

GAO

Report to the Chairman,
Committee on Finance, U.S. Senate

June 1989

HEALTH CARE

Home Care Experiences of Families With Chronically Ill Children





United States
General Accounting Office
Washington, D.C. 20548

Human Resources Division

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The Honorable Lloyd Bentsen
Chairman, Committee on Finance
United States Senate

Dear Mr. Chairman:

In response to your request, we are submitting this report on home health care for chronically ill children. We reviewed the experiences of families with such children in obtaining necessary medical and support services in the home.

Copies of the report will be sent to the Department of Health and Human Services and to others.

This report was prepared under the direction of J. William Gadsby, Director, Intergovernmental and Management Issues. Other major contributors are listed in appendix VII.

Sincerely yours,

A handwritten signature in cursive script that reads "Lawrence H. Thompson".

Lawrence H. Thompson
Assistant Comptroller General

Executive Summary

Purpose

From 10 to 15 percent of all U. S. children have a chronic health condition, health researchers estimate, and about 1 million of these have a severe form of the condition. Historically, children with severe chronic conditions remained in hospitals for treatment. However, advances in medical technology have moved much of the treatment to the home. The Senate Finance Committee asked GAO to review the experiences of parents with chronically ill children in obtaining necessary medical and support services in the home.

Background

In general terms, a chronic illness is a condition that lasts for a substantial period of time and has continuing and often debilitating effects. Some conditions are rare, while others are common; some illnesses are life-long, but a number can be corrected during childhood. Years ago, children born with certain of these conditions would not survive, but medical advances over the past 25 years have reversed that situation. Today, the majority of chronically ill children survive into adulthood.

While some changes in service delivery and financing have supported the home care concept, families still reported difficulties in obtaining needed services. To identify the factors that have hindered or eased service delivery in the home care setting, GAO surveyed parents of children who had the more severe forms of one of 10 selected medical conditions. (See p. 9.) In a major study, these conditions were considered representative of the various chronic illnesses for which parents have difficulty in obtaining home care.

Working in 11 states and the District of Columbia, GAO (1) contacted 14 hospitals that cared primarily for children, (2) surveyed 892 parents whose children were discharged from these hospitals concerning their experiences and spoke with 96 of the parents to obtain more detailed information, and (3) queried 60 service providers and organizations in the local service areas of 9 hospitals about service availability. (See pp. 9-10.)

This work gave GAO broad perspectives on the problems parents experienced in obtaining care for chronically ill children. These perspectives became the basis for examining systemic barriers to obtaining community-based care and recommending solutions for overcoming the problems. GAO did not develop potential solutions in the financing area because these were being explored by the requestor through other efforts.

Results in Brief

The majority of families had no difficulty obtaining medical services, but most said they had difficulty obtaining needed support services. In all but a few instances, the medical services were obtained, while in many cases support services were not.

Parents told us that three factors commonly accounted for their difficulties. Lacking were financing because of health insurance coverage limitations, information on services available, and a focal point to contact when help was needed with home care. Parents who did not have difficulty reported that information was available and/or outside help was provided that made it easier for them to obtain services.

The positive experiences reported by some parents suggest means by which access to needed services might be improved. Among possible improvements are (1) consolidating information on existing services and making it available to all organizations serving chronically ill children, (2) providing this information to parents during the hospital discharge planning process, and (3) referring parents who need help in the home care setting to organizations providing case management services (help in getting information and coordinating care).

GAO's Analysis

Need for Services Varies

Nearly all (98 percent) of the parents surveyed reported their children needed one or more of seven medical services (see p. 12), particularly physician office visits and medications. About one-half also needed equipment and supplies. Their needs varied according to which of the 10 medical conditions the child had.

About three-quarters of the parents reported needing one or more support services. (See p. 14.) The services most frequently mentioned were baby sitting, counseling, day care, and transportation. Support service needs generally did not vary much by the child's medical condition.

Medical Services Easier to Obtain Than Support Services

A little over one-fourth (27 percent) of the parents whose children needed medical services and just over one-half (56 percent) of the parents needing support services experienced difficulty in getting them. (See pp. 17-18.) Parents reported that three factors accounted for many medical and support service difficulties:

1. Paying for services was most frequently a problem. Insurance copayments and deductibles resulted in significant out-of-pocket expenses for such medical services as medications, medical equipment, and therapies. While costly and not covered fully by insurance, medical services needed by the child generally were obtained. On the other hand, insurance coverage limitations for support services sometimes forced families to forego services or incur large out-of-pocket expenditures for such services as baby sitting, day care, and transportation. (See p. 21.)

2. Lack of information about support services and availability of the services was another common difficulty. At the time of the child's discharge from the hospital, parents generally received information on medical services but not always on support services. Left on their own, they said they spent an inordinate amount of time and effort finding services. Some parents could not obtain support services because of the lack of providers or the refusal of providers to serve their children. (See p. 23.)

3. Lack of help with home care was experienced by some parents. Such parents said that their home-care situation would have been eased considerably had someone contacted them after their child's discharge to see how they were adjusting and to help them provide care. (See p. 25.)

Some Parents Had Little Difficulty

Some parents had little or no difficulty in obtaining services. In many areas, providers told GAO that information was available that enabled parents to locate needed services. Also, some parents received outside help in the form of case management in the transition to home care. Different forms of case management were provided through a variety of public, private, and voluntary agencies. (See pp. 27-31.)

Recommendation

Policy and program guidance are needed to facilitate the consolidation and publication of information on services for chronically ill children and ensure that case management services are available when needed. GAO recommends that the Secretary of Health and Human Services direct the Office of the Assistant Secretary for Health to take a leadership role in developing such guidance for state maternal and child health agencies. The policy should be aimed at ensuring that (1) information on providers and services in a given community is consolidated and made available to organizations serving chronically ill children, (2) this information is provided to parents at time of discharge, and (3) case

management services are made available to those who need direct assistance.

Agency Comments

A draft of this report was provided to the Department of Health and Human Services, which concurred with GAO's recommendation. (See p. 33.)

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Abbreviations

GAO General Accounting Office
HHS Department of Health and Human Services

Introduction

Nationally, between 10 and 15 percent of all children have a chronic health condition, health researchers estimate, and about 10 percent of them—or 1 million children—have a severe form of it. In general, a chronic illness is a condition that lasts for a substantial period of time and has continuing and often debilitating effects on the body. Some such conditions are rare, while others are more common. Also, while certain chronic illnesses are long-term, others can be corrected during childhood.

At one time, children born with some of these conditions would not survive, but medical advances over the past 25 years have reversed that situation. Historically, children with chronic conditions were treated in hospitals. Over the past decade, however, the health care community has shifted its opinion and now feels they should be treated at home whenever possible.

Background

In response to the increasing emphasis on home care and because such care could cost less, the Congress amended federal law to allow payment for it. For example, under Medicaid, states now may pay for home care services. Also, the Maternal and Child Health Services block grant authorizes home and community-based services for children with special health care needs.

These and other changes have supported the home-care concept. But families still have experienced difficulties getting services at home, studies have shown. In some cases, services were not available, while in others, the costs were financially burdensome. This occurred in part because (1) the insurance industry (both public and private) was slow to change its traditional institutional care focus, (2) insurance did not cover the full cost of services needed by children and their families in the home setting, and (3) states' federally supported health care programs' eligibility requirements did not always include the full range of chronic conditions or serve all children that have them.

Objectives, Scope, and Methodology

In August 1987, the Senate Finance Committee asked us to (1) review the experiences parents with chronically ill children have in obtaining necessary medical and supportive nonmedical services in the home setting, (2) identify the factors that hinder or ease service delivery, and (3) propose solutions to overcome problems identified, except those concerned with financing, which were being explored by the requestor through other efforts.

Scope

We based our review on children who had the more severe forms of the following 10 conditions:

- Juvenile-onset diabetes
- Asthma
- Spina bifida
- Cleft palate and other craniofacial anomalies
- Congenital heart disease
- Leukemia
- End-stage renal disease (kidney failure)
- Sickle cell anemia
- Cystic fibrosis
- Muscular dystrophy

Some of these conditions (such as diabetes, cystic fibrosis, and spina bifida) are long-term, while others (such as heart conditions and cleft palates) often can be corrected early in life (see app. I). Also, the 10 conditions are among those included in a 1985 study at Vanderbilt University of public policies affecting chronically ill children and their families.¹ According to the study, the experiences of the families studied were representative of the problems and costs generally faced by parents in obtaining care for all kinds of chronic illnesses. As the basis for our detailed review, we used 55 primary diagnoses that medical experts identified as representing the more severe forms of the 10 conditions.

