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## **Technology-dependent children in the community: definitions, numbers and costs<sup>1</sup>**

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### **Summary**

**Objectives** To assess available data on the numbers of technology-dependent children living at home in the UK and estimate the costs of caring for them.

**Design** Data were obtained from all known secondary sources, including surveys of children with specific conditions known to specialist paediatric departments and the database of applicants to the Family Fund Trust. The costs of all services received by three hypothetical exemplar 'case study' children were calculated.

**Results** All existing sources of data have some shortcomings. Taking these shortcomings into account, it is estimated that there may be up to 6000 technology-dependent children living at home. They appear to be disproportionately young and may be distributed unevenly between different regions of the UK. The total service costs of caring for each child will vary according to the types of technologies involved and local patterns of services, but may be as high as £150 000 a year.

**Conclusions** Because of the very high costs of services, routine information on the numbers of technology-dependent children discharged home is urgently needed. This should include details of the duration of technology dependence and the local area to which the child is discharged. New opportunities for joint

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**service planning and purchasing should improve the co-ordination of services for these children.**

**Keywords:** technology dependence, prevalence, home care

## **Introduction**

Over the past two decades, survival rates for premature babies and children with serious congenital abnormalities have improved, as have the prognosis and quality of life of children with illnesses such as cancer and cystic fibrosis. Long-term institutional care for ill or disabled children is now discouraged and early hospital discharge advocated. Meanwhile, portable technical devices have been developed, which can be accommodated in domestic settings and operated by trained lay people rather than only by professionals in hospitals.

Together, these factors have resulted in growing numbers of children who are able to live at home while dependent on complex medical technology. Although the levels and costs of their care are very substantial, appropriate, well-coordinated services for technology-dependent children and their families nevertheless remain underdeveloped (Kirk 1999). Moreover, there is no accurate, comprehensive information on the total numbers of such children, their characteristics or their service needs. Without better information on these issues, it will be difficult to bring about improvements in the planning, purchase and delivery of services. The availability of accurate data on which local services can be properly planned is important to prevent children remaining in hospital longer than necessary because community-based services are not available. Accurate data is also crucially important because of the very high (direct and indirect) costs of caring for technology-dependent children at home.

Drawing on the limited data which are currently available, this paper provides the first estimate of the prevalence of technology-dependent children in the UK and the first estimates of the costs of the services required to support them and their families at home.

## **Definition of technology dependence**

Reflecting the lack of attention given so far to this group of children, there is no accepted UK definition of technology dependence. Indeed, it is possible that some technology-dependent children may have been included within other

studies of severely disabled (Beresford 1995), chronically or terminally ill (While *et al.* 1996; Robinson & Jackson 1999) children, so their particular circumstances and needs have remained unidentified.

A widely used North American definition helpfully delineates a group of children who, although they may share many characteristics in common with severely disabled or chronically ill children, have two additional, clearly identifiable needs: 'a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability' (Wagner *et al.* 1988). Thus, according to this definition, children who need extra care (e.g. because of severe learning disability) which does not involve mechanical/technical equipment, or children dependent on technical equipment (e.g. communication aids) but who have no additional nursing needs, are not included. Those who are included will be receiving treatments such as mechanical ventilation, tracheostomy and oxygen therapy; enteral and parenteral nutrition; intravenous drug therapies; and peritoneal and haemodialysis.

Technology-dependent children are a diverse group and vary according to:

- Cause — congenital or genetic condition, illness, accident or extreme prematurity.
- Age at onset of the dependency — from (premature) birth through to adolescence.
- Duration — from months (e.g. while the respiratory system of a premature infant matures), to several years (e.g. while awaiting corrective surgery), to life-long. Both temporary and long-term technology dependence may be associated with poor prognosis and early death.
- Incidence and severity of associated disabilities — some technology-dependent children are unimpaired, others have severe multiple disabilities.
- Frequency of using technology — continuous (e.g. mechanical ventilation), daily (e.g. home peritoneal dialysis) or intermittent (e.g. intravenous antibiotics for cystic fibrosis).

