
Chapter 1
Summary

INTRODUCTION

Long-term dependence on expensive and sophisticated health technology, and its use in settings other than the acute-care hospital, is not new. The polio epidemics of the first half of this century led to the use of respiratory rehabilitation centers (131), and by the end of the 1950s there were over a thousand polio survivors requiring respiratory support living at home (102). Since then, sophisticated technologies such as hemodialysis, intravenous feeding, and now intensive ventilator care have been moved home. With each have come newly recognized needs for patient and family training and, increasingly, full-time complex nursing care.

Unlike the children who were part of the earlier polio population, the present population of technology-dependent children is a diverse group of individuals with a great range of medical diagnoses, many of them very rare. These children require a broad array of technologies and have similarly diverse care and nursing needs. Without recent advances in medical technology, many of these children would not be alive. Positive-pressure ventilation, using machines that force air into the lungs through a face mask or through a surgical opening directly into the trachea (wind-pipe), began to be used regularly on hospital patients outside the operating room in the 1950s (31).

Medical technology is defined as the drugs, devices, and medical and surgical procedures used in medical care, and the organizational and support systems within which such care is provided.

SUMMARY OF FINDINGS

The Population

“Technology-dependent” is a term used to describe a small subset of the disabled child population who rely on life-sustaining medical technology and typically require complex, hospital-level nursing care. In this technical memorandum, **the**

The sophistication of these devices and their management to make them suitable for long-term use on infants fueled the subspecialties of neonatology and critical care pediatrics in the 1960s (69). New intravenous feeding technologies were added to the neonatologists’ repertoire over the next decade; the first person in the United States to respond to long-term total intravenous feeding was an infant born without a functional intestine in 1968 (46). But it is only since the beginning of the 1980s that more than a handful of hospitals and physicians have begun to consider the home environment appropriate for high-risk, technology-dependent children.

When these sophisticated medical technologies should be used, how and where they should be provided, and who should pay for them are currently subjects of public debate. To provide some of the foundation for this debate, this technical memorandum addresses four specific questions. They are:

1. Who are the technology-dependent children?
2. How many technology-dependent children are there in the United States?
3. What services do these children require, and what are the costs and effects of receiving those services at home rather than in institutional settings of care?
4. To what extent does private and public insurance cover the services needed by technology-dependent children?

technology-dependent child is defined as one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability. This definition is independent of the setting of care or the particular credentials of

the caregiver. The ongoing nursing care, usually required for substantial parts of each day, may be provided by a professional nurse or by a trained and skilled parent or other lay caretaker.

This definition can apply to a wide variety of cases, ranging from children requiring the continuous assistance of a device and highly trained caretaker to those requiring less frequent treatment and intermittent nursing care. Where one draws the line on this continuum largely determines the size of the population categorized as technology dependent. OTA identified four separate populations, distinguished from one another by their clinical characteristics, that might reasonably be considered technology dependent:

- Group I: Children dependent at least part of each day on mechanical ventilators.²
- Group II: Children requiring prolonged intravenous administration of nutritional substances or drugs.
- Group III: Children with daily dependence on other device-based respiratory or nutritional support, including tracheotomy tube care, suctioning, oxygen support, or tube feeding.
- Group IV: Children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near-daily nursing care. This group includes:
 - infants requiring apnea (cardiorespiratory) monitors,
 - children requiring renal dialysis as a consequence of chronic kidney failure, and
 - children requiring other medical devices such as urinary catheters or colostomy bags as well as substantial nursing care in connection with their disabilities.

The first three groups are narrowly defined and limited to children whose technology dependence is both life-threatening and requires frequent and complex nursing tasks. The fourth group of chil-

dren is less susceptible than the others to long-term hospitalization, largely because the frequency or complexity of required nursing care is substantially lower than for the first three groups. Under a very strict definition of technology dependence, this fourth group might not be included. OTA has included it to demonstrate how rapidly the technology-dependent population grows as additional groups are included in the definition.

