Families with children with special health care needs face exceptional challenges when trying to obtain care in a managed care program. Under federal Medicaid waiver requirements in the Balanced Budget Act (BBA) of 1997, Connecticut and other states that mandate managed care enrollment for children with special health care needs are required to establish safeguards for ensuring that they receive the care they need. Children with special health care needs are defined in the BBA as those who receive Supplemental Security Income (SSI), receive benefits under title V of the Social Security Act, receive federal foster care or adoption assistance under title IV-E of the Social Security Act, and children who are in foster care or out-of-home placements funded from other sources.¹ There are also other children enrolled in HUSKY Part A who have chronic, intensive health care needs or disabilities.

In order to assess access to care and satisfaction among children with special health care needs who are enrolled in HUSKY Part A (Medicaid managed care), the Children’s Health Council conducted a statewide survey of their families. This survey was conducted for the Connecticut Department of Social Services as one part of their approach to monitoring access and quality of care received by these children. The objectives of the survey were:

- To determine families’ satisfaction with care received from primary care providers, specialists, and therapeutic care providers;
- To determine families’ satisfaction with assistance provided by health plans to facilitate access to and utilization of needed services; and
- To identify unmet needs for care or assistance obtaining care.

**METHODS**

**Sample:** Children under 19 who were continuously enrolled in Medicaid managed care in one health plan in calendar year 1999 were identified. The subset that lived in households with telephones (89%) was then identified. Medicaid managed care enrollment data were used to select children who received SSI benefits in 1999. Children who received Title V program benefits were identified with the cooperation of the Department of Public Health (DPH). Children in foster care or subsidized adoptions and had been in one home for six months or more in 1999 or the first half of 2000 were identified with the cooperation of the Department of Children and Families (DCF). Additionally, Medicaid managed care encounter data were used...
to identify other children who received care in 1999 for disabilities or chronic, intensive health conditions included in a list developed for this project (see Appendix A). One child per family was selected from households with more than one child with special health care needs. This sampling approach resulted in identification of 15,204 children (20%) for the sampling frame.

**Survey instrument:** A survey instrument developed by New England SERVE was selected for this study and modified to address program questions. The tool was reviewed by an advisory workgroup and local experts, critiqued by staff from two related programs, and pilot-tested with families from the sampling frame. The survey instrument is in Appendix B.

**Advance letter:** A letter explaining the purpose of the survey was sent from DSS to all families with children in the sampling frame (see Appendix C). Information about questions, time required to complete the survey, and assurances of confidentiality were included in English and Spanish versions of the letter.

**Survey conduct:** Telephone interviews were conducted between mid-May and mid-June 2000 for most children and in September 2000 for children in foster care or subsidized adoption. Computer-assisted telephone interviewing was conducted in English or Spanish by trained interviewers. At least five attempts were made to reach every family with a child in the sampling frame.

**RESULTS**

Telephone interviews with 1,230 families with children with special health needs were completed. The distribution of these children across health plans and across categories used to indicate special health care needs is shown in Table 1. Overall, the response rate was 40%, including 52% for children in the Title V program, 37% for children who received SSI benefits, an estimated 33% for children identified by special diagnoses, and 58% for DCF children. Compared to the children in the sampling frame for Title V, SSI, and special diagnoses, children enrolled in BlueCare are slightly under-represented and children in Community Health Network and Yale Preferred One are slightly over-represented among the families that were reached. Overall, results by health plan were remarkably similar; these findings will not be shown here.

The sociodemographic characteristics of the children are shown in Table 2. Since slightly different methods were used to select and interview families of children in foster care or subsidized adoption, their responses will be reported separately. Most families who were interviewed had children twelve or under. Children in the Title V, SSI or special diagnosis group were disproportionately male. Children in DCF custody were significantly younger and more likely to be Black/African American than children in the Title V, SSI or special diagnosis group.

Health status and health care utilization are described in Table 3. Not surprisingly, children who received Title V or SSI benefits or had special diagnoses were not as healthy and were more likely to have used health care services in 1999, compared to children in foster care or subsidized adoption. They were more likely to have made regular visits for physical health care, more likely to have been seen for emergency care, and more likely to have been hospitalized. Utilization of behavioral health care services was about the same. Nearly one in four children in
both groups reported having gone to the emergency room because the primary care provider was unavailable. A remarkably high percentage of children in both groups received dental care.

Overall satisfaction and quality ratings are shown in Table 4. Nearly all families were satisfied with the choices of providers available to them. Nearly all families reported good communication with providers and involvement in care decisions. Nearly all families rated the most responsible provider highly; however, fewer families rated the quality of dental care as highly. Health plans were rated similarly and fairly highly overall.

Responses pertaining to access to care are described in Table 5. Most families reported having chosen their children’s primary care provider and being able to get timely appointments when needed. Most families reported getting help when needed during office hours or after hours. Children who received Title V or SSI benefits and children with special diagnoses were more likely to have seen medical specialists. Nearly all children were able to get enough approved visits with the specialists. However, just two out of three reported being able to get appointments in four weeks or less. Few families reported having any significant problems obtaining referrals. Over one in four children in each group saw specialists for behavioral health care. Most reported getting enough approved visits and being able to obtain timely appointments. Just two out of three families reported usually being able to get dental care in less than four weeks; however, most were satisfied with the length of time it took to be seen.

Access to special services is described in Tables 6a to 6c. Nearly all the children in the Title V program, on SSI, or with a special diagnosis had needed and obtained prescription medicine. Fewer children in DCF custody needed prescriptions and most were able to obtain them. Among the few who needed equipment or therapeutic services, nearly all received the needed items or assistance. Access to enabling services was somewhat less. Few children needed special accommodations for access, special transportation, or interpreters; however, among those who did, a relatively high percentage were not able to get what they needed. Among all these children with special health care needs, just 9% had a case manager assigned by the health plan.

One important aspect of access is the ability to complain when needs are not met. Table 7 shows families’ responses to questions about complaints and grievances. Most were aware that they could complain. Few had felt a need to make a formal complaint, but among them, less than half had actually complained to the health plan. Few reported that their children’s health care services had been cutback, but among them, only one in three reported having been notified in writing.

CONCLUSIONS

- One in five children continuously enrolled in one of the four HUSKY Part A health plans was identified as having special health care needs.

- The health and health care needs of these children are not uniform across this definition of children with special health care needs.
Families were generally satisfied with their health plans and with the quality of care from providers.

Access to care varied, depending on whether families were seeking primary care, medical specialty care, or behavioral health care for their children.

While most children needed and obtained prescription medicine, relatively few needed other pharmaceutical, therapeutic, or enabling services.

Less than one in ten children with special health care needs had a case manager assigned by the health plan.

While most families said they are aware that they can make a formal complaint about health plan services, less than half those who felt the need to complain actually did so.

While few families reported having experienced a cutback in services for their children, only a third of those who did said they were notified in writing.

RECOMMENDATIONS

The Children’s Health Council has reviewed these findings and the literature on monitoring care for children with special health care need. The Council recommends that the Department of Social Services:

- Investigate the extent to which there are problems with access to primary or specialty care, availability of special transportation and interpreters, and compliance with notification requirements. The following areas could be systematically studied: appointment availability, transportation subcontracts and policies, availability of bilingual staff, use of translation services, and administrative procedures for notifying families of denial, reductions or termination of services.

- Ensure that health plans systematically assess their members’ needs for case management and that health plans provide individualized assistance with coordination of their children’s special health care needs.

- Develop and implement an ongoing, comprehensive approach to monitoring access to services, quality of care, coordination of care, and satisfaction for children with special health care needs. Measures should allow for comparison with the experiences of other children enrolled in HUSKY Part A. The monitoring plan should include:
  - Collaboration with DPH for identification of children in the Title V program;
  - Collaboration with DCF for identification of children in foster care and adoption;
  - Use of HEDIS-like measures of process and outcome;
  - Periodic surveys of families to assess access and satisfaction;
  - Periodic surveys of primary care providers who serve children with special health care needs; and
- Operations audits of health plan administrative procedures that affect access to enabling services, case management, and grievances/administrative hearing.

