
Chapter 4

Sources of Financing

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INTRODUCTION

Technology-dependent children typically incur high annual treatment costs that may go on for a number of years. As chapter 3 has shown, these costs are substantial in any setting. For example, in Maryland's program for children dependent on ventilators and other respiratory supports, the average third-party payment for long-term care in the hospital was approximately \$24,700 per month in 1985 (93). Home care for such children was about \$9,300 per month. Although the number of children who become technology dependent each year is small, the financial burden on their families can be staggering. In the absence of public or private insurance, other public funding, or private philanthropy and charity care, these costs would exceed or severely strain the resources of all but the wealthiest families.

The extent to which technology-dependent children have access to adequate financing for health

care, and particularly for home care, depends on three factors:

1. the degree to which this population is covered by private insurance or public health care programs,
2. whether the insurance or program covers long-term care at home for this population, and
3. whether the home care benefits are sufficient to finance most of the medical needs of these children.

This chapter first discusses the extent of private insurance coverage among technology-dependent children and the adequacy of insurance for those who are covered. It then discusses the extent of public payment for home care services across the spectrum of available sources of public third-party payment. These sources include not only Medicaid, but also diverse programs targeted to specific groups or providing specific services.

¹Parts of this chapter are adapted from a background paper prepared under contract for OTA by Harriette Fox and Ruth Yoshpe entitled, "Technology-Dependent Children's Access to Medicaid Home Care Financing," August 1986.

PRIVATE HEALTH INSURANCE COVERAGE FOR TECHNOLOGY-DEPENDENT CHILDREN

This section examines the adequacy of private health insurance in covering the costs associated with the care of technology-dependent children in the hospital and at home. The question is framed as follows: what is the likelihood that a technology-dependent child will have private insurance coverage that is adequate to cover the costs of care in the setting that is most appropriate for child and family?² The answer to this ques-

tion depends on two factors: the likelihood that a technology-dependent child will be privately insured at all; and, once insured, the amount and scope of coverage that the child is likely to have.

Extent of Coverage

Private health insurance is available to children through two avenues: employer-based group health policies offering coverage of employees' dependents, and self-purchase by the family. Self-purchased insurance is generally a great deal more expensive to the family than employer-based group insurance and covers only about 6 percent of all privately insured children (41).

²Note that this question differs from the usual approach to defining the adequacy of insurance coverage, where healthy people make judgments about their willingness to pay to cover the risk of given levels of expense. That *a priori* question may have a very different answer from the *ex post facto* question addressed in this section (see reference 52).

Table 16.—Number and Percent of Children Aged 0 to 12 Years Covered Only by Private Health Insurance, by Income Status, United States, 1986

	Income status			Total
	Less than 100% of poverty	1000% to 199% of poverty	More than 2000% of poverty	
Total number of children (in thousands)	10,861.6	9,997.7	23,658.9	44,518.2
Number with private health insurance (in thousands)	1,520.6	6,198.6	20,346.6	28,065.8
Percent with private health insurance	14 %	620/o	860/0	630/o

SOURCE U S Department of Commerce, Bureau of the Census, Current Population Survey, unpublished data, March 1986.

A substantial majority—62 percent—of American children between the ages of 0 and 12 have private health insurance as their sole source of third-party coverage (table 16). The likelihood of having private insurance depends primarily on the marital status of the mother and on income status. Almost 86 percent of children with family incomes above 200 percent of the Federal poverty level have private health insurance, while only 14 percent of poor children do (41).

Of course, lack of private health insurance does not necessarily imply lack of coverage. Many children (16 percent of those under age 13 in 1986) are covered by Medicaid, Medicare, or the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS). A small proportion of children (4 percent in 1986) have a mixture of public and private insurance. Nonetheless, about 19 percent of all American children under 13 years of age—8.5 million young children—had no health insurance of any kind in 1986.³

Technology-dependent and other severely disabled children may be less likely to have private health insurance than children without major health problems. The 1982 National Health Interview Survey found that 53.8 percent of noninstitutionalized children with severe limitations of activity had private insurance, compared with 74.3 percent of children without any limitations (58). The reasons for these disparities may include unavailability of individual coverage for severely disabled children, lack of coverage of preexisting

conditions under group plans, lack of coverage beyond lifetime maximum limits, differences in the employment status of parents in the two groups, and parental decisions to rely on public sources of support.

Adequacy of Coverage

The fact that a technology-dependent child is covered under a private health insurance policy does not necessarily mean that the insurance provides adequate financial resources. The insured person's exposure to out-of-pocket expenses depends on the following aspects, which vary widely among insurance plans:

- *First Dollar Deductible*: the amount that the insured must pay each year before he or she is eligible for coverage. This amount may vary by type of benefit (e. g., hospital v. medical).
- *Coinurance Rate*: the percent of the cost of covered services for which the insured is responsible.
- *Catastrophic Stop-Loss on Out-of-Pocket Expenses*: typically an annual upper limit on the beneficiary's out-of-pocket payments for insured services.
- *Overall Plan Maximums*: limits on the total amount the insurer will pay out on the policy, calculated either as annual, per episode, or life- time limits.
- *Limits on Covered Services*: limits on the type or number of insured services, such as maximum hospital days or home care visits covered.

Because expenses for technology-dependent children are typically catastrophic in nature, and be-

³This estimate is based on the Current Population Survey (4), which asks about health insurance coverage for the previous year. It is not clear whether the estimate relates to a point in time or to the entire previous year. The estimate is in line with point-in-time estimates of other surveys (see reference 152).

cause these children often require complex care, the three most important features of private health insurance plans for these children are the overall plan maximums, the catastrophic stop-loss provisions, and the covered services.

Overall Plan Maximums and Stop-Loss Provisions. —The most direct information on the exposure of privately insured children to overall plan maximums comes from the 1977 National Medical Care Expenditure Survey. In that year, approximately 50 million children under 18 years of age had private health insurance, and about 41 million (84 percent) had major medical coverage.⁴ Of those children with major medical coverage, only 23 percent had overall plan maximum limits above \$250,000 (53).

Several more recent surveys of employee group health plans, summarized in table 17, show how plan maximums and stop-loss features are distributed among private sector group plans. These surveys indicate that over three-fourths of plans (and employees) are subject to some kind of overall plan maximum, with more than one-half of all employees under policies with life-time maximum limits of **\$500,000** or less.⁵

Data on new group health insurance policies written by insurance companies in 1984 show a definite trend toward higher overall maximum limits. Ninety-three percent of the employees covered by a sample of new group policies written by commercial insurance companies had maximum limits of \$1 million or more (**80**). Although the data from all sources taken together suggest substantial improvement in adequacy since 1979, it is probable that over one-half of privately insured families still have insurance that is inadequate for the catastrophic expenses associated with long-term technology-dependent conditions,

The impact of low lifetime maximums can be demonstrated with preliminary data from the

⁴Major medical coverage provides for a wide array of services and usually includes an annual deductible, coinsurance requirements, and maximum benefit limits. By comparison, basic benefit plans usually provide first-dollar coverage, but cover only a very narrow set of services.

⁵The only exception is reported by Fox and Yoshpe, who surveyed a small sample (60 firms) of employers. This sample may be biased because it was drawn from a data source listing firms with net assets above a threshold, suggesting that even the smaller firms in the sample are disproportionately wealthy (.58).

Maryland and Illinois programs for children requiring respiratory support. If hospitalized, Maryland children would, on average, exceed a **\$250,000** maximum in about one year (even if the insurer paid only **80** percent of charges). Yet the average length of hospital stay for these children was 14 months (93). Even at home, these children would exceed this lifetime maximum within about 3 years. Of 63 children in Illinois' home care program, 42 were supported exclusively through Medicaid, **23** because their private insurance had lapsed (104).

The situation is somewhat better with respect to catastrophic stop-loss coverage. In 1984, more than three-fourths of plans and employees had an annual catastrophic limit on out-of-pocket expenses. Catastrophic limits ensure that families will not be wiped out by coinsurance requirements in the early months or years of expenditures for a technology-dependent child, but they do not lessen the exposure of families to lifetime maximum benefit limits.

Limitations on Covered Services.—Of particular interest to technology-dependent children is the availability of home care coverage. Almost one-half of employees in medium and large business establishments were without any home health care benefits in 1984 (175). Although home health benefits have been introduced increasingly in the recent past as a cost-containment measure (e. g., 11 percent of plans in a survey of large firms reported adding home health care benefits between 1980 and 1982 (121)) it appears that many children would not be eligible under their current plans. (Note that although health maintenance organizations are often thought of as providing comprehensive coverage, they too may have limited home health benefits.)

Not only is home health frequently an uncovered service in private insurance policies, but as structured, these benefits typically do not meet the needs of a child requiring continual nursing care. For example, although over **90** percent of Blue Cross/Blue Shield plans covered home health services in 1984, 95 percent of such plans limited the number of professional nursing visits.^b About one-half of the plans had annual limits on the

^bBlue Cross Blue Shield covers about 13 percent of employees in medium and large firms (175)

Table 17.—Surveys of Employer-Sponsored Group Health Insurance Plans

Study	Survey year(s)	Sample	Employee groups covered by survey	Percent of plans (p) or employees (e) with maximums	Percent of plans (p) or employees (e) with lifetime maximums of \$500,000 or less	Percent of plans (p) or employees (e) with lifetime maximums of less than \$1 million	Percent of plans (p) or employees (e) with stop-loss catastrophic coverage
U.S. DOL-BLS	1984	Probability sample of 1,326 business establishments meeting industry-specific minimum size requirements (ranging from 100 to 240 employees)	Full-time employees	1984: 82% (e) ^a	1984: 52-570/o (e)	1984: 53-58°/0 (e)	1984: 76°/0 (e)
W y a t t C o	1978-84	In 1984, 1,115 firms of all sizes (but mostly large) participating in the study	Salaried employees	1984: 870/0 (p) 1980: 880/0 (p)	1984: 52% (p) 1980: 600/0 (p)		1984: 880/0 (p)
Hewitt Associates	1979-84	250 major employers; 680/0 in Fortune 100, 32% in Fortune 500	Salaried employees	1984: 82-870/0 (p) 1979: 89-900/0 (p)	1984: 560/0 (p) ^b 1979: 750/o (p)		1984: 870/0 (p) 1979: 590/, (p)
Fox & Yosphe.	1986	Random sample of 60 firms of all sizes selected from Dunn & Bradstreet's U.S. Business Directory (small firms) and Business Insurance Directory (medicine and large firms)	All employees	1986: 67% (p)	1986: 16,30/, (p)	1986: 25.50/. (p)	1986: 800/0 (p)
B a t t e l l e / E B R I	1977-78	Probability sample of small nonagricultural business establishments (less than 250 employers)	All employees	1978: 75-830/. (e) ^c			

^aCalculated as percent of employees with major medical coverage who are subject to overall plan maximum. About 90 percent of plan participants in this sample had major medical coverage. The remainder had basic benefits only, which may not be subject to lifetime limits but which are often subject to specific maximum limits on services.