Our review was performed in 11 states and the District of Columbia. These locations were selected on the basis of geographic diversity and variety of public health programs. We visited 14 hospitals that primarily cared for children, choosing those that enabled us to compare parents' experiences in urban and nonurban areas. Appendix II lists the states, localities, and hospitals selected.

In addition, we obtained information from recent studies related to chronically ill children, such as a 1987 report by the Office of Technology Assessment and a 1988 report by the Department of Health and Human Services (HHS).²

¹Nicholas Hobbs, James M. Perrin, and Henry T. Ireys, Chronically Ill Children and Their Families: Problems, Prospects, and Proposals from the Vanderbilt Study, Josey-Bass Inc., 1985.

²Office of Technology Assessment, Technology-Dependent Children: Hospital v. Home Care. A Technical Memorandum, May 1987; and Department of Health and Human Services, Fostering Home and Community-Based Care for Technology Dependent Children: Report of the Task Force on Technology Dependent Children, April 7, 1988.

Methodology

To address our study objectives, we contacted parents of chronically ill children and care providers. In addition to surveying parents by mail about their general experiences, we spoke with some of them to obtain more detailed information. We contacted providers in selected local areas to obtain information about service availability and other matters. The details of our methodology are presented in appendix III.

Parent Mail Survey

Most children with the 10 chronic conditions we selected are treated at children's hospitals. Therefore, we asked the 14 children's hospitals in our review to help us identify families with such children. During the 12 months ending June 30, 1987, 8,557 children meeting our criteria were discharged from these hospitals. We selected 2,191 children to survey, and hospital officials mailed our survey form to their parents (one form to a family); of these forms, 1,990 went to valid addresses and 201 were returned as undeliverable.

Parents returned 892 completed forms or about 45 percent of the 1,990 surveys mailed to valid addresses: 621 (70 percent) from urban areas and 250 (28 percent) from nonurban areas. About 26 percent of the usable returns provided narrative comments. According to our public survey consultant, the normal return rate for a survey of this type would have been about 15 to 20 percent, so that our return rate of 45 percent is considered high, particularly given the sensitivity of the subject. We were not able to determine the profile of those who did not respond because of our confidentiality arrangements with the hospitals.

Parent Interviews

We talked with 96 parents who returned our survey, either in group settings or individually. Their profile was similar to the profile of those who returned the survey form as to income, insurance coverage, education, and the child's condition. In the meetings, we asked them why they did or did not have difficulty obtaining services in the home care setting.

Local Organization Interviews

When chronically ill children and their parents look for services after the child's discharge, they turn to the health care and support service providers in their local area. To ascertain their role, we contacted health care and support service organizations and providers in the localities we visited. We asked whether they served our population of chronically ill children and their families and what information and/or services they provided. Also, we sought to learn whether and how the service providers coordinated and interacted with one another.

The interviews gave us broad perspectives on the problems parents experienced obtaining care for chronically ill children. These perspectives became the basis for examining systemic barriers to obtaining community-based care and recommending solutions for overcoming the problems.

Limitations

As this was not intended to be a comprehensive survey of the availability of medical and support services in a community, we focused our review on the experiences of parents. Further, our report contains views and experiences of only those parents who responded to our survey, and does not represent all parents nationally or other parents in the areas surveyed.

Our review was performed in accordance with generally accepted government auditing standards between February and September 1988.

Families' Needs for Services Vary

Families with chronically ill children at home have diverse needs for services. Among those most often needed are physician office visits, medications, baby sitting, counseling, day care, and transportation. The needs of families in urban and nonurban areas are similar for most services. For medical services, the need is great and generally varies by medical condition. For support services, the need is less and generally does not vary much by condition.

Need for Medical Services Great, Varies by Condition

Nearly all families needed medical services for their children, parent survey responses showed, and the vast majority needed more than one. As table 2.1 shows, 848 respondents (about 98 percent) said that they needed one or more of seven medical services.

Table 2.1: Families' Needs for Specific Medical Services

Service	Number	Percent
Physician office visits	823	97
Medications	759	90
Medical equipment	470	55
Medical supplies for equipment	464	55
Rehabilitative and other therapies	273	32
Skilled nursing visits	208	25
Physician home visits	102	12

Note: Of the 865 valid responses to GAO's question about medical service needs, 17 (2 percent) said they did not need any medical services.

Because some services were not needed as often as others, we analyzed how frequently services were cited as needed among the 10 conditions. Frequency of need varied by the child's medical condition, as table 2.2 shows.

Table 2.2: Average Number of Medical Services Needed, by Child's Condition

Medical condition	Number of services needed
Muscular dystrophy	5.0
End-stage renal disease	4.6
Spina bifida	4.5
Cystic fibrosis	4.5
Juvenile-onset diabetes	4.2
Leukemia	4.0
Asthma	3.9
Congenital heart disease	3.1
Cleft palate/craniofacial anomaly	3.1
Sickle cell anemia	2.8
Multiple conditions	4.5

The differing medical service needs can be illustrated best by contrasting parents' survey responses on cystic fibrosis with those for cleft lip or palate:

- Children with cystic fibrosis need office visits, medical equipment, supplies, and medications. In addition, the typical child with cystic fibrosis also needs vitamin supplements, postural drainage therapy at least once each day, and periodic hospitalization for more intensive treatments, according to parents with whom we spoke.
- Children with cleft lips or palates frequently need office visits and medications, and, less frequently, rehabilitative and other therapies. Beside this, parents need to learn how to feed their children using special nipples and squeeze bottles, because the clefts do not enable them to suck normally.

Some parents whose children's chronic conditions have been corrected or stabilized need fewer medical services. For example, the hole in one child's heart had been corrected through surgery, her parent wrote, and the child now was able to lead an "active" life, needing only physician office visits. Similarly, after corrective surgery for a cleft lip or palate, children's needs for medical services were reduced, some parents commented.

Needs for Support Services More Uniform and Less Affected by Condition

About three-fourths of our respondents (634) reported that they needed support services—some 25 percent fewer families than those needing medical services. Four support services were needed by at least one-half of the respondents: baby sitting, counseling, day care, and transportation (see table 2.3).

Table 2.3: Families' Needs for Specific Support Services

Service	Families needing service	
	Number	Percent
Baby sitting	412	65
Counseling	368	58
Day care	336	53
Transportation	320	51
Case management	266	42
Respite care	152	24
Homemaker	129	20

Note: Of 840 valid responses to GAO's question about the need for support services, 206 (25 percent) indicated that they did not need these services.

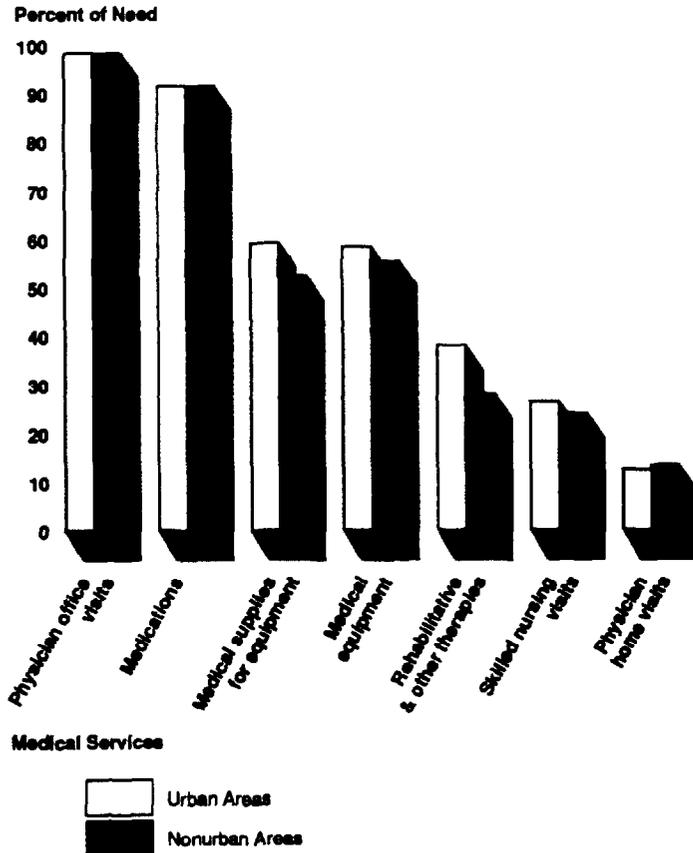
This overall pattern of need generally was consistent for the 10 medical conditions. On average, about three different support services were needed per child, ranging from about four for muscular dystrophy to about three for juvenile-onset diabetes, asthma, cleft lip/palate, and sickle cell anemia.

