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Overview

Introduction

The US Department of Health and Human Services Maternal Child Health Bureau funds the states to develop and implement programs focused on children with special health care needs (CSHCN). These are *children that have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

Children with special health care needs and their families who live in Delaware receive care and services from state and community agencies. The Office of Children with Special Health Care Needs in the Division of Public Health is responsible to ensure access to services and coordination of those services for children with special health care needs from birth to 21 years of age. Service is to be family-centered, community-based, culturally competent, coordinated, comprehensive, cost-effective, and compassionate.

Currently, Delaware does not have a comprehensive CSHCN program or agency responsible to provide direct care and services. CSHCN represents a population of children with needs that are varied and complex. It is difficult to obtain an accurate number of this population and their needs, since there is no one agency that serves as the point of entry for service delivery. Therefore, a comprehensive needs assessment is needed to effectively identify the needs of CSHCN of Delaware.

The strategy selected by the State of Delaware is being executed through the accomplishment of three objectives. First, a statewide steering committee has been formed from a selected group of public agencies and consumers. They provide oversight for the execution of the strategy. Second, sources of data available that can inform the strategy must be identified or developed. Third, a needs-assessment must be developed that will identify and document the resources and the strengths, as well as the unmet health care needs or gaps in health services.

This report is one component of the overall needs assessment. It examines the current health status of and services received by a sample of children with special health care needs. This information should assist the steering committee in their oversight role and the Division of Public Health in their future planning and execution of the strategy to serve this population.
Methodology

The method chosen to gather the information about this population was a telephone survey. The survey instrument was designed by the University of Delaware’s Center for Disabilities Studies, the Division of Public Health, and the CSHCN steering committee. The Center for Applied Demography and Survey Research (CADSR) refined, edited, pre-tested and executed the survey.

The study began with a list of 1500 children ages 4 to 7 drawn from the Integrated Services Information System (ISIS) database of clients held by the Delaware Department of Health and Social Services. This list was culled based on the service coordinator’s name to 505 children who were originally part of Delaware’s early intervention program, Child Development Watch (CDW), when they were ages 0 to 3. This group of children would have qualified as special needs children at the time of their CDW eligibility.

Because there were significant issues with respect to the protection of human subjects, a precise protocol was developed and executed to ensure that participants and non-participants were protected from any concerns that they might have had. The protocol required that each potential participant (505) be contacted first by mail by the CSHCN Director. A second letter was mailed to all non-respondents and a phone call was made to the remaining non-respondents.

Participants were required to return an informed consent form. That form also confirmed their personal information and indicated a preferred time for contact by telephone. Each respondent was sent a letter with specific information about the telephone survey date and time. A CADSR interviewer then contacted the individual by telephone to conduct the interview. All of those who completed the survey were mailed a check for $25.00 and an immunization schedule.

Of the 505 potential participants, 116 agreed to participate and completed the survey. While the response rate is not as high as was hoped for, it is perhaps understandable given the length of time that had elapsed since the participants were active clients, as much as 4 years. Given the exploratory nature of this research, perhaps the low response rate is less of a concern. However, the results presented here should be extrapolated to the entire population with caution.
The instrument itself explored a number of different aspects of the CSHCN study participants. Sections of the survey included primary care, specialty care, hospital care, durable medical equipment, health care, therapies and other services, childcare, case coordination, and demographics. Many of these areas were quite detailed. However, the limited number of interviews will preclude an in-depth analysis in many cases. Where possible, the detailed information is aggregated to provide a higher-level interpretation of the results.

The report is divided into three primary sections that follow this overview. The first substantive section deals with the respondents. This section addresses their characteristics with appropriate comparisons to the target population and/or families in Delaware. The intent is to provide a basic understanding of the nature of the sample and how it differs (if at all) from the target population and families in general.

The next section examines the health care circumstances and the environment in which the respondent’s family lives. This analysis establishes the larger framework within which health care occurs. In addition, some measures of satisfaction with services delivered will be presented. This material will give some guidance on the degree of unmet needs in this sample.

The last substantive section covers a range of health care services that may or may not be used by the respondents. The two primary issues addressed will be the availability of and the satisfaction with this spectrum of services.
Demographics

In order to properly interpret the information in the survey of CSHCN families, it is important to understand the characteristics of the sample obtained. There are two issues that must be addressed. First, any needs assessment must understand the basic characteristics of its target clientele and how they compare with families in Delaware overall. Second, it is important to understand the relationship between those who responded to the survey and the entire group of potential respondents. This latter issue frames the question as to how comfortable one should be in extrapolating from the sample to the population from which it was drawn.

Figure 2.1
Gender of the Child

<table>
<thead>
<tr>
<th></th>
<th>Sample</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>67.2</td>
<td>55.8</td>
</tr>
<tr>
<td>Female</td>
<td>32.8</td>
<td>44.2</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

The list of CDW children used for obtaining a sample of respondents also contained several demographic characteristics that help in understanding the nature of that population and the sample obtained. The first of these is the gender of the child, which is shown in Figure 2.1, above. The sample clearly has a larger percentage of males than the population from which it was drawn, 67.2% compared with 55.8%. (In any given year approximately 51% of all births are males.) However, from a statistical perspective, the difference is significant since sampling error can only account for about 8% of the 11.4% difference. Within the sample, 14% of the
respondents felt that their child no longer had a special health care need. That group was significantly weighted toward females. If non-respondents were more likely to feel that their child no longer had this need, then that could explain the difference. In any event, all indications are that the male children are more likely to have a special health care need.

**Figure 2.2**

Race of the Child

<table>
<thead>
<tr>
<th></th>
<th>Caucasian</th>
<th>African American</th>
<th>Other Race/Multi-racial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample</td>
<td>71.6</td>
<td>21.6</td>
<td>6.8</td>
</tr>
<tr>
<td>All</td>
<td>57.1</td>
<td>30.1</td>
<td>12.8</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

The racial distribution of the sample is found in Figure 2.2, above. The Caucasian respondents were more likely to participate in the survey than either African American families or those of other races. The differences observed are statistically significant, but once again they are not major distortions of the underlying population. The sample results are similar to Delaware’s racial distribution (79% Caucasian). The CDW population from which the sample was drawn has a much higher proportion of minorities than is found in Delaware. Both sets of information suggest that CSHCN are somewhat more likely to come from minority families, but not remarkably so.

The rapid growth of the Hispanic community in Delaware, particularly in Sussex County, makes this population of particular interest. There have been concerns about the lack of sufficient Spanish speakers in the health care provider community and this would be particularly important if many Hispanic children qualify as CSHCN candidates. The distribution of Hispanic origin is found in Figure 2.3, below.
The Non-Hispanic respondents were more likely to participate in the survey than those of Hispanic origin (2.6% compared with 8.9%). The differences observed, however, are statistically significant, but once again they are not major distortions of the underlying population. Two additional Hispanic families who responded by mail were unable to be contacted by phone during the survey period. If they had been contacted, the sample proportion would not have been significantly different than that of the population. The sample results are similar to Delaware’s Hispanic distribution (4% Hispanic). The CDW population from which the sample was drawn tends to be weighted toward Hispanics. However, neither set of data can suggest that CSHCN clients are more likely to be Hispanic.

The age of the child is constrained by the population from which it was drawn. The CDW children were all ages 0 to 3 four years ago and thus are 4 through 7 years of age during the survey period. The age distribution of the sample and the population from which it was drawn is shown in Figure 2.4, below.
The sample mirrors the population from which it was drawn with the exception of the seven-year olds. Even there, the differences are not statistically significant. The average of the sample is 5.7 years, while the average age of the CDW population was 5.6 years. This variable has not been appreciably altered by any non-response bias.

This distribution is quite different from that found in the population at large where all four groups would be nearly equally distributed, i.e., 25% in each category +/- 1%. This difference is probably attributable to the fact that the more time passes from birth, the higher the probability of identifying a special health care need.

Two variables that help describe the CSHCN family’s living arrangement are found in Figures 2.5 and 2.6, below. The first attribute is the size of the respondent’s household. This distribution is contrasted to the size of families in the state as a whole. (No information is available for the population (CDW) from which the sample was drawn.) While the two distributions are not at all dissimilar, the CSHCN families do tend to be a bit larger.
**Figure 2.5**
Size of the Child’s Household

![Bar chart showing size of child's household](image)

<table>
<thead>
<tr>
<th>Size of Household</th>
<th>Sample</th>
<th>Delaware</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>2.6</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>19.8</td>
<td>28.8</td>
</tr>
<tr>
<td>4</td>
<td>44</td>
<td>33</td>
</tr>
<tr>
<td>5</td>
<td>22.4</td>
<td>22</td>
</tr>
<tr>
<td>6+</td>
<td>11.2</td>
<td>8.2</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

**Figure 2.6**
Number of Children in the Household

![Bar chart showing number of children in household](image)

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Sample</th>
<th>Delaware</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13.8</td>
<td>33.3</td>
</tr>
<tr>
<td>2</td>
<td>47.4</td>
<td>44.8</td>
</tr>
<tr>
<td>3</td>
<td>23.3</td>
<td>14.9</td>
</tr>
<tr>
<td>4+</td>
<td>15.4</td>
<td>7</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
The reason for this difference in household size is more apparent when the number of children in the household is considered (see Figure 2.6, above). There are more children in CSHCN families than in Delaware families in general.

There are several implications associated with this finding. First, larger numbers of children in the family may mean that there are fewer resources available to any one that may have special health care needs. Second, it may simply mean that the more children that are in a family, the higher the probability that one will have a special health care need.

Figure 2.7
Child’s Caregiver

Another characteristic of interest is the identity of the caregiver. That information is provided in Figure 2.7, above. The figure holds few surprises. Mothers are overwhelmingly the primary caregivers. As family structure and custody arrangements change, this may not hold true in the future. Today, grandparents are raising nearly five percent of Delaware children. In addition, the number of families with children under the age of 18 headed by unmarried males has nearly doubled from 3% to 6% in Delaware over the last decade.
Figure 2.8
Family Income of the Child’s Household

![Bar chart showing family income distribution.]