- Investigate the utility, feasibility, and cost of screening for special health care needs when children enroll in HUSKY Part A.

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1 The BBA definition of children with special health care needs also includes children who receive Medicaid benefits under the Katie Beckett state plan option for children living at home who would be eligible for Medicaid if they were institutionalized. Connecticut does not mandate managed care enrollment for these children.


3 In addition to staff from the Children’s Health Council and the Connecticut Children’s Health Project, the advisory workgroup included representatives from DSS, DPH, DCF, HUSKY health plans, the Children’s Health Council, the Medicaid Managed Care Council, and Qualidigm, Inc. Stephen A. Horan, Ph.D., consultant to the Connecticut Children’s Health Project, and Mary Alice Lee, Ph.D., Assistant Director of the Children’s Health Council, directed the project.

4 Compared to children in the sampling frame for Title V, SSI, and special diagnoses, children in families that were interviewed were somewhat older, less likely to be Black/African American and more likely to be Hispanic/Latino. More children than expected were from New Haven and fewer were from Hartford.
### Table 1. Description of Sample by Health Plan and Special Health Care Needs Category

<table>
<thead>
<tr>
<th>Health Plans:</th>
<th>Title V</th>
<th>SSI</th>
<th>Special diagnoses</th>
<th>DCF</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>BlueCare</td>
<td>44</td>
<td>110</td>
<td>85</td>
<td>172</td>
<td>411 (33%)</td>
</tr>
<tr>
<td>Community Health Network</td>
<td>14</td>
<td>112</td>
<td>86</td>
<td>57</td>
<td>269 (22%)</td>
</tr>
<tr>
<td>Physicians Health Services</td>
<td>17</td>
<td>125</td>
<td>101</td>
<td>50</td>
<td>293 (24%)</td>
</tr>
<tr>
<td>Yale Preferred One</td>
<td>16</td>
<td>111</td>
<td>88</td>
<td>42</td>
<td>257 (21%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>91 (7%)</strong></td>
<td><strong>458 (37%)</strong></td>
<td><strong>360 (29%)</strong></td>
<td><strong>321 (26%)</strong></td>
<td><strong>1,230 (100%)</strong></td>
</tr>
</tbody>
</table>

**Note:** The overall response rate was 40%, including 52% for children in the Title V program, 37% for children who received SSI benefits, an estimated 33% for children identified by special diagnoses, and 58% for DCF children.

### Table 2. Sociodemographic Characteristics of the Sample

<table>
<thead>
<tr>
<th>Children with Special Health Care Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title V, SSI, special diagnoses</td>
</tr>
<tr>
<td>Total</td>
</tr>
<tr>
<td><strong>909 (74%)</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age:</th>
<th>Title V</th>
<th>SSI</th>
<th>Special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;5</td>
<td>209 (23%)</td>
<td>115 (36%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-12</td>
<td>417 (46%)</td>
<td>142 (44%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13-18</td>
<td>283 (31%)</td>
<td>64 (20%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender:</th>
<th>Title V</th>
<th>SSI</th>
<th>Special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>358 (39%)</td>
<td>163 (51%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>551 (61%)</td>
<td>158 (49%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/ethnicity:</th>
<th>Title V</th>
<th>SSI</th>
<th>Special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African American</td>
<td>256 (28%)</td>
<td>157 (49%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>310 (34%)</td>
<td>88 (27%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>336 (37%)</td>
<td>74 (23%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>7 (&lt;1%)</td>
<td>2 (&lt;1%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>County:</th>
<th>Title V</th>
<th>SSI</th>
<th>Special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fairfield</td>
<td>234 (26%)</td>
<td>71 (22%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hartford</td>
<td>180 (20%)</td>
<td>85 (26%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Litchfield</td>
<td>15 (2%)</td>
<td>12 (4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middlesex</td>
<td>16 (2%)</td>
<td>6 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Haven</td>
<td>383 (42%)</td>
<td>120 (37%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New London</td>
<td>42 (5%)</td>
<td>14 (4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tolland</td>
<td>6 (&lt;1%)</td>
<td>3 (&lt;1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Windham</td>
<td>33 (4%)</td>
<td>10 (3%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3. Description Of Health Status and Health Care Utilization

<table>
<thead>
<tr>
<th></th>
<th>Children with Special Health Care Needs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Title V, SSI, special diagnoses</td>
<td>DCF</td>
</tr>
<tr>
<td>Total</td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
</tbody>
</table>

**Health status:**
- Has chronic condition $^a$ 88% 43%
- Health is excellent or very good 61% 81%
- Health is satisfactory 23% 14%
- Health is fair or poor 15% 4%

**Primary care:**
- Has PCP from health plan 99% 99%
- PCP is a pediatrician 88% 89%

**Ambulatory health care:**
- Made regular visits for physical health condition 74% 28%
- Visited a medical specialist 52% 23%
- Made regular visits for mental health condition 39% 30%
- Visited a behavioral health care provider 29% 26%
- Visited hospital emergency room 59% 34%
  - Went to ER because PCP was unavailable 35% 18%

**Hospital care:**
- Ever hospitalized overnight 18% 9%
  - Received aftercare services from health plan 84% *
- Hospitalized for behavioral health condition 4% 1%
  - Received aftercare services from health plan 76% *

**Dental care:**
- Saw a dentist 67% 75%

$^a$ Chronic condition was defined as a physical condition, mental health condition, or otherwise activity-limiting condition lasting at least 12 months. Families of children identified by special diagnoses were interviewed only if they reported that the child had chronic condition. Families of children identified by program participation (Title V, SSI, DCF) were interviewed, whether they reported that the child did or did not have a chronic condition.

*Cell size less than 30.*
Table 4. Satisfaction and Quality of Care

<table>
<thead>
<tr>
<th>Satisfied/very satisfied with choice of:</th>
<th></th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
<tr>
<td>Satisfied/very satisfied with choice of:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care providers</td>
<td>96%</td>
<td>97%</td>
</tr>
<tr>
<td>Medical specialists</td>
<td>94%</td>
<td>92%</td>
</tr>
<tr>
<td>Behavioral health care providers</td>
<td>84%</td>
<td>88%</td>
</tr>
<tr>
<td>Dentists</td>
<td>80%</td>
<td>83%</td>
</tr>
<tr>
<td>Quality of relationship with most responsible provider: a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider always/usually involved in care decisions</td>
<td>87%</td>
<td>95%</td>
</tr>
<tr>
<td>Caretaker always/usually involved in care decisions</td>
<td>92%</td>
<td>95%</td>
</tr>
<tr>
<td>Provider always/usually gave enough information</td>
<td>94%</td>
<td>96%</td>
</tr>
<tr>
<td>PCP communicated regularly with specialist</td>
<td>76%</td>
<td>78%</td>
</tr>
<tr>
<td>Overall quality:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most responsible provider a rated very good/excellent</td>
<td>86%</td>
<td>91%</td>
</tr>
<tr>
<td>Dental care rated very good/excellent</td>
<td>67%</td>
<td>76%</td>
</tr>
<tr>
<td>Health plan rated ≥8 (1 low to 10 high)</td>
<td>79%</td>
<td>74%</td>
</tr>
</tbody>
</table>

a Primary care provider or specialist most involved in child’s care.
<table>
<thead>
<tr>
<th></th>
<th>Title V, SSI, special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
</tbody>
</table>

**Access to primary care:**
- Chose primary care provider: 73% 69%
- Usually able to get appointment in ≤4 weeks: 87% 93%

**Access to help by telephone:**
- Ever called for help during office hours: 72% 64%
  - Always/usually received needed help: 92% 94%
- Called for help in the evening or on a weekend: 50% 38%
  - Always/usually received needed help: 93% 94%

**Access to medical specialists:**
- Saw a medical specialist: 52% 23%
  - Saw two or more specialists: 56% 46%
  - Had three or more visits: 65% 47%
  - Had enough approved visits: 90% 90%
  - Usually able to get appointment in ≤4 weeks: 69% 68%
- Needed referral from primary care provider: 72% 71%
  - Had a big problem getting referral: 6% 14%

**Access to behavioral health care providers:**
- Saw a behavioral health care specialist: 29% 26%
  - Saw two or more specialists: 42% 31%
  - Had three or more visits: 73% 87%
  - Had enough approved visits: 76% 75%
  - Usually able to get appointment in ≤4 weeks: 85% 80%

**Access to out-of-network providers:**
- Believe that members can see out-of-network providers: 66% 51%
- Tried to get approval to see an out-of-network provider: 12% 5%
  - Got approval: 64% *

**Access to dental care:**
- Usually able to get an appointment in ≤4 weeks: 64% 71%
- Satisfied with length of time to get appointment: 79% 80%

*Note: Percentage who reported **always or usually** having obtained prescriptions and equipment, received therapeutic or enabling services as needed.

