Chapter 2

The Size of the Technology= Dependent Child Population

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INTRODUCTION

Although the technology-dependent population is frequently discussed, it has never been defined. Simply put, technology-dependent' children are a vaguely defined subset of the much larger disabled child population. **In this technical memorandum, the term "technology-dependent" refers to those children who use a medical technology (embodied in a medical device[2]) that compensates for the loss of normal use of a vital body function, and who require substantial daily skilled nursing care to avert death or further disability.**

This definition has four important characteristics. First, medical devices are used as a basis for defining the population, because device use is observable. Second, OTA is including only life-sustaining technologies in the definition. A great many other children exist with extensive health care needs, but they are not included here. Third, the dependence is assumed to be prolonged. "Prolonged" is not defined directly, and its meaning varies somewhat with the type of technology, but it is assumed not to include situations such as a premature newborn who outgrows the need for ventilation after only a few weeks. Finally, "skilled nursing care, " as used in this technical memorandum, means any care that requires highly technical nursing skills, including care provided by nonprofessionals such as parents trained in these skills.[3] Technology-dependent children often have mental, behavioral, or emotional disabilities in addition to the above characteristics, but they are set apart by the level and nature of care—both in terms of medical device support and skilled nursing care—required by their chronic physical disabilities.

This chapter begins with a description of some of the problems encountered in defining technology dependence and the use of this term by others. [q] The chapter then translates the general definition into a working definition for the purpose of estimating the number of technology-dependent children. Four clinically distinct groups of children are identified. Three are unquestionably technology dependent under the general definition; the fourth group meets the technical definition of technology dependence but has nursing needs that are substantially lower than those of the first three groups. (App. C presents some potential implications of this working definition. Those implications are not discussed directly in this chapter.)

The central part of this chapter presents the existing evidence on how many children are in each group. Finally, the chapter describes trends in the population at risk of technology dependence, particularly evidence on changes in the number and survival of children with chronic diseases, high-risk infants, and children with progressive, terminal illnesses.

[1]Some people prefer the term "technology-assisted" to the term "technology -dependent," but the latter term has been more common in recent legislation and is used in this technical memorandum.

[2]A medical device is any instrument, apparatus, or similar or related article that is intended to prevent, diagnose, mitigate, or treat disease or to affect the structure or function of the body (161).

[3]Nursing services are generally recognized as a group of medical services that cannot be performed by the average person without considerable training. They differ from custodial and personal care services (e g., dressing, bathing, or feeding a patient) which less trained people can perform safely.

[q]The development of this chapter was greatly aided by the discussion at a workshop conducted by OTA on the subject. The workshop agenda and a list of participants are included in app. B.

PROBLEMS IN DEFINING THE POPULATION

The need to define the technology-dependent child population arises not from any inherent attribute of this group but from the organization and priorities of the health care payment system in the United States. The home health care benefits of most third-party payers—private insurers, State governments, and Federal health programs —have been limited both in scope and in amount. The adaptation of sophisticated medical devices and services to the home setting were likewise limited. Over the past decade, however, the adaptation of these technologies to the home has greatly expanded. Today, there are children with *very* high long-term hospital costs who could be cared for at home with such technology if payment for that intense level of home care were available, Many third-party payers have come to pragmatically define technology-dependent children as those children whose care is likely to be very expensive, who could safely be cared for at home given sufficient services, *and who are likely to cost less to the payer* if cared for in this environment. But such a definition does not provide clinical or functional criteria for identifying technology-dependent children. Rather, it is a criterion for case-by-case waivers of a payer's usual limits to home health benefits and services.

This pragmatic, payment-based definition presents a serious problem because it excludes seemingly similar technology-dependent children who might benefit greatly from nonhospital care, but who may cost more in the home due to their particular family or home characteristics. Moreover, this pragmatic definition provides no basis for estimating the number of technology-dependent children, even the number who would fit the definition as stated, because there exists no systematic way to count such children.

Legislation introduced in 1985 attempted to provide more specific definitions of "technology dependent. " S. 1793 defined a "medical technology dependent child" as "an individual under the age of 21 who *has a medical condition (specified by the Secretary in regulations)* which would require inpatient hospital services in the absence of home or community-based care, and who is dependent upon medical technology in order to avoid death or serious injury" (emphasis added). In contrast, H.R. 2703 would have provided home care benefits only to ventilator-dependent people, irrespective of age. These persons would be eligible for benefits if they required a ventilator at least *6* hours per day; had required this technology for a month while in a hospital or skilled nursing facility; and would require institutionalization if the necessary respiratory services were unavailable at home.

These definitions illustrate two congressional concerns regarding a definition of the technology-dependent child population. First, the population of greatest concern is those children who, but for the availability of special services and financing, could not be cared for at home. Second, "technology" has been used to mean medical devices, rather than only skilled medical services. Both of these criteria reflect a desire to accommodate the needs of technology-dependent children while maintaining control over Medicaid costs.

The prototype of the technology-dependent child is one who cannot breathe without a mechanical ventilator (see box A). The life of such a child depends on an expensive and sophisticated piece of equipment, trained personnel to perform the necessary procedures that accompany its use, and a multiplicity of other devices, drugs, and therapies, Until very recently, such a child was nearly always cared for in an acute-care hospital until the child died or could be weaned from the ventilator, a process that could take months or years.

While all agree that the child on a ventilator is technology dependent, there is still a great deal of confusion over what other groups of children meet this description. The population of children who might be considered technology dependent is enormously diverse, Variations occur in the length of dependence; a child may be ventilator-dependent for 10 years, or *2* years, or *2* months. Care needs vary in frequency and intensity across children as well. While one child may need skilled nursing care *24* hours a day, another might need such care only *8* hours a day, or 2 times a day for 2 hours each. Some children require minimal medical equipment but a great deal of skilled nurs-

Box A.–Profile of a Ventiilator-Dependent Child

Conditions leading to ventilator dependence may develop anytime in childhood or adolescence. A teenager, for example, may suffer permanent breathing impairment due to chronic illnesses such as cystic fibrosis or muscular dystrophy. Spinal cord trauma, which can damage the nerves that enable breathing, is also a fairly common cause of ventilator dependence in children and adolescents. Or, ventilator dependence may be due to breathing difficulties present at birth.

A ventilator-dependent child sometimes begins life as a premature baby, initially given oxygen and 24-hour ventilator support because he (or she) is unable to breathe adequately on his own. Since the baby is also unable to suck adequately, he must be tube fed as well. A physician may create a gastrostomy (a surgical opening into the stomach) to make feeding easier.

When attempts are made to reduce mechanical ventilation, it becomes clear that the infant cannot breathe on his own even for a few minutes. The infant's windpipe becomes irritated from having the nasal tube changed. The physician creates a tracheotomy (a surgical opening in the throat) so ventilation can be administered more directly to the lungs. A tube, which can be connected directly with the ventilator, is inserted into the windpipe; this tube must be suctioned frequently, so it does not become clogged with secretions, and changed regularly with great care to prevent infection at the tracheotomy site. Since a clogged tracheotomy tube would cut off all air, the infant must be watched constantly. The nurse must perform these duties as well as administer nutrients several times a day through the gastrostomy tube, take frequent blood samples to check the level of oxygen and other gases, administer aerosols and antibiotics to moisten the airway and prevent infection, and still offer all the normal comfort and care a newborn infant must receive. A physical therapist may begin exercises to help the infant maintain physical development; a respiratory therapist may perform procedures to help his breathing. The infant's parents may spend a great deal of time with him to hold him and learn to care for him. If circumstances permit, they may take him home.

As the infant matures, he may gradually be able to sustain breathing for longer and longer periods of time on his own and may begin to learn to eat normally. Finally, if he becomes able to both eat and breathe satisfactorily on his own, the tracheotomy and gastrostomy openings are surgically closed. No longer so dependent on equipment, he may still receive frequent treatments for respiratory infections and asthma-like attacks. He continues to receive physical and speech therapy to bring him up to the level of other children his age.

ing (e. g., a child with both uncontrolled diabetes and severe epilepsy), while others may need sophisticated medical equipment but only periodic supervision (e. g., a capable older child receiving overnight intravenous nutrients).