^bCalculated as the percent of all employees with lifetime maximums less than this amount. An additional 4 percent of employees who were not subject to lifetime maximums in 1984 were subject to annual or "per cause" maximum.

^cThis is a overstatement, because employees subject to more than one maximum are double-counted.

SOURCES: See references 33, 58, 83, 175, 186.

number of visits, with a median limit of 90 visits per year; only 7 plans covered at least 2 visits per week (20). These plans also vary in the specific home health services covered. For example, physical therapy is covered by all plans with home health benefits, but respiratory therapy is not a covered service in 22 percent of plans (20). None of the Blue Cross/Blue Shield plans in the 1984 survey included hourly ("shift") nursing as a regular home health benefit.

Increasingly, States are using their regulatory authority to require health insurers to offer home health benefits. At present, 13 States have laws requiring coverage of home health services under health insurance plans (5). These State laws cover only those policies written by health insurance companies and do not apply to health plans provided by employers on a self-insured basis. The latter are exempt from State regulation by Section 514 of the Employee Retirement and Income Security Act of 1974 (ERISA, Public Law 93-406). The exemption from State regulation has been a powerful spur to self-insurance by employers, and further increases in mandated benefits are likely to increase the proportion of employers who self-insure (7). Thus, to the extent that families are insured through employer self-insurance, State action to mandate home health benefits is not likely to be an effective mechanism to increase coverage of services to technology-dependent children in the home.

Recent initiatives within the insurance industry itself are more promising. Several health insurance companies have initiated individual benefit management programs, in which the contractual limitations on covered services are waived for certain high-cost patients. Under these programs, the insurance company will pay for services in home

and other settings that would normally not be covered, provided that by doing so the company will reduce the rate of outflow of total benefit payments. Four examples of such individual management programs are presented in box D. In a recent survey of employer-sponsored health plans, Fox and Yoshpe found that 53 percent of employers had an individual benefits management program (58),⁷ although these programs may not all operate to encourage nonhospital care for technology-dependent children.

As promising as they are, individual management programs by insurers do not eliminate the problems caused by low overall plan maximums, for the insurer typically will not pay beyond those contractual limits. Individual case management *can* extend the length of time before the maximums are reached. However, insurers may have little incentive to offer this important service if they think they will still end up paying out the maximum amount.

A handful of private insurance plans have considered increasing coverage of specific complex home services to beneficiaries as a group. For example, three of the plans responding to the Blue Cross/Blue Shield 1984 survey reported that they were developing or implementing pilot programs specifically for chronically ill children, including ventilator-dependent children. Another three plans were implementing programs for expanding high-technology services in the home, such as intravenous nutrition and drug therapy, but these programs were not specifically targeted at children (20).

⁷For reasons discussed in footnote 5 above, the percentage of plans may be overstated.

MEDICAID

Background Issues

Medicaid⁸ provides health insurance to very poor people who are also aged, blind, disabled,

⁸The Medicaid program is in reality 54 separate State- and territorial-administered programs that are jointly funded by the Federal and State governments. As a condition of Federal funding, the Federal Government requires that the States provide certain serv-

ices to designated eligible populations; it also limits the services that will be supported by the Federal Government. States, on their part, retain considerable latitude in tailoring their programs to fit their needs.

Arizona is the only State without a formal Medicaid program. It does have a Medicaid demonstration program, but this program does not include all of the services that are mandated by the Federal Government to be covered in other States.

Box D.—Individual * Among Private Insurers

A few private insurance companies provide care for augmented home care to technology-dependent children when it can be shown that by doing so the insurer is likely to save money, or at least to extend the length of time the child will be covered before reaching a lifetime maximum. Following are brief descriptions of four examples.

Blue Cross/Blue Shield Federal Employees Benefits Program

The Blue Cross/Blue Shield Association negotiates, on behalf of the 90 independent plans, a benefits package contract with the U.S. Office of Management. This contract is one of many health insurance options that a Federal employee may choose. All Blue Cross and Blue Shield plans agree to provide this benefit package to enrolled Federal employees in their local jurisdictions. The present contract provides employees with the option of a "high" plan, with benefits including 90 home health days of medically necessary service and no hospital limit, or a "low" plan, with a lower premium, higher deductibles and coinsurance, a \$2 million limit on covered benefits, and no home health benefits.

Under a pilot project, begun when the first case was brought to the attention of the program in 1983, the Blue Cross/Blue Shield Federal Employees Program home benefits in excess of the contracted benefits for technology-dependent children, including children, who: 1) would be eligible for coverage if in the hospital, and 2) will be less expensive to care for at home. A number of individuals who have been extended special benefits under this pilot project have been children, primarily infants with respiratory disorders, heart disease, tube feeding or parenteral nutrition requirements, and multiple handicaps.

Aetna

Aetna Life & Casualty is a national for-profit insurance company with regional offices that administer its plans. The company offers augmented home benefits to any policyholder who would be eligible for coverage if in the hospital and will be less expensive to care for at home. Aetna has provided this service since 1983 to all age groups. The company estimates that the program saved \$3.5 million in the first year of implementation, \$12 million in the second year, and \$26 million in the third (38).

Aetna had served 26 children under age 16 in the program as of March 1986. Savings for each case under the program are calculated at least every 6 months, and all cases over \$6,000 in cost or with care lasting longer than 6 months are monitored and reviewed by the company's medical director. Benefits can range from an apnea monitor to purchase, nursing, and therapy. Benefits cease when the patient is completely rehabilitated or the lifetime benefit level is reached. In the latter case, the patient may keep purchased equipment (38).

The Equitable

The Equitable Life Assurance Society of the United States, a for-profit insurance company, offers a Medical Case Management program as an optional amendment to group health insurance policies. The policy amendment itself carries no extra charge, but in agreeing to the amendment the group policyholder (the employer) agrees to pay the cost of a case coordinator for any relevant cases that arise. As of January 1, 1986, 255 group policyholders had a medical case management agreement with The Equitable, covering approximately 910,000 employees about 2,500,000 total persons (employees plus eligible dependents) (136).

Patients may be referred to the case management program by the company's pre-admission review service, the source of eligibility verification, the employer, the employee or dependent, claims personnel, or providers. The company uses a diagnosis-based trigger for identification of appropriate cases to ensure early referral and the opportunity to establish a rapport with the patient, family, and provider. Included in the diagnostic profile are a number of diagnoses associated with neonatal problems (e.g., congenital heart anomalies or respiratory distress syndrome) and trauma. More diagnostic categories can be added to accommodate the client's need (136).

Under the case management program, case coordinators at The Equitable screen potential cases, assess the medical and other needs of accepted patients, prepare care plans, coordinate the necessary care, and monitor progress. Patients in the program can receive services that would not be reimbursed under the usual insurance contract, such as home modification, family counseling, and transfer to a special rehabilitation hospital (136).

John Hancock

John Hancock Mutual Life Insurance Co., which has a health insurance component, operates a medical case management program that is very similar to The Equitable's. It concentrates on serving trauma patients, high risk infants, and (in the case of older patients) stroke. The program brings a case consultant to certain of these cases to coordinate care and provide benefits not normally available to beneficiaries, such as specialized rehabilitation services and home services, in order to reduce costs while providing appropriate care (56).

members of families with dependent children, or first-time pregnant women ("categorically eligible"). In 35 States and the District of Columbia, people in these categories can also qualify for Medicaid if their medical expenses are sufficiently high that they become poor as a consequence ("medically needy"). Each State has an approved Medicaid plan that details eligibility, coverage, and reimbursement features in that State.

Two features of the Medicaid program are particularly important in the context of care for technology-dependent children. First, eligibility is a vital issue because the Medicaid program is often the third-party payer of last resort for a technology-dependent child. Second, the coverage of complex health services under the State's usual Medicaid rules, and the way these services are paid, affect the setting and amount of care the child receives. Over the past 5 years, concerns about these two features of the program have led to changes in the Federal statute and regulations regarding coverage and reimbursement under special Medicaid rules. Many States have taken advantage of these changes, described later in this section, to enhance coverage for community services provided to technology-dependent children.

Eligibility

All persons receiving payments under the Aid to Families with Dependent Children program (AFDC) are automatically eligible for Medicaid. (Note that in some States, two-parent families

cannot qualify for AFDC even if they are very poor.) In addition, Medicaid eligibility in most States is extended to all aged, blind, and disabled individuals (including children) who receive cash assistance under the Federal Supplemental Security Income (SSI) program.⁹ Medically needy persons—those who would qualify for these programs but for their incomes, and who have very high medical expenses—can also be made eligible if the State opts to include them.

To be eligible for SSI, an individual must have a disability that is expected to last at least a year (or until death) and must have available income and resources no higher than established limits. By statute, the income and resources of certain relatives, specifically a parent or spouse if he or she is living in the same household as the individual, must be deemed available to the individual. After one month in an institution, however, the individual is considered to be not living in the family household and the relative's income and resources are irrelevant to the eligibility determi-

⁹In providing Medicaid coverage to SSI beneficiaries, States may select one of two options. They can make all SSI recipients eligible and, if they choose, also provide Medicaid to individuals receiving only optional State payments; or they can limit Medicaid eligibility to individuals who meet requirements more restrictive than those under SSI. The State may be more restrictive in setting financial requirements for income or resources, more restrictive in defining blindness or deafness, or both. Each requirement, however, may not be more restrictive than that in effect under the State's Medicaid plan on Jan. 1, 1972. As of 1983, 14 States required SSI recipients to meet eligibility standards more restrictive than the Federal standard (168).

nation (20 U.S.C. 416). In some circumstances, the application of these rules may encourage the institutionalization of individuals who could be cared for at home if Medicaid financing were available.