*Cell size less than 30.*
### Table 6a. Access to Prescriptions and Equipment

<table>
<thead>
<tr>
<th></th>
<th>Title V, SSI, special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
<tr>
<td>Needed prescription medicine</td>
<td>85%</td>
<td>42%</td>
</tr>
<tr>
<td>Obtained as much as needed</td>
<td>94%</td>
<td>93%</td>
</tr>
<tr>
<td>Needed disposable medical supplies</td>
<td>11%</td>
<td>6%</td>
</tr>
<tr>
<td>Obtained as much as needed</td>
<td>87%</td>
<td>*</td>
</tr>
<tr>
<td>Needed durable medical equipment</td>
<td>23%</td>
<td>9%</td>
</tr>
<tr>
<td>Obtained as much as needed</td>
<td>94%</td>
<td>97%</td>
</tr>
<tr>
<td>Needed adaptive equipment</td>
<td>12%</td>
<td>6%</td>
</tr>
<tr>
<td>Obtained as much as needed</td>
<td>94%</td>
<td>*</td>
</tr>
</tbody>
</table>

**Note:** Percentage who reported always or usually having obtained prescriptions and equipment as needed. *Cell size less than 30.

### Table 6b. Access to Therapeutic and Diagnostic Services

<table>
<thead>
<tr>
<th></th>
<th>Title V, SSI, special diagnoses</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
</tbody>
</table>

**Therapeutic services:**

| Needed physical or occupational therapy | 26% | 11% |
| Received physical or occupational therapy | 88% | 100% |
| Needed speech therapy | 14% | 7% |
| Received speech therapy | 90% | * |
| Needed nutrition counseling | 11% | 6% |
| Received nutrition counseling | 80% | * |
| Needed nutrition products and special diets | 8% | 3% |
| Received nutrition products, special diets | 79% | * |
| Needed home health care | 9% | 5% |
| Received home health care | 78% | * |
| Needed personal care attendant | 3% | 2% |
| Had personal care attendant | 86% | * |

**Diagnostic services:**

| Needed genetic counseling or testing | 7% | 5% |
| Received genetic counseling, testing | 84% | * |

**Note:** Percentage who reported always or usually having received therapeutic or diagnostic services as needed. *Cell size less than 30.
Table 6c. Access to Enabling Services and Care Coordination

<table>
<thead>
<tr>
<th></th>
<th>Children with Special Health Care Needs</th>
<th>Total</th>
<th>DCF</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
<tr>
<td>enabling services:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>needed special accommodations for access</td>
<td></td>
<td>9%</td>
<td>4%</td>
</tr>
<tr>
<td>rarely/never had difficulty getting in and around</td>
<td></td>
<td>30%</td>
<td>*</td>
</tr>
<tr>
<td>needed special transportation services</td>
<td></td>
<td>10%</td>
<td>4%</td>
</tr>
<tr>
<td>able to get special transportation services</td>
<td></td>
<td>62%</td>
<td>*</td>
</tr>
<tr>
<td>needed an interpreter</td>
<td></td>
<td>9%</td>
<td>3%</td>
</tr>
<tr>
<td>able to get an interpreter</td>
<td></td>
<td>73%</td>
<td>*</td>
</tr>
<tr>
<td>care coordination:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>needed help coordinating care among doctors</td>
<td></td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>obtained help coordinating care</td>
<td></td>
<td>86%</td>
<td>*</td>
</tr>
<tr>
<td>needed help arranging home health care or nursing</td>
<td></td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>obtained help with home health care</td>
<td></td>
<td>85%</td>
<td>*</td>
</tr>
<tr>
<td>needed help arranging for durable medical equipment</td>
<td></td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>obtained help with durable medical equipment</td>
<td></td>
<td>93%</td>
<td>*</td>
</tr>
<tr>
<td>needed help arranging transportation</td>
<td></td>
<td>17%</td>
<td>3%</td>
</tr>
<tr>
<td>obtained help with transportation</td>
<td></td>
<td>77%</td>
<td>*</td>
</tr>
<tr>
<td>had a case manager from the health plan</td>
<td></td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>case manager gave information about support services</td>
<td></td>
<td>71%</td>
<td>57%</td>
</tr>
<tr>
<td>case manager had enough time to meet and talk</td>
<td></td>
<td>44%</td>
<td>43%</td>
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</table>

Note: Percentage who reported always or usually having received enabling services and care coordination as needed.
*Cell size less than 30.

Table 7. Complaints and Grievances

<table>
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<th></th>
<th>Children with Special Health Care Needs</th>
<th>Total</th>
<th>DCF</th>
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<tr>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>909 (74%)</td>
<td>321 (26%)</td>
</tr>
<tr>
<td>believe that a member can make a formal complaint about services</td>
<td></td>
<td>87%</td>
<td>87%</td>
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<tr>
<td>felt the need to make a formal complaint</td>
<td></td>
<td>8%</td>
<td>8%</td>
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<tr>
<td>actually made a formal complaint to the health plan</td>
<td></td>
<td>45%</td>
<td>*</td>
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<tr>
<td>had needed services cutback by the health plan</td>
<td></td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td>was notified in writing</td>
<td></td>
<td>34%</td>
<td>*</td>
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*Cell size less than 30.
Appendices

A. Special diagnoses

B. Survey instrument

C. Letter to families (English, Spanish versions)
<table>
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<tr>
<th>ICD-9 CODE</th>
<th>DIAGNOSIS</th>
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<td>Injury to nerve roots and spinal</td>
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<td>Injury to other nerve(s) of trunk, excluding shoulder and pelvic</td>
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Introduction

Hello, my name is _____________. I am calling on behalf of the Connecticut Department of Social Services. We recently sent you a letter asking for your help with a study we are doing to find out how well HUSKY health plans are serving children. Husky A is Connecticut's Medicaid Managed Care Program. The information you provide is private and will be used to improve how health plans serve families like yours. Your answers will not affect the benefits you or your child get.

The survey will only take about 20 minutes of your time. Is that okay? If not, is there a good time for me to call back?

Callback

Hello, this is ___________ calling on behalf of the Connecticut Department of Social Services. We started an interview earlier and I'm calling back to complete the interview. Is that okay?

Contact Verification

1. INTERVIEWER: Please verify the phone number in our CATI system.

   Correct (Go to 3)
   Incorrect

2. INTERVIEWER: Enter the correct area code and phone number.

   (___) ____-__________
I. Background and Health Status

First we would like to confirm some information about your child's health plan.

3. Our records show that your child (name) was enrolled in the Connecticut Husky A program during the entire year of 1999. Is this correct?

   Yes
   No
   Don't know
   Refused

(If other than Yes, ask if child was enrolled at all, and for how long, thank the respondent, and conclude interview)

4. Our records show that (name) was enrolled in (plan name) during the entire year of 1999. Is that correct?

   Yes (Go to 6)
   No
   Don't know
   Refused

5. What plan was (name) enrolled in during 1999?

   Bluecare
   Community Health Network
   Physicians Health Services
   Yale Preferred One

   INTERVIEWER: If more than one health plan is mentioned, end the survey.

Now I would like to ask a few questions about (name's) health.

6. How would you rate (name)'s overall health right now? Would you say it is ...

   Excellent
   Very Good
   Satisfactory
   Fair
   Poor
   Don't know
   Refused
7. During 1999, did (name) have a physical or mental health condition that kept him/her from doing any kind of activity that other children or youth his/her age usually do?