### **Numbers of technology-dependent children in the UK**

In the USA in 1988 it was estimated that there were 100 000 children dependent on medical technology (Wagner *et al.* 1988). In order to estimate the numbers of technology-dependent children in the UK, information was assembled from a variety of sources (Table 1).

**Table 1** Sources of information on numbers of technology-dependent children in UK

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- The register and surveys (Beresford 1994) of applicants to the Family Fund Trust – an independent organization (albeit fully government funded) which provides grants and information to families caring for a severely disabled child. Help is targeted at relatively disadvantaged families. It is estimated that between 50 and 70% of eligible families apply (Lawton & Quine 1990). Since June 1996 the Trust has recorded whether a child is technology dependent at the point at which the first application from a family is received.
  - Studies of specific clinical conditions or technology use, including long-term ventilation (Jardine *et al.* 1999), tracheostomy (Jennings 1990) and artificial feeding (Streetsheaver Healthcare Computing, personal communication; Townsley & Robinson 1999).
  - Research on the use of children's hospices (Robinson & Jackson 1999)
  - Local child health registers (While *et al.* 1996)
  - Interviews with specialist hospital services and health purchasers carried out as part of a study of families caring at home for a technology-dependent child (Kirk & Glendinning 2000).
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Each of these data sources has some limitations. Surveys of individual paediatric specialties have hitherto been characterized by poor response rates and may lead to the double counting of children who depend on more than one type of technology. If these surveys are carried out from specialist regional centres, they are likely to lack information on the localities to which children have been discharged, particularly if the hospital is still providing substantial levels of outreach medical care. Local child health registers used for surveillance and screening purposes do not always record information on clinical diagnoses or on technology dependence, particularly once children reach school age. These registers may also under-represent children who continue to receive very substantial amounts of care from a regional hospital.

Estimated take-up rates of the Family Fund Trust enable the number of technology-dependent children potentially eligible for help from the Trust to be calculated. However this latter figure still excludes families who would be unlikely to receive any help from the Trust, particularly those with higher incomes. The Trust's data are also largely restricted to families' circumstances at the time of application; any changes in the child's condition are not routinely recorded. They therefore exclude severely disabled children who subsequently become technology-dependent, while continuing to include those who grow out of technology dependence.

Bearing these shortcomings in mind, the available data nevertheless suggest that there may be currently be as many as 6000 technology-dependent children in the UK. These include around 2800 receiving artificial feeding – naso-gastric, naso-jejunal or gastrostomy feeding and parenteral nutrition – according to the British Artificial Nutrition Survey (Streetsheaver Healthcare

Computing, personal communication). The Association of Children with Tracheostomies estimates that its current membership of 500 families represents about half of the total number in the UK. In relation to intravenous infusions, one specialist regional hospital is supporting over 60 children with cystic fibrosis who receive intravenous antibiotics at home; another regional centre estimates there are 1000 children with haemophilia receiving intravenous Factor VIII at home. Two of the UK's 13 paediatric renal centres each report supporting about 12 children at home on peritoneal dialysis. Again extrapolating from the experience of a specialist regional centre, around 800 children depend on oxygen at home; an unknown additional number are likely to receive this treatment following discharge from local district hospitals. About 100 children are likely to be dependent on long-term ventilation at home (Jardine *et al.* 1999), although Jardine's survey is thought to underestimate considerably the actual numbers of children using assisted ventilation (Noyes 1999).

The total figure of around 6000 children may double-count some children who are dependent on more than one type of technology. For example, some children with cystic fibrosis may depend on gastrostomy feeding, receive oxygen each night and also have courses of intravenous antibiotics every few weeks.

Examination of the available data on applicants to the Family Fund Trust supports estimates of this type of magnitude and also hints at some of the other features of this population of children. Between June 1996 and December 1998, just under 7% of the 24 679 applicants to the Family Fund Trust were recorded as technology-dependent (this figure does not double count those dependent on more than one technology). When estimated take-up rates to the Trust are applied, a total of 2390 technology-dependent children would have been eligible for Trust help during this 2-and-a-half-year period, plus an unknown number of upper income families who did not apply. It is difficult to extrapolate these figures over a longer time period with any reliability, given the very rapid developments in medical treatments and technology which have taken place in the past few years and which may indeed continue in the future.

