Prevalence of Medical Technology Assistance Among Children in Massachusetts in 1987 and 1990

JUDITH S. PALFREY, MD
MARILYNN HAYNIE, MD
STEPHANIE PORTER, RN, BSN
TERENCE FENTON, EdD
PAULA COOPERMAN-VINCENT, BA
DEIRDRE SHAW, BA
BENJAMIN JOHNSON, BA
TIMAREE BIERLE, RN, BSN
DEBORAH KLEIN WALKER, EdD

Seven of the authors are with the Children's Hospital, Boston, MA. Dr. Palfrey is Chief, Division of General Pediatrics; Dr. Haynie is Director, Birth Defects Services; Ms. Porter is Nurse Coordinator; Ms. Cooperman-Vincent, Mr. Johnson, and Ms. Shaw are Research Assistants; and Ms. Bierle is Assistant Nurse Coordinator, all with Project School Care. Dr. Fenton is Lecturer in Biostatistics, Harvard School of Public Health. Dr. Walker is Assistant Commissioner, Bureau of Family and Community Health Programs, Department of Public Health, Boston.

Tearsheet requests to Judith S. Palfrey, MD, Judge Baker 2, 300 Longwood Ave., Boston, MA 02115, telephone 617–735–6714.

Synopsis

In 1987 and 1990 in Massachusetts, surveys were conducted to determine the size, pattern of distribution, and trends in the population of children assisted by medical technology. The authors obtained an unduplicated count of all Massachusetts children from 3 months to 18 years of age who used one or more of the following: tracheostomy, respirator, oxygen, suctioning, gastrostomy, jejunal or nasogastric feedings, ostomies, urethral catheterization, ureteral diversion, intravenous access, or dialysis. By comparing counts obtained from medical and educational sources, the authors were able to perform a capture-recapture analysis to estimate the overall number of children dependent upon these technologies.

The number of children identified in our surveys increased from 1,085 in 1987 to 1,540 in 1990. However, the capture-recapture analysis yielded estimates of 2,147 plus or minus 230 for 1987 and 2,237 plus or minus 131 for 1990. This suggests that the population of children dependent upon medical technology was essentially stable during this period, and that the 42 percent increase in the number of children identified in our survey reflected improved sampling techniques.

During the 3 years, shifts in the pattern of technology use were noted, however. Use of oxygen and gastrostomy increased, and urostomy use declined. A change in the age distribution of the children was also documented, with a shift in the preponderence of technology use from 12 to 24 months in 1987 to children in the first year of life in 1990.

Using the 1990 estimate and the 1990 U.S. census figures, an overall prevalence estimate of 0.16 percent was calculated. Applying this to the U.S. child population yields an estimate of 101,800 children assisted by medical technology nationwide (assuming comparable technology use in other States). This information will facilitate policy analysis and program planning on regional and national levels for this medically complex group of children.

In recent years, the care of children with disabilities and chronic illness in the United States has come to include increased reliance on a variety of medical technologies, such as tracheostomies, gastrostomies, respirators, and central venous lines (*1–6*). In 1987, our study group carried out a statewide census in Massachusetts to determine the size of the population of children with chronic illness assisted by medical technologies (*7*). In 1990, we repeated the census to assess whether there had been growth in the size of the population or change in the composition of the group of children assisted by medical technologies. This paper reports the results of that second census effort.

Children assisted by medical technology are increasingly visible in both medical and community settings. Physicians, nurses, educators, and policy makers are concerned about the adequacy of care plans for these children and their families (*8–13*). Several national commissions have been convened to

Table 1. Response rates of surveys sent to medical and education providers

Sources	1987			1990		
	Responses	Contacts	Percent	Responses	Contacts	Percent
Overall[1]	829	1,608	52	2,320	3,703	63
Medical sources (institutional)[1]:						
Hospitals-actual contacts[2]	78	84	92	48	93	52
Major hospitals	43	101	42	134	281	48
Community hospitals	73	79	92	87	495	18
Nursing homes	5	7	72	10	10	100
Visiting Nurse Associations[3]	44	67	67	117	165	71
Department of Public Health case manager[4]	. . .	. . .	. . .	11	20	55
Educational sources:						
Public schools[5]	264	340	78	1,542	1,798	86
Private schools	233	828	28	279	732	38
Special educational collaboratives	21	41	51	23	35	66
Massachsetts Association of Public and Private Special Schools	81	145	56	99	109	91
State schools	10	10	100	8	11	73
Early intervention	35	50	70	37	42	88