The linkage of Medicaid eligibility to SSI payments, and SSI payments to institutionalization, allows a child with a long-term disability and inadequate private insurance to receive hospital services under Medicaid, regardless of the income of the child's family. A number of technology-dependent children who would not otherwise be eligible for Medicaid can thus receive hospital services under this rule without their families having to become impoverished. However, until very recently these children were almost invariably ineligible to receive Medicaid reimbursement for equivalent medical care at home, because once home, their families' resources would be deemed to be available to them. This situation received national attention in 1981, after the family of a hospitalized ventilator-dependent child appealed her case to Congress and the President. Limited options for the States to avoid the link between hospitalization and Medicaid benefits now exist and are described later in this section.

Basic coverage and reimbursement

States may pay for hospital care in a number of alternative ways, and they may place restrictions on the amount of hospital care they will pay for (see table 18). States pay hospitals according to a variety of methods, including:

- the costs incurred in serving Medicaid patients;
- prospectively set rates per day, or per admission;
- prospectively set rates arrived at through competitive hospital bidding or through predicted Medicaid caseloads as a proportion of hospital budget; or
- prepaid health plans, in which a health care provider is paid a set amount per enrolled Medicaid individual, regardless of the actual medical care use of that individual.

Under the prepaid or prospectively set rate systems, hospitals have an incentive to reduce the length of hospital stays as much as possible, be-

Table 18.—Medicaid Hospital Inpatient Stay Maximums and Units of Payment in the 50 States^a and the District of Columbia, 1985

State	Inpatient hospital stay maximum	Inpatient unit of payment
Alabama	12 days/year	per diem
Alaska		percentage of charges
Arizona		competitive bidding
Arkansas	35 days/year	per diem
California		per diem
Colorado		per case
Connecticut		per case
Delaware		cost-based
District of Columbia		per case
Florida	45 days/year	per case
Georgia		per case
Hawaii		per case
Idaho	40 days/year	per case
Illinois	45 days/year	per diem
Indiana		cost-based
Iowa		per diem
Kansas		per diem
Kentucky	14 days/spell of illness	per diem
Louisiana	15 days/year	per case
Maine		global charges
Maryland	separate maximums for each case type	per case
Massachusetts		percentage of charges
Michigan	18 days/year	per case (DRGs)
Minnesota		per case (DRGs)
Mississippi	15 days/year	per diem
Missouri		per diem
Montana		cost-based
Nebraska		per diem
Nevada		per case/per diem
New Hampshire		cost-based
New Jersey		per case (DRGs)
New Mexico		cost-based
New York		per diem
North Carolina	maximums per diem	per diem
North Dakota		cost-based
Ohio	30 days/spell of illness	per case (DRGs)
Oklahoma	10 days/spell of illness	per diem
Oregon	18 days/year	per case (DRGs)
Pennsylvania		per case (DRGs)
Rhode Island		global charges
South Carolina	12 days/year	cost-based
South Dakota		per case (DRGs)
Tennessee	20 days/year	per diem
Texas	30 days/spell of illness	cost-based
Utah		per case (DRGs)
Vermont		per diem
Virginia	21 days/spell of illness	per diem
Washington		per case (DRGs)
West Virginia	20 days/year	cost-based
Wisconsin		per case
Wyoming		cost-based

^aArizona's program is a Statewide Medicaid demonstration program.

^bSome States with limited covered hospital days allow longer stays for EPSDT eligibles.

^cEarly and Periodic Screening, Diagnosis and Treatment program.

SOURCE: US Department of Health and Human Services, Health Care Financing Administration, *Health Care Financing Program Statistics: Analysis of State Medicaid Program Characteristics, 1984* (Baltimore, MD DHHS, August, 1985), and S.S. Laudecina, *A Comparative Survey of Medicaid Hospital Reimbursement Systems for Inpatient Services, State by State, 1980-1985* (Washington, DC George Washington University 1986).

cause they do not recoup any extra payment for longer stays or extra services. Furthermore, even in some States with cost-based reimbursement, hospitals are paid by Medicaid for care only up to a limited number of days. The net effect of these payment methods and limits is to provide hospitals with an incentive to discharge patients as soon as possible, or as soon as the day limit has been reached. If a child cannot be cared for outside the hospital, the hospital is faced with providing indefinite charity care. Medicaid payment thus may cover only a small fraction of the total hospital costs of caring for a technology-dependent child.

States are not required to cover either pediatric nursing home stays or pediatric home care in their Medicaid programs. If they do cover the former, however, they must also cover the latter; and, covering home care means that certain minimum services must be provided. 10 States covering pediatric home care as a normal part of their Medicaid programs (all but three do) must provide some basic services, such as home nursing visits, medical equipment, and supplies (167). States may also cover numerous optional services. As is evident from table 19, the result is considerable variation in the services covered (and the limits to coverage) across States.

Very few States cover the full range of services and technologies needed by a technology-dependent child in a nonhospital setting as a part of their regular Medicaid benefits. For example, 30 States provided no home shift nursing (i.e., private duty nursing) at all in 1984 (167). Furthermore, Medicaid home services vary dramatically in amount even where they are provided. All States covering home services under Medicaid must offer intermittent or part-time home nursing, for instance, but the number of covered nursing visits varies from 50 to 300 visits per year (167).

Special Options for Financing the Home Care of Technology -Dependent Children Under Medicaid

Four special options have been available under the Medicaid program for States to use in extending eligibility and expanding the range of covered services for technology-dependent children who can be cared for in their homes. Three of these options require the States to obtain a federally approved waiver of usual Medicaid rules in order to provide additional services, while the fourth allows changes in eligibility rules but not services. The options are:

1. the individual "Katie Beckett" waiver (phased out after 1984),
2. the Section 2176 regular home- and community-based waiver,
3. the Section 2176 model home- and community-based waiver, and
4. an amendment to a State's Medicaid plan.

A summary of the various provisions of each of these options is presented in table 20.

Individual Waivers

An individual waiver program, created in 1982 by the Secretary of the Department of Health and Human Services (DHHS), was the first Medicaid option designed to address the problems of individuals who remained institutionalized because returning home for less costly medical treatment would result in the loss of SSI and Medicaid eligibility. Commonly referred to as "Katie Beckett" waivers (after the first child to receive one), they were intended as a temporary strategy to permit specified individuals to have Medicaid coverage at home while States pursued the longer range options of 2176 waivers or State plan amendments (47 FR 24274).

Requests for these waivers were accepted from State Medicaid agencies between June 1982 and December 1984. A DHHS interdepartmental review board determined whether or not the usual SSI deeming rules should be applied in each particular case.¹¹ For each nominated child, the board

¹⁰As of 1980, States may, at their option, provide case management and home respiratory care services under Medicaid (Public Law 99-453).

¹¹Due to the large number of applications that were not resolved, the board continued to act into 1986.

Table 19.—Summary of Medicaid Home Health Services Provided in 50 States and the District of Columbia, 1984

State	SERVICE						
	Private duty nursing	Part-time nursing	Therapies ^a	Home health aide	Personal care services	Medical supplies/equipment	Prosthetic devices
Alabama	N	A,L	N	A,L	N	L	A,L
Alaska	N	A	A	A	N	A	A
Arkansas	N	U	L	U	N	U	A,L
California	N	A,L	A	A,L	N	A	A,L
Colorado	N	A	A	A	A,L	A	A,L
Connecticut	L	L	U	L	N	U	U
Delaware	A,L	U	U	U	N	U	L
District of Columbia	U	U	L	U	U	A,L	A,L
Florida	N	U	N	U	N	L	L
Georgia	N	L	A,L	L	N	A	L
Hawaii	N	U	U	U	N	A	A
Idaho	N	L	L	L	N	A,L	N
Illinois	A	A	A	A	N	A	L
Indiana	L	A	A,L	L	N	A	A
Iowa	N	U	L	U	N	L	L
Kansas	A,L	L	L	L	N	A,L	A,L
Kentucky	N	L	L	L	N	A	A,L
Louisiana	N	L	L	L	N	A,L	A,L
Maine	N	U	U	U	N	U	L
Maryland	N	L	L	L	N	L	A,L
Massachusetts	A,L	U	L	L	U	L	A
Michigan	N	U	L	U	L	L	L
Minnesota	L	U	L	U	L	A,L	A,L
Mississippi	N	L	L	L	N	L	N
Missouri	N	L	L	L	L	A	A,L
Montana	L	L	U	L	L	A	A
Nebraska	A	U	U	L	L	A,L	A
Nevada	A	A	A	A	A	A	A
New Hampshire	A,L	L	A	L	A	A	A,L
New Jersey	N	A	A	A	N	A	A
New Mexico	N	A,L	A,L	A,L	N	A	A
New York	A	A	L	A	N	A	A
North Carolina	N	L	L	L	N	L	N
North Dakota	U	U	U	U	N	U	U
Ohio	L	U	A,L	U	N	L	A,L
Oklahoma	N	L	N	L	A	L	L
Oregon	N	A	A	A	A	A	A
Pennsylvania	N	L	L	L	N	A	A,L
Rhode Island	N	A,L	A,L	A,L	N	A	A,L
South Carolina	N	L	L	L	N	A,L	A,L
South Dakota	N	A	A,L	A	L	L	L
Tennessee	N	L	L	L	N	L	A
Texas	N	A,L	N	A,L	N	A,L	A,L
Utah	A	U	A,L	U	N	A	L
Vermont	N	L	U	L	N	L	L
Virginia	N	U	U	U	N	A,L	N
Washington	A,L	L	A,L	L	N	A	A
West Virginia	A	U	U	U	N	A	A
Wisconsin	A	U	A,L	U	A,L	L	A,L
Wyoming	N	L	L	U	N	L	L
Total: #N	30	0	4	0	30	0	4
#U	2	16	8	16	2	5	2
#A	13	14	17	13	9	29	31
#I	10	30	39	32	14	27	29
							28

KEY: N = not provided; U = no limits; A = prior authorization required; L = other limits
 aphysical, occupational, and speech and hearing. Respiratory therapy has recently been added as an optional Medicaid home health service, but it was not allowable in 1984.
 SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, *Health Care Financing Program Statistics: Analysis of State Medicaid Program Characteristics, 1984* (Baltimore, MD: U.S. DHHS, August 1985).