   Yes
   No (Go to 9)
   Don't know (Go to 9)
   Refused (Go to 9)

8. Has this condition been going on for at least one year, or is it expected to go on for at least one year?

   Yes
   No
   Don't know
   Refused

Now I would like to ask about (child's) physical health in particular.

9. During 1999, did (name) go to a medical doctor or specialist for a physical health condition on a regular basis?

   Yes
   No (Go to 13)
   Don't know (Go to 13)
   Refused (Go to 13)

10. Was this because of a physical health condition that (name) still has?

    Yes
    No
    Don't know
    Refused

11. Has this condition been going on for at least one year, or is it expected to go on for at least one year?

    Yes
    No
    Don't know
    Refused
Now I would like to ask about (name's) mental health.

13. During 1999, did (name) go to a counselor, psychiatrist, or psychologist on a regular basis?

   Yes
   No (Go to 17)
   Don't know (Go to 17)
   Refused (Go to 17)

14. Was this because of a condition that (name) still has?

   Yes
   No
   Don't know
   Refused

15. Has this condition been going on for at least one year, or is it expected to go on for at least one year?

   Yes
   No
   Don't know
   Refused

II. Access to Primary Care

Now I would like to ask a few questions about primary care for (name). A primary care provider is the doctor in health plan who would see (name) for regular checkups. A primary care provider might also send (name) to other doctors or providers in the plan when there is a need for special health care services.

17. During 1999, did (name) have a primary care provider with (plan name)? A primary care provider is the doctor who would see (name) for regular checkups or send (name) to other doctors or providers in the plan when there is a need for special health care services.

   Yes (Go to 19)
   No
   Don't know (Go to 24)
   Refused (Go to 24)
18. Why didn't (name) have a primary care provider?

Did not want one
Could not find one
Other (specify)
Don't know
Refused

(Go to 24)

19. Did (name) have one primary care provider for the entire year, or did he/she have more than one primary care provider?

One
More than one
Don't know
Refused

If more than one, preface 20 with: Thinking about the most recent primary care provider:

20. Did you choose (name)'s primary care provider, or was the provider assigned to him?

I chose the provider
Provider was assigned
Kept same provider as child had before enrolling in plan
Don't know
Refused

21. Was this provider a pediatrician, a family physician, or some other type of provider?

Pediatrician
Family physician
Other (specify)
Don't know
Refused

22. How satisfied were you with the choice you had in selecting a primary care provider for (name)? Would you say ...

Very satisfied
Satisfied
Dissatisfied
Very dissatisfied
Don't know
Refused
23. How long did it usually take to get appointments with (name)'s primary care provider? Would you say ...

Less than four weeks
Four - six weeks
More than six weeks
Don't know
Refused

III. Access to Medical Specialty Care

Now I would like to ask you about medical specialists. Medical specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care.

24. During 1999, did (name) see any medical specialists other than his/her primary care provider? Medical specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care.

Yes
No (Go to 33)
Don't know (Go to 33)
Refused (Go to 33)

25. How many different medical specialists did (name) see through (plan name) during 1999? Would you say ...

One
Two - three
Four - five
More than five
Don't know
Refused

26. How satisfied were you with the choice you had in selecting medical specialists for (name) through (plan name)?

Very satisfied
Satisfied
Dissatisfied
Very dissatisfied
Don't know
Refused
27. How many times did (name) see a medical specialist through (plan name) during 1999? Would you say ...

None
One - two times
Three - five times
Six - eight times
More than eight times
Don't know
Refused

28. Do you think the number of specialty care visits approved by (plan name) was enough to meet (name)'s needs?

Yes
No
Don't know
Refused

29. How long did it usually it take to get appointments with (name)'s medical specialist(s)? Would you say ...

Less than four weeks
Four - six weeks
More than six weeks
Don't know
Refused

30. Have you ever needed (name)'s primary care provider to refer him/her to a specialist?

Yes
No (Go to 32)
Don't know
Refused

31. How much of a problem, if any, was it to get a referral to a specialist from (name)'s primary care provider? Would you say ...

A big problem
A small problem
No problem
Don't know
Refused
32. Does (name)'s primary care provider communicate with (name's) other specialist(s) on a regular basis?

   Yes
   No
   Don't know
   Refused

IV. Access to Behavioral Health Care

Now I would like to ask you some questions about behavioral health care. These might include mental health conditions or substance abuse problems.

33. During 1999, did (name) see any behavioral health care providers, such as a psychiatrist, psychologist, or counselor for a mental health or substance abuse problem?

   Yes
   No (Go to 39)
   Don't know (Go to 39)
   Refused (go to 39)

34. How many different behavioral health care providers did (name) see through (plan name) during 1999? Would you say ...

   One
   Two - three
   Four - five
   More than five
   Don't know
   Refused

35. How satisfied were you with the choice you had in selecting behavioral health care providers for (name) through (plan name)?

   Very satisfied
   Satisfied
   Dissatisfied
   Very dissatisfied
   Don't know
   Refused
36. How many times did (name) see a behavioral health care provider through (plan name) during 1999? Would you say ...

None
One - two times
Three - five times
Six - eight times
More than eight times
Don't know
Refused

37. Do you think the number of behavioral health care visits approved by (plan name) was enough to meet (name)'s needs?

Yes
No
Don't know
Refused

38. How long did it usually take to get appointments with (name)'s behavioral health care provider(s)? Would you say ...

Less than four weeks
Four - six weeks
More than six weeks
Don't know
Refused

V. Quality of Care from Most Responsible Provider

Now I would like you to think back through all of (name)'s medical and behavioral health care providers. Without telling me the provider's name, think about the one provider who was most responsible for his/her care.

39. How involved was this provider in the planning and delivery of (name)'s health care? Would you say the provider was...

Always involved
Usually involved
Sometimes involved
Rarely involved
Never involved
Not sure
Don't know
Refused
40. How often did this provider include you in decisions about (name)'s care? Would you say ...

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

42. How often did this provider give you enough information about (name)'s medical condition? Would you say ...

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

48. Have you ever called this provider's office or clinic during regular office hours to get help or advice for (name)?

Yes
No (Go to 50)
Don't know (Go to 50)
Refused (Go to 50)

49. How often were you able to get the help or advice you needed when you called during regular office hours?

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused
50. Have you ever tried to reach this provider on evenings or weekends to get help or advice?

Yes
No (Go to 52)
Don't know (Go to 52)
Refused (Go to 52)

51. How often were you able to get the help or advice you needed when you tried to reach this provider on evenings or weekends?

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

52. Please rate the overall quality of care your child received from this provider during 1999. Think about the questions just asked as well as any other factors you think are important. Would you say the overall quality was ...

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

VI. Other Health Care and Therapeutic Services

Now I would like to ask you about some other health care and therapeutic services for (name).

(Note: 54 and 55 are asked for each service identified as needed in 53.)

53. During 1999, did (name) need:

- [ ] Physical or occupational therapy
- [ ] Speech therapy
- [ ] Nutrition counseling
- [ ] Genetic counseling and testing
- [ ] Home health care (including home nursing)
- [ ] Personal care attendant
54. How often were you able to obtain as much of this service as (name) needed?

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

55. How would you rate the quality of this service?

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

VII. Medical Supplies and Equipment

Now I would like to ask you about medical supplies and equipment.

(Nota: 57 and 58 are asked for each type of equipment/supplies identified as needed in 56.)

56. During 1999, did (name) need:

- Prescription medicines
- Disposable medical supplies (such as special dressings, ostomy supplies or other supplies)
- Durable medical equipment (such as a feeding pump, ventilator, or other equipment)
- Adaptive equipment (such as a wheelchair, hearing aid, or other equipment)
- Nutrition products and special diets

Yes
No
Don't know
Refused
57. How often were you able to obtain this item when needed?

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

58. How would you rate the quality of this item?

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

59. How good of a job did (health plan) do in meeting (name's) needs for medical equipment and supplies? Think about the questions just asked as well as any other factors you think are important. Would you say (health plan) did:

An excellent job
A very good job
A satisfactory job
A fair job
A poor job
Don't know
Refused

VIII. Emergency And Inpatient Hospital Services

Now I have a few questions about emergency and inpatient hospital services.