In addition to the foregoing services, a few parents of school-age children said tutoring services were needed when their child had to remain at home or in a hospital periodically for treatment of the condition.

Needs of Families in Urban and Nonurban Areas for Most Services Similar

The medical needs of families living in nonurban areas were generally similar to those in urban areas, although families in urban areas had a somewhat greater need for medical supplies and therapies (see fig. 2.1).

Figure 2.1: Need for Medical Services in Urban Versus Nonurban Areas



Similarly, nearly equal proportions of urban and nonurban families needed five of the seven support services (see fig. 2.2). There was a somewhat greater need for counseling among urban families and a much greater need for transportation among nonurban families.

For Many, Support Services Hard to Get

Overall, more than half (358 of 634) of the respondents who needed support services had difficulty obtaining them. The extent to which families needed and experienced difficulty obtaining each of the seven support services is shown in table 3.2.

Table 3.2: Extent of Difficulty in Obtaining Support Services

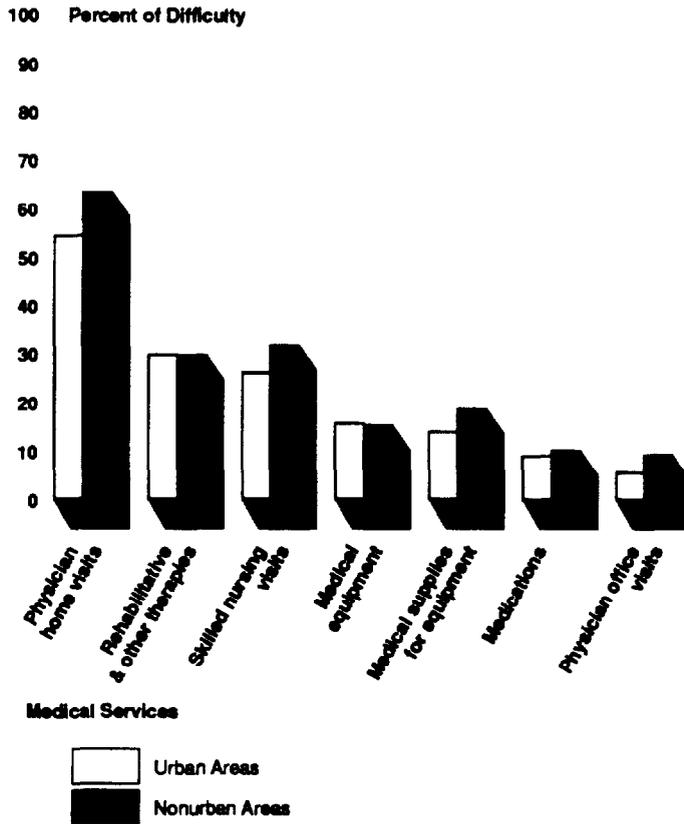
Support service	Number with need	Number having difficulty	Percent having difficulty
Baby sitting	412	238	58
Day care	336	190	57
Respite care	152	80	53
Homemaker services	129	64	50
Transportation	320	103	32
Counseling	368	117	32
Case management	266	82	31

About one-third of the 358 respondents had difficulty with one support service, another one-third with two services, and one-third with three or more services. Support service difficulties were similar for nearly all 10 medical conditions. Most respondents experienced difficulty with two services more than half of the time.

Nonurban Parents Experience Somewhat More Difficulty Obtaining Services

Respondents living in nonurban areas experienced more difficulty in obtaining most medical and support services than those in urban areas. But the differences were not always great. Obtaining five of seven medical services was somewhat more difficult for nonurban respondents than for urban respondents, as figure 3.1 shows.

Figure 3.1: Difficulty Obtaining Medical Services in Urban Versus Nonurban Areas

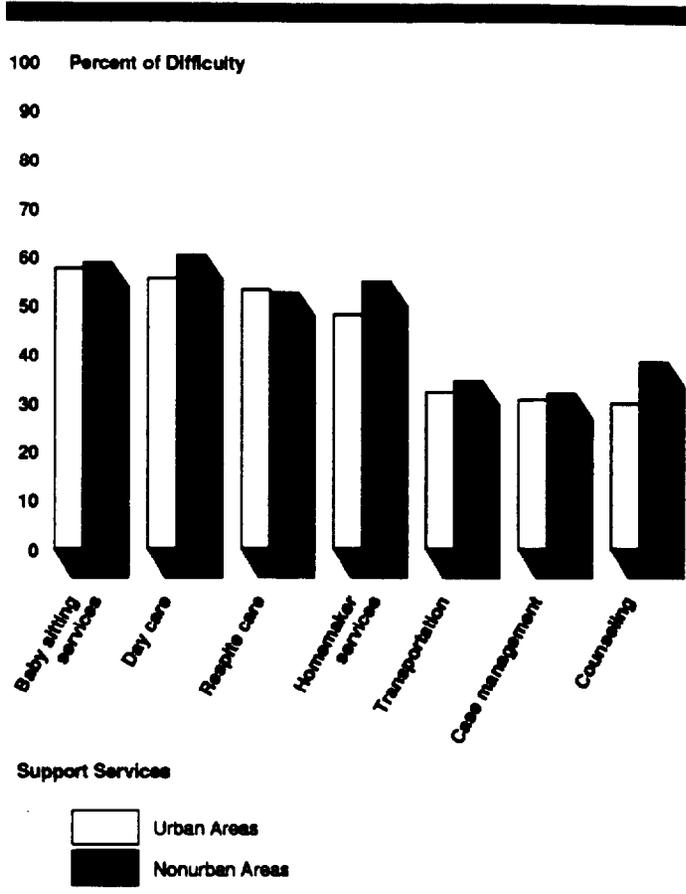


For support services, nonurban parents had somewhat more difficulty obtaining six of the seven services (see fig. 3.2). Only for respite care did they experience less difficulty than did urban parents.

Problems Obtaining Medical, Support Services Often Similar

Parents encountered similar difficulties obtaining both medical and support services, they said in discussions and in their survey comments. Most frequently cited was paying for services; because of insurance coverage limitations, copayments, and deductibles, parents had large out-of-pocket expenses. Another common difficulty was the process parents went through to obtain services; they expended considerable time and effort before they could locate providers and get the services needed. Finally, parents lacked a focal point to contact when they needed help with home care. In all but a few instances, the medical services were obtained, but in many cases the support services were not.

Figure 3.2: Difficulty Obtaining Support Services in Urban Versus Nonurban Areas



Paying for Services Difficult

Paying for medical and support services was a major difficulty, many parents said. Their comments, which were elaborated on by the local organizations we contacted, are presented below.

Parents Comment on Cost

Parents most often commented that, even though they had health insurance, they still incurred significant out-of-pocket expenses for medical services because of copayment and deductible requirements for covered services, and because certain services were not covered. The specific services they most often mentioned were medications, medical equipment, and therapies. For example, the parent of a child with spina bifida living in Florida said:

“The availability of services is not the problem. The expense is the problem. Even with insurance, we have to pay approx. \$2500.00/year, and that would be with no hospitalizations that year.”

Parents said they also had significant out-of-pocket expenses for support services not covered by insurance. They often singled out baby sitting and day care. Some parents said that transportation and associated expenses also were difficult because of (a) the distance they had to travel, (b) the frequency of travel, or (c) their own food and lodging costs when their child was hospitalized for medical treatment away from home. For example:

- “The very serious problem we had was babysitting and expenses during [son’s hospital] stay. [Son] was 5.5 years old and really needed mom or dad to be with him all the time ... We ... had the expenses of food, travel, housing ... we ran thousands of dollars.” (Parent of a child with a heart condition living in Massachusetts)
- Arizona parents said home-care expenses were out-of-pocket and that they were living “paycheck to paycheck.”
- “... the costs - financial and emotional - have been staggering. Our child care expenses have more than doubled.” (An Ohio parent of a child with leukemia)
- Ohio parents found day care providers that would serve their children, but they could not afford them. One said, “The in-home day care centers are outrageous. The cheapest one I found was \$7.95 an hour. They make more than me.”
- Baby sitting and day care for a child with leukemia were difficult to obtain. “We have had to hire a baby sitter to come to our home to care for our child ... Insurance does not pay anything on the child care.” (A Georgia parent)

Sometimes, there were broader financial ramifications for families as a result of their situations, parents’ comments suggested. Examples of these comments follow:

- “About the insurance. I’ve paid more than I was supposed to and CHAMPUS [Civilian Health and Medical Program of the Uniformed Services] still has not paid and now I have bad credit.” (Parent of a child in Ohio with asthma)
- Concerning copayments for an Ohio child with a cleft lip/palate and complications of brain damage, “ ... if the patient fails to pay, the[ir] accounts are turned over for collection. The patient gets squeezed by the pirates and can do nothing about it.”

