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BRIEF

## Children with Special Health Care Needs and Access to Specialty Care from Physicians: A Fact Sheet on Findings

### Issues Addressed

There is national concern about whether children with special health care needs (CSHCN) experience access problems when obtaining specialty care from physicians. At a time of rapid change in our health care system, CSHCN may need care from specialists more frequently than typically developing children. The extent of access problems encountered by families of CSHCN who require these services is thus of great importance for parents, health plans, 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 services from specialty physicians in the preceding year?
- ◆ To what extent did parents of CSHCN report problems obtaining specialty care from physicians when their children needed this care?
- ◆ Were particular characteristics of these parents or children associated with lower or higher rates of access problems with care from specialty physicians?

### Study Methods

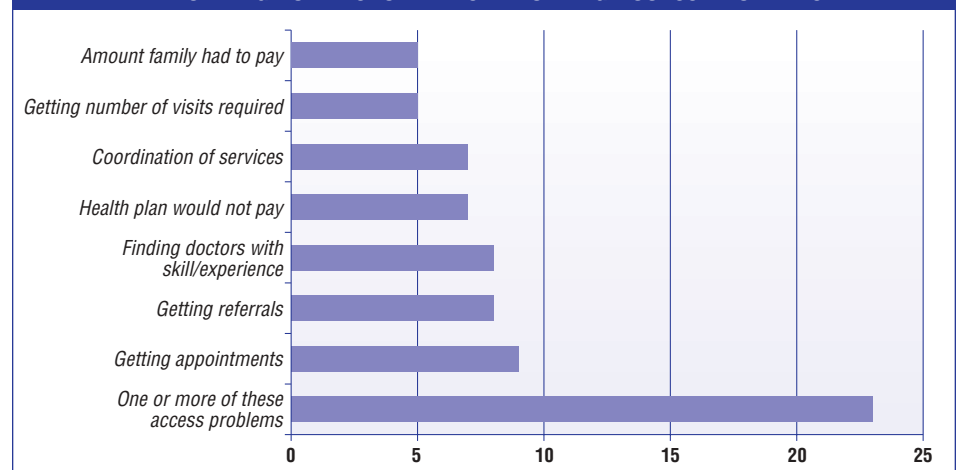
The information presented here is based on data from a survey conducted in 1998-1999 of 2,220 parents of CSHCN in 20 states. Brandeis University and Family Voices partnered to design and conduct the survey project. In this fact sheet, we focus on problems reported by parents of CSHCN in obtaining needed care from specialty physicians. 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, obtaining the number of visits needed, or coordination between the specialty doctor and others involved in the child's care. For those parents whose children needed or used

specialty physician services, the number experiencing these problems was calculated. In addition, analyses were conducted to examine whether specific characteristics of these families and children were associated with specialty physician access problems.

### Findings

- ◆ **Most respondents in the survey (82%) reported that their child needed care from a specialty physician in the preceding year.**
- ◆ **Almost a quarter (23%)** of the respondents whose child needed care from a specialty physician reported at least one of the access problems inquired about in the survey. The rates of any one access problem ranged from five to nine percent as shown in the graph.

PERCENTAGE OF RESPONDENTS REPORTING ACCESS PROBLEMS



◆ **Three characteristics** were associated with an **increased** chance of reporting at least one of these access problems (after also accounting for the respondent's education level, marital status and employment status, family income, and the child's age, race/ethnicity, severity of health conditions and Medicaid status):

◆ **Unstable health care needs.** Respondents who indicated that their child's health care needs were unstable ("changing all the time") were about twice as likely to report one or more access problems compared to respondents whose children had more stable needs.

◆ **Behavior, mental health problems, or autism.** Respondents who indicated their child had behavior problems, mental health problems and/or autism were about twice as likely to report any access problems for specialty physician services when compared to respondents whose children did not have these conditions.

◆ **More than one child with special health care needs.** Respondents who had more than one CSHCN in the family were about one and a half times more likely to report any of these access problems compared to families with only one CSHCN.

◆ **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 over two times less likely to report any of the access problems when obtaining specialty physician services for their child compared to respondents in good, fair or poor health.

◆ **Public secondary health care coverage.** Respondents who reported their child had a public, secondary insurance plan (such as Medicaid) were over two times less likely to experience one or more access problems for services from specialty physicians, compared to respondents whose children did not have this coverage.

## Summary

◆ Most respondents (82%) reported that their child needed care from a specialty physician in the preceding year.

◆ A sizable minority (23%) of parents in this study reported one or more access problems when obtaining care their children needed from specialty physicians. The most frequently reported problems included getting appointments, getting referrals and finding a doctor with the needed skill and experience.

◆ Several kinds of families and children in this study were at higher risk of access problems when seeking care from specialty physicians for their children. Families in which there was a parent in poorer health or more than one CSHCN reported access problems at a higher rate, as did families with a child who had unstable health care needs or a behavioral health condition.

◆ Families with public secondary coverage (such as provided by

Medicaid in many states) were less likely to report an access problem than families 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](http://www.consortiumnrrtc.org)*



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