- Sample
  - $0 to $20k: 20.6%
  - $20k to $35k: 27.6%
  - $35k to $50k: 13.8%
  - $50k to $75k: 18.1%
  - $75k up: 16.4%
  - DK/RF: 3.5%

- Delaware
  - $0 to $20k: 15.3%
  - $20k to $35k: 18.9%
  - $35k to $50k: 16.2%
  - $50k to $75k: 22.9%
  - $75k up: 26.7%
  - DK/RF: 3.5%

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 2.9
Participation of the Child’s Household in Government Programs

![Bar chart showing government program participation.]

- Participate?
  - Medicaid/PA: 41.4%
  - SSI: 12.1%
  - Food Stamps: 13.8%
  - WIC: 12.1%
  - SSDI: 6%

Source: Center for Applied Demography & Survey Research, University of Delaware
The next two variables considered in this section address family resources and resources that they may be receiving from the state. The results for these are found in Figures 2.8 and 2.9, above.

The level of family income is usually a good indicator of whether the family has access to resources to cope with the special health care needs of a child. It may also suggest whether or not they may be able to access state government programs that are means tested.

It is important to note that Child Development Watch is Delaware’s Part C of the Individuals with Disability Education Act. Therefore, CDW is an entitlement program to ensure early intervention services to all children.

As the graph shows, the respondent families have a tendency toward the lower end of the income distribution. More than 48% of the families in the sample are in the lower two income groups in comparison with 34% for the state as a whole. However, the fact that more than 16% of the sample families have incomes exceeding $75,000 indicates that the program has broad applicability.

The findings with respect to income levels are corroborated by the data in Figure 2.9, above. More than 40% of the sample families have access to Medicaid, which means they roughly must have incomes below 180 percent of the poverty level. The poverty level for the 1 to 5 year olds is 133% and 6 to 7 year olds is 100% of poverty level. Disabled Children’s Medicaid is not based on income. About 12% of the families also have access to the WIC program for women, infants, and children and nearly 14% are using food stamps.

The final variable considers the existence of multiple special health care needs children in the same household. This situation puts additional strain on the resources of the family, as well as the caregiver’s time available to provide the necessary attention and management. In Figure 2.10 below, more than a quarter of the CSHCN families are coping with more than one child with a special health care need. The Not Applicable class reflects those families that feel they no longer have a special health care need. The demands of this situation will vary considerably depending on the intensity of the problem. The fact that this proportion is so high must be taken into account when providing support and coordination of services to the families.
Overall, the demographic information suggests that the CSHCN strategy is impacting a wide spectrum of children in need across the state. Further, there are indications that it is reaching families who are likely to have fewer resources to deal with their challenges. While the data from the sample departs somewhat from the population of former CDW children that formed the population for the study, the differences do not appear to be large enough to influence the interpretation of the rest of the results.

In the next section, the health care environment of the CSHCN families will be addressed in detail.
Health Care Environment

Introduction

The health care environment, that the child is part of, to some extent will determine how well the needs of these children are met. In this section, four general areas are considered.

The first area is the child’s overall condition. The nature and the intensity of the special health care need will heavily influence the need for a strategy like CSHCN. Those with multiple conditions and varied treatment protocols will particularly benefit from service coordination.

The second area is the family’s current experience with those providing primary care. The primary care physician is a key part of the management of the child’s condition. If there are problems with this relationship or simply access to the primary care physician, outcomes could be less than optimal.

The third area is childcare. Access to childcare that can deliver the appropriate supervision and attention in the absence of the primary caregiver can be crucial.

The final issue is the current situation with respect to health care coverage for the child. Access to appropriate health care is significantly impacted by the type and extent of health coverage. Those families who are uninsured or underinsured and do not qualify for alternative sources of coverage, such as Medicaid, may not be able to provide the services required by their child.

For the most part only information provided by the sample is available. On occasion, contrast information for the US or Delaware will be provided.

Health Status

Each respondent was asked to give a general assessment of the child’s health. Their responses are displayed in Figure 3.1, below. To provide a contrast, the distribution for all children 4 to 7 years of age in the US is also included. (Delaware data for that age group in CADSR databases was too small to be reliable.)
More than half of the children in the sample are considered to be in **excellent** health according to their caregiver. This proportion compares very well with the US proportion and is not statistically different from it. The major differences are clearly at the lower end of the distribution in particular the proportion of children in **fair** health.

![Figure 3.1]

**Child’s General Health**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Sample</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>56.9</td>
<td>51.5</td>
</tr>
<tr>
<td>Very Good</td>
<td>28.5</td>
<td>30.5</td>
</tr>
<tr>
<td>Good</td>
<td>8.6</td>
<td>15.8</td>
</tr>
<tr>
<td>Fair</td>
<td>6</td>
<td>1.9</td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
<td>0.3</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

These results may seem contradictory until the range of possible conditions that could qualify a child as having a special health care need is considered. This is made clearer by Figure 3.2, below. In Figure 3.2, the most frequently occurring conditions are **speech problems** (47.4%), **developmental delay** (44%), and **learning disabilities** (31.9%). While these conditions are serious, they may not be perceived as affecting physical health. Clearly the caregiver is making a distinction when providing the information about health status.

Of the physical conditions, **asthma** is the only one that afflicts more than 10% of the sample (19.8%). **Hearing impairment** is second and affects 9.5% of the sample. The spectrum of conditions is broad with only three of the 29 conditions failing to surface in a sample as small as this.
**Figure 3.2**
Child’s Medical Conditions

<table>
<thead>
<tr>
<th>Special Need</th>
<th>Patients</th>
<th>% of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood Disorder</td>
<td>4</td>
<td>3.4%</td>
</tr>
<tr>
<td>Cancer</td>
<td>1</td>
<td>0.9%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>9</td>
<td>7.8%</td>
</tr>
<tr>
<td>Asthma</td>
<td>23</td>
<td>19.8%</td>
</tr>
<tr>
<td>Cystic fibrosis</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Cleft lip/palate</td>
<td>2</td>
<td>1.7%</td>
</tr>
<tr>
<td>Chronic rheumatic disease</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Congenital heart disease</td>
<td>3</td>
<td>2.6%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>0.9%</td>
</tr>
<tr>
<td>Digestive disorder</td>
<td>9</td>
<td>7.8%</td>
</tr>
<tr>
<td>Kidney disease</td>
<td>3</td>
<td>2.6%</td>
</tr>
<tr>
<td>Seizure disorder</td>
<td>4</td>
<td>3.4%</td>
</tr>
<tr>
<td>Brain injury</td>
<td>5</td>
<td>4.3%</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>2</td>
<td>1.7%</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>3</td>
<td>2.6%</td>
</tr>
<tr>
<td>Paralysis</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Neurological disease</td>
<td>1</td>
<td>0.9%</td>
</tr>
<tr>
<td>Orthopedic problem</td>
<td>9</td>
<td>7.8%</td>
</tr>
<tr>
<td>Autism</td>
<td>4</td>
<td>3.4%</td>
</tr>
<tr>
<td>Behavior problem</td>
<td>22</td>
<td>19.0%</td>
</tr>
<tr>
<td>Other mental problems</td>
<td>7</td>
<td>6.0%</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>2</td>
<td>1.7%</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>7</td>
<td>6.0%</td>
</tr>
<tr>
<td>Learning disability</td>
<td>37</td>
<td>31.9%</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>11</td>
<td>9.5%</td>
</tr>
<tr>
<td>Vision impairment</td>
<td>8</td>
<td>6.9%</td>
</tr>
<tr>
<td>Speech</td>
<td>55</td>
<td>47.4%</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>51</td>
<td>44.0%</td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
<td>13.8%</td>
</tr>
</tbody>
</table>

*Source: Center for Applied Demography & Survey Research, University of Delaware*

One other aspect of this issue is displayed in Figure 3.3, below. Many of the children are afflicted with multiple conditions. In fact, more than a fifth of the sample exhibits five or more of the listed conditions. This undoubtedly presents significant challenges for the caregiver in coordinating and accessing services for the child.
Figure 3.3
Number of Medical Conditions

Percent

<table>
<thead>
<tr>
<th>Conditions</th>
<th>None</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 or More</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21.6</td>
<td>20.7</td>
<td>15.5</td>
<td>12.9</td>
<td>8.6</td>
<td>20.7</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 3.4
Time Known about Child’s Special Need

Percent

<table>
<thead>
<tr>
<th>Time</th>
<th>37.9</th>
<th>4.3</th>
<th>13.8</th>
<th>30.2</th>
<th>13.8</th>
</tr>
</thead>
<tbody>
<tr>
<td>From Birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>less than 1 year</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 to 3 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 3 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No special Need</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
The final aspect of this issue was when the condition was first discovered. This is addressed in Figure 3.4, above. There is definitely a bi-modal distribution here. The largest single subset of the sample is diagnosed at birth. The second group is diagnosed at a much later time. Of course, the developmental conditions will not reveal themselves as expeditiously as do many of the other conditions. One implication of this distribution is that there is a need for a good medical home so that these late developing or latent conditions can be detected as soon as possible.

**Primary Care**

For the reasons mentioned above and many others, it is important that these children and, in fact, all children have a medical home. Fortunately, all but two of the respondents to the survey responded that their child had a medical home. Given that 15% of all children in Delaware age 0 to 17 are without health insurance, these results are particularly positive. This also may be the result of being associated with the CDW program as well or it may reflect the fact that the caregiver, when faced with the special needs of the child, is particularly aggressive in obtaining appropriate care.

**Figure 3.5**

Child has a Medical Home

<table>
<thead>
<tr>
<th>Medical Home?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>98.3</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
Figure 3.6
Location of Child’s Medical Home

<table>
<thead>
<tr>
<th>Location</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private Office</td>
<td>71.9</td>
</tr>
<tr>
<td>Hospital Clinic</td>
<td>19.3</td>
</tr>
<tr>
<td>Public Health Clinic</td>
<td>1.2</td>
</tr>
<tr>
<td>Other</td>
<td>7.6</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 3.7
Satisfaction with Child’s Medical Home

<table>
<thead>
<tr>
<th>Satisfied?</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>84.1</td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td>13.3</td>
</tr>
<tr>
<td>Unsatisfied</td>
<td>2.6</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

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The responses with respect to the location of the medical home are tabulated in Figure 3.6, above. The most notable feature of this display is that nearly 20% use a hospital clinic. This may reflect the duPont Hospital for Children’s outreach efforts through their satellite PCP offices. While these facilities are not technically clinics, the participants may be reporting them as such. Unfortunately, there appears to be no comparable data source to see how different this profile is from the general population.