- “I cannot go back to work because it is impossible to find a competent baby sitter.” (Divorced parent of an Ohio child with a cleft palate)
- “... copayments and uncovered or under-covered expenses have depleted our resources. We also fear ‘pre-existing condition’ clauses and that has had a detrimental effect on [husband’s] career (he is in a field where upward mobility is achieved by changing companies).” (Texas parent of a child with a heart condition and other complications)
- “The most difficult area for our family is having to rely on one income as opposed to two.” (Texas parent whose child had a kidney transplant)
- “In the case of a chronically ill child, only one parent can work and the financial burden becomes a daily problem for the family ... ” (Parent of a child with leukemia in Mississippi)
- “Income has been hard because we also have three other children and it is very hard, in fact, impossible for mother to work because we cannot leave our son.” (California parent whose child has diabetes)
- “I do not work, to be home with my son ... because how would I keep him healthy in [a day care center] ... he catches everything and keeps it longer than the average child. So we did not put him in [the center] and survive on less.” (Arizona parent whose child has a congenital heart condition)
- An Ohio mother gave up her career to care for her sick child. “I stay home because I can’t pay day care.”

In other instances, parents said they were fortunate that they did not need to work and were able to be home to care for their chronically ill children.

Service Providers Offer Insights

Various organizations we contacted in nine local communities provided some insight as to why parents reported financial difficulties in obtaining services. In some instances, the organizations commented on private insurance industry practices; in others, on public program provisions. They cited three problem areas:

1. Some services are not covered by public or private insurance. For example, the costs of braces, special diapers, and special shoes for children with spina bifida are not covered by a local health maintenance organization and a state health program, a Los Angeles local provider told us. Some private insurance companies in Florida generally view medical day care as unskilled custodial care, which they do not cover, officials told us, while two state programs cover this service. Most private insurance plans cover hospital and physician costs but seldom

cover treatment in the home and family support services, such as counseling or respite care, according to an October 1987 report by a Minnesota advocacy group.

2. Both public and private insurance reimbursement rates are low. Because California's Medicaid insurance payments are usually below market rates for services such as nursing specialists, a provider in Los Angeles told us, quality, affordable care for chronically ill children is difficult to find. Private insurance companies in the Washington, D.C. area have placed limits on the amounts they will pay for orthodontia treatment that children with cleft palates need, according to a local cleft lip/palate support group. Also in Washington, an official of a local sickle cell anemia clinic told us that private insurance pays for 52 percent of clinical treatment costs and Medicaid, 25 percent.

3. Program eligibility requirements presented barriers to care. For example, hospital representatives in California and Arizona said that middle-income families can face difficulties if they do not qualify for public programs. Medicaid eligibility requirements exclude some middle-income families who need financial assistance with their medical costs, according to hospital officials in Minnesota and Ohio.

Information and Services Often Lacking

Finding providers of needed medical and support services was also a problem. A common theme was parents' frustration in locating providers because they lacked adequate information about service availability. In most cases, however, they were able to obtain the medical services but not as often the support services.

With regard to medical services, hospital discharge processes, for the most part, adequately addressed the medical care needs of their children and the parental roles in this, including follow-up care at the hospital. But the hospital discharge process did not always include information on service providers other than the hospital. In some cases, parents felt that the hospital staff seemed to assume that the parents knew where to obtain services. Parents did not know, they told us, and consequently had to do a lot of searching before they found providers. Parents used such sources as telephone books, other parents, and support groups. An example of these kinds of experiences came from a parent in Minneapolis:

"I had to get some supplies ... I tried to call around. You get the yellow pages out and call all the medical suppliers and find out who has what ...

You go one place for one thing and one for another thing. And you have to go out and get it. It's way out in the suburbs."

Although some parents experienced these difficulties, in all but a few instances they were able to get the medical services. When they were unable to, it was mostly because either there were no providers or the service was too expensive. For example, the parent of a child with a heart condition in California wrote:

"The only home care problem was in the rehabilitation area. We attempted to get services for this but could not find anyone with services available other than the children's hospital. By the time someone became available, our child did not need the service."

Parents also encountered a variety of difficulties when seeking support services. Among the most frequent were (1) spending considerable time and effort locating providers and obtaining the services and (2) lack of providers. Home care instructions from the hospital generally did not include information about support service availability and providers, parents told us. The following examples typify parents' difficulties:

- "... trying to get information concerning grants, funds, special schools or programs is difficult at best. It's like a secret society - no one wants to share information that should be public knowledge." (Parent of a child with muscular dystrophy in Maine)
- "It takes a lot of research to find adequate services for and information about our child's disability. Some parents don't know how to find help and the child suffers." (Parent of a child with asthma and the complications of Down syndrome in Georgia)
- A parent in Minneapolis told us that "Any kind of help that we needed as far as durable health supplies, mental health counseling, day care, respite care, respiratory therapy — all of that you had to get for yourself ... the hard way"

In some cases, parents were unable to get support services mainly because providers were lacking or existing providers refused to serve their children. Most often mentioned in this context were baby sitting and day care, followed by respite care and counseling. The following comments are typical:

- "The only problem that I wish could be resolved is that people wouldn't be so afraid of a child's condition. As soon as I mention he has a heart

condition people back off and won't even hold him. It is as if they are afraid he will have a heart attack." (Ohio parent)

- "To this day we don't have a baby sitter ... People are afraid ... They don't want to take care of him, so we don't go out." (Ohio parent)
- Concerning a child with a heart condition, "Everyone was afraid to care for her in case an emergency happened ... " (California parent)
- Regarding where to find day care or respite care, "I'm not aware of anything being out there and if it is, I'm sure it's not in my budget." "The only care givers I have for [child] are my family ... No one else would touch him ... " "We have nobody to take care of our kids on the weekend who's willing to give shots." (Minnesota parents)
- Concerning a child with a heart condition, "The main problem we experienced was finding in-home baby sitters with some nursing experience. They were nearly impossible to find and the cost (approx. \$10 per hour) was prohibitive." (Minnesota parent)
- "The doctors and social workers did not mention any supportive services to us. We would like any information on these services sent to us please" (Parent of a child with cystic fibrosis in California)

Focal Point for Help Needed

Parents needed help in coping with their home care situation, they said. In some cases, the home-care situation would have been eased considerably had someone visited them after their child's discharge from the hospital to see how they were adjusting and to give them advice on providing care. In other cases, just having had someone to talk to who shared the same or similar experiences would have helped them greatly, they said, in being able to initially deal with and adjust to the home-care situation. Typical comments along these lines were:

- "The aspect of [child's] care that I feel is most lacking involves our lack of association with a regional or national foundation for asthma. I would like to have access to timely information on this disease, but I have found no one to give me any encouragement or direction in this area." (An Ohio parent)
- "At the time my child had his surgery - and the time leading up to his surgery - I would have appreciated a support group or some sort of counseling . Doctors are usually cooperative; but when it is not their children, you wonder how much to believe them. To talk to some who had been through the same thing - with their own children would have been greatly appreciated." (An Ohio parent)
- Concerning a child with a cleft lip/palate, "Medical services were very good as far as the surgeon was concerned ... Support groups and contact persons were not available and it would have been such a relief to talk

to a person who had gone through as we after the birth of our daughter." (Minnesota parent)

- "I wish we had someone who knew the ropes ... how to get what I need and avoid all the tiny frustrations." (Minnesota parent)
- Regarding another child with a cleft lip/palate, "I had to gavage [tube] feed my baby her first 3 months. They should have a nurse come to the house and see that the parent or main person taking care of the child is doing the procedure right. This way of feeding is very dangerous if not done right." (A Texas parent)

Positive Experiences Point to Possible Solutions

Although many parents of chronically ill children had difficulty obtaining services, especially support services, some did not. Two factors accounted for positive experiences: (1) availability of information that enabled parents to locate needed services and/or (2) the direct assistance of an individual in identifying providers and obtaining needed services.