Table 1 presents OTA's estimates of the prevalence of technology-dependent children in each of the four groups. Precise estimation of prevalence is impossible because of data limitations, so a range of estimates is provided for each group. **Table 1 makes it clear that the number of technology-dependent children is quite small (less than 17,000 children) when the definition is limited to Groups 1-111 but increases dramatically when Group IV is included.** Furthermore, a large number of additional children not captured by this device-based definition of technology dependence require at least as great a level of care as the children in Group IV. These children include the proportion of children with chronic diseases such as diabetes, hemophilia, and epilepsy who require constant or very frequent nursing care as a consequence of the complexity and quantity of drugs and therapy they receive. If the definition of tech-

Table 1.—Summary of OTA Estimates of the Size of the Technology-Dependent Child Population, 1987

Defined population	Estimated number of children
Group 1:	
Requiring ventilator assistance	680 to 2,000
Group II:	
Requiring parenteral nutrition	350 to 700
Requiring prolonged intravenous drugs	270 to 8,275
Group III:	
Requiring other device-based respiratory or nutritional support	1,000 to 6,000
Rounded subtotal (1+11+111)	2,300 to 17,000
Group IV:	
Requiring apnea monitoring	6,800 to 45,000
Requiring renal dialysis	1,000 to 6,000
Requiring other device-associated nursing	Unknown, perhaps 30,000 or more

SOURCE: Office of Technology Assessment, 1987

²In this technical memorandum, ventilators refer both to devices that apply negative pressure, such as the "iron lungs" that were used to treat polio patients, and to devices that use positive pressure to force air into the lungs.

nology dependence were broadened to include these chronically ill children, the population of technology-dependent children might be several times again as large.

In large measure, medical practice and parental attitudes determine how many technology-dependent children exist. In an area where parents and physicians are aggressive in managing high-risk infants, terminally ill children, and severe trauma victims, many children may survive with long-term technology dependence. In contrast, such children may die or may subsist with less intensive long-term support in areas where treatment is less aggressive due to social preference, customary practice patterns, a lack of facilities, or low payment. The physician's decision regarding when to wean a child from a life-sustaining device such as a mechanical ventilator also affects the number of technology-dependent children, and there are large variations in weaning practices among different physicians and different hospitals.

There is little evidence regarding the proportion of technology-dependent children who are hospitalized, except that it seems to vary widely among States. Children currently cared for at home generally meet discharge criteria such as a capacity for self- or family care; supportive, stable home environments; and funding for necessary equipment, supplies, and professional nursing services. Those who remain hospitalized are less likely to meet these criteria.

The population of technology-dependent children has increased in both size and visibility over the past 25 years, and it will probably continue to increase for several more. In 1960, only 3 out of every 10 very-low-birthweight (under 1,500 g) newborns survived for at least a month; by 1980, nearly twice as many were surviving (170,171). Most newborn infants in this weight group require at least temporary respiratory assistance, and the increased survival rate has certainly increased the rate of technology dependence. In fact, much of the survival is a result of that technology. Twenty-five years ago, the technology for long-term intravenous nutrition did not exist; now, children who have never been able to digest food are surviving to adulthood.

New technologies, such as improvements in the ability to prevent chronic lung disease in newborns, could reduce the size of the population, but they will not have substantial effects on the incidence of respiratory dependence for at least 2 to 5 years. Meanwhile, the number of very-low-birthweight infants surviving will probably continue to rise, increasing the total number of children with respiratory dependence. The spread of acquired immunodeficiency syndrome (AIDS) in the U.S. population will increase the number of children with dependence on intravenous nutrition and medication. Aggressive treatment of patients with ultimately fatal diseases such as cystic fibrosis and muscular dystrophy, and of infants with intestinal tract disorders that would otherwise be fatal within days, also is becoming more widespread. These developments will expand the population of children who are dependent on respiratory and nutritional technologies well into adulthood. Payment policies that adequately cover long-term care for these children will strengthen this trend. Thus, it is likely that the incidence³ of dependence on the technologies used by children in Groups I, II, and III may as much as double in the next few years, stabilizing or even declining somewhat in later years. Long survival of those who are dependent, however, means that the total number of technology-dependent children will probably not decline.

Relative Effectiveness and Costs of Home v. Hospital Care

Little objective evidence exists on the relative effectiveness of home v. institutional care on the medical status and development of technology-dependent children. Hospitals have generally been considered the most appropriate and effective setting for complex medical care, while the family home has been considered the most appropriate and effective setting for child growth and development. Considerable experience has been gained in moving complex medical care into the home in recent years, with much success. Many parents and health care professionals now consider the

³Incidence is the number of new cases during a specified period of time. Prevalence, by comparison, is the total number of cases during a period of time.

home preferable to an institution as a setting of care for even the most technology-dependent child whenever home care is possible.

