### Issues Addressed

There is national concern about whether children with special health care needs (CSHCN) experience access problems with home health services. Home health care can include a variety of services important for these children, such as home nursing, help with feeding, bathing or dressing, or help with medical equipment and medications. While home health is rarely needed by typically developing children, it is a critical service for children with complex medical needs and the families that care for them in the community. As our health care system continues its rapid evolution, the extent of access problems encountered by these families is of great importance for parents, service providers, purchasers, regulators and administrators of health plans, as well as for health policy analysts. This fact sheet addresses three questions:

- Amongst a diverse sample of CSHCN, what percentage of children needed home health services in the preceding year?
- To what extent did parents of CSHCN report problems obtaining home health services when their children needed this care?
- Were particular characteristics of these parents or children associated with lower or higher rates of access problems?

### Study Methods

The information presented here is based on data from a survey conducted in 1998-1999 of 2,220 parents of CSHCN in 20 states. Brandeis University and Family Voices partnered to design and conduct the survey project. In this fact sheet, we focus on problems reported by parents of CSHCN in obtaining needed home health services. A series of questions was posed in the survey regarding whether the responding parent (or guardian) experienced problems in a variety of possible areas, such as the amount the family had to pay for the service, finding reliable providers who come when scheduled, or coordination between the provider and others involved in the child’s care. For those parents whose children needed or used home health services, the percentage experiencing such problems was calculated. In addition, analyses were conducted to examine whether specific characteristics of these families and children were associated with home health services access problems.

### Findings

- **About one-third of the respondents in the survey (30%) reported that their child needed home health services in the preceding year.**

  - **Almost one half** (47%) of the respondents whose child needed home health services reported at least one of the access problems inquired about in the survey. The rates of any one access problem ranged

<table>
<thead>
<tr>
<th>Access Problem</th>
<th>Percentage of Respondents Reporting Access Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting referrals</td>
<td>0%</td>
</tr>
<tr>
<td>Coordination of services</td>
<td>10%</td>
</tr>
<tr>
<td>Amount family had to pay</td>
<td>20%</td>
</tr>
<tr>
<td>Health plan would not pay</td>
<td>20%</td>
</tr>
<tr>
<td>Finding reliable providers</td>
<td>30%</td>
</tr>
<tr>
<td>who come when scheduled</td>
<td></td>
</tr>
<tr>
<td>Finding providers with skill/experience</td>
<td></td>
</tr>
<tr>
<td>One or more of these access problems</td>
<td>40%</td>
</tr>
</tbody>
</table>

*3 BRIEF*
Two characteristics were associated with an increased chance of reporting at least one of these access problems (after also accounting for the respondent’s education, marital status and employment status, the number of CSHCN in family, the child’s race/ethnicity and age, the stability of the child’s health care needs, specific child medical conditions, and the child’s Medicaid status):

- **Severe health care condition(s).** Respondents who rated the severity of their child’s condition(s) as being high were more likely to report access problems with home health services than their counterparts.

- **Public secondary health care coverage.** Respondents who reported their child had a public, secondary insurance plan were about one and a half times more likely to report access problems when compared to respondents whose children did not have this coverage.

- **Two characteristics** were associated with a decreased chance of reporting any of these access problems:

  - **Very good or excellent parental health.** Respondents who reported themselves to be in very good or excellent health were about two times less likely to report any of the access problems when obtaining home health services for their child compared to respondents in good, fair or poor health.

  - **Low income families.** Respondents who reported an annual family income of less than $20,000 were about two times less likely to report any of the access problems relative to families with “high” incomes ($40,000 and over). The percentage of families with “middle” incomes ($20,000 to $39,999) reporting access problems was not statistically different from either the low-income group or the high-income group.

**Summary**

- About one-third of the parents in this study reported that their child needed home health services in the preceding year.

- Almost half (47%) of the parents obtaining home health services for their child in this study reported one or more access problems. The most frequently reported access problems involved finding reliable providers, finding providers with the needed skill and experience and refusal of payment by the main health plan.

- Parents in the study who reported their children to have severe health conditions were at a higher risk of reporting an access problem. In addition, parents who had a public secondary health plan for their child were more likely to report access problems.

- Parents in the study who reported themselves to be in very good or excellent health were less likely to report access problems than their counterparts. In addition, it was found that respondents who reported a low family income were less likely to report access problems.

This is the first in a series of fact sheets describing CSHCN and access to health and rehabilitative services. More detailed fact sheets are available for each of the service areas described in this document and can be obtained directly from the Consortium for Children and Youth with Disabilities and Special Health Care Needs.

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For further information on these analyses, please contact the authors of this fact sheet: Marty Wyngaarden Krauss, Ph.D. (brauss@brandeis.edu) or Stephen Gulley, MSW (gulley@brandeis.edu) at the Heller School for Social Policy and Management, Brandeis University.

For further information on the Consortium for Children and Youth with Disabilities and Special Health Care Needs, its partners or projects, please go to the consortium website, at: www.consortiummrrtc.org

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