this summary.

For SSI sample members, this Unmet Need percentage ranges from a low of less than 1 percent to a high of 8.4 percent. Showing the most unmet need is respite care (8.4%) followed by speech therapy (7.3%) and specialty dental care (7.3%). These in turn are followed by occupational therapy (5.8%) and physical therapy (5.8%). The remaining items have Unmet Need percentages less than 5 percent, and the order can be seen in Table 6b.

*Question 6a - DSCC SAMPLE
Selected Health Access Service Items,
Ordered by Unmet Need Percentage**

Health Access Item	Total Need	Need / Use	Need / Not Use*
DSCC SAMPLE (n = 4140)			
Dental care	63.5%	53.4%	8.6%
Respite care	19.2%	11.5%	6.6%
Specialty dental care	22.4%	15.6%	5.9%
Speech therapy	42.6%	34.0%	5.3%
Occupational therapy	36.0%	28.7%	4.8%
Physical therapy	41.8%	35.0%	4.3%
Primary care	67.7%	62.6%	3.7%
Home health aide	10.4%	5.6%	3.7%
Well child care	73.9%	68.6%	3.5%
Nutritional counseling	16.8%	12.5%	3.5%
Mental health/counseling	12.6%	8.6%	3.4%
Prescription medications	72.2%	66.3%	3.1%
Genetic testing	12.3%	8.7%	2.9%
In-home nursing care	11.8%	8.1%	2.9%
Specialty care	68.1%	63.9%	2.8%
Immunizations	40.7%	34.2%	2.8%
Emergency room care	33.9%	30.2%	2.7%
Special dietary products	18.5%	14.8%	2.7%
Early intervention services	19.9%	15.8%	2.6%
Medical equipment/supplies	46.7%	41.7%	2.5%
Hospital care	41.3%	37.5%	2.5%

Table 6a

*The Unmet Need Percentage is the percentage of all respondents who reported having a need but who did not use the service. Note that the sum of "Need/Use" and "Need/Not Use" does not equal the "Total Need" percentage because it could not be determined whether some respondents who needed a service actually had used it.

*Question 6b - SSI SAMPLE
Selected Health Access Service Items,
Ordered by Unmet Need Percentage**

Health Access Item	Total Need	Need / Use	Need / Not Use*
SSI SAMPLE (n = 191)			
Respite care	12.6%	3.7%	8.4%
Speech therapy	55.4%	45.5%	7.3%
Dental care	39.2%	30.9%	7.3%
Occupational therapy	47.7%	39.8%	5.8%
Physical therapy	45.6%	38.2%	5.8%
Early intervention services	44.0%	37.2%	4.7%
Nutritional counseling	27.7%	22.5%	4.7%
Specialty dental care	12.5%	7.3%	4.7%
Well child care	81.7%	77.5%	3.7%
Mental health/counseling	18.8%	15.2%	3.1%
Home health aide	7.8%	4.2%	3.1%
Immunizations	70.2%	61.3%	2.6%
In-home nursing care	18.9%	14.7%	2.6%
Special dietary products	15.7%	12.6%	2.6%
Prescription medications	69.6%	66.5%	2.1%
Primary care	62.3%	58.6%	2.1%
Medical equipment/supplies	41.9%	37.7%	2.1%
Genetic testing	19.3%	16.2%	2.1%
Hospital care	54.0%	50.3%	1.6%
Specialty care	51.9%	50.3%	1.6%
Emergency room care	52.9%	50.3%	0.5%

Table 6b

*The Unmet Need Percentage is the percentage of *all respondents* who reported having a need but who did not use the service. Note that the sum of “Need/Use” and “Need/Not Use” does not equal the “Total Need” percentage because it could not be determined whether some respondents who needed a service actually had used it.

Travel Time for Services

The results for how long it took to travel for the respective services *among those who used the service and who gave a travel time response* are presented in Table 6c for the DSCC sample and in Table 6d for the SSI sample. (The percentage who indicated using the service is also reported in these tables.)

Note that in these tables, the total percentage who said it took more than one hour is presented along with a breakdown into those who said: more than one hour up to two hours; more than two hours up to three hours; and more than three hours.

For the SSI sample results, be particularly careful in making too much of results where the respondent number is less than 30.

For DSCC sample members who used the respective service, travel time exceeds one hour for about half of those using respite care (51%), and proportions nearing or exceeding 40 percent for: specialty care (45%), genetic testing (42%), and hospital care (39%). The percent who traveled more than one hour approaches one-third for nutritional counseling (32%), approaches one-quarter for specialty dental care (24%), and is about one-fifth for medical equipment/supplies (20%). The order of the other items, by percent who traveled more than one hour, can be seen in Table 6c.

For SSI sample members who used the respective service (and when at least 30 gave travel time responses), travel time exceeds one hour for about 40 percent of those using specialty care (41%); for about one-quarter of those using hospital care (27%) and medical equipment/supplies (24%); and for around one-fifth of those using emergency room care (21%), well child care (20%), occupational therapy (19%), speech therapy (18%), and physical therapy (18%). The order of the other items, by percent who traveled more than one hour, can be seen in Table 6d.

*Question 6c – DSCC SAMPLE
Selected Health Access Service Items,
Ordered by Percent Who Traveled More than One Hour to Use*

Health Access Item	Need / Use*	Used: Up to 30 mins	Used: 31 to 60 mins	Used: Total over 1 hour	Used: >1 to 2 hrs	Used: >2 to 3 hrs	Used: >3 hrs	n
DSCC SAMPLE (n=4140)								
Respite care	11.5%	36.8%	12.3%	<i>51.0%</i>	12.3%	3.2%	35.5%	155
Specialty care	63.9%	23.8%	31.2%	<i>45.0%</i>	28.4%	10.6%	6.0%	2564
Genetic testing	8.7%	25.1%	32.7%	<i>42.3%</i>	30.2%	8.3%	3.8%	315
Hospital care	37.5%	31.6%	29.3%	<i>39.1%</i>	23.3%	9.0%	6.8%	1460
Nutritional counseling	12.5%	36.9%	31.2%	<i>31.9%</i>	21.7%	6.9%	3.3%	420
Specialty dental care	15.6%	46.9%	29.6%	<i>23.5%</i>	18.0%	3.5%	2.0%	605
Medical equipment/supplies	41.7%	51.2%	29.1%	<i>19.7%</i>	13.7%	3.5%	2.5%	983
Early intervention services	15.8%	64.9%	19.2%	<i>15.9%</i>	10.1%	2.4%	3.4%	208
Mental health/counseling	8.6%	60.7%	25.0%	<i>14.2%</i>	9.7%	1.9%	2.6%	308
Well child care	68.6%	63.6%	22.7%	<i>13.7%</i>	9.4%	2.6%	1.7%	2718
Dental care	53.4%	65.1%	22.6%	<i>12.3%</i>	9.5%	1.6%	1.2%	2126
Emergency room care	30.2%	68.6%	20.9%	<i>10.5%</i>	5.9%	1.6%	3.0%	1199
Primary care	62.6%	70.0%	20.7%	<i>9.3%</i>	6.5%	1.5%	1.3%	2479
Physical therapy	35.0%	70.7%	21.5%	<i>7.9%</i>	5.1%	0.7%	2.1%	907
Occupational therapy	28.7%	71.4%	21.7%	<i>6.9%</i>	4.7%	0.3%	1.9%	695
Speech therapy	34.0%	72.5%	19.2%	<i>8.3%</i>	5.0%	1.0%	2.3%	817
Special dietary products	14.8%	77.2%	16.7%	<i>6.1%</i>	2.2%	1.4%	2.5%	276
Immunizations	34.2%	77.2%	19.2%	<i>3.7%</i>	2.7%	0.6%	0.4%	1300
Prescription medications	66.3%	89.3%	7.1%	<i>3.6%</i>	1.7%	0.7%	1.2%	2396
In-home nursing care	8.1%	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	
Home health aide	5.6%	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	

Table 6c

*The Need/Use percentage is slightly higher than the number responding to the miles traveled question because of some respondents who did not respond to the latter. They are not counted in the miles traveled percentage results reported.

*Question 6d – SSI SAMPLE
Selected Health Access Service Items,
Ordered by Percent Who Traveled More than One Hour to Use*

Health Access Item	Need / Use**	Used: Up to 30 mins	Used: 31 to 60 mins	Used: total over 1 hour	Used: >1 to 2 hrs	Used: >2 to 3 hrs	Used: >3 hrs	n
SSI SAMPLE (n=191)								
Specialty care	50.3%	29.3%	29.3%	41.3%	28.3%	7.6%	5.4%	92
Genetic testing	16.2%	33.3%	28.6%	38.1%	14.3%	4.8%	19.0%	21*
Hospital care	50.3%	40.9%	31.8%	27.2%	19.3%	6.8%	1.1%	88
Medical equipment/supplies	37.7%	57.6%	18.2%	24.2%	24.2%	0.0%	0.0%	33
Mental health/counseling	15.2%	59.1%	18.2%	22.7%	18.2%	4.5%	0.0%	22*
Nutritional counseling	22.5%	48.1%	29.6%	22.2%	14.8%	3.7%	3.7%	27*
Emergency room care	50.3%	55.6%	23.3%	21.1%	15.6%	3.3%	2.2%	90
Well child care	77.5%	55.3%	24.1%	20.5%	17.0%	2.1%	1.4%	141
Occupational therapy	39.8%	51.4%	29.7%	18.9%	13.5%	5.4%	0.0%	37
Speech therapy	45.5%	61.5%	20.5%	18.0%	7.7%	7.7%	2.6%	39
Physical therapy	38.2%	52.9%	29.4%	17.6%	14.7%	2.9%	0.0%	34
Early intervention services	37.2%	59.4%	25.0%	15.6%	12.5%	3.1%	0.0%	32
Primary care	58.6%	67.9%	21.7%	10.3%	9.4%	0.0%	0.9%	106
Specialty dental care	7.3%	50.0%	40.0%	10.0%	10.0%	0.0%	0.0%	10*
Dental care	30.9%	69.4%	22.4%	8.2%	8.2%	0.0%	0.0%	49
Immunizations	61.3%	70.2%	22.1%	7.6%	3.8%	1.9%	1.9%	104
Prescription medications	66.5%	81.5%	13.0%	5.5%	3.7%	0.9%	0.9%	108
Special dietary products	12.6%	85.7%	14.3%	0.0%	0.0%	0.0%	0.0%	14*
Respite care	3.7%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	2*
In-home nursing care	14.7%	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	
Home health aide	4.2%	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	<i>not asked</i>	

Table 6d

*Be careful in placing much credence in these results since the number responding is less than 30.

**The Need/Use percentage is slightly higher than the number responding to the miles traveled question because of some respondents who did not respond to the latter. They are not counted in the miles traveled percentage results reported.

What Families Wrote . . .

About Community Health Access

“I would like to know if anyone can find a respiratory therapist that comes out to my home once a week, just like early intervention.”

“My pediatrician is excellent. I am not happy with the amount of times I have been forced to change neurologists . . . now having to travel one hour each direction for typically a 10-15 minute appointment. Most services are available through his/her school (i.e., PT, OT, speech, vision, etc.) . . . The only thing I have problems with is finding a dentist for him/her. He/she never has been to one and he/she really needs to go. All I have to say is if it wasn't for DSCC my child would not have the things he/she has today.”

“Our biggest concern right now is behavior and we've had a difficult time getting help. . . . There isn't a good system to help keep kids in their homes vs. institutions. In our case, the alternative for my child is hospitalization. There are also very few pediatric dentists, therapists that are Medicaid providers.”

“My child has insurance but it is not covered dental service. My child is (in school) now (and) needs dental services...”

“All I want is special doctors to be closer to home! (City) is too far away and I don't understand why all the best doctors are not in all areas besides (City)!!!! We need more specialists . . . in every area.”

“I am interested to take my child for further checkups . . . but, I don't have available car which reaches (City) and I am not familiar (with) (City) places.”

“My child has had a medical card which is secondary after my health insurance and DSCC picks up 3rd for my special needs child. I don't know of a caseworker that will help me unless I call DSCC. I need info on respite, personal assistance and doctors closer to home. Now my (spouse) has been out of work since (date) and was diagnosed with (a chronic illness.) We need a break. I need more info on transition since my child is almost (a teenager).”



CARE COORDINATION

Care Coordination (CC)

A section of the questionnaire titled “**Care Coordination**” focused on “how often [the respondent] ask[s] for help from someone (for example, your DSCC care coordinator, your physician, a local community agency staff person, school personnel, a state agency staff person, etc.) regarding each” of 22 different kinds of help.

Respondents were asked how often they had done so in the last twelve months. They were asked to respond using the categories of: *often*; *sometimes*; *rarely*; and *never*. A category of “*does not apply*” was also included.