60. How many times, if any, did (name) visit a hospital emergency department in 1999?

None (Go to 62)
One - two times
Three - five times
Six - eight times
More than eight times
Don't know (Go to 62)
Refused (Go to 62)
61. Did (name) ever have to go to a hospital emergency department because his/her primary care provider was not available to see him/her?

   Yes (What time of day was that?)_________
   No

62. How many times, if any, did (name) stay overnight in a hospital during 1999, other than for behavioral health care?

   None (Go to 65)
   One - two times
   Three - five times
   Six - eight times
   More than eight times
   Don't know (Go to 65)
   Refused (Go to 65)

64. Were you satisfied with the number of hospital days approved for (name)?

   Yes
   No
   Don't know
   Refused

64a. When (name) was discharged from the hospital, did (plan) give you the services you needed to take care of him/her at home?

   Yes
   No
   Don't know
   Refused

65. Did (name) need to stay overnight in a hospital for behavioral health care in 1999? This might include a stay for a mental health condition or substance abuse.

   Yes
   No (Go to 67)
   Don't know (Go to 67)
   Refused (Go to 67)
65a. Were you satisfied with the number of hospital days approved for (name?)

   Yes
   No
   Don't know
   Refused

66. When (name) was discharged, did (health plan) give you enough services to help (name) get better and not have to go back to the hospital?

   Yes
   No
   Don't know
   Refused

IX. Dental Services

Now I would like to ask a few questions about dental services.

((Note: Ask only if age two or older))

67. Did (name) see a dentist through (plan name) in 1999?

   Yes
   No (go to 72)
   Don't know (Go to 72)
   Refused (Go to 72)

68. How satisfied were you with the choice of dental providers available to (name)?

   Very satisfied
   Satisfied
   Dissatisfied
   Very dissatisfied
   Don't know
   Refused

69. How long did it usually take to get appointments with (name)'s dental care provider(s)?
   Would you say ...

   Less than four weeks
   Four - six weeks
   More than six weeks
   Don't know
   Refused
70. Were you satisfied with this length of time?

Yes
No
Don't know
Refused

71. Please rate the overall quality of dental services received. Think about the questions just asked as well as any other factors you think are important.

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

X. Care Coordination

Now I would like to ask you some questions about coordination of care for (name).

((Note: 73-75 are asked for each type of care coordination identified in 72))

72. During 1999, did you need help ...

__ coordinating care among different doctors?
__ arranging home health care or nursing services in your home?
__ arranging for durable medical equipment?
__ arranging for transportation to or from health care appointments?

Yes
No
Don't know
Refused

73. Were you able to obtain help?

Yes
No
Don't know
Refused
74. Who helped you most?

PCP
Other doctor
Health plan
Title V/ Center at Yale/New Haven
Title V/Connecticut Children's Medical Center
DCF
Other (specify)
Don't know
Refused

75. How would you rate the quality of the help you received?

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

75a. During 1999, did (name) have a case manager from (health plan)?

Yes
No (Go to 76)
Don't know (Go to 76)
Refused (Go to 76)

75b. Did this case manager give you information about parent-to-parent and family support services?

Yes
No
Don't know
Refused
75c. How often did this case manager have enough time to meet and talk with you? 
   Would you say ...

   Always
   Usually
   Sometimes
   Rarely
   Never
   Don't know
   Refused

76. Please rate the overall quality of the care coordination (name) received from (health plan) during 1999. Think about the questions just asked as well as any other factors you think are important.

   Excellent
   Very Good
   Satisfactory
   Fair
   Poor
   Don't know
   Refused

Now I would like to ask you some general questions about (name's) health plan.

77. If you are not satisfied with a decision made by (plan name) about services for (name) can you make a formal complaint about the decision?

   Yes
   No
   Don't know
   Refused

78. During 1999, did you feel a need to make a formal complaint about (name's) care?

   Yes
   No (Go to 81)
   Don't know (Go to 81)
   Refused (Go to 81)
79. Did you actually make a formal complaint during 1999?
   Yes (Go to 81)
   No
   Don't know
   Refused

80. Why didn't you make a formal complaint?
   Too time-consuming and/or confusing
   Afraid I might lose services
   Didn't think it would do any good
   Didn't know it existed
   Other (specify)
   Don't know
   Refused

81. Are you allowed to get approval from (plan name) to see a doctor who is not part of the plan, if you think it is needed?
   Yes
   No
   Don't know
   Refused

82. During 1999, did you ever try to get approval for (name) to see a doctor who is not part of (plan name)?
   Yes
   No (Go to 84)
   Don't know (Go to 84)
   Refused (Go to 84)

83. Were you able to get approval?
   Yes
   No
   Don't know
   Refused
84. During 1999, were any of the health care services you or your doctor thought (name) needed cut back or stopped by (plan name)?

Yes
No (Go to 86)
Don't know (Go to 86)
Refused (Go to 86)

85. Were you told about this change in writing?

Yes
No (go to 86)
Don't know (Go to 86)
Refused (go to 86)

85a. Were you offered a Fair Hearing?

Yes
No
Don't know
Refused

86. During 1999, did you ever need an interpreter when you brought (name) in for health care?

Yes
No (Go to 88)
Don't know (Go to 88)
Refused (Go to 88)

87. How often was an interpreter available when you needed one? Would you say ...

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused
88. Does (name) have any disability or special equipment that sometimes makes it difficult to get in and around a place?

Yes  
No (Go to 90)  
Don't know (Go to 90)  
Refused (Go to 90)

89. During 1999, how often did you have difficulty getting into and around health care providers' offices with (name)? Would you say ...

Always  
Usually  
Sometimes  
Rarely  
Never  
Don't know  
Refused

90. Does (name) require special transportation services to get to and from appointments?

Yes  
No (Go to 92)  
Don't know (Go to 92)  
Refused (Go to 92)

91. During 1999, how often were you able to get the special transportation services (name) needed? Would you say ...

Always  
Usually  
Sometimes  
Rarely  
Never  
Don't know  
Refused

92. Finally, thinking about all of the questions we have asked in this interview, how would you rate the services provided by (plan name) in 1999? Please rate the plan on a scale of 1 to 10, where 1 is the worst rating, and 10 is the best rating.

1 2 3 4 5 6 7 8 9 10

That is the end of my questions, and I would like to thank you for participating in our survey.
We want you to know that if you have any questions or problems getting care for your child, there is help available.

FOR MEMBERS OF PHYSICIANS HEALTH SERVICES

The Children’s Health Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak to a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free and confidential.

FOR MEMBERS OF BLUECARE

If you need help from your child’s health plan, you can call Jackie Stupakevich at BlueCare Family Plan. Her number is 1-800-738-1386. The call is free.

If you wish, you can also call the Children’s Health Infoline. The Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak with a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free.

FOR MEMBERS OF PREFERRED ONE

If you need help from your child’s health plan, you can call Jo-Ann Villano at Preferred One Member Services. Her number is 1-800-925-3606. The call is free.

If you wish, you can also call the Children’s Health Infoline. The Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak with a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free.

FOR MEMBERS OF CHN

If you need help from your child’s health plan, you can call Aida Ayala at Community Health Network Member Services. Her number is 1-800-859-9889, ext. 3016. The call is free.

If you wish, you can also call the Children’s Health Infoline. The Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak with a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free.
SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS
IN CONNECTICUT'S HUSKY A PROGRAM
Children in the care of the Department of Children & Families
Telephone Survey Format (Revised 8/15/00)

Introduction

Hello, my name is _____________. I am calling on behalf of the Connecticut Department of Social Services. We recently sent you a letter asking for your help with a study we are doing to find out how well HUSKY health plans are serving children. Husky A is Connecticut's Medicaid Managed Care Program. The information you provide is private and will be used to improve how health plans serve families like yours. Your answers will not affect the benefits you or your child get.

The survey will only take about 20 minutes of your time. Is that okay? If not, is there a good time for me to call back?

Callback

Hello, this is ___________ calling on behalf of the Connecticut Department of Social Services. We started an interview earlier and I'm calling back to complete the interview. Is that okay?