The largest majority of respondents is very satisfied with the child’s medical home (see Figure 3.7 above) with a very small number indicating that they were unsatisfied. These results are very similar, although not strictly comparable, to those observed annually in the Consumer Assessment of Health Plans Survey (CAHPS) conducted monthly for the Delaware Health Care Commission.

One of the better measures of access to health care is the wait time for an appointment. Respondents were asked how long they would have to wait for an appointment if their child were sick. The results were overwhelmingly positive with 92% reporting same day service (see Figure 3.8 above). Physicians report that their typical wait times for a non-emergency appointment is 8.6 days. This suggests the medical community is being very responsive in almost all cases.

Figure 3.8
Wait time for an Appointment for a Sick Child

<table>
<thead>
<tr>
<th>Wait Time</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same day</td>
<td>92</td>
</tr>
<tr>
<td>Next day</td>
<td>7.1</td>
</tr>
<tr>
<td>2+ days</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
The immunization record is another indicator of the child’s medical care and in particular, how systematic it is. Respondents were asked if their child’s immunizations were up to date and their responses are found in Figure 3.9, below. It shows that almost all of these children have been properly immunized. However, before one uses this information, there is considerable discussion in the health care arena about the accuracy of self-reported immunization compliance. The results of independent studies rarely agree with state immunization registries. The latest information from the Centers for Disease Control and Prevention suggests that 81% of Delaware’s 0-3 population has had the required series. That is well below what is reported in the sample. This may reflect the high proportion with a medical home.

**Childcare**

The challenge of finding appropriate childcare at a reasonable cost for a child with special health needs may be significant. The first issue is how many of CSHCN children and families are in this situation. The results for the sample are shown in Figure 3.10, below.
Figure 3.10
Child Requires Childcare

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Care?</td>
<td>38.8</td>
<td>61.2</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 3.11
Is Childcare Hard to Find?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hard to Find?</td>
<td>13.3</td>
<td>86.7</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
Within this particular sample somewhat less than half of the families with CSHCN children require childcare services. Since we don’t know the employment status of the caregiver, it is hard to say whether this is a large number or a small one with respect to the population in general. Approximately 60% of all children under the age of 13 are in need of childcare services, i.e., the parent(s) are employed. The proportion would be smaller for families since those with multiple children would only be counted once. This suggests that the proportion observed in this sample is probably not inconsistent with the overall population.

In the spring of 1999 the Division of Public Health conducted a Healthy Child Care Survey to determine ways that the state can further promote the health and safety of children (birth to 12) in Delaware’s child care system. The statewide survey was sent to 2,279 licensed child care providers, including 304 child care centers and 1,975 family day care providers. The overall response rate was 25.1 percent. The response rate for childcare centers was 33.9 percent, as compared to 23.4 percent family day care providers. Of the child care centers, 65 percent are located in New Castle County, with the remaining generally equally distributed between the more rural Kent and Sussex counties (16 and 19 percent, respectively). The distribution of family daycare providers was 56, 19, and 25 percent in New Castle, Kent, and Sussex counties, respectively.

Overall, the majority of childcare providers, 69 percent, state they do serve CSHCN. Types of health conditions experienced by CSHCN in child care settings include: allergies, asthma, ADHS, developmental delay; speech disability; special diet; hearing disability; seizure; apnea; visual disability; mental retardation; and major organ condition. It is important to note that technically dependent children were not represented in this population. Also, medical treatment is rarely provided by medically trained staff.

Respondents were asked if they had any difficulty finding appropriate childcare. As can be seen in Figure 3.11 above, the answer is largely **no**. Less than 15% of the families that need childcare services report any problem finding the required services.
Childcare services are delivered at a variety of locations as is shown in Figure 3.12 above. There are two primary sources; the formal daycare center setting and the home of another individual. This latter option has always been heavily exercised within the minority community. It also is likely to be the only option for infants in some areas, although that does not apply in this case. Somewhat more than half of Delaware’s schools have some type of daycare arrangements and that is reflected in these numbers as well.

Those respondents who used childcare were asked how much they were paying for those services (see Figure 3.13, below). The overwhelming majority of respondents pay under $100 out-of-pocket per week. Given that the average cost for pre-school children in a center-based setting is slightly under $100 out-of-pocket per week, the results for the sample are quite consistent.
Figure 3.13
Cost of Childcare Services

<table>
<thead>
<tr>
<th>Cost/week</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>$0 to $100</td>
<td>93.2%</td>
</tr>
<tr>
<td>$101 to $200</td>
<td>4.6%</td>
</tr>
<tr>
<td>Over $200</td>
<td>2.2%</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 3.14
Medical Services Needed in Childcare

<table>
<thead>
<tr>
<th>Services</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>88.6%</td>
</tr>
<tr>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>2 or more</td>
<td>5.4%</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
There are those who pay much more for childcare and that may be related to the number of medical services that are required by the child while in the daycare setting. This is suggested in Figure 3.14, above. The vast majority of respondents report that their children do not require any services. Surprisingly, there is very little correlation between the higher payments for childcare and the number of services required. It may be that these services are not paid for “out-of-pocket”.

Health Insurance

A person’s access to health care is significantly influenced by that person’s access to health insurance of some type. Earlier in the report it was shown that almost all sample respondents had a medical home. This is also a key indicator of having health insurance.

![Figure 3.15](image-url)

This is confirmed in Figure 3.15, above. Over 98% of the CSHCN children have that access. This compares very favorably with 86.6% of children 4 to 7 who have health insurance statewide.
Part of the reason why this rate is so high can be seen in Figure 3.16, above. As was shown earlier in the demographic section, nearly half of this sample has access to health care through Medicaid. (The percentages in the table do not add to 100% because some respondents have access to more than one kind of health coverage.) This reflects the lower income characteristic of the sample and the fact that some disabled children have access to Medicaid independent of their family income level.

The level of satisfaction that was found with the child’s medical home is not replicated with the health plan. Less than 60% are very satisfied with the child’s health plan (see Figure 3.17, below). Usually this is related to coverage or associated out-of-pocket costs. In the CAHPS survey satisfaction with the health plan was only slightly less than satisfaction with their physician. Those data are only available for adults, but the correlation with the experience of their children should be high. In this case, the problem may be that the demands placed on the health plans are more extensive given the conditions exhibited by the children.
Figure 3.17
Satisfaction with Child’s Health Care Plan

<table>
<thead>
<tr>
<th>Satisfied?</th>
<th>Very Satisfied</th>
<th>Somewhat Satisfied</th>
<th>Unsatisfied</th>
<th>Don’t Know</th>
</tr>
</thead>
</table>
| Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 3.18
Length of Time Covered by Child’s Health Care Plan

<table>
<thead>
<tr>
<th>Time</th>
<th>Less than 1 year</th>
<th>1 to 2 years</th>
<th>2 to 5 years</th>
<th>More than 5 years</th>
<th>Don’t Know</th>
</tr>
</thead>
</table>
| Source: Center for Applied Demography & Survey Research, University of Delaware
Finally, the length of time the child has been in the current health plan is displayed in Figure 3.18, above. Since these children are all 4 years old or older, there is substantial evidence of switching or being forced to switch plans. In a truly stable environment, one third of the sample would not have switched plans during a four-year period. It is possible that a change in the economic circumstances of the family made Medicaid eligibility a possibility and thus a shift occurred.

There are also significant reasons for switching plans. Two managed care organizations withdrew their Medicaid programs forcing parents to seek another plan. If the child becomes disabled, the child becomes eligible for Disabled Children’s Medicaid. Changes in PCPs, specialists, therapists, and other vendors may be a contributing factor as well.

In the next section, services delivered to the child by the health care system will be examined. In particular, experiences with specialists, hospitals, and the availability of medical durables will be addressed.
Services

Introduction

In order to better understand the variety and complexity of services required by children with special health care needs, respondents were asked about four major areas. After discussing each area, this section closes by examining the coordination of these services.

The first area concerns the use of specialists. The range of specialists reveals the range of services that must be coordinated. The second area focuses on hospital care to the extent that it is needed at all. The third area addressed is the use of durable medical equipment. A range of potential aids is considered. Finally, respondents were asked about the therapies that their child might require.

Specialty Care

Earlier in the section on the health care environment, the various conditions experienced by the sample of families were detailed. Since that list was broad, if not deep, it is no surprise to find a wide variety of specialists serving this group of children. The results are found in Figure 4.1, below.

All of the specialties addressed in the survey had at least one respondent reporting the use of their services. Undifferentiated dental services were the leader and this is not a surprise. What may be of concern is the somewhat lower proportion of those who need the service that actually receive it. This may have something to do with the shortage of dentists who would treat Medicaid patients in earlier years. The CADSR’s 1998 dental survey is an excellent reference that validates the statewide dentist shortage. Currently, the DPH has a Dental Director who is addressing the dental issues.