[1]A supplementary mailing was sent to the American Academy of Pediatrics mailing list of pediatricians in Massachusetts without extensive followup. Response rate was only 13 percent in 1987 and 12 percent in 1990. This mailing is not included among the sources contacted.

[2]In 1987, fewer providers per institution were contacted than in 1990 and followup with community hospital senior administrators was more aggressive, but the yield of cases was low. Therefore, in 1990 followup concentrated more heavily on specialty providers in the major hospitals.

[3]Includes home health agencies for 1990.

[4]In 1987, served as a double check only.

[5]In 1987, only nursing supervisors were contacted directly, who then contacted their own staff. In 1990, direct mailings were sent to school nurses.

ensure that appropriate attention is being devoted to this emerging group of children with complex medical conditions (*10,11*).

The increased interest in and concern about this group of children has led to a need for accurate data on the size of the population and any trends which may be occurring. To date, there have been no longitudinal studies following trends in the population assisted by medical technology. Such data are critically important for medical outcomes measurement, quality assurance, and program planning both at the hospital and the community levels.

With two data points (1987 and 1990), we can begin to address the following questions about children with technology dependency in Massachusetts:

- Can an estimate of the number of children assisted by medical technology in Massachusetts be derived?
- Have there been significant changes in the number of children assisted by medical technologies during the 3 years from 1987 to 1990?
- Are the age distributions of these children comparable in 1987 and 1990?
- Are the distributions of diagnoses, organ systems involved, and etiologies similar?
- What community supports are the children receiving?
- Has the pattern of community support changed during the 3 years?

The results of the study have important implications for medical and social planning relative to children with severe disabilities and complex chronic illnesses.

Method

Sampling method. The census was designed to obtain an unduplicated count (as of April in 1987 and March in 1990) of all Massachusetts children from 3 months to 18 years of age who required one or more of the following: tracheostomy, respirator, oxygen, suctioning, gastrostomy, jejunal or nasogastric feeding tubes, ostomies, urethral catheterization, ureteral diversion, central venous access, or dialysis described in table 2. Both medical and educational professionals were asked to identify children dependent upon these technologies. This permitted use of a capture-recapture analysis, a statistical technique which uses independent samples to generate an estimate of the overall population size (*14,15*).

Medical and education providers who care for children with special health care needs were asked to fill out a data form on each child known to them who was assisted by medical technology. In 1987, 1,608 survey forms were distributed to health and education institutions, with an overall response of 52 percent. This rate varied considerably among institutions, with high response rates for such educational institutions as the 10 State schools for the mentally disabled (100 percent), 50 early intervention programs (78 percent), and 340 public schools (78 percent), and low rates from the 828 private schools (28 percent).

Table 2. Comparison of medical technology in 1987 and 1990 in Massachusetts

Technology	Actual observed			Adjusted estimate [1]		
	1987	1990	Percent change	1987	1990	Percent change
Overall	1,085	1,540	42	[2]2,147	[3]2,237	4
Tracheostomy	107	151	41	212	219	.3
Suctioning	197	299	52	390	434	11
Respirator	39	48	29	77	70	–9
Oxygen	159	279	75	315	405	29
Nasogastric tube	52	83	60	103	121	17
Gastrostomy tube	361	669	85	714	972	36
Ileo-colostomy	54	81	50	107	118	10
Jejunostomy tube[4]	. . .	46	. . .	. . .	67	. . .
Urostomy	50	29	–22	99	42	–58
Catheterization	318	362	14	629	526	–16
Intravenous	151	206	36	299	299	0
Dialysis	25	33	32	49	48	–2

[1]The adjusted estimates are based upon the capture-recapture analysis. Each entry in the "Actual observed" columns was multiplied by the ratio of the overall number of patients estimated in the capture-recapture analysis to the overall number actually observed in the sample for a given year. Thus, the estimate of 212 tracheostomies for 1987 is performed as follows: (actual count of tracheostomies) X (overall estimate + overall observed) = 107 X (2,147 + 1,085) = 212. For 1987, the information on whether the data were from a medical or educational observation was not available for 80 records. These were prorated to reflect the distribution of observastions for the other 1,005 cases.

