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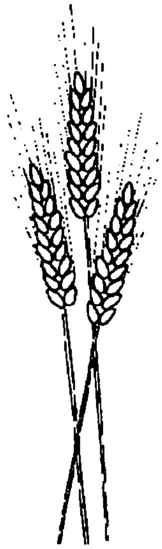
ABSTRACT

This report discusses the outcomes of a study that investigated the characteristics of 959 families participating in the Minnesota TEFRA program, a federal Medicaid option for children with disabilities which allows caregivers to purchase support needed to keep the children in the community. Findings indicate that families of children with special needs in Minnesota use TEFRA to help finance acute care which is either not covered by private health plans or is covered, but with high co-pays and deductibles. In addition, the TEFRA option funds many long-term care supports needed by the children and their families which are not typically covered by private health plans. The varying strengths, needs, and resources of these children and their families preclude the depiction of a typical child on TEFRA. However, their family circumstances were found to be fairly reflective of average Minnesota families in terms of income, education, and geographic distribution. The study indicated that families of children with special needs incurred out-of-pocket health care costs nearly 5 times those of families without children with special needs. It concludes that the availability of TEFRA ensures that cost does not serve as a barrier to necessary health care. (CR)

Caring For Our Children: A Study of TEFRA in Minnesota

Research By Minnesota Children with Special Health Needs



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Minnesota Department of Health
Division of Family Health

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Caring For Our Children:
A Study of TEFRA in Minnesota

Research by Minnesota Children with Special Health Needs
August 1998

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The authors of this study would like to acknowledge with gratitude the advice and support of our colleagues within the Minnesota Department of Health, the Department of Human Services, the Department of Children, Families and Learning and the University of Minnesota.

We are profoundly grateful to the families of the children enrolled in the TEFRA program. Each survey completed helped contribute to a more in-depth understanding of the children and their families.

For further information about this study contact:
Minnesota Children with Special Health Needs
Minnesota Department of Health
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Executive Summary

Background

The 1988 Minnesota Legislature authorized the Department of Human Services to implement TEFRA, a federal Medicaid option for children with disabilities. The TEFRA Option provides a door to Medicaid for anyone who has a child with disabilities, to purchase supports needed to keep that child in the community. Eligibility for the program is based on the individual child's disability and the need for care at the same level or intensity that is typically provided in a hospital or nursing home. Financial eligibility is based upon the child's own income and assets. However, once a child is determined eligible, the family's financial obligation is determined by a fee schedule based upon family income and size. TEFRA provides eligible children access to the standard list of services covered by Medical Assistance, Minnesota's Medicaid program. All the rules applicable to Medical Assistance apply to TEFRA as well.

Concern over TEFRA expenditures led the 1995 legislature to more closely examine and evaluate eligibility and scope of services. Hours of debate in the legislature resulted from a proposal to modify or eliminate the TEFRA option. During this discussion, it became evident that the information available regarding TEFRA was either anecdotal or in the form of claims data from Minnesota Department of Human Services (DHS). This information, while helpful, provided a somewhat limited perspective of the TEFRA program and those who use it. To understand more fully the issues faced by children and families who use TEFRA, to develop an in depth understanding of service use, total costs and payment sources, and to evaluate the potential impact of proposed changes in the TEFRA Option, Minnesota Children with Special Health Needs (MCSHN) section of the Minnesota Department of Health, through an interagency agreement with the Department of Human services, conducted a research study of the children on TEFRA as of June 1995.

The Department of Human Services provided a data file of 3770 children enrolled in the TEFRA program as of June 30, 1995. Approximately two thousand children were randomly selected to be subjects of the survey. A total of 959 questionnaires were returned.

Diagnoses and Ongoing Needs

Children using the TEFRA option are a heterogeneous group who are among the most disabled of Minnesota's children. They are children who are likely to be experiencing multiple diagnoses and conditions impacting all facets of their daily lives. Eighty percent of the children on TEFRA have more than one diagnosis. Dependence in activities of daily living, ongoing medical treatments, increased need for supervision, frequent hospitalizations and frequently missed school days are the realities confronting children on TEFRA.

- Sixty-seven percent of the children require prescription drugs; the mean number of prescriptions in current use per child was nearly three;
- More than one-fourth of the children were hospitalized in the year preceding the survey;
- About one-fifth of the children are totally dependent in all activities of daily living;
- Thirty-five percent need durable medical equipment;
- Eighty-two percent require constant or frequent supervision beyond that required by same aged peers.

Basic care for these children includes a myriad of acute care providers and ongoing chronic care providers. Beyond this basic care, the children can require supports that make it possible to remain with their families, to function successfully within their communities, and which promote the survival of an intact family.

Direct Costs and Payers

Average annual costs were calculated to be $34,790. These are total costs to all payers, not just the cost to TEFRA. DHS reported TEFRA expenditures for 1995 as $7,000 per child during 10.4 months of eligibility ($8140 annualized). Annualized, TEFRA pays 23% of the total costs. The remaining 77% is paid by other payers, including private health plans, families and schools.

Seventy-nine percent of the survey respondents reported that their child on TEFRA had private health plan coverage. Managed care is more than two times more common than indemnity plans. Thirty three percent of the policies have exclusions or limits related to the child's needs.

Families with a child on TEFRA spend more than 11% of their adjusted gross income on medical care - excluding out-of-pocket expenses for non-disabled family members. Minnesota families in general spend about 5.5% of their income on medical care for the entire family.

Indirect Costs

Families were asked to describe how their child's condition affected the child and family. Forty nine percent of the respondents included statements regarding parental exhaustion and stress. Concern for other children in the family, family financial integrity, the ability to maintain employment while caring for their child and social isolation were common themes. The presence of a chronically ill or disabled child in the family also affects parental employment, family income, place of residence and relationships with extended family and the larger community.

- Sixty four percent responded that their employment was affected in some way - with the most frequent response being "accepted a lower paying job with more flexibility or fewer demands";

- Forty two percent of those families who sought child care reported they had been turned down by a child care provider or encouraged to seek care elsewhere;

- Thirty percent of the families responded that their family members had received counseling in the preceding 12 months;

- Forty two percent of the respondents said they had not been able to get a break when they needed one.

Children with Mental Health Issues

Children with mental health disorders were studied separately due to the concerns about this population as users of TEFRA.

- Of the families who responded, 13% had a child with one or more mental health diagnoses without a concurrent physical or developmental diagnosis;

- The estimated annual cost for services of this sub-population was $17,919 -- the least costly cohort compared to the costs of services for children with developmental delays and physical disabilities;

- Compared to the rest of the children in the study, these children are more likely to be adopted children, to come from families with lower income, less likely to be covered by insurance, and less likely to receive home care and respite care.

Home Care

Home care, a service often excluded from commercially available health plans, is a service used by fewer than half of the children on TEFRA. The availability of home care for those who need it strengthens a family's ability to cope with the added responsibilities of caring for their children with special needs, improving the likelihood that placement outside the family is prevented or delayed. Analysis revealed need factors (e.g., having multiple diagnoses, need for constant and frequent supervision, dependence in activities of daily living and equipment, etc.) are dominant factors in predicting use of home care services. For instance, children who need constant or frequent supervision are twice as likely to use home care and six times as likely to use personal care attendants (PCAs) than those children without such a need. Other interesting findings include that children in rural counties are less likely to use home care, and families who had been turned down by a child care provider are slightly more likely to use PCAs.

Conclusion

This study demonstrated that families of children with special needs in Minnesota use TEFRA to help finance acute care which is either not covered by private health plans, or is covered but with high co-pays and deductibles. In addition, the TEFRA option funds many long term care supports needed by the children and their families which are not typically covered by private health plans. The varying strengths, needs and resources of these children and their families preclude the depiction of a "typical child on TEFRA." However, their family circumstances are fairly reflective of average Minnesota families in terms of income, education, and geographic distribution. It is, therefore, unlikely that these are families who would turn to a governmental program for assistance, but for the presence of a medically needy child.

Summary

There has been considerable policy debate about the continuation of TEFRA and alternatives to the financial support it provides for care for children with special needs. TEFRA must be understood in the context of a *system* of resources for children with special needs. This study showed that each element of our existing system of financing -- private health plans, schools, counties, TEFRA and the families themselves -- contributes to the care of the children. The absence of TEFRA, therefore, would impact other parts of the existing system.

Private health plans have been developed with a generally healthy, adult population in mind. Cost-sharing arrangements and benefit limitations that are integral to private health plans are intended to discourage inappropriate use of resources thereby controlling premium costs. When applied to children with chronic health conditions and disabilities, these cost-sharing mechanisms have the potential to limit access to critically needed services. TEFRA makes it possible for children with special needs to access needed services while accepting the limitations of existing health plans. In the absence of a standard benefit package designed to meet the needs of this population and universal health coverage, supplemental programs are necessary to assure access to necessary services and to prevent more costly institutional care.

The study showed that families of children with special needs incurred out of pocket health care costs nearly five times those of families without children with special needs. This, coupled with their moderate incomes and the severity of the childrens' needs, makes it unlikely that shifting current expenditures from TEFRA to families would be sustainable on the part of the families. The availability of TEFRA, therefore, ensures that cost does not serve as a barrier to necessary health care.

Introduction

Children with special needs are those children who have -- or are at risk for -- a broad range of physical/emotional difficulties and chronic illnesses that occur any time during childhood or adolescence. Children with special needs and their families live with a variety of serious, long term illnesses and disabilities caused by disease, trauma or congenital factors. More than 200 chronic conditions affect children; with the exception of asthma, these conditions are uncommon or rare. Consequently, the resources needed by children who evidence these needs are often highly specialized, scarce, centralized and costly.

Children with special needs have the same array of needs, hopes and desires as children who do not have a chronic illness or disability. Like all children, they are an integral part of present and future generations and require full access and participation in their community. In addition, they are uniquely dependent on their families for nurturing and development; are among the most vulnerable and at-risk groups in our society; require a greater amount of health, medical and assistive services over a longer period of time in a greater number of settings; and have higher medical costs and are more expensive to raise than children without a disease or disability.[1]

Children who access the Minnesota Medical Assistance program through an option referred to as TEFRA are a subset of the pediatric special needs population.

Background

The 1988 Minnesota Legislature authorized the Department of Human Services to implement Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. The TEFRA option provides children who have certain disabling conditions access to Medicaid funding for health and health-related services.

Eligibility for the program is based on the individual child's disability and the need for care at the same level or intensity typically provided in a hospital, ICF-MR (Intermediate Care Facility for Persons with Mental Retardation) or nursing home. Financial eligibility is based upon the child's own income and assets. However, once a child is determined eligible, a fee schedule based upon family size and income determines the family's financial obligation.

Concern over TEFRA expenditures led the 1995 legislature to more closely examine and evaluate eligibility and scope of services. A proposal to modify or eliminate the TEFRA option was debated. The deliberative process and testimony by parents of children with special needs gave policy makers a better understanding of the issues and concerns confronted by program administrators, children with special health needs, and their families.

During this discussion it became evident that policy makers did not share a clear understanding of why families use TEFRA. Anecdotal information showed that TEFRA:

- Increased the number of families who could continue to care for their child at home, rather than requiring out of home placement.
- Filled gaps between the child's needs and what was provided through insurance and other sources.
- Enabled greater independence for the child and strengthened the family's security.

At the same time, concerns were expressed that loss of the TEFRA option might lead to:

- Increased out-of-home placement, resulting in higher costs to the state.
- Diminished access to medically necessary care, leading to increased illness and disability and further costs.

- Increased financial, emotional and physical stress on families, leading to family breakdown.

- Foregoing employment in order to access Medicaid through the welfare system.

Underlying the TEFRA debate was the question: "Should Minnesota continue participation in TEFRA?" Compounding the difficulty of that decision was the fact that there was little objective data available upon which to make the decision. The information available to legislators was either anecdotal (in the form of family testimony) or Medicaid claims data which provided limited information on service utilization (only those services paid for by M.A.) which gave an incomplete picture of actual utilization. In-depth information on demographics, diagnoses, ongoing care needs, service use, payment sources and total costs were not known. Furthermore, it was not known how meeting the needs of children with disabilities impacted their families or what would happen to children and their families if TEFRA were not available.

To better understand the issues faced by children and families using TEFRA, the Minnesota Children with Special Health Needs (MCSHN) Section of the Minnesota Department of Health conducted a survey of this population.

TEFRA Overview

History

To understand the history of TEFRA, it is helpful to examine the historical context of children with disabilities. Until the latter third of this century, in order for children with disabilities to receive an education or treatment, their parents had to surrender them physically and legally to the care of the state. While the state then bore the entire financial responsibility, it also became the primary decision maker as to where children lived and the care and treatment each child received.

The early 1980s brought a new era for children with disabilities and their families. As community-based care was implemented, families exchanged the certainty and security of institutional placement for the opportunity to keep their families intact and nurture all of their children together. This opportunity required families to meet the ongoing needs of children who were sometimes difficult to manage and to become the primary source of financial support for care and treatment.

Because the benefits of de-institutionalization outweighed the cost to the state, programs to enable and encourage community-based care were developed under a variety of policy initiatives at the state and federal levels. The TEFRA option was among several responses to the growing need to finance community-based care for children with chronic illnesses and disabilities.

Coinciding with the commitment to community-based care, technological advances in medicine extended the lives of children with severe illnesses and ensured the survival of many children who would previously have died. Some of those children who survive because of these advances do so with lifelong illness or disability. These same advances in technology contribute to the quality of life for children with special needs. For example, the development of home medical devices makes it possible for critically ill children to live at home instead of in a hospital, and successful therapies for certain conditions enable children to learn and play with their siblings and friends.

Because of these changes, maintaining a child with a chronic illness or disability at home is now commonplace. Society now expects that children with chronic illness and disabilities will be cared for by their families and will be included in community life. The cost of health care for children with special needs has increased beyond the financial reach of many families. TEFRA has, for some, become a supplemental health policy funding the acute and chronic health care costs of children with severe disabilities and chronic illnesses.

How TEFRA Works

TEFRA is a federal Medicaid state plan option for children with disabilities authorized under Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. As of May 1996, 18 state legislatures had approved their states' participation in this Medicaid option.

TEFRA provides eligible children access to the standard list of services covered by Medical Assistance. TEFRA pays only for those services, which, according to the Minnesota Health Programs Manual:

a). are determined to be medically necessary,

b). are effective for the medical needs of the recipient,

c). meet quality and timeliness standards, and

d). are found to be the most cost effective health service available for the medical needs of the recipient.

All the rules applicable to Medical Assistance recipients apply to TEFRA recipients including use of Medical Assistance-enrolled providers, obtaining prior authorization for certain services, and certification for inpatient hospital admissions.

Similarly, the rules for Medical Assistance providers apply in TEFRA, including the following:

- Providers must accept Medical Assistance reimbursement as payment in full for covered services provided. A provider cannot request or accept payment in addition to the amount allowed under the Medical Assistance program from the recipient or the recipient's relatives.

- If a child is covered by private insurance or an HMO, that private health plan is the primary payer and, in general, is billed first. Once the private health plan has reviewed the claim and meets the financial obligation it has to the provider, they submit the bill to the Medical Assistance program.

- Medical Assistance pays the lesser of:

  a). the difference (if any) between what the provider has received from other third party payers and the allowable Medical Assistance reimbursement rate for the service,

  b). the difference between the provider charge and the amount paid by all liable third-party payers, or

  c). the total patient liability after the provider has accepted a reduced payment under an agreement with the insurer.

TEFRA eligibility often protects families from excessive financial outlays without actual expenditures by the Medicaid program.

One practical implication of these rules is that TEFRA eligibility protects families from excessive financial outlays with no actual expenditure on the part of Medical Assistance as shown in the following example:

The provider charges $100.00 for services rendered. The private health plan pays at 80% for a total payment to the provider of $80.00. The allowable Medical Assistance (TEFRA) reimbursement rate for the service is $80.00. Since there is no difference between what the private plan reimbursed and the allowable Medical Assistance rate, MA pays nothing. Because a provider cannot request or accept payment from the family in addition to the amount allowed under the Medical Assistance, the family is not billed for the remaining amount.

In Minnesota, unlike other states, parents pay a monthly fee for TEFRA participation that is based upon their income and family size.

As of June 30, 1995, a child's eligibility for TEFRA was determined principally by the Supplemental Security Income (SSI) definition of disability. Within that definition, the following factors have particular relevance for TEFRA:

- a). A child less than 18 years of age may be determined to be disabled with a physical or mental impairment that is comparable in severity to one that would prevent an adult from working and that is expected to last at least 12 months, or results in death.

  b). In addition to the existence of an illness or disability, eligibility considerations include the effect of that illness or disability on the child's ability to perform normal daily activities appropriate to healthy children of a similar age.

  c). Eligible disabilities are those expected to continue and to result in severe functional limitation in three or more of the following life activities: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

- Children must need the level of care provided in a hospital, nursing home or Intermediate Care Facility for Persons with Mental Retardation (ICF-MR).

- The cost to the Medical Assistance program for necessary care at home must not exceed the amount that Medical Assistance would pay for the child's care in a medical institution.