Question 7

In the last twelve months, how often did you ask for help from someone (for example, your DSCC care coordinator, your physician, a local community agency staff person, school personnel, a state agency staff person, etc.) regarding each of the following? (please circle the answer that best applies)

- Finding specialty medical care for treatment of your child’s health problem
- Finding a primary care doctor who treats your child for common illnesses or routine checkups
- Finding medical equipment or supplies for your child
- Finding speech therapy services for your child
- Finding physical therapy services for your child
- Finding occupational therapy services for your child
- Finding routine dental care for your child
- Talking to your child’s medical providers
- Understanding the medical treatment plan for your child’s health condition
- Understanding the changes in your child’s medical condition
- Talking to your insurance company so your child could get medical care

*Question 7
continued*

- Understanding the rules of your insurance for your child
- Talking to KidCare/Medicaid (Medical Card) staff so your child could get medical care
- Understanding the rules of KidCare/Medicaid (Medical Card)
- Learning your child's rights for early intervention
- Meeting with your child's early intervention providers to help decide on your child's needs
- Meeting with your child's school to help the teachers plan for your child's special needs
- Learning your child's rights for school
- Helping your child get special school services
- Learning about services in your community that may help your child or family
- Finding a family you can talk to who has a child with a medical condition like your child
- Learning where to find help for other basic needs (food, housing, etc.)

Response to Question 7:

The results for the DSCC and the SSI samples are reported in Table 7a and Table 7b, respectively. Coordination items are ordered by the percent of respondents who answered "often." Note the percentage results for the "often" to "never" responses are based on all those who gave a substantive response to the items. Presented at the right-most side are the percentages who indicated the item "did not apply" and who did not answer. These percentages are based on all sample members.

Education/school and medical providers/condition are two common themes in the assistance items for which help is most commonly sought.

For DSCC respondents, the assistance item with the highest percent of relevant respondents saying they "often" ask for help relates to meeting with [your] child's school to help the teachers plan for the child's special needs, with nearly 40 percent (38%) of the relevant respondents saying they have "often" asked for help in this area in the past twelve months. This is followed by five additional assistance items for which 30 percent of the DSCC respondents said they "often" asked for help: helping your child get special school services

(33%); talking to medical providers (30%); understanding changes in the child's medical condition (28%); learning the child's rights for school (28%); and understanding the child's medical treatment plan (28%). Four additional items received "often" responses by about one-fifth of the respondents: finding specialty medical care; understanding insurance rules; talking to insurance to get care; and meeting with early intervention providers.

SSI respondents are generally more prone to have sought help across the board than DSCC respondents have been. More than half of the SSI relevant respondents indicated they have "often" sought help for three assistance items: understanding their child's medical treatment plan (56%); understanding changes in their child's medical condition (54%); and talking to medical providers (51%). Almost one-half said so for two additional items: meeting with the school to help teachers plan for their child's special needs (49%); and helping their child get special school services (47%). More than 40 percent had "often" asked for help with two further items: learning their child's rights for school (43%); and finding specialty medical care (42%).

*Question 7a - Selected Care Coordination Items,
Ordered by the Percent Saying “Often” Ask for Help*

DSCC Sample

Type of Help	Often	Some- times	Rarely	Never	N	Does Not apply	No answer	n
DSCC Sample								
Meeting w/school to help teachers plan	38.3%	30.8%	11.2%	19.7%	3346	17.1%	2.1%	4140
Helping child get special school services	32.9%	28.1%	13.8%	25.3%	3272	18.7%	2.3%	4140
Talking to medical providers	30.2%	28.0%	12.3%	29.5%	3681	7.7%	3.4%	4140
Understanding changes in med condition	28.3%	26.9%	16.1%	28.6%	3629	9.6%	2.7%	4140
Learning child's rights for school	28.3%	27.8%	15.3%	28.6%	3298	17.9%	2.4%	4140
Understanding med treatment plan	28.2%	27.1%	16.3%	28.4%	3690	8.2%	2.7%	4140
Finding specialty medical care	19.9%	30.4%	18.4%	31.3%	3574	10.0%	3.7%	4140
Understanding insurance rules	19.8%	25.4%	18.9%	35.9%	3417	14.4%	3.1%	4140
Talking to insurance to get care	19.7%	24.6%	18.8%	36.9%	3409	15.2%	2.5%	4140
Meeting with early intervention providers	19.6%	23.3%	14.5%	42.6%	2585	34.2%	3.4%	4140
Learning about community services	16.8%	24.6%	21.6%	37.1%	3599	10.9%	2.1%	4140
Finding medical equipment/supplies	16.0%	26.6%	17.1%	40.2%	3303	17.1%	3.1%	4140
Learning child's rights/early intervention	14.5%	18.8%	17.2%	49.5%	2657	32.5%	3.4%	4140
Finding speech therapy services	14.1%	13.7%	13.5%	58.6%	3019	24.0%	3.1%	4140
Talking to KC/Medicaid staff to get care	12.4%	19.6%	15.9%	52.0%	2910	27.3%	2.4%	4140
Understanding KC/Medicaid rules	12.4%	19.3%	15.9%	52.5%	2805	29.2%	3.1%	4140
Finding physical therapy services	12.0%	14.9%	13.4%	59.8%	2946	25.9%	2.9%	4140
Finding routine dental care	11.1%	20.6%	15.5%	52.8%	3363	15.7%	3.1%	4140
Finding occupational therapy services	11.0%	13.0%	12.8%	63.2%	1814	27.6%	3.1%	4140
Finding primary care doctor	10.7%	15.9%	14.1%	59.3%	3436	14.0%	3.0%	4140
Where to find help for other basic needs	9.5%	16.2%	18.1%	56.2%	3278	18.8%	2.1%	4140
Finding similar family	8.1%	14.1%	19.3%	58.5%	3542	12.2%	2.2%	4140

Table 7a

*Question 7b - Selected Care Coordination Items,
Ordered by the Percent Saying “Often” Ask for Help*

SSI Sample

Type of Help	Often	Some- times	Rarely	Never	<i>n</i>		Not apply	No answer	<i>n</i>
SSI Sample									
Understanding med treatment plan	56.5%	19.2%	13.6%	10.7%	177		5.8%	1.6%	191
Understanding changes in med condition	54.1%	20.0%	13.5%	12.4%	170		8.4%	2.6%	191
Talking to medical providers	50.6%	20.5%	12.5%	16.5%	176		5.2%	2.6%	191
Meeting w/school to help teachers plan	48.8%	24.0%	7.4%	19.8%	121		34.0%	2.6%	191
Helping child get special school services	46.9%	23.8%	10.0%	19.2%	130		29.8%	2.1%	191
Learning child's rights for school	43.2%	16.8%	14.4%	25.6%	125		31.9%	2.6%	191
Finding specialty medical care	41.6%	33.1%	13.9%	11.4%	166		8.4%	4.7%	191
Meeting with early intervention providers	36.2%	28.9%	10.5%	24.3%	152		17.3%	3.1%	191
Learning child's rights/early intervention	34.6%	23.1%	14.1%	28.2%	156		14.1%	4.2%	191
Finding speech therapy services	32.9%	21.4%	11.4%	34.3%	140		23.0%	3.7%	191
Finding primary care doctor	29.0%	22.8%	16.7%	31.5%	162		11.5%	3.7%	191
Finding occupational therapy services	28.9%	20.7%	14.0%	36.4%	121		32.5%	4.2%	191
Where to find help for other basic needs	28.2%	18.4%	20.9%	32.5%	163		13.1%	1.6%	191
Learning about community services	27.8%	26.6%	21.3%	24.3%	169		10.5%	1.0%	191
Understanding KC/Medicaid rules	25.3%	23.3%	20.7%	30.7%	150		19.4%	2.1%	191
Talk to KC/Medicaid staff to get care	24.8%	23.6%	22.3%	29.3%	157		16.2%	1.6%	191
Understanding insurance rules	24.7%	23.3%	18.5%	33.6%	146		20.4%	3.1%	191
Finding physical therapy services	24.6%	23.0%	14.3%	38.1%	126		30.9%	3.1%	191
Talking to insurance to get care	23.2%	21.8%	18.3%	36.6%	142		23.6%	2.1%	191
Finding medical equipment/supplies	21.4%	25.2%	16.8%	36.6%	131		27.7%	3.7%	191
Finding routine dental care	16.7%	22.0%	15.2%	46.2%	132		27.7%	3.1%	191
Finding similar family	12.2%	11.0%	22.0%	54.9%	164		11.0%	3.1%	191

Table 7b

What Families Wrote . . .

About Care Coordination

“Need more help in school, with 504 plan and child’s personal education rights. Need an advocate or counselor who is up-to-date on Wrights Law, and the laws governing IEP’s and 504 Plans.”

“My child’s case worker is wonderful, (and) has been with (my child) since birth and has always been there for us to answer questions, help with locating doctors and even attended an IEP to help with some school related issues. Their support and professionalism and compassion is a constant and we are extremely grateful to have our (case worker) in our lives.”

“I am pleased overall with the services provided by DSCC. I understand how difficult it must be to coordinate care for special kids like mine and I appreciate the effort. Although, I feel that we are treated personally, I think it would help to be able to put a face with the name of our DSCC care coordinator and to know what their background is (i.e., nurse, therapist, etc.). I really don’t know what qualifies our coordinator to assist us and others.”

“I think that the reason we have had such a good experience with DSCC is because we work very well together with the case worker. Parents have to do their part to help the case worker help them. The case worker cannot be expected to do everything. DSCC has been a blessing to our family and has made our lives a lot more comfortable by being able to count on them. Thank you for being such a great organization. God Bless You!!!”

“At this time in our child’s life-our care coordinator gives mostly advice and direction. However, in the past we have needed financial help due to the fact we were unable to obtain medical insurance. Now we have (insurance) so there is no pre-existing. Our care coordinator has been with us since our child was (very young). I don’t know what I would have done without her. Her emotional support has been priceless. When we had no insurance, she helped our child get the best care available. We are now nearing the end of our eligibility and I will greatly miss her help and understanding. (Our care coordinator) has been our ‘angel.’ She is giving us transitional help into adult care.”

“My child has been treated for (condition) since (date) - I have had excellent support and flow of information with DSCC. My insurance or lack there of, my financial status and my life have gone through some dramatic changes in that time. I have always felt informed and resolute in conveying my child’s concerns to my DSCC representative. Also, I have dealt with the same people in that time. Having consistent knowledgeable staff is very comforting for a mother of a child with a birth defect. There are so many other obstacles to overcome. Healthcare should not be one of them.”



PAYING FOR HEALTHCARE

Paying for Healthcare (PHC)

In this section, respondents were asked a series of questions relating to how they pay for healthcare and questions about selected consequences of healthcare costs.

Question 8

Do you currently have a source(s) to help with payment of your child's medical care? (Please circle the number that best applies)

- 1 Yes***
2 No

Response to Question 8:

Respondents were first asked whether they “currently have a source(s) to help with payment of [their] child’s medical care.”

Those respondents who indicated having a current source(s) to help with payment of their child’s medical care were then asked what type of help they have.

Those who indicated health insurance and/or KidCare or Medicaid (Medical Card) were then asked whether they are in any of the following: managed care plan (Health Maintenance Organization [HMO], Preferred Provider Organization [PPO], or Point of Service [POS]).

The results are presented in Table 8. The columns “yes” and “no” include some respondents who did not actually answer the particular question but for whom a “yes” or “no” response could be inferred from their other response activity.

As seen in Table 8, over nine in ten DSCC respondents (93%) indicated they currently have a source to help with payment of their child’s medical care. Nearly 7 percent indicated they do not (combining the “inferred no” and “no” results). On the other hand, somewhat fewer than nine in ten SSI respondents (87%) indicated they currently have such a source while nearly 12 percent indicated they do not.

Question 8 - Current Incidence of Having a Source to Help with Payment of Child's Medical Care

Currently have source to pay for medical care?	Yes	No	na	n
DSCC surveys	92.6%	6.9%	0.5%	4140
SSI surveys	87.0%	11.5%	1.6%	191
As reported in survey:				
Only DSCC services	94.1%	5.6%	0.4%	2556
Only SSI benefits	87.9%	10.7%	1.3%	224
Both	92.3%	7.3%	0.4%	1262

Table 8

Question 8a

If yes, what type(s) of help do you have? (Please circle ALL number(s) that apply)

- 1 Health insurance**
- 2 KidCare or Medicaid (Medical Card)**
- 3 DSCC**
- 4 Don't Know**
- 5 Other (describe)**

Response to Question 8a:

Those respondents who indicated having a source(s) to help with payment of their child's medical care were then asked what type of help they have. The results are presented in Table 8a. Note the column "Health Insurance or KC/MC." These are respondents who did not answer this question but whose response to the next item indicated they have either health insurance or KidCare/Medicaid.

*Question 8A: Type(s) of Sources to Help with Payment of Child's Medical Care
[among those having a source(s) of help]*

What types of help do you have? (among those who have help)	Health Insur	KidCare or Medicaid	Health Insur or KC/MC (not specified)	DSCC	Other	dk	n
DSCC surveys	53.3%	44.2%	3.7%	63.9%	4.5%	0.4%	3834
SSI surveys	22.9%	75.9%	2.4%	12.7%	7.2%	0.0%	166
As reported in surveys:							
Only DSCC services	65.1%	31.3%	4.3%	71.5%	3.5%	0.1%	2404
Only SSI benefits	22.8%	74.6%	4.1%	5.1%	6.1%	0.5%	197
Both	28.2%	73.1%	1.9%	60.7%	6.1%	0.8%	1165

Table 8a

Among the respondents currently having a financial source to help pay for their child's medical care, the most common source identified by DSCC respondents is DSCC (64%) followed by health insurance (53%) and then KidCare or Medicaid (44%). For SSI respondents, the most common source is KidCare or Medicaid (76%) followed by health insurance (23%) and then DSCC (13%).

