



Breathing Space: Community Support Of Children On Long Term Ventilation - Summary

Authors: *Anna Ludvigsen and Jan Morrison (PRIU)*

Report Date: *July 2003*

Background Information

Commissioned by: *Barnardo's*

Funded by: *Barnardo's*

Outputs: *Breathing Space - a campaign report to highlight the issues from the point of view of the children and their families; and a seminar for key policy makers and planners in July 2003*

Background

Barnardo's campaign on Poverty is being continued in 2003 with a focus on Poverty and Health Inequalities. Last year, PRIU published a document called *Still Missing Out*, which focused on the issues facing families with a disabled child. By focusing on real life situations and case studies, Barnardo's feels it is able to make a stronger case to government departments, policy makers and planners. Using personal accounts, Barnardo's has, therefore, commissioned this piece of research to help bring about improvements in the quality of life for children who require long term ventilation (LTV).



Objectives

To bring about improvements in the quality of life for children who require LTV with the aim of influencing policy and planning at national and regional level.

Methodology

- Literature review
- Interviews with children and their families
- Six case studies of children and their families to illustrate the range of experiences- good and bad to be presented primarily from the children's point of view.

Summary of issues arising from case studies

The case studies presented here cannot be taken to represent the experiences of all long-term ventilated children. The four children in these case studies were identified through Barnardo's services, and two of them were living with foster carers. This reflects the type of children with whom Barnardo's works -namely; the most vulnerable children. Nevertheless we believe that some of the issues highlighted here are common to many other long-term ventilated children in Britain.

Issues for the children

- All the children stayed longer than necessary in hospital. They spent between 7 and 18 months (an average of 13 months) longer than medically necessary.
- Long-term ventilated children who - for a multitude of reasons - are unable to live with their families spend longer or indefinite periods in hospital. In some cases they may lose contact with their families altogether.
- Parents and carers described their children as having become 'institutionalised' as a result of their prolonged hospitalisation. They had all endured periods of isolation while in hospital. Being isolated from other children had impacted on their social and emotional development. A study by Noyes of children and young people's view of being in hospital supports this point. She found that young people found it difficult to get out and about, and had '*a sense of being in limbo and socially excluded*' (Noyes, 2000: 121 I).
- The children hated being in hospital and often cried when taken back for medical appointments or readmissions. The young people in Noyes's study also describe their boredom, apathy and hatred of hospitals (ibid).
- While they were in hospital the children were vulnerable to a variety of infections. The physical health of all the children improved significantly after they came home. They had fewer hospital-acquired infections, such as MRSA, chest infections, diarrhoea, colds and coughs. The overall amount of time they spent on the ventilator was also reduced, with most of them requiring only night-time ventilation.
- Parents and carers highlighted the social and emotional benefits of home care. Back at home the children are described as 'blooming' and having 'come out of themselves'. Their personalities developed, they were able to smile and they were clearly happy as a result of being in a home environment with their families. This finding is supported by Margolan's study which found that '*the general health, wellbeing*

and development of children on [long-term ventilation] had significantly improved since being at home' (Margolan, 2001: 34).

- Attending school provided the children with opportunities to interact and play with other children, which again helped their sense of independence and belonging in the community.
- The requirement that a carer is always present both delays the discharge of the children and impacts on their quality of life. This is particularly pertinent as they reach adolescence and want to form personal relationships.
- It is particularly difficult to maintain an ordinary home environment, and long-term ventilated children frequently experience a lack of privacy, choice and independence.

Issues for parents and carers

- The provision of short breaks varies significantly. However; all parents and full-time carers depend on adequate short breaks in order to continue the care of their children in the long term.
- It is at times stressful and intrusive having carers in your home, but parents and full-time carers recognise their dependence on these workers. It is important for them to find a balance between privacy and the need for support.

Other issues

A number of other issues should be highlighted from the literature on long-term ventilated children.