TEFRA Expenditures in Minnesota

The Minnesota Department of Human Services reported TEFRA expenditures to average approximately $675.00 per month of eligibility per recipient in early 1995.[2] Based on cost estimates developed and discussed later in this report, TEFRA pays 23% of the annual total health and health-related costs of enrolled children. The remaining costs are met by private health plans, family out-of-pocket payments, schools, counties and other payers.

TEFRA pays about 23% of the annual total health and health related costs of enrolled children.

Research Questions

This study was undertaken to develop answers to the following research questions:

- Why do families use TEFRA?
- What are the characteristics of families that use TEFRA?
- What are the characteristics of children with special needs in these families?
- What types of services do these families and children use?
- Who pays for those services?
- What is the impact of having a child with special needs on families?
- What support do these families have now?

Methods

Questionnaire Development

This study used a written questionnaire developed by a team of MCSHN staff using other studies. The final draft of the questionnaire was pretested with a group of fifteen families of children on TEFRA. The pretest showed the questionnaire to be understandable and that most parents could complete the form in approximately 30 minutes. Minor revisions were made in the questionnaire based upon comments made by pretest participants.

The data collection process was carefully selected based on research and studies on data collection and its applications.[3] The purpose of this study was to gather information about the children with special needs and their families and subsequently to evaluate the potential impact of the policy change in the TEFRA Option. Clinicians know the clinical picture of the child but may not capture all the conditions with which families are living. Payers know what they have paid but not necessarily their relationship with other payment sources. Families have knowledge of the "whole child and family," are the only source of all the needed information and can provide it in a timely manner. *Therefore, families were selected as the primary informants.* While parent reporting may be viewed by some with skepticism, research demonstrates that parents are ready sources of information, can accurately report about their child's functioning[4], and can be used to provide two broad types of data: appraisals including concerns, estimations and predictions; and descriptions including recall and report.[5]

In most items in the questionnaire, respondents are asked to recall events that took place in the last 12 months regarding the medical, behavioral support and daily living needs of their child with special needs; health services used by their child with special needs; and the source of payment for those services.

Questions also covered the effect of TEFRA on the family and the child with special needs, and various descriptive information. A copy of the questionnaire is included in Appendix C.

Sample

In October 1995, the Department of Human Services through an interagency agreement, provided MCSHN with an electronic file of data on 3770 Minnesota children (age birth to 18) enrolled in TEFRA on June 30, 1995. That data file served as the sampling frame for the survey, from which 2008 children were randomly selected to be subjects of the survey. This sample size was the greatest number of children that could be surveyed within budgetary constraints.

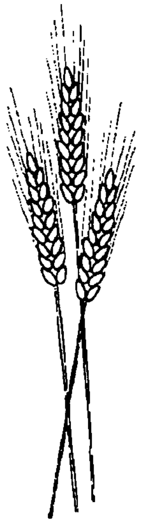
Data Gathering

During the first week of December 1995, questionnaires were mailed to the parents of each of the 2008 children in the sample. A cover letter explained the purpose of the study and requested that the questionnaires be completed and returned within two weeks. The cover letter was signed by the MCSHN Program Manager, and included the name and phone number of an MCSHN staff person whom parents could call with questions about the questionnaire. Between 55 and 60 phone calls were received from surveyed parents. However, few of these calls related to the questionnaire or the survey process. Rather, the calls related to various aspects of the TEFRA coverage of the child: availability of benefits, coverage for specific services, etc.

The cover letter stated that "your child's name and your individual responses will be held confidential." The questionnaire did not carry the name of the sampled child, but did include a code number so that selected respondents could be surveyed again at a later date.

While the code number was not referenced in the cover letter or on the questionnaire, the cover letter stated: "We hope to send another survey to some families in about a year." The envelope carrying the cover letter and questionnaire was addressed to "the parents of (child's name)," and the cover letter was addressed to "parents of children on TEFRA." The cover letter stated "If more than one of your children is eligible for TEFRA, please complete the survey for the child whose name appears on the label."

An addressed, postage-paid return envelope was enclosed with the cover letter and questionnaire. No follow-up mailings were conducted, and no contact was made with families of sampled children, other than the single mailing of the questionnaire.



Findings

Response Rate

Of the 2008 surveyed families, a total of 959 questionnaires (47.7%) were returned. Of these, 10 were sufficiently incomplete as to require their removal from the analysis, and another 13 were received after significant portions of the analysis had been conducted. Overall, most of the data discussed in this report derive from 936 completed questionnaires received in time to be included in the analysis -- a response rate of 46.6%. Where possible in the analysis, responses from some or all of those "late" 13 completed questionnaires are included, raising the total N to a maximum of 949 (a response rate of 47.2%).

Characteristics of Respondents

Characteristics of Parents

More than four fifths (81%) of the responding parents are married, and another 2% are remarried (following divorce or death of a spouse). Very few (3%) are single, and 13% are divorced, separated or widowed.

Only 2% of the responding parents have not completed high school, 20% have completed high school only, and 21% graduated from a technical school. More than half (56%) of the respondents attended college: 35% are college graduates, and 13% have attended graduate school.

Families in the survey live in 83 of Minnesota's 87 counties; forty percent live outside the 7-county metropolitan area.

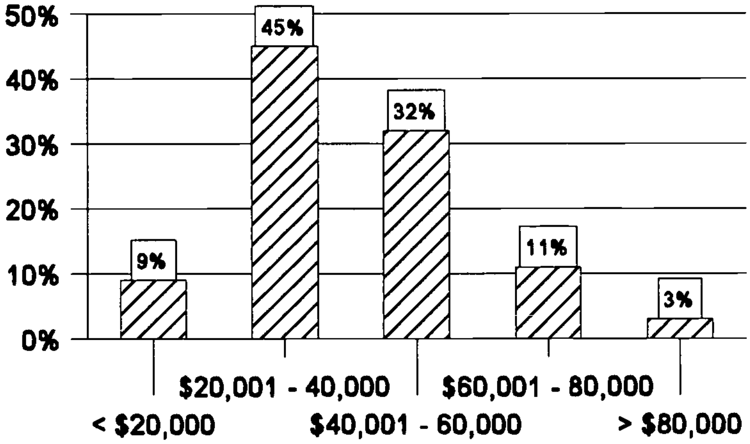
Family Income

The questionnaire asked respondents to identify the "family's adjusted gross income in 1994 (approximate)." Table 1 shows the reported incomes of respondent families. Nearly half (45%) of the respondents reported incomes between $20,001 and $40,000, and another third (32%) reported incomes between $40,001 and $60,000. The median family income reported by respondents was $38,000, just 3% below the 1994 median income of $39,200 for all families in Minnesota.[6]

The annual median income of TEFRA families is $38,000, slightly below that of Minnesota families in general.

Figure 1

Family Income



Age, Ethnicity, and Birth Status of Children with Special Needs

Of the children in this study, 29% were five years of age or younger at the time of the survey, 40% were six to 11 years old, and 31% were 12 to 18 years old. In terms of ethnicity, 92.5 % of the children with special needs in this study are white (non-Hispanic), 1.3% are black (non-Hispanic), 0.4% are Native American, 1.5% are Hispanic, 2.1% are Asian/Pacific Islanders, and 1.3% were reported as "other". Six percent of the surveyed children with special needs are adopted.

Residence of Children With Special Needs

Parents were asked if the child to whom the questionnaire referred lived with them. At the time of the survey, as expected, almost all (96.8%) of the children live with their parents.

Respondents vs. Non-Respondents

Data from the file from which the sample was drawn were used to compare respondents and non-respondents on selected characteristics. Tables 1 and 2 show that there were no significant differences between the two groups in terms of either the gender of the child with special needs or the percent living in the Twin Cities metropolitan area. However, children with special needs in responding families were significantly younger than those in families who did not respond: 9.35 years vs. 10.07 years ($t = 3.5$, $p = .001$).

Table 1
Respondents vs. Non-Respondents: Gender of child with special needs

	Respondents	Non-Respondents
Gender		
Female	373 (40%)	399 (37%)
Male	565 (60%)	671 (63%)

$\chi^2 = 1.3, df = 1; p > .05$

Table 2
Respondents vs. Non-respondents: Urban vs. Rural County of Residence

	Respondents	Non-Respondents
County		
Rural	378 (40%)	392 (37%)
Urban	560 (59%)	678 (63%)

$\chi^2 = 2.84, df = 1; p > .05$

Respondents and non-respondents were also compared on the basis of the diagnosis of the child with special needs. This comparison was possible for only 1592 of the 2008 children in the original data file because it required supplemental data on diagnosis (of children of non-respondents), derived from a re-certification data base maintained by DHS. Those data were grouped into mutually exclusive categories based on the diagnostic information reported by the surveyed parents.

Table 3 presents the data on the child's diagnosis for the 1592 children for whom comparable data were available. Those data show that, while there is very little difference between the two distributions of diagnoses in most categories, parents of children in the "psychological" diagnosis group are under-represented among respondents. Given the comparability between respondents and non-respondents in all other diagnostic groups, though, it is unlikely that this difference has great bearing on the findings of the study.

Table 3
Respondents vs. Non-Respondents:
Diagnoses of child with special needs

	Respondents	Non-Respondents
Diagnostic Group	**# (%)**	**# (%)**
All Diagnoses	18 (2)	17 (2)
Developmental	185 (23)	172 (22)
Physical	207 (25)	182 (23)
Physical / Developmental	236 (29)	197 (25)
Physical / Psychological	16 (2)	19 (2)
Psychological	118 (15)	172 (22)
Psychological / Developmental	34 (4)	19 (2)
Total	814 (100)	778 (98)

$\chi^2 = 19.4$, df = 6; p=.004

Respondents and non-respondents were also compared on the basis of the costs incurred by TEFRA for the care of the child with special needs. This comparison used data from a DHS cost summary file on children on TEFRA. Because the cost summary data file was developed earlier than the data file from which the survey sample was drawn, cost data on some children in the study were not available for this comparison. However, cost data were available for 93% of the respondents and non-respondents in the sample. Comparison of these data shows that the mean monthly TEFRA cost for children of respondents was $755.30, and the cost for children of non-respondents was $779.80 -- the difference between these two figures is not statistically significant ($t = 0.35$, $p = .73$).

Diagnoses and Ongoing Needs

Diagnoses and Conditions

Survey respondents were asked to identify the diagnoses and conditions affecting their children by checking items from a list. The list included diagnoses expected to be found in a population of children with special needs and an option for additions. Table 4 shows the diagnoses/conditions identified by respondents in order of frequency. Eighty percent of the children in this study have more than one diagnosis or condition, with a mean of 3.9 diagnoses and conditions per child.

80% of the children on TEFRA have more than one diagnosis. The average number of diagnoses per child is 3.9.

Medications and Special Diets

In this survey, 67% of the children were found to require prescription medications; the mean number of prescriptions per child was 2.9. Almost one-third of the studied children take over-the-counter medications recommended by their physicians and nearly one-fifth (19%) require a special diet or formula. Most third party coverage requires co-payment for prescription medications and excludes coverage for over-the-counter medications and special diets or formulas.

Table 4
Conditions / Diagnoses of Children With Special Needs in Survey

Diagnosis	Percent having diagnosis	Diagnosis	Percent having diagnosis
Mental Retardation	30.3	Severe Emotional Disorder	7.7
ADD/ADHD	24.0	Kidney/Urinary	5.1
Orthopedic	23.3	Spina Bifida	4.5
Behavior Disorder	20.6	Traumatic Brain Injury	4.3
Cerebral Palsy	20.6	Immune Deficiency	3.1
Seizure Disorder	17.6	Cancer	2.9
Allergies	16.7	Cystic Fibrosis	2.9
Prematurity	16.1	Muscular Dystrophy	1.8
Asthma/Respiratory	14.1	Cleft Lip/Palate	1.3
Vision Loss	13.0	Hemophilia	0.7
Paralysis/Weakness	12.1	Diabetes	0.6
Autism	10.9	Juvenile Arthritis	0.5
Hearing Loss	10.8	Other	0.2
Down Syndrome	9.4	HIV/AIDS	0.1
Heart Condition	8.1		

The percentages do not add up to 100% due to the comorbidities.

Hospitalizations and Missed School Days

Hospitalizations and missed school days are indicators of the health of a child with special needs, as well as of emotional and financial stress on the family. The children studied in this survey evidence a good deal of missed school. It should be noted that 42% of the children in the study did not miss any days in the previous school year due to their special health needs. However, among those children who did miss school because of their special health needs, the mean number of days lost in the previous school year was 14.5 days -- compared with the mean of 5.3 days missed in the school-aged population as a whole.

58% of the children in the survey missed an average of 14.5 school days.

More than one-fourth (27%) of the children in this study were hospitalized in the year preceding the survey, compared with 4% of the general population of children under 18 years of age in the 1993 National Health Interview Survey (NHIS). For those children in the study who were hospitalized during the year preceding the survey, the mean number of nights spent in the hospital was 13, as compared with six nights for boys and eight nights for girls under the age of 18 in the general population.[7]

Activities of Daily Living

About one-fifth (21%) of the children in this survey are totally dependent or need assistance in *all* activities of daily living: communication, ambulation, toileting, eating and drinking, and mobility within their homes. Nearly one-third (32%) of the children require the use of diapers and incontinence supplies (excluding children who would normally use them because of their age), 35% need durable medical equipment, and 82% require constant or frequent supervision.

Mental Health and Behavioral Needs

There is a strong correlation between the number of chronic conditions an individual child has and the presence of learning disabilities and developmental delays.

Behavioral problems were identified across all diagnostic categories. Many children in the study exhibit one or more maladaptive behaviors; the most frequent occurring are disruptive behaviors (55%), withdrawal or inattentive behavior (52%), and unusual or repetitive behaviors (49%). Developmental delay, learning disability, and speech/language disorders were among the 10 most frequent conditions reported, but always in conjunction with another diagnosis.

A 1994 study by Newacheck and Stoddard[8] found the proportion of children with delays in development increased rapidly with the number of conditions reported. This Newacheck study also found that children with three or more chronic conditions were three times as likely to be reported as having a learning disability or an emotional-behavioral problem than children with one chronic condition. Similar findings result from this survey -- both the proportion of children who evidence delays in development and the proportion with learning disabilities increase as the number of diagnoses increases.

Twenty percent of the studied children were reported to have a mental health disorder, such as hallucinations, multiple personalities, suicidal thoughts or attempts, or sudden mood changes. Over one-third (38%) of the children have a severe or critical mental health or behavioral problem.

Newacheck and Stoddard[9] also suggest that children with multiple diagnoses are likely to evidence more morbidity than children with only one diagnosis. In their study, adolescents with multiple chronic conditions had more mental and physical health problems than adolescents with a single chronic condition. Compared to peers with only one chronic condition, adolescents with three or more conditions spent more than twice as many days in bed and out of school, and were more than three times as likely to have limitations of activity.

It is evident from Table 5 that the number of diagnoses in the children studied in this survey was greater than might be expected in children with special needs in general. The comparison of the children studied in this survey with similar children studied in the 1992 National Health Interview Survey shows that the children in this study are more than 2.5 times more likely to have multiple diagnoses.

Table 5
Frequency of Multiple Diagnoses:
NHIS vs. TEFRA Survey

Condition/Diagnosis	NHIS	TEFRA Survey
One diagnosis/condition	70.0%	20.5%
Two diagnosis/conditions	21.0%	16.0%
Three or more diagnosis/conditions	9.0%	63.5%

In the present study, a number of diagnoses or conditions experienced by the children were related to indices of health status. There was a significant positive correlation between the number of diagnoses and the number of school days missed (r = .11, p = .001), as well as with the child's health status as described by the parent (r=.23, p =.0001). The correlation between the number of diagnoses and the number of nights spent in the hospital was not significant. However, despite the significance of the correlations between number of diagnoses and the two indices of health, it should be noted that the variance in number of diagnoses accounts for only a small amount of the variance in the two health indices.

Table 6 shows the relationship between individual diagnoses affecting the children with special needs in this study and the need for help with activities of daily living. The effect of diagnosis on the need for help with activities of daily living varies with the nature of the diagnosis.

Table 6
Proportion of Children with Various Diagnosis Who Need Help with Activities of Daily Living (ADLs)

Diagnosis	% Needing Help with ADLs	Diagnosis	% Needing Help with ADLs
Developmental Delay	55.4	Paralysis/Weakness	15.9
Mental Retardation	38.3	ADD/ADHD	14.9
Speech Language Disorder	38.1	Behavior Disorder	14.9
Orthopedic Problems	30	Autism	13.3
Cerebral Palsy	27.8	Hearing Loss	13.3
Seizure Disorder	21.5	Down Syndrome	12.2
Vision Loss	16.8	Heart Condition	9.6

Chronic illnesses are long lasting and vary in their intensity. Some children may spend months in remission with only occasional periods of acute episodes; others may be in a nearly perpetual state of illness or recuperation. Treatments and their accompanying side effects also vary. As new medications, surgeries, and treatment regimens become available and are tried, children are subject to unpredictable fluctuations.

The descriptive statistics create a look at a group of children who have similarities such as having multiple diagnoses, using more services and having more and longer hospitalizations.