Linking Parents to Information

Some parents obtain information on service availability from various medical care and support service providers and organizations. The key factors here are to have information available and to link parents to it.

Various Information Sources Exist

Many public and private service providers and organizations in the nine communities maintained directories of providers and services. The completeness of the directories varied but some were considered by the local organizations we contacted to be quite complete, for example:

- Cincinnati had three major sources of information on service providers: a United Appeal and Community Chest directory of community services contained an estimated 2,000 providers; a directory of services for persons with disabilities listed 360 providers; and an early intervention service matrix contained 246 providers.
- The Atlanta area's United Way directory listed 638 service providers.
- In Pinellas County, Florida, the United Way directory of human services listed 168 service providers.
- Dallas' Community Council's directory of services was identified by 8 of the 10 organizations we contacted as being a complete inventory of medical and support services; all used the directory.

Yet parents we interviewed from the last three areas either did not mention the directories or told us that they were unaware of them. Likewise, although a San Antonio hospital social worker told us he knew of two day care centers in the city that accept children with disabilities, two San Antonio parents said they were unable to find centers that would accept their children.

Other organizations also had information on services and service providers. Some of these organizations considered their information complete, while others did not. For example, two local health departments told us they had complete information on services and providers, while three said their information was incomplete.

Parents' access problems would be eased if information regarding service availability and providers were centralized, as a California state official remarked. At the University of South Carolina, a framework for a national, centralized system has been developed. The National Information System, supported in part with federal funds, contains information on medical conditions, services, and service providers in each state. Like most of the local service provider directories we encountered, however, this national database is not complete because it contains only those who have volunteered to be included in the system.

Nevertheless, the system has been developed, tested, and is operational and would be more useful if additional organizations participated. Access to it is through a tollfree number (800-922-9234). According to officials operating the system, several states have developed state-wide systems modeled on the national system. In the local communities we surveyed, the most centralized information sources were the United Way directories.

Information at Time of Discharge

Often, when a chronically ill child is discharged from the hospital, insufficient information is provided on the availability of support services, many parents told us. The discharge planning process and plans tended to focus information on the medical care needed by the child, our work in several hospitals showed, and usually did not address the support services the family needed. Physicians often do not take the whole family into account when making discharge decisions, a hospital social worker commented. While social workers are part of the discharge planning team, their roles are advisory, the worker said. According to one hospital's assistant director of social work, the hospital maintained no central listing for support service referrals. An official from a parent support group who had continually given information on the group to hospital personnel said they always seemed to lose it.

Ways to provide information on services were suggested by health officials. For example, each tertiary center, such as a children's hospital, could employ coordinating persons to help parents gain access to available services, an Ohio official said. Also, parents might be given a list of all community resources by illness, including telephone numbers, when a child is discharged, according to a Texas hospital official. On the other hand, a hospital official in California did not think that the hospital should assume ultimate responsibility for identifying all services available and directing parents to appropriate providers. As the geographic

area covered by the hospital was large, the official thought it impractical to manage this outside the immediate area.

Some children, at time of discharge, had been identified as being eligible for services under public programs and had been referred to the organizations operating these programs. However, children not identified as eligible for these programs were not always given information on where to obtain help. For these children, we believe a referral to the local health department or other appropriate sources would be a good way to facilitate access to needed services.

Providing a Focal Point for Information and Help

Some parents had little or no difficulties in obtaining services because they received help. These parents were assisted by various organizations in the community that helped them avoid or minimize service problems.

Various Sources of Help Cited

The most frequent source of help in obtaining services that parents mentioned was the children's hospital; others were health maintenance organizations, support groups, and state and local programs. The organization or an individual either provided the services or helped the parents find out about services and get them. Typical comments were the following:

- "If not for an exceptional Social Worker at [hospital] all the services listed on this survey would have been unknown to me including SSI [Supplemental Security Income] disability which had been invaluable to me." (Parent of a Massachusetts child with leukemia)
- "... since the day my son was born he has gotten the best of care. The staff at [hospital] have provided the utmost care and health services possible. They also provided H.M.O. [Health Maintenance Organization] medical services, when we were no longer eligible for Medicaid, and our insurance would not cover the entire cost of his medical expenses. They also provided transportation to and from the hospital, whenever we needed it." (Ohio parent of a child with a heart condition)
- "Our experiences at [the hospital] have been very good. They supply medication, support groups, and everything we have needed." (California parent whose child has leukemia)
- "[The Children's Medical Services program] has a good triage nurse, who is our go-between when we need help; she does an excellent job of finding what we need." (Florida parent of child with asthma)

- “After we were referred by [the hospital] to Children’s Medical Services because of a financial problem, we have received good case management services.” (Another Florida parent of an asthmatic child)
- “... [Child with a cleft palate with complications] is enrolled in a county [early intervention] program which covers physical therapy, occupational therapy, hearing & speech & a general, overall teacher to put all programs together to view him as a whole. It is hard to keep up with the visits, but is easy to obtain the care needed.” (Maryland parent)

Common to these examples was the involvement of an organization or individual who undertook the responsibility to help the family obtain services.

Case Management Provides Framework

A focal point concept, commonly referred to as case management, has been used over the years in health programs. Under this concept, an individual—the case manager—provides, among other things, information and coordinates services. The concept has been implemented by many organizations, but in various forms and sometimes limited in scope. For instance, case management may deal with only the child’s medical needs or it may address the total needs of the child and the family, as discussed above.

Our review identified various case management practices and providers. For example, case management as performed by hospitals and the state’s crippled children’s services agency in Los Angeles was usually a short-term, episodic approach during a crisis, service providers there said. An Ohio state agency provided case management that focused solely on the medical needs of the child. Local health departments also offered case management services. For example, the Hennepin County health department case-manages certain children, beginning while they are in the hospital and continuing until they no longer need services. Their case management activities include coordinating needed services and equipment, acquiring nursing services, managing finances, solving problems, and visiting children every 2 to 3 months.

Some parents, however, seemed inundated with case management. A Florida state official told us the problem was too many case managers. For example, each developmental services client had an assigned case manager. If the child also received medical services through the state’s Children’s Medical Services, the child was assigned a case manager from that agency. The child also may have had a case manager in the school system. A parent in our Minneapolis group interview told us:

- "...We have a social worker through the county, a social worker from [name omitted] who does the waived services coordination, and I understand we'll get another one because of the school district changes. I don't think we need three social workers. I think I need a social worker to coordinate all of them."

Views as to what case management is, who should provide it, and under what circumstances varied among parents, service providers, and organization officials. For instance:

- A case manager was defined as a person who coordinates services and tells parents what services they need. (A Florida service provider)
- The long-term needs of the patient should be considered by someone who is independent of the hospital. This individual should be trained to advise families on long-term financial and medical planning throughout the child's illness. (An Ohio state health official)
- When parents lack the capabilities or means to coordinate their child's care, a case manager should be made available to fulfill that function. (A Cincinnati health care provider)
- A case manager is frequently required when the child's multiple needs necessitate involvement of various agencies and support services. (A Texas service provider)

Not everyone discharged from the hospital needs an individual to provide case management. As discussed previously, some parents need only information, and can act as their own case managers. Others need help with the transition from hospital to home environment. Providing case management services can help parents with their information and home care needs.

Under one definition of case management, each family is provided with a single service coordinator—the case manager. The family's needs for medical and support service information, planning, coordination, and patient advocacy are recognized. This concept is defined in the April 1988 report on technology-dependent children by a Department of Health and Human Services task force. We believe, however, that it also applies to the broader population of seriously chronically ill children.

In discussing varying case management practices, the HHS task force report also pointed out that there was no single widely accepted definition. Thus, the task force proposed a common interpretation of case management to ensure that all necessary services would be provided when needed. It also recommended that the programmatic responsibility

for organizing and monitoring case management be assigned to the states' maternal and child health agencies. At the federal level, the task force recommended that HHS Bureau of Maternal and Child Health and Resources Development be responsible for policy and program development, coordination, and oversight of the state processes.