Because of the lack of existing criteria and the diversity of the population that might be considered technology dependent, it is difficult to distinguish technology-dependent children from the larger population of disabled children of which they are a part. As a child's disability becomes gradually more (or less) immediately life-threatening, and the frequency and level of skilled medical intervention increases (or lessens), the boundaries between technology dependence and less life-threatening disabilities blur. A child with muscular dystrophy, for instance, loses muscle strength gradually, first requiring braces, then a wheelchair, then occasional supplemental oxygen or ventilation, and perhaps finally a full-time ventilator. The process may be reversed for an infant on a ventilator whose breathing problems resolve over time.

Table 2 describes children who are presently served by several programs that offer alternatives to hospital care for severely physically impaired children. These children display a wide range of medical problems. While many are obviously technology dependent, requiring both highly sophisticated medical equipment and highly skilled and intensive nursing care, others require constant caretaking and monitoring that depends neither on expensive equipment nor on intensive medical training.

Table 2.—The Population of Children Currently Served in Programs Emphasizing Alternatives to Hospital Care

Categories	Description	Services	Sample diagnoses
Children who have acute *medical/surgical problems*	Children with acute medical/ surgical problems who are discharged early from the hospital but who continue to need individualized technical care for limited periods of time	These children may require medications, unusual feedings, monitoring of vital signs, certain forms of technical treatment, etc.	Severe infectious disease Postoperative conditions Low-birthweight infants
Children who have a *terminal illness*	Children requiring technical care for a terminal illness that is expected to result in death within 6 months.	These children may for a period of time require oxygen, assistance in feeding, and/or medication for comfort.	Terminal cancer Renal failure
Children who are *severely intellectually disabled*	Children who as the result of an illness, trauma, congenital anomaly, or hereditary disease are severely intellectually disabled so that they cannot and will not in the future be able to care for themselves.	These children require varying degrees of assistance in feeding, defecation, urination, positioning, and other personal care.	Severe microcephaly Severe post meningitis Severe hydrocephalus
Children who have *chronic medical problems*	Children who will have chronic medical problems for long periods of time and are dependent on technical care.	These children may require complex alimentation, certain medications, suctioning, catheterization, intravenous therapy, tracheotomies, equipment monitoring, prescribed therapy regimens, and/or colostomies/ ileostomies.	Chronic malabsorption syndrome Severe cystic fibrosis Multiple congenital anomalies Severe seizure disorder Dystrophies Atrophies Myasthenia Chronic aspiration syndrome Short gut syndrome
Children who have *chronic respiratory problems*	Children who will be oxygen dependent for relatively long periods of time.	These children will require oxygen and may require suctioning or cardiopulmonary monitoring	Chronic bronchopulmonary dysplasia (BPD)
	Children who need ventilation assistance for periods of time	These children will require ventilator care and bronchial suctioning. They may require cardiopulmonary monitoring and gastrostomy feeding.	Chronic BPD Post encephalitis Progressive CNS disease Tracheo-bronchial malacia Ondine's curse
	Children who are completely ventilator dependent	These children require constant ventilator care, bronchial suctioning, and cardiopulmonary monitoring and may require gastrostomy feeding.	Chronic BPD Post encephalitis Progressive CNS disease
Children who have Central *Nervous System (CNS) dysfunction*	Children who have CNS problem, either the result of trauma or CNS disease so that they cannot and will not be able to care for themselves.	These children may require assistance in physical positioning, feeding, defecation, and/or urination. (Some may also be ventilator dependent.)	Progressive CNS disease Spinal cord trauma

SOURCE J MacQueen, "Alternatives to Hospital Care, " unpublished, Aug. 5, 1986

ESTIMATING THE PREVALENCE OF TECHNOLOGY DEPENDENCE

OTA's Working Definition

To estimate the size of a population quickly and with reasonable accuracy, criteria are needed that can easily distinguish this population from others, Therefore, concrete characteristics (e.g., a particular diagnosis or the use of a very visible technology) should be the basis of the definition, and data sources must be available whose categories are consistent with the definition. The most easily identifiable aspect of technology-dependent children is their continual dependence on a medical device to replace or compensate for a vital body function or avert immediate threat to life. Thus, in this study, four groups of children are identified whose reliance on medical devices and nurs-

ing care for maintenance of life make them candidates for classification as technology dependent:

- Group I: Children dependent at least part of each day on mechanical ventilators. [s]
- 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 groups are designed to be mutually exclusive. If a child requires technologies from more than one group, he or she is considered only as part of the applicable group with the lowest number. For example, a child requiring both ventilation and parenteral nutrition would be placed in Group I.

Groups I, II, and III comprise children whose characterization as technology dependent is generally accepted in discussion among parents, providers, payers, and policy makers (although the range of service needs of such children varies widely). In contrast, Group IV encompasses a broad range of children whose technology dependence is less life-threatening and requires less frequent or less complex nursing tasks. The children in this group are less susceptible than children in the first three groups to long-term institutionalization as a consequence of their disabilities, and they are not universally recognized as technology dependent. They are included here because they demonstrate how the numbers of technology-dependent children change as additional groups are included in the definition.

[s] In 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.

Data Sources and Sampling Problems

The lack of a formal definition of technology dependence, its rarity, and the difficulty in detecting it have thus far prevented any reasonable estimation of the size of the population from existing common health surveys. Table 3 summarizes a number of these surveys and the populations they describe. They are generally of two types: institution-based surveys, such as surveys of hospital discharge records (which list items such as age, diagnosis, and surgical procedures for a large sample of hospital patients); and household interview surveys, in which family members are asked about various aspects of their health. None of the information from these surveys is directly correlated with technology dependence as defined in this technical memorandum.

Approximately 2 percent of noninstitutionalized children (over 1 million children) are limited in their major daily activity (e. g., attending school) (123,124). An additional group of mentally and physically handicapped children reside in institutions. Whatever the exact size of the technology-dependent child population, it must be considerably less than this total disabled population. There are two basic approaches to estimating the size of such a small population: counting it directly, and statistical estimation based on a sample of children. Because technology dependence is rare, a sound statistical estimate would require a very large sample. As table 3 shows, there are no major national health surveys that are comprehensive enough or detailed enough to support a prevalence estimate for this population.

The primary sources of data used as the bases for the OTA estimate of the number of technology-dependent children are State-based programs (in most cases relating to home care provided under public medical aid programs) and national home nutrition program registries. Table 4 sum-

Table 3.— Major National Health Surveys and Data Systems

Survey or data system	Population surveyed	Periodicity	Relevant data elements	Selected limitations
National Health Interview Survey (NH IS)	Approximately 40,000 households (about 30,000 children).	Annually	Activity limitations, certain chronic conditions, hospital and physician use	Institutional population excluded, sample too small to detect very rare conditions, functional limitation measures very general
NHIS Child Health Supplement	1 child per above household (about 15,000 children)	1981; may be done in future again	Detailed perinatal and child care, child development, child health problems	Same as NHIS
National Medical Care Utilization and Expenditures Survey	Approximately 6,600 households (about 4,500 children)	1977, 1980, planned 1987	Same as NHIS plus additional data on income, Insurance, medical expenditures	Same as NHIS
National Hospital Discharge Survey	Discharges from approximately 420 short-stay hospitals	Annually	Age, race, sex, medical diagnoses, procedures done in the hospital	Sample too small to detect very rare conditions, not an unduplicated count of persons, no data on outpatients, nonhospitalized children
National Ambulatory Medical Care Survey	Office visits to approximately 3,000 physicians	Annually from 1983-1981 ; 1985	Age, race, sex, reason for visit, diagnoses, procedures performed	Sample too small to detect very rare conditions, excludes clinic and institutional visits, not an unduplicated count of persons
National Health and Nutrition Examination Survey	Households, Including about 6,000 to 7,000 children	1971-1975; 1976-1 980; planned 1988	Data from physical exam and laboratory tests	Small sample, institutionalized population excluded
Birth Defects Monitoring Program	Discharges from 928 hospitals, about 22% of U.S. births	Annually	Discharge abstract data for 161 birth defect categories	May not be representative sample of births, newborn data only, cannot directly detect technology dependence
office of Special Education	State-reported data on children served in special education programs	Annually	Number of children served by handicapping condition categow	Handicapped categories very broad, categories not consistently defined among States, do not include children not served by programs
Survey of Institutionalized Persons	Persons living in facilities with average stays over 30 days	1976 only	Age, race, sex, cost of care, condition treated, physical limitations	Limitation categories very broad, noninstitutionalized population excluded, data old, analysis excluded some institutions
Census of the Population	All households; sample of institutionalized persons	Every 10 years	Age, race, sex, education, region, type of institution	No health-related functional data included, institutional categories very broad