Overall, the respondents indicate that they are getting the services that they need. This may in large part reflect the fact that the children in this sample are covered by a health plan and have a medical home. This may not be true for the broader population of children with special health care needs.
### Figure 4.1
Specialty Care by Type

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Patients</th>
<th>% of Children Needing Service</th>
<th>Patients Using</th>
<th>% of Children Receiving Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergist</td>
<td>11</td>
<td>9.5%</td>
<td>10</td>
<td>90.9%</td>
</tr>
<tr>
<td>Cardiologist</td>
<td>7</td>
<td>6.0%</td>
<td>7</td>
<td>100.0%</td>
</tr>
<tr>
<td>Dentist</td>
<td>116</td>
<td>100%</td>
<td>90</td>
<td>77.6%</td>
</tr>
<tr>
<td>Ear, Nose, &amp; Throat</td>
<td>31</td>
<td>26.7%</td>
<td>25</td>
<td>80.6%</td>
</tr>
<tr>
<td>Endocrinologist</td>
<td>3</td>
<td>2.6%</td>
<td>2</td>
<td>66.7%</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>6</td>
<td>5.2%</td>
<td>6</td>
<td>100.0%</td>
</tr>
<tr>
<td>Hematologist/Oncologist</td>
<td>3</td>
<td>2.6%</td>
<td>3</td>
<td>100.0%</td>
</tr>
<tr>
<td>Nephrologist</td>
<td>3</td>
<td>2.6%</td>
<td>3</td>
<td>100.0%</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>26</td>
<td>22.4%</td>
<td>25</td>
<td>96.2%</td>
</tr>
<tr>
<td>Orthopedist</td>
<td>11</td>
<td>9.5%</td>
<td>10</td>
<td>90.9%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>15</td>
<td>12.9%</td>
<td>12</td>
<td>80.0%</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>8</td>
<td>6.9%</td>
<td>7</td>
<td>87.5%</td>
</tr>
<tr>
<td>Pulmonary Specialist</td>
<td>4</td>
<td>3.4%</td>
<td>4</td>
<td>100.0%</td>
</tr>
<tr>
<td>Rheumatologist</td>
<td>1</td>
<td>0.9%</td>
<td>1</td>
<td>100.0%</td>
</tr>
<tr>
<td>Urologist</td>
<td>8</td>
<td>6.9%</td>
<td>1</td>
<td>87.5%</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

### Figure 4.2
Number of Specialists Per Child

<table>
<thead>
<tr>
<th>Number of Specialists</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>42</td>
</tr>
<tr>
<td>2</td>
<td>37</td>
</tr>
<tr>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>5 or more</td>
<td>6</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
The complexity of the problems faced by the children and their families is also evident in Figure 4.2, above. More than half of the families must deal with more than one specialist and a small number have to coordinate services with five or more.

**Figure 4.3**

*Number of Specialists Needed but Not Seen*

<table>
<thead>
<tr>
<th>Specialists</th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>68.1</td>
<td>28.4</td>
<td>3.4</td>
</tr>
</tbody>
</table>

*Source: Center for Applied Demography & Survey Research, University of Delaware*

The data displayed in Figure 4.1 showed the difference between children needing a specialist and actually seeing that specialist. Figure 4.3 above, complements that information by looking across all specialists. Nearly 70% of the children are being seen by all of the specialists that they require. Almost 80% of those who have not seen one of the required specialists need to see a dentist. Overall, it appears that the children are receiving most of the services they need.

Finally, respondents were asked who had suggested that their child should see a specialist. Those results are found in Figure 4.4, below. If anything is surprising in these data, it is the fact that less than one third of the respondents report that their physician/nurse suggested that they do so. In fact, family members are almost as likely to do so. The reason here may be found in the fact that many of the conditions referenced (behavior, learning disability, developmental delay and speech) are not viewed as within the purview of all primary care physicians.
Figure 4.4  
Who Suggested that a Specialist was Needed?

![Bar chart showing the percentage of children suggested by different sources.](chart1)

<table>
<thead>
<tr>
<th>Source</th>
<th>Doctor</th>
<th>Family Member</th>
<th>Friend</th>
<th>Teacher</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>31.9</td>
<td>29.3</td>
<td>10</td>
<td>7.8</td>
<td>74.1</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 4.5  
Child Admitted to a Hospital

![Bar chart showing the percentage of children admitted to the hospital.](chart2)

<table>
<thead>
<tr>
<th>Admitted</th>
<th>None</th>
<th>Once</th>
<th>More than Once</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>88</td>
<td>6.9</td>
<td>5.1</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
Hospital Care

Respondents were asked a series of questions about their experiences with hospitalization of their child. Unfortunately, the sample size precludes any in-depth analysis of the responses. For this sample only 12% of the children were hospitalized during the past year (see Figure 4.5, above).

While most of the admissions were to Delaware hospitals, a few were to hospitals out of the state. The most frequently stated reason for going to another state was that the service was not available in Delaware. The majority of the admissions were for purposes of surgery.

Durable Medical Equipment

Respondents were asked if their child required any of the following durable medical equipment i.e., a wheelchair, braces, hearing aids, glasses, communication device, and/or respiratory equipment. The sample sizes were too small to produce meaningful information for any one item. However, it is possible to report the responses in aggregate. Those data are displayed in Figure 4.6, below.

Figure 4.6
Child Needs Durable Medical Equipment

<table>
<thead>
<tr>
<th>Equipment</th>
<th>No</th>
<th>One item</th>
<th>More than One Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source: Center for Applied Demography &amp; Survey Research, University of Delaware</td>
<td>74.1</td>
<td>16.4</td>
<td>9.5</td>
</tr>
</tbody>
</table>
Just over one quarter of the respondents report needing access to one or more of the listed equipment. And nearly 10% needed access to more than one item. However, needing equipment of this type and actually having it can be two different things. Fortunately, for this sample, their needs are largely being met. In Figure 4.7 below, over 93% of those in the sample who have a need for durable medical equipment have acquired the necessary items.

**Figure 4.7**
Child Has Unmet Needs for Durable Medical Equipment

<table>
<thead>
<tr>
<th>Equipment?</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>93.1</td>
<td>6.9</td>
</tr>
</tbody>
</table>

*Source: Center for Applied Demography & Survey Research, University of Delaware*

**Therapies**

Respondents were asked if their child required any of the following therapies or services i.e., audiology, nursing, nutrition, occupational therapy, physical therapy, counseling, respite care, speech therapy, transportation, or vision services. The small sample size restricts the depth of the analysis although some findings are appropriate to report.

Over 60% of the respondents replied affirmatively to one or more of the options. In fact, 44% of the respondents reported that their child received two or more of these services and nearly 20% required four or more. These findings reflect the complex and varied nature of the conditions found within this sample of children.
**Figure 4.8**
Child Has a Need for Therapies/Services

<table>
<thead>
<tr>
<th>Therapies</th>
<th>None</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>37.9</td>
<td>17.2</td>
<td>18.1</td>
<td>7.8</td>
<td>19</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

**Figure 4.9**
Location of Therapy

<table>
<thead>
<tr>
<th>Location</th>
<th>Home</th>
<th>Daycare</th>
<th>Hospital</th>
<th>School</th>
<th>Doctor</th>
<th>Clinic</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>9.7</td>
<td>2.8</td>
<td>7</td>
<td>80.6</td>
<td>16.7</td>
<td>9.7</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
The vast majority of all services are delivered in the schools rather than at home or in a day care (see Figure 4.9 above). This may make it easier or it may make it harder to coordinate services depending on the individual child’s situation. Issues of least restricted environment/natural environment, lack of parent involvement, and carry over of therapeutic interventions to functional activities of daily living presents a challenge to therapies provided exclusively in the school setting.

**Service Coordination**

Based on the information provided in this section, it is not difficult to conclude that many families with children having special health care needs are facing a challenging task in obtaining and organizing the services the child needs. One way of alleviating the difficulty of this task is to assign a service coordinator who has the expertise to help families navigate through the health care maze of providers, services, and health care benefits.

![Figure 4.10](image)

**Child has a Service Coordinator**

The information provided in Figure 4.10 above, shows that in large part the respondents do not currently have a service coordinator. The reason for this is simply because comprehensive service coordination is lost once a child leaves CDW. Case management may be provided through other State and community agencies; however, comprehensive care
Figure 4.11
Service Coordinator Helps with Scheduling Services

<table>
<thead>
<tr>
<th>Schedules?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>73.9</td>
<td>26.1</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

Figure 4.12
Location of Service Coordinator

<table>
<thead>
<tr>
<th>Location</th>
<th>Health Department</th>
<th>School</th>
<th>Other</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21.7</td>
<td>17.4</td>
<td>43.5</td>
<td>21.7</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware
coordination is not provided to the child with special health care needs and his/her family. For that reason, most of the respondents report that the caregiver is the service coordinator.

Those respondents that did have a service coordinator were asked if that person helped with scheduling. Those results are found in Figure 4.11 above. Almost three quarters of the respondents report that the service coordinator does help with scheduling. Apparently the others only assist with locating the needed services but do not take the next step.

Respondents that had an assigned service coordinator were asked where they were located. The choices included the following: hospital; doctor’s office; health department; managed care organization; mental health agency; school; don’t know; and other. As is evident in Figure 4.12 above, only four of those choices were mentioned. It appears that they are all in the state and/or community sector and that is to be expected. Of the specific responses, the Division of Public Health and the schools are the most frequently mentioned. The high number of “don’t know” responses suggests only that the respondents relate to people and not agencies.

Figure 4.13
Caregiver Coordinates Service Delivery

<table>
<thead>
<tr>
<th>Schedule?</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>83.6</td>
</tr>
<tr>
<td>No</td>
<td>16.4</td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

For the most part the caregivers coordinate the services for the child with special health care needs. This is apparent in Figure 4.13, above. This will undoubtedly create some problems with the delivery of services.
Even when asked for their own evaluation of how well coordinated the delivery of services is, only about two thirds of the respondents feel that the services are well coordinated (see Figure 4.14, below). In addition, there is very little difference between the evaluations from the full sample and those where the caregiver is responsible for these tasks. In short, it appears that this job requires someone other than the caregiver to be engaged. From the data, it also appears that service coordinators may have to increase their activities as well.

**Figure 4.14**
Level of Coordination of Service Delivery

<table>
<thead>
<tr>
<th>Percent</th>
<th>Always</th>
<th>Usually</th>
<th>Occasionally</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>63.5</td>
<td>14.8</td>
<td>16.5</td>
<td>5.2</td>
<td></td>
</tr>
<tr>
<td>Yourself</td>
<td>62.9</td>
<td>15.5</td>
<td>16.5</td>
<td>5.2</td>
<td></td>
</tr>
</tbody>
</table>

Source: Center for Applied Demography & Survey Research, University of Delaware

In the last section of this report, some concluding observations will be offered. These are intended to summarize and also to encourage further investigation of this topic.
Observations

- This report is intended as part of an overall needs assessment for the CSHCN strategy. The voluntary nature of the respondents and the sample size achieved limits generalization to the larger population of families and their children with special health care needs. Even with these limitations, there are interesting patterns within the data set that offer one direction for policy analysis and program development.