Further analysis of the register of applicants to the Family Fund Trust reveals some clear trends which warrant urgent further investigation. Technology-dependent applicants are significantly younger than average (Table 2). Technology dependence is also significantly associated with lung and respiratory impairments (Table 3), suggesting that some of these younger applicants to the Trust may have time-limited problems associated with extreme prematurity.

**Table 2** Age of technology-dependent children applying to Family Fund Trust June 1996 – December 1998.

Age	Technology dependent (%)	Base <i>n</i>
<1	26	2715
1–2	11	2855
3–4	4	7877
5–7	3	4441
8–10	3	3306
11–16	3	3455
Total	6.8	24649

**Table 3** Disabling conditions significantly associated with technological dependency among applications to Family Fund Trust June 1996 – December 1998

Principal disabling condition	Technology dependent (%)	Base <i>n</i>
Cancer	13.7	761
Leukaemia	21.6	440
Other blood conditions	12.3	308
Central nervous system disorders (exc. spina bifida/hydrocephalus)	9.2	760
Heart disease	18.1	833
Cystic fibrosis	15.7	369
Asthma	12.5	798
Other lung/respiratory system*†	50.2	642
Renal disease	12.8	273
Digestive system disorders‡	26.6	158
Alimentary tract disorders†	22.1	290
Foetal environment and developmental defects	18.8	218
Total	6.8	24625

\*Most notably premature lung disease.

†Most notably conditions linked to tracheostomies.

‡ Most notably oesophageal atresia.

Children with leukaemia and other cancers, heart disease and cystic fibrosis whose families applied to the Trust were also at significantly greater risk of technology dependence than children suffering other disabling conditions. For these children, technology dependence is more likely to have arisen after infancy and in response to a deterioration in a pre-existing condition.

The Family Fund Trust does not routinely collect information on changes in applicants' circumstances; any such details are volunteered spontaneously by families. Even so, a significantly higher proportion of technology-dependent

children were recorded as having died since their application to the Trust — 5.1% compared to the overall known mortality rate of 1.0% among all Family Fund Trust applicants during the same period ( $\chi^2 = 319, P < 0.001$ ). This indicates that information on the dynamics and the duration of technology dependence is urgently needed.

The Family Fund Trust data also show marked regional variations in the proportions of children applying to the Trust who are known to be technology-dependent (Table 4).

One reason for these variations may be regional differences in the incidence of those medical conditions associated with technology dependence, such as extreme prematurity and congenital malformations; these may in turn reflect underlying regional social and economic inequalities. Regional variations may also reflect distinctive patterns of disease management and expertise in the different specialist regional children's hospitals, and in individual departments within those hospitals. There may also be regional variations in the speed with which health and other purchasers can commission complex packages of home care services, so that children in some areas may be discharged home earlier than others and thus come within the scope of the Family Fund Trust. Given the very high costs involved in the home care of such children and the size of the apparent regional variations, these regional inequalities warrant urgent investigation, as the resource implications for health and local authorities in some areas may be considerably higher than in others.

**Table 4** Regional variations in applications to Family Fund Trust from families with technology-dependent children

Social services region	Technology dependent (%)	Base <i>n</i>
Northern Ireland	10.9	1 146
North-west	7.9	2 997
Yorks and Humberside	7.6	2 482
Wales	7.1	1 942
London	6.9	2 591
East Midlands	6.8	1 556
North London	6.7	2 182
West Midlands	6.2	2 317
Northern	6.2	1 717
Southern	5.7	2 014
Scotland	5.5	2 132
South-west	4.8	1 553
Total	6.8	24 629

$$\chi^2 = 61.7, P < 0.001.$$

### **The costs of caring for technology-dependent children**

The total (public and private) costs of caring for technology-dependent children at home were estimated. Three 'exemplar' case studies were constructed to illustrate a range of medical and other circumstances; these were derived from some of the children involved in a recent study of families caring for a technology-dependent child (Kirk & Glendinning 2000).