Contact Verification

1. INTERVIEWER: Please verify the phone number in our CATI system.
   Correct (Go to 3)
   Incorrect

2. INTERVIEWER: Enter the correct area code and phone number.
   (____) _____-__________
I. Background and Health Status

Before we begin, you have (number) children in your household that we would like to ask you questions about. If you have time now, I would like to complete this survey about (child 1) and then continue with your other children.

3A. How many months has (name) been in your care between January 2000 and June 2000?

ENTER NUMBER OF MONTHS ONLY

(If less than six months, conclude the interview.)

3. Our records show that your child (name) was enrolled in the Connecticut Husky A program from July 1999 to June 2000. Is this correct?

Yes
No
Don't know
Refused

(If other than Yes, ask if child was enrolled at all, and for how long, thank the respondent, and conclude interview)

4. Our records show that (name) was enrolled in (plan name) from July 1999 to June 2000. Is that correct?

Yes (Go to 6)
No
Don't know
Refused

5. What plan was (name) enrolled in from July 1999 to June 2000?

Bluecare
Community Health Network
Physicians Health Services
Yale Preferred One

INTERVIEWER: If more than one health plan is mentioned, conclude the interview.
Now I would like to ask a few questions about (name's) health.

6. How would you rate (name)'s overall health right now? Would you say it is ...

   Excellent
   Very Good
   Satisfactory
   Fair
   Poor
   Don't know
   Refused

7. From July 1999 to June 2000, did (name) have a physical or mental health condition that kept him/her from doing any kind of activity that other children or youth his/her age usually do?

   Yes
   No (Go to 9)
   Don't know (Go to 9)
   Refused (Go to 9)

8. Has this condition been going on for at least one year, or is it expected to go on for at least one year?

   Yes
   No
   Don't know
   Refused

Now I would like to ask about (child's) physical health in particular.

9. From July 1999 to June 2000, did (name) go to a medical doctor or specialist for a physical health condition on a regular basis?

   Yes
   No (Go to 13)
   Don't know (Go to 13)
   Refused (Go to 13)

10. Was this because of a physical health condition that (name) still has?

    Yes
    No
    Don't know
    Refused
11. Has this condition been going on for at least one year, or is it expected to go on for at least one year?

Yes
No
Don't know
Refused

Now I would like to ask about (name's) mental health.

13. From July 1999 to June 2000, did (name) go to a counselor, psychiatrist, or psychologist on a regular basis?

Yes
No (Go to 17)
Don't know (Go to 17)
Refused (Go to 17)

14. Was this because of a condition that (name) still has?

Yes
No
Don't know
Refused

15. Has this condition been going on for at least one year, or is it expected to go on for at least one year?

Yes
No
Don't know
Refused

II. Access to Primary Care

17. From July 1999 to June 2000, did (name) have a primary care provider with (plan name)? A primary care provider is the doctor who would see (name) for regular checkups or send (name) to other doctors or providers in the plan when there is a need for special health care services.

Yes (Go to 19)
No
Don't know (Go to 24)
Refused (Go to 24)
18. Why didn't (name) have a primary care provider?

- Did not want one
- Could not find one
- Other (specify)
- Don't know
- Refused

(Go to 24)

19. Did (name) have one primary care provider for the entire year, or did he/she have more than one primary care provider?

- One
- More than one
- Don't know
- Refused

If more than one, preface 20 with: Thinking about the most recent primary care provider:

20. Did you choose (name)'s primary care provider, or was the provider assigned to him?

- I chose the provider
- Provider was assigned
- Kept same provider as child had before enrolling in plan
- Don't know
- Refused

21. Was this provider a pediatrician, a family physician, or some other type of provider?

- Pediatrician
- Family physician
- Other (specify)
- Don't know
- Refused

22. How satisfied were you with the choice you had in selecting a primary care provider for (name)? Would you say ...

- Very satisfied
- Satisfied
- Dissatisfied
- Very dissatisfied
- Don’t know
- Refused
23. How long did it usually take to get appointments with (name)'s primary care provider? Would you say ...

   Less than four weeks
   Four - six weeks
   More than six weeks
   Don't know
   Refused

III. Access to Medical Specialty Care

24. From July 1999 to June 2000, did (name) see any medical specialists other than his/her primary care provider? Medical specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care.

   Yes
   No (Go to 33)
   Don't know (Go to 33)
   Refused (Go to 33)

25. How many different medical specialists did (name) see through (plan name) from July 1999 to June 2000? Would you say ...

   One
   Two - three
   Four - five
   More than five
   Don't know
   Refused

26. How satisfied were you with the choice you had in selecting medical specialists for (name) through (plan name)?

   Very satisfied
   Satisfied
   Dissatisfied
   Very dissatisfied
   Don't know
   Refused
27. How many times did (name) see a medical specialist through (plan name) from July 1999 to June 2000? Would you say ...

None
One - two times
Three - five times
Six - eight times
More than eight times
Don't know
Refused

28. Do you think the number of specialty care visits approved by (plan name) was enough to meet (name)'s needs?

Yes
No
Don't know
Refused

29. How long did it usually it take to get appointments with (name)'s medical specialist(s)?

Would you say ...

Less than four weeks
Four - six weeks
More than six weeks
Don't know
Refused

30. Have you ever needed (name)'s primary care provider to refer him/her to a specialist?

Yes
No (Go to 32)
Don't know
Refused

31. How much of a problem, if any, was it to get a referral to a specialist from (name)'s primary care provider? Would you say ...

A big problem
A small problem
No problem
Don't know
Refused
32. Does (name)'s primary care provider communicate with (name's) other specialist(s) on a regular basis?

Yes
No
Don't know
Refused

IV. Access to Behavioral Health Care

33. From July 1999 to June 2000, did (name) see any behavioral health care providers, such as a psychiatrist, psychologist, or counselor for a mental health or substance abuse problem?

Yes
No (Go to 39)
Don't know (Go to 39)
Refused (go to 39)

34. How many different behavioral health care providers did (name) see through (plan name) from July 1999 to June 2000? Would you say ...

One
Two - three
Four - five
More than five
Don't know
Refused

35. How satisfied were you with the choice you had in selecting behavioral health care providers for (name) through (plan name)?

Very satisfied
Satisfied
Dissatisfied
Very dissatisfied
Don't know
Refused
36. How many times did (name) see a behavioral health care provider through (plan name) from July 1999 to June 2000? Would you say ...

None
One - two times
Three - five times
Six - eight times
More than eight times
Don't know
Refused

37. Do you think the number of behavioral health care visits approved by (plan name) was enough to meet (name)'s needs?

Yes
No
Don't know
Refused

38. How long did it usually it take to get appointments with (name)'s behavioral health care provider(s)? Would you say ...

Less than four weeks
Four - six weeks
More than six weeks
Don't know
Refused

V. Quality of Care from Most Responsible Provider

Now I would like you to think back through all of (name)'s medical and behavioral health care providers. Without telling me the provider's name, think about the one provider who was most responsible for his/her care.

39. How involved was this provider in the planning and delivery of (name)'s health care? Would you say the provider was...

Always involved
Usually involved
Sometimes involved
Rarely involved
Never involved
Not sure
Don't know
Refused
40. How often did this provider include you in decisions about (name)'s care? Would you say ...

Always  
Usually  
Sometimes  
Rarely  
Never  
Don't know  
Refused

42. How often did this provider give you enough information about (name)'s medical condition? Would you say ...

Always  
Usually  
Sometimes  
Rarely  
Never  
Don't know  
Refused

48. Have you ever called this provider's office or clinic during regular office hours to get help or advice for (name)?

Yes  
No (Go to 50)  
Don't know (Go to 50)  
Refused (Go to 50)

49. How often were you able to get the help or advice you needed when you called during regular office hours?

Always  
Usually  
Sometimes  
Rarely  
Never  
Don't know  
Refused
50. Have you ever tried to reach this provider on evenings or weekends to get help or advice?

   Yes
   No (Go to 52)
   Don't know (Go to 52)
   Refused (Go to 52)

51. How often were you able to get the help or advice you needed when you tried to reach this provider on evenings or weekends?