- Strategies to recruit parents of CSHCN to participate in a needs assessment need to be investigated.

- Obtaining the proper care for a child with special health care needs tends to be varied and complex.

- Socioeconomic status does not discriminate the need for a comprehensive CSHCN service delivery model.

- Mothers/Stepmothers continue to be identified as the child’s primary caregiver.

- Many CSHCN have more than one special need.

- Many households have more than one child with special health care needs.

- The health conditions span a broad range of diagnoses.

- The majority of children have a medical home.

- The majority of children have medical insurance.

- Most of the families that responded did not have a service coordinator once they left Child Development Watch.

- The primary care giver is also the one who must coordinate and schedule services. This responsibility may be too much when examining the level of success that they achieve in doing this complex task.

- Most therapeutic services tend to be delivered in the schools and far fewer at home or day care. This impacts caregiver involvement in the therapeutic regimen and the carry-over to activities of daily living.

- Data generated from this survey will provide primarily information for future CSHCN needs assessments.
Recruitment Letter

January 3, 2000

Dear

Your child (name from ISIS) has been randomly picked from the Child Development Watch (CDW) database, to be part of a telephone survey. Parents or caregivers will be asked about their 4-7 year olds who have been in the CDW Program; about 500 parents will be surveyed. Participation in the survey is completely voluntary and refusal to participate will involve no loss of services to your child. A $25.00 incentive will be given to all parents or caregivers who complete the survey.

The Division of Public Health (DPH) will be doing the telephone survey for Children with Special Health Care Needs (CSHCN). The survey will identify and document resources and strengths in existing health services. It will also point out unmet health needs or gaps in health services. This survey will give parents or caregivers of CSHCN the chance to describe their children’s needs. The survey will also help DPH obtain the needed information to enhance existing services and possibly develop new services.

DPH has contracted with the University of Delaware to conduct the survey in the fourth week of January 2000. This will be a telephone survey and all information will be kept confidential. If you do not have a phone, other arrangements can be made to include you in the survey. DPH will receive a report from the University of Delaware that shows how all parents answered the questions. DPH will not receive any information specifically about your child and family.

Prior to the survey, you will receive a letter telling you the date and the time of the telephone call. The survey should take about 15 to 30 minutes. You may discontinue participation at any time or refuse to answer any question(s) on the survey. Enclosed with this letter is a response sheet and a postage paid return envelope. Please complete the response sheet even if you do not want to be involved in the telephone survey. Responses are due by January 12, 2000. Not all people responding will be chosen for the survey. Only those people completing the survey will receive the $25.00.

Thank you for your support in this project for CSHCN. Together we can make a difference in the lives of our children with special health care needs.

Sincerely,

Loretta Newsom MSN, RN
CSHCN, Director
DELAWARE HEALTH AND SOCIAL SERVICES
Children with Special Health Care Needs
Needs Assessment Survey

Your answers are very important to us and will be helpful in making health care programs better in ways that benefit your family. Your participation in this survey is completely voluntary and you can skip any questions you don't want to answer. Your answers will be used to help understand what health services are needed. Your answers will be kept strictly confidential, and will in no way affect the services your child is currently receiving. Your answers will be grouped with those of others, so no one will be able to identify you or your child from the final survey report. The questions should take between 15 and 30 minutes to answer.

1. Date Survey Completed ____ ____ 2000

What is your child's first name? (Use this name wherever NAME OF CHILD appears.)

PRIMARY CARE
I am going to ask you questions about your child's primary health care provider. This is the doctor or nurse practitioner who gives NAME OF CHILD his/her routine medical check-ups and care, and who you take NAME OF CHILD to when he/she gets sick.

2. Do you have a regular health care provider where you obtain most of the health care services for NAME OF CHILD?
   [1] No (Go to question 7)
   [2] Yes

3. Where do you take NAME OF CHILD to get his/her basic health care and routine medical check-ups?
   [1] Private Medical Office
   [3] Hospital Clinic
   [5] Other

4. How satisfied are you with NAME OF CHILD's primary health care provider?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

5. When NAME OF CHILD is sick and you call your primary care provider for an appointment, can NAME OF CHILD usually get seen the same day?
   [1] Yes
   [2] No, but I can get an appointment for the next day
   [3] No, and it usually takes 2 or more days to be seen
6. What kind of difficulties have you had getting care from your primary health care provider? (Include all that apply)
   [1] I haven't had any difficulties
   [2] The office isn't open during times that are convenient
   [3] Difficulty getting appointments
   [4] Denial from insurance company
   [6] Language barrier
   [7] Transportation problems (no car, no public transportation, etc.)
   [8] Difficulty finding childcare for other children
   [9] Other
   [10] Staff does not know how to take care of my Special Needs child

7. Do you think NAME OF CHILD's immunizations (shots) are up to date?
   [1] Yes
   [2] No

8. Where do you take NAME OF CHILD to get his/her immunizations?
   [1] Private Medical Office
   [3] Hospital Clinic
   [5] Other

SPECIALTY CARE

The following questions relate to care provided by specialists.

9. Was NAME OF CHILD supposed to be seen by an Allergist (rash doctor) in the past year?
   [1] No (Go to question 13)
   [2] Yes

10. How did you know that NAME OF CHILD needed to be seen by an Allergist?
    [1] A doctor or nurse
    [2] A family member
    [3] A friend told us
    [4] Teacher
    [5] Other

11. Was NAME OF CHILD actually seen by an Allergist in the past year?
    [1] No
    [2] Yes
12. What difficulties did you have obtaining services from an Allergist
   [1] None (no difficulties)
   [2] There were no Allergists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

13. Was NAME OF CHILD supposed to be seen by a Cardiologist (heart doctor) in the past year?
   [1] No (Go to question 17)
   [2] Yes

14. How did you know that NAME OF CHILD needed to be seen by a Cardiologist?
   [1] A doctor or nurse
   [2] A family member
   [3] A friend told us
   [4] Teacher
   [5] Other

15. Was NAME OF CHILD actually seen by a Cardiologist in the past year?
   [1] No
   [2] Yes

16. What difficulties did you have obtaining services from a Cardiologist
   [1] None (no difficulties)
   [2] There were no Cardiologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

17. Was NAME OF CHILD seen by a Dentist (teeth doctor) in the past year?
   [1] No
   [2] Yes
17a. How did you know that **NAME OF CHILD** needed to be seen by a Dentist?
   [1] A doctor or nurse
   [2] A family member
   [3] A friend told us
   [4] Teacher
   [5] Other

18. What difficulties did you have obtaining services from a Dentist?
   [1] None (no difficulties)
   [2] There were no Dentists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

19. Was **NAME OF CHILD** supposed to be seen by an Ear, Nose and Throat Specialist (ENT) in the past year?
   [1] No (Go to question 23)
   [2] Yes

20. How did you know that **NAME OF CHILD** needed to be seen by an Ear, Nose and Throat Specialist?
   [1] A doctor or nurse
   [2] A family member
   [3] A friend told us
   [4] Teacher
   [5] Other

21. Was **NAME OF CHILD** actually seen by an Ear, Nose, and Throat Specialist in the past year?
   [1] No
   [2] Yes

22. What difficulties did you have obtaining services from an Ear, Nose, and Throat Specialist
   [1] None (no difficulties)
   [2] There were no Ear, Nose, and Throat Specialists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other
23. Was NAME OF CHILD supposed to be seen by an Endocrinologist (a doctor that specializes in treating disorders of hormones and glands) in the past year?
   [1] No (Go to question 27)
   [2] Yes

24. How did you know that NAME OF CHILD needed to be seen by an Endocrinologist?
   [1] A doctor or nurse
   [2] A family member
   [4] Teacher
   [5] Other

25. Was NAME OF CHILD actually seen by an Endocrinologist in the past year?
   [1] No
   [2] Yes

26. What difficulties did you have obtaining services from an Endocrinologist
   [1] None (no difficulties)
   [2] There were no Endocrinologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

27. Was NAME OF CHILD supposed to be seen by a Gastroenterologist (a stomach and intestinal specialist) in the past year?
   [1] No (Go to question 31)
   [2] Yes

28. How did you know that NAME OF CHILD needed to be seen by a Gastroenterologist?
   [1] A doctor or nurse
   [2] A family member
   [4] Teacher
   [5] Other

29. Was NAME OF CHILD actually seen by a Gastroenterologist in the past year?
   [1] No
   [2] Yes
30. What difficulties did you have obtaining services from a Gastroenterologist
   [1] None (no difficulties)
   [2] There were no Gastroenterologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

31. Was NAME OF CHILD supposed to be been seen by a Hematologist/Oncologist (a specialist for blood problems and/or cancer) in the past year?
   [1] No (Go to question 35)
   [2] Yes

32. Was NAME OF CHILD actually seen by a Hematologist/Oncologist in the past year?
   [1] No
   [2] Yes

33. How did you know that NAME OF CHILD needed to be seen by an Hematologist/Oncologist?
   [1] A doctor or nurse
   [2] A family member
   [4] Teacher
   [5] Other

34. What difficulties did you have obtaining services from a Hematologist/Oncologist
   [1] None (no difficulties)
   [2] There were no Hematologists/Oncologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

35. Was NAME OF CHILD supposed to be been seen by a Nephrologist (kidney doctor) in the past year?
   [1] No (Go to question 39)
   [2] Yes
36. How did you know that NAME OF CHILD needed to be seen by an Nephrologist?
   [1] A doctor or nurse
   [2] A family member
   [4] Teacher
   [5] Other

37. Was NAME OF CHILD actually seen by a Nephrologist in the past year?
   [1] No
   [2] Yes

38. What difficulties did you have obtaining services from a Nephrologist
   [1] None (no difficulties)
   [2] There were no Nephrologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

39. Was NAME OF CHILD supposed to be seen by an Ophthalmologist (eye doctor) in the past year?
   [1] No (Go to question 43)
   [2] Yes