The costs of all equipment, consumables, staffing and other additional goods and services were calculated and attributed as appropriate to the NHS, local authorities, the Department of Social Security and families themselves. The costs of specialist equipment and consumables, home nursing and care services and enteral feeding were supplied by staff at two regional hospitals. The costs of community health and local authority services were obtained from Netten *et al.* (1998). Professional salary costs were derived from reports of relevant pay review bodies (Review Body for Nursing Staff & Health Visitors & Professionals Allied to Medicine 1999; Review Body on Doctors & Dentists Remuneration 1999). Some of the costs borne by families were drawn from a recent study of the costs of childhood disability (Dobson & Middleton 1998); the costs of other consumer items were obtained from mainstream High Street suppliers. All costs were updated to 1999 levels and grossed up to give annual amounts.

The costs itemized below are illustrative only. They will vary according to the assumptions which are used, for example, to impute the annual cost of capital equipment. In particular, they will vary from region to region and area to area, because of variations between specialist hospitals in the service packages which are considered appropriate to support discharge and because of local purchasing and service delivery policies.

#### **Child A**

A is 6 years old. She has a congenital neuromuscular condition requiring continuous ventilatory support and a gastrostomy; she is also incontinent. Her divorced mother gave up work to care for her. They live in specially adapted local authority housing; they use taxis or pay friends with cars to take A (and her ventilator) out. A attends special school. She has home visits from an outreach nurse from the regional children's hospital; monthly visits from the local paediatric nursing team; and weekly physiotherapy. A's mother has round-the-clock help from a team of specially trained home carers (who also care for A at school); home help services for housework and to take A's sibling to school;



**Table 5** Estimates of the costs associated with the home care of child A

Funding body	Cost per year		
	Minimum	Maximum	Average
Health Authority	£61 256	£72 004	£66 276
Local Authority	£41 801	£46 658	£44 229
Department of Social Security	£11 580	£11 580	£11 580
Family costs minus benefits received from the DSS	£303	£1 759	£1 030
Total	£114 941	£132 002	£123 116

and quarterly visits from a social worker. A's mother receives counselling and medication to help cope with the stress of caring for A. Although on Income Support, she spends extra on household insurance, phone bills and the costs of refreshments for the home carers, over and above those normally associated with a severely disabled child (Table 5).

### Child B

B suffered severe anoxia at birth 4 months ago. She has a tracheostomy and is fed through a naso-jejunal tube. Her parents live 50 miles from the regional children's hospital, but do not have a car. B's father switched from full- to part-time work to help with her care. They receive quarterly visits from a specialist outreach nurse from the hospital and monthly visits from local district nurses, health visitors, occupational therapists, physiotherapists and Portage workers. A weekly service removes clinical waste from the house. Trained home carers provide a break for B's parents 3 nights a week. A social worker is involved in multidisciplinary planning/review. B's parents use taxis instead of public transport, have purchased a mobile phone, spend extra on phone calls to hospital and pay extra household insurance to cover B's equipment (Table 6).

### Child C

C is 11 years old and has renal failure. He receives continuous cycling peritoneal dialysis every night and overnight gastrostomy feeding. His home has been adapted to improve hygiene and storage facilities. His father works full time; his mother has cut her hours and lost promotion opportunities because of C's care. C lives 20 miles from the specialist hospital, which he attends regularly; both parents therefore need extra time off work and incur extra travel

**Table 6** Estimates of the costs associated with the home care of child B

Funding body	Cost per year		
	Minimum	Maximum	Average
Health Authority	£15 703	£162 030	£15 945
Local Authority	£8 720	£8 894	£8 807
Department of Social Security	£4 680	£4 680	£4 680
Family costs minus benefits received from the DSS	£11	£1 966	£988
Total	£29 114	£31 743	£30 420

**Table 7** Estimates of the costs associated with the home care of Child C

Funding body	Cost per year		
	Minimum	Maximum	Average
Health Authority	£40 935	£41 624	£41 237
Local Authority	£58	£61	£59
Department of Social Security	£2 668	£2 668	£2 668
Family costs minus benefits received from the DSS	£204	£1 346	£775
Total	£43 864	£45 699	£44 739

costs. C has monthly home visits from a specialist outreach nurse and annual visits from the hospital dietician and social worker. C attends mainstream school and his parents have bought mobile phones/pagers in case of emergency.