   Always
   Usually
   Sometimes
   Rarely
   Never
   Don't know
   Refused

52. Please rate the overall quality of care your child received from this provider from July 1999 to June 2000. Think about the questions just asked as well as any other factors you think are important. Would you say the overall quality was ...

   Excellent
   Very Good
   Satisfactory
   Fair
   Poor
   Don't know
   Refused

VI. Other Health Care and Therapeutic Services

Now I would like to ask you about some other health care and therapeutic services for (name).

(Note: 54 and 55 are asked for each service identified as needed in 53.)

53. From July 1999 to June 2000, did (name) need:

   __ Physical or occupational therapy
   __ Speech therapy
   __ Nutrition counseling
   __ Genetic counseling and testing
   __ Home health care (including home nursing)
   __ Personal care attendant
54. How often were you able to obtain as much of this service as (name) needed?

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

55. How would you rate the quality of this service?

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

VII. Medical Supplies and Equipment

Now I would like to ask you about medical supplies and equipment.

(Note: 57 and 58 are asked for each type of equipment/supplies identified as needed in 56.)

56. From July 1999 to June 2000, did (name) need:

- Prescription medicines
- Disposable medical supplies (such as special dressings, ostomy supplies or other supplies)
- Durable medical equipment (such as a feeding pump, ventilator, or other equipment)
- Adaptive equipment (such as a wheelchair, hearing aid, or other equipment)
- Nutrition products and special diets

Yes
No
Don't know
Refused
57. How often were you able to obtain this item when needed?

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused

58. How would you rate the quality of this item?

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

59. How good of a job did (health plan) do in meeting (name's) needs for medical equipment and supplies? Think about the questions just asked as well as any other factors you think are important. Would you say (health plan) did:

An excellent job
A very good job
A satisfactory job
A fair job
A poor job
Don't know
Refused

VIII. Emergency And Inpatient Hospital Services

Now I have a few questions about emergency and inpatient hospital services.

60. How many times, if any, did (name) visit a hospital emergency department from July 1999 to June 2000?

None (Go to 62)
One - two times
Three - five times
Six - eight times
More than eight times
Don't know (Go to 62)
61. Did (name) ever have to go to a hospital emergency department because his/her primary care provider was not available to see him/her?

  Yes (What time of day was that?)
  No

62. How many times, if any, did (name) stay overnight in a hospital from July 1999 to June 2000, other than for behavioral health care?

  None (Go to 65)
  One - two times
  Three - five times
  Six - eight times
  More than eight times
  Don't know (Go to 65)
  Refused (Go to 65)

64. Were you satisfied with the number of hospital days approved for (name)?

  Yes
  No
  Don't know
  Refused

64a. When (name) was discharged from the hospital, did (plan) give you the services you needed to take care of him/her at home?

  Yes
  No
  Don't know
  Refused

65. Did (name) need to stay overnight in a hospital for behavioral health care from July 1999 to June 2000? This might include a stay for a mental health condition or substance abuse.

  Yes
  No (Go to 67)
  Don't know (Go to 67)
  Refused (Go to 67)
65a. Were you satisfied with the number of hospital days approved for (name?)

   Yes
   No
   Don't know
   Refused

66. When (name) was discharged, did (health plan) give you enough services to help (name) get better and not have to go back to the hospital?

   Yes
   No
   Don't know
   Refused

IX. Dental Services

Now I would like to ask a few questions about dental services.

((Note: Ask only if age two or older))

67. Did (name) see a dentist through (plan name) from July 1999 to June 2000?

   Yes
   No (go to 72)
   Don't know (Go to 72)
   Refused (Go to 72)

68. How satisfied were you with the choice of dental providers available to (name)?

   Very satisfied
   Satisfied
   Dissatisfied
   Very dissatisfied
   Don't know
   Refused

69. How long did it usually take to get appointments with (name)'s dental care provider(s)?
   Would you say ...

   Less than four weeks
   Four - six weeks
   More than six weeks
   Don't know
   Refused
70. Were you satisfied with this length of time?

Yes
No
Don't know
Refused

71. Please rate the overall quality of dental services received. Think about the questions just asked as well as any other factors you think are important.

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

X. Care Coordination

Now I would like to ask you some questions about coordination of care for (name).

((Note: 73-75 are asked for each type of care coordination identified in 72))

72. From July 1999 to June 2000, did you need help ...

__ coordinating care among different doctors?
__ arranging home health care or nursing services in your home?
__ arranging for durable medical equipment?
__ arranging for transportation to or from health care appointments?

Yes
No
Don't know
Refused

73. Were you able to obtain help?

Yes
No
Don't know
Refused
74. Who helped you most?

PCP
Other doctor
Health plan
Title V/Center at Yale/New Haven
Title V/Connecticut Children's Medical Center
DCF
Other (specify)
Don't know
Refused

75. How would you rate the quality of the help you received?

Excellent
Very Good
Satisfactory
Fair
Poor
Don't know
Refused

75a. From July 1999 to June 2000, did (name) have a case manager from (health plan)?

Yes
No (Go to 76)
Don't know (Go to 76)
Refused (Go to 76)

75b. Did this case manager give you information about parent-to-parent and family support services?

Yes
No
Don't know
Refused
75c. How often did this case manager have enough time to meet and talk with you?
   Would you say ...

   Always
   Usually
   Sometimes
   Rarely
   Never
   Don't know
   Refused

76. Please rate the overall quality of the care coordination (name) received from (health plan) from July 1999 to June 2000. Think about the questions just asked as well as any other factors you think are important.

   Excellent
   Very Good
   Satisfactory
   Fair
   Poor
   Don't know
   Refused

Now I would like to ask you some general questions about (name's) health plan.

77. If you are not satisfied with a decision made by (plan name) about services for (name) can you make a formal complaint about the decision?

   Yes
   No
   Don't know
   Refused

78. From July 1999 to June 2000, did you feel a need to make a formal complaint about (name's) care?

   Yes
   No (Go to 81)
   Don't know (Go to 81)
   Refused (Go to 81)
79. Did you actually make a formal complaint from July 1999 to June 2000?

   Yes (Go to 81)
   No
   Don't know
   Refused

80. Why didn't you make a formal complaint?

   Too time-consuming and/or confusing
   Afraid I might lose services
   Didn't think it would do any good
   Didn't know it existed
   Other (specify)
   Don't know
   Refused

81. Are you allowed to get approval from (plan name) to see a doctor who is not part of the plan, if you think it is needed?

   Yes
   No
   Don't know
   Refused

82. From July 1999 to June 2000, did you ever try to get approval for (name) to see a doctor who is not part of (plan name)?

   Yes
   No (Go to 84)
   Don't know (Go to 84)
   Refused (Go to 84)

83. Were you able to get approval?

   Yes
   No
   Don't know
   Refused
84. From July 1999 to June 2000, were any of the health care services you or your doctor thought (name) needed cut back or stopped by (plan name)?

Yes
No (Go to 86)
Don't know (Go to 86)
Refused (Go to 86)

85. Were you told about this change in writing?

Yes
No (go to 86)
Don't know (Go to 86)
Refused (go to 86)

85a. Were you offered a Fair Hearing?

Yes
No
Don't know
Refused

85. From July 1999 to June 2000, did you ever need an interpreter when you brought (name) in for health care?

Yes
No (Go to 88)
Don't know (Go to 88)
Refused (Go to 88)

87. How often was an interpreter available when you needed one? Would you say ...

Always
Usually
Sometimes
Rarely
Never
Don't know
Refused
88. Does (name) have any disability or special equipment that sometimes makes it difficult to get in and around a place?

   Yes
   No (Go to 90)
   Don't know (Go to 90)
   Refused (Go to 90)

89. From July 1999 to June 2000, how often did you have difficulty getting into and around health care providers' offices with (name)? Would you say ...

   Always
   Usually
   Sometimes
   Rarely
   Never
   Don't know
   Refused

90. Does (name) require special transportation services to get to and from appointments?

   Yes
   No (Go to 92)
   Don't know (Go to 92)
   Refused (Go to 92)

90. From July 1999 to June 2000, how often were you able to get the special transportation services (name) needed? Would you say ...