Effective home care is not an unqualified achievement, however. First, and most importantly, effective home care requires that parents want their child home. Second, families must be able to cope with living with the child and the intrusions on their own private lives as a consequence of the many other people also involved in the child's care. Third, the effectiveness of home care depends on the quality of services that are provided to the family. These include:

- adequate family training and preparation,
- professional caregivers trained in the relevant nursing skills,
- appropriately designed and well-maintained equipment,
- adequate social and psychological support services,
- high-quality respite care,⁴
- appropriate home renovation,
- appropriate transportation,
- locally available emergency facilities, and
- competent case management services.⁵

Thus, while most family homes can be expected to be appropriate and effective settings of care for technology-dependent children, a few will not be effective for reasons inherent in the family situation. Some others can be effective only if especially strong social support and nursing services are provided. Reducing the level or quality of these services decreases the cost of home care to third-party payers (at least in the short term), but it also decreases home care effectiveness. Inadequately prepared families and home environments (as might sometimes occur in very aggressive early discharge programs) are likewise a threat to high-quality, effective home care.

The costs of caring for technology-dependent children are both high and highly variable. In the hospital, these costs depend largely on the duration of dependence and the intensity of need for medical care. The care of ventilator-dependent

⁴Respite care is any care designed to give the family some relief from constant caregiving.

⁵Case management is the coordination and oversight of the package of health care and related services provided to an individual,

children tends to be most costly in acute-care hospitals because these children typically require the very intense level of nursing found in intensive care units; less expensive institutional care can usually be found only in special respiratory units of rehabilitation or long-term care facilities. Other technology-dependent children can be cared for in a variety of hospital settings, and some require a level of care that can be provided by a skilled nursing facility. However, nursing homes and other nonhospital facilities that accept young children and are equipped to serve their needs are rare,

The costs of home care depend less on the child's clinical condition and more on the attributes of the family and home environment. In the home, families have tended to bear a relatively high proportion, and third-party payers a relatively low proportion, of the total costs to society. This situation has occurred because the families of these children have provided most of the highest cost services—nursing and housing—themselves.

The care of many technology-dependent children is likely to be least costly both to society and to public or private insurers when it is provided at home. **Because the cost of home care depends so heavily on social and environmental, rather than medical, factors, it is not possible to identify a specific group of technology-dependent children based on clinical criteria alone for whom home care will be cost saving to third-party payers. However, if a child is medically stable, the home has a good potential for being a less expensive setting of care than an inpatient facility.** If family members are willing and able to provide some or most of the required nursing care, and if the child will be home long enough to offset the one-time startup costs such as training and renovation, the home is very likely to be the least expensive setting of care for insurers. However, the use of family members to care for these children can involve very high costs to the family in terms of lost income, career opportunities, leisure time, or time for routine household tasks. Reducing these costs to the family—e.g., by paying for a nurse when parents work outside the home—raises home care costs to the payer,

A few technology-dependent children cannot or should not live at home. For these children, foster care, hospital care, or other institutional care must be sought, and the relative costs and quality of care in these settings must be evaluated. Foster home care is often sought for children whose natural parents cannot provide their care, although this setting raises costs to the government over care in an appropriate natural home. It may be preferred over institutional care, but it is likely to be difficult to find foster placement for all technology-dependent children who need it. Other potential settings of care are:

- transitional or subacute wards of acute-care hospitals,
- rehabilitation or chronic care hospitals (particularly specialty wards of these hospitals),
- subacute care facilities,
- pediatric skilled nursing facilities, and
- specialized community group homes (which may sometimes be considered "group" foster homes).

In many areas, few or none of these alternatives may be available. Yet they are important alternative sources not only of long-term care, but of transitional and respite care.

Sources of Financing for Home Medical Care

Both public and private payers have expanded the coverage of alternative care options for technology-dependent children in the past 5 years. However, payment for nonhospital care is still hindered by lack of coverage and poor coordination between private and public payers.