[2]Plus or minus = 230.

[3]Plus or minus = 131.

[4]In the 1987 census, jejunostomy tubes were lumped with ostomies and, hence, cannot be separated out. However, there were thought to be almost no instances of these tubes recorded in 1987, as judged by the research investigators. Hence, jejunostomy tubes are not included in the 1990 ileo-colostomy cell, but have been placed in the jejunostomy tube row.

In general, a health professional from the educational facility was the respondent (for example, the school nurse). Among health providers, the institutional response rates were generally good, with a 92 percent response from at least one provider at the 84 community and specialty hospitals in the commonwealth, 72 percent from the 7 nursing homes, and 66 percent from the 67 Visiting Nurse Associations caring for children. A separate, special one-time mailing to 1,000 members of the State Chapter of the American Academy of Pediatrics netted only a small response (13 percent).

In 1990, a larger overall number of survey forms (3,703) were mailed out to health and educational institutions, since the experience in 1987 had provided us with an extensive network of contacts. The overall response rate in 1990 was 63 percent. The pattern of institutional response rates was similar to that in 1987 with the exception that the response rate from hospital sources was lower (52 percent), reflecting our less vigorous followup pursuit of community hospitals than in the 1987 effort. (For full details on the response rate see table 1.)

In both years, some contacting of specialty sites was necessary for several months after the designated census month. However, in all cases providers were asked to report the children's status as of the census month (April 1987 or March 1990).

Instrument and variable definition. The variables requested were child's initials, date of birth, sex, race, ZIP code, and primary diagnosis. Information was also requested about the medical supports and their duration of use, an estimate of the child's cognitive ability, the child's current residence, and type of educational service.

To exclude children placed transiently on devices in the newborn period, the survey began with those at least 3 months old. Children had to be legal residents of Massachusetts to qualify for the census. Respondents were asked how many nights out of seven the child spent at home, school, hospital, or other. In 1990, but not in 1987, there was an opportunity to indicate if the child was living in a foster home. The type of educational service was recorded according to the categories used by the Massachusetts Department of Special Education for placements under the Individuals with Disabilities Education Act.

Coding. To derive a better understanding of the children's underlying conditions, we analyzed the census data in two ways: by organ system and by putative etiology. The clinicians on the research staff assigned International Classification of Diseases, Ninth Revision (ICD–9) codes based on the diagnosis reported. Using these ICD–9 codes, organ system categories were designated for each major diagnosis. The categories included neurologic, cancer-hematologic, cardio-respiratory, gastrointestinal-metabolic, renal-genitourinary, musculoskeletal, immunologic, and multisystem. A separate category, other, was used for those diagnoses which did not

provide enough information to assign them to an organ system. The legend for table 3 gives examples for each organ system assigned.

Based on the child's diagnosis and its reported cause (if known), the most likely etiology for the problems was assigned. Congenital anomaly (or anomalies) described structural defect(s) present at birth for which a definite genetic-chromosomal cause is not currently known. The term chronic condition was used for longstanding diseases and disorders. Perinatal factors were those directly attributable to perinatal events. Hereditary-genetic were those conditions which have a known chromosomal marker or pattern of inheritance. Injuries included those diagnoses resulting from accidents and forms of trauma (other than perinatal). Infections were those conditions where a definitive infectious agent was implicated. Other included miscellaneous, nonspecific categories primarily of developmental and behavioral origin. The legend to table 4 delineates examples for each etiology category.

When there was difficulty assigning a diagnosis to a category, the decision was made by consensus among the authors. In both 1987 and 1990, we found it necessary in more than 20 percent of the cases to assign more than one ICD–9 code, rendering it impossible to assign only one organ system or one etiology.