We agree with the HHS task force that case management should be uniformly defined and that placing case management responsibilities under the Maternal and Child Health program is appropriate because the main objective of that program is to help ensure that basic health care is available to mothers and children. We also agree that federal officials need to work with state officials to implement case management programs at the local level, so that information on services and providers is available to parents needing it.

Conclusions

It is probably impossible to guarantee that all parents who need information on services and providers will obtain it. However, the positive experiences of some parents we contacted suggest that three steps could improve the process of linking parents to the information they need:

1. Consolidate information on services and providers in the community and ensure that it is available to all organizations serving chronically ill children.
2. Make this information available to parents during the hospital discharge planning process.
3. Refer parents who need help with the home care situation to a public or private organization providing case management services.

Some of this is being done to varying degrees by numerous public and private organizations at the state and local levels. Yet parents experienced problems in obtaining services. This occurs because there is no clear responsibility for consolidating and publicizing sources of information on services for chronically ill children or ensuring case management is available when needed. Any one of various organizations at the local level, such as hospitals, local health departments, or children's medical services agencies, could assume the responsibility. The appropriate organization will depend upon the health care structure in the state.

Recommendation

To facilitate the consolidation and publication of information on services for chronically ill children and ensure that case management services are available when needed, we recommend that the Secretary of Health and Human Services direct the Office of the Assistant Secretary for Health to take a leadership role in developing necessary policy and program guidance for state maternal and child health agencies. Such policy should be aimed at ensuring that (1) information on providers and services in a given community is consolidated and made available to organizations serving chronically ill children, (2) this information is provided to parents at time of discharge, and (3) case management services are made available to those who need direct assistance.

Agency Comments

A draft of this report was provided to HHS and its comments, summarized below, appear in appendix VI. HHS concurred with our recommendation and said it will develop a plan of action to implement it. HHS noted that some of the past activities of the Bureau of Maternal and Child Health and Resources Development in the Health Resources and Services Administration will aid in developing the necessary policy and program guidance. HHS cited the Bureau's involvement in the June 1987 Surgeon General's Report on children with special health care needs, its guidance to states regarding service networks and case management services, and its funding of a national information network.

HHS believed that we should have addressed programs administered by its Office of Human Development Services programs. These programs, HHS said, affect chronically ill children by providing Head Start, child welfare, respite care, and family support services. Our review at the local level was not intended to inventory all programs serving chronically ill children. Instead, information on a sample of local programs was gathered in each of the nine communities visited. Some social service agencies were included, such as Developmental Services in Florida, Department of Social Services in Prince George's County, Maryland, and Family Self Support Services in San Antonio. Besides social services agencies, our local contacts also included health agencies, human service agencies, educational agencies, parent support groups, and others. However, we did not inquire into the funding sources of any of the local organizations we contacted and thus could not determine which federal programs, if any, were providing financial support.

Descriptions of the 10 Chronic Conditions Used for the Review

The 10 chronic medical conditions on which we based our review are described below. The descriptive information on these conditions was drawn from the Vanderbilt study on chronically ill children and their families (cited on p. 9) and various other sources.

Juvenile-Onset Diabetes

In a healthy body, the pancreas secretes insulin, which breaks down sugar in the blood. These secretions occur when the person eats or is hungry, but if the person doesn't eat, the secretions stop. In the case of juvenile-onset diabetes, the pancreas either stops secreting insulin or produces an insufficient amount, resulting in a high blood sugar content. If not controlled, high blood sugar has debilitating effects on the body over time. Diabetes may affect one or more of several major organ systems (kidney, heart, eyes) and reduce life expectancy. To control the blood sugar content, insulin must be provided artificially to the body, such as by injection. However, the body may not use all of the insulin, leaving some in the blood. If too much remains, the body is in danger of an insulin reaction. To avoid a reaction, the blood sugar level must be increased through eating. Between meals, this can be done by drinking a sweet beverage or eating a candy bar. Consequently, a child with this condition needs to monitor his/her blood sugar content periodically and be able to take appropriate measures to keep the blood sugar content at acceptable levels.

Asthma

Asthma, one of the major causes of health impairment in children, is the most common long-term physical disorder of childhood. It is a chronic lung disease in which the muscles controlling the bronchial air passages are subject to spasms that restrict the air flow into the lungs and make breathing difficult. In addition, about 60 percent of children with severe chronic asthma also suffer from sinus blockage. The reasons for the spasms vary with each person, and in some cases may not be known. The more common causes are allergants (certain foods, fabrics, dust, pollen) and stress. Asthma attacks, which can be reduced in their intensity and/or prevented through a combination of monitoring and medications, take time to develop. An impending attack can be detected with a device called a peak flow meter, which measures the air capacity of the bronchial passages. If periodic monitoring during the day with the meter indicates that the bronchial air capacity is being reduced, the child can take medications that help to relax the bronchial muscles and prevent an attack or reduce its severity. Medications also are taken for sinus blockages.

Spina Bifida

Spina bifida is a birth defect in which the vertebrae in the spine fail to close properly as the fetus is developing and part of the spinal cord is exposed at birth and nerve damage occurs. Although the spinal cord is closed by surgery, the damage to the nerves cannot be corrected, resulting in varying degrees of paralysis in the lower half of the body and bowel and bladder complications. A child with this condition may need several medications, undergo multiple surgical procedures, and need physical and occupational therapy. Also, the child may be wheelchair-bound or dependent on braces or crutches.

Cleft Palate and Other Craniofacial Anomalies

Present from birth, cleft palate and other craniofacial anomalies are defects in the normal formation of the face and related structures. The range of conditions varies from minimal abnormalities in the formation of the roof of the mouth or soft palate (not visible at birth), to larger openings (clefts) involving the palate, jaw, and lip that are visible disfigurements. These conditions make eating for a baby difficult, as the cleft does not allow normal sucking. Thus, the baby must be held in a special position and specialized feeding nipples and squeeze bottles used. These conditions are correctable, depending on the severity, by one or more surgical procedures during childhood.

Congenital Heart Diseases

Congenital heart diseases are structural abnormalities in the development of the heart, such as holes and transposition of the major blood vessels, which reduce the oxygen content in the blood and the ability of the body to get oxygen. In the typical case, the condition can be surgically corrected when the child has grown to the point that the body is strong enough for the surgery. Until that occurs, there may be a need for frequent visits to physicians to monitor the condition and specialized care to deal with the body's weakness from lack of oxygen. The care includes medications to ward off diseases and special equipment to help in breathing and feeding.

Leukemia

Leukemia is the most common cancer of childhood and typically develops in the first 4 years of life. In leukemia, cells that would usually differentiate into normal white blood cells multiply instead in great amounts. They often prevent the body from making other normal blood components and may lead to the growth of abnormal cells in other parts of the body. The condition is treated with chemotherapy and medications. Currently, about 65 percent of children with leukemia are in the remission stage; i.e., they have lived 5 years past their last treatment.

End-Stage Renal Disease

In end-stage renal disease, the kidneys have ceased their function of removing impurities from the blood. To compensate for the loss of kidney function, several types of dialysis are used. These are methods of filtering that remove waste products from the body. For children, however, the preferred treatment is a kidney transplant, so that dialysis is used until a transplant can be done.

Sickle Cell Anemia

In sickle cell anemia, the red blood cells, which carry oxygen to the body, are abnormal in shape. They have a jagged irregular sickle shape instead of a disk or round shape. As a result, they contain less oxygen and pass less easily through veins and the smaller blood vessels. Also, their shape makes them prone to clumping, resulting in swelling and blockages of blood vessels and to damage to those organs and bodily areas from lack of oxygen. A child with the condition is particularly susceptible to infection. Infections and other effects of the condition usually are treated at specialty clinics.

Cystic Fibrosis

Cystic fibrosis is a genetic disorder that affects the digestive and respiratory systems. A body with this condition produces a thick sticky mucous that impedes proper digestion and lung function and makes the body susceptible to frequent lung infections. Blocking the ducts of the pancreas, the mucous prevents digestive enzymes from reaching the small intestine. The mucous also coats the insides of the lungs, blocking breathing passages and acting as a "glue" that enables bacteria to grow.

The digestive problems usually are controlled with medications and vitamins. To unclog the lungs, physical therapy called "postural drainage" is given two or more times each day for about 1 hour. This therapy involves vigorously clapping the ill person on the back and chest to dislodge the mucous so that it can be expelled from the lungs. At times, this is combined with the use of an inhalant spray. Lung infections are treated with antibiotics. The foregoing treatments can be provided daily in the home setting. But a person with the condition usually needs to enter a hospital two or more times annually for about a 2-week period to receive more intensive forms of these therapies.

