



Supporting families caring for a technology-dependent child in the community

Key findings

There is no accurate information on the numbers of technology-dependent children living at home or on the patterns and duration of their health problems. There may be up to 6000 children across the UK, but possibly with marked regional variations.

The costs of services for a technology-dependent child at home often exceed £100,000 annually. Better information on numbers and costs is needed to help health and social services' authorities plan services.

Parents provide most of their child's day to day care, which includes technically complex and life-sustaining procedures.

Appropriate community support is often not available; district nurses, health visitors and GPs need specialist information and advice on the care of technology dependent children as much as parents themselves.

Parents want health and social services' professionals to acknowledge their expertise, support and complement their own care-giving, and provide information and advice promptly.

Families receive help from many different sources, but these are rarely co-ordinated. Communication between hospitals and community services is poor. Parents frequently have to co-ordinate services themselves.

The supply of equipment, drugs and other special items is particularly poor. Parents often have to chase up supplies and find it easier to go back to the hospital or direct to private suppliers than rely on community health services.

Because the children need specialist care, conventional short-term break facilities are often not suitable. Families prefer short-term breaks to be provided in their own home, to reduce disruption and risk of infection.



Background - What is 'technology dependence'?

Medical advances enable increasing numbers of babies born very prematurely or with serious impairments to survive, and have improved the prognosis for children with serious illnesses like cancer and cystic fibrosis. Some of these children now depend on complex technological devices such as mechanical ventilators, artificial feeding and intravenous drug therapies. Most technology dependent children can now live at home, with their parents operating the technical equipment and providing substantial nursing care.

Most research on families caring for technology dependent children has been carried out in north America (Wagner et al 1988; McKeever 1991). There is only a small amount of research in the UK on families whose children need artificial feeding (Townesley and Robinson 1999), tracheostomies (Jennings 1990) and long-term ventilation (Jardine et al 1999). Yet trends in the survival of technology-dependent children present major challenges:

- to the expertise of doctors, nurses and other health professionals in the community;
- for the supply and maintenance of specialist equipment, drugs, dressings and solutions which are normally only used in hospitals;
- for the funding and co-ordination of complex packages of support for families.

Research carried out at NPCRDC between 1997 and 2000 addresses these issues.

Technology-dependent children in the UK

There is no reliable estimate of the numbers of technology-dependent children in the UK. They are a diverse group, varying by:

- cause - congenital or genetic condition, illness, accident or prematurity;
- age at onset - from (premature) birth through to adolescence;
- duration - from months to life-long;
- prognosis and life expectancy;
- incidence and severity of associated disabilities;
- frequency of using technology - continuous (eg. mechanical ventilation), daily (eg. peritoneal dialysis) or intermittent (eg. periodic intravenous antibiotics).

We examined all available sources of data on the numbers of technology-dependent children in the UK (Glendinning et al, 1999; forthcoming). Some studies focus only on children with one type of technology dependence (many children depend on two or more); some are carried out from specialist hospitals (and therefore give little information about where children live). There is no research on the duration (and therefore the overall prevalence) of children's technology dependence. Nevertheless we estimated that:

- there may be as many as 6000 technology-dependent children in the UK;
- a majority are probably very young and may either grow out of technology dependence (eg. as the lungs of premature infants mature) or die prematurely;
- there may be marked regional variations in the numbers of technology-dependent children living at home. This could reflect regional variations in the incidence of prematurity and congenital impairments, which give rise to technology dependence; and different patterns of management and expertise in specialist regional children's hospitals.



Parents' experiences of caring for a technology-dependent child at home

We interviewed 21 families caring at home for technology-dependent children who also had extensive nursing needs, and 3 families with children awaiting hospital discharge. Many of the children used more than one technology (Table 1). We also interviewed 44 professionals (doctors, hospital and community nurses, social workers, teachers and health authority purchasers) in contact with the families, about their experiences. In many instances, professionals' views echoed those of parents.