Table 20.—Comparison of State Medicaid Options for Extended Home- and Community-Based Care

Option	Categorical eligibility	Income eligibility	Number of individuals able to participate	Geographic areas	Allowable services	Time period
Individual waivers (no longer newly awarded)	Disabled Individuals who, because of relatives income, would otherwise be eligible for Medicaid only if institutionalized	Deeming rules are waived	One person per waiver	Not applicable	Regular State Medicaid services only	Individuals eligible until waiver no longer needed
Regular 2176 waiver	State may target to aged or disabled, mentally retarded or developmentally disabled, or mentally ill. Individuals must require level of care provided in ICF, ICF/MR, SNF, or hospital	States may waive deeming rules; may increase income eligibility to 3000/0 of SSI standard	All persons meeting eligibility criteria	May be less than statewide	Can offer certain services otherwise not authorized under Medicaid law; can provide more extensive coverage of regular services	3-year waiver; 5-year renewal
Model 2176 waivers	States can define specific categories of disabled individuals. Individuals must require level of care provided in ICF, in ICFIMR, SNF, or hospital	States must waive deeming rules	50 or fewer slots per waiver program	May be less than statewide	Similar to regular 2176 waivers; must offer at least one service in addition to those provided by regular Medicaid	3-year waiver; 5-year renewal
State plan amendment	Disabled individuals under age 19 who, because of relatives' income, would otherwise be eligible for Medicaid only if institutionalized; individual must require level of care provided in a hospital, ICF, ICF/MR, or SNF	Deeming rules are waived	All persons meeting eligibility criteria	statewide	Regular State Medicaid services only	State option

SOURCE: H. B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U. S. Congress, August 1986

determined whether it would be inequitable under the circumstances to consider family income and resources in assessing the child's eligibility for SSI payments (and thus Medicaid). For the board to waive the deeming requirements, it had to decide that:

1. enabling the individual to be eligible for home-based care would result in reduced Medicaid expenditures, and
2. the quality of the home-based care would be as good as or better than that provided in an institution.

The board also could impose additional standards in particular cases, depending on the facts presented.

Once a waiver was approved, it remained in effect—and the individual retained Medicaid eligibility at home—until the waiver was no longer appropriate. This would be the case if the individual could no longer meet the SSI disability criteria; if the countable income and resources of the parent (or spouse) fell below the SSI or State supplement standard; or if a waived child reached the age of 19, at which time he or she could qualify for SSI and Medicaid as an adult without consideration of parental income and resources.

The obvious attraction of the individual waiver option for States was the ability to provide more appropriate Medicaid coverage for selected individuals. States pursued the option as a short-term response to a small number of extraordinary cases, usually in the face of significant public pressure. But since the waiver only entitled individuals to regular Medicaid services, States without many Medicaid home care benefits may have found it difficult to use this option unless other sources of home care financing were available to the child as well.

States used this option not only to cover institutionalized children who needed the deeming rules waived in order to return home, but also to cover disabled children already at home. In some instances, these children needed Medicaid benefits as a backup for private insurance; in others, they already were SSI- and Medicaid-eligible and needed the deeming rules waived so that their parents would be permitted to earn higher incomes.

Regular 2176 Waivers

These waivers, authorized by Congress in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), enable States to finance a wide array of home- and community-based services for Medicaid recipients who otherwise would require institutionalization. Under the waivers, States can designate specific target populations who will be subject to broader income eligibility policies and receive a wider range of home- and community-based services than normally covered under the State plan.

Eligibility for regular 2176 waiver programs is limited to Medicaid recipients who, in the absence of home and community services, would require long-term care in a skilled nursing facility (SNF), intermediate care facility (ICF), or hospital. Special reference to hospital-level care for the ventilator population (Public Law 99-272) and for all other individuals (Public Law **99-509**) was added to the statute in 1986. Even before the addition, States could have included hospitalized individuals in these waiver programs, but this policy was unwritten and not clearly communicated to the States (59).

States must specify a projected number of people to be served under the waiver. In defining the population to be served, States must select a target group from one of the following three categories or subcategories of Medicaid recipients: aged or disabled, or both; mentally retarded or developmentally disabled, or both; or the mentally ill. (States can have more than one waiver if they wish to serve more than one group.) In addition, they may restrict eligibility for participation in the waiver to:

- individuals residing within a certain geographic area of the State,
- individuals being discharged from a long-term care institution, or
- those particular individuals for whom the Medicaid cost of providing home- and community-based services is less than the cost of providing institutional care.

A State can also expand income eligibility for the target waiver population beyond that of the regular Medicaid program in two ways. One is

to increase Medicaid income eligibility limits to a level equal to three times the maximum payment made to an individual under the SSI program. (Individuals becoming eligible under this higher income standard, however, would be required to contribute to the cost of their care.) The other option is not to deem a certain portion of the family's income to be available to an individual who receives care at home. Once a State has set its eligibility criteria for a 2176 waiver program, *all individuals who apply to the program and meet the specified criteria must be accepted until the projected limit is reached.*

States may provide services under the waiver that are otherwise not allowed by Medicaid, such as respite care and habilitation services.¹² They can also expand the amount, duration, or scope of coverage of regular Medicaid services offered in that State. Among the various regular Medicaid services that have been offered more extensively under the waiver are case management, hourly nursing care, home health aides, personal care services, medical supplies, and durable medical equipment. States may also offer other services approved by the Secretary, such as minor home modifications and utility expenses.

To receive waiver approval, it is essential for a State to show that its proposed program of augmented services will be no more costly to the Medicaid program than institutional care. Estimated per capita expenditures for all Medicaid services provided to all long-term care recipients, including both home and hospitalization, cannot be greater than they would have been in the absence of the waiver (42 CFR 441). States that want to serve technology-dependent children are able to compare the cost of their home care to the cost of hospitalization using the prescribed formula. Given that the waiver naturally increases the number of Medicaid recipients receiving long-term care services in the home, a waiver application usually is expected to demonstrate cost savings in two ways: by showing that the total cost of home- and community-based services is less than the total cost of institutional care, and by documenting that the waiver will afford a reduction in the number

of Medicaid beneficiaries receiving institutional care.

The advantage of the regular 2176 waiver is its flexibility. Eligible groups can be defined narrowly or broadly, and the waiver can be applied to the entire State or only to a small area. States can, if they wish, use a regular 2176 waiver to serve a relatively small group of disabled children who otherwise would be hospitalized. The often prolonged process of completing the very detailed waiver application, however, may have discouraged States from targeting these waivers to this small population. Regular 2176 waivers generally are perceived by the States as being for larger and more inclusive populations, such as the elderly and disabled, and incorporating technology-dependent children into such a waiver is not attractive to all States. For one thing, States appear reluctant to waive the SSI deeming rules for the large number of recipients who would be eligible under the waiver. For another, they seem to prefer to control the number of very high-cost individuals who come into the program for fear of exceeding their original cost estimates and having their renewal request denied.¹³

Model 2176 Waivers for the Disabled

Using its statutory authority for regular 2176 waivers, the Health Care Financing Administration (HCFA) developed a "model" 2176 waiver in December 1982 to encourage States to provide home- and community-based services to certain disabled individuals who otherwise would lose Medicaid eligibility outside of an institution. A model waiver is similar to a regular waiver except in two essential respects:

1. it may serve no more than 50 blind or disabled children and adults at any one time,^{*5} and

¹³Although the States perceive this as a real obstacle, HCFA staff report that they routinely grant approval for higher cost ceilings where States have incurred unanticipated expenses for medically necessary services. (Between March 1985 and April 1986, before Public Law 99-272 prohibited this practice, the Health Care Financing Administration had been denying Federal matching payments for Medicaid expenditures that exceeded a State's original cost ceilings.)

¹⁴See the State Medicaid Manual, Part S—Eligibility, transmittal no. 1, February 1983 and final regulations at 42 CFR 441.300.

^{*}Prior to the enactment of Public Law 99-272 in 1985, States operating under a model waiver were able to serve only 50 unduplicated recipients, which meant that participants who died or left the program for any reason could not be replaced.

¹²Habilitation services now include prevocational, educational, and supported employment services for discharged nursing home patients (effective Apr. 6, 1986) (Public Law 99-272).

2. it *must* provide that the SSI income deeming rules are waived to permit Medicaid eligibility for noninstitutional services.

HCFA's intention was to assist States in moving quickly through the waiver application process and to eliminate the need for individual waivers (47 FR 24274). States applying for the model waiver must meet all of the basic statutory and regulatory requirements for regular 2176 waivers but are required to offer only one home- or community-based waived service. As under the regular 2176 waiver, States may target their programs to particular subgroups of the disabled population.

Once a model waiver is approved, States can admit only those eligible individuals whose estimated home care costs are below the estimated costs for institutionalization. By contrast, under a regular waiver, States need only show that Medicaid's *average* per capita costs with the waiver would be less than they would be without the waiver.

The advantage of the model waiver is that it gives States a built-in cap on costs and a chance to gain experience with home care for the disabled on a small scale. In addition, States interested in serving children who otherwise would be hospitalized generally find that a model waiver request is more likely to be approved by HCFA than a regular waiver request. The standardized application form makes it possible to isolate a small, closely defined group of these children and show, on a case-by-case basis, the often dramatic program cost savings of caring for them at home. If the model waiver is targeted exclusively to technology-dependent children, the State also can avoid the requirement of the regular waiver to document a reduction in the number of nursing home residents. The 50-person limit, however, may mean that some States must apply for more than one waiver to serve this population adequately.

State Plan Amendment

In addition to the waiver options, States have the option of amending their State plans to expand Medicaid eligibility to disabled children under age 19 living at home who, because of the SSI deeming rules, otherwise would be eligible for

Medicaid only if institutionalized (Public Law 97-248). Only the normal range of covered Medicaid services in that State are available under this option; special services cannot be added solely for this particular group. States must ascertain for each child that home care is appropriate, and that the cost of this care is less than it would be in an institution of the appropriate care level. Once a State amends its plan, all children meeting the eligibility criteria, whether or not institutionalized, must be allowed to participate. A State can elect to discontinue coverage for this group of children at any time.

