**Issues Addressed**

There is national concern about whether children with special health care needs (CSHCN) experience access problems when they require rehabilitative/habilitative services. Many CSHCNs have an ongoing and developmental need for occupational therapy. The extent of access problems encountered by families of CSHCN who require occupational therapy services is thus 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 occupational therapy services in the preceding year?

◆ To what extent did parents of CSHCN report problems obtaining occupational therapy services when their children needed this care?

◆ Were particular characteristics of these parents or children associated with lower or higher rates of access problems with occupational therapy services?

**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 care from occupational therapists. For those parents whose children needed or used occupational therapy, the percentage experiencing these problems was calculated. In addition, analyses were conducted to examine whether specific characteristics of these families and children were associated with access problems.

**Findings**

◆ Half of the respondents in the survey (51%) reported that their child needed occupational therapy in the preceding year.

◆ Almost a third (31%) of the respondents whose child needed occupational therapy reported at least one of the access problems inquired about in the survey. The rates of particular problems are shown in the graph.

◆ The following characteristics were associated with an increased chance of reporting at least one of these access problems (after also accounting for the respondent’s marital status and employment status, the number of CSHCN in the family, the child’s race/ethnicity, age and Medicaid status):

  ♦ Severe health care condition(s) or unstable health care needs. Respondents who rated the severity of their child’s...
condition(s) as being high were more likely to report access problems than their counterparts. Further, respondents who indicated that their child’s health care needs were unstable were about twice as likely to report one or more access problems compared to respondents whose children had more stable health care needs.

- **Behavior, mental health problems, or autism.** Respondents who indicated their child had behavior problems, mental health problems and/or autism were about one and a half times more likely to report any access problems when compared to respondents whose children did not have these conditions.

- **Four 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 occupational therapy services for their child compared to respondents in good, fair or poor health.
  - **Low parental education.** Respondents with a high school degree or less were about one and a half times less likely to report any of the access problems relative to respondents with at least some college education.
  - **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). Similarly, respondents who reported a “middle” annual family income ($20,000 to $39,999) were about one and a half times less likely to report any of the access problems relative to families with “high” incomes.
  - **Public secondary health care coverage.** Respondents who reported their child had a public, secondary insurance plan (such as Medicaid) were about one and a half times less likely to report access problems when compared to respondents whose children did not have this coverage.

**Summary**

- Just over half of the parents/guardians in this study reported that their child needed occupational therapy in the preceding year. Almost a third (31%) of these parents reported one or more access problems when obtaining care their children needed from occupational therapists.

- Parents in the study who reported their children to have unstable health care needs and/or severe condition(s) were at a higher risk of reporting access problems when seeking care from occupational therapists for their children. In addition, parents whose child had either autism, behavior problems or mental health problems were more likely to report access problems than their counterparts.

- 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, respondents with low education and/or low income were less likely to report access problems.

- Parents with public secondary coverage for their child (such as provided by Medicaid in many states) were less likely to report an access problem than parents without this coverage.

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 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.consortiumnrrtc.org

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