40. How did you know that NAME OF CHILD needed to be seen by an Ophthalmologist?
   [1] A doctor or nurse
   [2] A family member
   [4] Teacher
   [5] Other

41. Was NAME OF CHILD actually seen by an Ophthalmologist in the past year?
   [1] No
   [2] Yes
42. What difficulties did you have obtaining services from an Ophthalmologist
   [1] None (no difficulties)
   [2] There were no Ophthalmologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

43. Was NAME OF CHILD supposed to be seen by an Orthopedist (bone doctor) in the past year?
   [1] No (Go to question 47)
   [2] Yes

44. How did you know that NAME OF CHILD needed to be seen by an Orthopedist?
   [1] A doctor or nurse
   [2] A family member
   [4] Teacher
   [5] Other

45. Was NAME OF CHILD actually seen by a Orthopedist in the past year?
   [1] No
   [2] Yes

46. What difficulties did you have obtaining services from an Orthopedist
   [1] None (no difficulties)
   [2] There were no Orthopedists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

47. Was NAME OF CHILD supposed to be seen by a Psychologist (mental health clinician who cannot prescribe medication, primarily used for counseling) in the past year?
   [1] No (Go to question 51)
   [2] Yes
48. How did you know that **NAME OF CHILD** needed to be seen by a Psychologist?
   [1] A doctor or nurse  
   [2] A family member  
   [4] Teacher  
   [5] Other

49. Was **NAME OF CHILD** actually seen by a Psychologist **in the past year**?
   [1] No  
   [2] Yes

50. What difficulties did you have obtaining services from a Psychologist
   [1] None (no difficulties)  
   [2] There were no Psychologists in my community  
   [3] Difficulty obtaining a referral from primary care physician  
   [4] The office isn't open during hours that are convenient  
   [5] Difficulty getting appointments  
   [6] Denial from insurance company  
   [7] Out of pocket costs  
   [8] Language barrier  
   [9] Transportation problems (no car, no public transportation available, etc.)  
   [10] Difficulty finding childcare for other children  
   [11] Staff does not know how to take care of my Special Needs child  
   [12] Other

51. Was **NAME OF CHILD** supposed to be been seen by a Psychiatrist (mental health doctor who can prescribe medications) **in the past year**?
   [1] No (Go to question 55)  
   [2] Yes

52. How did you know that **NAME OF CHILD** needed to be seen by a Psychiatrist?
   [1] A doctor or nurse  
   [2] A family member  
   [4] Teacher  
   [5] Other

53. Was **NAME OF CHILD** actually seen by a Psychiatrist **in the past year**?
   [1] No  
   [2] Yes
54. What difficulties did you have obtaining services from a Psychiatrist?
[1] None (no difficulties)
[2] There were no Psychiatrists in my community
[3] Difficulty obtaining a referral from primary care physician
[4] The office isn't open during hours that are convenient
[5] Difficulty getting appointments
[6] Denial from insurance company
[7] Out of pocket costs
[8] Language barrier
[9] Transportation problems (no car, no public transportation available, etc.)
[10] Difficulty finding childcare for other children
[11] Staff does not know how to take care of my Special Needs child
[12] Other

55. Was NAME OF CHILD supposed to be been seen by a Pulmonary Specialist (lung doctor) in the past year?
[1] No (Go to question 59)
[2] Yes

56. How did you know that NAME OF CHILD needed to be seen by a Pulmonary Specialist?
[1] A doctor or nurse
[2] A family member
[4] Teacher
[5] Other

57. Was NAME OF CHILD actually seen by a Pulmonary Specialist in the past year?
[1] No
[2] Yes

58. What difficulties did you have obtaining services from a Pulmonary Specialist
[1] None (no difficulties)
[2] There were no Pulmonary Specialists in my community
[3] Difficulty obtaining a referral from primary care physician
[4] The office isn't open during hours that are convenient
[5] Difficulty getting appointments
[6] Denial from insurance company
[7] Out of pocket costs
[8] Language barrier
[9] Transportation problems (no car, no public transportation available, etc.)
[10] Difficulty finding childcare for other children
[11] Staff does not know how to take care of my Special Needs child
[12] Other

59. Was NAME OF CHILD supposed to be been seen by a Rheumatologist (arthritis doctor) in the past year?
[1] No (Go to question 67)
[2] Yes
60. How did you know that **NAME OF CHILD** needed to be seen by a Rheumatologist?  
   [1] A doctor or nurse  
   [2] A family member  
   [4] Teacher  
   [5] Other

61. Was **NAME OF CHILD** actually seen by a Rheumatologist in the past year?  
   [1] No  
   [2] Yes

62. What difficulties did you have obtaining services from Rheumatologist  
   [1] None (no difficulties)  
   [2] There were no Rheumatologists in my community  
   [3] Difficulty obtaining a referral from primary care physician  
   [4] The office isn't open during hours that are convenient  
   [5] Difficulty getting appointments  
   [6] Denial from insurance company  
   [7] Out of pocket costs  
   [8] Language barrier  
   [9] Transportation problems (no car, no public transportation available, etc.)  
   [10] Difficulty finding childcare for other children  
   [11] Staff does not know how to take care of my Special Needs child  
   [12] Other

67. Was **NAME OF CHILD** supposed to be seen by a Urologist (a doctor who specializes in how your child uses the potty) in the past year?  
   [1] No (Go to question 71)  
   [2] Yes

68. How did you know that **NAME OF CHILD** needed to be seen by a Urologist?  
   [1] A doctor or nurse  
   [2] A family member  
   [4] Teacher  
   [5] Other

69. Was **NAME OF CHILD** actually seen by a Urologist in the past year?  
   [1] No  
   [2] Yes
70. What difficulties did you have obtaining services from a Urologist
   [1] None (no difficulties)
   [2] There were no Urologists in my community
   [3] Difficulty obtaining a referral from primary care physician
   [4] The office isn't open during hours that are convenient
   [5] Difficulty getting appointments
   [6] Denial from insurance company
   [7] Out of pocket costs
   [8] Language barrier
   [9] Transportation problems (no car, no public transportation available, etc.)
   [10] Difficulty finding childcare for other children
   [11] Staff does not know how to take care of my Special Needs child
   [12] Other

HOSPITAL CARE

71. Has NAME OF CHILD been hospitalized in Delaware overnight in the past year?
   [1] No (Go to question 95a)
   [2] Yes

72. Has NAME OF CHILD been in Beebe Hospital in the past year?
   [1] No (Go to question 75)
   [2] Yes

73. How many times has NAME OF CHILD been in Beebe Hospital in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times

73a. What type of service did NAME OF CHILD receive while at Beebe Hospital?
   [1] Surgery
   [2] Observation
   [4] Other

74. How satisfied were you with the care your child received at Beebe Hospital?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

75. Has NAME OF CHILD been in Christiana Hospital in the past year?
   [1] No (Go to question 78)
   [2] Yes

76. How many times has NAME OF CHILD been in Christiana Hospital in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times
76a. What type of service did NAME OF CHILD receive while at Christiana Hospital?
   [1] Surgery
   [2] Observation
   [4] Other

77. How satisfied were you with the care your child received at Christiana Hospital?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

78. Has NAME OF CHILD been in A.I. DuPont Hospital for Children in the past year?
   [1] No (Go to question 81)
   [2] Yes

79. How many times has NAME OF CHILD been in DuPont Hospital for Children in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times

79a. What type of service did NAME OF CHILD receive while at DuPont Hospital?
   [1] Surgery
   [2] Observation
   [4] Other

80. How satisfied were you with the care your child received at DuPont Hospital for Children?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

81. Has NAME OF CHILD been in Kent General Hospital in the past year?
   [1] No (Go to question 84)
   [2] Yes

82. How many times has NAME OF CHILD been in Kent General Hospital in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times

82a. What type of service did NAME OF CHILD receive while at Kent General Hospital?
   [1] Surgery
   [2] Observation
   [4] Other
83. How satisfied were you with the care your child received at Kent General Hospital?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

84. Has **NAME OF CHILD** been in Milford Memorial Hospital in the past year?
   [1] No (Go to question 87)
   [2] Yes

85. How many times has **NAME OF CHILD** been in Milford Memorial Hospital in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times

85a. What type of service did **NAME OF CHILD** receive while at Milford Memorial Hospital?
   [1] Surgery
   [2] Observation
   [4] Other

86. How satisfied were you with the care your child received at Milford Memorial Hospital?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

87. Has **NAME OF CHILD** been in Nanticoke Hospital in the past year?
   [1] No (Go to question 90)
   [2] Yes

88. How many times has **NAME OF CHILD** been in Nanticoke Hospital in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times

88a. What type of service did **NAME OF CHILD** receive while at Nanticoke Hospital?
   [1] Surgery
   [2] Observation
   [4] Other

89. How satisfied were you with the care your child received at Nanticoke Hospital?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

93. Has **NAME OF CHILD** been in St. Francis Hospital (in Wilmington, Delaware) in the past year?
   [1] No (Go to question 96)
   [2] Yes
94. How many times has **NAME OF CHILD** been in St. Francis Hospital in the past year?
   [1] 1 time
   [2] 2 times
   [3] 3 times
   [4] more than 3 times

94a. What type of service did **NAME OF CHILD** receive while at St. Francis Hospital?
   [1] Surgery
   [2] Observation
   [4] Other

95. How satisfied were you with the care your child received at St. Francis Hospital?
   [1] Very satisfied
   [2] Somewhat satisfied
   [3] Unsatisfied

95a. Has your child been in a hospital overnight outside of Delaware?
   [1] Yes
   [2] No (Skip to Q96)

95b. Why did **NAME OF CHILD** go to an out of state Hospital?
   [1] Services not offered in Delaware
   [2] Location
   [3] Preference for specialist
   [5] Other

**DURABLE MEDICAL EQUIPMENT**

96. Does **NAME OF CHILD** need a wheelchair?
   [1] No (Go to question 101)
   [2] Yes

97. Does **NAME OF CHILD** have a wheelchair?
   [1] No (Go to Q100)
   [2] Yes

98. How long did it take to get the wheelchair once the doctor ordered one?
   [1] Within one week
   [2] Within two weeks
   [3] Within one month
   [4] Within two months
   [5] Greater than two months
99. Was the wheelchair customized to meet your child’s specific needs?
   [1] No
   [2] Yes