Technological Dependence	Number
Tracheostomy	10
Oxygen Therapy	8
Mechanical Ventilation	6
Intravenous Drugs	4
Parenteral Nutrition	2
Peritoneal Dialysis	2
Others (eg gastrostomy)	13

Parenting vs nursing

Parents carried out most of their child's technical and nursing care - changing tracheostomy tubes, suctioning airways and giving intravenous drugs and feeds. This care carried risks of life-threatening infection and caused pain and distress to the child. Parents thought the emotional aspects of providing care (distress at inflicting pain on the child, the unremitting responsibility for providing therapies which literally sustained their child's life) were overlooked by professionals, who concentrated only on technical competencies.

Parents felt they had little choice about taking on these responsibilities. Given the level of care the child needed, the only way s/he could be discharged home was for them to provide it. However, as they became more confident, parents became more assertive and began to negotiate with professionals over taking on additional responsibilities.

The impact on family life

Family life was dominated by the child's medical needs. Homes were transformed by medical equipment and supplies, and privacy was compromised by the constant presence of professionals and paid carers who provided home-based support. Baby-sitters were limited to those who knew the child and his/her medical routines. Family activities outside the home were severely curtailed because cumbersome equipment had to be transported; parents and children also found it embarrassing performing procedures like gastrostomy feeding or tracheostomy suctioning in public. Holidays were organised near specialist hospitals, in case of a medical emergency.

Parents' sleep was disrupted when machine alarms went off, treatments were needed during the night, or an ill child needed constant vigilance. The additional costs of the child's care, coupled with reduced incomes if parents had given up work, could cause severe financial stress. Anxiety, exhaustion and stress led some parents to seek professional counselling.

Relationships between parents and professionals

Negotiating hospital discharge

Before discharge, parents felt it was assumed (rather than negotiated) that they would be willing to provide most of their child's daily care. Professionals also confirmed that technology-dependent children could only be discharged if their parents were able to care for them. Some community nurses worried that parents' feelings of obligation were exploited by hospitals keen to expedite the child's discharge.



Professionals and 'expert' parents

Looking after a technology-dependent child at home involved parents acquiring skills which in hospitals are the responsibility of nurses and doctors. Indeed, the very specialised techniques involved are often beyond the recent experience of GPs, community nurses and even local hospitals. Consequently, when parents needed help, they usually turned to the staff at the specialist regional hospital where the child had been a patient. Outreach clinical nurse specialists from these hospitals were an important source of advice and support, both to parents and to generalist community nurses.

Over time, parents gained confidence in carrying out complex and specialised procedures. They could often detect potential health problems (the onset of a chest infection, for example) earlier than professionals who did not know the child so well. Parents' expertise led them to challenge professional advice or refuse to comply with treatments which were incompatible with their own perceptions of the child's needs, particularly if such treatments had been advised by non-specialist health professionals.

Parents felt their expertise was sometimes not acknowledged, particularly by local hospital doctors and GPs. Only occasionally did professionals admit to feeling threatened by parents' expertise and competence, although some may simply have avoided contact with parents for this reason. Parents respected professionals who were honest about their lack of specialist knowledge and who, conversely, acknowledged and respected parents' own expertise.

What kinds of support from professionals did parents value?

Both parents and professionals identified similar types of activities as 'supportive' (that is, they enabled or helped parents to care for their child at home).

- *emotional support* Having easy access to a reliable professional promoted parents' confidence and enhanced their capacity to cope. Specialist nurses who carried pagers were particularly valued for their accessibility. Parents also valued continuity in their relationships with professionals. Social workers were not able to give as much emotional support as they would have liked, because their work was more crisis-oriented.
- *instrumental support* Parents valued practical help - applying for services or social security benefits on their behalf, or acting as an advocate in relation to other professionals.
- *information* Information was an important means of enhancing parents' sense of control. However, parents often received information which was inadequate, inappropriate or contradictory. They had to seek information themselves which they thought should have been volunteered by professionals familiar with their circumstances.