SOURCES: F M. Ellman, National Association of State Directors of Special Education, Inc , Washington, DC, personal communication. January 1976, M A. McManus, S.E. Malus, C H Norton, et al , Guide to *National Data on Maternal and Child Health* (Washington, DC: McManus Health Policy Inc., 1966), U S. Department of Commerce, Bureau of the Census, 1976 Survey of *Institufionalfzed Persons" A Study of Persons Receiving Long-Term Care,* Current Population Reports Special Studies, series P-23. no. 69, June 1978, U S Department of Education, Office of Special Education, 9th Annual Report to Congress on the Implementation of the Education of the Handicapped Act, 1987

Table 4.— Data Sources Used as Bases for OTA Estimates

Source	Population Included	Original purpose of information collection
State data		
Illinois	All ventilator-dependent children in State; all other children served In State program for handicapped children	State Information; evaluation program for similar State programs
Louisiana	Ventilator-dependent children served in special State home care program	State Information, evaluation program for similar State programs
Maryland	Children dependent on respiratory support devices who are served in special State home care program	State Information, evaluation program for similar State programs
Massachusetts	People dependent on ventilators for longer than 3 weeks	Survey to determine the numer of ventilator dependent Individuals
New Mexico	Ail children served by State Medicaid waiver for technology-dependent children; other similar children identified in State but not eligible for the program	State Information, Medicaid requirements
North Carolina	All children in State who are ventilator dependent and have been medically stable for at least 2 months	Demonstrate potential need for pediatric respiratory unit
Wisconsin	Children eligible for Medicaid home services on the basis of being disabled and at a level that would otherwise require institutionalization	State information, Medicaid requirements
American Associatlon for Respiratory Care	Res Respiratory therapists nationwide via their State representatives (37 States responded); asked to provide information on all ventilator-dependent patients they were serving	Document the number of ventilator-de~endent persons and the degree of institutionalization
Commercial nutrition reaistries	Individuals served by companies or organizations maintaining 'the registries between October 1984 and April 1985	Develop a database of persons on home nutritional support technologies
OAISIS registry, Oley Foundation	Patients served by hospital and community - based programs responding to a 1985 survey of such programs	Develop ongoing database of characteristics of persons using home nutritional support
Hambrecht & Quist home infusion market analysis	National hospital discharge data and detailed information from a nonrandom sample of hospitals	Provide estimates of the current and future market for home Infusion technologies
Abbott Laboratories home infusion market analysis	Not specified	Provide estimates of the current and future market for home Infusion technologies

SOURCES M J Aitken and L A Aday, Home *Care for the Chronically Ill and/or Disabled Technology Assisted Child An Evaluation Model,* unpublished. November 1985 E Lis, Crippled Children's Services Chicago, IL, personal communication, April 1986; K Valdez, Human Services Department, Santa Fe NM, personal commu nication July *22,* 1986, P Tschumper, Department of Health and Social Services, M adison, WI, personal communi cat ton J u l y *22.* 1986; G Worley, Duke University Medical Center, Durham NC, personal communication, July 1986, Care for Life, paper prepared for U S Congress Off Ice of Technology Assessment 1985, Oley Foundation, paper prepared for U S Congress, Off Ice of Technology Assessment 1985, B B Rucker and K A Holmstedt Home *Industry Therapy Industry* (San Francisco CA Ham brecht & Quist, April 1984), Blue Cross and Blue Shield Association, */n fusion Therapies in* Home *Health* Care (Chicaco, IL BC/BSA January 1986)

marizes these data sources and some of their characteristics. The OTA estimates are not derived from large random samples; their validity rests on the fact that very different and independent sources of information yield estimates that are within an order of magnitude of each other.

Estimating Prevalence

The number of cases of a disease in the population can be described in three ways:

- the number of new cases during a period of time (incidence),
- the total number of cases during a given period of time (period prevalence), and
- the total number of cases at a single point in time (point prevalence).

The size of the technology-dependent population depends on which of these measures are used and, for incidence or period prevalence, the length of the period. Point prevalence is analogous to an instantaneous total count of the population. Period prevalence is more relevant to surveys, which often take several months to conduct, and to programs, which usually estimate budgets for serving a population over a period of a year. Thus, period prevalence—specifically, the estimated total number of technology-dependent children during 1987—is used in this technical memorandum.

A major problem with the data sources used in this chapter to estimate the prevalence of technology dependence is that they enumerate cases during different time periods. Some of the surveys present the prevalence of a condition (e. g., ventilator dependency) over one or more months, rather than over a year. To obtain the total prevalence in a year, one should add to this monthly total the number of new cases that arose during the succeeding months in that year. However, there is no basis for estimating how many of those new cases would arise. In such cases OTA assumes an incidence and duration of technology dependence consistent with what few data are available. That assumption is stated in the discussion of the estimate.

In deriving consistent prevalence figures from the data, OTA also uses the implicit assumption that the incidence and duration of technology dependence are stable. However, there are indications that duration of technology dependence may be increasing as children on these technologies survive longer. Incidence may also be rising with increased survival of extremely premature babies and the advent of acquired immunodeficiency syndrome (AIDS), two conditions that can lead to technology dependence. An increase in either incidence or duration of technology dependence would increase the prevalence of the population. These and related issues are discussed further in the second half of this chapter.

Estimates

Group I: The Ventilator-Dependent Population

The most soundly-based estimates are those for ventilator-depedent children. To estimate the size of this population, OTA used the numbers obtained from each of the States and organizations that have attempted to identify such children. From these numbers, OTA obtained a rate per child under the appropriate age group (e. g., under age 18) in the State. That rate was then applied to the entire U.S. child population to obtain an estimate of the number of ventilator-dependent children that would exist if every State's medical practice patterns and other relevant characteristics were similar to the reference State. To accommodate differing age boundaries, OTA provides estimates both for children under age 18 and children under age 22. [b]

Table 5 presents the estimated number of ventilator-dependent children in six States and one multi-State survey documented during the past 3 years. The populations varied considerably among the States; different States identified or reported children in different age groups, ranging from children under age 16 (Massachusetts) to

[b]In extrapolating estimates to the different age groups, the lower bound of an estimate assumes that no individuals between the ages of 18 and 22 require the technology, while the upper bound assumes that these individuals have this attribute at the same rate as those under age 18,

Table 5.—Estimates of the Number of Ventilator-Dependent Children

State	Survey year	Survey period	Age group	Number ventilator dependent	Rate per million children	Extrapolation to US. per survey period		Extrapolation to U.S. per year[a]		Percent in institutions
						Under 18	Under 22	Under 18	Under 22	
Illinois . .	1985	1 year	0-21	74	19,0	1,191	1,500	1,191	1,500	3 6 %
Louisiana	1986	1 year	0-21	35	23.8	1,305	1,643	1,305	1,643	1 3 %
Maryland	1985	1 year[c]	0-17	26	23.9	1,498	1,886	1,498	1,886	2 3 %
Massachusetts .	1983	1 month	0-15	14	13.5[d]	843	1,062	1,096	1,381	8 6 %
New Mexico	1986	<1 month	0-21	4	74	577	726	753	948	7 5 %
North Carolina . .	1986	1 month	0-17	7[f]	4.3	268	337	421	530	43 "/0
AARC survey (37 States)	1985	1 month	0-17	445	8.3	520	655	679	845	5 5 %