However, understanding the diversity found in these children and their families is equally important. This diversity emerged as we listened to the descriptions provided by the parents on the survey. The case examples given in Appendix B provide a sense of the diverse nature of the children who are central to this report.

Service Use and Cost

Service Use

Children studied in this survey use an array of health services:

- 67% take prescription medications.
- 31% take over-the-counter medications recommended by their physicians.
- 75% had a well child visit with their primary care physician in the year preceding the survey.
- 19% receive a special diet or special formula.
- 53% received respite care in the year preceding the survey.
- 18% received county mental health services (44% of the children with mental health diagnoses received these services).
- Nearly all of the children received care from a specialty physician in the year preceding the survey. In addition to their primary care physician, 21% saw one specialty physician, 24% saw two specialists, and 45% saw three or more.

- Most of the studied families receive some form of case management/service coordination. Despite the availability of such services from formal sources, most families report they engage in case management activities as well.

- 46% of the children receive home care services. Of the survey population, 9% receive skilled nursing care in the home at an average of 5.5 hours per day, 41% use a personal care attendant at an average of 3.6 hours per day, and 3% use a home health aide.

Costs of Services

Difficulty of Estimating Costs.

Data on actual expenditures for services received by the children in this study are not available from the survey. Consequently, to develop an answer to the question, "How much does it cost to meet the needs of children participating in TEFRA?", developing a series of cost estimates was necessary. Those estimates were then applied to the levels of service use reported by parents. The methods used to develop the cost estimates are described in detail in Appendix A. In sum, the difficulties of this estimation derive from the following considerations:

- Because only services provided through the medical community are typically included in cost studies, the costs of services provided by agencies such as schools, county governments, and service agencies are difficult to assess.

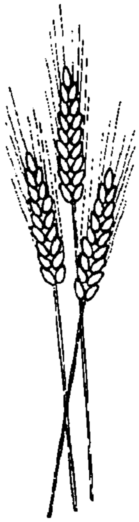
- The constellation of payers involved in paying for a particular service varies greatly across recipients.

- The price of a given item or unit of service may vary widely across payment sources.

- While the price of services provided to children may differ from that of services provided to adults, costs specific to the pediatric population are often not available.

- Minnesota-specific cost information is often unavailable, especially for those services used almost exclusively by children with special needs.

- Most cost studies do not include the costs incurred by the family in caring for a child with complex health problems. These might include the time spent providing care, time away from paid employment, and lost employment opportunities.



Direct Costs

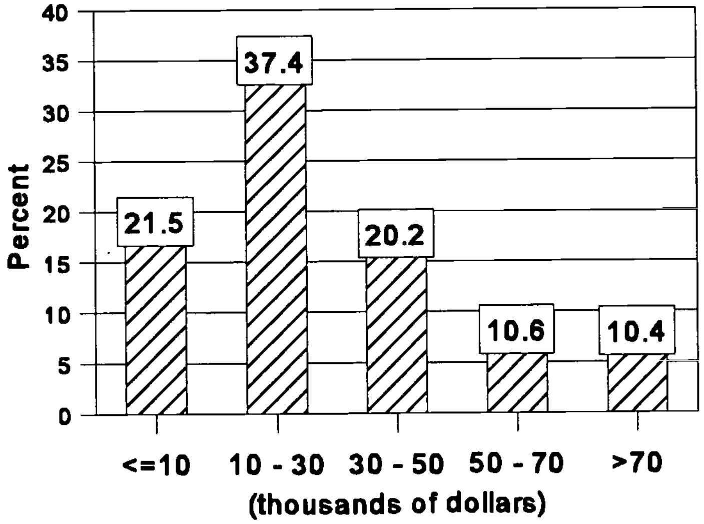
Following the formula in Appendix A, the direct cost estimates developed for each component of service were spread across all children in the study to arrive at a total monthly average cost for all children on TEFRA in Minnesota. Total annual costs for these services varied from zero to $356,223, with an average, as shown in Table 7, of about $34,790. This is an average cost regardless of payer.

Table 7
Average Monthly Costs Across TEFRA Population Regardless of Payer

Services	Average Monthly Cost Across TEFRA Population
Therapy (PT, OT, Speech and Respiratory Therapies)	$810.41
Medications and Special Diets	$243.32
Primary Care and Specialty Care Visits	$66.55
Inpatient and Same Day	$530.58
Equipment and Supplies	$146.32
Related Costs	$42.83
Home Care	$798.08
County-Based Mental Health Services	$62.22
Counseling	$106.97
Other Services (Respite Care and Case Management)	$91.88
Monthly Total	**$2,899.16**
Annual Average	**$34,789.92**

The distribution of costs by child is shown in Figure 2. Ten percent of the children incurred costs of more than $70,000 per year, and 58% of the children incurred annual costs between $10,000 and $50,000. Five percent of the children accounted for 21% of the total expenditures.

Figure 2
Percent of Children Incurring Annual Costs at Various Levels



Insurance Coverage

Of the families responding to the survey, 93% had at least one person covered by private insurance. Seventy nine percent reported that the child on TEFRA had health insurance. Four percent of these families carried a secondary policy. Twenty one percent of the children had no insurance coverage. (Figure 3).

Figure 3
Private Health Plan Status for Children on TEFRA

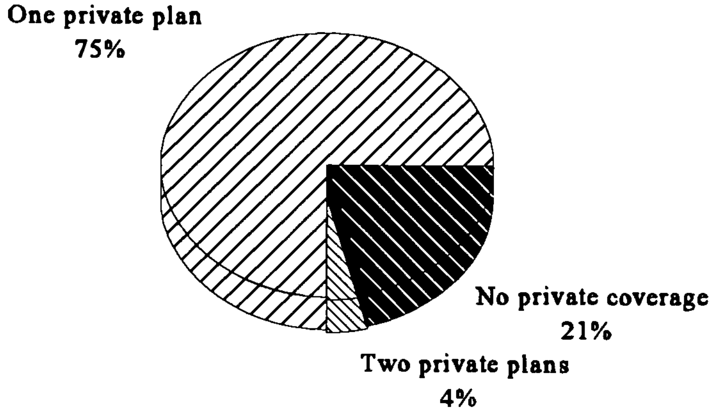
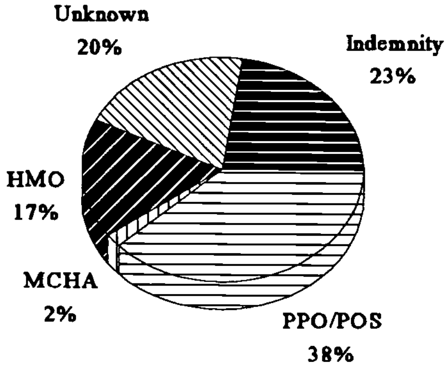


Figure 4 shows the type of insurance carried by those families that reported having insurance. Among those families whose type of insurance is known, managed care (health maintenance organization, preferred provider organization, or point of service plan) is more than two times more common than indemnity plans.

Figure 4
Type of Insurance Coverage

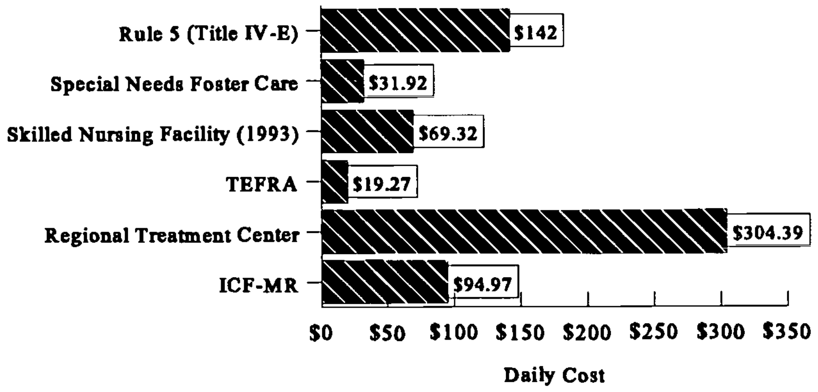


Costs to TEFRA

The Minnesota Department of Human Services reported average 1995 TEFRA expenditures of approximately $7,000.00 per recipient per year - with an average of 10.38 months of eligibility per recipient per year. When this figure is applied to the data on the children in this study and extrapolated to a full year of eligibility, TEFRA pays an average of 23% of their total health and health-related costs. The remaining 77% of costs are paid by private health insurance, family, school, county and other payers.

Figure 5 compares TEFRA expenditures with per diem costs for alternative programs likely to be used by at least some children currently using the TEFRA option.

Figure 5
Per Diem Cost Comparison:
TEFRA v. Institutional or Out of Home Care



Costs to Families

Families in the survey reported paying an average of $1502 per year for their private medical and dental insurance. This figure compares with a statewide average of $1355 for family health insurance premiums.[10] Data from the survey does not explain the difference in health insurance premiums between TEFRA families and all Minnesota families. However, it is possible that experience rating of insurance premiums -- basing rates on prior use of services by the insured family -- may account for the difference.

TEFRA families spend more than 11% of the family income on medical care - not counting out-of-pocket expenses for non-disabled family members. Most Minnesota families spend about 5.5% of family income on medical care.

In 27% of the surveyed families, TEFRA paid that portion of the health and dental premiums attributable to the child with special needs. This payment decreased the annual average premium cost for all families in the study by $124.00 per year.

Parents of children on TEFRA are required to pay a fee for their child's TEFRA coverage. The average parental fee paid by the respondents in this survey was $594 per year (with 41% of the families paying $300.00 per year or less). This average annual fee recoups 8% of the annual TEFRA expenditures.

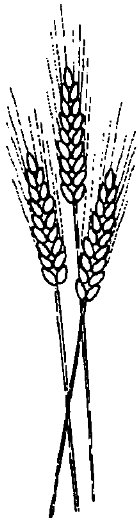
An analysis of costs showed that families with a child on TEFRA spend more than 11% of their adjusted gross income on medical care - excluding out-of-pocket expenses for non-disabled family members. Minnesota families spend about 5.5% of their income on medical care for the entire family.[11] The out-of-pocket annual medical costs average $2263 for the child on TEFRA compared with an average of $544 for Minnesota children generally.[12]

Table 8 summarizes these data and shows the difference in annual expenditures between families in this study and typical Minnesota families. In sum, families with children on TEFRA spend more than twice as much as average Minnesota families, despite the assistance they receive from TEFRA.

Table 8
Direct Family Health Care Expenditures: TEFRA Families vs. All Minnesota Families

Direct Health Costs	Annual Costs TEFRA Families 1995	Annual Costs Minnesota Families 1995
Annual Family Health Care Premium*	$1,501.80	$1,355.02
Out of Pocket Expenses for One Child	$2,263.00	$544.00
Annual TEFRA Fee	$594.00	
Sub-Total Direct Medical Costs	$4,358.80	$1,899.02
Annual TEFRA Payments Toward Premium for Child	($123.72)	
Direct Costs	$4,235.08	$1,899.02

* Does not include employer contribution.



Analysis of Patterns of Service Use and Cost

Patterns of service use and cost were analyzed by defining two classifications of use (high and low) and two classifications of cost (more expensive and less expensive). Services used by the study population were characterized by both a frequency of use designation and a cost of service designation (see Tables 9.1-9.4). Additionally, a cost and use matrix summary was developed to display combined categories of use and cost. The matrix is used to study the relationships between use, cost and payment source.

Use Classifications

Services used by more than 45% of the children were designated "high use" services; the remainder were designated "low use" services. (Tables 9.1 and 9.2.)

Nine of the 46 services used by children in the study fall into the high use classification. High use services include both primary care and chronic care services.

Table 9.1
High Use Services: Services Used by More Than 45% of the Children in the Study

Medical Specialty Care	Routine Dental
Occupational Therapy	Sick Child Visits
Physical Therapy	Speech Therapy
Prescription Drugs	Well Child Visits
Respite Care	

Thirty-seven services are in the low use category. Eighty-four percent of these services are used almost exclusively by persons with chronic illnesses or disabilities.

Table 9.2
Low Use Services
Services Used by 45% or Fewer of the Children in the Study

Adaptive Equipment	Family Counseling	Orthotics / Prosthetics
Assistive Technology	Foster Care*	Over the Counter Medications
Audiology	Glasses	Parent Counseling
Child Counseling	Hearing Aids	Parenting*
Counseling - Siblings	Home Care - PCA	Professional Family Treatment*
Crisis Management*	Home Care - skilled	Psychiatry
Day Treatment*	Home Modifications	Respiratory Therapy
Diapers	Inpatient Hospital	Same Day Procedures
Disposable Supplies	Lab work	Special Recreation
Durable Medical	Living skills*	Special Diets
Emergency Room	Medication Management*	Special Clothing
Emergency Transport.	Orthodontia	Vehicle Modifications
Extra Utility Charges		

*County-Based Children's Mental Health Service

Cost Classifications

Services costing $1000.00 or more per year (or per purchase, in the case of durable medical equipment that may be used over a number of years) were designated "more expensive". Those costing less than $1000.00 per year were designated "less expensive."

As shown in Table 9.3, the 29 more expensive services are used almost exclusively by persons with chronic illnesses or disability. Hospital-based services also fall into this category.

Table 9.3
More Expensive Services:
Services Costing $1000.00 or More Per Year or Per Purchase

Adaptive Equipment	Foster Care*	Parent Counseling
Assistive Technology	Hearing Aids	Prescription Drugs
Child Counseling	Home Care - skilled	Physical Therapy
Crisis management*	Home Care - PCA	Professional Family Treatment*
Day Treatment*	Home Modifications	Respiratory Therapy
Diapers	Inpatient Hospital	Same Day Procedures
Disposable Supplies	Living skills*	Special Diets
Durable Medical	Occupational Therapy	Speech Therapy
Emergency Room	Orthodontia	Vehicle Modifications
Family Counseling	Orthotics / Prosthetics	

*County Based Children's Mental Health Services

The 17 "less expensive" services include the more routine health services as well as services needed by the much smaller special needs population (Table 9.4).

Table 9.4
Less Expensive Services:
Services Costing Less than
$1000.00 Per Year or Purchase

Audiology	Parent Training*
Counseling - Siblings	Psychiatry
Emergency Transportation	Respite Care
Extra Utility Charges	Routine Dental
Glasses	Sick Child Visits
Lab Work	Special Clothing
Medical Specialists	Special Recreation
Medication Management*	Well Child Visits
Over the Counter Medications	

* Children's Mental Health Services

The cost and use categories were then combined to develop Table 10.1 which shows the distribution of services across the two categories of cost and use.

Table 10.1
Cost and Use Matrix Summary

High Use / More Expensive 4 services All chronic care Most provided by schools (see table 10.2)	**High Use / Less Expensive** 5 services Primary care Medical specialists Respite care (see table 10.3)
Low Use / More Expensive 25 services 31% related to mental health Most chronic care or community support Hospital-based (see table 10.4)	**Low Use / Less Expensive** 12 services 75% of the services chronic care or community support 25% acute care (see table 10.5)

Tables 10.2 through 10.5 identify the most frequent payer or combination of payers across the categories of cost and use.

Table 10.2 shows that, for one of the four services in the "high use, more expensive" category, the insurance/TEFRA combination was the most frequent payer, but that schools are the most frequent payer for three of the services in this category. All of the services in this table can be categorized as chronic care services.

Table 10.2
Most Frequent Payers for High Use, More Expensive Services

Service	Most Frequent Payer
Occupational Therapy	School (55%)
Physical Therapy	School (44%)
Prescription Drugs	Insurance/TEFRA (58%)
Speech Therapy	School (63%)

It should be noted that Medical Assistance is a potential, but seldom used payment source for health related services provided in schools. The complex relationship between primary and secondary payers described earlier in this report may impede school systems' ability to seek third party reimbursement for these services.

Services in the "high use, less expensive" category include for the most part primary and acute care services (Table 10.3). The family is the most frequent payer for one service, but the insurance / TEFRA combination is the most frequent payer for the remaining four services. Those services paid for primarily by the insurance / TEFRA combination are fairly routine medical services likely to be used by the non-special needs population, as well as those with special needs.

Table 10.3
Most Frequent Payers for High Use, Less Expensive Services

Service	Most Frequent Payer
Medical Specialists	Insurance/TEFRA (52.4%)
Respite Care	Family (51%)
Routine Dental	Insurance/TEFRA (29.0%)
Sick Child	Insurance/TEFRA (50.8%)
Well Child	Insurance/TEFRA (46.2%)

Among the less frequently used services, Tables 10.4 and 10.5 show that there is more variation in most frequent payers than is the case among more frequently used services.

Table 10.4 shows that over half the services used by children in the study fall into the "low use, more expensive" category, and that TEFRA is identified as the most frequent payer (usually in combination with counties or insurance) for 13 of the 25 services. Most of the services in this category are used exclusively by persons with chronic illnesses and disabilities.