Data analysis. Data were analyzed using the Statistical Analysis System (SAS). All forms were matched by initials, birth date, sex, race, and ZIP code to identify cases in which more than one provider had submitted a form describing the same child. A comprehensive list of all unique cases was generated after this check for duplicate reporting had been completed, and a unique record number was assigned to each case for the analysis.

When the unique cases were generated, if there was information available from more than one respondent, medical information was preferentially taken from the medical report and educational information from the school source. For instance, diagnosis would come from the specialty clinic and classroom placement information from the school nurse.

To estimate the extent of underreporting, the capture-recapture method was used (*15*). The analysis involved classifying the sources of information into two major groups—medical and educational—and a 2 x 2 contingency table was constructed to display the overlap between the children identified by the two sources (see box on this page).

2 X 2 Contingency Table

Medical	*Educational*		
	Yes	No	Total
Yes	*a*	*b*	*a+b*
No	*c*	*d*	*c+d*
Total	*a+c*	*b+d*	*a+b+c+d = N*

The best estimate of the size of the total population is the sum of the entries in the four cells of the contingency table: $N = (a+b+c+d)$. However, only three entries a, b and c are known. The last cell is unknown because it represents the children missing on both lists—the children not found using either approach.

The capture-recapture method provides a statistical means of estimating the number of entries which belong in cell d, since this number can be modeled as a function of the counts in the remaining cells. This method rests upon the same assumptions of independence that would underlie the computation of expected cell counts for a chi-square analysis.

Under the assumption of independence, the columns within the contingency table should have proportional cell counts (a to c = b to d). We have the cell counts from one column (cells a and c), and we have the cell count from one of the two cells in the other column (cell b). Assuming proportionality, it is possible to solve for the remaining cell d. The error surrounding this estimate is reflected in a standard error term, whose magnitude depends upon the sample size, as well as the distribution of data within the three cells for which counts are available. Combining this information with that in the remainder of the table, the size of the entire population N can be estimated (as can its standard error).

Constraints on Inference

The major concern with a survey of this nature is that specific groups of providers with important information may have been missed, resulting in *underreporting* from particular sectors. To obtain the most accurate information, the survey should be carried out as comprehensively as possible. On the other hand, since the surveys for 1987 and 1990 are being compared, the methodology should be the same across the two time points. Despite maintaining the overall methodology as closely as possible from 1987 to 1990, the prior experience clearly improved the capability of the study team, as witnessed by the higher absolute number of responses.

Table 3. Affected organ systems in the 1987 and 1990 censuses

System	1987		1990	
	Number	Percent	Number	Percent
Overall	1,085	. . .	1,540	. . .
Neurologic	637	59	781	51
Multisystem	139	13	274	18
Cancer-hematologic	114	11	158	10
Cardio-respiratory	89	8	194	13
Gastrointestinal-metabolic	85	8	156	10
Renal-genitourinary	40	4	57	4
Musculo-skeletal	39	4	52	3
Immunologic	7	.7	13	.8
Other	10	.9	14	.9

NOTE: Numbers total more than 1,085 and 1,540, respectively, and percentages are greater that 100 because of multiple representation in 2 or more systems for 71 and 161 children, respectively, for 1987 and 1990. See box for the method of assigning diagnosis to categories.

Diagnoses Assigned to the Various Systems Listed in Table 3

Neurologic-myelodysplasia: congenital anomalies of the central nervous system, spastic quadriplegia, neuromuscular disorders, spinal cord injuries, seizure disorders, central nervous system infections, hypoxic and other encephalopathies, and so forth;

Multisystem-cystic fibrosis: inborn errors of metabolism, chromosomal anomalies (for example, trisomy 21), acquired immunodeficiency syndrome, and so on;

Cancer-hematologic: leukemia, solid organ malignancies, thalassemia, sickle cell anemia, hemophilia, and so on;

Cardio-respiratory: bronchopulmonary dysplasia, asthma, chronic lung disorders, congenital heart disease, and so forth;