The State plan option does not require a State to prepare cost documentation or to await a lengthy approval process. States are free to develop their own implementing regulations. Yet, some States have viewed the option as being too broad and having the potential of extending Medicaid eligibility to large numbers of children who are currently being cared for in the community. From the perspective of families and providers, however, the option's major drawback is that in States with meager Medicaid home care benefits a technology-dependent child's requirements for services may not be adequately met.

State Use of Medicaid Options to Serve Technology-Dependent Children

An overview of State experience with the four Medicaid options is presented in table 21. This table summarizes waivers serving physically disabled, but not mentally or developmentally disabled, children. Although at least one State (New Mexico) uses a waiver for the developmentally disabled population as its major vehicle for providing extended Medicaid home care services to technology-dependent children, and other States may serve a few such children under such waivers, most States thus far include technology-dependent children under waivers for the physically disabled.

Thirty-three States were serving technology-dependent and other physically disabled children through a waiver as of April 1986.¹⁶ Eight States were providing these children with special home

¹⁶A number of States were renewing waivers in 1986, so these numbers may have changed.

Table 21.—State Activity in Medicaid Home” and Community”Based Service Options as of Apr. 15, 1986

State	Regular waivers serving disabled children		Model waivers serving disabled children		State plan amendment		Individual waivers for children (number of waivers)
	Approved waivers	Number of children served	Approved waivers	Number of children served	Approved plan change	Number of children served	
Alabama	1	9					
Alaska							
Arizona							
Arkansas					Yes	47	
California	1	60					
Colorado							Yes (7)
Connecticut			1	6			
Delaware							Yes (8)
District of Columbia							
Florida							
Georgia			3	7	Yes	0	Yes (18)
Hawaii							
Idaho	1	31	1	3	Yes	100	
Illinois			1	50			Yes (30)
Indiana							Yes (1)
Iowa			1	14			Yes (10)
Kansas							
Kentucky	1	36					
Louisiana							Yes (2)
Maine					Yes	66	
Maryland			1	13			
Massachusetts					Yes	a	Yes (28)
Michigan			2	38			
Minnesota			1	14	Pending ^b		
Mississippi			1	0			
Missouri	1	2					
Montana	1	30					
Nebraska							
Nevada					Yes	5	Yes (2)
New Hampshire							
New Jersey	1	3	3	40			Yes (6)
New Mexico			1	25			Yes (1)
New York			1	3			Yes (6)
North Carolina			1	7			
North Dakota							
Ohio			1	24			
Oklahoma							
Oregon							
Pennsylvania							Yes (13)
Rhode Island					Yes	12	
South Carolina							
South Dakota							
Tennessee							
Texas							
Utah							
Vermont							
Virginia							
Washington	1	15					
West Virginia							Yes (2)
Wisconsin					Yes	100	
Wyoming							
Total “yes” answers	8	207	19	244	9	331	14 134

^aMassachusetts began admitting children under this eligibility provision in fiscal Year 1987.

^bMinnesota's State Plan Amendment has been approved by the State and is pending in HCFA.

SOURCE: H.B. Fox and R. Yoshpe, “Technology -Dependent Children's Access to Medicaid Home Care Financing,” prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

care services under a regular 2176 waiver and 14 States were broadening their eligibility as well as their benefits through 19 separate model waivers. In addition, nine States had amended their plans (a tenth has now been added) and 14 had requested and received individual waivers.

Together these options have been serving 938 physically disabled children. Technology-dependent children who require device-based respiratory or nutritional support (equivalent to Groups I through III in this Technical Memorandum) appear to comprise over 60 percent of the under 21 population receiving home care under one of the three waiver programs (47).¹⁷ Among the other physically disabled children covered by the waivers, about 25 percent have central nervous system disorders (e.g., cerebral palsy, quadriplegic, or spina bifida), and about 10 to 15 percent are characterized by congenital, metabolic, or immune disorders (e.g., cystic fibrosis or congenital heart disease,) or by injury-induced trauma.

In the 17 States without either waivers or a State plan amendment, technology-dependent children are subject to the same Medicaid eligibility requirements and home care coverage that other Medicaid recipients are. In these remaining States, children who cannot qualify for Medicaid as categorically eligible or medically needy may rely on Maternal and Child Health program funds for some home services; or they may remain in an institution in order to retain Medicaid eligibility. Children who can qualify for Medicaid as poor or medically needy individuals may receive regular Medicaid home services; or, in one or two States, they may be able to receive certain additional home services under the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.¹⁸

¹⁷ Comparable diagnostic information was not available for children receiving home care services under a State plan amendment.

¹⁸ EPSDT is a separately authorized program under Medicaid offered to all low-income, Medicaid-eligible children. Its function is to detect and treat correctable abnormalities in children, such as vision and dental problems. EPSDT services are not subject to the same Federal limits and requirements as other Medicaid services, and under EPSDT States can offer services to poor children that are not available to other Medicaid beneficiaries.

Practices Limiting Use of the Medicaid Options

The special Medicaid options that can be used to extend services to technology-dependent children are limited by Federal statute and regulations, State implementation, and insufficient knowledge and understanding of the options. While some limits are unintended, others are the result of conscious efforts to control costs, or the result of serving technology-dependent children under waivers that were tailored primarily for the elderly population. For example, the requirement that a State must prove that a 2176 waiver will not increase Medicaid costs is one that for many States entails expensive and difficult documentation. In a second example, the fact that children with eligibility under the State plan amendment option can receive only regular Medicaid home health coverage means that this option may be only minimally useful in some States unless general coverage is expanded. And, expanding coverage would mean extending the home services available to all Medicaid recipients, including the elderly, which many States fear will be very costly.

A number of States have argued that HCFA procedures for waiver approval are unduly confusing and time-consuming. HCFA, on the other hand, argues that the process is relatively straightforward if States are adequately prepared and that HCFA itself offers assistance in preparing the applications. Both of these perspectives are probably valid. A lack of communication and understanding between HCFA and the States seems to have contributed to a reluctance on the part of some States to apply for waivers (or to implement State plan amendments), to follow through on the applications, or to tailor the waivers to the needs of technology-dependent children.

Although a substantial number of 2176 waivers and State plan amendments are in effect, in many States not as many technology-dependent children as might be expected are receiving the benefits of these options. Variation in the use of waivers is frequently a function of the way a program is structured with regard to income eligibility, categorical eligibility, cost-saving determinations, and service coverage. Specific State restrictions that

can limit access of technology-dependent children to Medicaid services include:

- not waiving SSI deeming rules (possible only under the regular 2176 waivers, since these rules must be waived under a model waiver),
- restricting eligibility for a waiver only to certain disease categories (possible only under model waivers),
- allowing waived services only to individuals actually discharged from an institution,
- not allowing home care costs to be compared against the costs of hospitalization (as opposed to SNFs or ICFs),
- limiting reimbursable hospital days (which may make it difficult to show program cost savings from home care to Medicaid),
- not covering skilled shift nursing (i. e., private duty nursing) as a regular or a waived service, and
- not expanding in other ways the range of regular Medicaid home services available when relying on an individual waiver or State plan amendment to serve the needs of the technology-dependent population.

Tables 22, 23, and 24 summarize the restrictions of the various home care options in specific States.

In some instances, the State's "attitude" toward financing the care of these high-cost children, a more subtle program feature to capture, is the real determinant of how many technology-dependent (and other physically impaired) children receive Medicaid home care benefits. For example, only

about one-half of the States operating Section 2176 waiver programs that include children routinely inform the families of children who face long-term hospitalization of their right to be evaluated for waiver program participation (59). Moreover, only one-fourth of the States with regular waivers and 15 percent of those with model waivers report that they publicize the availability of their programs. In Georgia, which sought (and received) three model waivers in response to great political pressure to help a few particular children, not even hospital discharge planners have been told about the waivers. Indeed, even among the Medicaid agency staff, there is much confusion and misinformation about whether additional children may be covered. A similar situation exists in Mississippi.

Many of the waiver and amendment programs have had long initial delays, often due to a shortage of case managers and home health agency personnel. In such instances, disabled children, like other potential participants, have been unable to obtain the intended home care benefits.

For the most part, the 2176 waiver programs—particularly the regular waivers—have been designed and used to serve populations other than physically impaired children. Accordingly, these waiver programs often have State restrictions intended as gatekeeping mechanisms to reduce program costs, but in practice the restrictions act to limit the usefulness of these programs for technology-dependent children.

STATE-PROVIDED SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Prior to 1981, States provided a number of specific health services to women and children under a series of categorical grants, authorized under Title V of the Social Security Act and jointly funded by the States and the Federal Government. These services included maternal and child health services; crippled children's services; supplemental security income services for disabled children; he-

mophilia treatment centers; and other programs aimed at specific groups or health problems. The 1981 Omnibus Budget Reconciliation Act (Public Law 97-35) replaced these categorical grants with a single block grant to each State, eliminating most of the requirement for specific services and allowing greater State discretion. A specified portion of the total funding continued to be set

Table 22.—State Policies and Practices That Limit Participation Under the Regular Waiver Programs That Theoretically Could Serve Physically Disabled Children, April 1986

State (year implemented)	Number and percent of participants under 21	Income eligibility restrictions			Categorical eligibility restrictions		Service limitations							
		Does not waive SSI income deeming rule	Does not allow income at 300% of SSI level	Does not include medically needy in addition to categorically eligible	Specifies certain disease categories	Requires participants to be in an institution	Does not use hospital cost comparison	Limits hospital day coverage and allows no exceptions	Does not use SNF cost comparison	Does not cover SNFs for individuals under 21	Requires every individual to show lower expected costs under the waiver	Package of waived services is not designed to serve physically disabled children	Does not cover skilled shift nursing (as a waived service or under the State plan	Relies heavily on private insurance, voluntary services and/or family-delivered services
Alabama (1984)	9 (0%)	X	X	N/A			X	X			X	X	X	
California (1985)	60 (48%)	X	X								X			
Florida (1985)	0 (0%)	X	X	N/A			X		X	X	X	X		
Georgia (1984)	0 (0%)	X	X	N/A			X	X	X					
Idaho (1984)	31 (12%)	X	X	N/A			X	X			X		X	X
Kentucky (1983)	36 (18%)	X	X	X			X	X					X	X
Missouri (1925)	23 (96%)	X	X	N/A										
Montana (1983)	3 (6%)											X		
New Jersey (1983)	3 (0%)			N/A			X				X			
Rhode Island (1982) (renewed 1985)	0 (0%)	X	X				X		X		X	X	X	
South Carolina (1984)	0 (0%)	X		X			X	X			X	X	X	
Virginia (1982) (renewed 1985)	0 (0%)						X				X	X	X	
Washington (1982)	15 (2%)			X		X	X							

NA — Not applicable in that State.