Table 10.4
Most Frequent Payer for Low Use, More Expensive Services

Service	Most Frequent Payers
Adaptive Equipment	Family (45%)
Assistive Technology	Family (37%)
Child Counseling	Insurance (57%)
Crisis management*	County (29%) Co/TEFRA (29%)
Day Treatment	TEFRA (29%) Co/TEFRA (29%)
Diapers	TEFRA (48%)
Disposable Supplies	Ins./TEFRA (35%)
Durable Medical	Ins./TEFRA (50%)
Emergency Room	Ins./TEFRA (55%)
Family Counseling	Insurance (31%)
Foster Care*	County (53%)
Hearing Aids	TEFRA (36%)
Home Care - skilled	TEFRA (45%)
Home Care - PCA	TEFRA (90%)
Home Modifications	Family (90%)
Inpatient Hospital	Ins./TEFRA (56%)
Living skills*	County (37%)
Orthodontia	Family (28%)
Orthotics / Prosthetics	Ins./TEFRA (61%)
Parent Counseling	Insurance (70.9%)
Professional Family Treatment*	County (30%)
Respiratory Therapy	TEFRA (41%)
Same Day Procedures	Ins./TEFRA(55%)
Special Diets	Family (65.9%)
Vehicle Modifications	Family (93%)

*County based children's mental health

TEFRA in combination with private insurance also predominates as the most frequent payer in Table 10.5 which shows the "low use, less expensive" category.

Table 10.5 also shows that, in 82% of the cases, families are the most frequent payer for over the counter medications, despite the eligibility of such medications for TEFRA coverage. As a number of medications used by children with special needs that have been available only by prescription become available over the counter, TEFRA expenditures in this category might be expected to increase.

Table 10.5
Most Frequent Payer for Low Use, Less Expensive Services

Service	Most Frequent Payer	Service	Most Frequent Payer
Audiology	Insurance/TEFRA (52%)	Over the Counter Medications	Family (82%)
Clothing	Family (87%)	Parent Training*	County (32%)
Emergency Transportation	Insurance/TEFRA (58%)	Psychiatry	Insurance/TEFRA (52%)
Glasses	TEFRA (36%)	Sibling Counseling	Insurance/TEFRA (29%)
Lab Work	Insurance/TEFRA (52%)	Special Recreation	Family (76%)
Medication Management*	Insurance/TEFRA (35%)	Utility Charges	Family (94%)

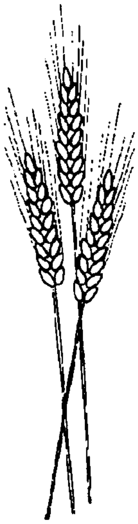
* County based children's mental health

Analysis of private health plan coverage in relation to service cost and use for this population reveals that private plans are most likely to pay for those services identified as "high use and less expensive" and least likely to pay for services identified as "high use and more expensive".

Table 10.6
Private Health Plan Identified As Most Frequent Payer*

High Use / More Expensive	**High Use / Less Expensive**
25% of the Services	80% of the Services
Low Use / More Expensive	**Low Use / Less Expensive**
36% of the Services	50% of the Services

*Almost always in conjunction with TEFRA as a secondary payment source.



Special Considerations

Analysis of Children's Mental Health Services

The children with mental health disorders were studied as a subgroup of the TEFRA population due to concerns about this population of children as users of TEFRA.

Throughout history, children with mental health disorders have been misunderstood, misdiagnosed and stigmatized. The past 25 years have seen revolutionary changes in the field of children's mental health. The trends in children's mental health include:

- The prevalence and severity of mental health issues in children appear to be increasing.
- Understanding of the etiology and diagnosis of mental health issues in children is improving.
- Children with mental illness show significant improvement when provided immediate, intensive and extensive treatment.
- Community-based programs are increasingly being chosen over inpatient treatment.
- Care and services are coordinated through interagency collaborative arrangements and include a single plan of care.
- Families are identified as integral to the treatment process rather than the cause of the mental health problem.
- School based mental health services are on the rise.

> *"People have a hard time accepting child disabilities that are not physical. Believing she has disabilities is difficult for people, especially teachers....It is very frustrating."*
> *- Parent*

Although these changes are taking place, the process is slow and the needs of children and families cannot wait until these improvements are made. According to public testimony TEFRA has provided many families with the resources to compensate for gaps in the current service and payment systems.

Of the families who responded to the survey, 13% had a child with a mental health diagnosis without a concurrent physical or developmental diagnosis. These diagnoses were grouped into three broad categories:

> *"Mental health coverage on both our policies has exceeded lifetime maximum coverage... As our child has suicidal tendencies, the lack of medical treatment due to financial limitations could result in her death."*
> *- Parent*

- *Attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD)*, a chronic disorder which affects between 3% and 20% of school-aged children and is characterized by inattention, impulsivity, and hyperactivity.[13]
- Behavioral disorders, including anxiety disorders, anorexia nervosa, bulimia, and oppositional defiant disorder.
- Severe emotional disorders, including schizophrenia, obsessive-compulsive disorder, bipolar disorder and major depression.

The distribution of diagnoses among children with mental health diagnoses in this study were:

- 72% ADD/ADHD
- 51% Behavioral disorder
- 28% Severe emotional disorder.

The average annual cost for services for children with mental health disorders was $17,919, compared with $20,912 for children with developmental delays, and $43,359 for children with physical disabilities. These costs are borne by the family, private insurance, schools, counties and TEFRA. Figure 6 shows the allocation of expenditures among various categories of services used by children with mental health disorders in the study. Fifty-eight percent of those expenditures are for hospital services, home care, and counseling.

The average annual costs for children with mental health diagnosis are approximately one half those of the survey population as a whole.

Figure 6

Distribution Of Expenditures For Services For Children With Mental Health Diagnoses

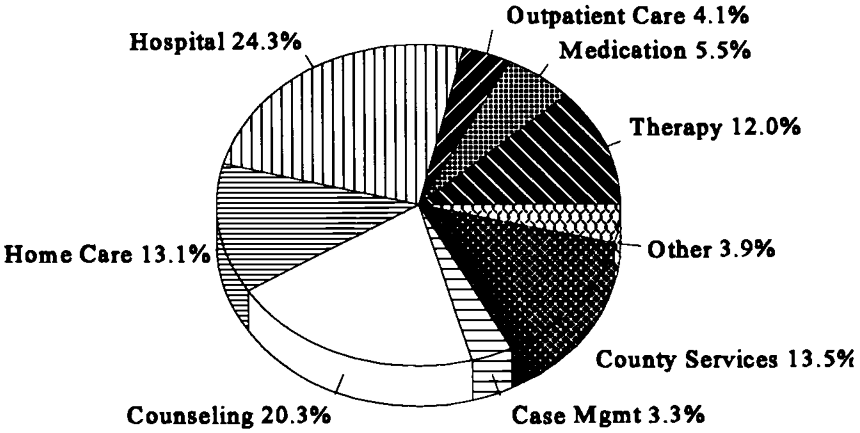
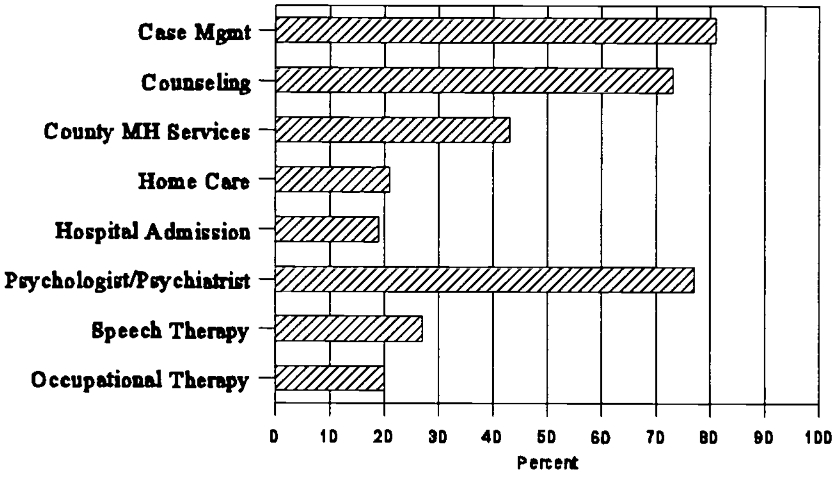


Figure 7 shows the use of services by children with mental health diagnoses in the study. As expected, high proportions of the children with mental health diagnoses use counseling services and the services of a psychologist or psychiatrist.

Figure 7

Service Use By Children With Mental Health Disorders



Tables 11.1 - 11.4 compare selected characteristics of children with mental health diagnoses and their families with those of children without mental health diagnoses and their families. The tables show that, in this study, the income of families with children with a mental health diagnosis is likely to be less than that of families with a child without a mental health diagnosis. On average, children in the study with a mental health diagnosis are older than children in the study without a mental health diagnosis.

Children with mental health diagnoses are more than three times as likely to be adopted as are children without mental health diagnoses. These findings are consistent with a number of other studies. A 1985 study found that, although adopted children make up only two percent of the general population, ten percent of the clients at group-care facilities were adopted.[14] Various studies have found that ADD/ADHD is two to ten times more likely in adopted children.[15]

This may be attributed to genetics, the biological mother's general health, inadequate prenatal care or substance abuse during pregnancy.

Limitations of this study do not allow for the determination of how many children in the study were children with known disabilities or risk factors at the time of adoption.

Table 11.1
Comparison of Demographics of Families of Children in study with and without Mental Health Diagnoses

	Mental Health Diagnoses (N=127)	Non-Mental Health Diagnoses (N=822)	Test	p-value
Income	$27,420.87	$36,872.13	t = 2.60	0.0000
Marital Status			0	0.0000
Single	6.5%	2.7%		
Married	63.7%	84.5%		
Divorced	24.2%	8.7%		
Separated	1.6%	1.4%		
Widowed	0.8%	0.4%		
Remarried	3.2%	2.3%		

There are significant differences between the families of children with mental health diagnoses and those of children without such diagnoses. Parent, sibling and family counseling are more common in the case of children with mental health diagnoses. The families of 10% of the children with mental health diagnoses have moved because their child's disability bothered their neighbors or landlord.

Table 11.2
Comparison of Children in study with and without Mental Health Diagnoses

	Mental Health Diagnoses (N=127)	Non-Mental Health Diagnoses (N=822)	Test	p-value
Age	11.96 years	8.91 years	t = -7.17	0.0000
Adopted	16.1%	5.0%	0	0.0000
Insurance Coverage	76.9%	87.2%	χ^2 =8.33	0.0039
Hurt Self	36.3%	31.4%	0	0.2735
Destroy Property	58.5%	31.0%	χ^2 = 35.68	0.0000

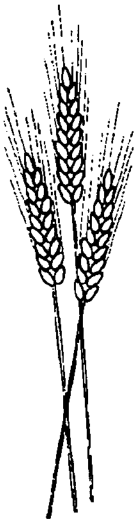
Table 11.3
Comparison of Children in study with and without Mental Health Diagnoses: Use of Services

	Mental Health Diagnoses (N=127)	Non-Mental Health Diagnoses (N=822)	Test	p-value
Counseling				
Family	30.7%	4.3%	χ^2 = 107.05	0.0000
Parents	40.2%	17.3%	χ^2 = 35.55	0.0000
Siblings	22.8%	6.8%	χ^2 = 34.63	0.0000
Home Care	21.1%	54.4%	χ^2 =44.11	0.0000

Families of children with mental health diagnoses were more likely to have considered out of home placement for their child than were parents of children without such diagnoses. Respite care is less likely to be available for children with mental health diagnoses.

Table 11.4
Comparison of Children in study
with and without Mental Health Diagnoses:
Ancillary Issues

	Mental Health Diagnoses (N=127)	Non-Mental Health Diagnoses (N=822)	Test	p-value
Moved - Child's Disability bothered Neighbors or landlord	9.8%	4.5%	$x^2 = 4.50$	0.0340
Respite Care Available	47.7%	60.0%	$x^2 = 5.84$	0.0156



Analysis of Home Care Use

Relationships between use of home care services and other factors were investigated in this study using a model developed by Anderson. [16] [17] [18] [19] That model proposes that utilization of health services is determined by three clusters of determinants as described below:

Predisposing characteristics: Some individuals have a greater propensity to use services than others. These propensities can be predicted by various individual characteristics occurring prior to the incidence of a specific illness episode. Predisposing characteristics can be demographic (such as gender or age), social structural (such as race, education, or occupation), or belief (such as health belief).

Enabling characteristics: While an individual may be predisposed to use health services, he or she does not do so unless able to. The ability to use health services depends on family resources (e.g., household income) and community resources (e.g., availability of health resources). If sufficient family and community resources exist to enable the individual to use health services, then the individual will be more likely to use those services.

Need characteristics: In the presence of the appropriate levels of predisposing and enabling characteristics, the individual (or the person responsible for the individual, e.g., the parent) must perceive some need to use health services. In other words, need is the basic and direct stimulus when the appropriate levels of predisposing and enabling characteristics arise. Need may be evaluated (clinical diagnosis) and/or subjectively assessed.

Anderson's model was applied to the data from the survey to examine the relationships between use of home care or personal care attendant (PCA) services and service utilization factors. The following model was developed:

Table 12
Predictors of Home Care Utilization

Dependent Variables	Explanatory Variables
A. Use of Home Care Services (Home Care; yes = 1, no = 0)	**1. Predisposing variables** Age Race
B. Use of PCA Services (PCA; yes = 1, no = 0)	**2. Enabling variables** Income Denial of Child Care Rural vs. Urban
	3. Need variables Diagnoses Independent in Activities of Daily Living Number of Children with Disabilities in the family Use of Equipment

1. While the predisposing variables in the Anderson model also include demographics, social structure and health belief, only age and race were used in this study.

2. Enabling factors are family and community resources. Enabling variables were presented in the data as income, urban/rural residence, and denial of child care (so used because being turned down by a child care provider is expected to increase the likelihood of using home care).

3. Need variables derived from the data included diagnoses, independence in activities of daily living (ADLs), number of children with special needs in the family, and equipment used.

Children whose diagnoses fell into more than one category were more likely to use home care.

The 31 diagnoses found in the study were grouped into four categories -- mental health disorder (13%), developmental disability (9%), physical disability (35%), and multiple diagnoses (43%).

A child was considered independent in daily activities when he or she was independent in walking, talking, eating, toileting, getting around the home and going to bed. Otherwise, the child was labeled dependent.

The use of durable medical equipment, adaptive equipment, and assistive technologies were signs of care needs and dependency and, thus, were included as covariates to explain the use of home care and a PCA.

For each dependent variable, the explanatory variables on the right-hand side of Table 12 were used to predict the utilization of services.

The following findings were developed from the regression analysis:

- Children with multiple diagnoses have a greater likelihood of using home care than children with a single diagnosis. The odds that a child with only a mental health diagnosis will use home care are only 45% of the odds that a child with multiple diagnosis will use home care. The odds for children with only a developmental disability diagnosis are 55% of those for children with multiple diagnoses, and the odds for children with only a physical disability diagnosis are only 37% of those for children with multiple diagnoses. These relationships are significant at the level of .05.
- For the use of PCA services, only the physical diagnosis group shows a significant result -- the odds of a child with only a physical disability diagnosis using PCA services are 32% of the odds of a child with multiple diagnoses using such services.

Children with high supervision needs were 6 times more likely to use PCA services.

- As might be expected, children in the survey who are independent in ADLs are less likely to use home care services. Children who are independent in ADLs are only 32% as likely to use home care and 29% as likely to use PCA services as children who are dependent in ADLs. In other words, children who are dependent in ADLs are three times more likely to use home care services.

- Similarly, children in the study with high supervision needs are twice as likely to use home care and six times as likely to use PCAs as children without such a need.

- Children who are dependent on equipment are also more likely to use home care. While the use of adaptive equipment was not statistically related to the use of home care services, children who use durable equipment are 2.5 times more likely to use PCAs as children who do not use such equipment.

- Children who use assistive technologies are 1.7 times more likely to use PCAs as children who do not use such equipment.

- Age, race and family income are not statistically significant predictors of home care use.

- Children living in urban counties are 1.5 times more likely to use home care and almost twice as likely to use PCA services as children in rural counties.

- There was no significant relationship between the use of home care services and the presence of more than one child with special needs in the family.

- Families who had been turned down by a child care provider are 1.5 times more likely to use home care services or PCAs than are families who have not been turned down by a child care provider.

Indirect Costs: The Impact of Chronic Illness and Disabilities on Families

> *"TEFRA makes it possible to keep our handicapped child at home with us."*
> *- Parent*

Children with special needs throughout Minnesota live in families, go to school and church, participate in community recreation programs, work, grow and develop, and otherwise participate in their communities. They and their families are supported by a variety of formal and informal programs and services including TEFRA, IDEA (Individuals with Disabilities Education Act), section 504 of the Rehabilitation Act, and ADA (Americans with Disabilities Act).

All children bring challenges to their families; children with special needs bring extra challenges -- some of these are explored in the sections below.

Parental Employment

Leaving a job or changing from full-time to part-time work often results in a loss of income, career disruption, limitations in job advancements, reduction of retirement options or loss of insurance coverage. When parents were asked if having a child with special needs affected their employment, 64% responded affirmatively. Table 13 shows the various effects on employment of those respondents.