Gastrointestinal-metabolic: inflammatory bowel disease, gastroesophageal reflux, dumping syndrome, malabsorption, necrotizing enterocolitis, congenital anomalies of the gastrointestinal tract;

Renal-genitourinary: chronic renal failure, congenital genitourinary anomalies, glomerulonephritis, other renal disorders, and so on;

Musculoskeletal: arthritis, osteomyelitis, osteogenesis imperfecta, Ehlers-Danlos syndrome, other congenital anomalies of the bones or connective tissues;

Immunologic-severe combined immunodeficiency disorders: agammaglobulinemia, hypogammaglobulinemia;

Other unspecified learning disabilities, unspecified developmental delays, unspecified behavior disorders.

The data are based solely on providers' reports, without independent verification of diagnoses. In particular, the information concerning mental impairment should be viewed as a "functional" definition of cognitive ability rather than a criterion or norm-referenced assessment.

Creating and maintaining this type of data set presents a series of challenges which can introduce a degree of error. The need for confidentiality precludes the use of positive identification, such as names or social security numbers. Thus, determining cases in which the same child has been identified in more than one survey depends upon a combination of computer analysis of demographic data and individual inspection of the forms.

A similar process was used in identifying children who have appeared in both the 1987 census and the 1990 survey. Having improved our computer algorithms to facilitate the 1990 analysis, we applied them to the 1987 data and found that some cases of *overreporting* had been missed by the original 1987 procedures. This highlights the fact that estimates derived from surveys, such as those reported in this paper, are subject to errors in determining whether two or more separate responses actually refer to the same child.

Finally, for 1987 data regarding whether the information came from a medical or an educational source were unavailable for 80 records. To carry out the capture-recapture analysis, it was necessary to assign a pro-rated value to each of those cases.

Results

From 1987 to 1990, the number of children reported to be using medical technologic assistance increased from 1,085 to 1,540—a 42 percent reported increase. However, the changes in technologies used were not uniform. The technologies and their comparative use for 1987 and 1990 are presented in table 2. The largest changes were reported for oxygen and gastrostomy use. Modest increases were reported for dialysis, tracheostomy, and the use of intravenous technology. Small changes were found for respirators and essentially no change in the report of use of catheterization. There was a decrease in the reported prevalence of urostomy.

Also shown in the table are adjusted estimates for technology use based on pro-rating the reported figures, applying the capture-recapture adjustment. While these figures are only estimates, they may be a more accurate reflection of the true prevalence of each technology used. The adjusted figures present somewhat different patterns than do the actual

reports. Oxygen use and gastrostomies show increases, while a decline in use is suggested for respirators, urostomy, and catheterization. Intravenous apparatus and dialysis remained unchanged.

A change in the age distribution of the reported cases (see figure page 240) from 1987 to 1990 was noted. While children between 1 and 2 years of age composed the largest group in 1987, those in the first year of life proved to be the largest group in 1990. When we examined specific technologies used to identify those contributing to this shift, we found large numbers of children younger than 1 year using oxygen (85 children) and gastrostomies (108 children).

The male-female ratio was remarkably similar from 1987 to 1990: 51.7 percent to 48.3 percent and 51.8 percent to 48.2 percent. The racial breakdowns were also very similar: 1987—white 83.4 percent, black 7.2 percent, Hispanic 8.0 percent, Asian 0.6 percent, and 1990—white 78.1 percent, black 8.1 percent, Hispanic 10.1 percent, and Asian 1.2 percent. The racial distributions for the State's total population are available from the 1990 U.S. census—white 85.7 percent, black 4.8 percent, Hispanic 4.6 percent, and Asian 2.3 percent.

Table 3 presents the organ systems affected in the children reported to be dependent on medical technology. For both time points, neurologic conditions accounted for at least 50 percent of the cases, with other systems showing far smaller proportions. The putative "etiologies" for the conditions of the children in the 2 years are presented in table 4. Again, the overlap in the categories between the 2 years is clear with a slight increase in 1990 in the relative proportion of children with "chronic conditions."

