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MEETING THE NEEDS OF CHILDREN IN A HOME-BASED SETTING

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Before the
Committee on Finance
United States Senate

Meeting the Needs of Children in a Home-based Setting

Summary of GAO Testimony

GAO's testimony focuses on two efforts: (1) a report just released on the home care experiences of families with chronically ill children and (2) a study in progress on home visiting as a means to improve child health and well-being.

About 1 million children have a serious chronic illness, but many of them may now be cared for at home. In reviewing families' experiences in obtaining needed medical and social support services for their children at home, GAO found several things. First, about three-fourths of the families contacted who needed medical services said they had no difficulty obtaining them. But about one-half of those needing support services said they had problems obtaining them. Second, parents attributed their access difficulties for both medical and support services primarily to high out-of-pocket costs, the lack of information about service availability and providers, and the lack of a focal point to contact when they needed help. In order to better link families to the information and services they need, GAO is recommending that the Secretary of Health and Human Services take a strong leadership role in developing the necessary policy and program guidance to (1) consolidate and publicize sources of information on services available for chronically ill children in a given community, (2) provide this information to parents at the time of hospital discharge or upon returning to their home community, and (3) ensure that a focal point is available when needed.

Home visiting is a service delivery approach that provides preventive health, social, or educational services directly to at-risk pregnant women and families with young children in their home. Based on preliminary work done in the U.S. and Europe, it seems that home visiting can be a cost-effective and efficient way to improve child health and decrease the risk of child abuse and neglect and developmental delay. While successful home visiting programs may differ in their goals, they share certain characteristics: clearly defined objectives, providers' skills matched with service delivery objectives, and stable program funding. While federal support of research and demonstration projects has helped to develop innovative approaches in home visiting, short-term funding has hampered institutionalizing successful approaches. Upon completing the review, GAO will develop recommendations for the Congress and HHS to consider in using home visiting to improve maternal and child health and well-being.

Mr. Chairman and Members of the Committee:

I am pleased to be here today to discuss two GAO efforts relating to meeting the needs of children in a home-based setting. The first is our report, which is being released today, on the home care experiences of families with chronically ill children. The second is our study, which is still in progress, on home visiting as a means to improve child health and well-being.

HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN

Nationally, about 1 million children have a severe chronic health condition. In the past, these children were treated in hospitals. But in recent years, advances in medical technology have made it possible to care for them at home. At your request, we reviewed the experiences of parents with chronically ill children in obtaining medical and support services at home.

To do this, we focused on children who had the more severe forms of 10 medical conditions, such as spina bifida, congenital heart disease, or cystic fibrosis (see att. I for complete list). Working in 11 states and the District of Columbia, we contacted 14 hospitals that care primarily for children, surveyed 892 parents, and had group discussions with 96 of these parents about their experiences. We also contacted 60 local service providers and organizations for information about services they offered in the communities where we conducted family interviews. What did we learn?

Families' Needs for Services and Difficulties in Obtaining Care Varied

Families with chronically ill children at home need both medical and nonmedical (or support) services. The need for medical services is great: virtually all of the parents we surveyed (98 percent) said their children needed services such as physician office visits, medications, or medical equipment and supplies (see att. II). About three-fourths of families needing these services (73 percent) said they had no difficulty obtaining them.

In contrast, although fewer families said they needed support services, obtaining them was more difficult. Three-fourths of the parents reported needing one or more support services, most commonly baby sitting, counseling, day care, or transportation. These support services sound like the typical needs of any family. But, where they involve a chronically ill child, providing them can become highly specialized. About one-half (56 percent) of the families said they had difficulty getting the support services they needed.

Lack of Financing and Information Create Difficulties in Obtaining Some Services

Parents attributed their difficulties in obtaining both medical and support services primarily to three factors: (1) high out-of-pocket costs, (2) a lack of information about service availability and providers, and (3) the lack of a focal point to contact when they needed help. Comments directly from parents can perhaps best illustrate these points.

A Texas parent of a child with a heart condition and other complications told us:

> "...[C]opayments 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 [my husband's] career (he is in a field where upward mobility is achieved by changing companies)."

A Maine parent of a child with muscular dystrophy said:

> "...[T]rying 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."

And a Minnesota parent of a child with a cleft lip/palate remarked that:

> "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 [what we have] after the birth of our daughter."

Possible Solutions

Although many parents had difficulty obtaining services for their children, especially support services, not all did. The positive experiences of some parents form the basis for possible solutions.

We believe that the conditions we found can be improved (1) by consolidating and publicizing sources of information on services available for chronically ill children in a given community, (2) by providing this information to parents at the time of hospital discharge or once they return to their own home community, and (3) by ensuring that a focal point (case manager) is available when needed. We are recommending that the Secretary of Health and Human Services take a strong leadership role in developing the necessary policy and program guidance to accomplish this. HHS has agreed with our recommendation.