[a]See footnote 7 in text for explanation of conversion from monthly to annual Prevalence
[b]Illinois, Louisiana and Maryland have active programs to place ventilator-dependent children at home
[c]Not reported, apparently at least a year
[d]Adjusted for 82 percent response rate Remaining institutions were assumed similar to responding Ones
[e]Figure applies t. all patients in the survey, including adults
[f]Four of th. seven children had been discharged home on ventilators during the past 3 years It is unknown whether all four children cared for at home are still alive and ventilator-dependent, but they were assumed to be so for the purposes of this table Thus, in converting from monthly to annual prevalence, 4/7 of the U.S extrapolation was not converted up, since this part of the number represents a 3-year prevalence rather than a 1-month one

SOURCES. Office of Technology Assessment, 1987 Data from K Kirkhart, Children's Hospital, New Orleans, LA, personal communication, January 1987; M.J Aitken and L A Aday, Home *Care for the Chronically Ill and/or Disabled Technology Ass/steal Child An Evaluation Model*, unpublished, November 1985, K Valdez, Human Services Department, Santa Fe, NM, personal communication, July 1986; G. Worley, Duke University Medical Center, Durham, NC, personal communication, July 1986, Care for Life, "Life Sustaining Technologies and the Elderly Prolonged Mechanical Ventilation," paper prepared for U S Congress, Office of Technology Assessment. 1985

children under age 22 (Maryland and New Mexico). The operational definition of individuals on "prolonged" ventilation also varied.

The lower bound of the ventilator-dependent estimate is based on a survey conducted during one month in 1985 by the American Association for Respiratory Care. This survey yielded data from 37 States, which when extrapolated to the U.S. population as a whole yielded an estimated *520* ventilator-dependent children under age 18 that month, or roughly *680* children per year.[7] This estimate is slightly higher than the lowest State-based estimate. It is used instead of that number because of the evidence that at least a few States have much higher prevalence. The highest estimate is based on data from Maryland which imply a nationwide population of 1,886 ventilator-dependent children per year under age 22. OTA has arbitrarily increased this number by 10 percent, to 2,000, to obtain an upper estimate. This upper bound accounts for both a possible undercount of the universe of ventilator-dependent children in Maryland and for any increases in the population between 1985 and 1987.

[7] "TO derive an annual prevalence from a monthly one, OTA assumes an average duration of 3 years for ventilator dependence (probably low but consistent with pre-1 984 data from Louisiana). The monthly incidence is then multiplied by 11 and added to the monthly prevalence to yield annual prevalence.

Group II: The Intravenous Therapy Population

Parenteral (Intravenous) Nutrition.—To estimate the number of children requiring parenteral nutrition, OTA extrapolated from the available State data to the United States as a whole and compared those numbers with nutritional registry data. Extrapolations and registry figures are summarized in table *6*.

The State data from Illinois, New Mexico, and Wisconsin are underestimates of the children on parenteral nutrition in these States, because they include only home patients who are monitored by these programs. However, since the universe of ventilator-dependent children is known in Illinois, and the proportion of those children served by the Services to Children with Special Health Care Needs program is also known, an estimate

Table 6.—Estimates of the Number of Children Requiring Parenteral Nutrition

Source	Basis for estimate	Comments on manipulation	Extrapolated U.S. estimate
Commercial registries, 1984-85	373 children under age 18 on home parenteral nutrition documented on one of two registries supported by home nutrition companies.	Assumed to be a national minimum estimate.	373 children on parenteral nutrition under age 18 (per 7-month period).
Illinois, 1985	5 children requiring parenteral nutrition served by State program (compared to 22 children in program on vent i lators).	Total of 74 ventilator-dependent children known in entire State. Assumed children on parenteral nutrition are represented in proportion.	341 children on parenteral nutrition under age 22 (at time of program documentation).
New Mexico, 1986	2 children on parenteral nutrition served by State program (compared to 5 children in program on ventilators).	Probably not total State population of children on parenteral nutrition, Used simple extrapolation.	232 children on parenteral nutrition under age 18; 292 under age 22 (at time of survey).
Wisconsin, 1986	4 children on parenteral nutrition served by State program (compared to 5 children in program on ventilators).	Probably not total State population of children on parenteral nutrition, Used simple extrapolation.	At least 192 children on parenteral nutrition under age 18 (at time of documentation). Fewer children on parenteral nutrition than *on* ventilators,
Hambrecht & Quist market estimate, 1983	Estimated U.S. home care market of **2,700** patients per year requiring parenteral nutrition,	About 13°/0 of patients in commercial registries under age 18; apply to this figure.	351 children on parenteral nutrition under age 18 in 1983 (for 12-month period); market assumed growing.

SOURCES Oley Foundation "Nutriltional Support and Hydration for critically and Terminally Ill Elderly, " paper prepared for Office of Technology Assessment, September 1985, E Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986, G Cleverly, Human Services Department, Santa Fe, NM, personal communication 1986 P Tschumper, Department of Health and Social Services, Madison, WI, personal communication, April 1986, B B Rucker and K A Holmstedt, Home Infusion *Therapy Industry* (San Francisco CA Hambrecht & Quist, Inc , April 1984)

of the universe of children on intravenous nutrition in Illinois can be derived by assuming that the latter children are represented in the program at the same rate as the former. If children on parenteral nutrition are less likely than ventilator-dependent children to be served by this program (e.g., if Medicaid or private insurers cover home parenteral nutrition costs more comprehensively than ventilation costs), this method will underestimate the nutrition population. [8]

Equivalent calculations cannot be performed with the Wisconsin or New Mexico estimates. Nonetheless, these data provide additional evidence that there are somewhat fewer children on prolonged parenteral nutrition than on prolonged ventilation.

The commercial registries provide the most comprehensive data on children who received home parenteral nutrition. The registry data available cover only 7 months, however, and not all patients served are represented by these data. The cumulative total from this source roughly agrees with the estimate from the market analysis report. Both sources are underestimates of the prolonged parenteral nutrition population, because they assume that no such children reside in institutions. Based on these figures and the State extrapolations, OTA's estimated lower bound for the number of U.S. children receiving prolonged parenteral nutrition is 350 children per year.

An upper bound for this population would accommodate several assumptions: 1) that the population documented in the registry would have been higher had the registry covered a full year, 2) that all children served at home even during that 7 months were not documented on the registry, 3) that some additional children on parenteral nutrition reside in institutions, and 4) that the population has increased somewhat since 1985. An upper bound of **700** (double the minimum estimate) accommodates these hypotheses to a reasonable degree. However, even this upper bound may soon be an underestimate given current trends in diseases and therapy (discussed later in this chapter).

[8] "Children requiring parenteral nutrition would be more likely to have adequate home care insurance coverage than ventilator-dependent children, for example, if shift (e. g., 8-hour) nursing were an uncommon benefit. Lack of nursing is more likely to absolutely prohibit a ventilator-dependent child from going home than a nutritional-dependent child.

Intravenous Antibiotic Therapy and Chemotherapy.—Intravenous drug therapies are generally administered for weeks or months, rather than months or years as is the case for other technologies. They are included here because they are technologies that require substantial skilled nursing and involve issues in nonhospital care that are very similar to the issues surrounding parenteral nutrition.

Market analyses and literature reports on the number of individuals served in various home intravenous drug programs are used as the basis of estimates of the size of this portion of the Group 11 population, because they are the only sources available. Table 7 summarizes these sources and the estimate derived from them. The foundation of the estimate is a market analysis figure. The primary data sources and reliability of the market analyses are unreported in detail. Data from specific programs are used to estimate the proportion of the relevant population that is children. To the extent that these programs are geared towards adults rather than children, they underestimate the population. Home program numbers were adjusted by OTA to account for equivalent children not served at home.

An estimate of the number of children who receive intravenous drugs and chemotherapy is particularly sensitive to whether one is considering patients per year or patients actually receiving intravenous therapy at a single point in time. The number of cases per year is estimated here. Based on the information presented in the table, between 268 and 8,275 children receive prolonged intravenous drug therapy per year.