As seen in table 5, the intelligence quotient distributions were bimodal with a little more than half the children on whom estimates of intelligence could be made being of normal intelligence and almost 25 percent in the severe-profound range. No estimates of intelligence were given for 27 percent of the cases—mostly infants. The number of children without access to some sort of educational placement (such as early intervention) was 7.7 percent in 1987 and 10.6 percent in 1990.

Table 6 presents the data on where the children were living. The vast majority for both time points lived at home (more than 75 percent). We found in 1990 that the percentage of children in foster placement was 4.0 percent. This is in contrast to a statewide foster care statistic of 0.9 percent. Schools were rarely the residences for these children (1 percent and 0.6 percent). In both 1987 and 1990, a

Table 4. Etiologies represented in the 1987 and the 1990 censuses

Type of disability	1987		1990	
	Number	Percent	Number	Percent
Overall	1,085	. . .	1,540	. . .
Congenital anomalies	502	46	653	42
Chronic conditions	377	35	636	41
Perinatal factors	108	10	191	12
Hereditary-genetic	80	7	120	8
Injuries	61	7	55	4
Other	29	3	12	.8
Infections	25	2	52	3

NOTE: Numbers total more than 1,085 and 1,540, respectively, and percentages are greater than 100 because of multiple representation in 2 or more etiologies for 95 and 179 children, respectively, from 1987 and 1990. See box for the method of assigning etiologies to the disabilities listed in table 4.

Etiologies Assigned to the Disabilities Listed in Table 4

Congenital anomalies: central nervous system malformations: (for example, hydrocephalus, myelodysplasia, cerebral dysgenesis), gastrointestinal malformations (for example, intestinal atresia), genitourinary malformations (for example, cloacal exstrophy), congenital heart conditions;

Chronic conditions: malignancies, cerebral palsy and other neuromuscular disorders, seizure disorders, immunodeficiency syndrome, asthma, chronic respiratory disorders (excluding bronchopulmonary dysplasia), congestive heart failure and other noncongenital heart conditions, renal disorders (for example, chronic renal failure, glomerulonephritis), malabsorption, chronic malnutrition, gastroesophageal reflux;

Perinatal factors: prematurity, bronchopulmonary dysplasia, meconium aspiration, perinatal asphyxia, necrotizing enterocolitis;

Hereditary-genetic: Cri du Chat, trisomy 18, trisomy 21, cystic fibrosis, Duchenne muscular dystrophy, mucopolysaccharidoses, other inborn errors of metabolism, Werding-Hoffman disease, Tay Sachs disease, sickle cell anemia, thalassemia, hemophilia, inherited immunodeficiencies, and so forth;

Injuries: accidents, inflicted injuries, near-drowning, head trauma, spinal cord injuries, cardiopulmonary arrest, burns;

Infections: congenital viral infections, osteomyelitis, meningitis, viral encephalitis, acquired immunodeficiency syndrome;

Other nonspecific categories of primarily developmental and behavioral nature, such as "severe developmental delay."

Age distribution of children dependent on medical technology in Massachusetts, 1,085 in Project School Care's census year 1987 and 1,540 in Project School Care's census year 1990

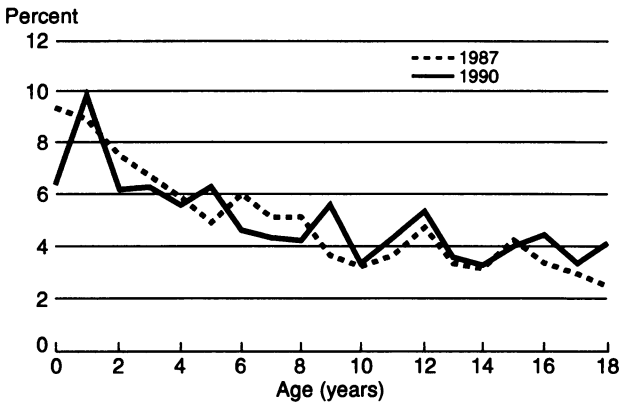

Table 5. Intelligence profile for children with technology dependency

Intelligence level (when known)	1987		1990	
	Number	Percent	Number	Percent
Normal	490	45	618	40
Mild or moderately retarded	146	13	136	9
Severe or profoundly retarded	257	24	373	24
No data, don't know	192	18	413	27