Technology-dependent children are more likely than other children to lack adequate private insurance. When they are insured, their benefits often do not cover their extraordinary expenses, particularly in the home, and they are likely to use up their families' insurance benefits rapidly. High lifetime maximum benefits (e.g., \$1 million rather than the still common \$250,000) and case management while under private insurance can extend private coverage, so long as the parent does not lose employment. Ultimately, however, virtually all very-long-term technology-dependent

children requiring a high level of nursing assistance will exceed the limits of their families' private insurance policies, will be uninsurable in the self-purchase insurance market because they are poor risks, and will end up on Medicaid. Poor technology-dependent children, or those whose families are uninsured, must turn to Medicaid from the start.

In most States, Medicaid does not routinely pay for full-time home nursing and other complex home medical services. Nor are many technology-dependent children normally eligible for Medicaid until their families have become impoverished. Since 1981, however, the Federal Government has permitted States to waive certain Federal rules regarding eligibility and services, allowing States to provide alternative mechanisms (separate from States' regular Medicaid programs) to pay for intensive home care for technology-dependent children. Three alternative options¹ are currently available to States:

1. regular 2176 "home- and community-based services" waivers, under which States can provide augmented Medicaid services to specified populations;
2. model 2176 waivers, a subset of the above waivers that can be targeted to very small and specific populations; and
3. amendments to State Medicaid plans to waive certain restrictive eligibility income requirements for individuals who meet specified criteria.

As of April 1986, 14 States had model 2176 waivers directed specifically at technology-dependent or other severely physically disabled children.² Ten States have now amended their State plans to extend Medicaid eligibility to more children in this population (59).

¹Between 1981 and 1984, individual waivers of Medicaid eligibility restrictions were also awarded to a few technology-dependent children across the country. These waivers are no longer awarded although a number are still in effect for the children who received them. Approximately 14 States still have children served under individual waivers (59).

²The exact number of States serving technology-dependent children under these waivers is unknown. States may cover such children under their 2176 waivers but not actually serve any; and many States were renewing their 2176 waivers in 1986, with some new provisions.

Although these options have enhanced the availability of Medicaid services to technology-dependent children, Medicaid still suffers from two general problems regarding home care coverage for this population. First, the Federal Government prohibits States from providing waivers of the usual Medicaid rules if program costs would increase by doing so. If Medicaid hospital payments in a State are routinely restricted (as, for example, when Medicaid limits the number of covered hospital days), it can be very difficult to show reductions in Medicaid costs when extensive home services are necessary. This restriction prevents many technology-dependent children from receiving home services. Second, apart from the waivers, States cannot offer expanded benefits to a small, defined population; once covered, a service must be made available to any Medicaid beneficiary who needs it. Both Federal and State governments have feared that expanding services to technology-dependent children would mean greatly increased expenditures as other beneficiaries also *use* these services. Medicaid's experience with expanded home benefits for the elderly has been that these benefits tended to increase, rather than decrease, program costs.

Where States have used available options to cover home care for technology-dependent children on a case-by-case basis, they have had some success in both increasing effective services and decreasing costs. However, neither States nor the Federal Government are too willing to put in place more general programs where costs will not be so tightly controlled. For the same reason, States have even been cautious in applying the waiver and State plan amendment options.

On the other hand, States are sometimes using Medicaid funds in ways that may not be strictly in line with Federal regulations in order to serve technology-dependent children more effectively. Many States find the Federal Medicaid rules increasingly complex and difficult to understand and implement.

Because the federally supported State Services to Children with Special Health Care Needs (CSHCN) programs⁶ offer more flexibility in im-

⁶Until recently, these programs were referred to as Crippled Children's Services (CCS).

plementation, a number of States have chosen them as the primary vehicle to provide and coordinate home services to technology-dependent children. The role of CSHCN as the source of case management and coordination for children served under Medicaid waivers has been particularly strong in some States (47). The CSHCN programs are more commonly perceived as active supporters of care for the disabled than is Medicaid. However, the freedom that allows State CSHCN programs to choose which groups of children they will support (e. g., ventilator-dependent children) also allows for extreme variation among States in available services, and variation within States regarding which disabled children receive extensive assistance. Other public programs (such as home-based social services) and services provided by charitable organizations supplement existing payment for home-based medical care to varying degrees across States and localities. **Thus, the availability of home medical care and related services depends on the State in which the child lives and his or her particular medical condition. A technology-dependent child may receive adequate services in one State through Medicaid, in another through the CSHCN program, in another through a combination of diverse sources, and in a fourth not at all.** A child requiring intravenous nutrition may have access to adequate home services in one State, while one who needs mechanical ventilation in that same State may receive no home services at all. And even if the child lives in a State where home benefits to serve his or her medical condition are theoretically adequate, the child's family may be given insufficient or conflicting information regarding the availability of those services.