Question 8b

If you circled one or two in the above question (8a) (Health Insurance, KidCare or Medicaid), are you in a managed care plan Health Maintenance Organization [HMO], Preferred Provider Organization [PPO], Point of Service [POS]? (Please circle the number that best applies.)

- 1 Yes.**
- 2 No**
- 3 Don't Know**

Response to Question 8b:

Those respondents who indicated either health insurance or KidCare or Medicaid were then asked whether or not they are in a managed care plan (HMO, PPO or POS). The results are presented in Table 8b.

Of those DSCC respondents with insurance or KidCare/Medicaid, nearly six in ten (59%) indicated they are in a managed care plan. The incidence for SSI respondents is far lower, at just under one-third (32%).

*Question 8b: Is Respondent in Managed Care Plan?
(among those with insurance or KidCare/Medicaid)*

Is it HMO, PPO or POS?	Yes	No	dk	na	n
DSCC surveys	59.1%	20.6%	16.5%	3.9%	3505
SSI surveys	32.3%	43.9%	19.4%	4.5%	155
As reported in surveys:					
Only DSCC services	70.8%	14.3%	12.2%	2.8%	2216
Only SSI benefits	32.6%	42.9%	19.0%	5.4%	184
Both	33.0%	35.0%	26.2%	5.8%	1049

Table 8b

Question 9

Has your source or type of financial help changed within the last twelve months? (Please circle the number that best applies.)

- 1 Yes***
2 No

Response to Question 9:

All sample members were first asked whether or not “their source or type of financial help changed within the last twelve months.”

Those whose source/type of help had changed were then asked whether they had to change doctors or other medical providers as a result of this change.

Those who had to change doctors/medical providers were then asked how this affected their child’s care, with the options being: care is better now; care is worse now; no effect on care.

Whether source or type of financial help changed within the last 12 months. *The table.* The results are found in Table 9. The columns “yes” and “no” again include some respondents who did not actually answer the particular question but for whom a “yes” or “no” response could be inferred from their other response activity.

About one-quarter (25%) of the DSCC sample members indicated they have had to change their source of financial help in the last twelve months. More than four in ten (44%) SSI respondents have had to do so.

*Question 9 - Incidence of Changes in Sources of Help
Within Last Twelve Months?*

	Yes	No	na	n
DSCC surveys	25.3%	74.1%	0.7%	4140
SSI surveys	43.5%	55.0%	1.6%	191
As reported in surveys:				
Only DSCC services	26.4%	73.1%	0.5%	2556
Only SSI benefits	31.2%	67.4%	1.3%	224
Both	23.7%	75.4%	1.0%	1262

Table 9

Question 9a

If yes, have you had to change doctors or other medical providers as a result of this change?

- 1 Yes*
- 2 No*

Response to Question 9a:

Those respondents who indicated their source of financial help had changed were then asked whether they have “had to change doctors or other medical providers as a result of this change.” The results are found in Table 9a. The “yes” column includes some respondents who did not explicitly answer the question but for whom a “yes” could be inferred from their other response behavior.

For those who indicated their source of financial help had changed, almost four in ten (38%) DSCC respondents indicated they had to change doctors as a result of this change. Just over one-quarter (26%) of SSI respondents in similar circumstances reported having had to change doctors.

*Question 9a - Had to Change Doctors / Providers
as a Result of Change in Help Source(s)?*

Had to change doctors / providers because of change in source(s) of help?	Yes	No	na	n
DSCC surveys	37.8%	68.6%	3.6%	1044
SSI surveys	26.2%	71.1%	2.4%	83
As reported in surveys:				
Only DSCC services	27.1%	69.7%	3.3%	676
Only SSI benefits	22.9%	75.7%	1.4%	70
Both	29.9%	65.1%	5.0%	298

Table 9a

Question 9b

If you have had to change doctors or other medical providers, how did this affect your child’s care?

- 1 Care is Better Now*
- 2 Care is Worse Now*
- 3 No Effect on Care*

Response to Question 9b:

Those respondents who indicated they have had to change doctors/medical providers were asked how this affected their child's care. Options presented were: "care is better now"; "care is worse now"; and "no effect on care." (See Table 9b)

For the DSCC respondents who had to change doctors/providers, a large plurality of about 46 percent reported the change had no effect on care, but more of them reported the care was worse now than reported it was better now (28% vs. 16%). (There are too few SSI respondents in these circumstances for the results to be meaningful.)

Question 9b - Effect on Child's Care if Had to Change Doctors / Providers as a Result of Change in Help Source(s)?

Effect on care	Care better now	Care worse now	No effect on care	na	n*
DSCC surveys	16.2%	27.9%	45.9%	10.0%	290
SSI surveys	40.9%	13.6%	40.9%	4.5%	22
As reported in surveys:					
Only DSCC services	16.9%	31.1%	43.2%	8.7%	183
Only SSI benefits	37.5%	12.5%	37.5%	12.5%	16
Both	18.0%	18.0%	56.2%	7.9%	89

Table 9b

Question 10

During the last twelve months, approximately how much have you paid "out of pocket" for your child's medical care? (Please check the answer which best applies)

Less than \$250

\$251 - \$500

\$501 - \$1,000

\$1,001 - \$5,000

More than \$5,000

Don't Know

Nothing

All sample members were next asked "approximately how much [they] have paid "out of pocket" for [their] child's medical care."

Response to Question 10:

The results are presented in Table 10. Note that while "nothing" appeared last in the response items in the actual questionnaire, it is presented first in this table. Also note that some respondents who paid nothing might have checked "less than \$250", the first response item, rather than reading through the whole list. Thus, it is useful to combine the first two categories ("nothing" and "less than \$250"), and this has been done in Table 10.

A plurality of DSCC respondents (44%) reported up to \$250 (including “nothing”) of “out of pocket” medical expenses during the past twelve months. Quite similar percentages reported spending \$251 to \$500 (15%), \$501 to \$1000 (12%), and \$1001 to \$5000 (14%), while about 3 percent reported spending more than \$5000. About 12 percent did not know or did not answer.

SSI sample members reported spending less “out of pocket” than did DSCC sample members, with over half (56%) of them reporting they spent up to \$250 (including “nothing”). Nearly one in ten reported (9%) spending \$250 to \$500, more than one in twenty (6%) reported spending \$501 to \$1000, and about one in ten (10%) reported spending \$1001 to \$5000. Nearly 3 percent reported spending more than \$5000. About 15 percent either did not know or did not answer the question.

Comparison with Illinois results from national survey. In the Illinois module of the national survey of households with children with special healthcare needs conducted from April 2000 through October 2002, respondents were also asked about their out-of-pocket expenses for their child’s healthcare. In this survey, just over one-fifth (22%) reported spending less than \$500; just over one-third (35%) reported spending between \$500 and \$999; and 38 percent reported spending \$1000 or more.⁵ While the response ranges do not exactly match, it is apparent that, compared to the Illinois respondents in the earlier national survey, a substantially greater proportion of both DSCC and SSI respondents in the current survey reported spending less than \$500 while substantially fewer of them reported expenditures in the two higher category ranges.

⁵ The survey cited is the National Survey of Children with Special Healthcare Needs. Results are from the Illinois module of the State and Local Area Integrated Telephone Survey. The results cited were reported by Deborah Rosenberg, Charles Onufer, Gerri Clark, Thomas Wilkin, Kristin Rankin, and Kristina Gupta, in “The Need for Care Coordination Among Children with Special Healthcare Needs,” *Maternal and Child Health Journal*, Vol. 9S, No. 2, June 2005, pp. S41-S47. In the article (Table III, page S45), the latter category actually reads “more than \$1000.” However, because the second category reads \$500 to \$999, this latter category is probably meant to be \$1000 or more.

*Question 10 - Approximate Amount Paid “Out of Pocket” for Child’s Medical Care
During the Last Twelve Months*

Pay out of pocket for medical care in past 12 months	Nothing	Less than \$250	Nothing to \$250*	\$251 - \$500	\$501- \$1000	\$1001- \$5000	More than \$5000	dk	na	n
DSCC surveys	18.6%	25.7%	44.3%	14.7%	11.8%	14.0%	2.7%	8.6%	3.9%	4140
SSI surveys	37.2%	18.8%	56.0%	9.4%	6.3%	10.5%	2.6%	10.5%	4.7%	191
As reported in surveys:										
Only DSCC services	12.3%	26.4%	38.7%	16.6%	13.9%	16.4%	3.1%	8.2%	3.2%	2556
Only SSI benefits	35.7%	17.0%	52.7%	12.5%	6.3%	12.5%	0.9%	9.8%	5.4%	224
Both	31.4%	26.9%	58.3%	11.0%	7.7%	7.2%	1.4%	9.5%	4.8%	1262

Table 10

*This is the combination of the percentages for “nothing” and “less than \$250.”

Question 11

In the last twelve months, was the cost of medical care a major factor in deciding whether your child received medical care?

- 1 *Yes*
- 2 *No*
- 3 *Don't Know*

Response to Question 11:

Less than one in five (17%) DSCC sample members reported that the cost of medical care was a major factor in deciding whether their child received care in the last twelve months. The result for SSI sample members is only slightly higher, still at just less than one in five (19%).

Question 11 - Incidence of Cost of Medical Care Being a Major Factor in Deciding Whether Child Received Care in Last Twelve Months

Was medical care cost a major factor in whether child received care?	Yes	No	dk	na	n
DSCC surveys	17.3%	74.9%	6.4%	1.4%	4140
SSI surveys	19.4%	70.2%	8.4%	2.1%	191
As reported in surveys:					
Only DSCC services	19.0%	75.0%	4.9%	1.1%	2556
Only SSI benefits	15.6%	72.8%	8.9%	2.7%	224
Both	13.8%	75.9%	8.9%	1.4%	1262

Table 11

Question 12

In the last twelve months, was your child denied healthcare because you couldn't pay?

- 1 *Yes*
- 2 *No*
- 3 *Don't Know*

Response to Question 12:

About one in twenty (5%) DSCC sample members reported their child was denied healthcare because they could not pay in the last twelve months. The result for SSI sample members is virtually the same (5%).

*Question 12 - Incidence of Child Being Denied Healthcare
Because Couldn't Pay in Last Twelve Months*

Child denied care because couldn't pay?	Yes	No	dk	na	n
DSCC surveys	5.1%	91.8%	2.1%	1.0%	4140
SSI surveys	5.2%	88.5%	2.6%	3.7%	191
As reported in surveys:					
Only DSCC services	4.7%	92.8%	1.7%	0.7%	2556
Only SSI benefits	3.6%	92.0%	1.8%	2.7%	224
Both	6.2%	89.9%	2.5%	1.4%	1262

Table 12

Question 13

Has your family had to do without necessities because of the costs of your child's medical care?

- 1 Yes**
- 2 No**
- 3 Don't Know**

Response to Question 13:

The results are presented in Table 13. Note that this question did not explicitly contain a time frame (such as "in the last 12 months"), but it does come after two questions which did explicitly contain this time frame.

Less than one in five (16%) DSCC sample members reported that their family has gone without necessities because of the cost of medical care in the last twelve months. The result for SSI sample members is only slightly higher, still at just less than one in five (19%).

*Question 13 - Has Family Gone Without Necessities
Because of Cost of Medical Care?*

Family had to do without necessities because of medical care costs?	Yes	No	dk	na	n
DSCC surveys	16.3%	76.6%	4.9%	2.2%	4140
SSI surveys	18.8%	73.8%	4.7%	2.6%	191
As reported in surveys:					
Only DSCC services	16.6%	76.6%	5.0%	1.9%	2556
Only SSI benefits	16.5%	77.2%	3.6%	2.7%	224
Both	15.0%	77.3%	4.6%	3.1%	1262

Table 13

What Families Wrote . . .

About Paying for Healthcare

“The continuing cost of providing outside therapies is of concern to us. As my (spouse) works for a small company and on commission, our income fluctuates. I'm employed part-time, but not enough to have healthcare benefits. This is an issue for our family, not just for our special needs child. When our financial situation worsened we applied for and received approval for DSCC assistance. For the most part we manage the therapies and doctor visits. Sometimes there is a lack of communication about number of visits covered - especially after a surgery rehab. We have had unanticipated out of pocket expenses . . . because of lack of coverage (insurance and DSCC).”

“Maintaining healthcare for our child has been difficult. Every few years, (my child) needs expensive testing or surgery. Each time this has occurred, we have received enormous increases in insurance premiums, forcing us to look for other coverage. Now, since (condition) as well as expensive medication prescribed, no insurance company will take (my child). If I can keep up the new premiums, we are OK for now. However, I have had to stop my insurance because I cannot pay for mine and (my child's). We all need dental care, but again costs are prohibitive. Because I work part-time, we are not accepted by KidCare. Section 8 Housing Vouchers will help our budget but they are not ever taking names for a waiting list.”