Table 13:
Effects on Employment among Those Parents Responding That Having a Child with Special Health Needs Has Affected Their Employment (N=607, 64% of Families Responding)

% of Families	Effect on Employment	Mother was affected	Father was affected
32%	Accepted a lower paying job with more flexibility or fewer demands.	24.9%	5.4%
27%	Given up a paying job. (An average period of 4.37 years)	38.0%	7.0%
26%	Had not changed jobs because a change would have meant losing benefits.	11.4%	12.8%
17%	Taken a second job or increased work hours.	6.1%	8.9%
7%	Changed jobs for better medical benefits.	3.3%	3.1%
5%	Lost a job.	3.4%	1.4%

Percentages reflect actual responses; the employment of one or both parents per family may have been effected.

The presence of a child with special needs in these families had consequences for the employment of that child's parents:

- In one-third of the families, one parent had taken a lower paying job with more flexibility;
- In more than one-quarter of the families, one parent had given up paid employment. The average length of time unemployed among these parents was 4.4 years.
- In more than one-quarter of the families, a parent had not changed jobs because a job change would have threatened the family's benefits.
- Someone in 5% of families lost a job; another 5% lost employer based health benefits due to their child's needs.

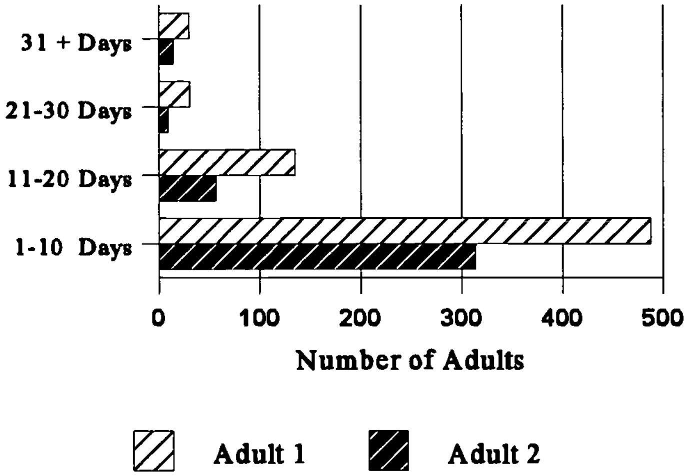
Table 13 also shows that, while the effect on employment is spread across both mothers and fathers, mothers are more likely to have experienced these effects.

While all parents sometimes miss work because of the needs of their children, parents of children with special needs must accommodate a greater range of needs, and are likely to miss work more often to access care for their child, repair or maintain special equipment, participate in planning the child's care or education, manage arrangements with home care or social service agencies, etc. Parents in this study were asked to identify the number of days each employed parent in the family missed because of the child's special health needs. On average, in the 12 months prior to the survey, one parent missed 8.3 work days (range = 0 - 200 days), and the other missed 3.2 days (range = 0 - 120 days). The responses are summarized in Figure 8.

Figure 8

Number of

Work Days Missed



Availability of Child Care

Appropriate child care is a necessity for the employment of any parent. However, children with special needs are often excluded from typical child care options because of their complex health needs, behaviors, or supervision requirements. In 66% of the families responding to this survey, parents reported a need for care for their child while they were at work. Among those families, 28% reported that child care was usually provided by "professionals" (child care or health care), 24% reported that relatives usually provided the care, and 19% reported that the care was usually provided by non-relatives who were not "professionals". Forty-two percent of those families who sought child care reported that they had been turned down by a child care provider or encouraged to seek care elsewhere because of the special needs of their child.

42% of the families who had sought child care had been turned down or encouraged to seek care elsewhere

Where a Family Lives

Families live where they do for many reasons, but the presence of a child with special needs in a family adds to those considerations. Factors such as access to health care or other services may play an important role in the family's choice of where to live. In this study, consideration of the special needs of the child appears to have played less of a role in families' decisions to move than in their decisions not to move. For example, 12% of responding families said they moved to be closer to services for their child; 10% said they moved because their previous home did not meet the child's physical needs; and 4% said they moved because their child's disability bothered their landlord or neighbors. In contrast, 17% of the families said they had not moved to a better home because of the cost of care for their child, and 27% said they had not moved because they did not want to lose their current services.

Time Demands of Caring for a Child with Special Needs

> *"Our lives revolve around [our child's] schedule. Her needs always come first.... We have learned not to make promises to other family members that might not be kept."*
> *- Parent*

As noted earlier, the children in this survey demonstrate a need for assistance in the activities of daily living to varying degrees. The involvement of parents and other family members in these activities requires time that is not available for participation in other family activities.

Table 14 shows the proportion of children in the study who were reported to need assistance in various activities. Beyond the needs identified in that table, 32% of the children used diapers or incontinence supplies (excluding children of normal diapering age), and 35% used special equipment that requires maintenance and repairs.

Children with special needs often require more and closer supervision than their typical peers due to their complex medical, emotional and behavioral needs. Eighty four percent of the families in the TEFRA survey responded that their child with a special need required more supervision or needed to be watched more closely because of the child's medical, physical, mental or emotional problems than children of his or her age. Of these families, 82% reported that their child needed constant or frequent supervision.

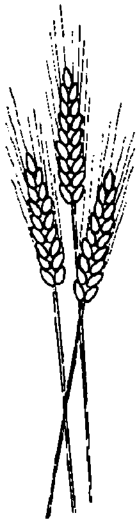


Table 14: Children's Needs for Assistance In Activities of Daily Living

Activity	% of Children Needing Assistance	Activity	% of Children Needing Assistance
Walking	34.3%	Dressing	69.7%
Talking	45.1%	Getting around inside the home	30.6%
Understanding others	58.0%	Getting around the community	77.0%
Eating or drinking	48.9%	Getting to/from bed, chairs, car or toilet	43.1%
Using the toilet	60.3%	Learning or completing tasks at school	84.1%
Bathing or showering	73.8%	Wheelchair mobility	37.3%

Children with special needs not only require more family time to meet their needs, their care is more demanding than typical children. Many routine activities of daily living such as feeding, bathing, dressing, grooming and toileting require more time, greater skill, and may extend beyond the age that typically developing children require assistance. Besides these tasks, other tasks include: monitoring medications, caring for medical equipment, shopping for and preparing special diets, scheduling and attending appointments, sometimes traveling long distances to obtain care, filling out forms to obtain assistance, negotiating with insurance plans, finding information or resources, and developing and maintaining a system of social supports for emotional and practical supports.

Finally, parents spend time managing the care of children with special needs. Nearly all (87%) respondents reported that someone coordinates, locates or manages the care their child receives.

In 67% of the families where the child was reported to receive case management, the parents reported that they provided that service and many others are involved in the process as well, as is shown in Table 15.

Table 15
Sources of Case Management Services

Parents	66.8%	Public Health Nurse	4.7%
School	51.5%	Insurance	7.8%
County	44%	IEIC	3.4%
Physician	31.6%	Hospital Staff	3.0%
Home Care Agency	23%	Other	7.3%

Psychological Impact of Caring for a Child with Special Needs

The extra demands on the family of caring for a child with special needs might be expected to increase the stress on that family. In this survey, respondents were asked if any family member had received counseling in the preceding 12 months. Nearly one-third (30%) responded affirmatively -- in 23% of the families, the child with special needs had received counseling; in 20% of the families, the parents had received counseling and in 9% of the families, the child's sibling(s) had received counseling.

A secondary measure of the stress on the family is the use of respite care, defined in this study as "a break from providing care for the child with special needs." When asked if they could get such a break in the 12 months preceding the study, 42% of the respondents said that they could *not* get such a break when they needed one. Of those families who used respite care, 40% depend upon an informal network of friends and relatives to provide that care.

Families in the survey reported in open ended questions comments regarding the impact of the child with special needs on their family. Parents reported concerns about other children in the family, isolation, parental exhaustion and stress, financial integrity, and the ability to maintain employment while caring for their child and fears that without TEFRA their child would not get needed care.

Finally, despite the desire of most parents to keep their children with them, and the availability and intent of TEFRA, the demands of caring for a child with special needs at home sometimes becomes so great a challenge that out of home placement becomes a consideration. In this study, 13% of families said that they had considered out of home placement for their child with special needs. Though TEFRA is for families who care for their children at home, a small percent of children were out of their homes at the time of survey completion. In these cases, parents cited costs of care at home, the physical demands of the care, the needs of other family members, difficulty of finding needed help, and the dangerous behavior of their child as factors in their decisions.

".....24 hours a day 7 days a week he needs directions, redirection. He would get lost walking back from the mailbox if he even got there in the first place. He wouldn't remember where he was going or why..."
- Parent

Why do Families Use TEFRA?

A common misconception is that families turn to the TEFRA program for the personal care or other home care services provided. This survey showed that less than one-half of the enrollees receive home care services. That being the case, the question remains - why do families use TEFRA?

While 79% of the children studied in this survey have private health insurance, 33% of those policies have exclusions or limitations that relate to the child's needs, 59% have deductibles, and 82% have co-payments. As discussed below, these limitations and exclusions represent significant costs to families.

Cost Sharing. Commercial insurance products are developed for a population of generally healthy adults -- that is, without serious disabilities or chronic conditions.

The level of financial responsibility these products place on the consumer varies across insurance products. Cost sharing arrangements, such as co-payments and deductibles, are common in both managed care plans and more traditional indemnity plans. Cost sharing is usually included in a policy to decrease use of inappropriate services and to encourage the use of less costly, preventive services. Cost sharing is also seen as a means for encouraging individual responsibility through the commitment of personal resources. Cost sharing also reduces the financial risk to the insurer.

Most health insurance plans protect families from catastrophic financial outlays by identifying a maximum for out-of-pocket expenditure, after which the insurer usually pays 100% of the covered expenses. Often, however, the out-of-pocket maximum applies only to co-insurance requirements and excludes deductibles and ongoing co-payments for specific medical services. The costs of services needed, but not included in the benefit package, are not applied to the out-of-pocket maximum.

> *"You need to know that our son is technology dependent and is reaching his cap on his $1,000,000 insurance policy.......We are hard working educated people who are left with no other option than to have our son on welfare."*
> *- Parent*

Benefit Limitations. Health insurance plans commonly include limitations on the benefits available to the insured. One especially problematic limitation for children with special needs is the requirement that therapy service be used to *restore* functioning which has been lost due to illness or injury. This requirement restricts coverage for children whose congenital problems have prevented functioning from being established and children who need therapy to *improve* functioning appropriate to their age. In addition, limitations on units, hours, or days of care are common. Benefits for the treatment of mental health disorders have historically been limited.

Exclusions. Some services needed by children with chronic illnesses are excluded from private health plans altogether. Examples include disposable medical supplies, hearing aids and adaptive equipment. Some of these services can be financed through the TEFRA option; others are paid for by families themselves.

Conclusions

Analysis of the information in this study leads to a number of conclusions about TEFRA and its relevance to families in Minnesota. These conclusions are summarized below:

Children using the TEFRA option are a heterogeneous group who are among the most disabled of Minnesota's children. They are children who are likely to be experiencing multiple diagnoses and conditions impacting all facets of their daily lives. Dependence in activities of daily living, ongoing medical treatments, increased need for supervision, frequent hospitalizations and frequently missed school days are the realities confronting children on TEFRA. The presence of a chronically ill or disabled child in the family also effects parental employment, family income, place of residence, relationships with extended family and the larger community.

Basic care for these children includes a myriad of acute care providers and ongoing chronic care providers. Beyond this basic care, the children can require supports that make it possible to remain with their families, to function successfully within their communities, and which promote the survival of an intact family.

The varying strengths, needs and resources of these children and their families preclude the depiction of a "typical child on TEFRA". However, their family circumstances are fairly reflective of average Minnesota families in terms of income, education, and geographic distribution. It is, therefore, unlikely that these are families who would turn to a governmental program for assistance, but for the presence of a medically needy child.

Conclusions

The TEFRA option provides a door to Medicaid for anyone who has a child with disabilities, to purchase supports needed to keep that child in the community. This study demonstrates that families of children with special needs in Minnesota use TEFRA to help finance acute care which is either not covered by private health plans, or is covered but with high co-pays and deductibles. In addition, the TEFRA option funds many long term care supports needed by the children and their families which are not typically covered by private health plans.

Also demonstrated was that families, for whatever reason, do not use TEFRA to the extent it could be used, for example, to defray the costs of insurance premiums, pay for diapers for older children or pay for over-the-counter medications recommended for use by their physicians.

There has been considerable policy debate about the continuation of TEFRA and alternatives to the financial support it provides for care for children with special needs. TEFRA contributes less than $20.00 per day toward the cost of caring for its enrollees -- approximately one half of which are federal dollars. The state's contribution is further decreased through collection of parental fees. Comparison to some likely alternatives to the community-based care that TEFRA supports, revealed that institutional care for these children or placement in a foster care setting are far more expensive alternatives.

Home care, a service often excluded from commercially available health plans, is service used by fewer than half the children on TEFRA. The availability of home care for those who need it strengthens the families' ability to cope with the added responsibilities of caring for their children with special needs, improving the likelihood that placement outside the family is prevented or delayed.

TEFRA must be understood in the context of a *system* of resources for children with special needs. This study showed that each element of our existing system of financing -- private health plans, schools, counties, TEFRA and the families themselves -- contributes to the care of the children. The absence of TEFRA, therefore, would impact other parts of the existing system.

Private health plans have been developed with a generally healthy, adult population in mind. Cost-sharing arrangements and benefit limitations that are integral to private health plans are intended to discourage inappropriate use of resources thereby controlling premium costs. When applied to children with chronic health conditions and disabilities, these cost-sharing mechanisms have the potential to limit access to critically needed services. TEFRA makes it possible for children with special needs to access needed services while accepting the limitations of existing health plans.

The study showed that families of children with special needs incurred out of pocket health care costs nearly five times those of families without children with special needs. This, coupled with their moderate incomes and the severity of the childrens' needs, makes it unlikely that shifting current expenditures from TEFRA to families would be sustainable on the part of the families. The availability of TEFRA, therefore, ensures that cost does not serve as a barrier to necessary health care.

Recommendations

The policy implications identified from the results of this study generate the following recommendations:

Continue supplemental programs, such as TEFRA, for children with special health needs. In the absence of a standard benefit package designed to meet the needs of this population and universal health coverage, supplemental programs are necessary to assure access to necessary services and to prevent more costly institutional care.

Careful analysis of public and private programs is necessary prior to implementing changes. Families of children with special needs use a variety of resources to support the care of their child at home. These resources are interconnected and dependent on each other. Analysis should include consideration of the following factors:

- Families use and need a combination of formal and informal, public and private programs, services and resources to care for their child with special needs at home.
- Changes in one part of the service delivery system cause change in other parts of the service delivery system.
- The need for necessary services does not disappear but, is shifted to another part of the service delivery system. If no other resources exist, this need becomes the family responsibility. If the family is unable to provide this service the child may go without the needed service.
- There are costs of not providing services. These costs can be financial, physical, emotional and social and can last a lifetime.

Ongoing monitoring and evaluating of programs are needed to understand the impact of the program on the people it serves and to identify unmet needs.

Recognition by private health plans of the unique and special needs of this population with efforts to address the following issues:

- Evaluation of the cost sharing structure of co-payments, deductibles, limitations and exclusions to assure appropriate use of payment for care through public programs.
- The definition of "medical necessity" must include allowances for the pediatric population in general and for the unique needs of children with chronic illnesses and disabilities in particular.
- Access to a continuum of care which includes pediatric primary, acute and chronic care and ancillary providers and services.
- Provision of flexible benefits based upon individualized treatment planning.
- Access to the intensity and duration of services appropriate to the developmental level of the child and the chronicity of the illness.
- Provisions for access to comprehensive pediatric multi specialty clinics for low incidence and rare disorders.
- Provision of "care coordination" by specially trained individuals who are knowledgeable about and committed to the care of children with special needs and who understand the public and private service delivery systems.

Support family care giving of children. Family care giving of children with special needs is the most appropriate and cost-effective method to assure quality care. The number of premature deaths, out of home placements and the costs of the care of children with special needs can be reduced by providing family centered, community based, coordinated and comprehensive care to families. Required for support of families to continue in their role as primary caregivers are:

- Assurances that policy makers will continue to support families roles as primary caregivers.
- Financial assistance with the extra costs of care giving.
- A system of specialized child care, including sick child care, that is safe, affordable, appropriate and which meets the complex health, behavior and supervision needs of the child from birth to independence.
- Availability of services wherever children live.
- A flexible, supportive work environment.
- Direct supportive services such as respite care and access services.
- Complete information on the services and benefits for which their child is eligible. For example: MA benefit book.
- An integrated plan of care across agencies and services to eliminate duplication and gaps.

Intensify efforts toward the development of a coordinated comprehensive system for children with mental health diagnoses. Children with mental health diagnoses, like all children with special needs, require immediate, intensive, extensive, appropriate and coordinated services by professionals qualified to serve children and adolescents in order to reduce or prevent the long term effect of a potentially handicapping condition and increase the likelihood that care can be managed at home. The development of a *system* of service delivery that identifies and serves children with mental health issues, lags behind systems serving children with other health problems.

Continue support of home care services as one component in a continuum of community-based services for children with special needs. Home care services, for those who need it, supports families in their efforts to maintain children at home and avoid more costly institutional care. Efforts toward decreasing home care use for this population should be carefully studied to assure that changes produce their intended benefits without resulting in undue harm.

