



1 Children with Special Health Care Needs and Access to Health and Rehabilitative Services: A Fact Sheet on Findings

Issues Addressed

Children with special health care needs (CSHCN) have a higher need for health and rehabilitative services than typically developing children. These children often require services from specialty physicians, mental health providers, physical, speech or occupational therapists and/or home health care agencies. At a time of rapid change in our health care system, there is a national concern that CSHCN and those caring for them may encounter problems when accessing the services these children need. Yet, CSHCN are diverse in their health status and in their requirements for services. Not only are each child's conditions and needs for services unique, so too are their personal and familial characteristics. A better understanding of the problems individual children and families may face when accessing health care 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 the following questions:

- ♦ Amongst a diverse sample of CSHCN, what percentage of

children needed each of the following six services during a twelve month period: care from specialty doctors, mental health services, physical, speech and occupational therapies and home health care?

- ♦ Within each of these service areas, what percentage of parents (or guardians) reported problems accessing care when their child needed it? What were the most commonly reported specific problems in each service area?
- ♦ Looking across these six services, were particular characteristics of these children or families associated with 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 care for their child. A series of questions was posed regarding whether the responding parent experienced any of a common set of access problems

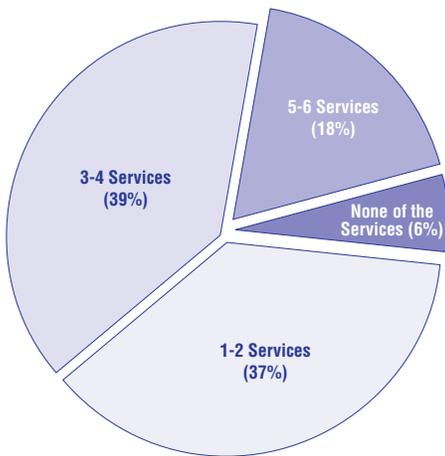
in each service area. The potential problems included such issues as getting referrals, finding a provider with the needed skill and experience, obtaining the number of visits needed, the amount the family had to pay, and coordination of services. For those parents whose children needed or used each particular service, the percentage experiencing such problems was calculated. In addition, statistical analyses were conducted to examine whether specific characteristics of the children and their families were associated with access problems.

Findings

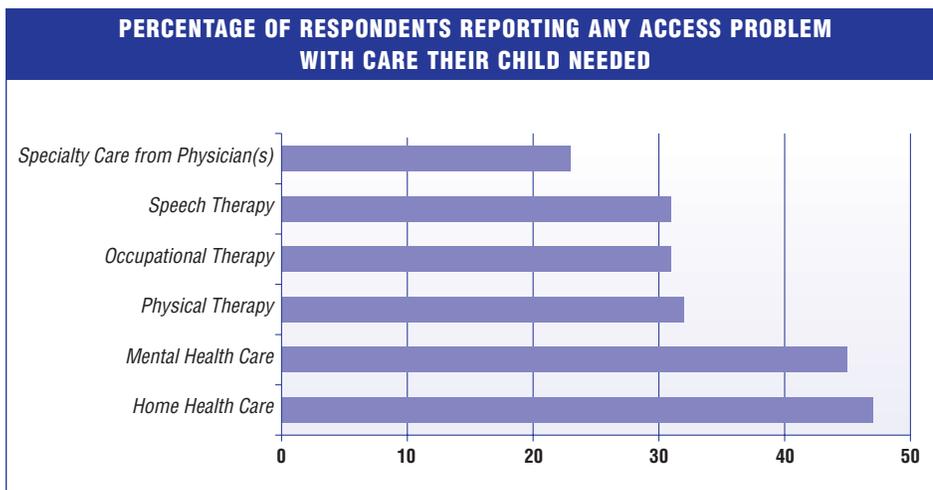
♦ The following percentages of parents reported that during the preceding year, their CSHCN needed the services listed below:

- ♦ 82% needed services from specialty medical doctors
- ♦ 49% needed speech therapy
- ♦ 48% needed physical therapy
- ♦ 48% needed occupational therapy
- ♦ 29% needed home health services
- ♦ 20% needed mental health services

◆ **Most respondents in the survey reported that their child needed multiple services in the past year.** As shown in the pie chart, 37% of the parents reported that their child needed one or two of the services listed above, while 39% reported their child needed three or four services and 18% said their child needed as many as five or all six of the services. Only six percent of parents indicated that their child needed none of these services.