“Medical costs are a great concern when you have a child with any special needs. Even with health insurance, it becomes costly and you don't want to be turned down for services. Also, filling out the endless paperwork to get things covered can be overwhelming. Parents need help in managing these things. The best resources for information are parents themselves and setting up and supporting more support groups. Thank you.”

“My (child's) only plan for medical care this year was the need for (therapy). Since our (specialist) left the area, I had our family physician order the (therapy). Our insurance started charging a co-pay for each appt. which left us a bill of \$120 a month to pay. When I contacted DSCC . . . to see if we could get help paying it, we were told that the therapy had to be ordered by a specialist or they wouldn't pay it. By that time I had not found a specialist . . . within our list of insurance doctors. We have found one and then couldn't get in until (date). Now we are stuck with (over \$1000) in co-pays. We skipped (month) for therapy because we felt intimidated that the therapist knew we weren't paying.”



SERVICE BARRIERS

Service Barriers (SB)

In the section titled, “Service Barriers,” respondents were asked to “tell us about things that get in the way of your use of services for your child.” Respondents were presented with 20 items to check. The respondents were also offered the opportunity to check “none of the above.” If they answered “none of the above,” they were instructed to identify “any other things that get in the way of your use of services for your child.”

In the last twelve months, what problems, if any, have you had in getting healthcare for your child?

Question 14

- *medical care providers don't share information with each other*
- *medical care providers didn't know about or didn't refer my child to available resources/services*
- *inconvenient office hours*
- *medical care providers don't include me in making decisions about my child's needs*
- *medical care providers don't communicate in my language*
- *delays in getting appointments when my child needs care*
- *delays in returning my telephone calls when I seek medical advice*
- *using an emergency room where doctors and nurses aren't used to taking care of a child with my child's condition*
- *needed service is too far from home*
- *don't have or can't afford transportation to services*
- *cannot travel due to my child's condition*
- *care is not covered by insurance*
- *my child's KidCare/Medicaid (Medical Card) is not accepted*
- *my child does not have health insurance*
- *waiting time in the doctor's office is too long*
- *my insurance or KidCare/Medicaid (Medical Card) prior approval process delays getting care in a timely manner*
- *getting needed paperwork done by my doctor*

Question 14
continued

- *difficulty getting or paying for medications due to my insurance requirements*
- *doctors don't know how to treat my child's medical condition*

Response to Question 14:

The results are presented in Table 14, with the service barriers ordered by DSCC sample results.

On the whole, SSI sample members identified somewhat more barriers than did DSCC sample members. Two pieces of evidence support this generalization. First, three-quarters (75%) of SSI sample members identified at least one barrier, somewhat more than 63 percent of DSCC sample members who did such. And second, *for those sample members who did identify a barrier*, the SSI respondents on average identified somewhat more barriers than did DSCC respondents. (The SSI average percentage across the listed barriers is about 19 percent compared to nearly 15 percent for DSCC respondents.)

For DSCC sample members who identified barriers, two barriers were identified by just over one-quarter: the needed service is too far from home (27%); and the care is not covered by insurance (26%). Two additional barriers were identified by about one-fifth: the waiting time in the doctor's office is too long (23%); and delays in returning phone calls (20%). Four additional barriers were identified by 17 to 18 percent of these DSCC sample members; another four barriers were identified by 15 to 16 percent; and still another five barriers were identified by 8 to 12 percent of them. (For the latter particular barriers, see Table 14 where the DSCC barriers are presented in order.)

For SSI sample members who identified barriers, four barriers were identified by more than three in ten: transportation – not have/afford (38%); the waiting time in the doctor's office is too long (35%); delays in getting appointments (34%); and the needed service is too far from home (33%). Another two barriers were identified by nearly this number: providers don't know or don't refer the child to available services (29%); and delays in returning phone calls (28%). About one in five respondents identified another three barriers: providers don't share information (23%); KidCare or Medicaid is not accepted (22%); and approval process delays by insurance companies (20%).

Three additional barriers were identified by 16 to 17 percent of these SSI respondents [inconvenient office hours (17%); using ER where staff is not used to take care of the child's condition (16%); and difficulty getting payment for medications due to insurance requirements (16%)].

And five additional barriers were identified by 10 to 13 percent of these SSI respondents [the care is not covered by insurance (13%); doctors don't know how to treat the condition (12%); providers don't include the respondent in decisions (11%); the child doesn't have health insurance (10%); and getting needed paperwork from the doctor (10%)].

*Question 14 - Service Barriers for DSSC-Related Respondents,
Ordered by Barriers Identified by DSCC Sample*

Service Barriers	Sample		Respondent Reports		
	DSCC	SSI	Only DSCC Services	Only SSI Benefits	Both DSCC & SSI
<i>Percent of all choosing any barrier</i>	63.3%	74.9%	61.9%	65.6%	68.7%
<i>n</i>	4140	191	2556	224	1262
<i>Of those choosing barriers:</i>					
Needed service too far from home	27.0%	32.9%	24.0%	37.4%	31.5%
Care not covered by insurance	26.5%	12.6%	30.7%	16.3%	16.1%
Waiting time in doctor's office too long	22.7%	35.0%	20.6%	29.9%	27.2%
Delays in returning phone calls	19.6%	28.0%	18.9%	32.7%	20.4%
Delays in getting appointments	17.8%	34.3%	18.2%	32.7%	17.6%
Inconvenient office hours	17.0%	16.8%	17.8%	16.3%	14.9%
KidCare/Medicaid not accepted	16.9%	21.7%	13.9%	24.5%	21.9%
Transportation - not have or afford	16.7%	37.8%	10.8%	27.9%	29.2%
Providers don't know / not refer child to available services	16.4%	29.4%	15.8%	28.6%	16.7%
Using ER where staff not used to taking care of condition	16.4%	16.1%	12.8%	15.6%	23.2%
Providers don't share info	16.3%	23.1%	15.9%	23.8%	16.8%
Difficulty getting paying for medications due to insur reqs	14.8%	16.1%	15.3%	17.0%	12.7%
Doctors don't know how to treat condition	11.8%	11.9%	10.8%	12.9%	12.8%
Approval process delays by insurance	10.9%	19.6%	8.9%	12.2%	15.9%
Child doesn't have health insurance	10.4%	9.8%	10.5%	15.0%	8.3%
Getting needed paperwork from doctor	9.0%	9.8%	7.9%	12.9%	9.9%
Language	7.7%	6.3%	5.9%	8.2%	9.7%
Cannot travel because of condition	5.1%	5.6%	3.4%	5.4%	8.9%
Providers do not include respondent in decisions	5.0%	11.2%	3.8%	10.9%	7.0%
Providers don't understand culture	2.1%	3.5%	1.9%	2.0%	2.4%
Other barrier	18.5%	12.6%	18.4%	16.3%	17.3%
<i>n</i>	2622	143	1581	147	867

Table 14

What Families Wrote . . .

About Service Barriers

“This last year I have had to take off of work around 30 days.”

“The only complaint I have is that no one can/is willing to help us with transportation for our child and family. We built a house ramp to cover the home and school/busing situation with the help of locals donating time and equipment. We are not ones who ask for help needlessly. We really need a van.”

“For instance, my (child) has needed some equipment since (date) when doctor ordered them. It is now (10 months later) and we still can't get them because Medicaid denied them stating that they aren't medically necessary. They are necessary, (my child) needs them to walk.”

“Some times the doctor appointments are in the afternoons which sometimes are difficult for us because I have a (child) who (has a condition) and I have to be at home for (her/him) to get off the bus. The waits at the offices are long. And some appointments take months to get into.”

“Probably the biggest problems we have is all the other things that come with caring for a child with special needs like diapers, vitamins, diet.”

“(My child's) used the same dentist since he/she was 3. This past (month), (the dentist) sent a letter stating (he/she) no longer accepted the medical card. I use to have insurance and only the past 3 years I used a medical card with the dentist. I think it's sad we now have to change.”

“My child is going to pre-k and needs therapy such as speech which can't be given in class so I have to take him/her to the school in the evening for speech therapy. I wish there was a way for him/her to get that service at home because I have... other kids at school that I have to attend to and sometimes can't get a baby sitter.”

“The main problem is transportation back and forth to (city) when we need to go for the medical transportation is really no good.”



PRIMARY CARE SERVICES

Primary Care Services (PCS)

In the section titled, “Primary Care Services,” sample members were presented with six statements relating to the behavior/attitude of their child’s personal doctor or nurse and were asked how strongly they agreed or disagreed with the statement. Respondents were also asked how often their child’s main medical provider made them feel like a full partner in the child’s care.

Question 15

How much do you agree or disagree with each of the following statements:

*Strongly Agree? Somewhat Agree?
Somewhat Disagree? Strongly Disagree?
Don’t Know?*

- *My child’s personal doctor or nurse knows my child’s health history.*
- *My child’s personal doctor or nurse treats my child with compassion and understanding.*
- *My child’s personal doctor or nurse is available in a timely way when my child needs care.*
- *My child’s personal doctor or nurse listens to my concerns.*
- *My child’s personal doctor or nurse involves me in decisions concerning my child.*
- *My child’s personal doctor or nurse helps me arrange for other healthcare services needed by my child.*

Response to Question 15:

In Table 15, the results for the six agree/disagree statements are presented, in order of the “strongly agree” percentage, for the two samples and the three service/benefit groups.

For the DSCC sample, the percentage who “strongly agree” surpasses three-quarters for evaluations of the compassion/understanding of primary care providers (78%). This percentage is just slightly lower – at the three-quarters level – for evaluations of involvement in decisions (75%) and listens to concerns (74%). This “strongly agree” percentage drops somewhat to the two-thirds level for evaluations of knowing the health history of the child (67%) and drops a bit further for evaluations of timely availability (63%) and helping to arrange for other services (60%). Total disagreement surpasses one in ten only for evaluations of helping to arrange for other services (12%).

For the SSI sample, the general order of the items remains very similar to the DSCC order, with only slight changes.⁶ But, for each item, the SSI sample percentage who “strongly agree” is lower than is the case for the DSCC sample. The SSI/DSCC differences here are greatest for evaluations of timely availability (63% vs. 52%). The percentage of SSI respondents who disagree surpasses one in ten for helping to arrange other services (12%) and is about one in six for timely availability (19%).

*Question 15 - Agreement/Disagreement with Six Statements
Relating to Primary Care Services*

My child's personal doctor or nurse ...	Strongly Agree	Somewhat Agree	Total Disagree	dk/na	n
DSCC Sample					
Compassion/understanding	77.5%	17.0%	3.0%	2.5%	4140
Involves in decisions	75.2%	17.7%	3.9%	3.2%	4140
Listens to concerns	74.5%	18.6%	4.0%	2.9%	4140
Knows health history	67.5%	23.4%	6.1%	3.0%	4140
Available in timely way	63.0%	26.1%	7.7%	3.1%	4140
Helps arrange services	60.5%	21.0%	11.5%	7.1%	4140
SSI Sample					
Compassion/understanding	72.3%	15.7%	5.8%	6.3%	191
Listens to concerns	69.1%	18.3%	8.9%	3.7%	191
Involves in decisions	67.0%	19.4%	7.8%	5.8%	191
Knows health history	60.7%	29.3%	6.3%	3.7%	191
Helps arrange services	53.9%	18.8%	11.5%	8.4%	191
Available in timely way	51.8%	31.4%	18.8%	5.2%	191
Only DSCC Services					
Compassion/understanding	77.2%	18.2%	2.7%	1.8%	2556
Involves in decisions	75.4%	18.6%	3.4%	2.7%	2556
Listens to concerns	74.1%	20.0%	3.6%	2.3%	2556
Knows health history	67.1%	24.0%	6.7%	2.3%	2556
Available in timely way	63.1%	27.0%	7.4%	2.5%	2556
Helps arrange services	59.4%	21.9%	11.4%	7.2%	2556
Only SSI Benefits					
Compassion/understanding	75.4%	15.2%	4.4%	4.9%	224
Listens to concerns	71.9%	19.2%	4.9%	4.0%	224
Involves in decisions	70.1%	20.5%	5.3%	4.0%	224
Knows health history	64.3%	28.1%	5.3%	2.2%	224
Helps arrange services	58.0%	20.5%	14.7%	6.7%	224
Available in timely way	52.2%	33.9%	9.3%	4.5%	224
Both Services/Benefits					
Compassion/understanding	78.4%	14.8%	3.3%	3.6%	1262
Listens to concerns	76.1%	15.1%	5.3%	3.4%	1262
Involves in decisions	75.6%	15.2%	5.0%	4.2%	1262
Knows health history	69.4%	21.4%	5.0%	4.2%	1262
Available in timely way	63.7%	23.7%	8.6%	4.0%	1262
Helps arrange services	62.8%	19.2%	11.8%	6.3%	1262

Table 15

⁶ Compared to the DSCC item order, the second and third items change positions, as do the fifth and six items. In both pairs, the “strongly agree” percentages for the two items are quite similar.

Question 16

In the past twelve months, how often did your child's main healthcare provider help you feel like a partner in your child's care? (Please circle the number that best applies)

- | | |
|---------------------------|----------------------------|
| 1 <i>Never</i> | 4 <i>Usually</i> |
| 2 <i>Rarely</i> | 5 <i>Always</i> |
| 3 <i>Sometimes</i> | 6 <i>Don't Know</i> |

Response to Question 16:

The results are presented in Table 16.