Inter-agency and inter-professional working

Few families received adequate, well co-ordinated services.

Poor co-ordination and communication

Poor communication between hospital, community health and social services was very common. Services were poorly co-ordinated and inadequately planned. Consequently:

- families could feel overloaded by numerous visits from different professionals;
- parents were unclear about the roles of different professionals, including whether their GP or the hospital consultant was responsible for the child's medical care at home;
- community professionals were not informed by hospital staff about changes in the child's condition or treatment;
- parents often had to pass information between professionals or co-ordinate services themselves.



Short-term breaks and home support services

Short-term break facilities were difficult to find because of the specialist skills needed to care for the child. Families preferred home-based 'breaks' because they were less disruptive and reduced infection risks. Many families therefore had home carers - Crossroads volunteers, agency nurses, foster carers, family aides and nursing auxiliaries - who had been specially recruited and trained to support them.

Disputes between health and social services authorities over the funding of home support services were common and could delay hospital discharge. There were wide variations in the amount of home support and short-term care received by families with similar needs, depending on local policies. Funding for support workers to enable children to attend mainstream nurseries and schools was a further source of inter-agency disagreement.

Specialist equipment and supplies

Disputes between hospitals, community trusts and GPs over funding for equipment, supplies and medication in the home were common; were these covered by existing service agreements or should additional funding 'follow the child' out of hospital. Again, such disagreements could delay hospital discharge.

GPs, local pharmacists, clinical nurse specialists, community children's nurses, health visitors and commercial companies could all be involved in providing medical supplies; many families received these from several sources. Supplies for children with tracheostomies seemed particularly problematic. Families receiving their supplies direct from private companies found this much more reliable than the community health services. Families who lived near enough often returned to the regional hospital for more supplies.

Community nurses found it difficult ordering specialised supplies, particularly if the child's condition was unpredictable. They complained that hospitals sometimes allowed insufficient time to obtain very specialised equipment before a child was discharged home.

Implications for policy and practice

- There is an urgent need for reliable and systematic information on the incidence, duration and outcomes of technology dependence in children in the UK, on which local health purchasers and professionals can plan service developments.
- The organisation of community services to support technology-dependent children at home has not kept pace with medical advances. Appropriate short-term care and support services are lacking and the funding and supply of equipment, consumables and special drugs is fragmented.
- The fragmentation of services could be reduced by health and local authorities taking advantage of the 1999 Health Act flexibilities to pool budgets, delegate commissioning to a single 'lead' agency or integrate services within a single organisation.
- Families would benefit from a designated 'key worker', as a point of first contact and to co-ordinate services. This recommendation has been made in many official and research reports (DHSS 1976; Glendinning 1987, Audit Commission 1994, DH 1998) and is long overdue.
- Specialist advice and support to both families and generalist health professionals could be improved by developing children's community nursing services in areas still without them.



About the studies

The main study reported here was carried out under the Department of Health 'Supporting Parenting' research initiative. It investigated the experiences of families and professionals involved in caring at home for a technology-dependent child. Families were recruited from 3 specialist regional children's hospitals in northern England; professionals were recruited via the families. A smaller linked study was commissioned by the Social Care Division of the Department of Health to estimate the numbers and the costs of caring for technology-dependent children in the community.

Publications arising from the studies to date

(Publications marked * are available free of charge from NPCRDC)

Kirk S. (1998) Families' experiences of caring at home for a technology-dependent child: a review of the literature. *Child: Care, Health and Development* 24, 2: 101-14.

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* Glendinning C, Kirk S, Guiffrida A and Lawton D. (1999) *The Community-based Care of Technology-Dependent Children in the UK: Definitions, Numbers and Costs*. Research Report. NPCRDC, University of Manchester.

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Other references

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Department of Health and Social Security (1976) *Fit for the future. The Report of the Committee on Child Health Services?* (Court Report) Cmnd 6684.

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