Where adequate coverage of home medical services is available, other problems have begun to arise. As well-compensated alternatives to hospital care become more widely available, payers have incentives to limit the availability of hospital care for technology-dependent children, and hospitals have increasing incentives to discharge them, *even if the family is not adequately prepared to take the child and no other options have been developed*. This danger is both very real and very great.

IMPLICATIONS

Home care is not only feasible and desirable for many technology-dependent children but in many cases can also reduce costs incurred by insurers. Consequently, interest in extending home care benefits to technology-dependent children is likely to increase. A difficult question for third-party payers is how to offer such benefits. Enhanced home care benefits could be offered to all beneficiaries, but this strategy would substantially increase insurance costs and might discourage efficient use of such services. If insurers choose to offer enhanced benefits to a narrowly defined set of beneficiaries, issues of fairness arise. There are no clinical criteria that can neatly separate children who deserve such benefits from those who do not. **The definition used in this technical memorandum which is based on the use of a medical device, does not capture all children who need substantial nursing care in the home.** It is not necessarily directly applicable in an insurance context.

Any expansion of home care benefits is likely to increase the number of technology-dependent children at home and will have important secondary effects. These will include:

- *Increased early discharge from neonatal intensive care units.* Some hospitals are beginning to encourage earlier discharge of premature newborns (24). Increased payment for home nursing, home phototherapy, apnea monitoring, and other services are likely to strengthen the trend.
- *Increased numbers of technology-dependent children discharged to homes before families feel prepared to accept them.* Overenthusiasm in discharging children to the home could have very serious consequences for the health of these children. Quality of care could be seriously impaired if children were discharged home without adequate long-term nursing support, equipment maintenance, and backup plans if home care becomes infeasible.
- *Problems in the quality of nursing care and equipment support in the home.* A shortage of trained professional nurses and inadequate equipment-related support is already reported in some places. The shortage could get much worse if financing availability outstrips service availability. The lack of uniform guidelines and technology-related skill certification among home care nurses will exacerbate the difficulty in obtaining skilled, high-quality nursing.
- *Increased charges for home services.* Greater demand for high-technology home care services offers opportunities for home health agencies to enter this field with high prices, particularly in geographic areas where there is little competition or in areas where professional nurses trained in these techniques are in great demand.
- *Greater-than-anticipated costs to payers due to the "woodwork effect."* To at least some extent, enhanced home care benefits will replace family care rather than hospital or other institutional care. This is certainly desirable to most of the families involved and may prevent later institutionalization of many children. Nonetheless, this factor will tend to increase program costs above what was originally anticipated.
- *Increased demand for appropriate foster care or institutional care.* Few options exist outside of the acute-care hospital for children who cannot return to a family home. Availability and payment for care in small group homes, pediatric nursing facilities, and other facilities is likely to become a significant issue. The need for a source of respite care outside of the home will add to the demand for appropriate facilities.
- *Increasing numbers of technology-dependent children attending public schools.* More children living outside of institutions will lead to more children in the schools. However, there are no Federal or State guidelines regarding who pays for the health care needed by these children while attending school, or who bears liability for any adverse effects they suffer in this setting. A lack of resolution of these issues could needlessly prevent many technology-dependent children from attending school.
- *Need to better define the role of case man-*

ager and to ensure that the manager is in a position to balance the interests of the family, the third-party payer, and other involved parties.

The population of technology-dependent children is one with a constant undercurrent of change. Although “technology-dependent” has often been used as a euphemistic label for children whose home care was expected to be less expensive than institutional care, changes in tech-

nology and underlying diseases continually alter its character. Children needing dialysis for kidney failure do not raise the same concerns as children needing ventilation, for the most part because payment for dialysis services is largely assured and outpatient or home care has become routine in most cases. New approaches to medical practice and health care financing may yet accommodate the most complex of today’s and tomorrow’s technology-dependent children as well.