100. Which of these have you had difficulty with, in terms of your child's wheelchair?
    [1] Difficulty obtaining an order from the doctor
    [2] Denial from insurance company
    [3] Out of pocket Cost
    [4] Lack of communication, coordination, or cooperation between service providers
    [5] Finding where to get it
    [6] None were available in my community
    [7] Lack of reliable car/transportation
    [8] Finding people to fix it
    [9] Language barrier
    [10] Repair and replacement parts
    [11] Understanding proper use and care
    [12] No difficulties

101. Does NAME OF CHILD need leg or ankle braces?
    [1] No (Go to question 106)
    [2] Yes

102. Does NAME OF CHILD have leg or ankle braces?
    [1] No (Go to Q105)
    [2] Yes

103. How long did it take to get the braces once the doctor ordered them?
    [1] Within one week
    [2] Within two weeks
    [3] Within one month
    [4] Within two months
    [5] Greater than two months

104. Were the braces customized to meet the changing needs of your child?
    [1] No
    [2] Yes
105. Which of these have you had difficulty with, in terms of your child's braces?
   [1] Difficulty obtaining an order from the doctor
   [2] Denial from insurance company
   [3] Cost
   [4] Lack of communication, coordination, or cooperation between service providers
   [5] Finding where to get it
   [6] None were available in my community
   [7] Lack of reliable car/transportation
   [8] Finding people to fix it
   [9] Language barrier
   [10] Understanding proper use and care
   [11] Repair and replacement parts
   [12] No difficulties

106. Does NAME OF CHILD need a hearing aid?
   [1] No (Go to question 116)
   [2] Yes

107. Does NAME OF CHILD have a hearing aid?
   [1] No (Go to question 110)
   [2] Yes

108. How long did it take to get the hearing aid once the doctor ordered one?
   [1] Within one week
   [2] Within two weeks
   [3] Within one month
   [4] Within two months
   [5] Greater than two months

109. Who provides the hearing aid?
   [1] School
   [2] Hospital
   [3] Doctor
   [5] Clinic
   [6] Hearing Aid dealer
   [7] Other
110. Which of these have you had difficulty with, in terms of your child's hearing aid?
   [1] Difficulty obtaining an order from the doctor
   [2] Denial from insurance company
   [3] Cost
   [4] Lack of communication, coordination, or cooperation between service providers
   [5] Finding where to get it
   [6] None were available in my community
   [7] Lack of reliable car/transportation
   [8] Finding people to fix it
   [9] Language barrier
   [10] No difficulties

116. Does NAME OF CHILD need glasses?
   [1] No (Go to question 121)
   [2] Yes

117. Does NAME OF CHILD have glasses?
   [1] No (Go to Q120)
   [2] Yes

118. How long did it take to get the glasses once the doctor ordered them?
   [1] Within one week
   [2] Within two weeks
   [3] Within one month
   [4] Within two months
   [5] Greater than two months

119. Do you have difficulty with repair and adjustments of the glasses?
   [1] No
   [2] Yes

120. Which of these have you had difficulty with, in terms of your child's glasses?
   [1] Difficulty obtaining an order from the doctor
   [2] Denial from insurance company
   [3] Cost
   [4] Lack of communication, coordination, or cooperation between service providers
   [5] Finding where to get it
   [6] None were available in my community
   [7] Lack of reliable car/transportation
   [8] Finding people to fix it
   [9] Language barrier
   [10] No difficulties

121. Does NAME OF CHILD need a communication device?
   [1] No (Go to question 126)
   [2] Yes
122. Does [NAME OF CHILD] have a communication device?
   [1] No (Go to Q125)
   [2] Yes

123. How long did it take to get the communication device once the doctor ordered one?
   [1] Within one week
   [2] Within two weeks
   [3] Within one month
   [4] Within two months
   [5] Greater than two months

124. Who provides the communication device?
   [1] School
   [2] Hospital
   [3] Easter Seals
   [4] Mail order company
   [5] Medical supply store
   [6] Other

125. Which of these have you had difficulty with, in terms of your child's communication device?
   [1] Difficulty obtaining an order from the doctor
   [2] Denial from insurance company
   [3] Cost
   [4] Lack of communication, coordination, or cooperation between service providers
   [5] Finding where to get it
   [6] None were available in my community
   [7] Lack of reliable car/transportation
   [8] Finding people to fix it
   [9] Language barrier
   [10] No difficulties

126. Does [NAME OF CHILD] need any respiratory equipment or monitors?
   [1] No (Go to question 131)
   [2] Yes

127. Does [NAME OF CHILD] have any respiratory equipment or monitors?
   [1] No (Go to Q130)
   [2] Yes

128. How long did it take to get the respiratory equipment or monitor once the doctor ordered one?
   [1] Within one week
   [2] Within two weeks
   [3] Within one month
   [4] Within two months
   [5] Greater than two months

129. Who provides the respiratory equipment or monitor?
130. Which of these have you had difficulty with, in terms of your child's respiratory equipment or monitor?
[1] Difficulty obtaining an order from the doctor
[2] Denial from insurance company
[3] Cost
[4] Lack of communication, coordination, or cooperation between service providers
[5] Finding where to get it
[6] None were available in my community
[7] Lack of reliable car/transportation
[8] Finding people to fix it
[9] Language barrier
[10] No difficulties

HEALTH CARE

131. Is NAME OF CHILD now on any health care plan that pays for medical bills?
[1] No (Go to question 136)
[2] Yes

132. What kind of plan is it (check all that apply)
[1] Private HMO
[2] Group coverage from an employer or union
[3] Any other private health insurance
[6] Other health coverage

133. What is the main health insurance plan of NAME OF CHILD? (Your child may have more than one source of health coverage. Please state the name of the plan you rely on most.)
[1] Aetna
[2] Amerihealth
[3] Blue Cross/Blue Shield
[4] CHIP (Children's Health Insurance Plan)
[6] Medicaid, but not an HMO
[7] Principal / Coventry
[8] Tricare (for military dependents)
[9] Other health coverage

134. All things considered, how satisfied are you with the above named health insurance plan?
[1] Very satisfied
[2] Somewhat satisfied
[3] Unsatisfied
135. How long has NAME OF CHILD been enrolled in this health insurance plan?
   [1] Less than 1 year
   [2] 1 to 2 years
   [3] 2 to 5 years
   [4] More than 5 years
   GO TO QUESTION 137

136. If NAME OF CHILD has no health insurance, what are the main reasons?
   [1] Coverage is too expensive
   [2] Employer does not offer health coverage
   [3] The health insurance plan through work does not include children or dependents
   [4] My spouse and I are not eligible for a health insurance plan through work
   [5] My child was refused coverage
   [6] My child used up all benefits
   [7] My child doesn't qualify for Medicaid or CHIP
   [8] Other

137. Have services been discontinued or delayed due to a change in your Health Care
insurance in the past year? (This includes loss of insurance in the last year.)
   [1] No (Go to question 141)
   [2] Yes

138. What services were discontinued or delayed due to this change in your Health Care
insurance?
   [1] Assistive Technology (durable medical equipment)
   [2] Audiology (Hearing)
   [3] Interpreter Services
   [4] Nursing Services
   [5] Nutrition Services
   [6] Occupational Therapy
   [7] Physical Therapy
   [8] Psychological Services/Counseling
   [9] Respite Care
   [10] Service Coordination/Case Management
   [12] Special Education Services
   [14] Transportation
   [15] Vision Services
   [16] Other

THERAPIES AND OTHER SERVICES
This section is looking at where children receive services the most.

141. Does NAME OF CHILD receive Audiology Services?
   [1] No (Go to question 143)
   [2] Yes
142. Where does NAME OF CHILD receive Audiology Services most frequently?
   [1] At home
   [2] Doctor’s Office
   [4] In a daycare setting
   [5] In a hospital setting
   [6] At school
   [7] Other

143. Does NAME OF CHILD receive Interpreter Services?
   [1] No (Go to question 145)
   [2] Yes

144. Where does NAME OF CHILD receive Interpreter Services most frequently?
   [1] At home
   [2] In a daycare setting
   [3] In a hospital setting
   [4] At school
   [5] Other

145. Does NAME OF CHILD receive Nursing Services?
   [1] No (Go to question 147)
   [2] Yes

146. Where does NAME OF CHILD receive Nursing Services most frequently?
   [1] At home
   [2] In a daycare setting
   [3] In a hospital setting
   [4] At school
   [5] Other

147. Does NAME OF CHILD receive Nutrition Services?
   [1] No (Go to question 149)
   [2] Yes
148. Where does NAME OF CHILD receive Nutrition Services most frequently?
   [1] At home
   [2] Public Health Clinic
   [3] WIC office (Women, Infant and Children program though HSS)
   [4] In a daycare setting
   [5] In a hospital setting
   [6] At school
   [7] Other

149. Does NAME OF CHILD receive Occupational Therapy?
   [1] No (Go to question 151)
   [2] Yes

150. Where does NAME OF CHILD receive Occupational Therapy most frequently?
   [1] At home
   [2] In a daycare setting
   [3] In a hospital setting
   [4] At school
   [5] Other

151. Does NAME OF CHILD receive Physical Therapy?
   [1] No (Go to question 153)
   [2] Yes

152. Where does NAME OF CHILD receive Physical Therapy most frequently?
   [1] At home
   [2] In a daycare setting
   [3] In a hospital setting
   [4] At school
   [5] Center based (i.e. Easter Seals, DE Curative)
   [6] Other

153. Does NAME OF CHILD receive Psychological Services/Counseling?
   [1] No (Go to question 155)
   [2] Yes

154. Where does NAME OF CHILD receive Psychological Services/Counseling most frequently?
   [1] At home
   [2] Doctor’s office
   [3] In a daycare setting
   [4] In a hospital setting
   [5] At school
   [6] Other
155. Does NAME OF CHILD's family receive Respite Care Services (support in caring for your child)?
   [1] No (Go to question 155a)  
   [2] Yes (Go to question 155b)  