Group III: Children Dependent on Other Nutritional or Respiratory Support

Group 111 children are similar in many ways to Group I and 11 children. Their nursing needs are often less intensive and complex than those of children in the first two groups, however, and these children may be more likely to be served at home or in other nonhospital settings, particularly children with very-long-term dependence.

Table 7.—Basis for Estimate of the Population of Children Requiring Extended Intravenous Drug Therapy

***/intravenous antibiotic* therapy:**	
Total home intravenous antibiotic therapy market, 1984 (patients/year)[a]	2,000 to 5,000
Proportion children (range given in literature reports of individual programs)[b]	4.3°/0 to 46.6°/0
Implied total number of children per year on home therapy	86 to 2,330
Inflation for past exclusion of patients for home care due to financial, medical, or psychosocial reasons[c]	166 "/0
Total number of children per year receiving prolonged antibiotic therapy	143 to 3,868
Intravenous chemotherapy:	
Total home intravenous chemotherapy market, 1984 (patients/year)[a]	2,500
Approximate proportion children[d]	5%
Total number of children per year, minimum estimate	125
California hospital discharges of children with leukemia undergoing venous catheterization (discharges/year)[e]	160
Extrapolation to U.S. (discharges/year)	1,469
Leukemia as proportion of all childhood cancers[f]	33%
Extrapolated U.S. number, all childhood cancers	4,407
Total number of children per year undergoing chemotherapy	125 to 4,407
Total intravenous drug therapy population, children per year	268 **to** 8,275

[a]See reference 137
[b]see references 50,78,%,130,151
[c]Up to 40 percent of all patients in the studies cited here were rejected for home therapy for these reasons Since 4 of every 10 original pattents were excluded and 6 of every 10 were Included, the figure for potential home antibiotic therapy must be re-inflated by 1660/0 to estimate the total maximum number of children that would be eligible if these barriers did not exist
[d]A Pennsylvania report on 139 patients receiving outpatient (not home) chemotherapy gives the range of ages of these patients as 16 to 86, with a mean age of 57 (86) It is unlikely that more than 5 percent of these pattents were under age 21
[e]See reference 15
[f]See reference 98

SOURCE Off Ice of Technology Assessment, 1987

Estimates of the number of children in Group III are derived primarily from two sources. First, the size of this population is estimated based on the prevalence of these children relative to ventilator dependence and other categories of disability in the various States. Second, registries of individuals on home enteral and parenteral nutrition programs are used as baselines to compare extrapolated estimates for tube feeding. In this case, however, comparisons are somewhat uncertain because many tube-fed patients may also be dependent on respiratory support.

From the data presented in table 8, the minimum number of medically stable children requiring Group III respiratory and nutritional support in the United States could be as low as 1,000. This would be the case if one assumed that most of the children on enteral nutritional support also require respiratory support. The upper bound, however, is much higher. Maryland data suggest that there are over 3,500 children on respiratory support (other than mechanical ventilation) alone; the high relative prevalence of Group 111 children in North Carolina, Wisconsin, and New Mexico indicates that these children may be more than 10 times as prevalent as ventilator-dependent children in some States. The Illinois-based extrapolation of about **2,500** Group 111 children is a more moderate middle estimate. Based on these numbers, a range of 1,000 to **6,000** Group III children seems reasonable. The actual number could easily reach the higher estimate if early hospital discharge of premature infants becomes more common.

Group IV: Children Requiring Other Life-Sustaining Medical Devices and Associated Skilled Care

Group IV comprises children who require life-sustaining medical devices but whose nursing care needs are generally less complex, less prolonged, or less frequent than the needs of children in Groups I through III. It includes three subgroups: 1) infants requiring apnea monitors, 2) children requiring renal dialysis, and 3) children requiring other life-sustaining medical devices in conjunction with substantial nursing care.

The Food and Drug Administration has estimated that approximately 40,000 to 45,000 home apnea monitors for infants are currently in use (173). There is considerable controversy regarding the appropriate indications for monitoring, and many of these children may be monitored for reasons not considered by all physicians to be sufficient. A National Institute of Health panel estimated that approximately 6,800 to 17,000 of home monitors are prescribed as a result of an apparentl$_y$ life-threatening episode in an infant (173). OTA has used 6,800 as the lower bound and 45,000 as the upper bound for an estimate of the number of medically necessary home apnea monitors in use and makes the simplifying as-

Table 8.—Basis for Estimate of the Number of Children Requiring Other Nutritional and Respiratory Support

Information source	Data	Implications	Comments
OASIS registry, Oley Foundation	147 children ages 0-10 in registry; 92 require parenteral nutrition	Ratio of enteral to parenteral nutrition is 1:1.67	Proportion of children also using respiratory support unknown; proportion of tube-fed population covered by registry unknown
Commercial registries	368 children in registry requiring enteral nutrition (i.e., tube feeding)	Ratio of enteral to parenteral nutrition is 1:1 .01	Same as Oley Foundation registry
Hambrecht & Quist market analysis	7,500 persons in U.S. received home tube feeding in 1983	990 tube-fed children per year in the U.S. at home	Based on discharge data and sample of hospitals. Extrapolation assumes that 13.2% of tube-fed populaton are children (from commercial registry proportion)
Abbott Laboratories market analysis	5,500 persons in U.S. received home tube feeding in 1983	726 tube-fed children per year in the U.S. at home	Unknown basis for estimate. Same assumption of 13.2% children as above
California hospital discharge data for children	97 gastrostomy procedures, 15 closures in 1983	777 children tube-fed through gastrostomies each year	Of net addition to population of 82 gastrostomies, assumes each child received only one gastrostomy and required it for one year
State data:			
Illinois	36 children on Group III technologies served by home care program	2,445 Group III children per year in the U.S.	Ratio of ventilator: Group III children in program 22:36; apply this to extrapolation of 1,500 ventilator-dependent children in U.S. to yield total Group III estimate
Maryland	87 children in State requiring respiratory support; 61 require other than ventilators	3,513 children in the U.S. per year requiring respiratory support other than ventilators	Assumes Maryland identified the universe of such children in the State
Wisconsin	49 children served in State program require tube feeding; 49 require respiratory assist devices (other than ventilators)	2,401 U.S. children requiring tube feeding at any one point in time; up to 4,800 requiring respiratory support. Ratio of ventilator: Group III supports about 1:10	Presumably is an underestimate if not all similar children are served by State program. Probably considerable overlap between tube feeding and respiratory support groups. Prevalence of Group II probably overstated
North Carolina	8 hospitalized children in State with prolonged oxygen dependence (compared to 3 on ventilators)	Ratio of ventilator: oxygen support about 3:8	One-month survey, hospitalized children only
New Mexico	1 ventilator-dependent child; 18 other children requiring respiratory and nutritional support	Ratio of ventilator: Group III supports about 1:18	Prevalence of Group III probably overstated due to small number of ventilator-dependent children served

SOURCES: M.J. Aitken and L.A. Adav. *Home* Care *for the Chronically Ill and/or Disabled Technology Assisted Child: An Evaluation Model*. unpublished. November 1985. J Bates, San Diego Children's Hospital, San Diego, CA, personal communication, July 1986; Blue Cross/Blue Shield Association, *Infusion Therapies in Home Health Care* (Chicago, IL: Blue Cross/Blue Shield Association, January 1966); G. Cleverly, Human Services Department, Santa Fe, NM, personal communication, August 19&; L.L Heaphey, The Oley Foundation, Albany, NY, personal communication, August 1986, E. Lis, Crippled Children's Services, Chicago, IL, personal communication, April 1986; Oley Foundation, Inc, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly" Utilization in the Home," contract paper prepared for the Office of Technology Assessment, U S Congress, Washington, DC, September 1985; B B Rucker and K A. Holmstedt, *Home Infusion Therapy Industry* (San Francisco, CA Hambrecht & Quist, April 1984); and P Tschumper, Department of Health and Social Services, Madison, WI, personal communication, April 1986.