Recommendations for future study

There have been a number of studies regarding various facets of childhood disability. Few have attempted as comprehensive an approach as this present study. Recommendations for topics of future study include the following:

- Reassessment of the population in the current study to determine the impact, if any, that changes in the TEFRA program had on the children and their families who lost TEFRA eligibility;

- The cost of comprehensive care for children with chronic illnesses and disabilities;

- Risk adjustment strategies to assure adequate compensation to health plans as well as service providers need further refinement;
- Outcome measures and standards of quality care relevant to children with chronic illnesses and significant disabilities;
- Criteria for the evaluation of programs serving children with special needs and their families;
- The factors influencing the availability of private health care coverage, or lack thereof;
- Identification of access issues or other barriers to home care utilization in rural Minnesota;
- The role private health plans do play or could play in meeting the needs of children with chronic illnesses and disabilities.
- If efforts are undertaken to reduce reliance on home care, careful evaluation of alternatives should be pursued. Based on this study, the following strategies hold some promise:

  Services and strategies that improve independent functioning. For example: therapies, assistive technology, special equipment, as well as home and vehicle modifications, *and*

  Alternative models combining respite care, child care and PCA services, *and*

  Improvement of child care training in caring for children with special needs for providers as well as access to funding to cover the extra cost of specialized child care, *and*

  Child care services for children above the age of 13 who need supervision due to their complex needs.

Appendix A: Estimates of Costs for Services

Calculation Formula

In the survey, parents identified the services received by their child and provided some estimate of the frequency of those services. Parents were not asked to identify the costs of services provided to their child because it was expected that parents would not have access to enough information about those costs, and the complexity of the necessary answers would make response difficult.

However, it was possible to arrive at estimates for total costs within and across services by the following steps:

- An estimated unit cost was developed for each type of service received by the children in this study. The methods used to calculate these estimated unit costs depended upon the type of service. The description of these estimating procedures constitutes the bulk of this appendix.
- The proportion of the surveyed children who used each service was derived from the reports of parents in the survey.
- The monthly frequency of the use of each service was either obtained from parents' reports of service utilization or estimated from levels of utilization expected in children with specific diagnoses.

- All weekly frequencies were converted to a monthly frequency by one of the following procedures:

  1. For services received from providers other than schools, the weekly frequency was multiplied by 52.14 (365/7, or the number of weeks in a year), and then divided by 12.

  2. For services received from schools (because they were assumed to be available for only 37 weeks per year), the weekly frequency was multiplied by 37, and then divided by 12.

- A fractional monthly frequency was calculated for services that were used less often than monthly. That fractional frequency was derived by dividing the annual frequency by 12.

- The unit cost was multiplied by the proportion of the studied children who used the service, and then by the monthly frequency.

Sources of Data

Because most of the children in this study are covered by some form of private health plan as a primary payer, Medicaid reimbursement rates were not the preferred sources of service costs. Instead, costs were based on information available through a variety of other sources, including provider billing information, vendor contracts, published literature, and unpublished survey results. However, where Medicaid is the primary payer for a service and where cost data were not available from other sources, Medicaid rate information was used in the estimates.

Every effort was made to obtain data specific both to pediatric care and to Minnesota. Where both criteria could not be met simultaneously, preference was given to data on costs in Minnesota. If neither criteria could be met, regional -- and then national -- costs information was used.

Table A-1
Monthly Cost Estimates

Service	Unit Cost	Percent Using Service	Average Frequency Per Month	Average Cost Per Month
Therapy Services				
Physical Therapy		50.5%		
Home	$62.00	15.7%	11.28	$109.80
School	$19.45	39.2%	6.56	$50.02
Outpatient	$62.00	14.6%	7.81	$70.70
Occupational Therapy		59.2%		
Home	$49.00	12.6%	9.98	$61.62
School	$13.18	50.9%	6.78	$45.48
Outpatient	$49.00	15.0%	6.94	$51.01
Speech Therapy		60.0%		
Home	$45.00	9.1%	12.15	$49.75
School	$18.12	54.1%	7.39	$72.44
Outpatient	$45.00	12.0%	6.94	$37.48
Respiratory Therapy		10.0%		
Home	$50.00	9.0%	47.74	$214.83
School	$7.76	2.9%	27.1	$6.10
Outpatient	$50.00	1.3%	63.36	$41.18
Total				$810.41

* Specific services may have been received by an individual child at multiple sites.

Table A-1
Monthly Cost Estimates

Service	Unit Cost	Percent Using Service	Average Frequency Per Month	Average Cost Per Month
Medications and Special Diets				
Prescription Drugs	$39.48	67.2%	2.9	$76.94
Prescription adjustment*				$111.67
Over the counter	$14.90	30.7%	2.4	$10.98
Special Diets	$7.73	18.6%	30.42	$43.74
Total				$243.32
Primary and Specialty Care				
Well child visits	$95.00	75.3%	0.17	$12.16
Sick child visits	$40.00	80.1%	0.3	$9.61
Dental (routine)	$23.96	78.0%	0.2	$3.74
Orthodontia	$83.33	10.1%	1	$8.42
Psychiatry	$45.00	34.9%	0.29	$4.55
Audiologist	$121.35	18.1%	0.18	$3.95
Lab work	$14.69	32.6%	0.28	$1.34
Specialist visit 1st visit	$95.00	66.7%	0.08	$5.07
Specialist visit follow-up	$45.00	66.7%	0.59	$17.71
Total				$66.55

* Discussed on page 84.

Table A-1
Monthly Cost Estimates

Service	Unit Cost	Percent Using Service	Average Frequency Per Month	Average Cost Per Month
Hospital and Emergency Services				
Emergency Room	$621.00	35.6%	0.19	$42.00
Inpatient Care	$1,435.00	27.0%	1.09	$422.32
Same Day Services	$1,198.57	27.9%	0.188	$62.87
Emergency Transport	$387.60	7.1%	0.123	$3.38
Total				$530.58
Supplies and Equipment				
Durable medical	$429.00	35.3%	0.158	$23.93
Orthotics / Prosthetics	$1,255.00	31.7%	0.092	$36.60
Adaptive Equipment	$109.71	16.9%	0.508	$9.42
Assistive Technology	$474.00	15.6%	0.1	$7.39
Hearing aids	$1,700.00	4.3%	0.028	$2.05
Glasses	$150.00	24.3%	0.042	$1.53
Diapers	$0.66	31.7%	178	$37.24
Disposable Supplies	$57.79	23.2%	2.1	$28.16
Total				$146.32

Table A-1
Monthly Cost Estimates

Service	Unit Cost	Percent Using Service	Average Frequency Per Month	Average Cost Per Month
Related Costs				
Home modification	$25.72	22.4%	1	$5.76
Vehicle modification	$35.64	13.4%	1	$4.78
Utilities-extra charges	$37.44	24.3%	1	$9.10
Clothes	$75.87	20.3%	1	$15.40
Special Recreation	$30.33	25.7%	1	$7.79
Total				**$42.83**
Home Care				
Home care - Skilled	$16.45	9.4%	167	$258.23
Home care - PCA	$11.56	41.2%	109.5	$521.52
Home health aide	$12.86	3.0%	47.52	$18.33
Total				$798.08

Table A-1
Monthly Cost Estimates

Service	Unit Cost	Percent Using Service	Average Frequency Per Month	Average Cost Per Month
County-based Children's Mental Health				
Case Management	$45.00	13.0%	2.6	$15.21
Medication Management	$30.00	4.4%	6.04	$7.97
Living Skills training	$17.31	3.0%	15.36	$7.98
Parenting	$17.31	3.5%	3.15	$1.91
Crisis management	$140.00	2.2%	2.5	$7.70
Professional family treatment	$70.00	2.7%	4.33	$8.18
Day treatment	$18.95	3.3%	13.2	$8.25
Foster Care	$31.92	2.5%	6.28	$5.01
Total				$62.22
Counseling				
Counseling Child	$65.80	22.9%	3.64	$54.85
Counseling Parent	$70.00	20.2%	2.45	$34.64
Counseling Siblings	$22.50	8.8%	2.51	$4.97
Counseling Family	$70.00	7.7%	2.32	$12.50
Total				**$106.97**

Table A-1
Monthly Cost Estimates

Service	Unit Cost	Percent Using Service	Average Frequency Per Month	Average Cost Per Month
Other Services				
Respite Care	$7.50	52.9%	10	$39.68
Case Management	$30.00	87.0%	2	$52.20
Total				$91.88

Derivation of Cost Estimates

Therapy Services

Assumptions:

- Each therapy visit lasts one-half hour.

Method

The costs for services provided at school were differentiated from those for services provided at home or an outpatient basis. Travel costs were not included in the estimates.

In the case of school-based services (excluding respiratory therapy), costs were derived from the special education expenditure reports provided by the Minnesota Department of Children, Families and Learning. These costs were then divided by the number of children receiving the service. Calculation of average costs for school-based services was based on 37 weeks of service rather than on an entire year.

The costs of non school-based services were taken from MCSHN fee-for-service billing records.

The Medical Assistance LPN non-vent rate was used to estimate the cost of school-based respiratory therapy.

Medications and Special Diets

Assumptions

- Prescriptions and some over-the-counter products were for daily use.
- For over-the-counter products where intermittent use seemed more likely than daily use, the number of days used to calculate annual cost totaled six months.

Method

The estimate of prescription drug costs was based on data on tax revenues paid by Minnesota pharmacies developed in a 1994 study conducted by the Minnesota Department of Health.[20] For most conditions, the average non-generic prescription drug cost for Minnesota was used. However, this average was deemed to underestimate the cost of drugs used in cystic fibrosis, immune deficiency and hemophilia. For these conditions, estimates were based on an unpublished study which obtained data from physicians and other health professionals.[21] This adjustment appears in the table as "prescription adjustment."

For over-the-counter medications, MCSHN developed a list of products required by children with chronic conditions and likely to be recommended by physicians. Package instructions for each product were used to determine dosage and frequency of use -- estimates are based on recommendations for an average-sized nine year old boy. Product prices were established from a survey of three metropolitan area pharmacies.

Cost information for special diets was based on the average cost reported in a previous study on medically-fragile children.[22]

Primary and Specialty Medical and Dental Care

Assumptions:

- The cost of orthodontia is generally based on a contract for work to be completed over a given period of time, rather than on a per-visit rate.

Method

The cost used to estimate both well child and sick child primary care visits was the established pediatric visit rate,[23] plus the actual reimbursement rate for immunizations. (While children are not immunized at each visit, the additional rate was used to accommodate charges for additional time and lab work required by children with special needs.) Specialty medical care costs were based on average charges for all specialty physicians (surgical and non-surgical) in the Midwest.[24] Costs for laboratory work outside of regular office visits was calculated from a list developed by MCSHN staff of 20 laboratory tests used by children with special needs.

Estimates of audiology costs and preventive dental costs were based on 1995 MA/AFDC fee-for-service cost projections.[25] Orthodontia cost estimates were derived from average per-year charges for MCSHN orthodontia contracts. Estimates of costs for psychiatric care were based on established fees.[26]

Hospital and Emergency Care

Assumptions:

- Emergency room care for children in this study is necessary and urgent in nature.

- The cost of emergency transportation for children in this study is not different from that for medically fragile children discussed in previous studies.

Methods

Estimates of costs for emergency room care were based on the average charge for urgent emergency room visits.[27] Inpatient hospital costs were based on 1995 MA/AFDC fee-for-service cost projections.[28] Same day procedure cost estimates were based on average costs for selected procedures developed by the Medicare Prospective Payment Assessment Commission.[29] Emergency transportation cost estimates were based on those reported in a previous study.[30]

Supplies and Equipment

Assumptions:

- Durable medical equipment was given a usable life of five years with straight line depreciation.
- Adapted car seats were given a usable life of four years.
- Hearing aids, communication devices and computers were given a usable life of three years.
- Eyeglasses were assumed to last for one year.
- Syringe use was assumed to be 100 per month.
- Diaper use was assumed to be six per day.
- Orthotics need to be fabricated annually to accommodate growth.

Methods

Costs for durable medical equipment, adaptive equipment, and orthotics were developed by a survey of providers conducted by MCSHN staff. Mid-range prices for electronic communication devices were used as the estimate for all communication devices. Computer costs were based on the costs of a dynamic speech program and two educational software programs.

Hearing aid prices were found to range from $300.00 to $4000.00. An estimate of $1700.00 was chosen after reviewing current literature and discussing the topic with an audiologist. Eyeglasses were estimated to cost $150.00 per pair. Diaper price estimates were based on Medicaid reimbursement rates. The Medical Assistance reimbursement rate was used for disposable supplies.

Related Costs

Assumptions

- Home modifications were assumed to be useful for 18 years; vehicle modifications were assumed to have a useful life of seven years.

Method

Home and vehicle modification costs were derived from expenditure reports in MCSHN's family Support Needs Assessment Project (FSNAP). Typical utility expenditures were developed by review of MCSHN records for contiguous months. (Through June 30, 1995, MCSHN provided financial support to families incurring extra utility charges because of their child's special needs. Up to 50% of the utility bill was available for reimbursement.)

Costs for special clothing and for special camps were developed from review of MCSHN records.

Home Care

Assumptions:

- Skilled home care was likely provided by a licensed practical nurse, and through an agency rather than an independent contractor.
- Children requiring the care of a registered nurse would be in a home and community-based waiver program.

Methods

Frequency of service was based on hours of service received, as opposed to hours authorized by the Medicaid Home Care Section. Service costs were based on Medicaid reimbursement rates.

County-based Mental Health Services

Assumptions:

- The following assumptions were made regarding duration of service:

case management services:	1 hour
parenting skills training:	.5 hour
crisis management:	2 hours per episode
professional family treatment:	1 hour sessions
day treatment:	1 hour per day

Methods

Cost estimates were based on fee-for-service rates provided by the Minnesota Department of Human Services. Costs for medication management services were developed from the average rates for services provided by a physician and by a registered nurse.

The estimate for foster care costs was based on the base rate plus mean difficulty of care points for 12-to 14-year-olds.[31]

Counseling

Assumptions:

- The following assumptions were made regarding duration of service:

  child counseling: 1 hour individual psychotherapy session
  parent counseling: 1 hour family psychotherapy session
  sibling counseling: 1 hour group psychotherapy session
  family counseling: 1 hour family psychotherapy session.

Methods

Estimates are based on Medicaid's fee-for-service rates for children's mental health services.

Other Services

Assumptions:

- Families received two hours of respite care per month.
- For case management, a threshold of two hours per month was established; an average hourly rate was assigned, regardless of who provided the service.

Methods

Costs for respite care were based on an estimate of $7.50 per hour.

The estimate for the cost of case management was based on the cost of the lower of two county-based service rates. That rate was $30.00 per hour.

Appendix B: Case Examples

Discussing the costs of children on TEFRA may have more meaning when applied in the context of real families and real circumstances. Five individual respondents are used to illustrate the range of health care costs from low, average and high cost care needs. The surveys were all fairly complete, but where there were missing pieces of information, averages for the entire survey population were inserted. Assumptions were made regarding wages and costs of missed work. For instance, where both parents were employed, unless otherwise stated, it was assumed that both parents contributed equally to the annual family income. Identifying information was removed to ensure anonymity.

The following scenarios give us some indication of the financial burdens families' face when having a child with complex health needs. In addition to cost-sharing through health plans, are the many out-of-pocket costs, lost wages, use of parental sick or vacation leave to care for the child, fees such as the TEFRA parent fees and county fees, and travel expenses.

The first column of table included with each scenario indicates the services that this particular child used throughout the year. The costs for given services were derived from the tables in Appendix A. If more specific cost information could be gleaned from the information on the survey itself, (for instance, one family gave the name of a specific drug and the daily dosage) those costs were calculated and used. The second column indicates what insurance or other health plan is likely to have paid for these services.

This information was derived from the name of the company, type of employer and responses to the questions throughout the survey relating to who paid for a particular service. The column labeled "Savings to Family due to TEFRA", does not refer to what the TEFRA program actually paid, since it may have actually paid nothing (see "How TEFRA works"). "Savings to Family due to TEFRA" refers to the family's financial liability were TEFRA not available.

Scenario 1: Toddler with a chronic illness

The first scenario involves a preschool boy with an immune disease resulting in chronic infections if not treated. He is independent in most activities of daily living, but needs some help with using the bathroom, bathing, dressing, getting around his community and learning at school. He exhibits no serious behavior problems.

His parents are married and live in rural Minnesota. There are five people in the family. The boy goes to day care while his parents are at work.

Because of his health condition, he needs to be watched more closely than other children his age, but not constantly. This child missed 10 days of day care last year due to illness. When he cannot go to child care, one of his parents stays home from work. The number of paid sick days allowed each year by the parents' employer is six. Overall, with medicine the child's health is good.

The boy takes one prescribed medication by injection every day. His insurance and TEFRA pay for the medicine. He takes three over the counter medications recommended by his physician for which his parents pay.

The family travels more than 120 miles two to four times per year to bring the boy to his well child check up, the medical specialist and for laboratory tests.