Muscular Dystrophy

Muscular dystrophy is a generic term that encompasses four basic types of genetic diseases of the muscles, which are represented by 40 specific diagnoses. In all of the diseases, the muscles slowly weaken and degenerate, resulting in early death. Some of the conditions are present at

Appendix I
Descriptions of the 10 Chronic Conditions
Used for the Review

birth, while others develop during early childhood. There is no known "cure" for any of the conditions (i.e., no way to reverse the weakening of the muscles), so the basic therapy is to make the individual as comfortable as possible through various physical therapies and surgeries.

Hospitals Visited for GAO Study and Mail-Out Areas

Hospital	Mail-out area	Type of area	Type of meeting
Children's Hospital National Medical Center, Washington, D.C.	Prince George's County, MD	Urban	Group
Boston Children's Hospital, Boston, MA	New England states	Urban and nonurban	Individual (Maine)
Cincinnati Children's Hospital Medical Center, Cincinnati, OH	Hamilton County, OH	Urban	Group
Columbus Children's Hospital, Columbus, OH	12 rural counties in Ohio	Nonurban	Individual
Children's Medical Center, Dallas, TX	Dallas County, TX	Urban	Group and individual
Santa Rosa Children's Hospital, San Antonio, TX	Bexar County, TX	Urban	Individual
University Hospital, Jackson, MS	21 counties surrounding the city of Jackson, MS	Nonurban	Group and individual
Scottish Rite Children's Hospital, Atlanta, GA	DeKalb County, GA	Urban	Group
Henrietta Egleston Hospital for Children, Atlanta, GA	28 counties in southern Georgia	Nonurban	None
All Children's Hospital, St. Petersburg, FL	Pinellas County, FL	Urban	Group
Children's Hospital of Los Angeles, CA	Los Angeles County, CA	Urban	Group
Valley Children's Hospital, Fresno, CA	Fresno County, CA, area	Nonurban	Individual
Phoenix Children's Hospital, Phoenix, AZ	Maricopa County, AZ	Urban	Group
Minneapolis Children's Medical Center, Minneapolis, MN	Hennepin County, MN	Urban	Group

Methodology

Our methodology for this study included a mail survey of parents of chronically ill children and interviews with selected parents and selected local service providers.

Parent Mail Survey

Children with the 10 conditions selected for our survey (see ch. 1) are most likely to be treated at children's hospitals, medical experts told us. Accordingly, we selected 14 hospitals that provided care to chronically ill children in urban and nonurban areas to serve as the base from which to survey parents' home-care experiences. Thirteen were children's hospitals and one was a university hospital in a state that lacked a children's hospital. We considered urban areas to be metropolitan counties and nonurban areas to be nonmetropolitan counties.

We asked the 14 hospitals to identify for us children, ages 13 and under, who were discharged to home care during the 12-month period ending June 30, 1987, and who had any of the 55 primary diagnoses that represent the severer forms of the 10 conditions. Age 13 was our cut-off because medical experts told us the diagnoses of the 10 conditions occur either at birth or during childhood, usually by age 13. In total, 8,557 children meeting our criteria were discharged from the 14 hospitals during the review period.

The information provided by the hospitals included the child's age, the diagnosis, the length of and the amount charged for the hospital stay, and the postal zip code of his/her residence. Children were not identified by name but by a number randomly assigned by the hospital. We sorted the discharge data by zip code to identify children who had been discharged to the states in which we were doing our review. Within each state, we selected urban and/or nonurban areas for our survey mail-out. For urban area mailings, we selected metropolitan counties having the greatest number of discharges. Between 73 and 200 survey forms were mailed to these. For nonurban area mailings, we selected counties outside metropolitan areas that had the greatest number of discharges; between 70 and 200 survey forms were mailed to these.

The mail-outs went to a cross section of the youngest children with the 10 conditions. We chose the youngest children because we wanted to contact parents who had experienced the transition from the hospital to the home-based care setting for the first time during the review period. Using the randomly assigned numbers, we provided our selections and our parent survey forms to each hospital for mailing. The hospitals made the initial and one follow-up mailing.

The parent survey form was designed to (1) obtain information on income, health insurance coverage, and the need for and the difficulty in obtaining one or more of 14 medical and supportive services in the home-based setting and (2) determine parent willingness to participate in a group meeting. From our review of past studies and other information related to home-based care, we had identified the 14 services as being generally needed by families with chronically ill children at home. The parent survey form appears as appendix IV and the responses to each question are in appendix V.

Parent survey forms were mailed to 2,191 parents (25.6 percent) in the selected areas. We received 892 usable returns, as shown in table III.1.

Table III.1: Results of Parent Survey Mail-Out

Total surveys mailed		2,191
Less:		
Post office returns	201	
Nonresponsive returns	16	
Not returned	1,082	1,299
Net usable returns		892

The 892 usable returns represent about 45 percent of the 1,990 surveys mailed to valid addresses: 621 (70 percent) were from urban areas and 250 (28 percent) from nonurban areas. About 26 percent of the usable returns also included narrative comments. According to our public survey consultant, the normal return rate for a survey of this type would have been about 15 to 20 percent, so that our return rate of 45 percent is high, particularly considering the sensitivity of the issues and subject matter. We were not able to determine the profile of those who did not respond because of the confidentiality arrangement we had with the hospitals.

Parent Interviews

Of the 474 respondents who indicated their willingness to meet with us, we met with 96, either in group settings or individually. In these meetings, we inquired into why parents either had or did not have difficulty obtaining services in the home care setting.

Nine group meetings were held, each with 5-12 parents and lasting about 2 hours. Eight of the nine groups had parents from urban areas, and the other group had parents from a nonurban area. The parents we talked to individually were from both urban and nonurban areas. We

selected parents to invite to the group meetings judgmentally, using the same criteria as for the mailings. The profile of parents we met with was similar to the profile of those who returned the survey form in terms of income, insurance coverage, the child's condition, and education.

Local Organization Interviews

When ill children are discharged to home care, their parents in trying to get services turn to the health care and support service providers in the local area. To ascertain the role of local service providers, we contacted 60 health care and support service organizations and providers in the nine localities where we conducted group interviews. In particular, we asked whether they served our population of ill children and their families, and the information and services they provided. We also inquired into whether and how the service providers coordinated and interacted with one another.

We selected these organizations judgmentally to obtain a mix of public and private service providers. Accordingly, the organizations included public and private home health agencies, children's medical services clinics, medical day care centers, parent support groups, and various disease associations and foundations.

GAO Parent Survey Form

United States General Accounting Office

GAO

Study of Chronically Ill Children

Instructions

The local children's hospital prepared a list of patients discharged from their facility during the period July 1, 1986, through June 30, 1987, and your child was included on that list. The child was not identified by name or any other information which would identify the child. The questions below pertain to that child. Please check or circle each response as indicated.

1. Please indicate which one of the following illnesses your child has.
(Check one)

- 1. Juvenile-onset diabetes
- 2. Asthma
- 3. Spina bifida
- 4. Cleft palate or other craniofacial anomaly
- 5. Congenital heart disease
- 6. Leukemia
- 7. End-stage renal disease
- 8. Sickle cell anemia
- 9. Cystic fibrosis
- 10. Muscular dystrophy
- 11. Other _____
- 12. Don't know

2. Your sick child's date of birth: _____

3. Date on which your child was first discharged from a hospital to home-based care for treatment of the illness:

Month/Year

4. Primary health insurance coverage for the child.
(Check one)

- 1. Medicaid
- 2. Medicare
- 3. Medical insurance received through your employer
- 4. Medical insurance purchased as an individual
- 5. Other (Explain) _____
- 6. The child is not covered by any medical insurance

Appendix IV
GAO Parent Survey Form

5. Since your child was first discharged from the hospital with his or her illness, to what extent has it been difficult or easy for you to obtain the different medical and nonmedical supportive services, listed below, for your child and family?

(Check one box for each service.)