Table 9.—Estimated Prevalence of Selected Chronic Conditions in Children, Age O to 20, 1983

Condition	Prevalence per 100,000 children, 1980	Approximate number of children in the United States, 1983
Mental retardation	2,500	1,781,300
Asthma (moderate and severe)	1,000	712,500
Diabetes mellitus	180	128,300
Congenital heart disease (severe)	50	35,600
Spina bifida	40	28,500
Sickle cell anemia	28	20,000
Cystic fibrosis	20	14,300
Hemophilia	15	10,700
Leukemia (acute lymphocytic leukemia)	11	7,800
Chronic renal failure	8	5,700
Muscular dystrophy	6	4,300
Traumatic brain injury	5	3,600

SOURCE Prevalence rates from G L Gortmaker and W. Sappenfield "Chronic Childhood Disorders: Prevalence and Impact, Pediatric Clinics of North America 31(1) 318, February 1984 Population size estimates calculated by OTA based on prevalence rates and U S Census population data

sumption that this range represents the number of monitors in use per year.

The minimum estimate of the number of children requiring renal dialysis is from Medicare End-Stage Renal Disease Program data. The Health Care Financing Administration, which administered Medicare, documented 1,713 patients age O to **19** receiving dialysis in 1985 (110,166). Adding a minimum of 171 patients to this figure to account for patients age 20 to 21 (one-tenth, or 2 average age years, of the initial figure) and inflating the total figure by 3.6 percent per year (the increase documented from 1983 to **1984),** yields a minimum of 2,022 children under age 22 on dialysis during 1987. This number underestimates the number of children requiring dialysis, since some are covered by private insurance. A maximum estimate assumes that all children with chronic renal failure require dialysis. The prevalence of this condition has been estimated at 8 per 100,000 children, or nearly 6,000 children under age 22 in the United States (see table 9).

There exist no appropriate data at all to estimate the number of children requiring other devices and associated nursing care such as urinary catheterization and colostomy care. [9] This group is very large; indeed, it may be larger than all other groups combined. If this group is included in the population of technology-dependent children, the size of that population will increase dramatically. Many children with spina bifida and other spinal conditions, for example, require urinary catheterization. The total number of children in this group could easily be 30,000 or more (see table 9).

If the definition of technology dependence used in this technical memorandum were not limited to children using medical devices, this group could potentially include a substantial proportion of children with hemophilia, insulin-dependent diabetes, and many other chronic diseases. While most such children require periodic injections of medications and a relatively modest amount of nursing care by family members, a few have more intensive needs for monitoring and nursing. It is only the lack of dependence on a major medical device, not necessarily a difference in nursing and care needs, that distinguishes this population from those children included in Group IV.

Table 9 presents prevalence estimates for several serious chronic illnesses in children. Unfortunately, no quantitative information on the level of technology and nursing needs for this or any other subpopulation of children with chronic illness exists. Some of these children have already been included in groups mentioned above; for example, children with cystic fibrosis, muscular dystrophy, traumatic brain injury, or severe asthma

[9] Data from the National Center for Health Statistics, which surveys a large sample of hospital discharges every year, suggest that the annual incidence of colostomies and ileostomies in children may be a few thousand per year (172). The survey is not large enough to estimate an accurate number of these procedures for children, but it is certainly less than 10,000 per year and probably less than 5,000

who meet the definition of technology dependence likely need respiratory or nutritional assistance and would be included in Groups I through III. Children with rheumatoid arthritis and leukemia would be included under Group 11 if they required periodic intravenous drug therapy.

Wisconsin data illustrate how large the population of "technology-dependent" children could be if the definition did not require dependence on a device that compensates for a vital body function as a necessary criterion (but retained the "substantial nursing needs" criterion). Wisconsin operates a program that, among other criteria, enables children to receive certain health care benefits if they would be permanently institutionalized without these benefits and could be served less expensively at home. Of 181 children served by this program in mid-1986, one-third of the total required a very high level of care but did not require nutritional, respiratory, or other mechanical support.

What sources of information might be tapped in the future for more precise estimates of the number of technology-dependent children? One possibility might be a school-based survey, targeted at the population most likely to include a significant proportion of technology-dependent children—those children who have been individually assessed prior to educational placement. A similar approach is currently being used in an ongoing study to estimate more accurately the number of children with hemophilia, cystic fibrosis, and spina bifida (73). The approach is fraught with its own problems, not the least of which is that very young children and children living in hospitals or long-term care institutions would not be captured. Also, technology-dependent children are rare even among children assessed for possible special education placement .'" A very large survey would be required to produce a reliable estimate of size of the population. Still, this source offers one possibility for estimating future apparent or real changes in the prevalence of technology dependence.

[10] In Fairfax County, Virginia, for instance, 700 children were served in home or school-based special education preschool programs (ages 2 to 4) in August 1986 (14). Of these 700 children, 6 might have qualified as technology dependent (4 served in classrooms had tracheostomies or gastrostomies, and 2 served at home had special medical problems).

TRENDS IN THE POPULATION

Future changes in the size of the technology-dependent population will depend on three separate factors:

1. changes in the number of children who have the diseases and conditions that lead to technology dependence;
2. technological change, which can either increase the size of the population (if new technologies lead to increased survival dependent on long-term life-saving equipment), or decrease population size (if new technologies allow less intensive equipment and service needs, or prevent the development of disabling conditions); and
3. changes in medical practice and social attitudes, which are themselves affected by factors such as the emergence of new technologies and the availability of third-party payment,

General Trends in Chronic Illness and Disability

Trends in chronic illness and disability over time are somewhat difficult to identify. National surveys show that the proportion of children with reported major activity limitation has increased substantially in recent years, from approximately 1.1 percent in 1967 to the present 2 percent (124). However, this finding may be caused by any of a number of influences. Some of the apparent increase may be due to changes in survey methodology and in families' awareness of illness over time (123,124), rather than to real changes in disability rates. Another explanation is increased survival of children with certain chronic illnesses, such as cystic fibrosis and spina bifida. A third possible explanation is that new technologies and new systems of care, such as intensive care units for newborn infants, are resulting in more chil-

dren who survive birth or trauma but with severe long-term disabilities. The absolute number of disabled and chronically ill children will increase as the children survive longer, even if the rates of onset of various disorders are unchanged .1'

The number of children with inherited chronic diseases that can lead to technology dependence is unlikely to change significantly due to changes in the incidence of these disorders. Gortmaker and Sappenfeld conducted an extensive review of the literature in 1980 to investigate the prevalence of a number of common childhood chronic diseases (72). They noted that the incidence of most such diseases has been stable over time. It is now possible that new technologies permitting prenatal diagnosis of muscular dystrophy and cystic fibrosis may decrease the incidence of these diseases, if couples choose to terminate pregnancies when a fetus has been identified as having a genetic marker associated with the disorder, However, these prenatal diagnostic technologies are unlikely to have a major effect on overall incidence of chronic disease.

A more important factor affecting the number of children with chronic diseases, and one with implications for technology dependence, is the significant improvements in survival for children with many life-threatening diseases. Improvements over the past two decades in survival rates for children with leukemia, diabetes, certain heart defects, sickle-cell anemia, and chronic kidney disease have greatly increased the number of such children who live to adulthood (72). Better and more aggressive treatments for spina bifida and muscular dystrophy have also increased the survival of children with these disorders (35). Children with cystic fibrosis who would have died in early childhood two decades ago are now surviving, and over 50 percent of them live into adulthood **(109).** Long-term survival of children with intestinal malformations will greatly increase the total number of children requiring parenteral nutrition.

Changes in head and spinal cord injury rates, and changes in the survival of severe trauma patients, could affect the size of the population. More important, however, is the rising incidence of acquired immunodeficiency **syndrome** (AIDS). AIDS is likely to continue to spread in infants as it spreads in women, since the virus can be communicated from mother to fetus at or before birth (40). This disease is likely to increase the number of children receiving prolonged intravenous drug therapy, nutritional support, and considerable nursing care. A few hospitals have experienced dramatic increases in the number of babies with AIDS and in the number of those babies growing up in the hospital (22).