He receives dental care and sick child visits near his own community. He went to the doctor for sick child visits at least five times last year.

The child had one same day procedure this last year. His insurance pays 80% of the costs for all the visits and TEFRA picks up the rest.

This child needs a variety of disposable supplies that go along with his daily injections. His family, insurance and TEFRA all pay for the supplies. The families share equaled about $50.00 last year for these supplies.

The family has not had any expenses such as home modifications. He does not need home care or counseling. The doctor and the family locate and manage whatever services the child needs. When his parents need a break from providing the care for him, a friend or relative usually care for the child.

After July 1, 1995, his parents began paying TEFRA a fee of $25.00 a month. They pay $195.62 each month for family health and dental coverage. Their health policy requires a $250.00 deductible per individual to be met each year and pays 80% of the costs after that. The father would like to change jobs but has not because the change would result in the loss of benefits. One of his parents is a high school graduate, the other graduated from technical college. Together, they earned $34,000 last year.

Table B-1
Average Cost Range
Toddler with a chronic illness

	Insurance	Family	Savings to Family due to TEFRA
Physician / labs	$609.60		$152.39
Medications / supplies	$30,757.76	$586.40	$7,639.44
Hospital	$958.86		$239.71
Insurance, fees, deductibles		$2,647.44	$250.00
Related costs		$432.00	
Missed Work		$261.53	
Total	$32,326.22	$3,927.37	$8,281.54
Total Expenditures			**$44,535.13**

Scenario 2: Preteen with multiple disabilities

Scenario two involves a school aged girl with a rare chromosomal anomaly affecting most organ systems. She has a seizure disorder, heart condition, orthopedic problems, mental retardation and other developmental delays. She is on medications for seizures and gastroesophageal reflux. She is fed by gastrostomy tube into her stomach and therefore needs special formula. This young girl is totally dependent in all activities of daily living. She is just learning to walk. It is hard for her to communicate with her family in any way.

At times this child disrupts the activities of others; she also, at times, hurts other people. Her family describes these as only mild problems. Because of her problems, this child needs constant supervision, certainly more than others in her age group.

Last year, she missed four months of school. Currently, her parent describes her general health condition as good.

The child gets physical therapy once a week, occupational therapy twice a week and speech and language therapy twice a week. These services are provided by the school with insurance, TEFRA and the school sharing the costs.

As noted earlier, this young girl takes two prescription medications which are paid for by her insurance and TEFRA. The special formula for her tube feedings is paid for by TEFRA. One of her regular medications was recently made available over the counter and it is likely her insurance will not cover this drug in future years, as private health plans seldom cover medications available over-the-counter.

Besides the well child check ups and dental care she received, (2-4 visits each), she needed at least five visits due to illness last year. All of these visits were within 60 miles of her home.

She saw five medical specialists in the last year. The specialists include a developmental pediatrician, cardiologist, child neurologist, gastrologist and otolaryngologist. She also saw an audiologist once. Except for the cardiologist and audiologist (seen once) she saw the other specialists 2-4 times. Insurance and TEFRA paid for the care. The family drives more than 60 miles to each of these professionals. With the exception of the audiologist, all other professionals are a part of her insurance provider network.

Although she was never admitted to the hospital, this child was in the emergency room between two and four times last year. She underwent at least two same day procedures. Insurance and TEFRA were used to pay for this care.

This child currently uses a wheelchair, but she will be getting a walker soon. She also uses a feeding pump for 13 hours a day. Her family also expects she will be getting braces soon. Her adaptive equipment includes a special car seat. She uses diapers both day and night. She requires an array of other disposable supplies related to her tube feedings. Insurance and TEFRA pay for the above supplies and equipment as well as repairs or replacement costs. Her family absorbs the added utility costs.

The child is authorized to receive up to 49 hours a week of personal care attendant (PCA) home care services. She actually receives about 15 hours per week. One other child in the family receives counseling. Someone from her school, her county social worker, the public health nurse and the physician all help the parents coordinate, locate and manage the services the child receives.

When the family needs a break from providing care for this child, they use a specialized professional care provider paid for by their county social service agency.

When the parents are at work, they depend upon professional care providers. Despite this, last year one parent missed two work days and the other missed between 10 and 15 work days. Neither parent gets paid leave. Due to his child's illness, the father accepted a lower paying job with more flexibility and has not changed jobs because the change would mean losing benefits. It appears the family would like to move, but because of the cost of caring for the child, and the fear of losing current services, the family has not been able to move.

This family has five members with health insurance through a small employer, including the child on TEFRA. The insurance appears to be an indemnity plan with a provider network from which to choose. There are limitations and exclusions related to the child.

Although there is no premium for which the family is responsible, there is a $450.00 deductible required before the insurance begins to pay. There is a $1,000,000 lifetime maximum benefit per individual. The family income in 1994 was $27,000. They therefore, do not pay a TEFRA parental fee.

Table B-2
Average Cost Range
Preteen with multiple disabilities

	Insurance	Family	School and County	Savings to Family due to TEFRA
Physician / labs	$1,104.46			$408.77
Meds / diet/ supplies	$3,045.60			$3,614.52
Hospital	$4,619.57			$839.14
Equipment / orthotics	$2,325.69			$581.42
Home care / respite	$4,508.40		$900.00	$4,508.40
Therapy	$1,819.66		$1,819.66	$1,819.66
Insurance, fees, deductibles				$450.00
Related costs		$629.28	$677.70	
Missed Work		$623.08		
Case Mgmt			$720.00	
Total	$17,423.38	$1,252.36	$4,117.36	$12,221.91
Total Expenditures				**$35,015.01**

Scenario 3: Teen with autism and behavior disorder

Scenario 3 involves an adolescent girl with several diagnoses including autism, orthopedic problems, behavior disorder, mild mental retardation, a learning disability and allergies. She has a speech and language disorder which is a primary feature of autism. She displays severe behaviors indicative of a mental health disorder, although not diagnosed as such.

While she is independent in many activities of daily living, she needs help with bathing and dressing and understanding others. She is dependent on others for getting around in the community and learning or completing tasks at school. On nearly a daily basis, this young woman exhibits a variety of problem behaviors, the most severe of which are her disruptive and uncooperative behaviors.

Due to her condition, this child requires constant supervision. In the last year, she spent 50 days in the hospital and missed 30 days of school. The child's general health, though, is described as good by her parents.

The child takes one prescription medication daily which costs approximately $250.00 per month at the current dose. Insurance and TEFRA pay for this.

She receives occupational therapy weekly and speech and language therapy daily, both of which are provided and paid for by the school. The child has had one well child check up in the last year and 2-4 sick child checks.

She receives regular dental care. She saw a psychiatrist or psychologist at least five times last year. She needed lab tests which were not a part of her doctor visits at least five times. All providers are within 60 miles of the family home. All are part of the family's insurance network of providers. The young woman was seen in the emergency room 2-4 times last year and was admitted to the hospital at least twice. She required emergency transportation at least twice. Both the hospital and emergency room were included in the provider network; the ambulance was not. All care was paid for by the combination of insurance and TEFRA.

The family's insurance, (possibly homeowners) paid for the cost of repairing and replacing non-medical equipment destroyed or worn due to their daughter's special needs. Home modifications to accommodate their child's needs were paid for by TEFRA.

The child is authorized to receive 35 hours a week of PCA services. The hours received vary. One parent receives counseling monthly paid for by insurance. The child receives counseling twice a month. When the family has needed respite care, their daughter goes to an Intermediate Care Facility for persons with Mental Retardation (ICF-MR), for which the parents and the county social service agency pay. The parents with the county social worker coordinate, locate and manage the services this child receives.

When the child is sick or unable to participate in her regular activities, a parent or other professional care giver provides the care. The family has been turned down by a child care provider or encouraged to seek child care elsewhere due to the special needs of the child. One parent missed three months of work in addition to having exhausted whatever sick leave benefits had been accrued.

In addition to the other costs, the family pays $156.00 per month for their TEFRA fee and a county social service agency sliding fee. The health plan appears to be an ERISA plan (self funded, therefore not state regulated) requiring the use of a preferred provider network and requiring copays for most services.

The insurance premium is paid by the employer. Their insurance deductibles total $125.00 per individual and $400.00 per family. There is a $1,000,000 lifetime maximum benefit allowed by the health plan.

This child has at least two siblings. She lives at home with her parents. Both parents are employed and together earned about $69,000 in 1994. The father is a high school graduate. Mother completed two years of college with an AA degree. Both parents have increased their work hours. Neither feels they can leave their job because the change could mean losing benefits. The cost of caring for their daughter as well as fear of losing current services has influenced where the family lives. The family carries private insurance through a large employer. In the last 12 months, the family has considered out of home placement for this child.

Table B-3
High Cost Range
Teen with autism, orthopedic problems, mental retardation and behavior disorder

	Insurance	Family	School and County	Savings to Family due to TEFRA
Physician / labs/dental	$327.92			$233.45
Medication	$2,880.00			$120.00
Hospital/ ER/Amb.	$60,103.24			$14,672.56
Therapy			$7,493.98	
Home care / respite			$1,900.00	$21,097.00
Counseling	$1,935.36	$168.00		$315.84
Related costs		$11,942.31		$5,556.00
Case mgmt			$720.00	
Insurance, fees, deductibles		$7,572.00		$125.00
Total	$65,246.52	$19,682.31	$10,113.98	$42,119.85
Total Expenditures				**$137,162.66**

Scenario 4: Teen with attention deficit and behavior disorder

Scenario 4 involves a 15-year-old diagnosed with a behavior disorder and ADD/ADHD. She is independent in activities of daily living. She has had difficulty with the law and school and has had episodes of violence. She exhibits an array of difficult behaviors, most difficult for her family are uncooperative behaviors, withdrawal and socially offensive behaviors. The youngster needs frequent supervision and is currently in court ordered foster care. Her physical health is described as good, however, in the last year she missed two to three weeks of school. The child receives special education services.

She takes one prescription medication three times daily. Her insurance and TEFRA pay for the medication. She has had 2 -4 well child visits and the same number of sick child visits in the last year. She has seen a psychiatrist five or more times in the last year and goes to outpatient day treatment. Her family's insurance and TEFRA paid for the visits. All providers are within the health plan provider network and, except for the psychiatrist, all are within 60 miles of the family's home. She had five or more same day or outpatient hospital visits in the last year which were paid for by her family, the health plan and TEFRA. She wears glasses purchased for her by her parents. She had one dental visit in the last year paid for by insurance.

The child goes to counseling three or four times a month and the parents go once or twice a month. The family goes to counseling together once or twice a month. The counseling is paid for by the family, TEFRA and insurance.

Her parents, school, county social worker and the foster parents all coordinate, locate or manage the services the child receives. The child receives mental health services through the county-based children's mental health. She receives crisis assistance, day treatment and foster care five or more times a month each, and case management services once a month or more as needed.

Insurance, TEFRA and the family all have paid for the day treatment and foster care in the last year. The county pays for crisis assistance and case management.

When the family needs a break from providing care for this child, friends or relatives provide it or it is provided through foster care paid by the county.

The family currently pays $152.00 per month in county parental fees and $59.62 to TEFRA. The parents make arrangements around their work schedules for medical appointments. The mother took a lower paying job to allow her the flexibility to meet the needs of this child. The family has moved to be closer to services for the child. The costs of care and concern about losing current services have prevented any further moves.

Four family members including the child with special needs have private insurance through an employer. The premium appears to be covered by the employer, although there are copays for medications, office visits and the emergency room.

Despite this child having mental health care needs for more than five years, the child has been on TEFRA for only about the last six months. The parents in this family are married. Both completed technical educations and their family income in 1994 was approximately $53,000.

Table B-4
Average Cost Range
Teen with attention deficit and behavior disorder

	Insurance	Parents	County	Savings to Family due to TEFRA
Prescribed drug	$2,916.00	$42.00		$42.00
Travel		$138.00		
Primary / specialty care	$543.96			$210.00
Glasses		$75.00		
Same day hospital	$5,942.85	$25.00		$25.00
Counseling	$4,503.60	$390.00		$390.00
Children's Mental Health			$10,855.20	$1,137.00
Respite			$900.00	
TEFRA fee		$715.44		
County fee		$1,824.00		
Total	$13,906.41	$3,209.44	$11,755.20	$1,804.00
Total Expenditures				**$30,675.05**

Scenario 5: Toddler with language and other developmental delays

Scenario 5 involves a 3-year-old boy with a history of acute medical problems, including cerebral atrophy and colostomy. These issues appear to be resolved but there are residual problems including a language delay, developmental delays and a learning disability. He is independent in walking, eating, indoor mobility and getting in and out of bed. However, he needs more frequent supervision than other children his age. He is unable to communicate his needs other than some gestures which are understandable only to his family. He has difficulty understanding others. He gets frustrated when he cannot communicate his wants or needs. His parent describes his overall health as good.

This boy receives occupational and speech/language therapy through the infant and toddler program (Part H) of the local school district. The school pays for his occupational therapy, the school and TEFRA pay for his speech therapy. He has well child checks every three months and has had two to four sick child visits in the last year. He saw the audiologist once in the last year.

The father is self-employed. Initially the family's health plan refused to cover the child, but then indicated he would be covered one year after surgery to close the colostomy. Unfortunately, it appears that during that year neurological problems were diagnosed prompting the health plan to decline coverage altogether. The family appears to have accessed private health coverage through a different company, but the premiums became unaffordable. Currently no one in the family has private health coverage.

The parents, school and Part H service coordinator all arrange for and coordinate needed services. The family does not pay a parental fee, indicating an income of less than $25,000 per year. The parents are married and both are high school graduates.

Table B-5
Low Cost Range
Toddler with language and other delays

	School	Savings to Family due to TEFRA
Physician / labs		$621.35
Therapies	$975.32	$1,225.63
Case Mgmt	$720.00	
Total	$1,695.32	$1,846.98
Total Expenditures		**$3,542.30**

> *"We love our daughter very much. She has taught us a lot about life, patience, acceptance of people with special needs and how to appreciate the smallest things in life. She has brought us joy over the last 13 years but, I could not do it without help.... We are tired. Tired of fighting the government, tired of doctor trips, tired from the lack of sleep, just tired...."*
>
> *Parent*

Appendix C: Survey Questionnaire

This survey is divided into 5 sections. The purpose of Section I is to gather information about the medical, behavioral and daily living needs of children on the TEFRA program. Section II tries to determine the services children on TEFRA use and who pays for services. Section III looks at how meeting the special needs of a child can impact family life. Section IV is included to look at the use of other funding sources which may or may not be available to families of children with special needs. Section V is included to provide us with an idea of the family situation of children using TEFRA.

Section I From the list below, please check all the diagnoses that apply to your child:

☐ 1. Allergies
☐ 2. ADD/ADHD
☐ 3. Asthma / Respiratory
☐ 4. Autism
☐ 5. Behavior Disorder
☐ 6. Cancer
☐ 7. Cerebral Palsy
☐ 8. Cleft Lip and/or Palate
☐ 9. Cystic Fibrosis
☐ 10. Developmental Delay
☐ 11. Diabetes
☐ 12. Down Syndrome
☐ 13. Hearing Loss
☐ 14. Heart Condition
☐ 15. Hemophilia
☐ 16. HIV/AIDS
☐ 17. Immune Deficiency
☐ 18. Juvenile Arthritis
☐ 19. Kidney/Urinary Condition
☐ 20. Learning Disability
☐ 21. Mental Retardation
☐ 22. Muscular Dystrophy
☐ 23. Orthopedic Problems
☐ 24. Paralysis or Weakness;
☐ 25. Seizure Disorder
☐ 26. Severe Emotional Disorder
☐ 27. Speech/Language Disorder
☐ 28. Spina Bifida
☐ 29. Syndrome (name)
____
☐ 30. Traumatic Brain Injury
☐ 31. Vision Loss
☐ 32. Other ______________
____

33. Was your child premature?
☐ **yes** ☐ **no**
If yes, how many weeks early?
__________ weeks

2. Describe how the diagnosis effects your child and family : ______________________

____

____

____

3. For each activity listed below, please check whether your child is **independent, needs some help or is dependent** on others to complete the activity as compared to other children of the same age.

Activity	**Independent**	**Needs Some Help**	**Dependent**	**Activity**	**Independent**	**Needs Some Help**	**Dependent**
Walking				Dressing			
Talking				Getting around inside the home			
Understanding others				Getting around the community			
Eating or drinking				Getting to/from bed, chairs, car or toilet			
Using the toilet				Learning or completing tasks at school			
Bathing or showering				Wheelchair mobility			

For infants and toddlers: How is caring for your child special compared to children of the same age?

____

____

____

4. Below is a list of behaviors experienced by some children with special needs. For each behavior listed, please check how often your child has the behavior and how serious a problem the behavior is.