- Long-term ventilated children who are medically stable and ready to be discharged, block intensive care beds for other ill children. A survey of 24 paediatric intensive care units in the UK found that 18 of 152 beds (12 per cent) were occupied by long-term ventilated children (Fraser et al, 1997). During the same period 143 children in the affected units were refused admission. Had these beds not been occupied by long-term ventilated children, an estimated extra 120 children could have been admitted. James (1996) reports an even higher percentage of bed blocking, with 42 per cent of acute paediatric intensive care beds in one NHS trust blocked by medically stable children dependent on long-term ventilation.
- Prolonged hospitalisation, especially in distant regional or tertiary hospitals, increases the risk of vulnerable families losing contact with their child and hence their chance of returning home.
- Long-term ventilated children and young people are often excluded from the decision-making process about their care and life. The rights of long-term ventilated children, as described in the UN Convention on the Rights of the Child, are frequently not respected in hospital (Noyes, 2000). It is also difficult to uphold their rights to an ordinary family life once they have been discharged.
- The main barriers to a rapid discharge are the difficulties in recruitment of home care staff; incomplete funding, unsuitable housing (Jardine et al, 1999) and local bureaucracy. Noyes also describes barriers, such as '*attitudes of professionals, lack of joint commissioning and accounting responsibilities, general poor management both within the health service and in collaborating with other services, complex social issues, housing problems and a general lack of auditing and outcome measures*' (Noyes, 2002: 26).

What it costs

It is difficult to establish the relative cost of long-term hospital care and community-based care. There are indications that home care - although expensive - tends to be cheaper than hospital care (Vick, 1996). Some cost savings may occur because parents are the primary care providers in the home rather than professional nursing staff (Kirk, 1998).

- The estimated annual cost of home ventilation (1998 costing) for a child receiving 24-hour care is £ 160,000 - £ 180,000 (cost compiled by South West Region, quoted in North/South Thames PICU Network).
- The annual cost of a bed in Great Ormond Street Hospital's Transitional Care Unit is £258,420 (ibid).
- Beds in Paediatric Intensive Care Units range between £438,000- £657,000 a year depending on location (ibid).
- The unit cost of a Barnardo's service providing a care worker in the child's home is approximately £10 per hour: This figure does not include the cost of training carers to meet the child's health care needs.
- Cost-cutting in the discharge process may be ill-advised, as the lack of short breaks and limited nursing care increase the stress felt by parents (Noyes et al, 1999). Exhaustion and burnout have been shown to reduce the primary carers' ability to cope with home care in the long term (Quint et al, 1990).

What needs to change

The emerging findings of the National Service Framework for Children in Hospital concerning Disabled Children and Long Term Conditions state that:

Families need a seamless child and family-centred service that addresses all types of need, provides continuity across all transitions in the child's family life, and is not limited by separate agency roles and responsibilities. A diagnostic and assessment process carried out promptly and leading to an agreed multi- agency plan can best meet the family's needs. In particular, many children require the timely provision of therapy services and community equipment services to help encourage inclusion in local community and the best possible developmental progress. (Department of Health, 2003b: 27)

A number of things need to change if this standard is to be reached.

- The particular needs of children on long-term ventilation must be a distinct focus of the ongoing work of the development of the National Service Framework.
- The ongoing care and support needs of these children must be recognised in the development of children's trusts.
- When children on long-term ventilation are ready for discharge, continuing care protocols should be used to ensure that they return home speedily.
- As outlined in the emerging findings of the National Service Framework, local multi-agency groups involving health, social care and education should be set up at a senior level in order to plan and commission services.

- Guidance on complex home care packages should be issued to overcome the transfer of funding issues from acute services to primary care trusts and the inconsistencies of funding within primary care trusts. The guidance should include the provision of pooled budgets.
- All long-term ventilated children should have access to an identified and effective key worker system, as outlined in the joint Department of Health/Department for Education and Skills guidelines 'Together from the Start' (2003).
- Multi-agency plans for children on long-term ventilation must acknowledge their educational needs and be clear about how these are to be met.
- While the vital importance of nursing care should not be minimised, a balance between children's ongoing nursing needs and their rights to a normal life must be achieved. This will require a shift in culture concerning what are acceptable and manageable levels of risk.

Contact for further information

Please contact Jan Morrison, Policy Officer, Disability or Anna Ludvigsen in Research and Development, Barnardo's

Email: [Jan Morrison](#) or [Anna Ludvigsen](#)