

**Access to Rehabilitation Services and Technology for
Children with Special Health Care Needs:
Findings and Recommendations for Families and Providers**

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Preface

The overall objectives of this research project were to:

- 1) Improve knowledge of predictors of access to rehabilitation services for children with special health care needs (CSHCN) and their families
- 2) Disseminate findings to consumers, researchers, providers, and insurance companies and
- 3) Contribute to health policy for CSHCN and their families

The primary purpose of this study was to identify barriers to rehabilitation services for CSHCN based on family reports of their experiences with their children's main health insurance plans. The three specific purposes for this study were to:

- 1) Determine predictors of access to rehabilitation services for CSHCN
- 2) Determine predictors of caregivers' ratings of performance of children's health insurance plans in providing therapy services for CSHCN and
- 3) Describe relationships between child, family, and insurance factors and caregivers' satisfaction with and access to durable medical equipment and medical and assistive technology for their CSHCN.

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Executive Summary

Research on access to specialized health services for CSHCN is a timely, important issue that is directly aligned with the purposes of Section 204 of the Rehabilitation Act of 1973 as amended (the Act). To be in compliance with the purpose of the Act, CSHCN must be fully integrated into the health care system in order to maximize their full potentials. This project examined the health care experiences of families of CSHCN to better understand whether children's rehabilitation needs are properly met in their health insurance plans. Recommendations to remove barriers are suggested by the researcher and parents of CSHCN.

The mission of the Office of Special Education and Rehabilitative Services National Institute on Disability and Rehabilitation Research (NIDRR) specifically emphasizes an agenda that includes research on health and function, including health care delivery systems such as managed care. The purpose of this research project is in alignment with the mission of NIDRR in that factors influencing access to specialized services for CSHCN in managed care arrangements were examined. The Institute identifies participatory research as a priority in examining changes in health care delivery systems. A unique feature of the Family Partners Project is that it uses a participatory research design to obtain information on the health care experiences of CSHCN. Because families are children's most important caregivers, it is essential that their experiences be a key part of the process in identifying barriers and improving access to care.

The three research studies within this project are discussed below.

Access to Rehabilitation Services: Findings from a National Survey of Families of Children with Special Health Care Needs

Access to rehabilitation services for CSHCN has become increasingly challenging in recent years. The primary purpose of this research study was to determine predictors of problems with access to rehabilitation services for CSHCN. A total of 1155 participants from the Family Partners Project database (52%) were included in this study.

Families indicated whether their children received rehabilitation services (physical, occupational, speech, or other therapies) with no problems (58%) or with some problems (42%). Items from the Family Partners Project questionnaire were identified as potential predictors of problems with access to services in three areas: insurance, child, and family factors. Results of logistic regression analysis indicated that the insurance factor was the strongest predictor of problems with access ($R^2=.19$). The family factor ($R^2=.06$) and child factor ($R^2=.05$) were significant but relatively weaker predictors of problems with access.

Findings indicate that the strongest risk factors of barriers to access are: caregiver's overall rating of satisfaction with their child's health plan; respondents from the Family Voices sample pool; financial hardships experienced by families due to their children's conditions; and number of managed care components in the child's health plan. Other risk factors for access were family burden in care giving and severity of the child's condition.

The insurance factor item that was the primary risk factor was caregiver level of overall satisfaction with their child's health plan. Problems with access were predicted by caregivers "dissatisfaction" indicating the importance of family (consumer) satisfaction as an outcome measure on accessible health care for their CSHCN. Another insurance item risk factor, managed care scale, indicated that increased numbers of managed care components in a child's health plan might present a barrier to access to therapy services. This finding is problematic given the number of CSHCN being enrolled into both private and Medicaid managed care arrangements. The protective items in the insurance factor (successful resolution of complaints to the health plan and family paid plans) indicated that families might have fewer barriers to access when they can successfully navigate the health insurance system and when they can pay for services out-of-pocket.

Future studies are indicated to examine issues on barriers to rehabilitation services for CSHCN. These studies should continue the work of the Family Partners Project but with the development of more specific questionnaires to determine the primary payer of rehabilitation services for CSHCN and to identify the most effective mechanisms for access to these services. CSHCN often receive complex rehabilitation services across several programs (health plans, schools, Early Intervention, Title V). It is important to understand the pathways to access both within and across programs to ensure timely access and quality in rehabilitation services for CSHCN.

Caregivers' Ratings of Health Plans in Providing Therapy Services for their Children with Special Health Care

The current health care system presents challenges to families with children with special health care needs (CSHCN) in accessing quality health care services. The primary purpose of this study was to identify predictors of caregivers' ratings of health plan performance in providing therapy services for their CSHCN. Participants in this study were identified from the Family Partners Project database. Seventy four percent (n=1640) of the database was eligible for this study.