A substantial majority of DSCC sample respondents (57%) indicated their main healthcare provider “always” makes them feel like a partner. Slightly fewer than half of SSI sample respondents (48%) said so. For DSCC and SSI respondents, just over one in five said “usually” (~22% for each sample). Almost one in ten DSCC respondents said “sometimes” (9%) while another 6 percent of DSCC respondents said “rarely” or “never.” Both of these figures are slightly to somewhat higher for SSI respondents (13% for “sometimes” and 9% for “rarely” or “never”).

Question 16 - How Often Main Provider Helps You Feel Like Partner in Care

How often did main provider help you feel like partner in care?	Never	Rarely	Some-times	Usually	Always	dk/na	n
DSCC surveys	2.4%	3.3%	9.1%	21.5%	56.7%	7.0%	4140
SSI surveys	4.2%	5.2%	12.6%	22.5%	47.6%	7.9%	191
As reported in surveys:							
Only DSCC services	2.3%	3.1%	8.9%	22.8%	56.8%	6.1%	2556
Only SSI benefits	1.8%	3.1%	12.5%	21.4%	52.2%	8.9%	224
Both	2.6%	3.8%	9.7%	18.8%	57.7%	7.4%	1262

Table 16

What Families Wrote . . .

About Primary Care Services

“I am lucky because I have a great working relationship with my child’s primary physician. When I run into problems, I have a terrific DSCC Coordinator to assist me.”

“Right now my child is going through some type of illness and his/her comfort and pain. I don't feel that all is being done for him/her . . . Because he/she can't talk I am his/her eyes and ears. I know him/her and I know when something is very wrong and I am not being taken seriously. I don't want them to be afraid to eliminate possibilities and find out what is wrong with him/her . . . I don't have the time and energy to just run back and forth to the doctor for nothing. We are getting nowhere.”

“My pediatrician helps me get the ball rolling when we feel more can be done. I thank (the pediatrician) for that but I feel frustrated with the communication with my child's specialist.”

“Dr. (name) was present at (my child's) birth. (Doctor) suggested (hospital) immediately and arranged transportation. (The doctor's) fast thinking saved my child's life . . . (he/she) has always listened with compassion and treated me with respect I wouldn't trade (him/her).”

“With the conditions (my child) has, we need a doctor/doctors to be personal and above all, caring. Not rushing you in and out and forgetting what you were there for just 2 days before. Out of the 6 main doctors, (my child) goes to on a regular basis I would say 2 are very concerned and caring people.”

“My child sees so many doctors that if a problem arises in one area from a medication stand point, I have to try and reach the other doctor to see if a different medication can be used to treat one problem because the current medication has side effects that are creating another problem. I really wish sometimes that the doctors could just call each other to discuss these issues without me always having to be the middle man relaying information back and forth from doctor to doctor. It gets very frustrating to have to contact a doctor and have to leave a voice mail, then have to wait for a call back so that you can relay this information to the other doctor to see how we should proceed with my child's treatment. It seems like I'm always waiting on a call back from one doctor or another.”



TRANSITION SERVICES

Transition Services (TS)

The last substantive section of the questionnaire dealt with “Transition Services” and was to be completed only if the respondent’s child was 14 years or older. (Respondents who answered this section and whose child was under 14 years old were not counted in these results.) The first three questions dealt with the child’s transition plan and the last question asked about whether their child/young adult has or will have special planning needs in selected areas.

Incidence of having or developing a plan to become independent

Question 17

Does your child/young adult have a plan to help him/her become independent after he/she leaves high school?

- 1 Has a Plan*
- 2 Currently Developing a Plan*
- 3 Don’t Believe My Child Needs a Special Plan*
- 4 Does Not Have a Plan*
- 5 Don’t Know*

Response to Question 17:

The section began by asking whether the child/young adult has “a plan to help him/her become independent after he/she leaves high school.”

The results are presented in Table 17.

For relevant DSCC sample members, over one-third (36%) indicated they either have a plan (12%) or are developing a plan (24%). This incidence is lower for relevant SSI sample members (13%, with 11% saying “developing a plan”).

Question 17 - Incidence of Child/Young Adult Having a Plan to Help Become Independent

	Has plan	Dvlping plan	Has or dvlping plan	Not need	Not have	dk	relevant na	n
DSCC surveys	12.4%	23.9%	36.3%	11.6%	35.5%	11.7%	4.9%	1638
SSI surveys	2.2%	10.9%	13.1%	4.3%	47.8%	26.1%	8.7%	46
As reported in surveys:								
Only DSCC services	12.5%	21.8%	34.3%	14.9%	36.9%	10.3%	3.6%	907
Only SSI benefits	14.4%	23.3%	37.7%	7.8%	37.8%	16.7%	0.0%	90
Both	11.2%	27.1%	38.3%	6.0%	35.8%	13.3%	6.7%	565

Table 17

Question 18

Who helped/will help you and your child/young adult with the planning? (Please circle ALL number(s) that apply)

- 1 School***
- 2 DSCC Care Coordinator***
- 3 My Child's Family Doctor or Specialist***
- 4 Division of Rehabilitation Services (DRS)***
- 5 Don't Know***
- Other (describe)***

Response to Question 18:

By far, the most frequent source of help for DSCC respondents is that of the school, checked by over two-thirds (69%) of the respondents. This is distantly followed by DSCC Care Coordinator, checked by about one-quarter (26%). About 16-17 percent each checked DRS and family doctor/specialist. Note that one in seven (14%) of the respondents indicated family/parents in the "other" option, basically a response that indicated no other help.

***Question 18 - Who Helped/Will Help You and Child with Planning?
(among those who have a plan and developing plan)***

	School	DSCC Care Coord	Family Doctor / Speclst	DRS	Family / parents *	Other*	dk	n
DSCC surveys	68.8%	26.1%	16.1%	16.9%	14.4%	6.0%	12.8%	522
SSI surveys	---	---	---	---	---	---	---	5
As reported in surveys:								
Only DSCC services	66.3%	26.6%	16.5%	13.5%	16.1%	3.0%	14.6%	267
Only SSI benefits	66.7%	22.2%	18.5%	25.9%	7.4%	3.7%	7.4%	27
Both	72.7%	27.3%	14.9%	21.1%	11.9%	11.3%	10.8%	194

Table 18

*The seven who responded "no one" (1.3% of all who responded to the question) are excluded from the results. (Alternatively, these responses could have been added to "family/parents," and "other" response that basically means no one else helped with the plan.) Additional "other" responses were given for: another state agency (1.3%); another agency (2.7%); ARC (0.8%); Access (0.8%); and pastor/priest (0.4%).

Question 19

How well do you believe the plan meets your child's/young adult's needs?

- 1 Extremely well***
- 2 Very Well***
- 3 Somewhat Well***
- 4 Not So Well***
- 5 Not Well At All***
- Don't Know***

Response to Question 19:

Over four in ten (45%) DSCC respondents indicated their transition service plan is serving their child's needs "extremely" or "very" well while about one-quarter (26%) said "somewhat well" and just over one in twenty (7%) said either "not so well" or "not well at all." Over one in five (22%) did not know or did not give an answer. When the percentages are based only on those who gave a substantive response [excluding the don't know/no answer (dk/na) respondents], the percent who indicated the plan serves their child's needs "extremely" or "very" well climbs to almost 58 percent (vs. 34% who said "somewhat" and 8% who said either "not so well" or "not well at all").

*Question 19 - How Well Does Plan Meet Child's/Young Adult's Needs
(among those who have plan and developing plan)*

	Extremely or very well	Some- what well	Not so well or not well at all	dk/na	n
DSCC surveys	44.6%	26.3%	6.6%	22.5%	529
SSI surveys	---	---	---	---	4
As reported in surveys:					
Only DSCC services	15.8%	27.3%	6.8%	20.9%	278
Only SSI benefits	18.5%	29.6%	7.4%	25.9%	27
Both	16.7%	25.0%	6.8%	25.0%	192

Table 19

Finally in this section, sample members were asked whether their child/young adult has or will have special planning needs in 18 need areas. These areas were grouped under five general topics.

Question 20

For each item below, circle if your child/young adult has or will have special planning needs for the following:

- Primary medical care*
- Adult specialty care*
- Dental care*
- Helping your child/young adult manage his/her own medical needs*
- Independent Living (see Table 20a)*
- Living arrangements*
- Personal care needs*
- Transportation*
- Self-advocacy*
- Education/Vocational Training/Work (see Table 20b)*
- Continuing education*

**Question 20
continued**

Obtaining vocational training
Working full-time
Supported employment
Sheltered workshops

Financial Independence (see Table 20c)
Paying for healthcare
Managing money
Making financial decisions
Paying for living arrangements

Social Skills (see Table 20d)
Recreational activities

Response to Question 20:

The results for the specific items, by general topical area, are presented in Table 20a for the main respondent groups. Note that the results for the SSI sample group should not be relied upon because they are based on only a few respondents.

As a summary of results for *DSCC respondents*, it is useful to examine the order of the 18 items by percent of relevant respondents indicating the need (and not organized by topical area). This is presented below.

	<i>Need Item</i>	<i>General Area</i>
<i>More than three-quarters</i>		
76.2%	Primary medical care	Medical Needs
<i>More than 70 percent</i>		
72.6%	Continuing education	Education/Training/Work
71.8%	Dental care	Medical Needs
<i>About two-thirds</i>		
69.5%	Help manage medical needs	Medical Needs
68.2%	Adult specialty care	Medical Needs
65.4%	Pay for healthcare	Financial Independence
<i>About 60 percent</i>		
60.8%	Transportation	Independent Living
59.8%	Personal care	Independent Living
<i>Mid-50 Percent</i>		
57.4%	Recreational activities	Social Skills
55.7%	Living arrangements	Independent Living
55.7%	Managing money	Financial Independence
54.8%	Self-advocacy	Independent Living
54.8%	Make financial decisions	Financial Independence
54.7%	Paying for living arrangements	Financial Independence

Around one-half

51.7%	Obtain vocational training	Education/Training/Work
46.9%	Supported employment	Education/Training/Work
46.5%	Work full-time	Education/Training/Work

About one-third

32.5%	Sheltered workshops	Education/Training/Work
-------	---------------------	-------------------------

Generally, we find the items relating to Medical Needs are toward the top of the need order, followed by those relating to Independent Living and Financial Independence (along with Social Skills). The specific items relating to Education/Training/Work are generally found at the bottom of the list. The exception, of course, is continuing education, an item second only to that of primary medical care.

Question 20 - Incidence of Special Planning Needs

Has or will have special planning needs for:	Sample		As reported in survey		
	DSCC Sample	SSI Sample*	Only DSCC Services	Only SSI Benefits	Both
Medical Needs					
Primary medical care	76.2%	88.9%	73.5%	80.8%	82.4%
Adult specialty care	68.2%	50.0%	64.6%	73.5%	75.5%
Dental care	71.8%	66.7%	69.1%	69.8%	78.4%
Help manage med needs	69.5%	62.5%	67.8%	70.8%	73.1%
<i>n's in question order</i>	952; 849; 934; 842	9; 6; 9; 8	506; 444; 498; 447	52; 49; 53; 48	330; 302; 324; 294
Independent Living					
Living arrangements	55.7%	70.0%	48.9%	57.4%	69.2%
Personal care	59.8%	63.6%	52.7%	66.7%	72.2%
Transportation	60.8%	80.0%	52.7%	69.6%	74.8%
Self-advocacy	54.8%	62.5%	51.1%	56.4%	62.3%
<i>n's in question order</i>	799; 825; 821; 736	10; 11; 10; 8	415; 425; 423; 393	47; 45; 46; 39	289; 306; 302; 252
Education / Vocational Training / Work					
Continuing education	72.6%	80.0%	71.2%	75.0%	74.0%
Obtain vocational training	51.7%	50.0%	49.4%	45.7%	56.7%
Work full-time	46.5%	66.7%	48.3%	41.7%	46.2%
Supported employment	46.9%	50.0%	45.5%	58.5%	51.1%
Sheltered workshops	32.5%	28.6%	25.9%	48.7%	42.0%
<i>n's in question order</i>	884; 755; 723; 691; 643	10; 8; 9; 8; 7	482; 409; 408; 382; 351	44; 35; 36; 33; 39	300; 261; 234; 231; 212
Financial Independence					
Pay for healthcare	65.4%	85.7%	69.8%	63.6%	59.3%
Managing money	55.7%	77.8%	54.6%	61.4%	57.5%
Make financial decisions	54.8%	80.0%	55.6%	53.3%	54.0%
Pay for living arrangements	54.7%	90.9%	53.0%	57.8%	60.5%
<i>n's in question order</i>	861; 814; 816; 803	7; 9; 10; 11	487; 445; 446; 436	44; 44; 45; 45	273; 273; 276; 276

(continued from previous page)

Social Skills					
Recreational activities	57.4%	70.0%	52.5%	63.3%	66.6%
<i>n's in question order</i>	838	10	448	49	290

Table 20a

*While presented, it should be noted that all SSI sample results are based on extremely few respondents and should not be relied upon.

