



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

Issues Addressed

There is national concern about whether children with special health care needs (CSHCN) experience access problems with mental health services. As our health care system continues its rapid evolution, the extent of access problems encountered by families of CSHCN with mental health service needs is of great importance for parents, service providers, school systems, 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 mental health services in the preceding year?
- ◆ To what extent did parents of CSHCN report problems obtaining mental 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 with mental health 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.

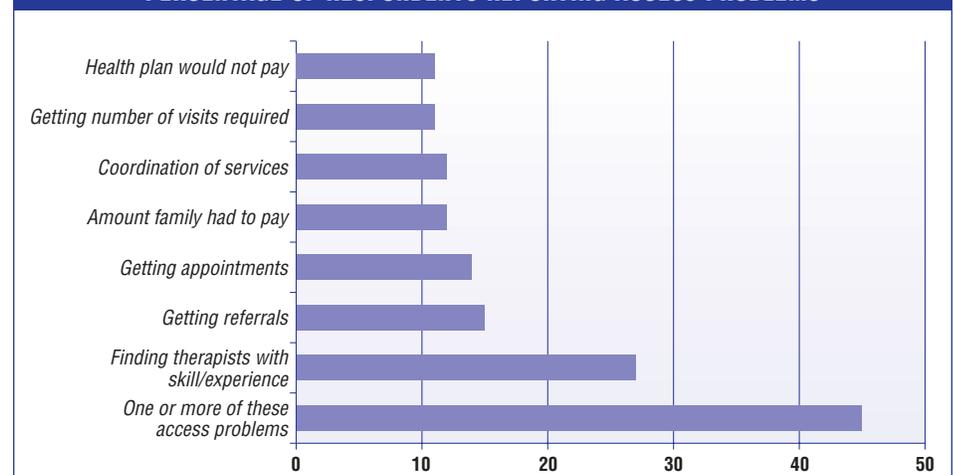
Brandeis University and Family Voices partnered to design and conduct the survey project. In this fact sheet, we focus on problems reported by parents of CSHCN in obtaining needed care from mental health service providers. A series of questions was posed in the survey regarding whether the responding parent (or guardian) experienced problems in a variety of possible areas, such as the amount the family had to pay for services, obtaining the number of visits needed, or coordination between the provider and others involved in the child's care. For those parents whose children needed or used mental 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 mental health access problems.

Findings

- ◆ **About one out of five respondents in the survey (21%) reported that their child needed mental health services in the preceding year.**
 - ◆ **Almost one half (45%)** of the respondents whose children needed mental health services reported one or more of the access problems inquired about in the survey. The rates of any one access problem ranged from eleven to twenty-seven percent as shown in the graph.
- ◆ **Three characteristics** were associated with an **increased** chance of reporting at least one

PERCENTAGE OF RESPONDENTS REPORTING ACCESS PROBLEMS



of these access problems (after also accounting for the respondent's education, marital status, employment status and overall health, family income, and the child's race/ethnicity, age, severity of medical conditions, Medicaid status and public secondary coverage status):

- ◆ **Unstable health care needs.**
Respondents who indicated that their child's health care needs were unstable ("changing all the time") were about one and a half times more 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 over one and a half times as likely to report any access problems when compared to respondents whose children did not have these conditions.
- ◆ **More than one child with special health care needs.**
Respondents who had multiple 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.
- ◆ **One characteristic** was associated with a **decreased** chance of reporting any of these access problems:
 - ◆ **Middle family income.**
Respondents who reported their annual family income to be between \$20,000 and \$39,999 reported access problems less

frequently than either families with "high" income (\$40,000 and over) or "low" income (\$20,000 or less).

Summary

- ◆ About one in five parents in this study reported that their child needed mental health services in the preceding year.
- ◆ Almost half (45%) of the parents in this study whose children needed mental health care reported one or more access problems when obtaining the services needed. The most frequently reported access problem was finding therapists with the needed skill and experience (27%). The remaining six access problems inquired about were reported at similar rates, from about eleven to fifteen percent.
- ◆ Parents in the study who reported their children to have unstable health care needs and/or a behavioral health condition were at a higher risk of reporting access problems when seeking mental health services for their children. In addition, parents who had more than one CSHCN were more likely to report access problems than parents with only one such child.
- ◆ Parents who reported a middle family income reported fewer access problems than parents from either low or high-income families.

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.

For further information on these analyses, please contact the authors of this fact sheet: Marty Wyngaarden Krauss, Ph.D. (krauss@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.consortiumnrrtc.org



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

Notice of Non-Discrimination

In accordance with the requirements of Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, Section 504 of the Rehabilitation Act of 1973, and implementing regulations promulgated under each of these federal statutes, Georgetown University does not discriminate in its programs, activities, or employment practices on the basis of race, color, national origin, sex, age, or disability. The statutes and regulations are supervised by Rosemary Kilkenny, Special Assistant to the president for Affirmative Action Programs. Her office is located in Room G-10, Darnall Hall, and her telephone number is 202/687-4798.