These estimates vary considerably according to the needs of individual children. Another recent estimate concluded that the total annual average cost of supporting a child on long-term ventilation at home was £108 000 (Snelling 1999). However this latter estimate excluded capital equipment costs, additional costs falling on the local authority and, most invisible of all, the extra costs borne by families themselves (net of any disability benefits received) (Table 7).

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## Discussion

Because of the very high costs associated with the home care of technology-dependent children, small increases in their numbers or extensions in the dura-

tion of their dependencies will have major resource implications for NHS and other services. Once discharged from full-time hospital care, specialist children's hospitals will continue to equip and staff the paediatric intensive care bed (or equivalent) from which the child has been discharged, as well as funding outpatient clinical care and outreach nursing services to the child's home. Meanwhile, NHS purchasers in the child's home area will need to fund all the equipment, consumables and other nursing support which she/he requires at home. If responsibility for prescribing drugs and consumable supplies also shifts from the hospital, this can constitute further major costs to the local health authority or primary care group budget. (The drugs prescribed to Child C, for example, were costed at £25 000 pa.) Local authorities also incur extra costs in providing home care and home help services, special support in schools and housing adaptations. Families themselves incur extra costs, including higher electricity bills to run equipment, higher home insurance, mobile phones in case of medical emergencies and refreshments for the support workers and carers working in the home. These are over and above the well-documented costs of caring for a severely disabled child (Baldwin 1985; Dobson & Middleton 1998) and are often met despite reduced family income and earnings (Baldwin 1985; Smyth & Robus 1989).

Managing low-incidence but high-cost risks is a continuing problem for the NHS and local authorities. There are however, a growing number of opportunities for such risks to be shared across and between statutory agencies and, most importantly, for the coherence and coordination of complex service packages for such families to be improved. For example, the Audit Commission (1997) recommended that clusters of health authorities within a region should combine to purchase specialist health services together, with one health authority designated as the lead commissioning authority on behalf of them all (Pilling & Walley 1995). Similarly, a number of contiguous Primary Care Groups could designate one to organize the purchasing of specialized equipment and drug products on behalf of them all (Kirk 1999). Finally, the flexibilities contained in the 1999 Health Act (Department of Health 1998) allow health and local authorities to pool budgets, in which the contributing resources 'lose' their health or local authority 'identity', in order to provide whatever services are appropriate.

On the basis of the very cautious estimates derived above, if the numbers of technology-dependent children were distributed evenly across the UK, there would be at least 500 such children in each region. However, it is likely that the distribution is far from even, so some regions such as Northern Ireland, NW England and Yorkshire and Humberside may contain over twice the numbers of some other regions.

More systematic, comprehensive and consistent data on technology-dependent children are urgently required. These should include the prevalence as well as the incidence of technology dependence, including details of its onset, duration and outcomes. Although anecdotally the incidence of technology dependence is believed to be increasing, it is still far from clear how long children remain technology-dependent; moreover, the duration is likely to vary for different groups of children. Without this information, it is impossible for health and local authority purchasers to estimate the cumulative numbers of technology-dependent children, now or in the future, and the consequent resource and service implications.

Information is also needed on the local authority and health authority areas which are bearing most of the cost of children's continuing care, as well as the specialist regional hospitals from which they have been discharged. Health authorities are likely to have information on the numbers of complex service packages they are funding (including contracts with specialist hospitals and commercial companies which supply equipment directly to families), especially as these will increasingly form part of Joint Investment Plans (Department of Health 1997a). However the robustness of these data may change, as and when responsibility for commissioning specialist hospital services shifts to NHSE Regional Offices (Department of Health 1997b) or when responsibility for Joint Investment Plans is devolved to Primary Care Groups.

Arguably the best method for improving information is for medical conditions, including technology dependence, to be routinely recorded on the proposed NHS children's minimum dataset. This is currently being planned by the NHSE information group and will be used for both clinical management and public health purposes. The proposed system of electronic health records (NHSE 1998) would also provide an opportunity to build up information on technology dependence and track the emerging geographical and temporal patterns.

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