Services	Service not needed	Very difficult to obtain	Difficult to obtain	Neither difficult nor easy	Easy to obtain	Very easy to obtain
	1	2	3	4	5	6
Medical Services						
1 Physician home visits						
2 Physician office visits						
3 Medical equipment						
4 Medical supplies for equipment						
5 Medications						
6 Skilled nursing visits						
7 Other _____						
Nonmedical supportive services						
1 Respite care						
2 Homemaker services						
3 Transportation						
4 Day care						
5 Baby sitting services						
6 Rehabilitative & other therapies						
7 Counseling						
8 Case management						
9 Other _____						

Parents' Responses to GAO Parent Survey Form

Between January and May 1988, we mailed 2,191 copies of the parent survey form (see app. IV) to parents of chronically ill children. (The recipients were selected as described in ch. 1.) Of the total, 201 were returned as having invalid addresses; of the 1,990 remaining, we received 892 usable returns or about 45 percent of the valid addresses. The responses analyzed below are from the 892 parents. Because some parents did not answer all questions, the percentages may not be the same as those presented in the tables in chapters 2 and 3. Percentages, where used, may not add to 100 due to rounding.

Table V.1: Medical Conditions of Children in Survey (Question 1)

Coverage	Percent of responses
Juvenile-onset diabetes	9%
Asthma	24%
Spina bifida	2%
Cleft palate/craniofacial anomaly	11%
Congenital heart disease	27%
Leukemia	5%
End-stage renal disease	2%
Sickle cell anemia	7%
Cystic fibrosis	5%
Muscular dystrophy	0%
Other	2%
Don't know	0%

Note: No. of responses, 890.

Table V.2: Primary Health Insurance Coverage of Children in Survey (Question 4)

Coverage	Percent of responses
Medicaid	18%
Medicare	3%
Medical insurance through employer	59%
Medical insurance purchased as an individual	6%
Other	8%
Child not covered by insurance	3%

Note: No. of responses, 883.

Appendix V
 Parents' Responses to GAO Parent
 Survey Form

Table V.3: Need for Medical and Support Services by Parents Surveyed
 (Question 5)

Services	Service not needed (Percent)	Service needed (Percent)	Number of responses
Medical services			
Physician home visits	87.7	12.3	830
Physician office visits	3.4	96.6	852
Medical equipment	43.9	56.1	838
Medical supplies for equipment	44.2	55.8	832
Medications	9.9	90.1	842
Skilled nursing visits	75.0	25.0	831
Rehabilitative & other therapies	66.0	34.0	804
Support services			
Respite care	79.7	20.3	747
Homemaker services	83.7	16.3	792
Transportation	60.4	39.6	908
Day care	58.5	41.5	810
Baby sitting	49.6	50.4	817
Counseling	53.9	46.1	799
Case management	65.3	34.7	767

Table V.4: Ease of Obtaining Services Reported by Parents Surveyed (Question 5)

Service	Degree of difficulty/ease (percent)					Number of responses
	Very difficult to obtain	Difficult to obtain	Neither difficult nor easy	Easy to obtain	Very easy to obtain	
Medical services						
Physician home visits	41.2	16.7	15.7	16.7	9.8	102
Physician office visits	2.4	4.0	12.4	41.7	39.5	823
Medical equipment	6.0	10.0	17.9	44.7	21.5	470
Medical supplies for equipment	5.6	9.7	16.4	44.8	23.5	464
Medications	2.6	6.6	12.5	45.5	32.8	759
Skilled nursing visits	15.9	11.5	26.9	27.9	17.8	208
Rehabilitative & other therapies	13.6	16.1	23.4	31.5	15.4	273
Support services						
Respite care	34.2	18.4	24.3	15.8	7.2	152
Homemaker services	31.0	18.6	29.5	15.5	5.4	129
Transportation	15.0	17.2	21.9	29.4	16.6	320
Day care	32.7	23.8	18.8	16.7	8.0	336
Baby sitting	34.5	23.3	16.5	17.7	8.0	412
Counseling	13.6	18.2	22.6	31.5	14.1	368
Case management	14.7	16.2	27.4	29.7	12.0	266

**Appendix V
Parents' Responses to GAO Parent
Survey Form**

Table V.5: Average Monthly Expenses for Services Reported by Parents Surveyed (Question 6)

Range of monthly expenses	Percent of responses
Under \$250	27.7
\$250 to \$999	23.6
\$1,000 to \$5,000	15.9
Over \$5,000	13.8
Don't know	18.9

Note: No. of responses, 867.

Table V.6: Insurance Coverage for Services for Children Surveyed (Question 7)

Range of coverage	Percent of responses
Child not covered by insurance	9.9
Up to 25%	2.4
About 26-50%	3.7
About 51-75%	14.7
About 76-100%	59.4
Don't know	10.0

Note: No. of responses, 871.

Table V.7: Education Level of Parents Surveyed (Question 13)

Highest education level	Percent of responses
Grades 1 through 8	4.0
Some high school	7.6
Graduated from high school or G.E.D.	42.7
Associate Degree	12.8
Bachelor's Degree	20.6
Master's or Doctorate Degree	12.4

Note: No. of responses, 885.

Table V.8: Annual Family Income of Parents Surveyed (Question 14)

Income level	Percent of responses
Under \$5,000	12.4
\$5,000 to \$9,999	10.3
\$10,000 to \$19,999	16.2
\$20,000 to \$29,999	18.9
\$30,000 to \$39,999	16.0
Over \$40,000	26.1

Note: No. of responses, 870.

Agency Comments



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

MAY 24 1989

Mr. Lawrence H. Thompson
Assistant Comptroller General
United States General
Accounting Office
Washington, D.C. 20548

Dear Mr. Thompson

Enclosed are the Department's comments on your draft report, "Health Care: Home Care Experiences of Families with Chronically Ill Children." The enclosed comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely yours,

A handwritten signature in dark ink, appearing to read "Dick Kusserow".

Richard P. Kusserow
Inspector General

Enclosure

COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
ON THE GENERAL ACCOUNTING OFFICE'S DRAFT REPORT, "HEALTH
CARE: HOME CARE EXPERIENCES OF FAMILIES WITH CHRONICALLY
ILL CHILDREN," APRIL 1989

General Comments

We believe that the General Accounting Office (GAO) review should have addressed the other programs impacting on chronically ill children which are administered by the Office of Human Development Services (OHDS), e. g., administration for children, youth and families, administration on developmental disabilities, administration for Native Americans. In addition to these service programs, OHDS also funds through discretionary authorities research and demonstration programs, i. e., child welfare, respite care, head start, and family support.

GAO Recommendation

To facilitate the consolidation and publication of information on services for chronically ill children and ensure that case management services are available when needed, we recommend that the Secretary of Health and Human Services direct the Bureau of Maternal and Child Health and Resources Development to take a leadership role in developing necessary policy and program guidance for state maternal and child health agencies. Such policy should be aimed at ensuring that (1) information on providers and services in a given community is consolidated and made available to organizations servicing chronically ill children, (2) this information is provided to parents at time of discharge, and (3) case management services are made available to those who need direct assistance.

Department Response

We concur. The Bureau of Maternal and Child Health and Resources Development (BMCHRD), Health Resources and Services Administration, has and will continue to exercise an active role in developing the necessary policy and program guidance. For example, BMCHRD assisted in the preparation of the June 1987 Surgeon General's Report entitled "Children With Special Health Care Needs, Campaign 1987." This report established a national agenda for developing a commitment to family-centered, community-based, coordinated systems of care, and addressed the three steps recommended by GAO. The agenda has the support of major volunteer and public and private agencies concerned with health care of chronically ill children in this country. Additionally, the Maternal and Child Health Services (MCHS) Block Grant statute already supports a wide range of activities including the three steps detailed in this recommendation. Moreover, BMCHRD has issued guidance to the States regarding service networks and case management services. In addition, MCHS Block Grant funds have been used to establish a national information network which includes an 800 number.

Major Contributors to This Report

**Human Resources
Division, Washington,
D.C.**

J. William Gadsby, Director, Intergovernmental and Management Issues,
(202) 275-2854
John M. Kamensky, Assistant Director
Robert F. Derkits, Evaluator-in-Charge
Endel Kaseoru, Site Senior

**Atlanta Regional
Office**

Nancy T. Toolan, Site Senior
Katherine Dubuisson, Evaluator

**Cincinnati Regional
Office**

Michael F. McGuire, Site Senior
Christine D. Dooley, Evaluator

Dallas Regional Office

Mary K. Muse, Site Senior
Jerilyn Green, Evaluator

**Los Angeles Regional
Office**

Alexandra Y. Martin, Site Senior
Aleta L. Hancock, Evaluator