Hurtful to self ☐ **yes** ☐ **no** (hits, kicks, bites, pinches, scratches other people

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Hurtful to others ☐ **yes** ☐ **no** (hits, kicks, bites, pinches, scratches other people

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Destructive to Property ☐ **yes** ☐ **no** **(breaks or** destroys things on purpose)

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Disruptive Behavior ☐ **yes** ☐ **no** (interferes with activities of others; pesters, teases, fights, laughs / cries without reason, yells)

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Unusual or Repetitive Habits ☐ **yes** ☐ **no** (pacing, rocking, sucking hands or objects, nervous tics, eating non-food items, eating too much or too little, staring at an object or into space)

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Socially Offensive Behavior ☐ **yes** ☐ **no** (talking too loud, swearing, standing too close or touching others too much, threatening, spitting at others, picking nose, belching, expelling gas, touching genitals or urinating in inappropriate places)

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Withdrawal or Inattentive Behavior ☐ **yes** ☐ **no** (difficulty being around others or paying attention; expresses unusual fears, little interest in activities, appears sad or worried, shows little concentration, sleeps too much, talks negatively about self)

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Uncooperative Behavior ☐ **yes** ☐ **no** (refusing to obey or follow rules, defiant, refuses to attend school or go to work, arrives late to work or school, refuses to take turns, lying, cheating, stealing or breaking laws)

How often
☐ 1 - 3 times a month
☐ 1 - 6 times a week
☐ 1 - 10 times a day
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a moderate problem
☐ a severe problem
☐ a critical problem

Mental Health Disorder ☐ **yes** ☐ **no** (sees or hears things that aren't there; multiple personalities; sudden changes in mood or feelings; suicidal thoughts, gestures or attempts, unable to develop values, morals or relationships; truancy, chemical abuse, runs away; flat or blunt affect;)

How often
☐ l. less than once a month
☐ 1 - 10 times a day
☐ 1 - 3 times a month
☐ one or more times an hour

How serious a problem is this?
☐ a mild problem
☐ a severe problem
☐ a moderate problem
☐ a critical problem

5. Supervision Needs and General Health

Because of physical, mental or emotional problems does your child need supervision or need to be watched more closely than other children his/her age? ☐ **Yes** ☐ **No**

If yes, what level of supervision does your child need?

☐ **constant** ☐ **frequent** ☐ **occasional** ☐ **infrequent**

During the last school year, how many days did your child miss school, preschool or nursery school because of his/her special health need? __________ days

How many nights in the last 12 months has your child spent in the hospital? __________nights

How would you describe your child's general health?

☐ **excellent** ☐ **good** ☐ **fair** ☐ **poor** ☐ **don't know**

Section II Service Utilization

1. Therapy and related services. Below is a list of services your child may have received in the last 12 months. If so, please check which therapies, the places your child received each service, how often the service was provided and who paid for the service.

☐ Physical Therapy	Number of times / week 1	2	3	Other	Who Paid? (check all that apply)
☐ Home					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ School					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Outpatient or Rehab Program					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Occupational Therapy					
☐ Home					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ School					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Outpatient or Rehab Program					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Speech / Language Therapy					
☐ Home					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ School					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Outpatient or Rehab Program					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Respiratory Therapy					
☐ Home					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ School					☐ Family ☐ School ☐ Insurance ☐ TEFRA
☐ Outpatient or Rehab Program					☐ Family ☐ School ☐ Insurance ☐ TEFRA

2. Medications and Special Diets. Some children with special needs take medications regularly or need a special diet. Does your child currently need medication or a special diet? ☐ **Yes** ☐ **No** If yes, please answer the following:

	How many?	Who Paid? (check all that apply)
Prescription Medications		☐ Family ☐ TEFRA ☐ Insurance
Over the Counter Medications recommended by a physician		☐ Family ☐ TEFRA ☐ Insurance
Special Diet or Special Formula		☐ Family ☐ TEFRA ☐ Insurance

3. Primary / Specialty and Outpatient Care Please check which of the following services your child received in the last 12 months, the number of visits, who paid for the service, the provider's network status and miles traveled.

Check which of the following services your child received in the last 12 months	Number of Visits in the last 12 months (check one)			Who Paid? (check all that apply)	Is this provider in your private health plan provider network? (This applies only if your private coverage requires you use specific providers.)				Miles traveled one - way
	1	2 - 4	5+		Yes	No	N/A	Don't know	
☐ Well child check ups				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Sick child visits				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Dental Care				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Orthodontia				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Psychiatrist / Psychologist				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Specialist (Specify type) ________				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Specialist (Specify type) ________				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Specialist (Specify type)				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Specialist (Specify type)				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Specialist (Specify type) ________				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Specialist (Specify type)				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Audiology				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Laboratory Tests not part of a doctor visit				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +

4. **Hospital / Emergency Care.** Please check which of the following services your child received in the last 12 months, number of visits, who paid for the service, the provider's network status and miles traveled.

Check which of the following services your child received in the last 12 months	**Number of Visits in the last 12 months (check one)**			**Who Paid? (check all that apply)**	**Is this provider in your private health plan provider network? (This applies only if your private coverage requires you use specific providers.)**				**Miles traveled one - way**
	1	**2 - 4**	**5+**		**Yes**	**No**	**N/A**	**Don't know**	
☐ Emergency Room Visits				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Hospital Admission (planned)				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Hospital Admission (unplanned)				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Same Day or Outpatient Hospital Procedures				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +
☐ Emergency Transportation (ambulance, helicopter, etc)				☐ Family ☐ Insurance ☐ TEFRA					☐ 0 - 60 ☐ 61 - 120 ☐ 121 +

5. **Equipment and Supplies.** Below is a list of equipment and supplies some children with special needs require. Please check which kinds of equipment or supplies your child currently uses, specify the type and who paid.

Equipment / Supply	**Specify Types**	**Who Paid? (check all that apply)**
☐ Durable Medical Equipment (wheelchairs, nebulizers, walkers)		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Orthotics or prosthetics (braces, artificial limbs)		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Adaptive equipment (eating utensils, special car seat, recreational items)		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Assistive Technologies, (learning aids, devices to assist with speech or daily living)		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Hearing Aids or Eyeglasses		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Diapers or other incontinence supplies(if your child would not normally use at his or her age)		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Disposable Supplies (distilled water, bandages, gloves, syringes, tubing)		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance
☐ Other		☐ Family ☐ School ☐ Other ☐ TEFRA ☐ Insurance

6. Related costs. Below are a list of expenses incurred by some families whose children have special needs. Did your family have any of the expenses listed below? ☐ **Yes** ☐ **No.** If yes, please check which costs you had and who paid.

Service	**Who Paid?**		**Service**	**Who Paid?**
☐ Repairs to or replacement of non-medical equipment destroyed or worn out due to your child's special needs	☐ Family ☐ Insurance ☐ TEFRA ☐ Other		☐ Extra charges on electric, utility bills, phone bills related to the special health needs (include pagers or cellular phones if needed due to child's special needs)	☐ Family ☐ Insurance ☐ TEFRA ☐ Other
☐ Modifications to home to accommodate child's special needs	☐ Family ☐ Insurance ☐ TEFRA ☐ Other		☐ Special or Additional clothing	☐ Family ☐ Insurance ☐ TEFRA ☐ Other
☐ Purchase or modifications to a vehicle to transport the child with special needs	☐ Family ☐ Insurance ☐ TEFRA ☐ Other		☐ Special Camps, recreational activities, etc.	☐ Family ☐ Insurance ☐ TEFRA ☐ Other

7. Home Care. Is your child authorized to receive home care services or did they receive home care services in the last 12 months? ☐ **Yes** ☐ **No.** If yes, please answer the following:

Which services? (check all that apply)	**Hours / Week Authorized**	**Hours / Week Received**	**Who Paid? (check all that apply)**
Skilled Nursing Services (RN or LPN)			☐ Family ☐ Insurance ☐ TEFRA ☐ Other
Personal Care Attendant Services			☐ Family ☐ Insurance ☐ TEFRA ☐ Other
Homemaker			☐ Family ☐ Insurance ☐ TEFRA ☐ Other
Home Health Aide			☐ Family ☐ Insurance ☐ TEFRA ☐ Other

8. Counseling Services. Some children with special health needs or their families receive counseling services. Did anyone in your family receive counseling services in the last 12 months? ☐ **Yes** ☐ **No.** If yes, please answer the following:

Who received counseling	**How many times per month?**	**Who Paid? (check all that apply)**
☐ Child		☐ Family ☐ TEFRA ☐ School ☐ Insurance ☐ Other
☐ Parents		☐ Family ☐ TEFRA ☐ School ☐ Insurance ☐ Other
☐ Brothers/Sisters		☐ Family ☐ TEFRA ☐ School ☐ Insurance ☐ Other
☐ Family		☐ Family ☐ TEFRA ☐ School ☐ Insurance ☐ Other

9. Case Management

Are there people who coordinate, locate or manage the services your child receives? ☐ **Yes** ☐ **No**

If yes, who does this? (check all that apply)

- ☐ **parent**
- ☐ **school**
- ☐ **county social worker**
- ☐ **county public health nurse**
- ☐ **birth - 3 service coordinator**
- ☐ **hospital staff**
- ☐ **other (specify)** ____________________
- ☐ **physician**
- ☐ **home care agency**
- ☐ **insurance company**

10. County-Based Children's Mental Health Services. Below is a list of services children sometimes receive if they are eligible for county mental health services. Has your child received county-based mental health services in the last 12 months? ☐ Yes ☐ No If yes, please check each service your child or family received.

Mental Health Service	Frequency per month	Who Paid?
☐ Case management		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Medication management		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Assistance in developing independent living skills		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Assistance in developing parenting skills		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Crisis assistance		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Professional home based family treatment		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Day Treatment		☐ Family ☐ TEFRA ☐ Insurance ☐ County
☐ Foster Care		☐ Family ☐ TEFRA ☐ Insurance ☐ County

11. Respite Care. In the last 12 months, when you have needed a break from providing care for your child with special needs, were you able to get it? ☐ **Yes** ☐ **No.** If yes, who provided this service and who paid for it?

Provider		Who Paid?
☐ friend or relative ☐ non-specialized professional care provider ☐ private social or religious organization	☐ specialized professional care provider ☐ foster care ☐ ICF/MR Facility ☐ other	☐ parents ☐ county social service agency ☐ private charitable fund ☐ other

13. Out of Pocket Costs. What were the total costs to the family for services received in the last 12 months which were not reimbursed by another source? (You can use the tables you have already filled out to help you think of how much you spent.)

Expense	Cost	Is this an estimate or do you keep records? (check one)	
		Estimate	Records
Therapy and related services	$		
Medications and Special Diets	$		
Primary / Specialty and Acute Care	$		
Hospital / Emergency Care	$		
Equipment and Supplies	$		
Related costs	$		
Home Care	$		
Counseling Services	$		
Case Management	$		
Children's Mental Health Services	$		
Respite	$		

14. TEFRA Parental Fee

What was your monthly fee for TEFRA before 7/1/95? $________
What is your monthly fee for TEFRA after 7/1/95? $________
Was the change, if any, the result of a change in family income? ☐ **Yes** ☐ **No**

Section III. The next series of questions will help us gather information about the impact of having a child with special needs.

1. Child Care Who usually provides care for your child when the adult or adults in your household are at work?
☐ None needed ☐ Relative ☐ Non-relative ☐ Professional
Who provides care for your child when your child is sick and cannot participate in his or her regular activities?
☐ None needed ☐ Relative ☐ Non-relative ☐ Professional
Have you ever been turned down by a child care provider or encouraged to seek child care elsewhere due to the special needs of your child? ? ☐ **Yes** ☐ **No**

2. In the last 12 months, how many work days did an employed adult in the home miss due to the child's special health needs? (include illness, medical appointments, IEP meetings)

Adult #1		**Adult # 2**	
Number of Days missed in the last year ________		Number of Days missed in the last year ________	
Company policy regarding absences		**Company policy regarding absences**	
☐ Paid leave for employee illness only; ☐ Paid leave, but at a lower pay than usual	☐ Paid leave for illness of employee or family ☐ No paid leave ☐ Other	☐ Paid leave for employee illness only; ☐ Paid leave, but at a lower pay than usual	☐ Paid leave for illness of employee or family ☐ No paid leave ☐ Other

3. Parental Employment Has having a child with special needs effected parental employment? ☐ Yes ☐ No
If yes, please check all that apply and whose job was effected.

Due to the special needs of your child, has anyone in your household:	**Who?**
☐ Given up a paying job? If yes, for how long? ____________	☐ Mother ☐ Father ☐ Other
☐ Lost a job? If yes, for how long unemployed? ____________	☐ Mother ☐ Father ☐ Other
☐ Changed jobs for better medical benefits?	☐ Mother ☐ Father ☐ Other
☐ Accepted a lower paying job with more flexibility or fewer demands?	☐ Mother ☐ Father ☐ Other
☐ Taken a second job or increased work hours?	☐ Mother ☐ Father ☐ Other
☐ Not changed jobs because the change would have meant losing benefits?	☐ Mother ☐ Father ☐ Other

4. Family Residence

HAS YOUR CHILD'S SPECIAL NEED INFLUENCED WHERE YOUR FAMILY LIVES?	**YES**	**NO**
Our family moved to be closer to services for our child.		
Our family moved because our home did not meet our child's physical needs and we were unable to make the needed modifications		
Our family moved because our child's disability bothered the landlord or neighbors.		
We have NOT MOVED to a better home because of the cost of care for our child		
We have NOT MOVED because we do not want to lose our current services		

Section IV. Available Services
1. Does your child use any of the following: (please check all that apply)
☐ **Food Stamps** ☐ **WIC** ☐ **SSI** ☐ **Early Childhood Family Education** ☐ **Headstart** ☐ **Special Education**

2. Please check which of the following programs your child uses and describe what services your child receives. (If your child is on a waiting list, please describe the services you plan on receiving.)

Program	Description of Services
☐ MR/RC Waiver ☐ on waiting list?	
☐ Traumatic Brain Injury Waiver ☐on waiting list?	
☐ CAC Waiver ☐on waiting list?	
☐ CADI Waiver ☐on waiting list?	
☐ Vocation Rehab	
☐ Minnesota Children with Special Health Needs	
☐ Public Health Nursing	
☐ Other	

3. Insurance Some children served by TEFRA also have private insurance. Please answer the following questions for both your medical and dental health plans.

	Medical	Dental
How many family members are covered by private health insurance?		
How much does your family pay each month for private health insurance?		
Is your child with special needs covered by private health insurance?	☐ Yes ☐ No	☐ Yes ☐ No
Are there currently any limitations or exclusions on the policy related to the child with special needs. If yes, please describe:	☐ Yes ☐ No	☐ Yes ☐ No
Has anyone in your family ever lost employer based insurance because of your child's special needs?	☐ Yes ☐ No	☐ Yes ☐ No
Are there copays for which you are responsible? If yes, what is the amount? Meds $ Office visits $ E.R.$	☐ Yes ☐ No	☐ Yes ☐ No
Is there an individual or family deductible which must be met before the health plan begins to pay for covered services? How much is the deductible per individual per year? How much is the deductible per family per year?	☐ Yes ☐ No $ $	☐ Yes ☐ No $ $
Is there a lifetime maximum benefit your health plan will pay per individual? If yes, what is that amount?	☐ Yes ☐ No $	☐ Yes ☐ No $
Does TEFRA pay any part of your private health care premiums? If yes, how much does TEFRA pay each month?	☐ Yes ☐ No $	☐ Yes ☐ No $

4. If your child with special health needs has other insurance besides TEFRA, please answer the following: What is the name of the private health plan or plans(s). Please give the exact name of the plan as shown on the membership card.

Primary Plan **Secondary Plan (if any)**

______________________ ______________________

If this insurance is through an employer, please name the employer

______________________ ______________________

Section V. Family Information

1. How many children in your family have special needs? ____________
2. How many children in your family are currently eligible for TEFRA? ____________
3. How old are the children in your family who are currently on TEFRA? ____________
4. Birth date of child for whom this survey was completed. ____________
5. How long has your child been on TEFRA? ____________

6. Child's ethnic group (check one) ☐ White (non-Hispanic) ☐ Black (non-Hispanic) ☐ Native American ☐ Hispanic ☐ Asian/Pacific Islander ☐ Other____________

7. Is this child adopted? ☐ **Yes** ☐ **No**

8. Does this child live with you? ☐ **Yes** ☐ **No**

   a. If No, where does this child live? ☐ Other family members ☐ Group home ☐ Foster home ☐ Other: (please describe) ____________________

   b. If No, why? (check all that apply); ☐ Costs of care at home ☐ Physical demand too much ☐ Needs of other family members ☐ Too many strangers in the home ☐ Unable to find the necessary help ☐ Other: ____________________

9. In the last 12 months, have you considered out of home placement for your child? ☐ **Yes** ☐ **No**

10. Parent's marital status: ☐ Single ☐ Married ☐ Divorced ☐ Separated ☐ Widowed ☐ Remarried

11. Education level of parents:

Parent 1 (check highest level reached)	**Parent 2** (check highest level reached)
☐ Less than high school graduate ☐ High school graduate ☐ Technical school graduate ☐ Some college ☐ College graduate ☐ Post Graduate course work	☐ Less than high school graduate ☐ High school graduate ☐ Technical school graduate ☐ Some college ☐ College graduate ☐ Post Graduate course work

12. Family's adjusted gross income in 1994? (approximate) $ ____________________

13. Is there something you would like to tell us that we have not asked?

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Thank you for completing this survey!

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