Question 20 - Special Planning Needs: Medical Needs

	Primary medical care		Adult specialty care		Dental care		Help manage needs	
DSCC surveys	76.2%	952	68.2%	849	71.8%	934	69.5%	842
SSI surveys	88.9%	9	50.0%	6	66.7%	9	62.5%	8
As reported in surveys:								
Only DSCC services	73.5%	506	64.6%	444	69.1%	498	67.8%	447
Only SSI benefits	80.8%	52	73.5%	49	69.8%	53	70.8%	48
Both	82.4%	330	75.5%	302	78.4%	324	73.1%	294

*Table 20b**Question 20 - Special Planning Needs: Independent Living*

	Living arrangements		Personal care		Transportation		Self-Advocacy	
DSCC surveys	55.7%	799	59.8%	825	60.8%	821	54.8%	736
SSI surveys	70.0%	10	63.6%	11	80.0%	10	62.5%	8
As reported in surveys:								
Only DSCC services	48.9%	415	52.7%	425	52.7%	423	51.1%	393
Only SSI benefits	57.4%	47	66.7%	45	69.6%	46	56.4%	39
Both	69.2%	289	72.2%	306	74.8%	302	62.3%	252

*Table 20c**Question 20 - Special Planning Needs: Education/Vocational Training/Work*

	Continuing educ		Obtain voc training		Work full-time		Supported empl		Sheltered workshops	
DSCC surveys	72.6%	884	51.7%	755	46.5%	723	46.9%	691	32.5%	643
SSI surveys	80.0%	10	50.0%	8	66.7%	9	50.0%	8	28.6%	7
As reported in surveys:										
Only DSCC services	71.2%	482	49.4%	409	48.3%	408	45.5%	382	25.9%	351
Only SSI benefits	75.0%	44	45.7%	35	41.7%	36	58.5%	33	48.7%	39
Both	74.0%	300	56.7%	261	46.2%	234	51.1%	231	42.0%	212

Table 20d

Question 20 - Special Planning Needs: Financial Independence/Social Skills

	Pay for healthcare		Managing money		Make financial decs		Pay for living arrngm		Recr activities	
DSCC surveys	65.4%	861	55.7%	814	54.8%	816	54.7%	803	57.4%	838
SSI surveys	85.7%	7	77.8%	9	80.0%	10	90.9%	11	70.0%	10
As reported in surveys:										
Only DSCC services	69.8%	487	54.6%	445	55.6%	446	53.0%	436	52.5%	448
Only SSI benefits	63.6%	44	61.4%	44	53.3%	45	57.8%	45	63.3%	49
Both	59.3%	273	57.5%	273	54.0%	276	60.5%	276	66.6%	290

Table 20e

What Families Wrote . . .

About Transition Services

“I am concerned - what if my child doesn't get a job (after college I hope) with great insurance. As an adult DSCC doesn't help adults. Our first ‘transition’ meeting is scheduled for (date).”

“Transition planning with school to assist and follow through in all aspects of (my child's) needs, not just scholastic and work-related, but day to day living management.”

“Our consultant is wonderful, knowledgeable and helpful as we start transition planning. We are back in new territory, learning what's out there very similar to having a newborn with disabilities and needing help. You have a wonderful program.”

“I feel that there is not enough information available to parents regarding life after school. Young adult programs. Recreational programs, how to go about applying for these, rights etc.”

“Our child is severely and profoundly mentally retarded. We have legal guardianship. He/she is totally dependent on us for all of his/her needs. We advocate for him/her to the best of our abilities. We will never put him/her in a group home; he/she will always live with us. He/she is happy and we love him/her very much. If our child needs medical care and IPA or our insurance won't pay for it, we make sure (our child) gets it, and we make payments until it is paid off!”

“We are concerned on how to go from high-school to nothing. We are not really sure on what kind of job (our child) will be able to do. Also concerned about medical and dental care after (our child) is out of school . . . in one more year.”

“It is extremely difficult to answer any and all transitional questions about my child who is chronologically (a teenager) and emotionally (middle school). It is hard to know anything about planning for future needs with a child whose physical needs are extensive and who does not accept their disabilities . . . I have a child whose Christmas list runs from Fisher Price toys to age appropriate CD's and Nintendo games. There are such huge gaps between abilities and needs. I feel completely lost sometimes. The future feels like one huge vacancy. No clues, and a little hopeless and helpless . . .”

“Because of (my child's) disorder, it will be hard . . . to obtain private insurance without riders to exclude his/her medical problems. This is a big concern. The medication, etc is very expensive and will be hard for a young adult to pay for without prescription coverage.”

**FURTHER ANALYSES
MOST SERIOUS
HEALTH CONDITION**

FURTHER ANALYSES – MOST SERIOUS HEALTH CONDITION OF CHILD

Further analyses were conducted that relates to the most serious health condition of the child.

First, the incidence of the respective conditions by the race/ethnicity of the child was examined. In other words, we examined the distribution of the respective conditions for the five major race/ethnicity groups.

In other analyses, various characteristics were examined by the most serious health condition of the child. In other words, we examined the distribution of these characteristics for each of the respective health conditions. Characteristics examined here included: selected opinions about the nature of primary care providers; service barriers; and unmet need percentages.

It should be noted that multiple health conditions were coded if identified in the survey. It should also be recognized that these are the most serious health conditions, as reported by the parent(s) in the survey and not those on which eligibility is necessarily based. DSCC and SSI sample respondents are analyzed together in this section.

The distribution of the most serious health condition of the child by the child's race/ethnicity is found in Table MSHC-1. In this table, read down each column to see the percentage of children in the respective group who were identified as having the coded health conditions.

*Most Serious Health Condition of Child,
by Race/Ethnicity of Child*

Health Condition	Race/ethnicity of child				
	African-American	Asian	Hispanic	White	Other / Mixed
Nervous system	37.0%	23.3%	31.9%	32.3%	34.4%
Hearing	13.6%	21.1%	13.7%	14.8%	10.8%
External body	10.0%	15.6%	14.0%	12.2%	9.7%
Cardiovascular	6.5%	3.3%	7.1%	11.5%	7.5%
Orthopedic	8.2%	4.4%	7.6%	9.6%	12.9%
Respiratory	10.8%	6.7%	6.3%	6.3%	7.5%
Eye	5.0%	8.9%	5.1%	5.9%	3.2%
Mental disorders	8.0%	11.1%	4.6%	4.9%	8.6%
Inborn error	2.8%	4.4%	4.1%	4.1%	3.2%
Urinary	0.9%	3.3%	3.0%	2.7%	0.0%
Cystic fibrosis	0.2%	0.0%	0.3%	1.7%	0.0%
Hemophilia	1.9%	2.2%	0.7%	1.4%	1.1%
Other specific	4.3%	5.6%	4.3%	5.4%	5.4%
General	13.4%	12.2%	15.9%	6.6%	8.6%
<i>number responding</i>	462	90	605	2743	93

MSHC-1

Results

Generally, there is a great deal of similarity in the incidence of the respective health conditions across the race/ethnic groups. This is indicated by the general decreasing percentages found in each column (except for “other specific” and “general” conditions.)⁷

The most frequently identified condition is the same for all race/ethnic groups, that of problems relating to the nervous system. And, for four of the five groups (all but the “other/mixed” group), this is followed by hearing and external body conditions.

However, there are some differences across race/ethnic groups. Among the largest differences are the following.

- The incidence of respiratory conditions among African-Americans is nearly twice the incidence identified for other groups.
- The incidence of mental disorders is higher among Asians (11%) and African-Americans (8%) than it is among whites or Hispanics (under 5% for each).
- The incidence of cardiovascular problems is higher among whites (12%) than it is for Hispanics or African-Americans (about 7% each). The incidence for Asians is even lower (3%).
- Compared to other groups, Asians have a higher incidence of hearing problems and a lower incidence of nervous system problems, with the result that hearing problems are a close second to nervous system problems for Asians. Asians also have the highest incidence of eye disorders.

⁷ The health conditions in Table MSHC-1 were ordered by the overall results.



SELECTED OPINIONS ABOUT PRIMARY CARE SERVICES

SELECTED OPINIONS ABOUT PRIMARY CARE SERVICES
BY MOST SERIOUS HEALTH CONDITION OF CHILD

Three selected opinions about primary care services were analyzed by the most serious health condition of the child: degree of agreement/disagreement that the primary care provider (doctor or nurse) listens to your concerns; degree of agreement/disagreement that the primary care provider helps arrange for other healthcare services; and reported frequency that the primary care provider makes the respondent feel like a partner. The results follow in Tables MSHC-2a, 2b and 2c, respectively.

In each of these tables, read across for the opinion percentage results for each of the respective health conditions. With the exception of “other specific” and “general” conditions (which are always placed last), the health conditions in each of the three tables are ordered by the frequencies of the most positive response.⁸

*Doctor/Nurse Listens to Your Concerns,
by Most Serious Health Condition of Child*

Condition	Strongly agree	Somewhat agree	Total Disagree	dk/na	n
Cystic fibrosis	86.3%	13.7%	0.0%	0.0%	51
Respiratory	81.0%	11.8%	3.9%	3.2%	279
Inborn error	80.0%	16.9%	2.5%	0.6%	160
Cardiovascular	77.2%	16.1%	3.5%	3.2%	403
Nervous system	77.0%	17.4%	3.5%	2.2%	1324
Orthopedic	76.2%	16.2%	4.9%	2.7%	370
Hemophilia	75.4%	21.1%	3.5%	0.0%	57
Eye	74.2%	20.2%	4.3%	1.3%	233
External body	73.8%	18.5%	5.0%	2.6%	496
Urinary	70.6%	21.6%	6.9%	1.0%	102
Mental disorders	70.0%	18.8%	5.8%	5.4%	223
Hearing	67.5%	25.0%	4.6%	3.0%	593
Other specific	77.4%	16.8%	5.3%	0.5%	208
General	72.4%	17.7%	5.0%	5.0%	362

Table MSHC-2a

⁸ Results for those with “other specific” and “general” conditions are not commented upon below because of their diverse and/or undisclosed nature.

*Doctor/Nurse Helps Arrange for Other Healthcare Services,
by Most Serious Health Condition of Child*

Condition	Strongly agree	Somewhat agree	Total Disagree	dk/na	n
Cystic fibrosis	72.5%	11.8%	15.7%	0.0%	51
Hemophilia	64.9%	19.3%	12.3%	3.5%	57
Cardiovascular	63.3%	22.3%	7.2%	7.2%	403
Respiratory	62.7%	19.4%	11.5%	6.5%	279
Inborn error	62.5%	20.0%	8.8%	8.8%	160
Urinary	61.8%	27.5%	4.9%	5.9%	102
Nervous system	61.5%	20.5%	12.8%	5.1%	1324
Orthopedic	60.8%	20.3%	13.2%	5.7%	370
External body	60.3%	20.4%	11.3%	8.1%	496
Eye	59.2%	20.2%	13.7%	6.9%	233
Mental disorders	59.2%	17.0%	15.7%	8.1%	223
Hearing	51.8%	26.0%	12.6%	9.6%	593
Other specific	57.7%	23.1%	14.4%	4.8%	208
General	57.5%	21.3%	12.4%	8.8%	362

Table MSHC-2b

*How Frequently Main Provider Helps You Feel Like a Partner,
by Most Serious Health Condition of Child*

Condition	Always	Usually	Some-times	Rarely / never	dk/na	n
Cardiovascular	63.3%	19.6%	7.4%	4.0%	5.7%	403
Respiratory	62.7%	19.7%	9.0%	4.3%	4.3%	279
Cystic fibrosis	58.8%	25.5%	9.8%	3.9%	2.0%	51
Inborn error	58.8%	23.8%	8.1%	3.1%	6.3%	160
Nervous system	57.6%	22.7%	8.8%	5.5%	5.4%	1324
External body	57.5%	18.5%	9.5%	6.0%	8.5%	496
Hemophilia	56.1%	17.5%	7.0%	8.8%	10.5%	57
Orthopedic	55.9%	21.1%	11.1%	5.7%	6.2%	370
Urinary	52.9%	26.5%	11.8%	4.9%	3.9%	102
Hearing	52.8%	23.4%	10.6%	5.2%	7.9%	593
Eye	51.9%	27.9%	8.6%	6.9%	4.7%	233
Mental disorders	50.7%	24.2%	11.2%	8.5%	5.4%	223
Other specific	63.9%	17.3%	9.6%	2.9%	6.3%	208
General	47.2%	23.8%	10.2%	8.3%	10.5%	362

Table MSHC-2c

Doctor/nurse listens to your concerns. The percent who strongly agree ranges from a low of about two-thirds to a high of over 85 percent. At the high end, we find that over 85 percent of respondents who have children with cystic fibrosis strongly agree that their main provider listens to their concerns, and over 80 percent of those who have children with respiratory conditions and inborn error conditions do so as well. At the low end, we find that two-thirds of respondents who have children with hearing

Selected Opinions About Primary Care Services

problems strongly agree and about 70 percent of those who have children with mental disorders and urinary problems do so. Strongly agree percentages for the remaining health conditions only range from 74 to 77 percent.