Table 6. Where do the children live?[1]

Location	1987		1990	
	Number	Percent	Number	Percent
Home	821	76	1,150	75
Foster home	(2)	. . .	62	4
School	11	1	10	.6
Nursing home	86	8	115	7
Hospital	78	7	84	5
Other, don't know	89	8	119	8

[1]This table reflects where children stayed 4 or more nights per week. Some children lived at a combination of residences.
[2]No separate data.

substantial number of children (12–15 percent) were reported to spend four or more nights per week in a hospital or nursing home. This proportion increased with increasing age.

Discussion

A major goal of this research was to estimate the number of children assisted by medical technology in Massachusetts. Our initial analysis of the 1987 data using a capture-recapture statistical technique (*7*) gave an estimate of 3,650 such children (based on an unduplicated count of 1,244 cases). Re-analysis of this data, using an improved computer algorithm for identifying duplicates among children on whom surveys were submitted, indicated there were a greater number of children who were both "captured" by medical professionals and "recaptured" by educators than we had originally detected (reducing the unduplicated count to 1,085). This resulted in a substantial reduction in the number of children estimated to be technologically dependent, from 3,650 (plus or minus 382) to 2,147 (plus or minus 230). (The numbers in parentheses represent 95 percent confidence intervals.)

For the 1990 survey, the capture-recapture analysis produced an estimate of 2,237 (plus or minus 131). This number is essentially the same as the estimate for 1987. We believe this is actually a tighter estimate than that reported in 1987. This improvement is reflected in a much narrower confidence interval around the estimate, and by the fact that the percentage of children identified by both physicians and educators increased dramatically (280 percent), enhancing the reliability of the 1990 estimate.

While the capture-recapture analyses of the 1987 and 1990 data indicate relative stability of the overall population of children assisted by medical technology, the unadjusted reports reveal an uneven pattern of changes in the uses of different technologies. These patterns bear attention and monitoring because such nonproportional changes could not be explained on the basis of improved methodology alone. Thus, there appears to be evolving reliance on some forms of care, shifts in other types of care (*16*), and even potential changes in the epidemiology of some chronic conditions (*17*).

Implications

This survey has produced an estimate of the size of the population of children assisted by medical technology in Massachusetts in 1990—approximately 2,237 children. With a 95 percent confidence interval of plus or minus 131, the estimate from this survey is far tighter than any previous estimate of the number of children assisted by medical technology (*9*). Moreover, because the survey was carried out in 1990, U.S. census figures are available, indicating the number of children ages 0–17 who resided in Massachusetts during that year. Using these figures, we can estimate the prevalence rate of technological dependency at 0.16 percent for children in this age range. Applying this rate to the child population of the United States gives us an estimate of 101,800 children assisted by medical technology nationwide

(assuming comparable experience from State to State). These State and national estimates should be useful for policy analysis and program planning. The data inform those interested in both acute and long-term care provision for children assisted by medical technology.

With regard to acute care, the longitudinal results from 1987 to 1990 suggest increasing use of techniques such as supplemental oxygen and gastrostomy tube feeding. This trend raises some important questions. Are these technologies being applied only as life-sustaining measures, or are they beginning to be used as adjuncts to other therapy as an enhancement of function? Are these technologies being used for less serious conditions than previously? Or, are we seeing improved life chances for more seriously involved children who are now living longer and appearing in the pool of children picked up by the census? How long will the trend toward reliance on these technologies continue?

With only two points on the curve, it is hard to know whether we are yet seeing the full extent of the use of these technologies. The impact of surfactant and high frequency ventilation may reverse the direction for oxygen supplementation, but there is no comparable development in the nutrition field. It is possible that success with gastrostomy feedings of children with chronic illnesses and disabling conditions may lead to ever more extensive use of this therapeutic technology (*18*).

Because these one-State data raise many questions about current acute care practice, it would be helpful to have cross sectional data among States to compare practices. Such data have been very informative in neonatology, where the detection of non-comparabilities in treatment patterns has allowed the correlation of specific outcomes to specific intervention modalities (*19*).