SOURCE: H.B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U.S. Congress, August 1986.

Table 23.—State Policies and Practices That Limit Participation Under the Model Waiver Programs, April 1986

State (year implemented)	Number and percent of participants under age 21	Categorical eligibility restrictions			Service cost limitations		Service limitations			
		Specifies certain disease categories	Requires certification for ICF level-of-care	Does not cover SNFs for individuals under 21	Requires participants to be in an institution	Does not use hospital cost comparisons	Limits hospital day coverage and allows no exceptions	Package of waivered services is not designed to serve physically disabled children	Does not cover skilled shift nursing (as a waivered service or under the State Plan)	Relies heavily on private insurance, voluntary services, and/or family delivered services
Connecticut (1982)	7 (86%)					X				X
Georgia I (1983)	3 (100%)	X			X	X				
Georgia II (1984)	2 (100%)	X			X					
Georgia III (1984)	2 (100%)	X			X	X				
Idaho (1983)	30 (10%)					X	X		X	X
Illinois (1984)	50 (100%)									
Iowa (1984)	14 (67%)					X			X	
Maryland (1985)	13 (100%)									
Michigan I (1983)	40 (100%)				X	a				
Michigan II (1985)	3 (100%)	X				X				
Minnesota (1985)	14 (100%)									
Mississippi ^b (1983)	0 (0%)					X	X		X	
New Jersey I ^c (1983)	23 (52%)									
New Jersey II ^c (1985)	14 (39%)									
New Jersey III ^c (1985)	3 (100%)				X					
New Mexico (1984)	25 (100%)		X			X				
New York I (1984)	3 (100%)				X	X				
New York II (1985)	0 (0%)					X		X		
North Carolina (1983)	25 (100%)									
Ohio I (1983)	42 (100%)									
Ohio II (1985)	0 (0%)					X		X		

^aMichigan compares the cost of home care to 60 percent of the DRG hospital reimbursement.

^bThe Mississippi model waiver has not served any clients and therefore has no program experience.

^cNew Jersey's Medically Needy Program began in July 1966, but the waiver programs do not cover the medically needy.

SOURCE: H. B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U. S. Congress, August 1986.

Table 24.—State Policies and Practices That Limit Participation Under the State Plan Amendment, April 1986

State (year implemented)	Service limitations			Service cost limitations			
	Number of children covered under this provision	State plan does not cover skilled shift nursing	State relies heavily on private insurance, voluntary services, and/or family delivered services	Does not use hospital cost comparison	State plan limits hospital coverage and allows no exemptions	Does not use SNF cost comparison	State plan does not cover SNFs for individuals under age 21
Arkansas (1985)	47	x	x				
Georgia (1982)	0	x		x		x	
Idaho (1984)	100	x	x	x	x		
Maine (1983)	49	X ^a					
Massachusetts (1986)	0 ^b						
Nevada (1982)	5						
Rhode Island (1985)	12	x					
South Dakota (1985)	1	x		x			
Wisconsin (1983)	100		x				

^aMaine is amending its State plan to include skilled nursing.

^bMassachusetts began admitting children under this eligibility provision in fiscal year 1987.

SOURCE: H. B. Fox and R. Yoshpe, "Technology-Dependent Children's Access to Medicaid Home Care Financing," prepared for the Office of Technology Assessment, U. S. Congress, August 1986.

aside, however, for special demonstration projects, training, and genetic disease and hemophilia programs (158).

Under the present Maternal and Child Health (MCH) block grant program, States must match every 4 Federal dollars with 3 State dollars. ¹⁹An evaluation of the implementation of the block grant program by the General Accounting Office (GAO) found that States tended to spend their allotments in ways substantially similar to prior patterns (158). In all 13 States studied by GAO in 1984, States were offering extensive services to crippled children (recently redesignated "children with special health care needs" (CSHCN)). Services offered by the States were extensive. Most States had actually increased their funding for these services, and four of the 13 States had added new services. The programs themselves showed great diversity, however, maintaining differences that existed before the block grant was established. Most program funds are now spent on screening

and treatment of handicapping conditions. However, they also fund a variety of ongoing support services such as counseling and case management. A few States operate State-owned hospitals for handicapped children.

The population served by the CSHCN program has changed considerably since 1935, when the program was first enacted. Originally, Title V specified that the program was to provide diagnostic, corrective, and rehabilitation services to children with crippling conditions, such as polio and cerebral palsy. Over time, however, the original program has expanded in many States to serve children with a wide range of chronic health conditions, and the ventilator-dependent child is a recent example of the new population (107).

The States interviewed by GAO typically provided CSHCN services through State health agencies and physicians on a fee-for-service basis. Services include "screening, diagnosis, surgical and other corrective procedures, hospitalization and after care, and speech, hearing, vision, and psychological care" (158). The Federal legislation establishing the MCH block grant prohibits the charging of fees to low-income mothers and chil-

¹⁹The Federal Government spent \$67 million on handicapped children's services in 1983, most of it from the block grant (amounting to 23 percent of the total MCH grant) (8). States spent an additional \$247.6 million, some of which was matching MCH funds.

dren and requires that when fees are charged they reflect the income, resources, and family size of the beneficiary. A number of States have sliding fee schedules for services (158).

CSHCN is a strongly clinic-based program in most States, actually providing some or all of the covered services (rather than simply reimbursing for them, as Medicaid does) (36). It is often coordinated with Medicaid; in many clinics, the CSHCN program provides the services and Medicaid reimburses the clinic for services provided to Medicaid-eligible individuals (135).

Despite the traditional emphasis of clinic-based care, most CSHCN programs fund or provide at least a limited amount of home care services, and some provide a fairly wide array of such services. The CSHCN program in Los Angeles County, California, for example, will provide or pay for home nursing services, physical and occupational therapy, respite care, and other home services. The program also provides case management for children receiving home health services, and training for families of technology-dependent children (103).

The CSHCN programs are a particularly significant source of funded care for technology-dependent children in Illinois, Louisiana, and Maryland. Between 1983 and 1986, these three States were recipients of MCH demonstration project funds for Special Projects of Regional and National Significance (SPRANS). They developed programs, extensions of their CSHCN programs, aimed at appropriate long-term care for ventilator-depen-

dent children. The programs had two principal design objectives:

1. to develop a regionalized system of care for such children; and
2. to develop a comprehensive, coordinated model of care.

The SPRANS programs of the three States differ in a number of ways. Illinois and Louisiana originally targeted only ventilator-dependent children under age 22, while Maryland targeted all children requiring some specialized respiratory support under age 18. Louisiana and Illinois run their programs out of single hospital-based centers, while Maryland's program is based in a consortium of several hospitals with a coordinating board. All programs, however, emphasize training of parents and professionals, case management and coordination of care, and care in nonhospital settings.

Through the SPRANS projects, the CSHCN program has focused attention on ventilator-dependent children and their problems in acquiring community care. These projects, and programs in certain other States, have centered on the CSHCN program as a coordinator of care. Observers and program administrators have noted that children's health services have tended to be fragmented and disease-specific, and that State CSHCN programs should seek a role in the coordination, not just the provision, of services required by technology-dependent children (106,177). Some of the State CSHCN agencies appear eager to take on this responsibility.

A COMPARISON OF HOME CARE BENEFITS IN FIVE STATES: THREE HYPOTHETICAL CASES

Because eligibility criteria, covered services, and payment mechanisms for Medicaid and CSHCN services vary so dramatically across the 50 States, it is difficult to describe generally a technology-dependent child's access to publicly financed home health services. A child may have access to excellent services in one jurisdiction but be able to receive little or no financial assistance for noninstitutional care in another. Furthermore, a State that offers little access to Medicaid services to one child may offer substantial services through its

CSHCN program, and the reverse might be true in another State. Some States that seem, on paper, to offer few services in reality have innovative ways of extending certain vital services to at least a limited population. On the other hand, States with apparently generous benefits may be very strict in actually authorizing them.

In order to portray the diversity among States, this section examines the opportunities for home care coverage that three hypothetical children

could expect in five different States: California, Georgia, Kansas, Maryland, and Missouri. The States were chosen to reflect diversity in size, geography, and urban-rural composition, and also to represent a wide range of Medicaid and CSHCN program designs. The services available to the three hypothetical children in each State are described below.

Case 1: “K”

“K” is a hospitalized 8-month-old infant with severe bronchopulmonary dysplasia. She is medically stable but still requires full-time ventilator and tracheotomy care (suctioning up to 50 times a day) and special formula feeding through a nasogastric tube five times a day. She also receives medication treatments, chest physical therapy, and range of motion exercises four times daily. The monthly cost of her home care is projected to be about \$7,620 (\$6,650 for paid nursing, \$300 for equipment, \$600 for supplies, \$50 for medication, and \$20 for a physician visit). There would be additional initial costs of approximately \$900 to cover equipment and supplies. Costs could decline as she is weaned from the ventilator.

“K” ’s mother is single and unemployed; she will rely on AFDC and food stamps to support “K” and two other children. “K” grandmother also lives with the family.

Medicaid Services

“K,” as an AFDC recipient, would be automatically eligible for regular Medicaid home care services in all five States. In Maryland, California, and Missouri, “K” would be eligible to receive augmented home services through a 2176 waiver program. (Maryland has a model waiver program to serve severely disabled children. California and Missouri both operate regular waiver programs that can include disabled children and allow home care costs to be considered against the cost of hospitalization.) In these three States, the waivers are routinely used to serve ventilator-dependent children and could provide all of the home care benefits that “K” requires.