Doctor/nurse arranges for other healthcare services. The percent who strongly agree ranges from a low of 52 percent, for those who have children with hearing problems, to a high of 72 percent, for those who have children with cystic fibrosis. The strongly agree percentages for all the remaining groups only range from 59 to 65 percent.

How often main provider makes you feel like a partner. The percent who indicated their main provider “always” makes them feel like a partner ranges from a low of just over 50 percent to a high of 63 percent. At the high end are respondents who have children with cardiovascular problems (63%) and respiratory problems (63% each). At the low end are respondents who have children with mental disorders (51%), eye problems (52%), hearing problems (53%), and urinary problems (53%). The percent who indicated “always” for the remaining groups only ranges from 56 to 59 percent.

Service Barriers, by Most Serious Health Condition of Child

The table. Identified service barriers were analyzed by the most serious health condition of the child, and the results are found in Table MSHC-3. Read down each column to see the percent identifying any barriers for the respective health condition groups. Then read further down to see the percent who identified a specific barrier *among those who cited any barrier*.

The percent who identified any service barrier ranges from a low of 55 percent (among those who have children with cystic fibrosis) to a high of 73 percent (for those who have children with respiratory problems). See the table for more specific results.

Service Barriers, by Most Serious Health Condition

Service Barriers For Respective DSCC Office Areas	Cardio-vascular	Cystic fibrosis	External body	Hearing	Hemophilia	Inborn error
<i>Percent of all choosing any barrier</i>	58.8%	54.9%	64.1%	60.5%	70.2%	68.8%
<i>n</i>	403	51	496	593	57	160
<i>Of those choosing barriers:</i>						
Providers don't share info	16.9%	17.9%	17.0%	13.4%	15.0%	16.4%
Providers don't know/do not refer child to available services	18.6%	10.7%	14.5%	18.1%	15.0%	12.7%
Inconvenient office hours	16.5%	14.3%	17.9%	17.3%	17.5%	18.2%
Providers do not include respondent in decisions	5.9%	14.3%	2.5%	4.2%	15.0%	5.5%
Language	5.1%	7.1%	7.9%	8.9%	5.0%	9.1%
Delays in getting appointments	23.2%	3.6%	18.9%	15.3%	12.5%	15.5%
Delays in returning phone calls	24.1%	21.4%	17.9%	13.6%	17.5%	18.2%
Using ER where staff not used to taking care of condition	17.7%	14.3%	8.5%	8.9%	37.5%	22.7%
Needed service too far from home	30.4%	21.4%	19.2%	22.8%	25.0%	31.8%
Transportation – do not have or can't afford	14.8%	10.7%	16.0%	12.0%	17.5%	22.7%
Cannot travel because of condition	4.6%	3.6%	4.7%	1.1%	0.0%	5.5%
Care not covered by insurance	27.0%	10.7%	24.8%	44.0%	12.5%	20.9%
KidCare/Medicaid not accepted	16.5%	10.7%	18.9%	12.0%	2.5%	19.1%
Child doesn't have health insurance	12.2%	7.1%	13.8%	10.9%	15.0%	10.9%
Waiting time in doctor's office too long	25.3%	7.1%	21.1%	16.2%	25.0%	30.9%
Approval process delays by insurance	8.4%	10.7%	7.9%	8.1%	7.5%	11.8%
Getting needed paperwork from doctor	8.0%	7.1%	7.5%	6.1%	7.5%	7.3%
Difficulty getting/paying for medications due to insurance requirements	18.6%	35.7%	15.7%	14.2%	17.5%	16.4%
Doctors don't know how to treat condition	11.8%	3.6%	8.2%	5.6%	20.0%	13.6%
Providers don't understand culture	1.3%	0.0%	2.2%	2.2%	5.0%	3.6%
Other barrier	18.1%	32.1%	15.4%	19.2%	15.0%	17.3%
<i>n</i>	237	28	318	359	40	110

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Table MSHC-3

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Service Barriers, by Most Serious Health Condition

Service Barriers For Respective DSCC Office Areas	Nervous system	Orthopedics	Urinary	Eye	Mental disorder	Respiratory	Other
<i>Percent of all choosing any barrier</i>	71.1%	62.7%	66.7%	65.2%	69.5%	73.1%	76.9%
<i>n</i>	1324	370	102	233	223	279	208
<i>Of those choosing barriers:</i>							
Providers don't share info	19.2%	16.8%	16.2%	19.7%	23.2%	22.1%	20.0%
Providers don't know/do not refer child to available services	17.0%	17.7%	13.2%	17.8%	26.5%	15.7%	16.9%
Inconvenient office hours	17.7%	15.5%	17.6%	19.1%	20.6%	18.1%	18.8%
Providers do not include respondent in decisions	5.7%	6.0%	5.9%	5.9%	5.2%	4.9%	5.6%
Language	6.7%	7.3%	4.4%	9.2%	7.7%	7.4%	6.3%
Delays in getting appointments	18.8%	16.4%	17.6%	19.1%	20.0%	18.6%	21.3%
Delays in returning phone calls	22.1%	15.9%	19.1%	16.4%	20.6%	19.6%	21.9%
Using ER where staff not used to taking care of condition	20.8%	23.3%	23.5%	8.6%	12.3%	23.5%	23.1%
Needed service too far from home	29.2%	31.0%	30.9%	30.9%	24.5%	26.0%	40.0%
Transportation – do not have or can't afford	19.1%	17.2%	17.6%	23.7%	16.1%	23.0%	24.4%
Cannot travel because of condition	7.7%	5.6%	1.5%	4.6%	5.8%	13.2%	8.1%
Care not covered by insurance	23.5%	22.0%	22.1%	33.6%	29.0%	18.6%	25.6%
KidCare/Medicaid not accepted	18.9%	19.0%	8.8%	21.7%	25.2%	14.7%	18.8%
Child doesn't have health insurance	7.6%	10.3%	14.7%	7.9%	10.3%	6.4%	6.9%
Waiting time in doctor's office too long	24.5%	18.5%	20.6%	26.3%	27.7%	28.9%	25.0%
Approval process delays by insurance	14.2%	12.5%	5.9%	9.9%	13.5%	13.7%	10.0%
Getting needed paperwork from doctor	10.4%	12.5%	7.4%	7.2%	11.0%	9.3%	10.0%
Difficulty getting/paying for medications due to insurance requirements	13.9%	11.6%	22.1%	14.5%	15.5%	19.1%	16.3%
Doctors don't know how to treat condition	14.9%	15.9%	17.6%	14.5%	15.5%	17.6%	18.1%
Providers don't understand culture	2.0%	1.7%	2.9%	2.0%	1.9%	2.0%	1.9%
Other barrier	19.5%	21.1%	35.3%	14.5%	21.9%	24.0%	14.4%
<i>n</i>	942	232	68	152	155	204	160

Table MSHC-3

Unmet need for selected health services by most serious health condition of child

Unmet need percentages (i.e., those who said they had a need but do not use services for it) were analyzed by the most serious health condition of the child, and the results are found in Table MSHC-4. Read down each column to see the unmet need percentages in the respective areas for each of the health condition groups. Read across to compare the unmet percentages across the health condition groups. The services are presented in the order in which they were asked in the questionnaire. (No commentary is offered for the results of this table.)

Unmet Need Percentages, by Most Serious Health Condition*

Condition	Cardio-vascular	Cystic fibrosis	External body	Hearing	Hemo-philia	Inborn error
Well child care	3.5%	2.0%	4.0%	4.9%	8.8%	3.8%
Primary care	3.2%	0.0%	5.6%	5.4%	5.3%	4.4%
Specialty care	3.0%	0.0%	2.8%	3.4%	0.0%	3.8%
Dental care	7.9%	2.0%	9.3%	9.1%	8.8%	10.6%
Specialty dental care	5.5%	5.9%	4.6%	5.1%	5.3%	6.9%
Emergency room	2.2%	0.0%	3.4%	3.2%	5.3%	1.3%
Hospital care	3.5%	0.0%	2.8%	2.0%	0.0%	2.5%
Immunizations	3.2%	2.0%	4.0%	3.2%	5.3%	2.5%
Physical therapy	3.2%	0.0%	4.6%	2.9%	3.5%	3.8%
Occupational therapy	3.5%	2.0%	4.6%	2.4%	1.8%	4.4%
Speech therapy	5.5%	2.0%	6.0%	5.4%	3.5%	4.4%
Early intervention services	2.7%	2.0%	3.8%	2.2%	0.0%	3.8%
Genetic testing and counseling	2.7%	0.0%	3.4%	2.2%	3.5%	4.4%
Mental health and/or counseling services	1.7%	3.9%	3.6%	2.9%	3.5%	3.8%
Nutritional counseling	2.5%	0.0%	3.2%	2.2%	3.5%	5.6%
Prescription medications	4.5%	0.0%	4.0%	4.0%	3.5%	3.8%
Medical equipment / supplies	3.0%	0.0%	3.2%	2.4%	1.8%	3.1%
Special dietary products	2.0%	0.0%	3.0%	1.9%	0.0%	2.5%
In-home nursing care	1.5%	0.0%	3.0%	2.0%	0.0%	1.9%
Home health aide	1.7%	2.0%	2.8%	2.0%	0.0%	2.5%
Respite care	5.2%	2.0%	4.8%	3.0%	3.5%	4.4%
<i>number responding</i>	<i>403</i>	<i>51</i>	<i>496</i>	<i>593</i>	<i>57</i>	<i>160</i>

(continued on next page)

Table MSHC-4

*The Unmet Need Percentage is the percentage of all respondents who reported having a need but who did not use the service. The number of respondents is not presented because it is based on all DSCC sample members in the respective regions.

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Unmet Need Percentages by Most Serious Health Condition*

Condition	Nervous system	Orthopedic	Urinary	Eye	Mental disorder	Respiratory	Other
Well child care	3.2%	3.8%	2.0%	2.6%	3.1%	3.2%	4.3%
Primary care	2.8%	3.8%	3.9%	2.1%	4.5%	4.3%	3.8%
Specialty care	1.8%	4.9%	2.0%	2.1%	2.2%	3.9%	2.9%
Dental care	8.8%	9.2%	6.9%	9.0%	9.4%	8.2%	11.1%
Specialty dental care	6.6%	6.8%	2.0%	6.9%	8.5%	9.0%	9.6%
Emergency room	3.0%	2.7%	2.0%	1.3%	2.7%	2.5%	1.9%
Hospital care	2.9%	3.0%	1.0%	1.3%	2.2%	2.9%	1.4%
Immunizations	2.0%	2.7%	3.9%	1.7%	3.1%	1.8%	1.9%
Physical therapy	6.0%	6.2%	3.9%	5.2%	6.3%	5.7%	6.3%
Occupational therapy	7.2%	7.0%	2.9%	6.0%	5.4%	6.1%	6.3%
Speech therapy	6.3%	5.4%	3.9%	4.3%	5.4%	6.5%	10.1%
Early intervention services	2.3%	3.0%	2.9%	2.6%	4.0%	2.5%	2.9%
Genetic testing and counseling	3.0%	3.0%	2.9%	2.1%	3.6%	2.9%	3.8%
Mental health and/or counseling services	3.8%	3.2%	2.9%	2.1%	6.7%	2.5%	3.4%
Nutritional counseling	4.2%	3.8%	2.0%	3.0%	5.4%	3.2%	3.8%
Prescription medications	2.2%	2.7%	2.0%	3.9%	4.0%	2.2%	2.9%
Medical equipment / supplies	2.2%	3.8%	2.9%	0.9%	3.6%	2.9%	2.9%
Special dietary products	3.2%	3.0%	2.0%	3.0%	4.0%	1.8%	3.4%
In-home nursing care	3.2%	3.0%	2.0%	2.1%	4.0%	1.8%	3.4%
Home health aide	5.1%	3.0%	2.9%	3.0%	4.5%	2.5%	4.3%
Respite care	10.6%	5.9%	5.9%	4.7%	7.2%	7.9%	9.1%
<i>number responding</i>	<i>1324</i>	<i>370</i>	<i>102</i>	<i>233</i>	<i>223</i>	<i>279</i>	<i>208</i>

Table MSHC-4

*The Unmet Need Percentage is the percentage of all respondents who reported having a need but who did not use the service. The number of respondents is not presented because it is based on all DSCC sample members in the respective regions.



**FAMILY COMMENTS
DSCC MAKES
A DIFFERENCE**

What Families Wrote . . .

About DSCC

DSCC Services Make a Difference

“What you do for families and children makes such a difference. Dealing with so many obstacles, it is very comforting to know DSCC is always in your corner. Thank you for everything you have done for us!”

“DSCC has been wonderful. I don't often need help, but when I do my rep is super and I love the comfort I feel with her. Kid Care is another important part of our lives w/ the kids. Our medical expenses are nearly nothing. Very helpful when on a tight budget and your child's healthcare is so important.”

“I could not be happier with the attention and care we receive from our doctors, dieticians and nursing consultant. My (child) has been well taken care of since birth and is now almost (age). Our nursing consultant is always helpful and available and is worth her weight in gold! Our doctor and dietician have always been very helpful and answered any questions we may have had. If my (child) had to have something in his/her life that was challenging, I couldn't have asked for better people to care for him/her. A difficult experience and challenge has turned out 500% better than we could have foreseen... years ago. I have nothing but good things to say about DSCC and all of the people who have helped my (child) grow into a wonderful young (adult). Thank you to all of you who had anything to do with my child. . .”