These data underscore the need for long-term community-based planning for children assisted by medical technology. Nursing care interventions are likely to be the largest component of cost for children assisted by medical technology (*20*). Many of the procedures required by children assisted by medical technology can be performed by well-trained lay persons, but there remain needs for monitoring and supervision of the care provided.

The major implication of this survey is the ongoing and critical importance of planning efforts directed at systems of care which emphasize discharge planning, community development of appropriate care providers, and increased accessibility of community services (such as day care programs and schools) for children assisted by medical technology (*21*).

References

1. Burr, B. H., et al.: Home care for children on respirators. N Engl J Med 309: 1319–1323, Nov. 24, 1983.
2. Cairo, M. S., et al.: Long-term use of indwelling multipurpose silastic catheters in pediatric cancer patients treated with aggressive chemotherapy. J Clin Oncol 4: 784–788 (1986).
3. Dorney, S. F., Ament, M. E., and Berquist, W. E.: Improved survival in very short bowel of infancy with long term parenteral nutrition. J Pediatr 107: 521–525 (1985).
4. Gauderer, M. W., et al.: Feeding gastrostomy button: experience and recommendations. J Pediatr Surg 23: 24–28 (1988).
5. Freezer, N. J., Beasley, S. W., and Robertson, C. F.: Tracheostomy. Arch Dis Child 65: 123–126 (1990).
6. Hendren, W. H., and Lillehei, C. W.: Pediatric surgery. N Engl J Med 319: 86–89, July 14, 1988.
7. Palfrey, J. S., et al.: Technology's children: report of a statewide census on children dependent on medical support. Pediatrics 12: 233–239 (1991).
8. Report of the Surgeon General's Workshop on Children with Handicaps and Their Families. DHHS Publication PH3–83–50194. U.S. Government Printing Office, Washington, DC, 1983.
9. Office of Technology Assessment: Technology-dependent children: hospital v home care. A technical memorandum, OTA–TM–H–38, Washington, DC, 1987.
10. Maternal and Child Health Task Force: Task Force on Technology-Dependent Children: Fostering home and community based health care for technology-dependent children. Department of Health and Human Services, Washington, DC, 1988.
11. Fox, H. S., and Yoshpe, R.: Technology-dependent children's access to Medicaid home care financing. Office of Technology Assessment, U.S. Congress, Washington, DC, 1987.
12. Crain, L. S., et al.: Health care needs and services for technology-dependent children in developmental centers. West J Med 152: 434–438 (1990).
13. Goldberg, A. I., and Monohan, C. A.: Home health care for children assisted by mechanical ventilation: the physician's perspective. J Pediatr 114: 378–383 (1989).
14. Bishop, Y. M., Feinberg, S. E., and Holland, P. W.: Discrete multivariate analysis. MIT Press, Cambridge, MA, 1975.
15. Sudman, S., Sirken, M. G., and Cowan, C. D.: Sampling rare and elusive populations. Science 240: 991–996, May 20, 1988.
16. Crooks, K. K., and Enrile, B. G.: Comparison of the ileal conduit and clean intermittent catheterization for myelomenigocoele. Pediatrics 72: 203–206 (1983).
17. Yen, I. H., et al.: The changing epidemiology of neural tube defects. United States, 1968–1989. Am J Dis Child 146: 857–861 (1992).
18. Rempel, G. R., Colwell, S. O., and Nelson, R. P.: Growth in children with cerebral palsy fed via gastrostomy. Pediatrics 82: 857–862 (1988).
19. Avery, M. E., et al.: Is chronic lung disease in low birth weight infants preventable? A survey of eight centers. Pediatrics 79: 26–30 (1987).
20. Fields, A. I., Rosenblatt, A., Pollack, M. M., and Kaufman, J.: Home care cost-effectiveness for respiratory-technology dependent children. Am J Dis Child 145: 729–737 (1991).
21. Palfrey, J. S., et al.: Project school care: integrating children assisted by medical technology into educational settings. J Sch Health 62: 50–54 (1992).