The most profound changes in the incidence and prevalence of disorders leading to technology dependence seem to be occurring in neonatal care. It has been widely asserted that the increased survival of very-low-birthweight (less than 1,500 g) infants, due to improved, aggressive neonatal intensive care, has resulted in a sharp surge in the number of ventilator- and other technology-dependent children. If this is true, continued advances towards survival of very-low-birthweight infants can be expected to increase the number of such children. If, on the other hand, technologies are successfully developed that can prevent prematurity y or moderate the development of chronic lung disease in newborn infants, the number of infants on long-term ventilation and nutritional support may be considerably reduced.

Most medical evidence thus far supports the contention that the increased survival of very-low-birthweight infants has not increased overall rates of disability, but it may have increased the actual number of severely disabled children. A study of changes in infant morbidity and neonatal mortality between 1976 and 1978-79 found that neonatal mortality decreased by 18 percent during this time, while infant morbidity also decreased by 16 percent **(144).** Overall, therefore, newborn survival did not lead to an increase in long-term disability. However, the detected decrease in disability was among the minor disability categories; "the proportion of children with severe or mod-

11 Evidence from public school records tends to support the Premise that the number ot children with severe disabilities, or at least the number being served by public schools, has increased. The proportion of multihandicapped children, for instance, increased from 0.12 to 0.16 percent of school enrollment between 1 976-77 and 1982-83 (187), However, school data on disability is generally considered unreliable because 01 the greatly varying det initions different school distric t\ use

crate congenital anomalies or developmental delay did not change" (144). Other evidence supports three conclusions:

1. within groups of infants of a given birthweight, handicap rates remain stable or decrease over time;
2. handicap rates are greatest in the lowest birthweight groups; and
3. infants in the lowest birthweight groups are surviving in increasing numbers (162).

If the incidence of severe disorders is unchanged or even declines somewhat, but the total number of neonatal survivors increases, then the number of infants with severe disabilities increases overall. Box B describes a common source of respiratory disability in infants and the differing rates of incidence of this disorder in infants of different birthweights.

Future Changes Due to New Maintenance and Treatment Technologies

The most promising technologies to decrease the incidence of long-term technology-dependence are those aimed at preventing the need for long-term respiratory support in infants. Current efforts to combat chronic lung disease in newborns are described in box C. One or more of these technologies may eventually greatly reduce the number of infants with long-term technology dependence. However, significant changes are not likely to be apparent for a few years yet.

New technologies may have other direct effects on trends in the technology-dependent population, aside from their effects in reducing the underlying disorders that lead to technology dependence. For example, advances in implantable infusion pumps for long-term chemotherapy and implantable phrenic nerve pacers to stimulate breathing could reduce the constant, complex nursing needs associated with many technology-dependent children.

Enhanced access to transplant technology may either increase or decrease the number of children requiring intensive long-term nursing services. As the number of infants and children receiving bone, liver, heart, and other organ transplants grows due to increased transplant experience and enhanced insurance coverage, children recuperating from transplants may become a group for whom intensive home medical care is both socially and financially desirable. Access to intensive medical services in the home setting might allow these children to leave the hospital earlier than would otherwise be possible, and they may have ongoing nursing and technology needs. On the other hand, increased transplant success could obviate the need for very-long-term dependence on technologies such as insulin (through pancreas transplants), parenteral nutrition (through bowel transplants), and dialysis (through kidney transplants).

Changes in Medical Practice

The wide range of prevalence estimates for technology dependence suggests that medical practice patterns may vary considerably among regions, States, and medical centers. Some of these differences may be in simple treatment protocols. For example, there is some evidence that differences in medical practice can inadvertently affect the incidence of chronic lung disease in newborns. In an examination of treatments and rates of bronchopulmonary dysplasia in eight hospitals with regional neonatal intensive care units, Avery and colleagues found that the rates of this newborn chronic lung disorder varied considerably among centers, even after adjusting for differences in the newborn populations (11). They concluded that the differences in routine treatment practices among these centers were probably responsible for the differences in the rates of this disorder, implying that changes in the routine practices of hospitals with higher rates could reduce the incidence of dependence on long-term respiratory support.

Other researchers have documented the variation in routine treatment patterns among physicians treating people with fatal chronic diseases. A 1981 study demonstrated that positive-pressure ventilation may extend the lives of children and adults with muscular dystrophy by an average of 7 years (12). Only one-third of the patients in the study had tracheotomies. By comparison, in a **1985** survey of Muscular Dystrophy Association

Box B.—Bronchopdrnmary Dysplasia

One of the most common sequelae of neomtal intensive care, and one with particular implications for technology dependence, is bronchopuhnonary dysplasia (BPD). First remgnized in the early 1960s (154), this condition sometimes occurs in infants requiring mechanical ventilation soon afterbirth. An infant with BPD is unable to be weaned from ventilation during the first month after birth due to certain changes in the lung that can often be detected by X-ray (71).

Pneumonia, meconium aspiration, patent ductus arteriosus, and apnea of prematurity are among the many conditions that can lead to the initial need for assisted ventilation (and, thus, sometimes BPD) in newborns (71). The most common reason for initial ventilation, however, is respiratory distress syndrome. This syndrome, characterized in its initial stages by an increasing need for oxygen, is often experienced by very premature infants because art essential lining layer in the lung (pulmonary surfactant) has not yet developed (99).

Table 10 presents estimates of the annual incidence of BPD by birthweight category. There are no nationally representative data on the incidence of BPD. A multi-center study of 700 to 1,500 g babies in 1983 and 1984 found that one-third of the survivors had chronic lung disease (11). OTA used this 33 percent estimate for very-low-birthweight infants, although other researchers reported rates of BPD incidence among their institutional populations varying from 25 to 75 percent of respiratory distress syndrome survivors under 800 g at birth, and from 13 to 62 percent of survivors weighing less than 1,000 g at birth (17,25,45,74,85,138).

Researchers have not reported in the literature on BPD incidence among the larger Iow-birthweight infants, but the authors of a recent review article about BPD estimated its incidence at 10 to 20 percent among infants with RDS who receive mechanical ventilation and survive (71). OTA adopted the low end of this estimate, 10 percent, in calculating the BPD incidence among babies weighing 1,501 to 2,500 g.

Only a relatively small proportion of the babies developing BPD are obvious candidates for technology-dependent home care. In their eight-center study, Avery and colleagues found that about 4 percent of infants weighing less than l,500 g at birth still needed supplemental oxygen at 3 months of age (although the range among institutions was considerable) (11). BPD can take mild, moderate, or severe forms, and infants are weaned from the ventilators and/or oxygen support after variable periods of time.

In the future, the incidence of BPD will likely decline, although extremely Iow-birthweight babies susceptible to BPD—including babies weighing less than 500 g at birth-are increasingly surviving (162). Refinements of existing techniques and newly introduced neonatal technologies might substantially reduce BPD in premature infants within a few years.

Table 10.-Estimated incidence of Bronchopuimonary Dyspiasia, 1984

Birthweight (grams)	U.S. births (1964)	U.S. neonatal mortality (1960)	Neonatal survivors	Percent survivors with BPD	Total infants with BPD per year
500-1,500g	39,045	43.1 %	22,217	33%	7,332
I,501-2,500g	202,606	2.4%	197,743	1 %[a]	1,977
				Total	9,309

[a]Goldberg and Bancalari (71) estimate that approximately 10 percent of infants with respiratory distress syndrome (RDS) get BPD. If approximately 10 percent of all surviving infants get RDS (174), then approximately 1 percent of all survivors get BPD.

SOURCE: Office of Technology Assessment, 1S87. Numbers of U.S. births from U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics, "Advance Report of Final Natality Statistics, 1SS4, Table 24," *Vital Statistics Report* 35 (4, supp.):July 18, 1988. Neonatal mortality rates from U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, "National Infant Mortality Surveillance (NIMS)," unpublished tables, May 1988. BPD Incidence rates approximated from M.E. Avery, Boston Children's Hospital, Boston, MA, personal communication, July 23, 1988; and ranges presented in J.D. Horbar, "A Multicenter Survey of 28 Day Survival end Supplemental Oxygen Administration in infants 701-1500 Grams," paper presented at the Rosa Laboratories Special Conference on Topics on Neonatality, Washington, DC, Dec. 7-9, 1s88.