“Without the services of DSCC, my child and family would have had to go through financial and emotional distress due to the medical needs and care my special need child required. Our families' viability would have been greatly stressed. I would like to thank all of those involved for their help and support.”

“Thank you so very much for all the help so far. It's very hard at times but with your help we can do it. Our child has special needs and we just found out about a new problem.”

“I don't know what we would have done without DSCC. They are always a big help. They call to check on things, give us reminders of follow ups. They also listen when there is a family issue. They treat us like we mean something to them. I can't say enough about their kindness. I just know without them I would be so lost. They are angels. They go above any other help we ever got. They are like a part of our family. Thank you.”

What Families Wrote . . .

About DSCC

DSCC Services Make a Difference

“None of the barriers we have experienced have been due to DSCC. We have had all questions addressed to your agency answered politely and in a timely manner. In fact, during this trying situation, DSCC may have been the only place we've had no problems. This has been a breath of fresh air for our family. Thank you.”

“I personally believe DSCC is a wonderful program. I am very happy with it. I really like the staff's involvement with my child's care. I wish his/her own M.D. was as understanding. Thank you for all you do for these children. Someone cares. We do.”



APPENDIX A NEEDS ASSESSMENT SURVEY INSTRUMENT

COMMUNITY HEALTH ACCESS (Cont'd)

Services	In the last twelve months, did your child need this service?		If your child needed the service, did you use it?		About how much time did you travel one way to get to the service?
	<i>(Please circle yes or no)</i>		<i>(Please circle yes or no)</i>		<i>(Enter hours [Hrs] / minutes [Mins])</i>
Specialty Dental Care (orthodontia).....	No	Yes →	No	Yes →	Hrs____ / Mins____
Emergency Room Services.....	No	Yes →	No	Yes →	Hrs____ / Mins____
Hospital Care for Children (inpatient or outpatient)	No	Yes →	No	Yes →	Hrs____ / Mins____
Immunizations	No	Yes →	No	Yes →	Hrs____ / Mins____
Physical Therapy (PT).....	No	Yes →	No	Yes →	Hrs____ / Mins____
Occupational Therapy (OT).....	No	Yes →	No	Yes →	Hrs____ / Mins____
Speech Therapy (ST).....	No	Yes →	No	Yes →	Hrs____ / Mins____
Early Intervention Services (birth to age three).....	No	Yes →	No	Yes →	Hrs____ / Mins____
Genetic Testing and Counseling	No	Yes →	No	Yes →	Hrs____ / Mins____
Mental Health and/or Counseling Services	No	Yes →	No	Yes →	Hrs____ / Mins____
Nutritional Counseling	No	Yes →	No	Yes →	Hrs____ / Mins____
Prescription Medications	No	Yes →	No	Yes →	Hrs____ / Mins____
Medical Equipment/Supplies.....	No	Yes →	No	Yes →	Hrs____ / Mins____
Special Dietary Products.....	No	Yes →	No	Yes →	Hrs____ / Mins____
In-Home Nursing Care	No	Yes →	No	Yes →	N/A_____
Home Health Aide (personal attendant).....	No	Yes →	No	Yes →	N/A_____
Respite Care (A break for caregivers and families. A service in which temporary care is provided to a child or adult with disabilities or chronic illness.).....	No	Yes →	No	Yes →	Hrs____ / Mins____

CARE COORDINATION

7. In the last twelve months, how often did you ask for help from someone (for example, your DSCC care coordinator, your physician, a local community agency staff person, school personnel, a state agency staff person, etc.) regarding each of the following? *(Please circle the answer that best applies)*

How Often Did You Ask For This Help In The Last Twelve Months?					
Type of Help	Often	Sometimes	Rarely	Never	Does Not Apply (N/A)
Finding specialty medical care for treatment of your child's health problem	Often	Sometimes	Rarely	Never	N/A
Finding a primary care doctor who treats your child for common illnesses or routine check ups	Often	Sometimes	Rarely	Never	N/A
Finding medical equipment or supplies for your child	Often	Sometimes	Rarely	Never	N/A
Finding speech therapy services for your child	Often	Sometimes	Rarely	Never	N/A
Finding physical therapy services for your child	Often	Sometimes	Rarely	Never	N/A
Finding occupational therapy services for your child	Often	Sometimes	Rarely	Never	N/A
Finding routine dental care for your child	Often	Sometimes	Rarely	Never	N/A
Talking to your child's medical providers	Often	Sometimes	Rarely	Never	N/A
Understanding the medical treatment plan for your child's health condition	Often	Sometimes	Rarely	Never	N/A
Understanding the changes in your child's medical condition	Often	Sometimes	Rarely	Never	N/A
Talking to your insurance company so your child could get medical care	Often	Sometimes	Rarely	Never	N/A
Understanding the rules of your insurance for your child	Often	Sometimes	Rarely	Never	N/A
Talking to KidCare/Medicaid (Medical Card) staff so your child could get medical care	Often	Sometimes	Rarely	Never	N/A
Understanding the rules of KidCare/Medicaid (Medical Card)	Often	Sometimes	Rarely	Never	N/A
Learning your child's rights for early intervention	Often	Sometimes	Rarely	Never	N/A
Meeting with your child's early intervention providers to help decide on your child's needs	Often	Sometimes	Rarely	Never	N/A
Meeting with your child's school to help the teachers plan for your child's special needs	Often	Sometimes	Rarely	Never	N/A
Learning your child's rights for school	Often	Sometimes	Rarely	Never	N/A
Helping your child get special school services	Often	Sometimes	Rarely	Never	N/A
Learning about services in your community that may help your child or family	Often	Sometimes	Rarely	Never	N/A
Finding a family that you can talk to who has a child with a medical condition like your child	Often	Sometimes	Rarely	Never	N/A
Learning where to find help for other basic needs (food, housing, etc.)	Often	Sometimes	Rarely	Never	N/A

PAYING FOR HEALTH CARE

8. Do you currently have a source(s) to help with payment of your child's medical care?
(Please circle the number that best applies)
- 1 Yes
 - 2 No (If no, please skip to question 9 below)
- 8a.** If yes, what type(s) of help do you have? (Please circle **ALL** number(s) that apply)
- 1 Health Insurance (If Health Insurance, please answer 8b)
 - 2 KidCare or Medicaid (Medical Card) (If KidCare/Medicaid, please answer 8b)
 - 3 DSCC
 - 4 Don't Know
 - 5 Other (describe): _____
- 8b.** If you circled one or two in the above question (8a), are you in a managed care plan (Health Maintenance Organization [HMO], Preferred Provider Organization [PPO], Point of Service [POS]).
(Please circle the number that best applies)
- 1 Yes
 - 2 No
 - 3 Don't Know
9. Has your source or type of financial help changed within the last twelve months?
(Please circle the number that best applies)
- 1 Yes
 - 2 No (If no, please skip to question 10)
- 9a.** If yes, have you had to change doctors or other medical providers as a result of this change?
- 1 Yes
 - 2 No (If no, please skip to question 10)
- 9b.** If you have had to change doctors or other medical providers, how did this affect your child's care?
- 1 Care is Better Now
 - 2 Care is Worse Now
 - 3 No Effect on Care
10. During the last twelve months, approximately how much have you paid "out of pocket" for your child's medical care? (Please check the answer that best applies)
- | | |
|--|--|
| <input type="checkbox"/> Less Than \$250 | <input type="checkbox"/> More Than \$5,000 |
| <input type="checkbox"/> \$251 - \$500 | <input type="checkbox"/> Don't Know |
| <input type="checkbox"/> \$501 - \$1,000 | <input type="checkbox"/> Nothing |
| <input type="checkbox"/> \$1,001 - \$5,000 | |
11. In the last twelve months, was the cost of medical care a major factor in deciding whether your child received medical care?
(Please circle the number that best applies)
- 1 Yes
 - 2 No
 - 3 Don't Know
12. In the last twelve months, was your child denied health care because you couldn't pay?
(Please circle the number that best applies)
- 1 Yes
 - 2 No
 - 3 Don't Know

PAYING FOR HEALTHCARE (Cont'd)

13. Has your family had to do without necessities because of the cost(s) of your child's medical care?
(Please circle the number that best applies)

- 1 Yes
- 2 No
- 3 Don't Know

SERVICE BARRIERS

Please tell us about things that get in the way of your use of services for your child.

14. In the last twelve months, what problems, if any, have you had in getting health care for your child?
(Please circle **ALL** number(s) that apply)

- | | |
|--|--|
| 1 Medical care providers don't share information with each other | 11 Cannot travel due to my child's condition |
| 2 Medical care providers didn't know about or didn't refer my child to available resources/services | 12 Care is not covered by insurance |
| 3 Inconvenient office hours | 13 My child's KidCare/Medicaid (Medical Card) is not accepted |
| 4 Medical care providers don't include me in making decisions about my child's needs | 14 My child does not have health insurance |
| 5 Medical care providers don't communicate in my language | 15 Waiting time in the doctor's office is too long |
| 6 Delays in getting appointments when my child needs care | 16 My insurance or KidCare/Medicaid (Medical Card) prior approval process delays getting care in a timely manner |
| 7 Delays in returning my telephone calls when I seek medical advice | 17 Getting needed paperwork done by my doctor |
| 8 Using an emergency room where doctors and nurses aren't used to taking care of a child with my child's condition | 18 Difficulty getting or paying for medications due to my insurance requirements |
| 9 Needed service is too far from home | 19 Doctors don't know how to treat my child's medical condition |
| 10 Don't have or can't afford transportation to services | 20 Medical providers don't understand my culture |
| | 21 None of the above (If none of the above, please answer question 14a) |

14a. Other (Please describe any other things that get in the way of your use of services for your child)

PRIMARY CARE SERVICES

15. How much do you agree or disagree with each of the following statements: Strongly Agree? Somewhat Agree? Somewhat Disagree? Strongly Disagree? Don't Know?
(Please circle the number that best applies)

Statement	Strongly Agree 1	Somewhat Agree 2	Somewhat Disagree 3	Strongly Disagree 4	Don't Know 5
My child's personal doctor or nurse knows my child's health history.	1	2	3	4	5
My child's personal doctor or nurse treats my child with compassion and understanding.....	1	2	3	4	5
My child's personal doctor or nurse is available in a timely way when my child needs care.....	1	2	3	4	5
My child's personal doctor or nurse listens to my concerns.	1	2	3	4	5
My child's personal doctor or nurse involves me in decisions concerning my child.....	1	2	3	4	5
My child's personal doctor or nurse helps me arrange for other health care services needed by my child.	1	2	3	4	5

16. In the past twelve months, how often did your child's main health care provider help you feel like a partner in your child's care? (Please circle the number that best applies)
- | | |
|-------------|--------------|
| 1 Never | 4 Usually |
| 2 Rarely | 5 Always |
| 3 Sometimes | 6 Don't Know |

TRANSITION SERVICES

Complete the following Questions 17 – 20 only **IF your child is 14 years old or older**
(Please go to question 21 if your child is 13 years or younger)

17. Does your child/young adult have a plan to help him/her become independent after he/she leaves high school?
(Please circle the number that best applies)
- 1 Has a Plan
 - 2 Currently Developing a Plan
 - 3 Don't Believe My Child Needs a Special Plan (Please go to question 20)
 - 4 Does Not Have a Plan (Please go to question 20)
 - 5 Don't Know (Please go to question 20)
18. Who helped/will help you and your child/young adult with the planning? (Please circle **ALL** number(s) that apply)
- 1 School
 - 2 DSCC Care Coordinator
 - 3 My Child's Family Doctor or Specialist
 - 4 Division of Rehabilitation Services (DRS)
 - 5 Don't Know
- Other (describe) _____

TRANSITION SERVICES (Cont'd)

19. How well do you believe the plan meets your child's/young adult's needs.
(Please circle the number that best applies)

- | | |
|------------------|-------------------|
| 1 Extremely Well | 4 Not So Well |
| 2 Very Well | 5 Not Well at All |
| 3 Somewhat Well | 6 Don't Know |

20. For each item below, circle if your child/young adult has or will have special planning needs for the following:
(Please circle the number that best applies)

Medical Needs	Yes	No	Not Applicable
Primary medical care	1	2	3
Adult specialty care	1	2	3
Dental care	1	2	3
Helping your child/young adult manage his/her own medical needs	1	2	3
Independent Living	Yes	No	Not Applicable
Living arrangements.....	1	2	3
Personal care needs	1	2	3
Transportation	1	2	3
Self-advocacy.....	1	2	3
Education/Vocational Training/Work	Yes	No	Not Applicable
Continuing education	1	2	3
Obtaining vocational training.....	1	2	3
Working full-time.....	1	2	3
Supported employment.....	1	2	3
Sheltered workshops.....	1	2	3
Financial Independence	Yes	No	Not Applicable
Paying for health care	1	2	3
Managing money.....	1	2	3
Making financial decisions	1	2	3
Paying for living arrangements.....	1	2	3
Social Skills	Yes	No	Not Applicable
Recreational activities	1	2	3
Other special planning needs (describe) _____			