Although Georgia operates a model waiver program specifically for ventilator-dependent children and “K” would meet the established eligibility criteria, it is not clear whether she could participate. Thus far, the State has elected to serve only three ventilator-dependent children, each of whom is comatose. Medicaid staff report that, for financial reasons, the agency is not interested in increasing the number of children receiving intensive home care services under the model waiver.²⁰

“K” would be dependent on nonwaivered Medicaid services in Kansas and probably also in Georgia.²¹ In Kansas, most of her home care needs could be reimbursed through EPSDT, because the State allows home care benefits up to \$240 per day through this special Medicaid program. However, “K” ’s home care needs most likely could not be met in Georgia, where she would receive only those Medicaid services regularly available under the State plan—physician services, medication, a limited number of intermittent nursing visits, and the ventilator equipment itself.

CSHCN Support

Extensive case management assistance for “K” ’s family could be provided in California, Kansas, Maryland, and Missouri, because the CSHCN program in each of these States has agreed to manage the care of Medicaid children with complex medical needs. In Georgia, though, CSHCN case management expertise would not be available.

Basic differences in home care benefits among CSHCN programs could affect “K” ’s potential for hospital discharge. In California and Maryland, two States in which Medicaid benefits available to “K” are already substantial, CSHCN programs would be willing to provide certain gap-filling services that may not be fully financed through Medicaid. Missouri CSHCN also could provide

²⁰Many children meet the model waiver criteria but have not been brought into the program. At present, in one hospital alone, there are more than 20 ventilator-dependent children unable to obtain home care financing.

²¹Georgia uses a maximum monthly home care service limit of \$1,200 in determining an individual child’s eligibility. Kansas uses a standard of \$240 per day. However, since total parenteral nutrition would be an additional inpatient hospital cost, it is calculated as an additional home care cost above the maximum day rate.

equipment, supplies, and some therapeutic services. Yet in Georgia, neither Medicaid nor the CSHCN program would cover “K”’s skilled nursing care.

Case 2: “M”

“M” is an 18-month-old toddler who has been hospitalized since birth due to multiple metabolic and developmental problems, including insulin-dependent diabetes, congenital heart disease, seizures, liver dysfunction, and failure to thrive. “M”’s mother, who is divorced and has no other children, is eager to bring him home and would provide much of his care herself. Once home, “M” will continue to require an evaluation and adjustment of his diet on a daily basis, monitoring of his blood glucose level four times each day, and 12 different medications, some of which must be taken two or three times daily. The estimated monthly cost of his home care is \$4,320 (\$3,700 for nursing, \$70 for equipment, \$280 for supplies, \$250 for medication, and \$20 for a physician visit).

“M”’s mother earns \$14,500 per year and has saved \$2,800. Her employee health benefits were meager and ran out quickly during “M”’s prolonged hospital stay.

Medicaid Services

“M”’s disability and low family income make him eligible to receive SSI cash benefits. In four of the five States—California, Georgia, Kansas, and Maryland—he, therefore, would be eligible for Medicaid (and regular Medicaid home health benefits) as well. Missouri, however, has elected not to provide Medicaid benefits to SSI recipients under age 21 unless they are residents of an ICF. “M,” in fact, would have no opportunity to be covered by Medicaid in Missouri. His mother’s income places them far above the AFDC payment level and Missouri does not provide benefits to the medically needy.

Under the Maryland and California waiver programs, “M” could be covered by Medicaid for his complete home care package. He would also be covered in Kansas under its EPSDT program,

which in that State is used to fund extensive treatment services for certain chronically ill children. In Georgia, the most expensive part of his care—the skilled shift nursing service—could not be reimbursed, although medication, equipment, supplies, and physician visits could. Although Georgia has three model waivers for disabled children, “M” would not be able to participate in any of these.

CSHCN Support

In Maryland and Kansas, two of the three States where “M”’s home care needs could be financed adequately by Medicaid, case management and family training would be provided through an arrangement with the CSHCN program. The Maryland and also the California program could contribute certain services, supplies, and equipment in the event that these were not covered by Medicaid. The California CSHCN program does not charge Medicaid recipients, but the Maryland program would require “M”’s family to pay a small co-payment charge. In Georgia, where the Medicaid home care benefits available to “M” would be minimal, the CSHCN program could provide his family no additional assistance. “M” would be financially eligible for CSHCN services at no charge, but the agency neither finances nor arranges for skilled shift nursing care at home.

In Missouri, where “M” would not have access to Medicaid benefits at all, he would be financially eligible for all CSHCN services, although his family would have to pay a small fee. The program, however, does not provide skilled shift nursing or other extended home care services. It would cover only “M”’s physician visits, equipment, supplies, and medication.

Case 3: “T”

“T” was diagnosed at birth as having short gut syndrome and malabsorption. Now age 6, he has been hospitalized approximately 20 times for varying periods. When at home, “T” attends school regularly with a nurse. His daily home care requirements include 20 hours of intravenous nutrients, care of the central line, and frequent monitoring of his

glucose level. The monthly cost of his care is \$17,035 (\$10,000 for nutritional supplies, \$7,000 for nursing, and \$35 for a physician visit).

"T" 's parents, who have three children, both are employed full time and have a combined annual salary of \$.52,000. They have \$6,500 in the bank, two cars, and are paying off the mortgage on their home. "T" 's hospital and home care both had been covered under his father's company insurance plan, but the family recently reached the \$1,000,000 lifetime benefit maximum.

Medicaid Services

"T" cannot become eligible for Medicaid in Missouri, where the medically needy are not covered, but in the other four States he could become eligible as a medically needy recipient. His parents, however, would have to reduce their savings and incur very substantial medical expenses in order for him to qualify. The actual amounts would vary from State to State:

- in California, the family first would have to reduce its savings to \$3,000 and then spend \$2,405 for medical care each month to become eligible;
- in Georgia, the family first would have to reduce its savings to \$2,700 and then spend \$16,332 in each 6-month period before becoming eligible (an average of \$2,722 per month); and
- in Kansas, the family first would have to reduce its savings to \$1,700 and then spend \$15,438 in each 6-month period (an average of \$2,573 per month).²²

²²These spend-down figures are based on the SSI eligibility determination methodology and each State's medically needy income level (MNIL) for one person. (The family's monthly income and an estimated \$30 in bank interest were added together, \$336 was subtracted as a living allowance for the other two children, \$1,008 was subtracted as a living allowance for the parents, and \$65 plus \$20 was subtracted as an exclusion from the parent's earned income. The remainder, minus a \$20 exclusion, was deemed available to the disabled child. Then each State's MNIL for one person was applied, as appropriate, on a 1-month or 6-month basis.)

None of the State Medicaid agency staff contacted by Fox and Yoshpe (s9) would have followed the SSI methodology as it is prescribed by the Social Security Administration. In fact, one of the States would have used its AFDC methodology. Of the three that would have used the SSI methodology, two would have used a different methodology appropriate when no other children are in

Spend-down requirements of this magnitude (ranging from \$28,860 to \$32,664 annually) obviously would place an enormous financial burden on the family. Only in Maryland could "T" be brought into the Medicaid program without his family first having to meet the spend-down requirement, because under Maryland's model waiver "T"'s family income would not be deemed available to him.

Georgia operates three model waiver programs, but "T"'s condition is not covered by any of them. Having amended its State plan, Georgia also provides Medicaid to certain children who, because of the deeming rules, otherwise would be eligible only in an institution. Under this provision, though, the State restricts eligibility to children whose home care costs would be less than the cost in an SNF or ICF, and "T" would not qualify.²³ In California, "T" could participate in the regular waiver program, but since the SS1 deeming rules would not be waived, "T" would be eligible for the program only after his family met the medically needy standard. Both California and Maryland offer parenteral nutrition as a regular Medicaid benefit and provide skilled shift nursing care as a waived service.

In the two States where "T" could receive only non waived services, his chances for adequate benefit coverage would differ dramatically. Kansas covers all necessary treatment services for children through its EPSDT program, which is not subject to the service limits of its regular Medicaid plan. Thus, after an initial screening, "T"'s parenteral nutrition and skilled nursing care both could be authorized under EPSDT.²⁴ Georgia, in contrast, does not use EPSDT to expand coverage for treatment services beyond what is regularly available under the State plan. "T" would be covered for the intravenous equipment, physician visits, and rehospitalizations, but not for

the family, two would have used the MNIL for either a three- or five-person family, and none would have included the unearned bank interest income.

²³Georgia uses a maximum monthly home care service limit of \$1,200 in determining an individual child's eligibility.

²⁴Kansas uses a standard of \$240 per day. However, since total parenteral nutrition would be an additional inpatient hospital cost, it would be calculated as an additional home care cost above the maximum day rate.

his nutritional products or skilled shift nursing care.

CSHCN Support

CSHCN programs in three of the States—Kansas, Maryland, and Missouri—provide case management and family training services to technology-dependent children enrolled in Medicaid. “T”’s family, therefore, could receive these services in Kansas and Maryland, where he would qualify for Medicaid coverage.

In California and Kansas, where SSI deeming rules could not be waived, “T” would need case management and any other available CSHCN services prior to meeting the Medicaid spend-down requirement. In California, the CSHCN program could purchase “T”’s equipment and parenteral nutrition, deliver 3 months of skilled shift nursing care, and provide continuous case management support; his family would be charged an amount equal to two times their State income tax. In Kansas, though, CSHCN covered services

—which include many of the services “T” needs—are available only to children whose family income falls below the poverty line or who are eligible for Medicaid. “T” could not receive these services during the spend-down period.

CSHCN services in Georgia, not unlike many other States, do not include any high-cost home care services. If “T” and his family lived in Georgia, therefore, they could not depend on either Medicaid or the CSHCN program to finance, even partially, the skilled shift nursing care that “T” requires.

Unfortunately, in Missouri, where “T” has no opportunity at all for Medicaid coverage, he also would have no way of obtaining home care services through CSHCN. The program, like Georgia’s, emphasizes treatment of crippling conditions and, while it has purchased sophisticated equipment on occasion, “T”’s family would be financially ineligible even for this benefit. The annual income cut-off for a family of four is \$19,000.