   Always
   Usually
   Sometimes
   Rarely
   Never
   Don't know
   Refused

92. Finally, thinking about all of the questions we have asked in this interview, how would you rate the services provided by (plan name) from July 1999 to June 2000? Please rate the plan on a scale of 1 to 10, where 1 is the worst rating, and 10 is the best rating.

   1  2  3  4  5  6  7  8  9  10

That is the end of my questions, and I would like to thank you for participating in our survey.
We want you to know that if you have any questions or problems getting care for your child, there is help available.

FOR MEMBERS OF PHYSICIANS HEALTH SERVICES

The Children’s Health Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak to a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free and confidential.

FOR MEMBERS OF BLUECARE

If you need help from your child’s health plan, you can call Jackie Stupakevich at BlueCare Family Plan. Her number is 1-800-738-1386. The call is free.

If you wish, you can also call the Children’s Health Infoline. The Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak with a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free.

FOR MEMBERS OF PREFERRED ONE

If you need help from your child’s health plan, you can call Jo-Ann Villano at Preferred One Member Services. Her number is 1-800-925-3606. The call is free.

If you wish, you can also call the Children’s Health Infoline. The Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak with a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free.

FOR MEMBERS OF CHN

If you need help from your child’s health plan, you can call Aida Ayala at Community Health Network Member Services. Her number is 1-800-859-9889, ext. 3016. The call is free.

If you wish, you can also call the Children’s Health Infoline. The Infoline is available to anyone who needs help getting healthcare services in the HUSKY program. You can speak with a trained care coordinator who can answer questions and help you solve problems. You can reach the Children’s Health Infoline at 1-800-434-7869. The call is free.
Dear

We need your help. The Department of Social Services (DSS) wants to find out about the care that children get from HUSKY health plans. By answering some questions, you can help us to better understand how well HUSKY health plans are serving children. This information will be used to help the health plans serve families better.

In the next few weeks, someone from the Connecticut Children’s Health Project will call to ask you to take part in a telephone interview. The interviewer will ask questions about the care your child got through your HUSKY health plan in the past year, such as:

- What do you think about the services your child gets from your health plan?
- Do you have any problems getting care for your child?

You and your family have been chosen to help us learn more about your health plan. Of course, what you have to say is private. Your answers will be part of a pool of information from others like you. The answers that you give will not be shared with DSS or your health plan. The interview will take about 20 minutes. **You may choose to do the telephone interview or not. If you choose not to take part, your choice will not affect the benefits you or your child get.**

If you have any questions, please call The Children’s Health Infoline at the Connecticut Children’s Health Project at 1-800-434-7869. All calls to this number are free. **Do not call your DSS worker or your health plan. Your DSS worker and the health plan are not involved in the survey.**

We hope you will take this chance to tell to us about your child’s health care. Thanks in advance for your help!

Sincerely,

David Parrella
Director of Medical Care Administration
Department of Social Services
Estimado

Necesitamos su ayuda. El Departamento de Servicios Sociales (DSS) quiere saber acerca del cuidado médico que sus niños están recibiendo por los planes de salud de HUSKY. En contestar estas preguntas, usted puede ayudarnos a mejorar entender si los planes de salud de HUSKY le están sirviendo bien a sus niños. Esta información se usará para ayudar que los planes de salud sirvan mejor a las familias.

En las próximas semanas, alguien del Proyecto para la Salud de los Niños de Connecticut (Connecticut Children’s Health Project) lo llamará para preguntarle si puede tomar parte en una entrevista telefónica. El entrevistador le hará preguntas sobre el cuidado que su niño recibió bajo el plan de salud de HUSKY en el año pasado, tal como:

- ¿Qué piensa sobre los servicios que su niño recibe de su plan de salud?
- ¿Tiene cualquier problemas en recibir cuidado para su niño?

Usted y su familia han sido escogidos para ayudarnos ha aprender más sobre su plan de salud. Por supuesto, lo que diga será mantenido privado. Sus respuestas serán parte de una colección de información de otras personas como usted. Sus respuestas no se compartirán con DSS o su plan de salud. La entrevista tomará aproximadamente 20 minutos. **Puede escoger hacer la entrevista telefónica o no. Si escoge no tomar parte en la entrevista, su opción no cambiará los beneficios o servicios que usted o su niño reciben.**

Si tiene alguna pregunta, favor de llamar la Línea de Información de Salud para Niños del Proyecto para la Salud de los Niños de Connecticut al 1-800-434-7869. Todas la llamadas a este número son gratis. **No llame a su trabajor de DSS o a su plan de salud. Ellos no están envueltos en este estudio.**

Esperamos que tome esta oportunidad para decirnos sobre el cuidado de salud de su niño. ¡Gracias en adelantado por su ayuda!

Sinceramente,

David Parrella
Director de Administración del Cuidado Médico
Departamento de Servicios Sociales
Dear

The Department of Children and Families (DCF) and the Department of Social Services (DSS) would like your help to find out about the care that children receive from HUSKY health plans. By answering some questions, you can help us to better understand how well HUSKY health plans are serving children. This information will be used to help the health plans better serve families.

In the next few weeks, someone from the Connecticut Children’s Health Project will call to ask you to take part in a telephone interview. The interviewer will ask questions about the care your foster/adopted child received through his/her HUSKY health plan in the past year. The following are examples of the type of question that will be asked:

- What do you think about the services your child gets from your health plan?
- Do you have any problems getting care for your child?

Your and your family have been chosen to help us learn more about your health plan. Of course, what you have to say will be kept confidential. Your answers will be part of a pool of information from others like you. The answers that you give will not be shared with DCF, DSS or your health plan. The interview will take about 20 minutes. You may choose to do the telephone interview or not. If you choose not to take part, your choice will not affect the benefits your foster/adopted child receives.

If you have any questions, please call The Children’s Health Infoline at the Connecticut Children’s Health Project at 1-800-434-7869. All calls to this number are free. Do not call your DCF or DSS worker or your health plan since they are not involved in the survey.

We hope you will take this chance to tell to us about your child’s health care. Thanks in advance for your help!

Sincerely,

David Parrella
Director of Medical Care Administration
Department of Social Services
Estimado Padres de Crianza/Padres Adoptivo:

El Departamento de Niños y Familias (DCF) y el Departamento de Servicios Sociales (DSS) necesita su ayuda en saber acerca del cuidado médico que sus niños están recibiendo por los planes de salud de HUSKY. **En contestar estas preguntas, usted puede ayudarnos a mejor entender si los planes de salud de HUSKY le estan sirviendo bien a sus niños.** Esta información se usará para ayudar que los planes de salud sirvan mejor a las familias.

En las próximas semanas, alguien del Proyecto para la Salud de los Niños de Connecticut (**Connecticut Children’s Health Project**) lo llamará para preguntarle si puede tomar parte en una entrevista telefónica. El entrevistador le hará preguntas sobre el cuidado que su hijo adoptivo recibió bajo el plan de salud de HUSKY en el año pasado. Aquí hay ejemplos de las preguntas que le harán:

- ¿Qué piensa sobre los servicios que su niño recibe de su plan de salud?
- ¿Tiene cualquier problemas en recibir cuidado para su niño?

Usted y su familia han sido escogidos para ayudarnos ha aprender más sobre su plan de salud. Por supuesto, lo que diga será mantenido confidencial. Sus respuestas serán parte de una colección de información de otras personas como usted. Sus respuestas no se compartirán con DCF, DSS, o su plan de salud. La entrevista tomará aproximadamente 20 minutos. **Puede escoger hacer la entrevista telefónica o no. Si escoge no tomar parte en la entrevista, su opción no cambiará los beneficios o servicios que su hijo adoptivo recibe.**

Si tiene alguna pregunta, favor de llamar la Línea de Información de Salud para Niños del Proyecto para la Salud de los Niños de Connecticut al 1-800-434-7869. Todas las llamadas a este número son gratis. **No llame a su trabajor de DCF o DSS, o a su plan de salud porque ellos no están envueltos en este estudio.**

Esperamos que tome esta oportunidad para decirnos sobre el cuidado de salud de su niño. ¡Gracias en adelantado por su ayuda!

Sinceramente,

David Parrella
Director de Administración del Cuidado Médico
Departamento de Servicios Sociales