Box C.—Changing Technology in the Neonatal Intensive Care Unit

Preventing the complications of mechanical ventilation in newborns has been a focus of research for some time. Changes in the way artificial ventilation is administered to newborns have been an important part of that research (71,153). However, medical practices and the use of technology still vary widely among perinatal centers. Avery and her colleagues surveyed eight centers in 1983 and 1984 for their experience with chronic lung disease in infants weighing 700 to 1,S00 g. The researchers found that some institutions did significantly better than others, and that routine management techniques used for the very small infants might explain the differences (11). Refinements in existing techniques may thus hold promise for reducing the development of bronchopulmonary dysplasia (BPD) in ventilated infants in the future. Some new technologies, such as the high frequency ventilator (which delivers multiple small breaths instead of slower, larger ones) and extracorporeal membrane oxygenation (essentially a heart-lung machine for newborns with severe asphyxia), may also have some effect.

Other technologies under investigation focus on preventing respiratory distress syndrome (RDS), the precurser of BPD in most infants. The administration of steroids to mothers in preterm labor in order to accelerate infant lung maturation has been used and studied for 16 years (9), but concerns about the long-term effects of the therapy have prevented its routine use (43). Recent large-scale studies are somewhat contradictory but suggest that the technology can reduce the incidence and severity of RDS, and may improve survival in some very premature infants, with no evidence of negative long-term effects (43,174). Even if antenatal steroid therapy does become generally accepted as useful, however, it will have several limitations. It clearly does not work for all babies. And in addition, because the therapy must be initiated at least 24 hours before delivery in order to be effective, many women in preterm labor cannot be candidates for its use.

Treating surfactant deficiency by administering artificial or natural (animal lung) surfactant to the lungs of very premature babies at or soon after birth has the potential to greatly reduce the incidence of severe RDS. The bask chemistry of lung surfactant has been known for a long time, but research is ongoing regarding the best mixture, the optimum dose, and the timing and frequency of administration. At least five recent clinical trials testing natural surfactants document that surfactant-treated infants have less severe RDS (and, presumably, less likelihood of developing BPD) than control infants (66,89,100). Studies with artificially produced surfactant, on the other hand, have shown essentially no benefit to respiratory function (76,183).

Large-scale, multi-center trials are being undertaken in Europe, Japan, and the United States to continue to test surfactant experimentally. It is possible that surfactant therapy could become generally available for preterm babies within 2 to 5 years (10,143).

clinics around the country, 43 percent of ventilated patients were found to have permanent tracheotomies (35). This difference may represent an increasing willingness over time to treat end-stage muscular dystrophy patients aggressively,

The 1985 clinic survey also revealed that 24 percent of the responding physicians did not provide respiratory support systems to individuals with degenerative neuromuscular disorders, while 33 percent prescribed such supports routinely and the remaining 42 percent provided them only under specialized circumstances (35). The researchers found no standard patient-selection processes or established protocols for respirator use. If all physicians applied the same criteria for ventilator support as those physicians who prescribe this treatment routinely, the number of people with end-stage muscular dystrophy using mechanical ventilation could triple.

Other differences in medical practice and social attitudes may also be reflected in rates of technology dependence. Some centers now treat newborns weighing less than 500 g (1.1 lbs) aggressively, although these babies are highly unlikely to survive (74). The promulgation of "Baby Doe" regulations and accompanying social attitudes has probably had at least some marginal influence on physicians' decisions to treat severely premature or disabled infants aggressively in the United States (14.5). It is likely that the trend toward ag-

gressive treatment of very small newborn babies will continue, at least in the short term.

Whatever the reasons, differences among medical centers and geographic areas do exist. As has been noted by one clinician, “There are some centers that just don’t seem to have children that require home ventilation” (91). Whether this difference is due to more aggressive attempts to wean ventilated children in those centers, or other factors that result in fewer infants who both survive and require long-term ventilation, is unclear.

Finally, improved access to funding for nonhospital long-term care, particularly home care, could result in more technology-dependent children and their more visible participation in society. It is possible that providing opportunities for children to be in home or home-like settings, combined with enhanced funding for long-term care, eliminates some of the social, financial, and medical disincentives to initiate and maintain long-term technology dependence. The three States with the highest identified prevalence of ventilator-dependent children all have aggressive home care programs to serve such children; North Carolina, a State with few ventilator-dependent children, does not. More families may consider it worthwhile to maintain the life of a terminally ill child as long as possible if they can afford to take the child home, and more physicians may consider it appropriate medical care to prescribe long-term ventilation for children.

CONCLUSIONS

Defining the population of technology-dependent children is a necessary first step for both enumerating the population and providing health care benefits directed at this population. That arriving at such a definition is not easy is clear from the fact that, after 5 years of public debate about the issue, no satisfactory definition exists. From a clinical perspective, the crucial distinguishing characteristic of these children is that they require special equipment and an intense level of medical services that are beyond the normal capabilities of untrained families. From an insurance program perspective, the crucial characteristic of these children is that it may be possible to care for them more appropriately and less expensively at home if the funding and services are made available. Although the two populations described by each of these characteristics overlap considerably, in that both require some form of hospital care if services in other settings are unavailable or unaffordable, they are not identical.

OTA’s estimates of the size of the medically stable, technology-dependent child population at any one point in time, based on available sources of data for four alternative groups, are as follows:

1. Approximately 680 to 2,000 children per year in the United States are substantially or completely dependent on mechanical ventilation.
2. Approximately 600 to **9,000** children require intravenous therapy each year, including 350 to 700 children dependent on intravenous nutrition.
3. Approximately 1,000 to 6,000 children are dependent on some other kind of device-based respiratory or nutritional support, such as suctioning, tracheotomy care, oxygen, or tube feeding. The cumulative number of children in the above three groups is between approximately 2,300 and 17,000 technology-dependent children per year.
4. Expanding the definition of technology-dependent children to include children requiring apnea monitors and kidney dialysis would increase the size of the technology-dependent child population to between approximately 11,000 and **68,000** children per year. Adding children requiring urinary catheterization and colostomy/ileostomy care to this population could raise the upper bound of this estimate to as high as 100,000 children.

There is no evidence of overall increase in the incidence of most severe chronic disabling conditions. However, the number of technology-dependent children appears to have been increasing over the past ten years, due primarily to increased survival of very-low-birthweight infants, who have a high incidence of chronic lung disease, and in-

creased survival of children with certain inherited and congenital chronic disorders, particularly cystic fibrosis, muscular dystrophy, and congenital anomalies. AIDS is also increasing the technology-dependent population. This trend is likely to continue for several years. In the long run, it is not clear whether the trend will continue, level off, or represent a "bump," analogous to the polio and rubella epidemics that produced many severely disabled children earlier this century.

Factors that may *increase* the size of the population include:

- wider acceptance of medical practices such as aggressive treatment of individuals with end-stage disease, severe trauma, and severe newborn disabilities; and less aggressive attempts to wean ventilated children;
- consequent increased survival of children with conditions that would be fatal if not aggressively treated, and are highly likely to result in technology dependence if they are treated;
- new severe chronic diseases, such as AIDS;
- lessened acceptance of abortion;
- sufficient financing to encourage aggressive medical practices;
- technologies that improve survival outcomes for burn patients or transplant patients, but at the cost of extended recuperative care; and
- increases in the apparent size of the existing population due to new opportunities to obtain funding for home care.

Factors that may *decrease* the size of the population include:

- improved prenatal diagnostic tests for severe, chronic disease;
- technologies that can prevent trauma (accident prevention), premature births (prenatal care), and specific neonatal disorders;
- technologies that can lessen the intensity or duration of technology dependence, such as oral insulin or transplants to correct diabetes; and
- increased acceptance of palliative care for fatal disorders.

It is likely that the expansion of current medical practices tending to increase the size of the technology-dependent population will continue in the short run, perhaps for a decade or longer. Thus, the population size estimates given in this chapter will probably be lower than the actual population size within a short time. In the longer term, opposing factors—most significantly, technologies to prevent premature birth or its complications—may eventually lead to stabilization or even a decrease in the technology-dependent population.