HOME VISITING AS A PREVENTIVE STRATEGY

Now, I would like to briefly discuss our ongoing work concerning home visiting programs in the United States and Europe. This job, which we are doing at the request of the Senate Appropriations Committee, should determine if such programs might be effectively used on a wider basis in the United States.

What do we mean by "home visiting?" Basically, we mean a service delivery approach that provides preventive health, social, or educational services directly to at-risk pregnant women and families with young children in their home. Many researchers and practitioners believe that home visiting is a cost-effective and efficient way to improve health and decrease the risk of child abuse and developmental delay.

Our work has two components. First, through extensive interviews and a literature search, we have identified key characteristics that seem to make home visitor programs effective. Second, we are testing, through case studies in five states (Illinois, Michigan, Rhode Island, South Carolina, and Texas) and in two European countries (the United Kingdom and Denmark), whether these key characteristics have produced programs that meet their stated goals. Based on the field work we have done to date, it seems there are at least three important characteristics to any successful home visiting program. These are:

-- clearly defined objectives,

-- providers' skills matched with service delivery objectives, and

-- stable program funding.

I'd like to talk for a moment about why each of these is important.

Clearly Defined Objectives

Clearly defined objectives are important because they provide the framework for deciding who to serve and with what services, monitoring program progress, and evaluating outcomes. One place with such clearly defined objectives is the Roseland Adolescent Parent Project in Chicago. This project serves teenage mothers with first-born children who lack a family or other "support systems." By routinely monitoring program activities, such as seeing whether infants get a minimum number of pediatric visits, program managers are evaluating their progress in reaching stated goals and desired outcomes.

Providers' Skills Matched With Service Delivery Objectives

Matching the skills of the provider to service delivery objectives is a key to success for home visitor programs. Programs focusing primarily on preventive health objectives often use highly skilled public health nurses. Trained lay workers, on the other hand, are often used to provide social support and referrals to other existing services.

The United Kingdom's program, for example, uses health visitors who are highly skilled and highly trained nurses functioning as part of a primary medical team. Among other things, they provide preventive health services, such as immunizations and well-baby check-ups, in the home. In contrast, the Resource Mothers Program in South Carolina uses lay workers to provide social support, health education, and referral information to pregnant teens in rural areas. In each case, program managers believe their program's objectives--whether primarily medical or social--are best met by the type of home visitors they are using.

Stable Funding Sources

Another vital contributor to success seems to be stable funding. Effective home visiting programs need providers who can develop rapport with program participants and maintain a relationship over time with the families they visit. Experience shows it can take 2 to 3 years to develop a program, put it in place, and begin to show results. Yet, in the past, much of the federal support for home visiting has been for research and demonstration projects. While this federal support has been valuable in demonstrating that home visiting works, such programs need stable sources of funding to continue or to be replicated in other locations. Without such funding, programs often lapse or become less effective.

A home visiting program in Elmira, New York, was particularly effective in its initial phase when it received federal and private research and demonstration funding. When these funds ran out, the local health department continued to support the program, but in a different and diluted form. Because of funding constraints, the home visitors found they had to shorten their visits and drop families earlier (when the baby was 4 months old, as compared to 2 years under the demonstration program). County officials told us that the current project is no longer having the same impact as the original demonstration project because the same level of intensive services is no longer provided.

When we have finished this review, Mr. Chairman, we will develop recommendations for the Congress and HHS to consider in using home visiting to improve maternal and child health and well-being.

Mr. Chairman, this concludes my statement. I would be pleased to respond to any questions you or other members of the Committee may have regarding our work.

10 CHRONIC HEALTH CONDITIONS COVERED IN GAO REVIEW

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 are long-term (such as diabetes, spina bifida, and cystic fibrosis), while others (such as heart conditions and cleft palates) can often be corrected early in life.

These 10 conditions are among those included in a 1985 Vanderbilt University study (Nicholas 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) and are considered to be representative of the problems and costs parents faced in obtaining care for a wide variety of chronic illnesses.

FAMILIES' NEEDS FOR SPECIFIC SERVICES AND DIFFICULTIES IN OBTAINING THEM

	Families who had a need for services		Families with a need who had difficulty obtaining services
Medical services[a]	No.	Percent	Percent
Physician office visits	823	97	6
Medications	759	90	9
Medical equipment	470	55	16
Medical supplies for equipment	464	55	15
Rehabilitative and other therapies	273	32	30
Skilled nursing visits	208	25	27
Physician home visits	102	12	58
Support services[b]			
Baby sitting	412	65	58
Counseling	368	58	32
Day care	336	53	57
Transportation	320	51	32
Case management	266	42	31
Respite care	152	24	53
Homemaker	129	20	50

[a] Of 865 valid responses to GAO's question about medical service needs, 848 (98 percent) said they needed one or more of these services.

[b] Of 840 valid responses to GAO's question about support service needs, 634 (75 percent) said they needed one or more of these services.