155a. Do you have a need for Respite Care Services?
   [1] No (Go to Q161)  
   [2] Yes  

155b. Which of these have you had difficulty with, in terms of Respite Care Services?
   [1] Difficulty obtaining an order from the doctor  
   [2] Denial from insurance company  
   [3] Cost  
   [4] Lack of communication, coordination, or cooperation between service providers  
   [5] Finding where to get it  
   [6] None were available in my community  
   [7] Lack of reliable car/transportation  
   [8] No one capable of handling Special Needs child  
   [9] Language barrier  
   [10] No Difficulties  

If said NO to Q155A SKIP TO Q159  

156. Where does NAME OF CHILD's family receive Respite Care Services most frequently?
   [1] At home  
   [2] In a daycare setting  
   [3] In a hospital setting  
   [4] At school  
   [5] Other  

156a. How satisfied were you with the Respite Care your child received?
   [1] Very satisfied  
   [2] Somewhat satisfied  
   [3] Unsatisfied  

161. Does NAME OF CHILD receive Speech and Language Services (speech therapy)?
   [1] No (Go to question 163)  
   [2] Yes
162. Where does **NAME OF CHILD** receive Speech Therapy most frequently?
   [1] At home
   [2] Center based (ie. Easter Seals, Delaware Curative)
   [3] In a daycare setting
   [4] In a hospital setting
   [5] At school
   [6] Other

163. Does **NAME OF CHILD** receive Transportation Services?
   [1] No (Go to question 165)
   [2] Yes

164. Where does **NAME OF CHILD** receive Transportation Services most frequently?
   [1] Between home and day care
   [3] Between home and school
   [4] Between home and therapies
   [5] Other

165. Does **NAME OF CHILD** receive Vision Services?
   [1] No (Go to question 167)
   [2] Yes

166. Where does **NAME OF CHILD** receive Vision Services most frequently?
   [1] At home
   [2] Doctor’s office
   [3] In a daycare setting
   [4] In a hospital setting
   [5] At school
   [6] Other

166a. Are services provided in a language you understand?
   [1] No
   [2] Yes

**CHILD CARE**

167. Do you use a child care provider?
   [1] No (Go to question 190)
   [2] Yes
168. Where is the child care provided?
   [1] In my home
   [2] In someone else's home
   [3] In an after school program
   [4] In a day-care center
   [5] In a specialized nursing facility

169. Should your child get medications while in child care?
   [1] No (Go to question 172)
   [2] Yes

170. Does your child get medications while in child care?
   [1] Never
   [2] Occasionally
   [3] Usually
   [4] Always

171. Who usually gives the medication while NAME OF CHILD is in child care?
   [1] Childcare provider
   [2] Visiting Nurse
   [3] Family/friend
   [4] Other

172. Should your child get respiratory or nebulizer treatments while in child care?
   [1] No (Go to question 175)
   [2] Yes

173. Does your child get respiratory or nebulizer treatments while in child care?
   [1] Never
   [2] Occasionally
   [3] Usually
   [4] Always

174. Who usually gives the respiratory or nebulizer treatments while NAME OF CHILD is in child care?
   [1] Childcare provider
   [2] Visiting Nurse
   [3] Family/friend
   [4] Other

175. Should your child get blood testing (finger sticks) while in child care?
   [1] No (Go to question 178)
   [2] Yes
176. Does your child get blood testing (finger sticks) while in child care?
   [1] Never
   [2] Occasionally
   [3] Usually
   [4] Always

177. Who usually does the blood testing while NAME OF CHILD is in child care?
   [1] Childcare provider
   [2] Visiting Nurse
   [3] Family/friend
   [4] Other

178. Should your child be monitored (breathing or heart) while in child care?
   [1] [1] No (Go to question 181)
   [2] [2] Yes

179. Does your child get monitored (breathing or heart) while in child care?
   [1] Never
   [2] Occasionally
   [3] Usually
   [4] Always

180. Who usually does the monitoring while NAME OF CHILD is in child care?
   [1] Childcare provider
   [2] Visiting Nurse
   [3] Family/friend
   [4] Other

181. Should your child get tube feedings while in child care?
   [1] [1] No (Go to question 184)
   [2] [2] Yes

182. Does your child get tube feedings while in child care?
   [1] Never
   [2] Occasionally
   [3] Usually
   [4] Always

183. Who usually gives the tube feeding while NAME OF CHILD is in child care?
   [1] Childcare provider
   [2] Visiting Nurse
   [3] Family/friend
   [4] Other
184. Should your child get catheterized (to empty his/her bladder) while in child care?
   [1] [1] No (Go to question 187)
   [2] [2] Yes

185. Does your child get catheterized (to empty his/her bladder) while in child care?
   [1] Never
   [2] Occasionally
   [3] Usually
   [4] Always

186. Who usually does the catheterization while NAME OF CHILD is in child care?
   [1] Childcare provider
   [2] Visiting Nurse
   [3] Family/friend
   [4] Other

187. How much do you pay (out-of-pocket) for child care each week for NAME OF CHILD?
   [1] $0 to $100
   [2] $101 to $200
   [3] more than $200

188. Did you have trouble obtaining a childcare provider because of NAME OF CHILD's special needs?
   [1] No (Go to question 190)
   [2] Yes

189. Why?
   [1] Couldn't find one near by
   [2] Had a hard time finding one that I could afford
   [3] Had a hard time finding one that would give NAME OF CHILD him/her medications and treatments
   [4] Many places didn't have an opening for a child NAME OF CHILD's age
   [5] Many places didn't have any openings
   [6] Didn't like the quality of care given by other day care providers
   [7] Language Barrier
   [8] Other

CASE COORDINATION/CASE MANAGEMENT/FAMILY SERVICE COORDINATION

190. Do you have a case coordinator/case manager, service coordinator?
   [1] No (Go to question 193)
   [2] Yes
191. Does your case manager help you understand and schedule the service **NAME OF CHILD** receives?
   [1] No
   [2] Yes

192. Where does your case manager or case managers work? (some families may have more than one case manager, in that case, more than one answer is expected)
   [1] Hospital
   [2] Doctor's office
   [3] Health Department
   [4] Managed Care Organization (MCO)
   [5] Mental health agency
   [6] School
   [7] Do not know
   [8] Other

193. Do you schedule and coordinate the services for **NAME OF CHILD** yourself?
   [1] No
   [2] Yes

194. Do you feel that services for **NAME OF CHILD** have been coordinated among all involved agencies, organizations and health care providers?
   [1] Always
   [2] Usually
   [3] Occasionally
   [4] Never

**DEMOGRAPHICS**

Please answer these questions about **NAME OF CHILD** who has special health care needs.

195. What is your relationship to **NAME OF CHILD**?
   [1] Mother/Step Mother
   [2] Father/Step Father
   [6] Uncle
   [7] Sister
   [8] Brother
   [9] Foster Parent
   [10] Other

196. Sex of **NAME OF CHILD**
   [1] Male
   [2] Female

197. What is **NAME OF CHILD**'s birthdate? (month and year)
Month ___________ Year ___________

198. Does NAME OF CHILD's have any of the following conditions? (Check all that apply)?
   [1] Blood disorder (such as sickle cell anemia or hemophilia)
   [2] Cancer or leukemia
   [3] Cerebral palsy or other neuromuscular condition
   [4] Asthma
   [5] Cystic fibrosis
   [6] Cleft lip and/or palate
   [7] Chronic rheumatic disease
   [8] Congenital heart disease
   [9] Diabetes
   [10] Digestive or gastrointestinal disorder
   [12] Seizure disorder (epilepsy, etc.)
   [14] Hydrocephalus
   [15] Spina bifida/meningomyelocele
   [16] Paraplegia/quadruplegia (paralyzed)
   [17] Neurological disease (such as muscular dystrophy)
   [18] Orthopedic or bone problems
   [19] Autism
   [20] Behavior problems
   [21] Other mental health problems
   [22] Down syndrome
   [23] Mental retardation (not including Down syndrome)
   [24] Learning disability (not mental retardation)
   [25] Hearing impairment
   [26] Vision impairment
   [27] Speech
   [28] Developmental Delay
   [29] Other

199. In general, how is NAME OF CHILD's health overall?
   [1] Excellent
   [2] Very good
   [3] Good
   [4] Fair
   [5] Poor

200. How long have you known about NAME OF CHILD's special health care needs?
   [1] From birth
   [2] Less than 1 year
   [3] 1 to 3 years
   [4] More than 3 years

201. How many children are there in the family (including NAME OF CHILD)
202. Do any of your other children have any special health care needs?
   [1] Yes
   [2] No

203. Is NAME OF CHILD of Hispanic, Latino, or Spanish origin?
   [1] Yes
   [2] No

204. To which Hispanic, Latino, or Spanish group does NAME OF CHILD belong?
   [1] Cuban
   [2] Mexican or Mexican American
   [3] Puerto Rican
   [5] South American

205. How would you describe NAME OF CHILD's race?
   [1] African American/Black
   [2] American Indian
   [3] Asian or Pacific Islander
   [6] Other

206. What language is spoken at home?
   [1] English
   [2] Spanish
   [3] English and Spanish
   [4] Other
   [5]

207. What is your zip code?
208. Is your annual household income from all sources:
Read as Appropriate

a. Less than $25,000 ➔ If "no," ask c; if "yes," ask b
($20,000 to less than $25,000)
b. Less than $20,000 ➔ If "no," code a; if "yes," ask c
($15,000 to less than $20,000)
c. Less than $15,000 ➔ If "no," code b; if "yes," ask d
($10,000 to less than $15,000)
d. Less than $10,000 ➔ If "no," code c
e. Less than $35,000 ➔ If "no," ask f
($25,000 to less than $35,000)
f. Less than $50,000 ➔ If "no," ask g
($35,000 to less than $50,000)
g. Less than $75,000 ➔ If "no," code h
($50,000 to $75,000)
h. $75,000 or above

209. How many people are living in your household? _____

210. Are you or your child CURRENTLY receiving……

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<th>Yes</th>
<th>No</th>
<th>Pending</th>
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<tr>
<td>Public Assistance</td>
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<tr>
<td>Social Security Disability Insurance</td>
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