◆ **The table below shows the percentage of parents reporting one or more access problems with services their child needed, by service area:**



◆ **The specific access problems reported most frequently by parents whose children needed each service are provided below.**

- ◆ **Services from specialty doctors:** problems getting appointments (9%), problems getting referrals (8%), finding providers with needed skill and experience (8%).
- ◆ **Speech therapy:** getting the number of visits needed (16%), health plan would not pay (15%), finding providers with needed skill and experience (12%).
- ◆ **Occupational therapy:** getting the number of visits needed (17%), health plan would not pay (15%), finding providers with needed skill and experience (12%).
- ◆ **Physical therapy:** getting the number of visits needed (18%), health plan would not pay (15%), finding providers with needed skill and experience (12%).
- ◆ **Mental health services:** finding providers with the needed skill and experience (27%),

problems getting referrals (15%), problems getting appointments (14%).

- ◆ **Home health services:** finding providers with needed skill and experience (30%), problems finding reliable providers (25%), health plan would not pay (18%).

It is important to note that these analyses were conducted for each service area separately. However, most respondents in the survey reported that their child needed multiple services and thus the percentage of respondents reporting an access problem with at least one of the services their child needed may be higher than the service specific estimates reported here.

- ◆ A series of analyses were performed within each service area to examine if the incidence of reported access problems was associated with **respondent and family characteristics** (such as parental health and education, family income, etc.), **child characteristics** (such as age, race, specific conditions, etc.) and **insurance characteristics** (such as having primary Medicaid coverage or having a secondary insurance plan.)

- ◆ With regard to **respondent and family characteristics**, the strongest and most consistent predictor of access problems across the service areas was the responding parent's health status. When parents reported themselves to be in very good or excellent health, they were significantly less likely to report

that their child encountered one or more of the access problems inquired about, and this finding occurred for most every service examined. In addition, parents with less formal education (e.g., high school degree or less) had fewer reported problems in some of the service areas (including specialty doctors, physical, speech and occupational therapies). Families with higher incomes (\$40,000 and over) tended to report access problems with mental health care and occupational therapy more frequently than families with incomes between \$20,000 and \$39,999. Higher income families also tended to report problems with physical therapy, occupational therapy and home health more frequently than families with incomes of less than \$20,000.

- ◆ With regard to **child characteristics**, the strongest and most consistent correlate of access problems was the stability of the child's health care needs. When respondents reported their child's health care needs to be "changing all the time" they were significantly more likely to report that they encountered one or more of the access problems, and this relationship held for most every service. Other correlates of access problems in many of the service areas include having a child with a severe condition (or conditions) and having a child with a behavioral health condition (such as having autism, a mental health condition or behavior problems).

- ◆ Regarding **insurance characteristics**, having a public secondary plan (such as provided by Medicaid in many states) was associated with a lower likelihood of reporting access problems—whether for specialty care from medical doctors, occupational therapy or speech therapy. However, it was also associated with higher reports of access problems with home health services.

Summary

- ◆ The range of specialty services needed by these children was extensive. Most children in the survey needed multiple services, with over half of the parents reporting that their child needed three or more of the services described above.
- ◆ Access problems were more frequently reported with regard to mental health services and home health services than the other service areas we inquired about. Almost half of the parents/guardians whose children needed either of these services reported an access problem.
- ◆ The specific kind of access problem(s) encountered varied across the services. However, the most frequently reported access problems were getting the number of visits needed and finding providers with the needed skill and experience.
- ◆ Families with certain characteristics were more likely to report access problems. Families in which the responding parent was in poorer health, in which the

child had unstable or severe health conditions or a behavioral health condition, and families without public secondary coverage (such as provided by Medicaid) were generally more likely to report access problems than their counterparts.

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.

The Consortium is funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. For their support of the survey upon which these findings are based, we also gratefully acknowledge the David and Lucile Packard Foundation, the Jack E. and Zella B. Butler Foundation, and the federal Bureau of Maternal and Child Health, Division of Services for Children with 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*



This project is supported by Grant H133B001200 from the National Institute on Disability Research and Rehabilitation, U.S. Department of Education.

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