Items from the Family Partners Project questionnaire were identified as possible predictors of caregivers' ratings of health plan performance for their children in three areas: insurance, child, and family factors. Caregivers used a four-point Likert scale to rate health plan performance in "providing skilled and experienced other specialists such as physical therapists (PTs), occupational therapists (OTs), and speech and language pathologists (SLP), etc." Ratings were as follows: excellent (n=417; 25%); good (n=463; 28%); okay (n=313; 19%); and poor (n=447; 27%).

Results of multiple regression analysis indicated a single factor solution. Six items in the insurance factor accounted for 40% of the variance in caregivers' ratings of children's health plan performance in providing skilled and experienced other specialists (PT, OT, SLP, etc.) ($F(6, 1060) = 119.07, p < .001$). Results suggest that insurance characteristics such as benefits packages and provider networks are most strongly associated with caregiver ratings on plans performance in providing therapy services.

Half of the six items in the insurance factor that were significant predictors of poor caregiver ratings suggest limitations in the structure of the health plans (limited benefits; limited providers; limited skills in providers). Also, caregivers whose children were in employer paid plans reported poorer ratings than caregivers whose children were in government or family paid plans suggesting that employer paid plans may have more restricted benefits. Overall satisfaction with health plans and number of managed care components were weak predictors of poor caregiver ratings of health plans in providing therapy services. These findings indicate that overall satisfaction may be too broad a construct to identify concerns with specific health care services and that number of managed care components may be less important than caregiver perceptions of limitations in the quality of structure of health care.

These results suggest that although child and family characteristics may be considered when determining the processes of care (types of therapy intervention and how these interventions will be delivered), these characteristics are not necessarily considered when determining the structure of the health plan. Thus, the health plan administrators may be determining a child's need for therapy based on policy decisions; plan definitions of medical necessity; or plan benefits rather than basing need for services on the identified and expressed needs of the family, child, and health provider.

Future studies should continue the work of the Family Partners Project but with the development of more specific questionnaires to identify the components of health plans that promote access to quality therapy services for CSHCN. Identification of those plans that are successful in providing comprehensive, quality care for CSHCN is necessary to develop better systems of rehabilitation services for these children.

Relationship of Insurance, Child and Family Factors to Caregiver Satisfaction with and Access to Durable Medical Equipment and Technology for their Children with Special Health Care Needs

Rehabilitation services such as therapy (physical, occupational, and speech); durable medical equipment; and medical and assistive technology may be necessary health care services for CSHCN. The primary purpose of this research study was to identify insurance, child, and family factors associated with problems with satisfaction with and access to durable medical equipment and technology for CSHCN. Participants for this study were identified from the Family Partners Project database. Forty-six percent (n=1016) of the database participants were eligible for this study.

Families indicated if their children got needed durable medical equipment and medical technology services (such as hearing aids, wheelchairs, ventilators, etc) and whether they were satisfied with the services. Items from three areas (insurance, child, and family) of the Family Partners Project questionnaire were identified as possible influencing factors of whether caregivers reported satisfaction (n=705; 69%) or dissatisfaction (n=153; 15%) with the equipment or technology their children received or if their children did not receive the needed services (n=158; 16%).

Descriptive and bivariate analyses were conducted to explore relationships between items in each of the three factors and satisfaction with or access to equipment or technology for CSHCN. Nearly one-fifth of caregivers (18%) reported dissatisfaction with their children's overall health plans and 40% indicated that their children's plans had only "okay" or "poor" performance in meeting the needs of the children. Over a third (36%) of caregivers reported that they had problems getting rehabilitation therapy services for their children.

Low ratings for specialty services (therapy, equipment, information about other resources) may indicate that CSHCN are underinsured in their current plans. Underinsurance is defined as inadequate benefits and coverage, and limited protection for out-of-pocket cost. Limited access to therapy services also may be due to the authorization policies and the definitions used for medical necessity used in a child's health plan. Underinsurance for these children also is suggested by over one half (55%) of caregivers reporting that they had out-of-pocket expenses for their children in excess of \$1000.00 in the year prior to the study.

Results of bivariate analyses suggest that the insurance factor is most strongly associated with satisfaction with and access to durable medical equipment and medical technology for CSHCN. Significant results for the insurance factor had moderate to strong associations (high chi-square values) indicating that decreased satisfaction or limited access to equipment and technology were associated with insurance factor items. These results further indicate that CSHCN may be underinsured especially as concerns specialty services.

Future studies are indicated to examine quality of health plans (structure, process, outcomes) to ensure effective and timely rehabilitation services for CSHCN. These studies should continue the work of the Family Partners Project but with the development of more specific questionnaires to identify the components of health plans that promote satisfaction with and access to quality durable medical equipment and assistive and medical technology services for CSHCN. Identification of those plans that are successful in providing comprehensive, quality care for CSHCN is necessary to continue to develop better systems of rehabilitation services for these children.