DEPARTMENT OF DEFENSE

The Department of Defense (DOD) provides medical care, or payment for medical care, to the dependents of active and retired military personnel. It does so in two ways: through its own hospitals, operated independently through each of the four Armed Services branches; and through CHAMPUS, which pays for care that cannot be obtained in the military hospitals. Armed services hospitals and CHAMPUS are operated independently of one another, but they provide access to the same general categories of services.

DOD pays for nonhospital long-term care in two ways. First are the regular home health benefits available under CHAMPUS. These benefits include:

- durable medical equipment, including ventilators;
- oxygen;
- parenteral and enteral nutrition therapies;
- physical therapy;
- skilled nursing care;

- medications and medical supplies; and
- physician visits.

Many technology-dependent children, however, may not be judged eligible for the full extent of these home benefits, however, because *neither military hospitals nor CHAMPUS may provide, or pay for, “custodial care”* (164). CHAMPUS’s policy manual defines “custodial care” as care rendered to a patient:

1. who has a mental or physical disability that is expected to be prolonged;
2. who requires a protected, monitored, or controlled environment, whether in an institution or in the home;
3. who requires assistance to support the essentials of daily living; and
4. who is not under active treatment that will reduce the disability to the extent necessary to enable the patient to function outside the protected environment (164).

If a military hospital (for a hospitalized child) or a CHAMPUS intermediary should determine that a technology-dependent child fits this definition, that child is then eligible only for a subset of the usual home benefits. These limited benefits include medications and medical supplies and up to 1 hour per day of nursing care.

CHAMPUS began a home care demonstration program on July 1, 1986, under which it provides extensive home care benefits (including 100 percent coverage of most costs and coverage of homemaker services) to patients who would otherwise be receiving hospital care. These patients could include children receiving intravenous drug therapy and many infants who can gradually be weaned from their dependence on respiratory or nutritional support. However, a child "must be receiving inpatient hospital care that is an otherwise authorized CHAMPUS benefit" in order to be eligible for the program (51 FR 23809). This pro-

vision still could exclude many technology-dependent children under current policy.

A second source of long-term care coverage is the Program for the Handicapped (PFTH), a special CHAMPUS benefit for handicapped dependents of military personnel. In order to receive benefits under this program, an individual must show that he or she cannot get services from public programs or institutions. Prior approval is required for coverage of all supplies and services under the program (164). PFTH covers institutional, outpatient, and home care but pays a maximum of only \$1,000 per month in benefits (164). In addition to those supplies and equipment covered under the basic program, it covers physical, occupational, and speech therapy and special educational services. Skilled shift nursing and homemaker services are not covered. PFTH, like the regular benefits program, does not cover custodial care,

OTHER PUBLIC PROGRAMS AND SERVICES

A wide variety of programs and services financed by Federal or State governments can affect the resources and services available to technology-dependent children. For example, the Federal Government provides SSI maintenance payments to disabled individuals, and it provides certain adoption and foster care incentive payments to assist in finding homes for needy children (159). States can, and often do, supplement these payments with their own. For example, most States provide supplemental payments to foster parents who provide care for handicapped or other children with special needs (159).

Certain in-home services, funded jointly by the States and by Federal Title XX social service block grants (Public Law 97-35), may be provided to low-income disabled individuals. Title XX funds are provided to States in order to prevent or remedy abuse of children and other family members; reduce inappropriate institutional care; secure admissions to and services in institutions when such a setting is appropriate; and prevent

or moderate the dependence of individuals on other persons (159). Services may include homemaker, home health aide, and other basic home services (e.g., transportation) that can supplement the home-based medical services available through Medicaid.

States may also have their own special programs, funded entirely through State and local taxes, that provide special benefits to targeted groups. Wisconsin, for example, has a State program that provides "gap-filling" funds to individuals, including children, who are at risk of institutionalization. Wisconsin also has a family support program that provides, separately from SSI, up to \$3,000 per year cash assistance to families with severely disabled children living at home (37). This example demonstrates that the resources available to a child can be enormously varied, depending on where the child lives—and on the access of that child's family to appropriate information and coordination of services.

CHARITABLE ORGANIZATIONS

Charitable organizations have long been visible sources of research and services to aid the disabled. About 20 national children's health charities operate in this field, ranging in size from very large organizations such as the National Easter Seal Society to small organizations such as the Retinitis Pigmentosa Foundation (117). The missions, disease orientations, and structures of the various charities are similarly diverse. The majority of national charitable organizations focus their efforts on one disease or closely associated set of diseases. However, an organization may concentrate on research, public education and political lobbying, direct provision of services, family education and support, or any of a number of other activities.

Charitable organizations have functioned as last-resort providers for many families with technology-dependent children. One of their most important functions in this regard is as a provider of family support and education. Table 25 lists

the expenses of selected foundations for various services, including medical services and patient education. Spending for these services range from 15 percent of expenditures (March of Dimes) to 92 percent of expenditures (Easter Seal Society) (27). "There is no strong relationship between prevalence of a chronic condition and relative magnitude of foundation support. . . . Consequently, children with certain disabilities have more resource available to them than others" (27). Researchers who interviewed a number of national charitable organizations concluded:

Although foundations expend a significant amount on direct services, they tend to provide assistance to cover only those services that are not otherwise reimbursable and that place an unreasonable financial strain on families with disabled children. These services included transportation, educational and recreational activities, physical and occupational therapy, special medical equipment, and to a lesser extent, medical care (27).

Table 25.—Total Amount of Expenses Allocated for Programs of Selected Foundations, 1979 and 1980 (millions of dollars)

Private foundation	Total program services	Research	Medical services and patient education	Public and professional education	Community services/advocacy
Muscular Dystrophy Association, 1979	\$56.6	\$18.0	\$33.3	\$5.3	
March of Dimes, 1980	49.9	10.2	7.6	18.4	\$13.6
Cystic Fibrosis Foundation, 1980	11.1	1.7	4.2	3.6	1.5
American Diabetes Association, 1980	9.7	1.7	2.7	3.6	1.7
Arthritis Foundation, 1980	6.0	2.9	^a	2.3	0.8 ^a
Leukemia Society of America, 1980	3.9	2.2	1.0	0.5	0.2
American Kidney Fund, 1979	1.5	0.04	0.9	0.2	0.4
Easter Seal Society, 1979 ^b	85.7	0.5	79.1	6.1	—

^aThe Arthritis Foundation combines patient and community services into one category

^bThe Easter Seal Society includes the combined expenditures for the national and all State and territorial Easter Seal Societies

SOURCE J A Butler, P Budetti, M A McManus, et al, "Health Care Expenditures for Children With Chronic Illnesses " In N Hobbs and J M Perrin (eds), *Issues In the Care of Children With Chronic Illness* (San Francisco, CA Jossey-Bass, 1985)

CONCLUSIONS

It is impossible to provide any accurate estimate of the proportion of technology-dependent children with private insurance whose insurance coverage includes intensive home care benefits, but it is possible to get a sense of how likely comprehensive coverage is. Although private health in-

surance is a major source of third-party payment for children, as presently structured it is inadequate to provide for the needs of technology-dependent children. It fails in several ways. First, many children are left uninsured as a result of their families' economic positions. Second, some tech-

nology-dependent children may find it difficult or impossible to obtain private insurance. Third, even those children who are privately insured have coverage that is likely to be inadequate to cover the expenses associated with these medical conditions. Finally, the structure of benefits under many policies is too rigid to deal with the needs of technology-dependent children when they are cared for in the home. Parents whose children require full-time monitoring and medical care dare not give up employment to provide some of this care, and yet in the majority of cases their insurance will not pay for a qualified professional caretaker.

Notwithstanding the seriousness of the current insurance situation for these families, the private insurance industry has made strides over the past 5 years towards accommodating payment systems to complex medical care in the home setting. It has done so primarily through case-by-case exception to normal home coverage limits.

The willingness of private insurers to provide at least case-by-case exception is vital to both beneficiaries and to public payers, because many technology-dependent children quickly lose their private benefits by reaching the maximum allowable benefit amount. The longer these children can stretch out private insurance through home care, the longer they have before they become dependent on Medicaid for health insurance.

Medicaid has likewise made some progress in the past few years towards accommodating this population. Showing cost savings to Medicaid by caring for a technology-dependent child at home is by no means impossible, and the current waiver programs have shown considerable success at serving at least a few children in this setting at less cost to the program. It is, however, generally much more difficult to show cost savings to Medicaid than cost savings to a private insurer, because Medicaid pays much less in the hospital. States have attempted to limit home and community costs by restricting eligibility or services in some cases. Unfortunately, the exclusion of certain expensive services—particularly skilled shift nursing—can absolutely prevent many technology-dependent children from coming home.

DOD has found it more difficult than Medicaid to adapt its payment system and benefits to

technology-dependent children. While the usual home benefits under CHAMPUS can be substantial, those benefits are not available to a technology-dependent child who is judged to need very prolonged, supportive care. Unless the regulations defining custodial care are changed, or the military hospitals and CHAMPUS undertake a much more liberal interpretation of the regulations when the prolonged care is very complex, long-term home care benefits for many technology-dependent children are unlikely to be forthcoming.

To the CSHCN programs in many States, the complex needs of nonhospitalized technology-dependent children offer a new opportunity to be a primary player in a significant health care issue. These programs have often acted as advocates for their clientele in the past, and they now have a significant new role to play as coordinators of payment and community services to this group of disabled children. The degree to which the programs are prepared to play this role, and their proficiency at it, undoubtedly varies from State to State. But the role seems an appropriate one, and it may give many of the programs new purpose and direction.

It is very possible that the extension of private and public insurance benefits into the home care setting will replace charity care to some extent. Charitable organizations, including local community and religious organizations, have helped many children obtain certain equipment and facility renovation. However, care coordination and skilled shift nursing have never been the province of charitable organizations, and these are the areas in which improved health insurance benefits are most likely to have an impact.

None of the solutions being implemented at the moment regarding technology-dependent children are applicable to children who will, due to some medical or home characteristic, be more expensive to care for at home than in the hospital. For some such children, home care may be the most effective and desirable even if it is not the least expensive. For other children, however, particularly those without a supportive family, other care alternatives will be necessary. Unfortunately, at present, appropriate and effective long-term care options other than the family home and the hospital are extremely rare.